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A Sociocultural Approach

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Preface

The United States is an advanced technological society. It has the largest gross domestic product (GDP, the total dollar value of all goods and services produced) of all of the world's nations. It also has the largest portion of GDP that is devoted to health care, 16.4 %.[1] Yet the U.S. infant mortality rate ranks 33rd of the 36 nations included in the Organization for Cooperation and Development (OECD—European Union, EU applicants and selected other developed countries). This low ranking is not a recent phenomenon—it has been observed for decades, ever since comparative infant mortality rates have been available. The reason for this low ranking is also clear, and has been stable for decades: the United States has a much higher rate of preterm births—infants delivered before their mothers' pregnancies reach term (at least 37 weeks gestation) than other developed countries. The U.S. actually has a lower mortality rate per preterm birth age than other countries, but this high survival rate is not sufficient to compensate for the larger number of infants born before they reach term.

The persistence of high preterm birth rates in the U.S. population has been labeled an enigma by biomedical researchers, an issue of concern by clinicians, an indicator of the need for political and health sector reform by social advocates, the trigger for ethical dilemmas in health care and social policy, and a human tragedy for the families involved. It is a complex phenomenon that involves many participants, each of whom has a different view and set of experiences: the mothers who experience an early end to their pregnancies and the fathers of infants born early; their physicians, nurses and hospitals; those who finance the care of these mothers and infants and those who worry about maintaining resources for such expenditures; scientists responding to the challenge of explaining preterm birth; politicians who feel pressured to respond to preterm birth when it is framed as a social problem; and advocates who believe that their agendas offer solutions to the problem, to name just a few. Each group is able to describe the phenomenon from

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[1] Based on OECD data for 2013. The next highest portions of GDP devoted to health care are Switzerland and The Netherlands, each with 11.1 %.

its own perspective, and each often believes that its perspective represents the issue of preterm birth overall. The situation is reminiscent of the ancient Indian story of the six blind men encountering the elephant: the one touching its side believes it is a wall, the one touching its tusk believes it is a spear, the one touching its trunk believes it is a snake, the one touching its leg believes it is a tree, the one touching its ear believes it is a fan, and the one touching its tail believes it is a rope. The blind men argue vehemently about who has the most accurate view of the elephant, when in fact none of them has complete knowledge of what the elephant is like.

The many parties involved in the issue of preterm birth in the U.S. are not blind, but it is easy to find one's vision narrowed by the emotions and high stakes—life and death, deeply held values and paradigms, resource commitments, revenue flows and life adjustments—that are challenged when an infant is born before it reaches full term. Also, with the demands of meeting the immediate challenges of preterm birth, it is easy to lose perspective on the historical circumstances that structure one's current decisions, and to be unaware of the impact that a set of decisions made in one situation can have on the array of choices available in other situations. For example, legal precedents for suing physicians for malpractice when infants die at birth puts pressure on hospitals to maintain neonatal intensive care units (NICUs) along with their maternity services. Following the advice of their lawyers, doctors and hospitals believe that if newborns are moved immediately to NICUs, the providers will be following best practice guidelines, and thus will be less likely to lose malpractice cases. The expansion in the number of NICUs, in part caused by this reasoning and in part caused by the potential to earn revenue from the care of preterm infants, reduces the average number of infants treated in each hospital's unit. This reduces the opportunities for staff to gain experience caring for high-risk newborns, and thus potentially lowers the quality of care available to the infants. At the same time, knowing that there are on-site NICUs with the capacity to care for preterm newborns shifts obstetricians' decisions about whether to intervene and deliver an infant before term if a pregnant woman experiences pregnancy complications. The segment of infants born preterm because of physician intervention accounts for the overall increase in preterm births in the U.S. over the last two decades; the number of preterm births occurring spontaneously has actually declined. Each of these decisions or events is ostensibly distinct, but each one alters the circumstances under which the next decision is made or the next event occurs.

The primary objective of this book is to explore multiple overlapping dimensions of preterm birth in the U.S. simultaneously, so that the view of each dimension of the issue can be illuminated both by history and by an understanding of the view from the other dimensions. The secondary objective of this book is to use the various features of preterm births in the United States to shed light on some broader themes in U.S. culture and social organization. The fact that some features of the issue of preterm birth in the U.S. differ from features in otherwise similar places, such as Canada, Great Britain, and other Western European countries, provides an opportunity to explore those aspects of U.S. society that are both unique and pivotal in their impact on the health of the population.

Six dimensions of preterm birth are explored in this book: the clinical, epidemiological (population-based), cultural, political, healthcare system, and ethical dimensions. Chapter 1 examines the clinical dimension of preterm birth as it reflects guiding interpretative paradigms in Western medicine, in particular the expectation that biological events can be consistently measured and altered by effective interventions. This expectation leads to the belief that preterm birth is a type of medical problem than can be prevented or "cured" once the correct therapy is identified. The chapter examines current clinical beliefs about the triggers for two types of early delivery, the type that occurs when pregnant women spontaneously go into labor before their pregnancy reaches 37 weeks gestation, and the type that occurs when physicians intervene to deliver a baby early, in order to avoid complications anticipated if the pregnancy is allowed to continue. It also describes the therapies that have been tried to prevent preterm births, and notes that nearly all of them have failed. Treatment for newborns born preterm is more successful than preventive interventions, but still a significant portion of infants born very prematurely die or suffer serious long-term consequences. At the same time, another significant portion of these newborns survive with minimal long-term problems. It is not possible, at the point of delivery, to determine with certainty what the outcome will be for any given preterm infant. After a discussion of alternative ways to think about preterm birth besides as a single syndrome or disease-like phenomenon, this chapter concludes with a discussion of the clinical perspective on the reasons that the U.S. preterm birth and preterm survival rates are higher than those in Canada, Great Britain, and Western Europe.

Chapter 2 examines the second dimension, that of the distribution of preterm births across the population. While the early ending of any particular pregnancy is not predictable, preterm births do not occur randomly across the population. Rather, they occur more frequently in certain sub-populations and under certain circumstances of fertility. This chapter explores the reasons for high rates of preterm birth in sub-populations, identified by age, race, ethnicity, socioeconomic status and whether women intended to become pregnant, among other features. At the same time, the chapter examines critically the ways that data are gathered and the ways that the population is divided up in order to create knowledge about these patterns. For example, in the U.S. it is fairly easy to characterize rates of preterm birth by race or ethnicity because these data are regularly recorded. It is difficult to characterize rates by poverty or socioeconomic status, because relevant information is seldom recorded. Ethnicity and race are considered meaningful characteristics to monitor in population composition, but it is less socially acceptable to think of the U.S. as anything other than an egalitarian or "classless" society, so income, wealth, and social status of newborns are generally not recorded. In lieu of such socioeconomic information, the differences in preterm birth rates by race and ethnicity are interpreted as meaning something about the relationship between poverty and preterm birth. This confounding of race and poverty obscures the understanding of the complex relationship between birth outcomes and both of these features of women's lives.

This chapter also discusses the attention placed on the impact of stigmatized maternal behaviors and health statuses—smoking, alcohol, drug use, and obesity—on preterm birth. Although these impacts are not large relative to other factors associated with birth outcomes, they receive considerable attention because they fit an ideologically preferred narrative about individual versus social responsibility for health, and about women's personal responsibility for their pregnancy outcomes. The comparison section of this chapter examines, from an epidemiological perspective, the reasons why preterm birth rates in the U.S. are higher than those of Canada, Great Britain, and Western Europe. Each high-risk segment of the population: non-White women living in predominantly White societies, teens, low-income women, and women with unintentional pregnancies, have higher preterm birth rates both in the U.S. and in the comparison countries. However, women with these characteristics comprise a larger portion of the population of childbearing women in the U.S. than in other places.

The third dimension, explored in Chap. 3, is that of the cultural view of preterm birth. As the term is used here, culture refers to the sets of shared understandings that members of a society use to communicate and interact meaningfully with each other. Every culture shares a set of understandings about childbirth. In contemporary Western cultures, childbirth is understood to be a medical phenomenon, and all members of these societies are expected to defer to medical authorities for the interpretation of the experience and for interventions that are supposed to guarantee a successful birth. This framing is usually referred to as "medicalization", and it contrasts with a framing that considers childbirth to be a natural, familial, or spiritual experience. Under the terms of a medicalized childbirth, attendants rely on pre-set algorithms such as the expected timing of labor and the definition of risk, rather than on observations, experience or the preferences of the laboring woman, to determine whether and when to initiate technological interventions such as drugs or surgery.

Medicalized childbirth itself is situated in the broader framework of social reproduction. Social reproduction refers to the ways a given society determines how it will continue across generations. Social reproduction is accomplished by laying out cultural rules for who becomes a parent, when and how, who claims responsibility for children, and how fetuses, infants and children are defined as independent and/or as intertwined with their families. Western cultures in general view fetuses as having an independent existence from early in pregnancy, and view pregnant women as primarily vessels for fetal development. This view is rooted in the patriarchal organization of these societies, in which a primary role for women is to continue a man's bloodline and insure that he has heirs.

Mothers are thought to be responsible for the outcomes of their pregnancies and their children through adulthood. There is thus a sense in U.S. culture that a preterm birth is the result of a mistake—deliberate or unintentional—made by a mother. The "wrong" types of mothers—those whose reproduction is not preferred in the social scheme, including young, unmarried, low income, and minority women—are most likely to make mistakes and this is why, according to this cultural logic, they are more likely to deliver before term. This cultural logic also explains why preterm births are popularly assumed to be preventable, even though, as discussed in Chap. 1, no clinical intervention to prevent preterm births has been identified. The worst mistake that a mother can make is to not follow the instructions of her physicians, so this set of beliefs both reinforces the authority of the medical system, and provides a rationale when the medical system fails to meet the expectation that it can guarantee a successful pregnancy outcome. That is, culturally based beliefs hold that any poor outcome is considered the mother's fault, and probably occurred because she did not follow her physicians' instructions.

The comparison section of Chap. 3 notes similarities in the medicalization of childbirth, but also some differences in the model of social reproduction in Canada, Great Britain, and Western Europe, compared to the U.S. The notion that some women should not have babies, and thus are probably at fault if their pregnancies have poor outcomes, is not as dominant in these other societies as it is in the U.S. In part this difference derives from the fact that historically these societies have been less racially and ethnically divided than the U.S.; healthy reproduction for all women has been considered to be a benefit to the society as a whole. Furthermore, these societies have long been concerned about low fertility rates in their populations, and the consequences of dwindling population size for their future viability. In the U.S. historically, low fertility rates in White middle- and upper-class women have been a concern, but public attention has been focused more on the supposedly high or too high fertility rates among Black, immigrant, and poor women. Concerns about low fertility rates are the basis for social policies that support pregnant women and new parents, for example, with paid pregnancy leave, family leave, and income subsidies, all of which are absent in the U.S. In addition, the regulation of abortion is framed differently, particularly in European countries, than it is in the U.S. In Europe, providing abortion under controlled circumstances is seen as a way to support families in difficult circumstances. In the U.S., abortion is framed as one manifestation of a presumed conflict between the interests of mothers and that of their future children. The ways that the relationship between mothers and fetuses is understood has an impact on several of the sociocultural dimensions of preterm birth.

Chapter 4 explores the political dimension of preterm birth, that is, how preterm birth plays into struggles over power and resources in U.S. Preterm birth is framed as a social problem—a social phenomenon that legitimately demands attention by political decision makers—in three political arenas in the U.S. The first is the arena of control over reproduction. The occurrence of preterm births is used to justify an argument for broader contraception availability, on the assumption that pregnancies that are planned and desired are less likely to end prematurely. At the same time, for those opposed to liberal abortion policies, the potential for preterm newborns to survive means that the distinction between fetuses and infants is arbitrary. This in turn bolsters the conviction that performing an abortion is equivalent to murdering a child. This chapter explores how the socially recognized problem of preterm births is used to justify proposals to limit access to abortion, and how policies promoted by opponents to abortion impact the care of preterm infants.

The second political arena where the social problem of preterm birth plays a role is in the efforts to ameliorate the effects of poverty. Ameliorating the effects of poverty has been contentious in the U.S. since the nation's founding, because acknowledging and addressing poverty implies that there are structural flaws in the U.S. economic system which could be addressed by restricting some aspects of free market capitalism. In contrast to addressing poverty directly, providing care for innocent babies is a legitimate political enterprise, and "baby saving" (as it was termed at the turn of the twentieth century) has been used as a vehicle for a variety of social welfare reforms, including efforts to institute universal health insurance coverage.

The third political arena where preterm births have been important is in efforts to address racial inequality in the U.S. Large disparities by race in preterm birth and infant mortality rates in the U.S. are taken as concrete evidence that racial inequality persists and has damaging consequences. Programs and resources to address preterm births in the Black population are an acceptable and politically attractive way to help defuse this political challenge, when more radical proposals for addressing racial inequity face resistance from entrenched interests.

The dynamics of these three political arenas are unique to the tensions and circumstances present in the U.S. Therefore, the perceived social problem of preterm birth does not play the same political role in Canada, Great Britain and Western Europe as it does in the U.S. In Western Europe, contraceptive policies are about sexuality rather than infant health, and abortion policies are about family welfare. However, concerns about high-risk pregnancies and preterm births have played a role in political struggles over the extent and design of social welfare programs, and in the structure of labor laws in these countries. In contrast, in the U.S., advocates for gender equity in the workplace have downplayed the relationship between work exposures and pregnancy risks, and the prevention of preterm births has not figured prominently in efforts to modify employment policies for women.

Chapter 5 examines the medical care provided to pregnant women who are perceived to be at high risk for preterm birth, as well as the care provided to preterm newborns. This is the healthcare dimension of preterm birth. In the U.S., this care often involves technologically focused interventions, including some that are of questionable effectiveness. There is variation around which pregnant women receive which interventions and what types of medical specialists are involved in their care. Care for preterm newborns is more uniform than care for pregnant women, and tends to involve aggressive resuscitation at very early gestational ages. This chapter examines the drivers of the generally maximalist approach to treatment in the U.S. for high-risk pregnant women and preterm newborns: provider competition, an urge to action in response to cultural expectations for the success of medical care, and commercial interest in increasing revenue by providing more goods and services. The chapter also examines the consequences of this approach, in terms of system organization (over-capacity of NICUs and a fragmented referral system), and high healthcare expenditures.

Women's experiences of high-risk pregnancies are conditioned by shared cultural understandings of preterm birth and affected by the dynamics of the healthcare delivery system. When women shift from defining their pregnancies as normal to defining them as likely to end prematurely or involve other complications, they enter into social roles that involve a set of expectations that are sometimes difficult to fulfill, such as extreme activity restriction and the acceptance of painful interventions with negative side effects. This chapter examines these expectations, and also the social expectations that women and their families assume once their preterm infants are born and enter into neonatal intensive care. Interfacing with a system geared to maximal treatment limits the range of decisions women can make for themselves and that parents can make on behalf of their infants.

The U.S. healthcare system operates as a set of interconnected commercial enterprises. Federal and state governments play relatively weak roles in setting policy for the system, although governments do collect and redistribute tax revenue to subsidize health insurance, and do provide some regulatory approval for new drugs and devices. Instead, suppliers (medical care providers) and financiers (insurance companies) are the primary decision makers. This is quite different from the active role that governments play in the healthcare systems of Canada, Great Britain and Western Europe. In all of these countries, the costs of health care are publicly financed, and in several of them facilities are publicly owned and some or all medical professionals are public employees. Maternity care systems in these settings are more primary-care focused and more systematically organized than in the U.S. This limits the over-treatment that sometimes occurs in the U.S. system, reduces practice variation and orients care providers to pay more attention to the clinical value of treatments. However, it can also mean that infants born prematurely have less immediate access to NICU care, relative to the U.S. The experience of high-risk pregnant women and the families of preterm infants are relatively similar across national settings.

The final dimension of preterm birth, explored in this book in Chap. 6, is the ethical dimension. Ethics refers to those decisions and behaviors that a society considers to be moral, and in that sense ethics are another aspect of culture, as defined in Chap. 3. Chapter 6 focuses on the ways that morality is defined in the context of high-risk pregnancy and preterm birth in the U.S.: which values and principles are invoked, how authority and agency to make moral decisions are understood, and what types of ethical problems commonly occur. Ethical problems include conflicts between two moral principles held by the same individual, conflicts between the moral views of different parties, and conflicts over which parties have the standing to be involved in ethical decisions.

For example, in several situations in the course of caring for high-risk pregnant women and preterm newborns, clinicians must decide between their own principles of respecting patient and parental autonomy—to refuse treatments, to choose whether to resuscitate infants born extremely prematurely—and of acting in what they perceive to be the best interests of women, fetuses and newborns. How should decisions be made if clinicians believe that the choices of a pregnant woman are harmful to her fetus? In other situations, multiple parties have different views which must be negotiated before a decision can be made. For example, most clinicians reach a point in the care of some extremely preterm infants when further interventions seem harmful rather than beneficial, but some parents believe that it is never ethical to stop treatment. In still other situations, there is disagreement about whether parties besides clinicians and families should have a role in ethical decision-making. For example, in some places in the U.S., legal authorities enforce mandates about the way pregnant women who use illicit drugs should be treated. These mandates conflict with clinical ethics guidelines concerning patient confidentiality and patient rights to refuse treatment, and also conflict with women's attempts to adhere to their own definitions of moral parenting. What is the societal role in decision-making around the treatment of high-risk pregnant women and preterm newborns?

In a spillover from the political struggle over abortion policy, advocates in the U.S. have used the legal system to enforce a particular moral view that structures the decisions that clinicians and families can make about withholding and withdrawing neonatal care. While the societal view concerning the preservation of life of a fetus or newborn is relatively influential in ethical decision concerning preterm birth in the U.S., societal views related to the optimal use of resources for the care of preterm newborns are seldom strongly expressed. In the U.S., it is generally considered ethical to limit healthcare expenditures if they are useless or wasteful, but unethical to consider restricting expenditures when newborns who might otherwise survive are likely to die without care. The difficulty in having these conversations is related, in part, to the structure of the U.S. healthcare system, in which no party has overall responsibility for resource allocation decisions, so trade-offs between resources allocated to maternity and neonatal care and the way those resources could be allocated to other investments is obscured.

Discussion of ethical issues in Canada, Great Britain, and Western Europe reflect all of the same concerns seen in the U.S.: what to do when pregnant women make choices that are thought to be harmful to their fetuses, when to respect and when to restrict parental autonomy for the benefit of infants, what criteria to use in determining whether life support for marginally viable preterm newborns should be withheld or withdrawn, and what is the best use of societal resources? However, the view that the interests of mothers and fetuses are in conflict is not as widely or firmly held in these societies, so there is less social and legal support for efforts to over-ride patient autonomy for perceived fetal benefit. There is more variability in the extent to which the belief in preservation of newborn life at all costs is upheld, so quality of life and the concerns that caring for disabled newborns will pose a burden on parents are issues that are considered legitimate to raise when making neonatal treatment decisions. In addition, the publicly financed nature of healthcare systems in these countries supports the consideration of resource expenditures and trade-offs as allowable components of ethical decision-making, in ways that are seldom done in the U.S.

This book ends with a short epilogue, which describes the aspects of U.S. culture and society that are most clearly illuminated by the way preterm birth manifests and is treated here. The framing of preterm births as medical problems, despite the fact that the early ending of a pregnancy does not fit well into a disease framework, illustrates how deeply rooted the framework is into overall U.S. ideology.

As undesirable outcomes of pregnancy, preterm births help to reinforce the medicalization of all pregnancy and childbirth experiences; they are presented as a cautionary tale for what happens when women do not adhere to instructions and expected behaviors. In this way also, along with medicalization of pregnancy and childbirth in general, preterm births help to support principles of the U.S. system of social reproduction. The pattern of the occurrence of preterm birth, as it indicates the distinctive impacts of both poverty and race, illustrate that stratification in U.S. society occurs at the intersection of race and class. The role that preterm births play in the political conflicts around fertility control, poverty, and racial inequity indicates the persistence of resistance to broader social reforms in these arenas. The placement of medicine and the healthcare system as the institutions which are expected to solve the preterm birth problem, as a proxy for addressing these broader social conflicts, helps to depoliticize the issues and to rationalize the investment of public resources in essentially private sector activities within the healthcare system.

I am a cultural medical anthropologist by training. However, most of my research work has not involved the typical anthropological activity of participant observation, that is, becoming deeply familiar with small-scale settings and producing detailed descriptions of people's modes of thinking and behaving, based on close observations and wide ranging conversations with natives in those settings. Rather, I have examined the U.S. healthcare system, focusing on the ways care is delivered to low-income populations, with a special emphasis on care for pregnant women and children. For the most part I have done this work by analyzing large data sets accumulated for other purposes, such as for paying insurance claims, recording births and deaths, or monitoring hospital use in particular states. In some cases I have been involved in fielding and analyzing the responses to telephone and mail surveys. My work has included evaluating innovative Medicaid payment systems and care arrangements for maternity care, examining the nonclinical factors associated with the transport of women in preterm labor to hospitals with the facilities to care for preterm infants, assessing the value of neonatal intensive care for the survival of preterm newborns and exploring the extent and reasons for practice variation among physicians providing care to high-risk women and preterm newborns. In the 1990s, I was part of a research team which received support from the federal Agency for Health Care Research and Quality to assess best practices for the care of low birth weight infants (the Low Birth Weight Patient Outcomes Research Team). Perhaps it could be said that I have been a participant observer in the community of researchers and clinicians involved in the care of high-risk pregnant women and preterm infants in the U.S.

However, three events piqued my interest in looking at the issue of preterm birth in the U.S. more broadly and more critically. The first was an offhand remark by a student taking a course I was teaching in public health ethics. She was a resident in Pediatrics, and she mentioned to me that she was surprised, during her rotation in the NICU, that no-one ever seemed to question whether it was worthwhile or appropriate to treat extremely preterm newborns with extensive invasive therapies. "It is as though that conversation is taboo" she said. Taboo is a word translated from Tongan, a Polynesian language, which refers to a behavior that is forbidden by collective consensus because it is considered to be dangerous, for reasons that cannot be rationally explained. The word was first used in English by Captain James Cook in 1777, to describe why natives of Tonga refused to eat specific foods. British anthropologist Mary Douglas examined taboos closely in her work examining how and why certain objects or experiences come to be considered impure or dangerous. Given the emphasis in modern Western medicine on rationality, efficiency, effectiveness, and choice about therapies, it is striking that conversations about such topics in the context of the care of preterm newborns would be considered dangerous, in some way, by the physicians involved in such care. Could understanding this taboo lead to a better understanding of the amount and pattern of resource use allocated to the care of preterm infants in the U.S.?

The second event happened a short time later. At the time, the Schools of Medicine and Nursing at my university organized monthly sessions, called "Schwartz Rounds", modeled after a program at Massachusetts General Hospital. Schwartz Rounds involve a multidisciplinary examination by care givers of the social and emotional aspects of a particular patient case. Often these sessions focus on cases where the care givers feel they have failed in some way. The case examined in the Schwartz Rounds that I attended focused on a Mexican woman, an immigrant with unknown legal status working in a poultry factory in a rural community about 2 hours from our city. She was hospitalized at our university hospital when she was 28 weeks pregnant because of dangerously high blood pressure.

Routine care in such cases is to attempt to lower the woman's high blood pressure with medication. If that is not immediately successful, physicians perform a cesarean section to rescue the newborn. In this case the medication treatment was unsuccessful, but the woman refused to have a cesarean section. Several attempts were made, involving different Spanish translators and a priest, to convince her to undergo an interventional delivery, but she continued to refuse. Her husband was reached on the telephone; he could not leave the rural community to be with his wife because he would lose his job at the poultry factory if he were absent. To the surprise and chagrin of the hospital staff, the husband seemed to be very concerned about the health of his wife, but not particularly concerned about the threatened demise of the fetus. He was not willing to attempt to convince his wife to undergo the delivery. The woman left against medical advice and returned to her home and her job. She continued to be seen by her local physician, and her baby was stillborn a few weeks later.

The caregivers in this case felt that they had failed. They had been taught that in obstetrics they had two patients, a mother and a baby, and they had been unable to provide appropriate care for one of their patients. The story evoked descriptions of similar cases of pregnant women leaving care settings and having miscarriages, some tears, and a discussion about whether pregnancy loss is considered more acceptable in Mexican than in American culture. Finally, one member of the audience, another nurse, raised this question. What would have happened if the woman had actually delivered the 28 week old newborn? How would she have cared for it during the weeks or months it would be hospitalized in the city? How would her family have survived financially if she was not able to work? Did she have other children, and what would happen to them? If the baby ended up with severe impairments, what resources would the family have to provide an ongoing care?

Of course, none of us in the audience or on the podium had any idea why the woman had refused to deliver her baby prematurely. This discussion highlighted for me the limitations of the clinical view of preterm birth for fully and accurately understanding this complex topic. It also showed how decisions are consistently being made, or at least attempted, in the clinical domain by participants who lacked the information to even speculate why patients or other parties might disagree with their approach.

The third event happened in the fall of 2009, during the intense and rancorous debate in the U.S. Congress over healthcare reform. In November, the well-respected National Center for Health Statistics (NCHS) released a brief examining the international ranking of the U.S. on infant mortality, and pointing out that the low rank—30th in the selection of nations used in the brief—was due to high preterm birth rates. The brief concluded simply that preventing preterm births is crucial to lowering the U.S. infant mortality rate. The brief made no mention of health care in the U.S. But the press coverage of the brief immediately drew the conclusion that flaws in the U.S. healthcare system were the cause of high infant mortality rates, and healthcare reform was the solution. The lead sentence from the Associated Press newswire report on the brief read as follows:

> Premature births, often due to poor care of low-income pregnant women, are the main reason the U.S. infant mortality rate is higher than in most European countries, a government report said Tuesday. (AP 2009)

The New York Times coverage of the NCHS brief included a comment from Alan Fleischman, the medical director of the March of Dimes (a foundation devoted to promoting research and improved care for preterm infants) stating that the brief "was an indictment of the U.S. healthcare system" for the poor job that it does taking care of women and children.

As a participant in the community of scientists generating authoritative knowledge about preterm births, I was surprised at this public spin on the NCHS report. I thought that it was widely understood that contemporary medical care includes no interventions that consistently prevent preterm births. It then became clear to me that the issue of preterm births was playing a role in the broader political struggle over altering the U.S. system for financing health care, whether or not the actual facts about preterm birth supported the desired rhetorical purpose. I became curious about what other political functions preterm birth plays in the U.S., and how that compares to the roles it plays in other political system. My intention to write this book came together at that point.

The content of this book is derived primarily from documents: published articles in the medical and social science literature, books, and government reports. These documents are used in two ways. In the first way, the content and conclusions drawn by the authors of this literature are taken at face value, and used, for example, to understand the population-level correlates of preterm birth, or to understand the history of medicalized childbirth in Europe, Great Britain, and the U.S. Much excellent research has been done on the topic of preterm birth and related areas from a broad set of academic disciplines. It has been a pleasure to discover it, particularly older works which may have been forgotten but are still relevant, and it is a pleasure now to introduce readers of the literature on preterm birth in one discipline or focused on one dimension to good work conducted from other points of view or other dimensions. This multidimensional examination of preterm birth in the U.S. has been made possible only because of the wealth of research that has been conducted on this subject.

The second way these publications are used in this book is as artifacts, pieces of information that indicate the way preterm birth is being understood in a particular context. For example, an editorial published in a clinical journal in 2010 was titled "Every 30 Seconds a Baby Dies of Preterm Birth. What Are You Doing About It?" (Berghella 2010). The actual editorial simply describes the content of a paper published in that issue of the journal which suggested that measurements of a short cervix during pregnancy, as indicated by ultrasound, are a good predictor of imminent delivery. However, the title communicates the contemporary clinical attitude about preterm births: that they are abnormal, common and deadly, and that physicians should be taking actions to stop them. In many cases, I have provided the historical and social context under which a document was produced or a scientific manuscript was published. These are all ways in which the documents that provide the data for this book are treated as objects of analysis.

A second source of information for this book comes from media reports, popular books, Web sites, and blogs about preterm birth. The availability of the Internet has created an easily accessible forum where advocates can post their views and interpretations of preterm birth issues, and individuals can relate their personal experiences with the issue. This provides a rich source of primary data which broadens our understanding of the issue when it is put into perspective. Chapter 3 of this book includes a content analysis of nine popular childbirth advice books, conducted in order to assess the type of advice about preterm birth that is commonly provided to pregnant women. Chapter 3 also includes an analysis of the most common themes found in a media search of two years of newspaper articles on preterm birth and neonatal intensive care. Chapters 5 and 6 each include paraphrases of exchanges posted on online forums for pregnant women which illustrate how women sort out and decide which medical interventions they request or refuse.

A third source of information is original analysis of quantitative data, mostly gleaned from reports or posted on interactive web sites. For example, analyses of vital records over several timeframes have been combined to chart time trends in preterm birth overall and for various sub-groups. In Chap. 2, parallel data from a selection of Western European countries, Great Britain, Canada, and the U.S. have been compiled to assess whether and how the childbearing population in the U.S. differs from the population in these other nations. In Chap. 5 I have used several years of American Hospital Association survey data to track time trends in the expansion of NICU services.

Although this book does not rely on intensive first-hand observation or interviews with participants in the preterm birth arena in the U.S., it still views the issue of preterm birth through an anthropological lens. What does this imply? In broad terms, the anthropological approach has three characteristics. First, it consistently takes into account the meaning that a phenomenon or event has for its participants. The fabric of meanings that shape people's understandings of their experience and shapes their responses is what is meant by the concept of "culture", so it is often said that "culture" is anthropology's master concept.

One example of the power of culture to frame the universal human experience of pregnancy loss or infant death is the contrast between anthropologists Nancy Scheper-Hughes' account of infant mortality in deeply impoverished Brazilian communities, and Linda Layne's account of the ways miscarriage is understood in the U.S. In the Brazilian context, infant death was so common that it was anticipated, and Scheper-Hughes found that maternal attachment to infants was relatively minimalized because of this expectation (Scheper-Hughes 1992). In Layne's account, many U.S. women with pregnancy losses constructed elaborate mourning rituals, giving names and purchasing gifts for children who were never born (Layne 2003). Each situation seems "unnatural" when viewed by an outsider, yet each seems inevitable or imperative for cultural participants. Although I have labeled Chap. 3 of this book an exploration of the cultural dimension of preterm birth, because it focuses on popular understandings of the issue and how they intersect with the more general way childbirth is interpreted in the U.S., it should be clear that an examination of cultural meanings threads through every dimension explored here.

A second aspect of the anthropological approach is that it includes the physical or biological components of a social phenomenon as objects of inquiry, rather than as the truth upon which the social dimensions of experience are based. This allows anthropologists to examine the range of ways that social organization and cultural interpretations impact biological circumstances, and to consider how the ability to notice and accumulate information about biological phenomena is structured by social interpretations.

For example, anthropologist Brigitte Jordan's study of childbirth in four cultures compared, among other aspects, the approach to pain in labor in the Yucatan, the U.S., Sweden, and Holland. As she described it, the experience of pain varied, depending both on culturally conditioned expectations of pain, and on whether childbirth was organized in such a way that women in labor had to negotiate with their care givers for anesthesia (the U.S.), could choose for themselves when and whether to use anesthesia (Sweden), or did not anticipate using pain relief (Holland and the Yucatan). Use of anesthesia in childbirth in turn affects the progress of labor which, depending on culturally defined expectations for this process, has an impact on whether childbirth proceeds vaginally or is accomplished by cesarean section. Mode of delivery then has an impact on particular complications experienced by the newborn. Jordan also explored the dramatic variations in what is considered to be "authoritative knowledge" about childbirth in different cultures (Jordan 1993). Here I address the clinical and epidemiological aspects of preterm birth in the first two chapters both by describing in detail what is currently known about the phenomenon while offering a cultural interpretation of how this knowledge is constructed. Chapter 5, on the healthcare system dimension, explores in more detail the way the clinical paradigm shapes obstetrical and neonatal interventions, which in turn shape prevalence and consequences of preterm birth.

Third, the anthropological approach often includes, implicitly if not explicitly, comparisons of phenomena across human cultures and societies. By identifying commonalities and contrasts in the way common experiences are understood and responded to in different societal contexts, the cross-cultural perspective helps us to notice which facts that we take for granted are actually contingent on particular cultural and social arrangements, and which core cultural and social principles are shared across societies.

Jordan's work on childbirth is an example of this, as is anthropologist Tsipy Ivry's own experiences with pregnancy when she was conducting fieldwork in Japan and when she was pregnant at home in Israel (Ivry 2010). The social context of each of her pregnancies was deeply conditioned by beliefs about the impact of the environment on fetal development and about responsible reproduction which led to differences, for example, in the use of prenatal genetic testing and the healthcare system's expectations about parental responses to abnormal test results in the two cultural settings. Here, as noted earlier in this introduction, I provide a comparison section at the end of each chapter that explores the ways that preterm birth in the U.S. are similar and different from preterm births in Canada, Great Britain, and Western Europe on the dimension discussed in the chapter.

Although the history of anthropology is rooted in research conducted by British, Western European, and American scholars in unfamiliar settings, there is an ample contemporary literature that reflects anthropological work done in one's home setting, as I have done here. Commenting on this body of work, Jessica Cattelino acknowledges that the anthropology of the United States is challenging because this society is so complex and diverse. She finds that knowledgeable scholars strive to avoid either focusing on exotic sub-populations as though they were not living in the broader U.S. contemporary context, or focusing on White "heartland" or middle-class populations and misrepresenting them as standing for all of the U.S. social experiences. Successful anthropological work in the U.S. by natives of the U.S. often selects themes such as gender relations or domains of activity such as medicine or social activism. Even in these focused studies though, anthropologists must be conscious of aspects of U.S. society that they take for granted as "natural", since they do not have the advantage working in their nonnative setting where everything seems unfamiliar (Cattelino 2010). I believe that the approach I have taken here, using the six dimensions of clinical care, epidemiology, culture, politics, medical care, and ethics to focus on the same phenomenon, preterm birth, has been helpful as a way to challenge what we take for granted.

Finally, issues related the phenomenon we call "race" play out in all six of the dimensions of preterm birth discussed in this book. After all, individuals identifying as Black or African-American comprised 13.2 % of the U.S. population in 2014, according to the U.S. census. They comprised 14.8 % of the women who gave birth in 2014, but their newborns comprised 20.4 % of all infants born preterm in that year. In 2014, the preterm birth rate for Black women in the U.S. was one and a half times the rate for White women.

Race is an identity people choose for themselves and also a way that U.S. society itself distinguishes and divides the population. Race refers to people who have a common ancestry but, distinct from the category of ethnicity, the use of the term race also implies that the group shares physical or biologically based characteristics which distinguish them from others. In the U.S., the term race is most commonly used to distinguish individuals with ancestry that traces to sub-Saharan Africa from individuals who trace their ancestry to other places. The term African-American is sometimes used for these individuals, to contradict the assumption that they share a unique biology and to equate race more closely to ethnicity. The term Black is used to emphasize the way U.S. society has differentiated Americans of sub-Saharan African descent from those with other ancestry. Critics of the use of the term African-American point out that Italian-Americans tend to lose their ethnic identity after living in the U.S. for several generations, while one's identity as an African-American is not subject to attenuation over generations.

It is not a coincidence that Black Americans are thought to share distinct biological traits, while such an assumption is not always made about individuals who trace their ancestry, for example, to Japan or Mexico. It is also not a coincidence that the designation "Black" is applied to individuals whose ancestry includes a mix of people from various continents, if any one of those continents was sub-Saharan Africa. Individuals who identify themselves or are identified by others as Black in the U.S. are, for the most part, descendants of people brought to the U.S. from Africa as slaves between 1619 and 1866. Laws put in place at the time defined anyone descended from African slaves as belonging to that race. A belief in the unique and inferior basic nature of Black people is part of the ideology that rationalized slavery. These beliefs continue to be used to rationalize Black peoples' generally marginalized position in the economic, social, and political structure of the U.S., their poorer health status and higher mortality rates. The belief system that ascribes unique and inferior traits uniformly to individuals identified as Black is called racism. Racism renders the persistent social structures which disadvantage Black people as though their results were natural phenomena, and this makes these structures more difficult to identify and critique.

Beliefs about race are an important part of U.S. cultural understandings of reproduction. As noted above, birth rates in the U.S. are easily tracked by race, and stereotypes about Black women in a reproductive context have a profound effect on how they are treated and on the outcomes of their pregnancies. These issues are discussed in this book, particularly in Chaps. 2–4. Although it is typical in much of the literature cited here to treat racial categories as though they were objective phenomena that meaningfully describe segments of the population, readers of this book should keep in mind racial categories are really social conventions that point to a complex and loaded sociocultural phenomenon.

I am happy to have the opportunity to introduce a multidimensional sociocultural perspective on preterm births to the many different audiences with interests in this arena. I would like to acknowledge the advice and support that I have received from my colleagues at the University of Alabama at Birmingham (UAB), particularly Martha Wingate and Julie Preskitt, and also from colleagues at the University of Arkansas for Medical Sciences, particularly Curtis Lowery, Richard Nugent, and Richard W. Hall. I particularly appreciate the engagement of UAB doctoral students Kathryn Corvey, Lauren Wallace and Anne Epstein, and UAB Masters student Ashley Gilmore, who carefully read the manuscript and offered their comments. My family and friends, Hannah Klinger, Karen Klinger, Thomas Burgess, Joann Schultz, Patricia Dunlap, Marion Buckley, Phyllis Mark, and Lelie Hughes, provided the encouragement and support that enabled me to stay with this project to its completion.

I hope my work will be of benefit to everyone involved in the care of pregnant women and their newborns.

Birmingham, USA Janet M. Bronstein

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Contents

Chapter 1
The Clinical Dimension: Causes, Treatments, and Outcomes of Preterm Birth

The fact that some pregnancies end before the typical 9 months gestation period has been observed since ancient times, and in contemporary times cross-culturally in all human societies (Cone 1985). The British physician P.M. Dunn quotes the ancient Greek philosopher Aristotle as observing:

> [A]ll other animals bring the time of pregnancy to an end in a uniform way; in other words, one single term of pregnancy is defined for each of them. But in the case of mankind alone of all animals the times are diverse, for pregnancy may be of 7 months' duration or of 8 months or of 9 and still more commonly of 10 (lunar) months, whilst some women go even into the 11 month. (quoted in Dunn 2006 p. 76, reprinted with permission by the BMJ publishing group)

By contemporary definition, pregnancies usually last about 280 days (40 weeks or ten 28-day cycles) from a woman's last menstrual period. There is natural variability in the length of gestation, in the sense that labor for delivery begins spontaneously within a range of weeks in any given pregnancy. There is also uncertainty about actual lengths of gestation, since it is difficult to accurately determine the precise date of conception. Current practice is to consider pregnancies to have gone to term if they have lasted between 37 and 42 weeks from the last menstrual period. Infants born before 37 weeks gestation are considered preterm, and fetuses in pregnancies that last longer than 40 weeks are considered post-term, and are subject to interventions to induce delivery. The boundary of 37 weeks marks a point in a continuum of development, however, and newborns delivered between 37 and 39 weeks are less mature than those delivered at 40 weeks gestation or longer (Clark et al. 2009).[1]

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[1] In current terminology, deliveries that occur between 37 and 39 weeks gestation are referred to as "early term" deliveries. There has been a marked increase in early term deliveries in the past few decades, in part due to changing obstetrics practices which allow for scheduling deliveries by induction or cesarean section at the convenience of parents or physicians, rather than waiting for women to go into labor spontaneously.

J.M. Bronstein, *Preterm Birth in the United States*,
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1.1 Recognizing and Counting Preterm Births

While variability in the lengths of pregnancies has long been recognized, until the late nineteenth century infants born early, along with infants with other maladies, were classified together as “weaklings” or feeble. Some physicians and midwives attempted resuscitation of these weaklings, particularly infants born during or after the seventh month of a pregnancy, and particularly in cases where the birth attendant had induced labor in order to assure an easier delivery or to treat a condition of the mother. If social circumstances permitted, weak newborns that survived after delivery might be carefully nursed and kept warm in an attempt to assure their long-term survival, but it was also anticipated that many would die. Medical historian and neonatologist Jeffrey Baker cites the British nineteenth century health reformer William Farr as expressing a Darwinian sentiment regarding preterm infant mortality; deaths in infants born before term were part of a natural process that assured the healthy continuation of the species (Baker 1996). Neonatology historian and physician Marie Desmond describes this same “survival of the fittest” philosophy in American society in the late nineteenth century (Desmond 1991).

Although the designation of “prematurity” became popular in European medical circles in the latter half of the nineteenth century [it was added to the British vital statistics system as a cause of death in 1858 (Wilcox 2010)], the formal distinction between newborns born before term and newborns with other medical problems is usually credited to the French physicians who staffed the major maternity hospital in Paris in the 1880s. The context of the distinction was their development of two technical interventions intended to improve survival rates of such infants: incubators and gavage (artificial tube feeding). Stéphane Tarnier, Pierre Budin, and their associates accumulated data on the use of incubators and tube feeding with weakling infants. They found that the most dramatic improvements in survival rates for both interventions were found for those born at the youngest gestational ages. Because gestational age is difficult to measure accurately, they also adopted the new European convention of the time, and categorized newborns by birth weight. Thus, a widely distributed publication from this physician group in 1883 reported a decrease in infant mortality rates from 66 to 38 % among infants born at less than 2000 g, after the installation of incubators in the hospital. Another article, published in 1887, reported a mortality rate decline from 61 to 36.3 % among infants born at 7 months gestation, along with a decline from 78.5 to 47 % among infants born at 6.5 months gestation, for those treated with a combination of incubators and gavage. Had they reported the data without grouping the newborns by gestational age or birth weight, the results would not have been as dramatic. This is because the interventions addressed two conditions specific to premature infants: difficulty in temperature regulation and inability to suck. The French physicians coined the terms “*avant term*” (preterm) and “les prematures” for these younger and smaller infants (Baker 1996; Cone 1985).

In some ways it was the unique circumstances of these physicians in France that prompted the approach of emphasizing gestational age in categorizing weakling infants. According to Baker, the French medical orientation of the time tended to emphasize the constitution of individuals, in contrast to the more modern approach of the German medical tradition, which emphasized disease pathologies. Thus the French physicians were more prone to see respiratory distress, for example, as a complication of prematurity, while the German physicians were more focused on the unique characteristics of different respiratory pathologies themselves. Furthermore, because of the way medical care was organized in France, the same physicians and hospitals delivered infants and cared for them, so the French physicians were more likely to be aware of the gestational timing of the births of their patients than physicians in systems where separate pediatrics specialists cared for newborns. Finally, it was this group of physicians, with political and monetary support from a French government concerned about low fertility rates and population declines, who pioneered technologies, practices, and institutions devoted to improving the survival of newborn infants. They therefore had an interest in proving the effectiveness of their approach by identifying specific medical problems that the interventions, particularly incubators that kept newborns warm, could treat.

Disease definitions—frameworks for interpreting observations of the body—arise in a social context and are ways of creating meaning within the broader cultural language of the society (Rhodes 1996; Rosenberg 1997).[2] Putting the identification of preterm births as a medical problem in historical context is one way of recognizing how such definitions are socially constructed. The variability in the designation of diseases across historical periods and world cultures contrasts with the assumption about disease categories in the Western medical system[3]: that they are pure reflections of biological facts, waiting to be discovered and named.

In fact, the designation of a distinct category of premature babies in France in the late nineteenth century reflects several cultural features which remain characteristic of Western medicine (Gordon 1988; Hahn and Kleinman 1983; Rosenberg 1997). First, the occurrence of the condition defined as prematurity could be empirically defined and measured by gestational age, while the category of feeble or weakling could not. The late nineteenth century marked a definitive turning point in Western medicine toward positivism, the premise that all that is known to be true can be observed and measured. Second, all of the features observed as occurring to newborns categorized in this way could be reduced to physical phenomena related

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[2] A discussion of the history of framing pregnancy in general as a medical issue is presented in Chap. 3 of this book.

[3] The term Western medicine is used here to refer to the body of knowledge, definitions and therapies characteristic of contemporary European and American societies. Hahn and Kleinman (1983) prefer the term "biomedicine" to refer to this system, since it has penetrated societies around the world, but is no more contemporary than non-Western systems such as the Indian Aryuvedic system.

to this categorization. The Western system tends towards physical reductionism, holding that diseases are natural rather than social phenomena, and that they are fundamentally physical dysfunctions or deviations from normalcy. Third, and perhaps most importantly, the categorization of newborns as premature could be associated with a specific set of therapies that address the problem, and result in an improved outcome. The Western medical system has an action orientation which tends to frame health problems in terms of therapy, and sometimes defines medical problems only when therapies are available to treat them.[4]

Anthropologist Deborah Gordon refers to all of these as features of a framework of naturalism, which supports an individualistic view of human society that in turn places high value on rationality, autonomy, and freedom, all important features of Western culture (Gordon 1988). Naturalism and individualism reinforce the view that humans are singular and can be understood as distinct from society and their social context. This view is not universal across human societies. For example, anthropologist Olayinka Savage has described the attitude of the Belinke people in the Cameroons as emphasizing the societal connections of newborns, rather than their individualism. When a pregnancy loss occurs, it is understood that the baby had not intended to stay, but was just passing through. The remains are buried quickly and the incident is not discussed, to avoid attracting malevolent forces that could cause a repeat loss. There are no official mourning rituals. She writes, "Society only mourns its members. Since babies who die due to premature or stillbirths have no names, they are not members of society and cannot be mourned." (Savage 1996, p. 101).

Perinatal epidemiologist Wilcox (2010) notes that Pierre Budin himself suggested that 37 weeks be used as the threshold for measurement of prematurity; given variability in the length of gestation and the continuum of infant maturity at delivery, this threshold is relatively arbitrary. Wilcox bemoans the fact that between 1919 and 1961, European and U.S. practice shifted toward using a birth weight threshold of 2500 g as the definition of prematurity, in place of gestational age. Birth weight was a more attractive definition because it could be measured precisely, so the categorization of infants as premature did not depend on parental recall for estimations of the start of the pregnancy. British sociologist Ann Oakley associates the adoption of birth weight as a standard measure for infants as part of the movement to replace traditional child rearing practices with so-called "scientific motherhood," within which the regular monitoring of children's weight and weight gain became a way to evaluate (and in a sense, morally judge) mothers on their feeding and care practices. She also notes that the apparent precision of birth weight

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[4] Sociologist Peter Conrad identifies pharmaceutical companies as one of the engines for the contemporary framing of relatively common situations such as menopause or hair loss as "medicalized" conditions or diseases. Thinking of them as diseases justifies marketing the pharmaceutical company products as treatments (Conrad 2007).

is overstated, since birth weight is influenced by the particular scale that is used and how soon after delivery an infant is weighed (Oakley 1992).[5]

However, the most significant problem with the shift toward defining prematurity by birth weight is that birth weight and gestational age represent two different phenomena. While it is the case that infants born before 37 weeks tend to be small, infants born at term can also be low weight and preterm infants can be high weight due both to physiological issues affecting development, such as maternal obesity or gestational diabetes, and to natural human variability in size. In the 1950s, British epidemiologists with access to population-based measures of both birth weight and estimated gestational age, recorded in vital records, noted the lack of correlation between the two measures (less than half of infants with weights below 2500 g were actually preterm, and less than half of the preterm infants were less than 2500 g). In 1961, the World Health Organization recommended using the term “low birth weight” for infants born smaller than 2500 g. To avoid confusion, Wilcox writes, researchers have adopted the term “preterm” to indicate a birth at younger than 37 weeks, because the term “premature” is still associated with low birth weight in many contexts (Wilcox 2010, p. 199). The terms “small” and “large” for gestational age (SGA and LGA) are used to indicate infants who have compounded preterm and fetal growth issues.

Although attempts at creating comprehensive vital statistics systems that record data on all births in the population date to the early 1900s in the United States (Desmond 1991), national birth data, combining records from most or all of the states, have only been available since 1950. Figure 1.1 combines data from four separate summaries of U.S. vital statistics to track rates of preterm birth from 1950 to 2010. Preterm births are divided into two groups: those under 32 weeks gestation at delivery, and those 32–36 weeks gestation. The figure also shows the overall portion of births under 37 weeks.

Figure 1.1 shows that U.S. preterm birth rates have risen since the 1950s. Even if the data reported for the 1970s is discounted because of the exclusion of 12 states (these states did not collect gestational age by last menstrual period on birth certificates in this time period), rates have clearly risen since 1980, in the 30 years of consistent data collection. The increase in the overall preterm birth rate is driven primarily by the increase in births of newborns between 32 and 36 weeks gestation, as opposed to births of newborns younger than 32 weeks gestation.

The U.S. preterm birth rate has triggered considerable concern within the medical and public health communities. The upward trend has received waves of attention from politicians and policy makers, each wave often followed by allocations of public resources intended to address the issue. Each year’s preterm birth rates are examined in the hopes that they will reveal a decline from the previous year. As Chap. 4 of this book describes, the intense public interest in preterm birth

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[5] Oakley also notes that a common folk belief in Europe and Great Britain at the time was that weighing infants and children was damaging to their health. This belief had to be overcome by campaigners in order to institute regular weighing as a standard medical practice.

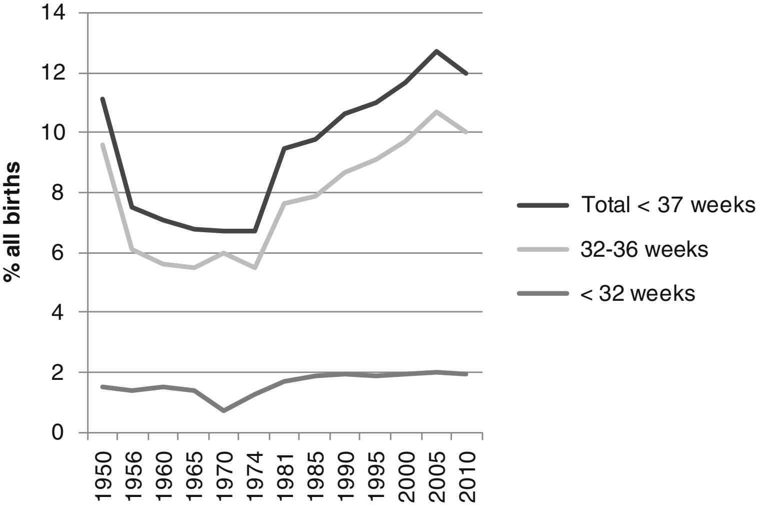

Fig. 1.1 Preterm birth rate in the U.S., 1950–2010, based on Chase and Byrnes (1970), Table 2; NCHS (1974), Table 17; NCHS (1976), Table 20; Martin et al. (2013), Table 24. *Note* 1950 data exclude Louisiana and Massachusetts, 1956 data exclude Maryland outside of Baltimore, Massachusetts and Washington, and 1960 and 1965 data exclude Maryland outside of Baltimore and Massachusetts. Data for 1970 and 1974 exclude Alabama, Arkansas, Connecticut, Delaware, Georgia, Idaho, Massachusetts, New Mexico, Pennsylvania, Texas, Virginia and Wisconsin

rates (and infant mortality rates) accrues in part because these rates are seen as a type of report card on U.S. society as a whole. In fact, the March of Dimes[6] annually grades states "A" through "F" based on the difference between their most recent reported preterm birth rate and a goal of 8.1 % preterm births by 2020. (March of Dimes 2015). This use of vital statistics as an indicator of what might be termed "civic worth" dates back to the earliest efforts to monitor infant mortality rates in the nineteenth century (Katz 1986). At a symbolic level, a rise in U.S. preterm birth rates over time represents a contradiction to an important ideological

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[6] The March of Dimes was initially the name of the major fundraising event conducted by the National Foundation for Infantile Paralysis, founded by President Franklin Roosevelt in 1938 to aid polio patients and raise funds for research on polio. The organization was extremely successful at fundraising, and in the 1950s supported the development of the polio vaccine, which successfully eliminated the threat of polio in the U.S. Rather than disbanding, the organization changed its name to the National Foundation and refocused its efforts on birth defects and infant mortality. The name was changed again to the March of Dimes Foundation in 1976. The foundation became very active in efforts to reorganize maternity and pediatric medical care in order to increase access to newly available neonatology interventions. In 2003, the March of Dimes officially added the reduction of rates of premature birth to its mission. It remains a major advocate for and funder of research on preterm birth, and also provides direct support to families of infants born prematurely. It is a relatively large charitable organization, with revenues of over $200 million in 2012.

premise (held in Western societies in general and dating from the Enlightenment era in the 17th century) that social progress is inevitable as societies advance technologically over time. By the dictums of the belief in social progress, preterm birth rates should be falling, not rising, over time as U.S. society becomes more technologically advanced.

However, the overall preterm birth rates shown in Fig. 1.1 obscure two important features of these trends in the U.S. The first is that preterm birth rates and trends over time are quite different across ethnic groups in the U.S., and in particular are higher for the Black population compared to other U.S. subgroups. Preterm birth rates are also higher for low income compared to higher income women. Thus the ranking of states in order of their March of Dimes prematurity grade, rather than being simply a direct representation of social progress or successful or unsuccessful action related to population health, tracks closely with state demographics (see Table 1.1). States with the highest grades for preterm birth rate have either the smallest proportion of Black residents in their populations or lower poverty rates, or both. States with the lowest grades, with the exception of Wyoming, all have much larger portions of Black and low-income people in their populations.

Table 1.1 March of Dimes prematurity grade and state population demographics

State	March of Dimes (2015) grade	2014 preterm birth rate (%)	Portion of Blacks in the state population, 2013 census estimates (%)	Portion below poverty level, 2009–2013 average, census estimates (%)
Oregon	A	7.7	2.0	16.2
Vermont	A	7.9	1.2	11.8
Washington	A	8.1	4.0	13.4
Idaho	A	8.1	0.8	15.5
New Hampshire	B	8.2	1.5	8.7
California	B	8.3	6.6	15.9
Maine	B	8.4	1.4	13.6
North Dakota	B	8.4	1.8	11.9
Colorado	B	8.4	4.4	13.2
Alaska	B	8.5	3.9	9.9
South Dakota	B	8.5	1.9	14.1
Massachusetts	B	8.6	8.1	11.4
Rhode Island	B	8.6	7.5	13.6
Kansas	B	8.7	6.2	13.7
Minnesota	B	8.7	5.7	11.5
New York	B	8.9	17.5	15.3
Arizona	B	9.0	4.6	17.9

(continued)

Table 1.1 (continued)

State	March of Dimes (2015) grade	2014 preterm birth rate (%)	Portion of Blacks in the state population, 2013 census estimates (%)	Portion below poverty level, 2009–2013 average, census estimates (%)
Utah	B	9.1	1.3	12.7
Nebraska	B	9.1	4.8	12.8
Connecticut	B	9.2	11.3	10.2
New Mexico	B	9.2	2.5	20.4
Virginia	B	9.2	19.7	11.3
Wisconsin	B	9.2	6.5	13.0
Delaware	C	9.3	22.1	11.7
Montana	C	9.3	0.6	15.2
Iowa	C	9.3	3.3	12.4
Pennsylvania	C	9.4	11.5	13.3
District of Columbia	C	9.6	49.5	18.6
New Jersey	C	9.6	14.7	10.4
Indiana	C	9.7	9.5	15.4
North Carolina	C	9.7	22.0	17.5
Missouri	C	9.8	11.7	15.5
Michigan	C	9.8	14.3	16.8
Florida	C	9.9	16.7	16.3
Arkansas	C	10.0	15.6	19.2
Hawaii	C	10.0	2.3	11.2
Illinois	C	10.1	14.7	14.1
Nevada	C	10.1	9.0	15.0
Maryland	C	10.1	30.1	9.8
Oklahoma	C	10.3	7.7	16.9
Ohio	C	10.3	12.5	15.8
Texas	C	10.3	12.4	17.6
Kentucky	D	10.7	8.2	18.8
Tennessee	D	10.8	17.0	17.6
Georgia	D	10.8	31.4	18.2
South Carolina	D	10.8	27.9	18.1
West Virginia	D	10.8	3.6	17.9
Wyoming	D	11.2	1.7	11.5
Alabama	F	11.7	26.6	18.6
Louisiana	F	12.3	32.4	19.1
Mississippi	F	12.9	37.4	22.7

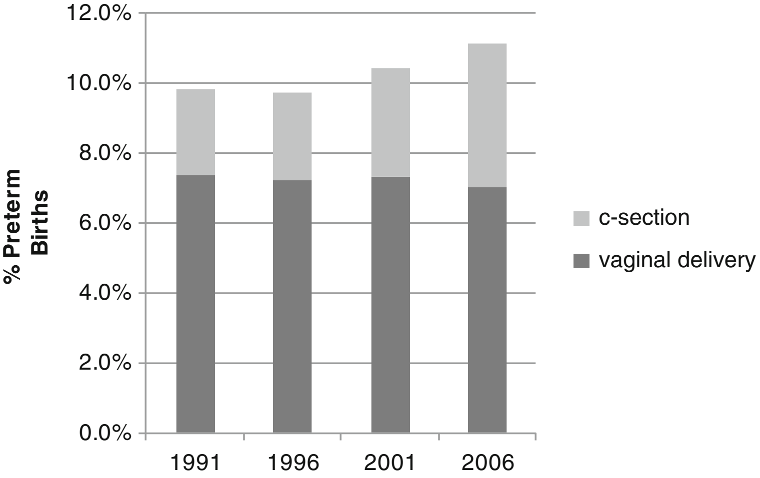

Fig. 1.2 Cesarean section and vaginal singleton preterm (<37 week) deliveries, data from MacDorman et al. (2010), Table 1

The second feature which is not apparent when overall preterm birth rates over time are examined is that, in recent years, the portion of preterm births that occur spontaneously has declined, while the portion that occur because physicians intervene to purposely deliver babies before they reach term has increased. This is illustrated in Figs. 1.2, using data on singleton births analyzed by the National Center for Health Statistics (MacDorman et al. 2010). The majority of the increase in preterm births observed over this 15-year period comes from deliveries that occurred after physician intervention. The portion of births delivered by cesarean section, as shown in this figure, is a slight under-representation of all interventional preterm births, because a small portion of the vaginal births occurred following an induction (an intervention, such as medication, to trigger of labor). As will be discussed in more detail below, some of the preterm births that occurred following a cesarean section or labor induction would have been delivered preterm even if the intervention had not occurred, but some of those preterm infants would have gone to term without intervention. Thus, at least to some extent, the current high preterm birth rate in the U.S. has been inflated by obstetric treatment.

1.2 Biological Pathways for Preterm Birth

Medical historian Charles Rosenberg (1997) notes that the identification of a causal explanation for a condition is always a component of defining, or in his terms "framing" a disease, but causes are defined according to a vocabulary that is time and place specific. He writes:

> In ancient times, for example, references to cooking provided a familiar source for a metaphorical understanding of the body's metabolism, the aggregate functions of which determined the physiological balance that constituted health or disease. Now, at the end of the twentieth century, hypothetical autoimmune mechanisms, or the delayed and subtle effects of virus infections are often used to explain diffuse chronic symptoms. (Rosenberg 1997 p. xviii, reprinted with permission from Rutgers University Press)

Historian Barbara Duden (1993) also notes how the metaphor of cooking or fermenting was used in earlier centuries in Europe to understand the process of fetal development during pregnancy, and the consequent ways this structured an understanding of miscarriage, abortion, and preterm birth. Miscarriages and early deliveries in this paradigm did not equate to a loss of life, because the contents of the uterus were not equated to a human being.[7]

Anthropologist Robbie Davis Floyd describes how the contemporary orientation which frames bodies as machines, and perceived health problems as mechanical dysfunctions, shape therapeutic actions taken for pregnant women, and contrast to alternative interpretations of pregnancy. When the uterus is understood as an involuntary muscle and labor is seen as the mechanical response of the muscle to hormonal signals, then the medical response when labor stops is to restimulate the uterus with a synthetic hormone. This is one aspect of labor induction. In contrast, midwives who think of the uterus as a responsive part of a whole woman respond to stopped labor by encouraging the laboring woman to rest. She is instructed to notify the midwife when labor restarts (Davis Floyd 1994). A 2013 survey of childbirth experiences for U.S. women found that 47 % of first time mothers who went into labor received induction before delivery; 63 % of all those who received induction had labor stimulated with synthetic hormones (Declercq et al. 2013). This is an indication that the mechanical view of the uterus as a muscle that must be artificially restimulated if contractions stop in the course of labor is very widespread in contemporary maternity practice.

1.2.1 Spontaneous Preterm Births

Spontaneous preterm births are those that occur because the pregnant woman goes into labor, with or without a rupture of the amniotic membrane that surrounds the developing fetus, at some point before the pregnancy reaches 37 weeks. Spontaneous preterm births account for about two thirds of all preterm births. Following the framing of women's uteruses as muscles that respond to hormonal signals, the contemporary causal model for spontaneous preterm birth is that labor or membrane rupture before a pregnancy reaches term occurs when maternal hormones, similar if not the same as those that function during term labor, are triggered early. Ordinarily, these hormones are triggered by some mechanism related to fetal

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[7] Debates over the early European framing of abortion and fetal life are discussed in Chap. 3 of this book.

maturity. Women carrying twins or triplets often go into labor before term, and it is thought that this may occur because their uteruses become stretched or distended early, and a stretched uterus may be part of the signaling of fetal maturity that triggers term labor. Wilcox (2010) points out that multiple infants born before term have lower mortality for their gestational age than singleton infants, perhaps because they are born after labor that is triggered in the same way as labor at term, rather than being triggered by an abnormal physiological situation.

However in most spontaneous preterm births, the labor-initiating hormones are triggered by different biological mechanisms from labor at term. The three primary preterm labor triggers are thought to be stress, immunological responses to infection, and intrauterine bleeding (Goldenberg et al. 2008). Each of these stimuli trigger the hormones in a different manner. In the case of stress, laboratory studies of placental cells exposed to a range of stress hormones, such as cortisol and epinephrine, release corticotropin-releasing-hormone (CRH), which is sometimes referred to as the "placental clock" because it regulates length of gestation by initially stimulating uterine contractions. For infections and inflammations, laboratory and experimental animal studies suggest that cytokines released as part of the body's immunological response trigger the release of prostaglandins, another hormone that stimulates uterine contractions. Infections may also stimulate the production of the fetal hormones which more typically signal fetal maturity, triggering the labor-initiating hormones in that manner. Furthermore, chronic stress may increase the production of cytokines during an immune response, so stress and infection may interact to trigger labor. Observations of cohorts of women with spontaneous preterm births show that they have much greater rates of several types of genital and urinary tract infections and bacterial infections than women with term pregnancies.

Third, in terms of the relationship between intrauterine bleeding and spontaneous preterm labor or membrane rupture, laboratory and animal studies show that the normal coagulation responses of the body to bleeding trigger muscle contractions. When bleeding occurs in the uterine environment, for example from a ruptured placenta, the thrombin released in response may trigger uterine contractions which then initiate the remainder of the labor hormones and responses (Behrman and Butler 2007).

As can be seen from this description, spontaneous preterm delivery is not a single physiological event. It is the outcome of multiple circumstances occurring in the bodies of pregnant women. These circumstances generate sets of responses that, at some point in the process, function in the same way as the hormones that result in labor and birth when a pregnancy reaches term. It is not clear when in the pregnancy these circumstances occur. For example, both bleeding and inflammation could be responses to the abnormal implantation of a fertilized egg in the uterus at the very initiation of pregnancy. Also it is likely that many of the other circumstances that trigger spontaneous preterm delivery, including infections, stress, and circulation issues, are present before a pregnancy begins. This complex picture of the causes of preterm birth and the variability of responses to these causes—some women with stress, infections, and inflammation deliver preterm and some do not—

violates our Western expectations that diseases can be reduced to unified physical causes. It is this disruption of these expectations that prompts observers to label spontaneous preterm birth as “an enigma” which persists despite extensive research into the phenomenon (Muglia and Katz 2010).

1.2.2 Interventional Preterm Births

While two thirds of preterm births occur spontaneously, the remaining third occur because physicians intervene before a pregnancy reaches term and either stimulate labor artificially and/or perform a cesarean section to deliver the baby. Some clinicians and researchers suggest that it is a mistake to categorize interventional preterm births as distinct from spontaneous preterm births because their causes overlap—some interventions are performed for the same clinical conditions that trigger spontaneous preterm birth in other situations (Klebanoff and Shiono 1995; Savitz et al. 2005). Combining interventional and spontaneous preterm births by apparent etiology in this way, for example, as related to maternal hypertension, is useful because it yields a larger number of cases for analysis. However, the approach of combining interventional and spontaneous preterm births also reflects the cultural tendency in Western medicine to diminish social causes and to emphasize the apparently biological causes of diseases and other health problems. This draws attention away from contextual factors that encourage or discourage physicians from intervening to perform a preterm delivery. The practice of terming this category “indicated” preterm deliveries, rather than the occasionally used term “iatrogenic” (induced unintentionally by medical treatment) preterm births similarly deemphasizes the role that social factors may play in the decision to intervene. This book will use the term interventional to refer to these deliveries, since they are neither unintentional (iatrogenic), nor always indicated by objective criteria.

One view of interventional preterm deliveries is that their increase in incidence in the last several decades has been accompanied by a decrease in rates of fetal and infant mortality. This suggests that infants born preterm through intervention would otherwise have died, so the recent increase in preterm births associated with increases in interventional deliveries in the U.S. is a positive rather than a negative finding. Lantos and Lauderdale characterize this view as follows:

> Such data suggest that the rise in preterm births may not be such a bad thing. It may reflect better obstetrical care with more sensitive assessments of fetal distress. When coupled with excellent neonatal intensive care, it may lead to improved outcomes for babies compared to an approach to obstetrics that is oriented towards examining rates of term birth. (Lantos and Lauderdale 2011 p. 7)

Canadian obstetrician K.S. Joseph proposes that pregnancy be thought of as a 9-month period when the fetus is at risk for a poor outcome (Joseph 2007; Joseph and D’Alton 2013). The role of the obstetrician at any juncture is to determine whether a given fetus is better off in utero or delivered, given the likelihood of potential negative outcomes as pregnancies continue. Joseph refers to “selective, carefully timed early delivery given fetal compromise” as the “cornerstone of modern obstetrics” (Joseph 2007, p. 2). This is an interesting view which reflects the tendency of obstetrics to view all pregnancies as potentially high risk and in need of medical intervention (Rothman 2007). By normalizing interventional deliveries as a substitute for spontaneous labor and delivery, the view also reflects the tendencies in Western culture, discussed further in Chap. 3 of this book, both of medicalizing pregnancy and of considering women primarily as the vehicles for producing (men’s) children (Rothman 2000). In addition, framing pregnancy from the point of view of the fetus, rather than that of the pregnant woman, intersects with the ideology underlying anti-abortion activism, which is that fetuses are equivalent to children, except that they have not yet been born. This is not to say that Joseph articulated his fetus-at-risk theory in order to provide a rationale for opposing abortion. Rather, his view illustrates the way themes in the broader culture of a society permeate how a particular health problem is understood at any given time (Rhodes 1996; Stein 1990).

Not all observers agree that rates of fetal and infant mortality have declined as interventional preterm delivery rates increased, nor do they agree that, when infant mortality does decline, that this represents a shift from stillbirths to preterm live births. MacDorman and fellow vital records analysts note that mortality rates did fall in the early part of the decades when interventional preterm birth rates increased, but not in the latter part (MacDorman et al. 2010). Rather than assuming that preterm births occurring through intervention are simply babies delivered more safely, before they had the opportunity to be born spontaneously preterm or to die, MacDorman and colleagues’ analysis is consistent with the premise that the threshold for intervening in a complicated pregnancy has lowered since the 1990s. Each complication identified in the vital records database, for example, pregnancy-induced hypertension or premature membrane rupture, had higher rates of delivery by cesarean section at the end of the study period than at the beginning. Joseph and colleagues made a similar observation in 2002, commenting:

> The very high infant mortality rate among preterm births in the 1950s made obstetricians reluctant to induce labor before the 35th week of gestation. This has changed markedly however, with improvements in neonatal care. The indications behind recent increases in preterm labor induction and preterm cesarean delivery include maternal and fetal conditions that cause or signal fetal compromise including hypertension, fetal distress, premature rupture of membranes, intrauterine growth restriction, and abruption placentae. This panoply of indications suggests a global decrease in the threshold for obstetric intervention. As mentioned, increased obstetric intervention has led to declines in stillbirth rates, while recent advances in obstetric and neonatal care (including antenatal glucocorticosteroid therapy for threatened preterm labor, exogenous surfactant and high frequency ventilation) have permitted higher survival at preterm gestation. (Joseph et al. 2002 p. 257, reprinted with permission from Elsevier)

Similar observations about the lowered threshold for intervention have been made by Raju et al. (2006) and Bettegowda et al. (2008).

Four conditions are most frequently associated with preterm births by intervention: preeclampsia (maternal high blood pressure with evidence of protein in the urine), placental abruption, fetal distress, and fetuses that are small for their gestational age. These conditions form a continuum of medical conditions that disrupt the flow of oxygen and nutrients to the developing fetus, and, in one large study, accounted for about half of the observed preterm births by intervention in Missouri from 1989–1997 (Ananth and Vintzileos 2008). Reasons for intervention in the other half of these births included congenital malformation (13 %), placenta previa (6 %), diabetes (5 %), hypertension (4 %), unexplained vaginal bleeding (4 %), and miscellaneous reasons (Ananth and Vintzileos 2006, 2008). One explanation for increasing interventional preterm birth rates, in addition to lowered thresholds for intervention, is the increasing prevalence of these maternal and pregnancy risk factors (Wong and Grobman 2011).

There is also considerable practice variation in the decision to intervene medically and deliver an infant before term. Studies have found a correlation between rates of interventional deliveries, race (Kramer et al. 2012), insurance status of women and practice characteristics of physicians (Holland et al. 2009), rates of obstetrical medical malpractice insurance premiums (Murthy et al. 2009), concerns about malpractice (Power et al. 2013), and cesarean section rates in the general obstetrics population (Zeitlin et al. 2010). The phenomenon of practice variation in the decision to perform interventional deliveries, and its relationship to organizational features of the healthcare system, is discussed in Chap. 5 of this book.

Finally, it should be noted that another reason for the increase in late-preterm births by intervention is that they are a spillover from a trend toward scheduling inductions or cesarean sections for term pregnancies. Scheduling a cesarean section at term is a substitute for allowing pregnancies to end in spontaneous labor; in a 2013 survey, 18 % of women who had given birth in the year reported that they had delivered with a previously planned cesarean section (Declercq et al. 2013). Scheduled deliveries are done for the convenience of physicians and pregnant women, and many are done for women whose previous delivery occurred via cesarean section. Many such elective deliveries are scheduled for the 37th to 39th week of gestation, rather than waiting until term at 40 weeks, to be sure they occur before labor starts spontaneously. Inaccurate gestational age dating inadvertently shifts some of these deliveries into the late-preterm period. Some obstetric practice guidelines even suggest that elective deliveries can be scheduled at 34–37 weeks, although current guidelines set 39 weeks as the threshold for delivery in uncomplicated cases (Fuchs and Gyamfi 2008). The practice of scheduling routine deliveries before term has been resistant to modification (Ashton 2010; Clark et al. 2009), but is currently a target for a number of quality improvement interventions, since most experts agree that the practice causes unnecessary medical complications for the newborn.

1.3 Therapeutic Evidence on the Causes of Preterm Birth

In the idealized view of scientific medicine, therapies are devised based on a thorough understanding of the biological pathways for a condition. They are targeted to appropriate populations based on clear indications of specific risk factors. In practice, however, it is not unusual for a range of therapies to be tested in patients who might benefit. The interventions might be based on logical hypotheses about therapies that could diminish the problem, and the results of therapeutic trials often generate new hypotheses about the biological pathways that cause the problem (Reissman 1983).

There have been numerous attempts to identify therapies that could work to prevent preterm birth, but very few have proven to be beneficial.

1.3.1 Prenatal Care

Through most of the twentieth century there was a high expectation that prenatal care, the monitoring of a pregnant woman's health by a health care provider, would, in and of itself, prevent preterm birth. An early proponent of medically monitored prenatal care was Scottish physician J.W. Ballantyne, who published his vision for inpatient-based care prior to childbirth in 1901 in British and American professional journals (Ballantyne 1901a, b). He described the knowledge that he thought could be gained by more research on obstetric conditions during pregnancy, and the potential for physicians in the future to be able to prevent poor pregnancy outcomes. In particular, he noted that hospitalization of employed women before delivery could lead to the delivery of larger and healthier babies, because the women would have an opportunity to rest. Ballantyne's primary interest was to monitor and intervene in pregnancy in order to ensure the production of a healthy and abnormality-free infant (Siegel 2014).

Prenatal care did not evolve in the direction of providing inpatient hospital care for pregnant women as Ballantyne had imagined,[8] but toward scheduling periodic visits with care providers over the course of a pregnancy, with visits scheduled more frequently closer to term. The first prenatal care in the U.S. began as home visits by nurses to low-income women in Boston. Subsequent charitable and publicly sponsored programs in homes or in clinics were incorporated as a way to address high rates of infant mortality among the poor. The federal Sheppard–Towner Act provided funds for the establishment of nurse-staffed prenatal care clinics across the U.S. in the 1920s, and the federal Children's Bureau, supporting the activities of academically-based obstetrics specialists, organized a physician

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[8] Although there was a retreat center established in Philadelphia in 1866 where "poor, white, married, pregnant women" could live at the end of their pregnancies, deliver, and remain for 30 days postpartum. The Center was open until 1953 (Thompson and Merkatz 1990).

panel to issue guidelines on the recommended content of ambulatory-based prenatal care in 1925 (Taussig 1937; Thompson et al. 1990).

Ballantyne's vision of prenatal care as potentially, eventually, enabling medical care to prevent premature deliveries and congenital abnormalities evolved rapidly into a belief that prenatal care would in fact prevent such poor birth outcomes (Alexander and Kotelchuck 2001; Oakley 1982). In their history of prenatal care written in 1990, Thompson et al. observe:

> In a 1914 study of 705 fetal deaths that occurred among 10,000 consecutive admissions at the Johns Hopkins Hospital, [J. Whitridge Williams, a founding figure in academic obstetrics] estimated that organized prenatal care could have reduced this mortality by 40 %. His emphasis in prenatal care was the detection and treatment of syphilis, but he considered the routine use of the Wasserman [syphilis screening] test financially unfeasible. He suggested that dystocia, toxemia, and premature birth could be reduced if prenatal care included a competent obstetrical examination before the onset of labor and instruction for the pregnant woman in personal hygiene, rest and diet. (Thompson et al. 1990 p. 15, reprinted with permission from Taylor & Francis Group)

The authors also describe a study conducted in 1928 by The Children's Bureau and Yale University that concluded that prenatal care could probably reduce prematurity, but it was not clear how, because of the lack of knowledge regarding the causes of the condition. Ironically, a companion chapter to this history of prenatal care in the book published in 1990 focused on the role of prenatal care in preventing preterm births and also concluded:

> Although the mechanisms are not clear, prenatal care apparently plays a role in reductions in preterm birth and low birth weight. Expanded availability of prenatal care should decrease preterm delivery and low birth weight births, and be most effective in low-income, high-risk women. Additional prenatal care should be targeted to these groups. (Klein and Goldenberg 1990, p. 525, reprinted with permission from Taylor & Francis Group)

Oakley (1982) tracks a similar historical continuity in Great Britain in the ideology that prenatal care can prevent poor birth outcomes, despite the absence of a rationale for exactly how this would occur.

In 1985, a comprehensive report by the Institute of Medicine (IOM, a nonprofit organization that provides summaries of scientific information for policy makers) reviewed observational data on the distribution of low birth weight births. The IOM concluded that women who receive more prenatal care are less likely to have low birth weight and preterm infants (IOM 1985). These findings served as a rationale for U.S. public policies of that era and through the 1990s, which guaranteed financing for prenatal care services to low-income women (Alexander and Kotelchuck 2001). However, over the next decade, more careful statistical analysis of these population birth data assessed whether women who use any prenatal care are systematically different from women who decide not to use this care. After making statistical adjustments for what is termed selection bias, studies failed to show an association between receiving prenatal care and avoiding a preterm delivery. Instead, the women who are more likely to use more prenatal care are the same women who are less likely to deliver before term. Similarly, actual tests that provided increased or enhanced prenatal care to intervention groups and compared them to control groups receiving routine prenatal care did not show a quantifiable effect of enhanced services on decreasing the likelihood of preterm births (Fiscella 1995; Lantos and Lauderdale 2011).

Trials of enhanced prenatal care do show that it is associated with improved maternal physical and mental health and improved satisfaction with care (Fiscella 1995; Klerman et al. 2001). Also, at least in theory, prenatal care may have benefits such as reducing fetal deaths by identifying high-risk women early in pregnancy and referring them for interventional deliveries or other medical services (Alexander and Kotelchuck 2001; Lantos and Lauderdale 2011). However, prenatal care per se does not appear to prevent the occurrence of a preterm birth.

1.3.2 Treatment of Infections

Another disappointment in the quest to identify effective interventions to prevent preterm birth, and thereby to understand the phenomenon better, is the failure of antibiotic treatment to prevent early delivery. This is the case even though it is clear that women who experience preterm deliveries are more likely to have genitourinary infections such as bacterial vaginosis than those who do not. In 1971, Elder et al. published a report of a study that administered tetracycline to pregnant women as a prophylaxis for urinary tract infections, and observed as a byproduct a reduced rate of preterm births in the intervention population (Behrman and Butler 2007). The finding was followed by several epidemiological studies that established an association between bacterial vaginosis and preterm delivery. Such infections are more prevalent among Black women than among other groups, so the finding was seen as a potential explanation for the markedly high rates of preterm birth in this group (Culhane and Goldenberg 2011). Early clinical trials suggested that treating symptomatic bacterial vaginosis with antibiotics reduced the likelihood of preterm birth, and in 1993, the Centers for Disease Control issued treatment guidelines recommending that these women receive treatment for the infection.

Once the guidelines were in place, clinical trials could only be conducted with women who had bacterial vaginosis but were asymptomatic, because withholding therapy in a research context, where treatment guidelines indicate it should be provided, is considered unethical. Subsequent studies yielded mixed results: treatment seemed to be irrelevant for asymptomatic low risk women, and might be beneficial for high-risk women, but it was not clear how to identify these women. Some studies actually showed an increase in preterm births for women treated prophylactically with antibiotics before pregnancy. These findings dampened the initial excitement about the potential for preventing preterm birth by systematically treating infections or administering antibiotics as a preventive treatment. Instead they suggested that the relationship between infection and preterm birth is mediated by some mechanism, possibly inflammation, which occurs in some cases of infection and not in others. Current treatment guidelines make no recommendations on the treatment of vaginosis during pregnancy, because of inconclusive evidence of its benefit (Behrman and Butler 2007; Hogan et al. 2011).

1.3.3 Tocolytics

A third significant disappointment in the quest for preventive therapy for preterm birth was the failure of medication used to relax spasms, called tocolytics, to do more than temporarily halt preterm labor. Three clinical truths about spontaneous preterm labor made investigations of the effects of tocolytics particularly challenging. First, approximately 30 % of cases of preterm labor resolve without intervention, with neonates eventually delivering at term. Only 10 % of cases of preterm labor result in deliveries within 7 days of identification (ACOG 2012b). This means that in studies of the use of tocolytics, it is difficult to distinguish the effect of the intervention, because preterm labor often halts on its own. Second, women who deliver preterm are often so advanced in labor at the point when they reach care that it is too late to stop the process by administering the medication. Third, the fact that preterm contractions usually resume within 24 hours after administering tocolytics suggests that the preterm labor mechanism has a different physiology than other muscle contractions, which often resolve with this type of medication. For these reasons, authoritative reviews have concluded that tocolysis can delay delivery long enough to transport women in preterm labor to facilities equipped to treat infants born preterm, and allow time for women to be administered a dose of corticosteroids, which promote lung maturation in neonates and thus improves outcomes for preterm infants (Behrman and Butler 2007; Klein and Goldenberg 1990). However, there are clinicians who disagree with the prevailing advice to use tocolytics only for short-term delay of preterm labor. They advocate for continuous use of tocolytic therapy, sometimes using wearable infusion devices, over several weeks to prevent preterm birth. This disagreement is discussed further in Chap. 5.

1.3.4 Bed Rest

Another very common therapy advised to prevent preterm delivery is activity restriction or bed rest. This may be prescribed at several levels, ranging from complete immobilization, sometimes with hospitalization, to simply advice to rest for an hour or less when contractions occur. Rest was advised in nineteenth century midwifery texts, and almost all obstetrics providers report advising activity restriction for some patients. It has been estimated that nearly 20 % of all pregnant women are advised to restrict their activities at some point in their pregnancies. Many reviews over the past 30 years have examined the effect of bed rest for the prevention of preterm birth, and all have failed to document any positive effect.

In fact, there is good documentation of negative physical, psychological, and social effects of bed rest, including the difficulties families face in complying with prescriptions of bed rest (Bigelow and Stone 2011; Goldenberg et al. 1994; Maloni 2010, 2011; Sciscione 2010). The reasons for the persistence of prescriptions of activity restriction, despite the lack of evidence that it is effective in preventing preterm birth, is also discussed in Chap. 5.

1.3.5 Stress Reduction

As noted above, "stress" is considered to be a trigger for preterm labor, and there have been many calls in the medical literature for clinical trials of stress reduction interventions, in order to elucidate further the pathways between exposure to stressful circumstances and preterm birth (Beydoun and Saftlas 2008; Lobel 1994). However, the methodological challenges of conducting such studies in a way that would meet the criteria for clinical trials have apparently discouraged researchers. As a partial substitute, because observational studies suggest that women who report less social support are more likely to have low birth weight (although not necessarily preterm) babies, social support has been studied as a way of addressing stress. Trials have provided interventions including home visits by midwives, nurses, or social workers, telephone contact or other supplemental interactions during prenatal care to increase social support and lower stress. Reviews of the findings of these controlled experiments show no relationship between the provision of social support and improvements in infant birth weight or preterm birth rates. However, as with augmented prenatal care, many studies show that the interventions do reduce maternal anxiety and depression and improve other health measures (Behrman and Butler 2007; Elbourne et al. 1989).

1.3.6 Cerclage

Finally, there are two interventions which are currently being promoted for the prevention of preterm birth for a targeted group of women who either have had a previous preterm delivery, who have a relatively short cervix (as measured by ultrasound as the distance between the vaginal and the uterine openings), or both. The first is cerclage, a surgical procedure that involves suturing the cervix closed. Cerclage is used for the small group of women with cervical dilation but no uterine contractions. This condition is referred to as having an insufficient or "incompetent" cervix. The practice of cerclage dates back as early as 1902, when physicians performed these surgeries in women with a history of mid-term miscarriages or preterm deliveries (RCOG 2011). Cerclage has been systematically studied since the early 1990s, with diagnosis of cervical insufficiency made on the basis of a history of prior preterm births, ultrasound findings, and physical examination.

Women with a history of preterm births and a short cervix appear to have prolonged pregnancies with cerclage, which is most effective when performed at about 16 weeks gestation. Women with short cervixes who do not have a history of preterm birth do not show a benefit from cerclage, and women carrying twins or higher multiples are actually more likely to have a preterm birth if they receive cerclage (Behrman and Butler 2007). A recent systematic review of studies of the procedure confirms that pregnancies are prolonged in certain subgroups of women when they receive cerclage, but side effects include vaginal discharge, bleeding, and fever. Women with cerclage are more likely to deliver by cesarean section (Alfirevic et al. 2012).

1.3.7 Third Trimester Progesterone Treatment

The second intervention that currently shows potential for preventing preterm deliveries in some women is the administration of a course of progesterone treatments in the third trimester of pregnancy, for women with a history of preterm birth and short cervical length. Observations dating back to the 1930s identified a role for the hormone progesterone in maintaining pregnancy by reducing uterine contractility. It was hypothesized that normal labor is triggered in part by a reduction of progesterone production (Keirse 2004). In the 1950s the pharmaceutical company Squibb marketed a progesterone drug called Delalutin for preventing miscarriages. Through the 1980s, several small studies with mixed study populations and treatment approaches were conducted to examine whether Delalutin could prevent preterm birth, but the studies yielded ambiguous results (Videaff and Ramin 2006). Two larger randomized controlled studies reported in 2003 suggested that a series of progesterone injections (in one study) or daily suppositories (in the other study) in mid-pregnancy helped to reduce the portion of women known to be at high risk for preterm birth from delivering preterm by about one third. The risk criterion was a prior preterm birth. Although there are several plausible mechanisms for this effect, it is not clear exactly why progesterone has this impact (Behrman and Butler 2007; Hall 2011; Hogan et al. 2011).

Current practice guidelines suggest that women who are pregnant with single infants and who have had a previous spontaneous preterm birth should be offered a course of weekly progesterone injections beginning between 16 and 24 weeks gestation. Women without previous spontaneous preterm births who are pregnant with single infants, who have a very short cervical length measured before or at 24 weeks gestation should be offered vaginal progesterone supplements. Studies examining the value of combining cerclage with progesterone are underway (ACOG 2012b).

Studies of the impact of progesterone on infants born after maternal treatment so far extend only through age four. Concern about the long-term unknown impact of the treatment on mothers and infants is likely one reason that the pharmaceutical company Squibb withdrew Delalutin from the market in 1999. The process of identifying an alternative channel to reintroduce progesterone commercially is an interesting story that reveals much about the dynamics of health care in the U.S. This is discussed further in Chaps. 3 and 5.

In sum, the phenomenon of preterm birth is clearly viewed as problematic. However, it does not fit well into our normative models of a disease state that can be better understood and simultaneously treated with medical therapies. The Institute of Medicine study on preterm birth, conducted in 2005–2006, included this observation:

> Most interventions are based on the traditional medical model of identifying and correcting each potential cause or risk factor for preterm birth, with the expectation that the rate of preterm births would decline in accordance with the contribution of that factor to the prematurity rate. Intervention trials have thus addressed the early identification of preterm labor through patient education, pharmacological suppression of uterine contractions, antimicrobial therapy of vaginal microorganisms, the use of cerclage sutures to bolster the cervix, reduction of maternal stress, improved nutrition and improved access to prenatal care, and reduced physical activity. Some trials enrolled women with the risk factor in question without regard to obstetric history (e.g., antibiotics for women with a positive culture for a genital microorganism), whereas others were limited to women with a prior preterm delivery (e.g., the European cerclage trials or the recent progesterone supplementation studies). Although successful elimination of single risk factors has been accomplished, for example, by antibiotic treatment of a targeted vaginal organism or suppression of contractions with tocolytic compounds (labor-inhibiting agents), successful removal of a risk factor has not produced a decrease in preterm birth rates. In fact, the overall rate of preterm birth has continued to rise (Behrman and Butler 2007 p. 273, reprinted with permission from National Academies Press).

1.4 Outcomes of Preterm Birth

1.4.1 *Infant Mortality*

Ever since the formal identification of the category of “preterm infant” in Europe in the late nineteenth century, the outcome that has received the most attention has been survival—did the preterm infant survive delivery, and if so, for how long? Survival for the youngest preterm infants depends on whether they are resuscitated at delivery, since at first they cannot breathe on their own. Thus, preterm survival rates at the earliest gestational ages depend in large part on whether attendants at delivery try to resuscitate the neonates, and on the level of technology available to keep them alive after resuscitation. Older preterm infants may be able to breathe on their own initially, but require assistance with feeding and temperature regulation to survive.

Table 1.2 shows 1-year mortality rates by gestational age for the decade of 2000–2010, based on United States vital records.

There was a modest decline in preterm mortality rates over the 2000–2010 decade, with minimal change in the distribution of preterm births by gestational

Table 1.2 One-year mortality rates for preterm infants by gestational age, 2000–2010, based on Mathews and MacDorman (2013), Table D

Period of gestation	% of all preterm births in 2000	Deaths per 1000 in 2000	% of all preterm births in 2010	Deaths per 1000 in 2010	% change in mortality rates
<32 weeks	16.4	180.95	16.7	165.57	−8.5
32–33 weeks 6 days	12.9	17.37	12.5	15.83	−8.9
34–36 weeks 6 days	69.8	7.96	70.8	7.15	−10.2
All <37 weeks	100	37.88	100	34.22	−9.7

age. Singh and van Dyck examined a longer historical trend in preterm mortality, and reported that the 2006 mortality rate for newborns under 32 weeks gestation represented a 70 % decline from the mortality rate in 1960 and a 17 % decline from 1985. The 2006 mortality rate for newborns 32–36 weeks gestation represents an 89 % decline from 1960 and a 48 % decline from 1985 (Singh and van Dyck 2010, Fig. 6). The period from 1960 to 2006 encompasses all of the major advancements in neonatal resuscitation and life support technology. Thus, measured over one decade, as in the table, or over four and a half decades, as in the historical study, marked improvement in mortality rates have been observed for all preterm newborns.

Part of the decline in mortality rates for the youngest preterm newborns is due to an ongoing trend of attempting resuscitation for neonates at the lowest gestational age limit for viability. Guidelines since the 1990s have consistently advised that neonates born at less than 23 weeks gestation are unlikely to survive (Kattwinkel et al. 2010), but there is considerable variation around attempts at resuscitation for 22–24 week infants and a trend toward resuscitating newborns at increasingly younger gestational ages (Seri and Evans 2008). Of course, survival rates are higher when resuscitation is attempted (Lantos and Meadow 2009). A recent population-based study conducted in England compared infants born at less than 26 weeks in 1995 and in 2006, and reported an increase in the probability of survival, from 40 to 50 % in that 11-year span. The entire improvement was accounted for by the reduction in deaths in the first week of life. More of the youngest of these newborns were admitted to neonatal intensive care units (NICUs), and the condition of newborns transferred from birth hospitals to hospitals with NICUs improved. This all suggests that survival rates among the youngest infants are improving because of a shift toward decisions to resuscitate and improved resuscitation practices at delivery (Costeloe et al. 2012).

Gains in survival rates over time also represent the impact of technological improvements in care. Tyson et al. (2008) found that administering corticosteroids (which hasten lung maturity) before delivery was equivalent to adding one week of gestational age to the probability of survival, and Ge et al. (2013) reported that corticosteroids, use of surfactant (facilitating respiration for immature lungs), and immediate receipt of ventilation improve the likelihood of survival for newborns under 30 weeks gestation. Both sets of authors also found that newborns with higher birth weights for their gestational ages and those who were female had higher survival rates.

The variability of survival rates for infants born at the same gestational ages exposed to the same resuscitation and treatment protocols indicates that factors in addition to immaturity play a role in the survival of preterm infants. Taking as a standard the survival rate for healthy twins, who are often born preterm simply because of early initiation of normal labor, Basso and Wilcox (2010) estimate that about 50 % of mortality risk for preterm infants is due to their gestational age, and another 50 % is due to some underlying pathology which likely played a role in triggering preterm birth in the first place. Similarly, physician Jose Villar and colleagues divided the preterm population into two groups, those whose mothers did and did not have pregnancy complications. Each of these groups were further divided into newborns born after preterm labor, after membrane rupture, and with an interventional delivery. Taking gestational age at delivery into account, the authors found that preterm newborns of mothers with complications had the highest mortality rates if delivered after spontaneous labor, lower if delivered after a spontaneous rupture of amniotic membranes, and lowest for interventional deliveries. Preterm newborns of mothers without complications all had lower mortality rates than the first group. The highest mortality rates in this subgroup were for newborns delivered after spontaneous labor. Newborns born after interventional deliveries had lower mortality rates, while newborns delivered after membrane rupture to mothers with no recorded complications had the lowest mortality rates of all six groups. This is another indication that the underlying pathology of the preterm birth has an impact on preterm newborn mortality (Villar et al. 2004).

Finally, Iams and Lynch (2011) note that studies of stillbirths suggest that there are different causes of death at different gestational ages. For example, the deaths at the youngest gestational ages are associated with either extreme immaturity or placental problems, while deaths at later gestational ages are associated with maternal hypertension and cord abnormalities. If fetal deaths (stillbirths) are thought of on a continuum with preterm births, it is likely that there are similar distributional differences in the underlying pathology of preterm infant mortality. Thus, a major challenge in furthering knowledge about variation in mortality rates at a given preterm gestational age is the inability to sort out the differential routes to or underlying pathologies of preterm birth (Kramer et al. 2012).

1.4.2 Short- and Long-Term Morbidities for Preterm Newborns

Like mortality, the short- and long-term health outcomes of preterm birth for those who survive their first five years of life vary by maturity (gestational age at delivery) and by the underlying pathology that triggered the preterm delivery.

Also like preterm infant mortality, the underlying pathologies that caused the preterm birth are often unknown. The consequence is that there is considerable unexplained variation in the health outcomes observed for preterm newborns at each gestational age. The Institute of Medicine's 2007 study of preterm birth adds a third source of complications for infants born preterm, in addition to the fragility and immature development of their organ systems and the impact of underlying pathologies in the infant and the uterine environment. This third category is the potential negative impact of some of the interventions used to keep the newborns alive (Behrman and Butler 2007).

Unlike mortality in the first year of life, which is straightforward to measure and often available on a population basis through vital records systems, there are several difficulties with tracking short- and particularly long-term outcomes for surviving preterm infants. First, there is disagreement about what types of outcomes to measure and how to measure them. Second, there is difficulty in maintaining contact with a population of preterm infants over long periods of time. Maintaining contact is particularly difficult in the United States, which has a fragmented system of health care delivery and no population-level health registry. Follow-ups of patients of specific hospitals or hospital networks are not a good substitute for population-based studies because they are not fully representative of the general population. Hospital-based studies tend to under-count the occurrence of good outcomes, because families of healthy children do not remain in contact with their initial caregivers (Vohr et al. 2005). Population-based studies tend to under-count the occurrence of poor outcomes because it is more difficult to locate marginalized populations whose outcomes may be more severe (Moore et al. 2012).

The third challenge in tracking long-term outcomes of surviving preterm infants is that some complications of preterm birth resolve over time, while others only become apparent at later ages. Thus the timing of the follow-up measures is important in describing the health outcomes of preterm birth. The fourth challenge is that any measurements made as children who were born prematurely mature towards adulthood reflect the impact of treatments received in the past, and thus may not produce a good indication of the likely outcomes for the current cohort of preterm infants. For example, it is difficult to predict now what the outcomes at age 18 will be for infants born at very early gestational ages such as 23 weeks, because 18 years ago, very few such infants survived to be assessed at 18 years of age (Hack et al. 2005; Lantos and Meadow 2009; McCormick 1997).

Still, the IOM 2007 report provides an extensive discussion of the negative short- and long-term outcomes that have been reported for preterm infants, although some studies examine outcomes by birth weight rather than gestational age. The report's discussion of short-term outcomes moves through organ systems, noting first that preterm infants are prone to respiratory distress syndrome (where breathing is impaired because the lung alveoli have not opened up), bronchopulmonary dysplasia (where lungs become inflamed because they are stiff when immature), and apnea, where breathing control is not fully matured and breathing sometimes stops. Impaired respiratory systems impact newborn growth, health, and neurodevelopment. Unfortunately, some treatments for respiratory immaturity, including postnatal corticosteroid administration, can lead to cerebral palsy, cognitive impairment, and gastrointestinal (G.I.) hemorrhage. Problems associated with immature G.I. systems include feeding intolerance due to difficulties digesting and difficulties coordinating sucking, swallowing, and breathing. Necrotizing enterocolitis (inflammation and injury of the intestinal tract which can lead to intestinal perforation and sepsis) is sometimes the result of feeding intolerance. However, the alternative mode of feeding, intravenously with a central line, can lead to liver damage, structural changes in the intestine, and sepsis related to the line itself. The skin of very preterm newborns can be fragile and gelatinous, leading to infections and fluid loss, and infection is complicated by immaturity of the immune system. One short-term cardiovascular outcome can be patent ductus arteriosus (where the heart chambers are slow to reach maturity) causing the fetal pattern of blood flow to remain after birth. Auditory and visual impairments are more common in preterm newborns, particularly retinitis of prematurity (blindness sometimes associated with exposure to too much oxygen during treatment with ventilation) (Behrman and Butler 2007).

Many of the respiratory and GI complications of preterm birth resolve over time if the infants survive, although children born preterm are more susceptible to asthma and other respiratory conditions as they grow older. The children are also more prone to slow growth and to chronic diseases as adults.[9] The complications related to preterm birth that receive the most attention are the neurological and neurodevelopmental consequences. These arise from immaturity itself and from injuries to fragile neural systems that result in intraventricular hemorrhage, or bleeding into the brain. Cerebral palsy, which is related to white matter injury in the brain and seems to be associated with maternal infection during pregnancy, is common in preterm newborns, as are cognitive impairments that lead to social dysfunction and learning disabilities. In early childhood, as many as 40 % of the youngest group of preterm infants have cognitive functions below norms for their ages, but in many cases these resolve with maturity. Children born preterm who have been assessed as teenagers on average were less assertive and had fewer social skills, and were also less likely to engage in risky behaviors such as alcohol and drug use (Behrman and Butler 2007).

A widely cited study using Norwegian population data reported long-term outcomes for surviving preterm infants born between 1967 and 1983 when they reached adulthood as measured in 2003. These data are shown in Table 1.3. The findings on relative risk are adjusted for infant sex, year of birth, multiple births, unmarried mothers, maternal age, maternal and paternal levels of education, and whether the parents were immigrants to Norway. Relative risk adjusted in this way

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[9] One current theory, the fetal origins hypothesis, suggests that some infants are born at low birth weights because of disruptions in their nutrition during pregnancy, and that these disruptions preprogram these individuals to be at higher risk for cardiovascular disease as adults. This could hold true for infants born preterm as well, if uterine blood flow and placental function disruptions were present during pregnancy (Wilcox 2010).

Table 1.3 Long-term neurodevelopmental outcomes for preterm births in Norway, 1967–1983, Moster et al. (2008), Table 2

	Gestational age at delivery				
	23–27 weeks	28–30 weeks	31–33 weeks	34–36 weeks	37+ weeks
N	362	1,686	6,591	32,187	853,309
	% (relative risk)	% (relative risk)	% (relative risk)	% (relative risk)	% (relative risk)
Cerebral palsy	9.1 % (78.9)	6.0 % (45.8)	1.9 % (14.1)	0.3 % (2.7)	0.1 % (1.0–reference)
Mental retardation	4.4 % (10.3)	1.8 % (4.2)	1.0 % (2.1)	0.7 % (1.6)	0.4 % (1.0–reference)
Schizophrenia	0.6 % (4.5)	0.1 % (0.9)	0.2 % (1.4)	0.2 % (1.3)	0.1 % (1.0–reference)
Autism spectrum	0.6 % (9.7)	0.4 % (7.3)	0.05 % (1.0)	0.03 % (0.8)	0.05 % (1.0–reference
Psychological development, behavioral, and emotional disorders	2.5 % (10.5)	0.7 % (2.9)	0.3 % (1.4)	0.3 % (1.5)	0.2 % (1.0–reference)
Other major medically disabling conditions	4.1 % (19.6)	2.2 % (9.3)	0.5 % (2.3)	0.3 % (1.5)	0.2 % (1.0–reference)
Any medical disability severely affecting working capacity	10.6 % (7.5)	8.2 % (4.8)	4.2 % (2.2)	2.4 % (1.4)	1.7 % (1.0–reference)

shows the impact of preterm birth on the outcome, taking other characteristics into account (Moster et al. 2008).

Other data using different measurements, time frames, and study cohorts show different rates of long-term complications, but three aspects observable in this table are reflected in other studies. First, individuals born before term have more negative health and functional outcomes than individuals born at term. Second, the earlier the preterm infants are born, the more negative outcomes they experience. But third, in every gestational age category, the majority of individuals function relatively well at adulthood, and do not have major negative long-term consequences of their preterm birth. This phenomenon is at the core of the dilemma facing clinicians as they consider how aggressively to intervene in resuscitation of preterm newborns: the probability of negative consequences is high, but the probability of positive outcomes is also high.

One of the impacts of the improvement in preterm survival rates discussed in the previous section is that more preterm newborns who are born today survive, and they survive deliveries at younger gestational ages and with more complicating conditions. Clinicians working in this field have long hoped that improvements in the care of preterm newborns might reduce the proportion of these newborns who survive with negative long-term effects. However, both hospital-based studies in the U.S. (Hintz et al. 2011) and population-based studies in England (Costeloe et al. 2012; Moore et al. 2012) identify improvements over time in the care of preterm newborns (in particular, a reduction in the use of corticosteroids after delivery, which improved lung function but was associated with neurological damage), but no major improvements in neurological outcomes through age three. Thus, as more very preterm newborns survive, there are more children with neurological, developmental, and other disabilities associated with preterm birth in the U.S. population.

The provision of care immediately after birth for preterm infants is extremely resource intensive. During childhood, infants born preterm, and particularly the small portion with the most severe negative outcomes, continue to use more health care resources than those born at term. Table 1.4 shows average outpatient health care expenditures for preterm infants in 1999–2004, during the years when they were ages one to seven. The data were extrapolated to the national level from data from an insured population in the Western U.S., in analyses conducted for the 2007 IOM study of preterm birth.

These data suggest that a small portion of the most immature preterm infants use the most resources. Resource use declines as the children mature. These data represent office medical care, therapies, medical equipment, and pharmaceutical costs, but not inpatient care.

In addition to medical care costs, children with neurodevelopmental issues and severe disabilities such as cerebral palsy require extensive early intervention, special education and disability support services (Clements et al. 2007; Petrou et al. 2011). How much of these resources are actually used depends in part on how many services are available. While some level of early intervention and support services are federally mandated (for education systems receiving federal funds) and supported in the states through federal Maternal and Child block grants, there are also variations across and within states in the extent, structure, and accessibility of care resources for affected children. Families with access to more resources, including

Table 1.4 Estimated out-of-hospital medical expenditures for preterm newborns ages 1–7, from Behrman and Butler (2007), Table 12.6

Gestational age (wks)	Age 1–2			Age 3–7		
	Median	Upper 25 %	Upper 5 %	Median	Upper 25 %	Upper 5 %
37–40 (term)	$475	$770	$1966	$575	$1238	$3149
32–36	$533	$915	$2658	$672	$1545	$3928
28–31	$785	$2083	$12,055	$866	$1664	$4432
<28	$3305	$7905	$21,117	$1106	$3510	$20,127

adult time, knowledge, and income, can provide more extensive support resources to preterm infants with disabling conditions than families with fewer resources. More resources have a positive impact on the long-term outcomes of preterm birth across the population (Hogan and Clark 2000; McGauhey et al. 1991).

1.4.3 Maternal Health and Family Outcomes

On a population basis, the impact of pregnancy on maternal health can be measured in three ways: by counting the number of maternal deaths during or within 1 year of a pregnancy that were caused by a pregnancy complication, by a chain of events initiated by pregnancy or by the aggravation of an unrelated condition by a pregnancy (Berg et al. 2010); by counting "near misses," women who nearly died during pregnancy, childbirth, or within 42 days of childbirth (Tuncalp et al. 2012); and by counting maternal hospitalizations for severe conditions during pregnancy, childbirth, or immediately afterward, where diagnoses are associated with the pregnancy (Callaghan et al. 2012). Because a portion of these outcomes are preventable with better medical care, these measures are increasingly used to assess the quality of maternity care, particularly in hospital settings.

Rates of all three measures, maternal mortality, near misses, and morbidity, have increased in the United States in recent decades (Berg et al. 2010; Callaghan et al. 2012; Hankins et al. 2012; Main 2010), even taking into account increased efforts to document these events. This is in part because of increases in the prevalence of complicating conditions, including cardiovascular conditions, obesity, and metabolic syndrome among pregnant women. In addition, cesarean delivery rates have increased, and these deliveries are associated with a higher rate of subsequent postpartum complications (Clark et al. 2008; Main 2010).

Assessments of the rates of maternal mortality, near misses, and morbidity generally do not record the gestational length of the pregnancy. One study which did so, a large study that examined the incidence of maternal mortality in delivery hospitalizations in a large U.S. hospital chain over several years, reported that 34 % occurred at term, 53 % occurred at 24–38 weeks gestation, and 14 % occurred before 24 weeks of pregnancy (Clark et al. 2008). This suggests that preterm birth often occurs in situations where there is a threat to maternal health. Preterm birth does not cause maternal morbidity and subsequent mortality, but maternal morbidity is one cause of preterm birth. As noted above, maternal preeclampsia and placental abruption are frequently precipitating conditions for interventional preterm births, and preeclampsia and hemorrhaging are among the most frequent causes of compromised maternal health outcomes. In the hospital study described above, preeclampsia was the most frequent single cause of maternal mortality, and 80 % of these deaths (12 of 15) were judged to have been preventable with earlier intervention.

While under these circumstances preterm delivery is essentially the treatment for pregnancy complications, in other circumstances, such as extended tocolytic therapy (ACOG 2012a) and stringent activity restriction (Maloni 2011), treatments proposed to extend pregnancies closer to term have adverse maternal effects. In either situation, the dilemma facing clinicians involved in these cases is choosing whether to treat maternal complications and risk compromising the fetus by initiating early delivery, or to risk the health of a mother in order to protect the fetus by supporting pregnancy continuation. This dilemma is unique to maternity care providers compared to other care providers because they see themselves as providing care to two patients, mothers and fetuses. To the extent that parents are involved in these decisions, they face social and sometimes legal pressure to sacrifice their own interests for those of the fetus, if the two sets of interests diverge. This dilemma is discussed further in Chap. 6 of this book.

The 2007 IOM report provides a brief overview of studies on the impact of preterm birth on maternal emotional state and family functioning (Behrman and Butler 2007). Mothers of preterm infants are more vulnerable to depression and distress than mothers of term infants. Parental relationships may also be stressed, and studies indicate that divorce rates are higher in families with preterm births (Swaminathan et al. 2006). Families may also experience financial burdens, limits on social life, stress, and dysfunction. Studies reported by the IOM and a recent re-examination of the issue (Schappin et al. 2013) suggest that the negative impact on mothers and families of a preterm birth depends on the severity of the child’s medical and developmental issues, and diminishes over time as the preterm infant matures. Education, social support, and more financial resources help to ameliorate this level of distress. Schappin and colleagues report that studies conducted more recently show lower levels of parental stress than studies conducted in earlier decades, perhaps due to improvements in the quality of care available for preterm infants. The IOM review also points out that some studies show that a preterm birth can increase marital closeness, and that parents can become more attached to their children over time.

1.5 Alternative Paradigms of Preterm Birth

Because a preterm birth deviates from the norm, both in terms of the course of the mother’s pregnancy and the health status of the newborn, the clinical approach to the circumstance is to treat it like a disease. However, as discussed in this chapter, preterm birth does not conform well to the expectations of disease in Western cultures. There is no singular identifiable physical cause, maternal and particularly infant outcomes are highly variable, it is difficult to identify risk factors that are predictably associated with its occurrence, and no preventive therapies or actions are consistently effective. This situation persists despite decades of intensive medical research and many social interventions intended to decrease preterm birth rates among vulnerable groups. Consequently, some clinicians and researchers have proposed alternative paradigms for understanding preterm birth.

In 2009, an international gathering of clinicians and researchers convened by the Global Alliance to Prevent Prematurity and Stillbirth (GAPPS) and supported by the Bill and Melinda Gates Foundation, the March of Dimes, Save the Children, the World Health Organization, the United Nations Children's Fund, and the Program for Appropriate Technology in Health (PATH) appointed a committee to create a new prototypical classification for preterm births. Commenting on the need for such a new classification, the committee members wrote:

> Preterm birth is an unusual entity because it is defined by time, not by a distinctive clinical phenotype. Consider the hypothetical analogy of premature death. Premature death (i.e., death occurring at an age earlier than expected; e.g., <65 years) would consist largely of deaths from cancer, coronary heart disease, unintentional injury, and suicide. Imagine the etiological research based on such an entity. Risk factors differ vastly for cancer, coronary heart disease, unintentional injury and suicide. A genome-wide association study, study of biomarkers, or investigation of physiological/biochemical mechanisms underlying premature death would be meaningless and uninterpretable. This is a similar situation to that currently faced by preterm birth and at least partly explains why we have not made much headway in understanding its etiology. (Kramer et al. 2012 p. 109, reprinted with permission from Elsevier)

Referring to the problem they set out to redefine as the "preterm birth syndrome," committee members retained the orientation toward defining phenotypes (categories of observable characteristics) of preterm birth, with the goal of creating a specific enough set of categories so that each one could be described by a set of etiologies, predicted by a set of risk factors, and prevented by appropriate therapies (Villar et al. 2012), as befits a well-defined disease in Western medical systems. Their proposed classification system encompasses deliveries occurring between 16 and 39 weeks of live infants, stillbirths, and miscarriages, including third trimester therapeutic abortions for congenital abnormalities. They suggest a categorization system that includes five features: at least one maternal factor (such as infection) if one is present; at least one fetal factor (such as restricted growth) if one is present; a pathophysiologic finding in the placenta; an indication of whether the labor process has begun (such as membrane rupture with or without contractions) or not; and a marker of whether the delivery was interventional—indicated or elective—or spontaneous. If data could be collected on all of these factors for a large enough population, research could then describe how the five features tend to co-occur, which risk factors are associated with each type of preterm delivery and what etiology could be proposed. While creating such a classification system is a challenge because some of the data elements are not routinely collected now, and because some of the categories created would be quite small and thus difficult to include in research studies, committee members indicated that the most controversial aspect of the proposal is probably the suggestion that data on previable miscarriages and fetal deaths be combined with stillbirths and live births, where these populations are typically treated separately (Iams and Lynch 2011).

Interestingly, these committee members did not discuss trying to associate the different preterm birth phenotypes with different short-term or long-term neonatal outcomes, and they did not explicitly include the gestational length of the pregnancy in the classification, although it is included in the examples provided. This is in contrast to the fetus-at-risk model discussed above, which does focus on mortality as a preterm birth outcome and relies on gestational age as a classification tool. In the fetus-at-risk model, other pathological issues facing the fetus are included [including the genetic heritage that associates the timing of a newborn delivery with the timing of delivery of the parents (Wilcox et al. 2008)], but features of the pregnancy, labor, or delivery process are excluded. The fetus-at-risk model is not oriented toward identifying interventions to prevent preterm birth, but toward assisting clinicians in the decision to intervene in a pregnancy and deliver the fetus. The contrast between these two models of the same "disease," or physiological dysfunction, illustrates the influence of the therapeutic context on the way observations are put together to create medical classification systems.

A more challenging alternative to the prevailing models of preterm birth was proposed in a paper published in the New England Journal of Medicine in 2010 by two pediatricians, one from Vanderbilt University in Nashville and one from the March of Dimes. This paper described spontaneous preterm birth as an enigma, pointed out that animal models are not useful for research because different mechanisms trigger labor differently across species, and listed the usual risk factors, along with familial factors transmitted genetically, as possible causes. Then, echoing some of the nineteenth century arguments about the early death of preterm infants being advantageous to overall population health, the authors write:

> The physiological changes in pregnancy that occur across mammalian phylogeny suggest that strong selective pressures have acted to maximize reproductive fitness in a species-specific manner. Are these evolutionary adaptations associated with pregnancy likely to promote or provide protection against preterm birth in humans? One possibility is that in certain circumstances preterm birth may be evolutionarily advantageous. For the relatively long gestation of human pregnancies, premature termination of an infected or otherwise compromised gestation may conserve maternal nutrition and, in severe cases, may preserve the viability of the mother or fetus. Moreover, earlier delivery of the fetus may minimize complications from cephalopelvic disproportion, a situation in which the size and position of the fetal head prevent descent through the birth canal. The combination of the large human brain and narrow pelvis places selective constraints on human birth that are different from the constraints on birth in our nearest primate relatives. The dictum of Theodosius Dobzhansky, that "nothing in biology makes sense except in the light of evolution," is thought-provoking when applied to human pregnancy. (Muglia and Katz 2010 p. 530)

This paper drew four letters to the editor, published 2 months later in the New England Journal. All four letters held that preterm birth could be prevented if various interventions were successfully implemented: one letter pressed for a reduction in maternal smoking (Braillon and Bewley 2010), a second called for addressing advanced maternal age and fertility treatments (Takayama and Matsuo 2010), a third for nutrition supplementation with folate (Antony 2010), and a fourth for a comprehensive reduction in social stress, particularly for the African-American population in the U.S. (Fry-Johnson and Rowley 2010). These reactions suggest the extent to which the alternative framing of preterm birth as a component of reproduction, and as natural or normal rather than dysfunctional, violates the cultural framework expected in the clinical domain.

Expansion of the issue of preterm birth out of the clinical and into the population-based and reproduction-focused context is the topic of Chap. 2. This chapter concludes with a comparison of clinical features of preterm birth in the U.S. with those in other Western developed countries.

1.6 Comparisons with Canada, Great Britain, and Western Europe

As discussed above, the increase over time in the U.S. preterm birth rate is surprising in part because the ideology of social progress supports the expectation that life circumstances will get better as societies advance. Even more surprising is the well-validated observation that the U.S. is not first or even among the top ten nations ranked by infant survival rates. In 2005 the U.S. ranked 30th, having declined in rank from 12th in 1960 to 23rd in 1990 and 29th in 2004. The driver of these relatively low infant survival rates is the high preterm birth rate in the U.S.: 12.4 % of all births in 2004 compared to 7.4 % for England and Wales, 6.3 % for France, and 5.5 % for Ireland, the European nation with the lowest preterm birth rate in 2004 (MacDorman and Mathews 2009). Higher preterm birth rates are also the explanation for historically higher infant mortality rates in the U.S. compared to Europe (Buekens et al. 1995).

The high preterm birth rate in the U.S. compared to other developed countries violates another social expectation, which could be termed the American superiority complex (Krugman 2011). The American superiority complex derives from the ideology of American exceptionalism. Scholar Deborah Madsden identifies American exceptionalism as a key and persistent component of the American cultural identity, dating from the time of the Pilgrims in the seventeenth century. She writes:

> Exceptionalism describes the perception of Massachusetts Bay colonists that as Puritans they were charged with a special spiritual and political destiny: to create in the New World a church and a society that would provide the model for all the nations of Europe as they struggled to reform themselves (a redeemer nation). In this view, the New World is the last and best chance offered by God to a fallen humanity that has only to look to His exceptional new church for redemption. Thus, America and Americans are special, exceptional, because they are charged with saving the world from itself and, at the same time, America and Americans must sustain a high level of spiritual, political and moral commitment to this exceptional destiny—America must be a ‘city upon a hill’ exposed to the eyes of the world. (Madsden 1998 pp. 1–2)

Like increasing rates of preterm birth in the U.S. over time, high preterm birth and infant mortality rates compared to other Western countries can be construed as a moral failure, since they indicate that the U.S. is not fulfilling the exceptionalist expectation of superior performance. International rankings have been the subject of much publicity and many calls for public action and resources for improvement.

Some critics argue that differences in preterm birth and infant mortality rates cross-nationally are primarily artifacts of two types of differences in population-based measurements. First, some European nations, particularly France, the Netherlands, the Czech Republic, and Poland, count as live births only those born at 22 weeks or 500 g or greater, while the U.S. and other nations count all live births. Since mortality is much higher for these very young and small newborns, eliminating them from the count automatically lowers the preterm and mortality rates for those nations. Second, in U.S. vital records, gestational age is recorded based on the reported date of the last menstrual period (LMP), with clinical estimates of gestational age used if gestational age calculated by LMP is inconsistent with reported birth weight. In many European countries and in Canada, gestational age is recorded by clinical estimate, which often (though not always) dates the infant as older than the LMP estimate. This again biases the U.S. count so it appears that there are more preterm infants here than in other places. Yet, when analyses are conducted that correct for these differences by excluding births less than 22 weeks gestation or 500 g birth weight and using clinical rather than LMP estimates, the U.S. preterm and infant mortality rates are still consistently higher than those of comparative populations (Ananth et al. 2009; MacDorman and Mathews 2009).

1.6.1 Differences in the Maternity Population

Why is the preterm birth rate so much higher in the United States than in other developed countries? One explanation is that several of the subpopulations with the highest preterm birth rates—women in poverty, teens, women who report their pregnancies as unintended, and women pregnant with multiple fetuses after fertility treatments—comprise larger portions of the child-bearing population of the U.S. than the child-bearing population of other developed countries. In addition, no comparison country has as large a population of non-White women who are not new immigrants, but who have been living as a minority group in the country for several generations, in their child-bearing population. As suggested above and discussed in Chap. 2, the high preterm birth rates of Black women have an impact on the overall U.S. preterm birth rate, although preterm birth rates for White infants are still significantly higher in the U.S. than in Canada, Great Britain, and Western Europe.

An additional possible explanation for higher preterm birth rates in the U.S. is a higher rate of preterm interventional deliveries. This is a logical hypothesis, given that the rates of interventional deliveries vary for nonclinical as well as clinical reasons. However, several studies of comparable populations, including Canada (Joseph et al. 2002; Kramer et al. 1998) and Great Britain, and Europe (Foix-L’Helias and Blondel 2000; Norman et al. 2009; Papiernik et al. 2003; Sorbye et al. 2014; Zeitlin et al. 2010) have found that the portion of preterm births delivered through intervention ranges from 27 % to nearly 50 %, compared to the rate reported for the U.S. of 37 % (Ananth et al. 2005) for the comparable time frames in the early 2000s. This suggests that the rate of interventional births, in and of itself, does not explain differences in preterm birth rates between the U.S. and other developed countries. Preterm birth rates have risen recently in many Western European countries, and while one explanation is an increase in the rate of multiple births occurring in European populations (Papiernik 2007), another is the increasing trend toward use of interventional preterm births (Zeitlin et al. 2010). Still, some observers contend that differential tendencies to perform interventional births accounts for at least some of the variation in cross-national preterm birth rates (Lisonkova et al. 2012).

The prevalence of maternal medical risk factors that precipitate both interventional and spontaneous preterm deliveries is higher in the U.S. child-bearing population. One indication of this is that the rates of maternal mortality, which have risen in the U.S. in recent years as discussed above, have been higher since the year 2000 in the U.S. than those reported in Germany, France, Italy, Great Britain, Israel, Canada, and Sweden (Main 2010). Cardiac and related conditions are a significant component of many of the causes of maternal mortality, and prevalence of these is higher in the U.S. A more direct indication of morbidity differences across populations is found in a recent study that compared the responses of recently pregnant women in parallel surveys conducted in the U.S. and Canada. This study found that women with preterm births in the U.S. were more likely to report being obese (BMI 30 and over, 19.3 % in the U.S. compared to 13.6 % in Canada), smoking during pregnancy (11.7 % in the U.S. compared to 10.5 % in Canada), and having three or more stressful life events during pregnancy (28.6 % in the U.S. compared to 17.1 % in Canada) (Garn et al. 2015). Stressful life events were measured using a standard scale and include events such as divorce, hospitalization or death of a family member, becoming homeless, or having a close friend or family member with a drinking or drug problem.

Another view is offered by French obstetrician Emile Papiernik. In a commentary disputing the conclusion of the 2007 IOM report on preterm birth, that no intervention except possibly progesterone treatment successfully prevents preterm birth, Papiernik proposed his own explanation for the marked differences between preterm birth rates in the U.S. and Western Europe. Discussing policies that were put into place in the 1930s and 1940s, he writes:

> During this time, most European countries introduced systems for the "protection of pregnant women and children" that included free access to prenatal care and to obstetrical and neonatal care. They also provided paid work-leave for all pregnant women for the last weeks of pregnancy (some at 28 weeks as in the UK, some at 32 weeks as in France) for the specific purpose of preventing preterm birth. This protective system was enacted in Sweden in 1935 and in 1945 in almost all other European countries, which enacted laws based on the Swedish model. No evaluations are available for these interventions, as the epidemiologic rules for such assessments had not yet been defined. An indirect evaluation is available, based on a comparison of the rate of preterm births in Sweden in 1920–24 (7.8 %) and in 1985 (5.8 %). Furthermore, an important argument for effectiveness of this preventive country-wide program was the observed reduction in the social gradient of risk

of preterm birth; the odds ratio of the difference between social categories was greater than 2.5 in 1920–24 and declined to 1.22 (0.94–1.58) in 1985. (Papiernik 2007 p. 408, reprinted with permission from Springer)

Supporting this hypothesis, Papiernik also described a 12-year intervention in France in the 1970s that provided a prescription for earlier maternity leave for women with risk factors suggesting imminent preterm birth or those with difficult working conditions. While this intervention did not reduce the likelihood of preterm birth for the subpopulations of women with the highest risks—those with a previous preterm birth, those with bleeding during pregnancy, teens or older women—on a general population basis preterm birth rates declined from 5.4 % in 1971–1974 to 4.0 % in 1975–1978 and 3.6 % in 1979–1982.[10] In addition, Papiernik described other studies indicating that very stressful working conditions, long hours and extensive standing during work, are associated with preterm birth.

1.6.2 Differences in the Preterm Newborn Population

Another of MacDorman and colleagues' findings on international comparisons of preterm birth, also widely validated and observed over time, is that gestational age-specific survival rates are higher in the U.S. than in comparison countries. Although more infants are born preterm in the U.S., those born at 22–23 weeks have a 71 % mortality rate in the U.S., compared to an 88 % mortality rate in England and Wales, and a 95 % mortality rate in Denmark, for example. Those born at 32–36 weeks have a 0.09 % mortality rate in the U.S., compared to a 1.1 % mortality rate in England and Wales, and a 1.0 % mortality rate in Denmark (MacDorman and Mathews 2009).

In part this survival difference may be due to differences in the availability of resuscitation interventions and in decisions made about resuscitation in these different settings. These differences are discussed further in Chaps. 5 and 6. However, another component of the explanation for relatively lower mortality rates per gestational age in the U.S. is that preterm newborns may be relatively less compromised to begin within the U.S. than preterm newborns in other countries. Neonatal mortality rates tend to be lower in countries with a larger portion of interventional deliveries (Lisonkova et al. 2012), either because infants are delivered in time to be resuscitated before they die, or because they are delivered early without true indications, and thus are less compromised than infants born prematurely in countries with lower intervention rates. Similarly, if the higher rates of preterm birth in the U.S. reflect more cases where a normal pregnancy is interrupted due to maternal factors such as stress, while the rates in other countries reflect more fetal

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[10] Papiernik notes that for ethical reasons the intervention was not implemented with a control group whose rates of preterm birth could be compared to those of women receiving the early maternity leave prescriptions, but was made available to all women.

compromise, the result would also be a population of preterm newborns in the U.S. with inherently better survival chances that those of other countries.[11]

The higher survival rates of preterm newborns in the U.S. do not draw much attention, since they are more in line with the expectation for continued social progress and superior performance in the U.S. compared to other nations. Not surprisingly though, poorer rankings on gestational age-specific survival have motivated some Western European countries to reorganize their perinatal care systems in order to assure that preterm newborns have immediate access to specialized neonatal care.

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[11] This point was made by perinatal epidemiologist Allen Wilcox in discussions with faculty at the University of Alabama School of Public Health during a visit in February 2011.

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Chapter 2
The Population Dimension: The Distribution of Preterm Births

The early ending of any particular pregnancy is not predictable, but preterm births do not occur randomly across the population. Rather, they are more common in some sub-populations (that is, groups of women who share some characteristic) than in others. These patterns are often used to help people make sense of preterm birth, and to direct conversations about appropriate interventions. However, the way population patterns are constructed and expressed is conditioned by sets of social expectations and cultural beliefs. This is well illustrated by the following exchange, which occurred at a hearing before a committee of the U.S. Senate in 2004, in preparation for a vote on increasing spending for research on preterm births

> Senator Lamar Alexander: But if a pregnant mom were watching today or reading later your statement, what are the two or three things that we do know that one ought to do to discourage prematurity? What actions an individual can take that are based on good research, on science that we know today?
>
> Dr. Peter Van Dyck (Health Resources and Services Administration): Well, let me start with that, if I may. First of all, planned pregnancy, 54 percent of the pregnancies in the United States, with all the information we have on what causes pregnancy – we know that pretty well, and we also have pretty good information in how to prevent pregnancy if we don't want to have it. In spite of all that, we still have 54 percent of the pregnancies in the United States unintended, unplanned, and there's very clear information that those pregnancies were…
> L. Alexander: Unattended?
> Van Dyck: Unintended.
> L. Alexander: Oh, oh. Unintended?
> Dr. Duane Alexander (National Institutes of Health): Yes. So there's also pretty good information that those pregnancies are at greater risk for prematurity, low birth weight than the intended, planned pregnancy. (U.S. Senate, Subcommittee on Children and Families, Education, Labor and Pensions Committee 2004)

The action orientation that characterizes the U.S. response to preterm birth, as discussed in Chap. 1, is evident here in the question from the chairman of the Senate committee, who wants to know what a pregnant woman can do to make sure that she does not deliver before term. The experts' first answer, that she should plan her pregnancy, of course does not make sense in this context, since the senator is asking what a woman should do if she is already pregnant. The answer does make

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sense in an ideological context however, since intention and planning are good behaviors, and therefore, at least theoretically, they should prevent bad outcomes.

2.1 Studying the Distribution Patterns of Health Problems

The study of the patterns of distribution of health and disease across populations is the domain of the public health discipline of epidemiology. Writing in the 1990s, epidemiologist Nancy Krieger identified the central framework in mainstream epidemiology as including two beliefs: first, that population patterns of health and disease can be explained by complex webs of interconnected risk and protective factors, and second, that public health can be improved by identifying and breaking selected strands of these webs. Krieger notes that this view departs from models within medicine which assume that specific diseases have single specific causes; the web model emphasizes that causal factors can be multiple and overlapping. Otherwise, however, she contends that this view of population patterns of disease is based on implicit beliefs that are fundamentally derived from clinical medicine. These include first, an emphasis on those biological determinants most amenable to intervention via medical care; second, a view that social factors are secondary to these biological determinants; and third, an assumption that population rates of disease are simply the sum of the problems that occur in individuals (Krieger 1994).

Because of this implicit biomedical or clinical orientation, findings of studies that examine the population distribution of diseases tend to identify features of populations with higher rates of a disease as "risk factors" for that disease. This is essentially the language used in the 2007 Institute of Medicine (IOM) report on preterm birth, which includes five chapters spanning a large scientific literature on population characteristics that seem to be related preterm birth, as identified in observational studies and in clinical trials of interventions. The risk factors identified in the body of the IOM report are categorized thematically in Table 2.1. A slightly different list of risk factors, identified in an appendix to the report, is summarized in Table 2.2, categorized as in the original document. This clinically oriented approach is reflected more generally in many discussions of the epidemiology or population patterns of preterm birth. These also describe population features as "risk factors" for preterm birth (for example Garn et al. 2015; Goldenberg et al. 2008)

These two sets of lists provide some interesting clues to the larger picture of the occurrence of preterm birth across the U.S. population. However, the clinical approach of conflating population associations with individual risk factors raises several concerns. The approach assumes that population-level patterns imply individual level disease mechanisms. Krieger (1994) refers to this as the "individualistic fallacy", and epidemiologist Geoffrey Rose (Rose 2001; Schwartz and Diez-Roux 2001) points out that the reasons that some individuals in any given population have a health problem can be different from the reasons that an entire population has higher rates of the problem. Rose cites as an example the finding that rates of hypertension are much lower among Kenyan nomads than among London

Table 2.1 Risk factors for preterm birth identified by the IOM Report, Behrman and Butler (2007), Chaps. 3–8

Behaviors preceding or occurring during pregnancy	Physical or mental health status	Social or environmental context	Timing and conditions of pregnancy
Tobacco smoking	Low pre-pregnancy weight	Physically demanding employment	Unintentional/unwanted pregnancy
Alcohol consumption	Low weight gain during pregnancy	Exposure to racism	Mother under age 16 or over age 35
Cocaine use	Micro-nutrient deficiency	African-American or U.S. born hispanic	Unmarried
Douching	Anxiety, depression, low self-efficacy, stress	Stressful life events and chronic stress	Short interval between pregnancies
Moderate exercise (protective)	Chronic disease—circulatory, diabetes	Low socioeconomic status	Multiple births, fetuses with congenital anomalies
Continued sexual activity (protective)	Obesity	Adverse neighborhood conditions	Infertility issues
	DES exposure during mother's pregnancy	Exposure to toxins and pollutants	Use of assisted reproductive technology
	Family history of preterm birth		

civil servants. Within each population, the reasons that some individuals have hypertension and some do not are basically the same, but these reasons do not explain why the population rates of hypertension are different. Emile Papiernik makes the same point about the intervention discussed in Chap. 1, in which pregnant women in France with difficult work conditions were given prescriptions for an early start to their maternity leave. The intervention did not change the likelihood that women with high-risk conditions, such as uterine bleeding, delivered preterm, but it was associated with a downward shift in the population rate of preterm births (Papiernik 2007).

The individualistic fallacy is well illustrated in the quote at the beginning of this chapter from the 2004 U.S. Senate hearings on allocating more research funding for premature births. Dr. Van Dyke of the federal Health Resources and Services Administration responded to Senator Alexander's question about what an individual pregnant woman could do to prevent giving birth prematurely by stating that unplanned pregnancies have higher rates of preterm delivery than pregnancies that are planned. While it is true that more women with unplanned pregnancies have

Table 2.2 Risk factors for preterm birth, identified in Appendix B of the IOM Report, from Alexander (2007)

Immutable medical risk factors
Previous low birth weight or preterm delivery
Multiple 2nd trimester spontaneous abortion
Prior first trimester induced abortion
Familial and intergenerational factors
History of infertility
Nulliparity
Placental abnormalities
Cervical and uterine anomalies
Gestational bleeding
Intrauterine growth restriction
In utero diethylstilbestrol exposure
Multiple gestations
Infant sex
Short stature
Low pre-pregnancy weight/low body mass index
Urogenital infections
Preeclampsia
Demographic risk factors
Race/ethnicity
Single marital status
Low socioeconomic status
Seasonality of pregnancy and birth
Maternal age
Employment-related physical activity
Occupational exposures
Environmental exposures
Possibly mutable risk factors
No or inadequate prenatal care usage
Cigarette smoking
Use of marijuana and other illicit drugs
Cocaine use
Alcohol consumption
Caffeine intake
Maternal weight gain
Dietary intake
Sexual activity during late pregnancy
Leisure-time physical activity

preterm births than do women whose pregnancies are planned, the many other features of women with unplanned pregnancies—their age, level of stress, socioeconomic status, familial setting, and short intervals between pregnancies—are additionally and independently associated with preterm birth. Thus the population-level pattern is not meaningful at an individual level; planning a pregnancy is not a therapeutic intervention that prevents a preterm birth.

Another problem with treating observations made about preterm birth rates in a population divided into categories, such as women over age 35, as though they are individual risk factors, is the way the lists are organized to imply that all of the listed factors have equal weight and operate, web-like, on equivalent levels of organization and in the same time frame. Krieger contends that this problem is a consequence of an unwillingness to propose an actual theory about the causes of health and disease distributions, emphasizing instead the technical methods which support a fine-grained understanding of the way factors overlap and are associated with an outcome. Political scientist Sylvia Tesh suggests that the web model of epidemiology provides a rationale for scientists to remain neutral on identifying actual preventive approaches to health problems. She writes

> The clear guidelines for action implicit in the germ theory's linear model here all subdivide, point to yet other causal factors, double back on one another, go both ways at once, and never lead out anywhere. The multifactorial model would be a maze except that there are no dead ends: everything is linked to everything else. Worse, the intricate connecting links make any one preventive action appear insignificant. To be effective, prevention policy seemingly has to attack all possible causes at once – a strategy that would stretch available resources far beyond their capacity and end up by devoting only a pittance to each. In practice, the multicausal model easily becomes a rationale for not taking action. Since everything is connected to everything, we are apparently hopelessly knotted into our own cultural practices, products and institutions. Thus we either have to accept the diseases that evidently go along with them or opt for revolution. Some tinkering around the edges is possible, but by and large, the multifactorial web seems to show, real disease prevention is nearly impossible. Better to concentrate on a cure. It may be more expensive, but it is simpler. (Tesh 1988, p. 62, reprinted with permission from Rutgers University Press)

In her critique, Nancy Krieger proposes a general image of an alternative, more theoretical approach to the web metaphor which she terms an "ecosocial" approach. Such an approach would frame a health problem as a product of a variety of exposures interacting with a range of susceptibilities in the population. These would unfold over time. Groups of individuals in the population would share some exposures and some susceptibilities. The focus would be on exposures and susceptibilities, some social and some biological, rather than on characteristics of the population (Krieger 1994). The contemporary "life course" perspective in the field of maternal and child health (Lu and Halfon 2003), discussed later in this chapter, is an attempt to create a model of pregnancy outcomes similar to the ecosocial approach described by Krieger. The life-course theory suggests that an array of risk and protective factors accumulate over a woman's lifetime and affect the likelihood of various pregnancy outcomes.

A third issue with the risk factor approach to understanding the population distribution of preterm birth and other health issues is that it tends to obscure the fact that knowledge only accumulates about aspects of populations that those who are charged with accumulating knowledge choose to inquire about. Understanding population patterns of health issues require collecting data on large groups of people. This requires resources, which in turn requires that individuals in control of such resources consider particular sorts of information important and justified by theories of disease causation. Theories of disease causation, in turn, are linked to political ideologies about the sources of social problems and the types of social change considered legitimate to use to address them (Krieger 1992; Tesh 1988).

Krieger is particularly attuned to the absence of information on social status—income, wealth, position in society—in nearly every U.S. health population database, even though the association between these factors and morbidity and mortality rates has been well-known since the early nineteenth century. In contrast, British health datasets include measures of both socioeconomic status and social position (Rose 1995; United Kingdom Data Service 2014). Krieger ascribes the absence of this type of information in U.S. datasets to the belief that the U.S. is a "classless" or egalitarian society, and that such information is therefore unnecessary or meaningless. On the other hand, every U.S. data set records "race" as a categorical variable, as though it were a biological characteristic with a meaning that transcends social context. As discussed in the Preface to this book, this categorical treatment of race reflects an ideology and history about the perceived nature of social differences in U.S. society (Centers for Disease Control and Prevention 1993; LaViest 1994).

In the U.S., race and ethnicity are often taken as indicators of poverty and socioeconomic status, although clearly race, ethnicity, poverty, and socioeconomic status are entirely different types of categorizations based on different characteristics. An example of the conflation of race, ethnicity, and poverty is this observation by syndicated columnist Stephen Chapman, arguing against expanding anti-poverty programs as a way to address high infant mortality rates

> No one denies the problem. Our infant mortality rate is double that of Japan or Sweden. But we live different lives, on average, than people in those places. We suffer more obesity (about 10 times as much as the Japanese), and we have more births to teenagers (seven times more than the Swedes). Nearly 40 % of American babies are born to unwed mothers. Factors like these are linked to low birth weight in babies, which is a dangerous thing.
>
> In a 2007 study for the National Bureau of Economic Research, economists June O'Neill and Dave O'Neill noted that "a multitude of behaviors unrelated to the health care system such as substance abuse, smoking and obesity" are connected "to the low birth weight and preterm births that underlie the infant death syndrome." Nicholas Eberstadt, a scholar at the American Enterprise Institute in Washington, also attributes the gap largely to conduct. Comparing white Americans to Norwegians in his 1995 book, "The Tyranny of Numbers," Eberstadt concluded that "white America's higher rates of infant mortality are explained not by poverty (as conventionally construed) or by medical care but rather by the habits, actions and indeed lifestyles of a critical portion of its parents."
>
> Whites are not unique in those types of behavior. African-American babies are far more likely to die than white ones, which is often taken as evidence that poverty and lack of health insurance are to blame. That's entirely plausible until you notice another racial/ethnic gap: Hispanics of Mexican or Central or South American ancestry not only do consistently better than blacks on infant mortality, they do better than whites. Social disadvantage doesn't explain very much. (Chapman 2009), reprinted with permission from Stephen Chapman and Creators Syndicate, Inc.

Using race and ethnicity to stand for poverty and/or social disadvantage obscures careful analysis, dialogue and public acknowledgement of the role that both sets of factors, poverty/social disadvantage and race/ethnicity, play in increasing the likelihood of a preterm birth (Isaacs and Schroeder 2004).

As another example of the way that ideological frameworks structure what we know about the distribution of health and disease, Tesh suggests that the assumption that lifestyle or behavioral factors cause disease taps into dominant cultural themes of individual free will, personal control, and upward social mobility (because taking care of one's personal health is a signal of membership in the affluent class) (Tesh 1988). In this framework, it is failure to adopt a healthy lifestyle that is the cause of disease. Therefore, only individual behavior change, not larger scale social interventions, can be expected to prevent disease (see also Crawford 1980). The view of health as a self-generated phenomenon encourages individuals to accept an obligation to adhere to a healthy lifestyle, in order to function effectively in the economic system. It discourages organized state involvement to improve the conditions for health, since that would be pointless if health is primarily a product of individual behavior. These beliefs about health are embedded in a broader political philosophy, sometimes called neoliberalism, which supports free trade, privatization, minimal government involvement in social issues, and a belief that social inequalities are a consequence of individual choice (Ayo 2012).

Data could be collected on an infinite array of personal behaviors and experiences that characterize what might be termed lifestyle. However, quite typically the items selected for data collection are currently stigmatized behaviors or personal characteristics. In Tables 2.1 and 2.2, in the listing of "risk factors" related to preterm birth, these include tobacco smoking, alcohol consumption, cocaine, marijuana, and other "illicit" drug use, obesity, and dietary intake. Intendedness of pregnancy and marital status could also be thought of as lifestyle issues, since they indicate that the pregnant woman had sexual intercourse irresponsibly, or in defiance of social norms. The power of the lifestyle model of disease distribution to frame policy issues is also illustrated by the quote from commentator Stephen Chapman. Here Chapman is arguing against using the low international ranking of the U.S. on infant mortality rates as a rationale for supporting healthcare reform in the U.S. By listing several stigmatized behaviors that can be associated with preterm and low birth weight births, while discounting the effect of poverty because only one and not all U.S. minority groups have higher rates of preterm birth, Chapman implies that no societal level intervention is warranted to address high rates of preterm birth. Rather, individuals are personally responsible if a preterm birth occurs for them, because the primary explanations for the incidence of preterm birth are related to individual behaviors. As Sylvia Tesh suggests, the emphasis on stigmatized behaviors in the causal model of prematurity, low birth weight, and infant mortality, is shaped by a belief that there is a limited need for government action to address issues such as poverty or discrimination.

While the framing of preterm birth as a disease or health problem is natural—given it represents an undesirable physical event—ultimately preterm birth is an aspect of a population's pattern of reproduction. In many cases, the data available for examining rates of preterm birth have been collected as part of efforts to monitor population growth and fertility patterns. It is thus possible in the U.S. to examine rates of preterm birth separately by maternal and paternal race and to some extent ethnicity, maternal age, parity, marital status, and other factors considered important for tracking trends in reproduction. Ideologically, the selection of factors to be examined in relation to preterm birth is conditioned by beliefs about reproduction and thus about parenthood. There is societal interest in identifying categories of women who should not be mothers according to prevailing social norms, such as teenagers, poor women on welfare, Black women, and alcohol and drug users. Dividing the population up into these categories and then assessing whether these categories of women have negative pregnancy outcomes such as preterm birth can be a way of reinforcing pre-conceived beliefs about the undesirability of reproduction for these groups.[1]

Keeping in mind the caveats that population frequencies are not the same individual risk factors, that associations have a causal hierarchy and operate over time, not all at once, and that belief systems shape which data are available for analysis, the next four sections of this chapter examine the research literature on four sets of characteristics that have been associated with preterm birth: features of a woman's pregnancy, features of health and health-related behaviors, poverty, and race and ethnicity.

2.2 Preterm Birth and Features of Pregnancy

2.2.1 Prior Preterm Birth

The most consistent predictor of having a preterm birth is having had a prior preterm birth, having a family history of preterm birth or actually having been born prematurely oneself. This is usually interpreted as evidence that there is a genetic component to the tendency to go into labor before a pregnancy reaches term, although other factors associated with preterm birth (such as a woman's health status or stress level) may also repeat in subsequent births. One study that tracked preterm birth across generations, using Swedish population registry data, found associations with maternal but not paternal preterm birth (Wilcox et al. 2008). The proportion of preterm births among women with a family history of preterm birth is 20–40 %, compared to the overall proportion in the U.S. population, which is about 12 %. A woman with one prior preterm birth is nearly 4 times as likely, and a woman with two prior preterm births is more than 6 times as likely to have another preterm delivery as a woman with a prior birth delivered at term (Behrman and Butler 2007).

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[1] Anthropologists Faye Ginsburg and Rayna Rapp have termed the division of populations into groups whose reproduction is supported and groups whose reproduction is discouraged "stratified reproduction" (Ginsburg and Rapp 1991, 1995).

2.2.2 Multiple Births

Multiple births, including twins, triplets, and higher order births are more likely to be born preterm than singleton births (Alexander 2007). The rates of multiple births have been increasing over time in the U.S., and also in Canada, Great Britain, and Western European countries. In part this is because maternal age at first birth is rising in all of these places, and older women are more likely to have multiple births. It is also due in part to increases in the use of fertility treatments which increases the likelihood of multiple births. Blondel et al. (2002) estimate that in the U.S. in the combined years 1995, 1996, and 1997, 10.3 % of preterm births were twin births, and 1.2 % were triplet births. In this time period, twins were 5.4 times more likely and triplets were 9.4 time more likely to be born preterm than singleton newborns.

This multi-national study found that the relative risk of preterm delivery increased 17 % for twins and 6 % for triplets in the U.S. between the early 1980s and the mid-1990s. Similarly, Kogan and colleagues found that preterm birth rates for twins in the U.S. increased from 41 to 55 % between 1981 and 1997 (Kogan et al. 2000). As noted in Chap. 1, multiple births are more frequently born preterm in part because the expansion of the uterus in a multiple birth helps to trigger labor in the same way that labor is triggered at term for singleton births (Wilcox 2010). However, both Blondel and colleagues and Kogan and colleagues suggest that the most likely reason for the increase in preterm birth rates among multiples in the 1980 and 1990s was an increase in the receipt of intensive prenatal care for women with multiple gestation pregnancies. More intensive monitoring is associated with an increase in interventional deliveries. In the Kogan et al. study, the portion of twin births occurring preterm with induction more than doubled between 1989–91 and 1995–97, the portion occurring preterm with cesarean section increased by 13 %, the portion born preterm without intervention increased by less than 1 % and the portion born at term and post-term declined by 11 %.

In addition to the increased occurrence of interventional deliveries for multiple gestation pregnancies, Blondel and colleagues suggest that women with multiple gestations who go into preterm labor are less likely to receive interventions to delay delivery than women pregnant with singletons. The decision to intervene with delivery and the decision not to delay spontaneous delivery of multiple births may be due in part to a belief among clinicians that multiple births mature earlier than singleton births and thus have fewer negative consequences from preterm delivery.[2]

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[2] Both sets of authors contend that this belief is not warranted (Blondel et al. 2002; Kogan et al. 2000).

2.2.3 Maternal Age

Table 2.3 shows the distribution of preterm birth rates by maternal age, separated into three racial/ethnic groups: Non-Hispanic White, Non-Hispanic Black, and Hispanic, as reported in the analysis of the most recently available vital records data. Maternal age is reported here in single years through age 19, and then grouped into 5 year categories through age 54. This precise focus on the rates at every year of teenage years is an indication of the importance attached to tracking preterm birth rates among teens, a category of women who are typically discouraged from reproducing.

As these data illustrate and other studies confirm, teenagers, particularly those under 18, are more likely to have preterm births than women in their 20s (Fraser et al. 1995; Schempf et al. 2007). This is particularly true for second or later births to teenagers. This higher rates of preterm birth for teenagers is thought to be due at least partly to their physical immaturity, sometimes complicated by low weight and poor nutritional status. Second or later births to teenagers are frequently separated by short intervals, which put them at additional risk, as will be discussed below.

In general, the negative effect of child-bearing in teens holds across racial/ethnic groups and socioeconomic groups. However, in many studies, Black teens are not at higher risk for preterm birth than are older Black women (Geronimus 1992; Schempf et al. 2007). This is because older Black women themselves are at high risk for preterm birth for different reasons. This can be interpreted to suggest that within the Black population, pregnancies at a younger age are at lower risk for poor outcomes than pregnancies at a later age, with the extended interpretation that perhaps teen pregnancy is not a universally negative phenomenon (Geronimus 1996). However

Table 2.3 U.S. preterm birth rates by maternal age and race/ethnicity 2013, based on Martin et al. (2015), Table 25

Maternal age (years)	Rate of births <34 weeks gestation			Rate of births 34–36 weeks gestation		
	White	Black	Hispanic	White	Black	Hispanic
Under 15	8.99	10.95	6.44	12.08	14.12	11.40
15	5.39	7.74	5.45	9.55	13.73	10.34
16	4.68	7.08	3.88	9.54	11.20	9.49
17	4.05	6.58	3.58	7.94	11.05	8.53
18	3.81	6.32	3.53	8.08	9.97	8.30
19	3.33	5.55	3.13	7.83	10.07	7.71
20–24	2.87	5.45	2.85	7.21	9.84	7.52
25–29	2.61	5.56	2.81	6.85	9.93	7.56
30–34	2.71	6.17	3.17	6.99	10.56	8.24
35–39	3.09	6.90	4.00	8.22	11.90	9.61
40–44	4.37	8.03	5.04	10.08	13.33	11.49
45–54	7.24	9.82	8.06	15.96	19.82	15.52

this does not mean that Black teenagers are immune from the negative effects of young age on pregnancy outcomes. The negative social and political reaction to Arline Geronimus' initial analysis, in which she pointed out the relatively positive outcomes of pregnancy for Black teens, is discussed in Chap. 4.

Table 2.3 also shows that women who become pregnant at later ages have higher preterm birth rates than women in their 20s. Several reasons have been suggested for elevated preterm birth rates among older women. First, some women become pregnant after many attempts, suggesting that they have a reduced ability to conceive. The biological reasons for this circumstance may contribute to pregnancy complications. For example, there might be difficulties with fertilized ovum implanting in the uterus. Second, some women become pregnant at later ages because of previous fetal losses, and thus similarly have physiological difficulties which affect their ability to maintain a pregnancy to term. Women who delay attempting child-bearing until a later age do not know whether they will have these fecundity issues.

A third circumstance that affects older pregnant women is the set of pregnancy complications that are associated with aging. In addition to their higher rates of multiple births, older women are more prone, than younger women, to hypertension and preeclampsia related to the increased blood volumes that occur in pregnancy. As noted in Chap. 1, these conditions are primary indications for medical interventions to deliver fetuses before term, with the rationale that an early delivery benefits the health of the mother and outweighs the risk of prematurity for the newborn. Other vascular complications related to the placenta—placenta previa and abruptions—are more common in older women and result in spontaneous preterm births. Adult onset and gestational diabetes are more common in older women and are associated with preterm labor and placental abruptions, and older women are more likely to have uterine abnormalities. Finally, older women are more likely to have pregnancies with chromosomal abnormalities due to the aging of their reproductive systems. Pregnancies with fetuses with abnormalities and congenital anomalies are more likely to end before term. (Cleary-Goldman et al. 2005; Montan 2007; Usta and Nassar 2008).

2.2.4 Intrapartum Interval

Many studies of population-based data on birth outcomes observe that preterm births are more common for women who become pregnant relatively soon after a previous delivery. Preterm births are more frequent for women with intervals ranging from 3 to 24 months, and for women with intervals between pregnancies of more than 60 months (Conde-Agudelo et al. 2006; DeFranco et al. 2007; Zhu et al. 1999). The observation holds true across Black and White women in the U.S. (Nabukera et al. 2008; Zhu et al. 2001) and has been documented internationally. Shorter birth intervals are more common for women with other risk factors for preterm birth, including young age, being unmarried and having a previous pregnancy loss, and for Black women, those with less education and those with lower incomes. When these factors are taken into account in statistical analyses, short intervals between births are still associated with preterm delivery, although the impact seems to be less for women without other risk factors for preterm birth (Behrman and Butler 2007, p. 154). The primary working hypothesis for the effect of short intervals on preterm birth is that, with shorter intervals between pregnancies, women are unable to regain adequate amounts of depleted nutrients (King 2003). Some studies also suggest that utero-placental bleeding, abruptions, and placenta previa are more common in women with shorter intervals between pregnancies. Long intervals between pregnancies may be associated with greater likelihood of preterm birth because of unmeasured issues such as low fecundity or other chronic conditions (Conde-Agudelo et al. 2007).

2.2.5 Assisted Reproductive Technologies

Assisted reproductive technologies (ART) are the various procedures in which ovum and sperm are handled before fertilization. In 2006, approximately 1 % of births in the U.S. involved some form of ART (Sunderam et al. 2009); the number of ART births doubled between 1996 and 2006 (Wright et al. 2008). Pregnancies involving ART are more likely to result in preterm births than other pregnancies. This is in part because these pregnancies are more likely to be multiples, given the practice of transferring more than one embryo to a woman in each cycle of fertilization. In the U.S. in both 2005 and 2006, about half of all pregnancies involving ART were multiple pregnancies (Sunderam et al. 2009; Wright et al. 2008). However, even when considering only singleton pregnancies, pregnancies involving ART are more likely to result in preterm births (McDonald et al. 2009). In both 2005 and 2006, the singleton preterm birth rate for pregnancies with ART in the U. S. was 13 %, compared to an overall population rate of about 11 %. Pregnancies involving assisted reproduction accounted for 4 % of all preterm births in the U.S., and 41 % of pregnancies with ART (singleton and multiple) ended before term (Sunderam et al. 2009; Wright et al. 2008).

2.2.6 Intendedness of the Pregnancy

The belief that unwanted pregnancies result in the birth of children with health problems is not recent; the argument dates from at least the discussions around fertility control and population growth that began in the late nineteenth century (Gordon 2002). Modern attempts to assess pregnancy intendedness in survey data began in the U.S. in the 1940s, as an offshoot of research into declining birth rates among middle class White families. Fertility surveys have continued, with the focus shifting first to increasing and then again to declining birth rates, and to examining the impact of new methods of birth control. A surprising feature of all of these surveys, starting in the 1940s, has been the small proportion of births that are fully planned, that is, wanted at the time that they occurred, according to the respondents' reports. In 1965, the portion of births which were fully planned was estimated at 26 % (Campbell and Mosher 2000). In 2008, the reported portion of pregnancies (as opposed to births) that were fully intended was estimated at 49 % (Finer and Zolna 2014). As will be discussed in Chap. 4, the argument that unintended pregnancies are likely to have poor outcomes, including preterm delivery, is the primary rationale used to promote public support for access to contraceptives. Pregnancy planning was the first intervention that experts suggested when asked in the 2004 Senate hearings how premature births could be prevented, as quoted at the beginning of this chapter. However, the actual evidence on the linkage between pregnancy intendedness and preterm birth is more complex than is usually presented.

To assess pregnancy intendedness, fertility surveys in the U.S. and internationally ask whether women who have recently given birth both whether they wanted to become pregnant at all, and whether they wanted to become pregnant when they did. Such measures of intendedness are imperfect, in part because women may change their minds about intention of pregnancy after their babies are born, and in part because intendedness really runs on a continuum but is often framed and analyzed as a dichotomy: intended or unintended (Bachrach and Newcomer 1999; Pulley et al. 2002). When pregnancies are categorized in this way, and other contextual factors are not taken into account, many studies suggest that unintended pregnancies are more likely to result in preterm birth and other negative outcomes (Kost et al. 1998; Orr et al. 2000; Pulley et al. 2002). A recent meta-analysis, combining multiple studies on the impact of pregnancy intendedness found that, again without adjusting for other characteristics, unintended (both mistimed and unwanted) pregnancies were more likely to result in a preterm births than intended pregnancies. Where mistimed and unwanted pregnancies could be distinguished, unwanted pregnancies were more likely to result in preterm births than wanted pregnancies (Shah et al. 2011).

In reality, however, the intended or unintended nature of a pregnancy does not occur in a vacuum. Having an unintended pregnancy is associated with young age and stressful life circumstances, maternal smoking, alcohol use, and less use of prenatal medical care. In many studies, when other life circumstances are taken into account, the direct association between pregnancy intendedness and preterm birth is not observed (Gipson et al. 2008; Kost et al. 1998). Other studies do show that the negative impact of unintendedness on preterm birth persists when such factors are taken into account (Shah et al. 2011). In these types of studies it is impossible to know whether all of the relevant factors have been taken into account in the analysis.

Based on their own survey of pregnant women in public prenatal clinics as well as their review of other literature, Messer et al. (2005) suggest that having an unintended pregnancy magnifies the perception of other negative life events and is associated with particular dysfunctional coping styles that in turn are associated with preterm birth. Stress, perhaps compounded by lack of social support, may be the major biological pathway that explains the association between pregnancy intention and preterm birth. Unintended pregnancies that proceed to deliveries create different levels of difficulty for women depending on their circumstances. This would explain why the association between intendedness and preterm birth varies by other features of women's lives.

A slightly different way of thinking about the impact of unintendedness on preterm birth might build from epidemiologist Geoffrey Rose's point, discussed above, that the reasons why an individual within a high-risk group has a health problem may be different from the reasons that the entire group has a greater frequency of the health problem. Here we could consider that, among a population of women whose life circumstances combined put them at higher risk for a birth that ends before term, those whose pregnancies were unintended are at elevated risk. This is actually what was documented in one of the first systematic studies of the association between intendedness and preterm birth (Orr et al. 2000), which focused on Black women receiving prenatal care at hospital-based clinics. Within this group, with higher preterm birth rates than the population as a whole, those women whose pregnancies were unintended had the greatest likelihood of delivering preterm. This means that, rather than being the case that all unintended pregnancies are at higher risk for ending before term, it may be the case that, among pregnancies exposed to various conditions which make it more likely that they will deliver preterm, those pregnancies that are unintended are the most likely to end early.

2.2.7 Marital Status

Many data sources used to assess pregnancy outcomes, particularly those built from vital records data, include information on the marital status of the mother. Vital records data also include data on infants' fathers, but these data are often missing if the father is not identified. Some surveys also collect marital status data, and it has also been extracted from medical records. Many studies indicate that preterm births are more common for unmarried and (although usually to a lesser extent) cohabiting women, who are not married but do identify and may reside with the father of the child. These associations have been observed in the U.S., Canada, and European settings (Luo et al. 2004; Messer 2011; Zeitlin et al. 2002).

Marital and cohabiting status of the parents of a newborn may serve as indicators of intendedness of a pregnancy when intention itself is not measured. In the U.S. in 2001, the portion of pregnancies that were unintended was estimated at 27 % for married women, 70 % for cohabiting women and 76 % for unmarried women (Finer and Henshaw 2006). However, more recent surveys suggest that the portion of pregnancies that are unintended is now closer to 50 % for cohabiting women and 66 % for unmarried women (Curtin et al. 2014). Alternatively, marital status could be an indicator of the extent of social support a pregnant woman receives, or marital status could be an indication of relative socioeconomic status (Shah et al. 2011a). Whatever marital status actually represents in these studies of association with preterm birth, the strength of the association between not being married and having a preterm birth seems to vary depending on how common births out of wedlock are, and thus perhaps how socially acceptable they are in a given setting (Luo et al. 2004; Zeitlin et al. 2002).

In the U.S., the portion of births to unmarried women peaked at 51.8 % in 2008 and was recorded as 44.8 % in 2013. In addition, an increasing portion of births to unmarried women are to women cohabiting with a partner (Curtin et al. 2014). Thus, it is not really clear that the observed association between marital status and preterm birth is particularly useful, in and of itself, for understanding population patterns of preterm birth.

2.3 Health and Health-Related Behaviors

2.3.1 Maternal Weight and Nutrition

Evidence is fairly strong and consistent that pregnant women who start their pregnancies when they are underweight for their height are more likely to deliver before term. The IOM report indicates that the risk of preterm birth is four times higher for underweight women than heavier women, and cites animal studies which suggest that under-nutrition at conception sets a placental clock which then triggers labor at an earlier gestational age than would otherwise occur. Dietary supplementation during pregnancy does not reduce the likelihood of preterm birth (Behrman and Butler 2007).

The association between preterm birth and maternal obesity or overweight status is more complex. Several studies have indicated that overweight women are less likely to have spontaneous preterm births, particularly in their first pregnancies (McDonald et al. 2010; Smith et al. 2007). One possible explanation for this is the observation that overweight women have fewer preterm uterine contractions (Ehrenberg et al. 2009). However, one large Swedish study did find that extremely obese women had a marginally greater likelihood of having a spontaneous delivery at a very early gestational age (Cnattingus et al. 2013). One Danish study suggests that obese women who have preterm membrane rupture are more likely to continue on to delivery, possibly because of higher levels of inflammation associated with obesity (Vasudevan et al. 2011).

Studies do consistently show that overweight women, particularly women with first pregnancies, are more likely to have interventional preterm deliveries than women who are not overweight. This occurs because they are more prone to chronic conditions which trigger pregnancy complications, such as hypertension, preeclampsia, and gestational diabetes (Cnattingus et al. 2013; McDonald et al.

2010; Smith et al. 2007). The American College of Obstetrics and Gynecology (ACOG) Committee Opinion on Obesity and Pregnancy advises

> Obese women are at increased risk of several pregnancy complications; therefore, preconception assessment and counseling are strongly encouraged. Obstetricians should provide education about the possible complications and should encourage obese patients to undertake a weight-reduction program, including diet, exercise, and behavior modification, before attempting pregnancy. Specific medical clearance may be indicated for some patients. (ACOG 2013, p.213, published by the American College of Obstetricians and Gynecologists)

In some studies, the lower risk of spontaneous preterm delivery and the higher risk of interventional preterm delivery balance out, resulting in a finding of negligible overall increase in preterm births related to obesity. But, as the prevalence of obesity and the rate of interventional preterm deliveries increase, overall rates of preterm birth related to maternal obesity will also increase. The relative risk of preterm birth for overweight compared to other women depends on the extent of medical intervention to deliver their infants before term, and thus varies over time and across settings.[3]

There is an extensive amount of social stigma associated with obesity in Western societies. Overweight individuals face discrimination in employment, education, and healthcare settings. Overweight people are widely perceived to have other negative traits, including poor self-discipline, laziness, incompetence, unattractiveness, and immorality. Despite the complexity of the biological and environmental factors that contribute to obesity, there is a strong culturally based conviction that individuals are responsible for their weight, and that weight gain and loss can be personally controlled (Puhl and Brownell 2001, 2003). The ACOG Committee opinion quoted above reflects this view.

The linkage between obesity and preterm birth fits neatly with an ideological framework that blames lifestyles rather than the social environment or biological factors for disease. As will be discussed further in Chap. 3, both popular childbirth education literature and media coverage frequently identify obesity as an important risk factor or cause of preterm birth. In fact, obesity does not cause preterm birth, but women who are obese are more prone to complications which physicians often address by intervening and delivering their newborns before term.

2.3.2 Maternal Tobacco Use

The evidence associating smoking with preterm birth is stronger than the evidence on the association between preterm birth and obesity. In one of the most recent of

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[3] Maternal overweight and obesity are also associated with higher rates of stillbirth, neural tube defects and other congenital anomalies, and more difficult recovery from surgical interventions (Vasudevan et al. 2011).

an extensive body of studies on the impact of smoking in pregnancy, analysts with the Centers for Disease Control and Prevention (CDC) (Dietz et al. 2010) examined vital records data for all infants born in the U.S. in 2002, and found that those whose mothers smoked were 50 % more likely to be born very preterm, 40 % more likely to be born moderately preterm, and 20 % more likely to be born in the late preterm period than those whose mothers did not smoke. Extrapolating these risk levels to the portion of women estimated to smoke during pregnancy (about 11.5 %), the authors suggest that smoking accounts for 5.3 % of all very preterm births, 4.6 % of all moderately preterm births and 2.6 % of all late preterm births. Smoking during pregnancy is also associated with low birth weight and with higher rates of mortality for infants born prematurely. The more cigarettes women reported smoking, the greater the risks. This study and others like it attempt to take into consideration the fact that women who smoke may have other risk factors for preterm birth, but the studies are limited by the availability of data to measure these other risks. The authors of this CDC study also note that the tobacco-associated risk levels they estimate may be associated primarily with heavy smokers, but their calculation of attributable risk is based on the assumption that all of the estimated 11.5 % of pregnant women who smoke will be exposed to that level of risk.

The Surgeon General's comprehensive report on the health consequences of tobacco smoking presents evidence that indicates that a primary impact of smoking is restricted blood flow, which contributes to placental problems—abruption and placenta previa—which can in turn lead to preterm birth. Also, tobacco smoking is associated with premature rupture of amniotic membranes, possibly by increasing inflammatory responses. There is some indication that spontaneous preterm birth through preterm labor may be associated with tobacco smoking, because higher preterm birth rates occur for tobacco smokers even when these other complications are absent. In contrast to the effects of obesity however, hypertension and preeclampsia occur at lower rates among smokers. Tobacco smoking restricts oxygen flow to developing fetuses, and is thus associated with fetal growth restriction, and low birth weight infants (USDHHS 2004).

Smoking came to popular attention as a public health risk in the 1960s, and anti-smoking public health campaigns became much more visible in the 1970 and 1980s. Pregnant women in particular have been targeted for interventions aimed at stopping smoking. In part, this is because the accepted rationale for resisting such health campaigns, which is the belief that individuals have a right to make decisions about their own health, is thought not to apply to pregnant women. As discussed in Chaps. 3 and 6 of this book, this norm of individual autonomy is overridden for pregnant women, who are expected to put the interests of their fetuses and children ahead of their own interests. The stigma of smoking is intensified by the fact that smoking during pregnancy, which has declined markedly since the 1980s, is now more common among low income women and teenagers. (Smoking is less common among Black and Latina women compared to white women). Anthropologist Laury Oaks, who has examined the social construction of smoking and pregnancy (Oaks 2001), notes that anti-smoking advocates and some health professionals have labeled smoking during pregnancy as a form of child abuse. Elsewhere, describing the cultural paradigm of smoking in pregnancy, she writes

> A pregnant woman who smokes activates the cycle: smoking during pregnancy results in the child's delayed physical and social development, repeated childhood illness, low self-esteem, poor school performance, dropping out of school, teen smoking, and teen pregnancy. Framed this way, cigarette smoking is not simply a personal health risk; it is a social risk. According to some health advocates, smoking by pregnant women represents a threat to "healthy families" and even to a "healthy society". (Oaks 2000, p.70, reprinted with the permission of the University of Chicago Press)

There is a coherence between the epidemiological evidence on tobacco smoking, the norms of good motherhood which label tobacco smoking as selfish behavior, and a political ideology that prefers individually oriented rather than socially targeted public health interventions. Even though tobacco exposure does not account for a large portion of preterm births (because not that many pregnant women are heavy smokers), smoking fits well into the cultural model of risk factors for preterm birth.

2.3.3 Maternal Alcohol and Illicit Drug Use

Heavy alcohol consumption in early pregnancy, either regularly or in the form of binge drinking, is associated with developmental problems in fetuses. Studies suggest that heavy drinking is also associated with an increased likelihood of preterm birth (Behrman and Butler 2007). There is more controversy over whether low to moderate levels of alcohol consumption also increase the risks of preterm births or low birth weight births. The consensus has been that low levels of alcohol consumption (less than one drink per day) are not harmful (Henderson et al. 2007), However, one recent British study that took into account nutritional intake and nicotine exposure found that both low (less than two drinks per week) and high (more than two drinks per week) consumption levels in the first trimester were associated with an increased risk of preterm birth; alcohol consumption before pregnancy and later in pregnancy did not show this effect (Nykjaer et al. 2014). Accurate studies of the effect of alcohol consumption are difficult to conduct for a number of reasons. As in the case unintended pregnancies, described above, alcohol consumption during pregnancy occurs in the context of other factors that increase the risk of preterm birth; one study cites "sociobehavioral factors such as poverty and smoking" as examples of confounding risks (O'Leary et al. 2007, p. 466). Also it can be difficult to measure alcohol consumption, and consumption before pregnancy and at different stages of a pregnancy in different amounts have different risks (O'Leary and Bower 2012).

Metabolites from drugs such as marijuana, cocaine, and opiates cross the placenta into the developing fetus, and there are studies which indicate that children exposed to these substances as fetuses show cognitive and neurological effects. The extent and persistence of these effects are a matter of debate, however. More than alcohol use, drug use during pregnancy is concentrated among a sub-group of pregnant women with many other factors associated with poor pregnancy outcomes, so it is difficult to isolate the impact of exposure. Also, it is possible that women identified as drug users during their pregnancies are not a representative sample of all pregnant women using drugs. They may instead be women with more complicated pregnancies, who have sought out medical care (Addis et al. 2001; Schempf 2007).

Still, to the extent that drug exposure can be measured, the only drug exposure identified as having an association with preterm birth per se is cocaine. Cocaine, opiate, and methamphetamine use are associated with growth restriction in fetuses; marijuana use has not been associated with either preterm birth or fetal growth restriction. Like tobacco, cocaine is associated with reduced blood flow, and thus with placental abruption; premature membrane rupture is also more common in women with either reported cocaine use or cocaine use identified through laboratory testing of newborns. The increased risk of preterm birth with cocaine use is not huge, and is lower than the risk of tobacco exposure (Bada et al. 2005; Minnes et al. 2011; Schempf 2007).

Although from a purely objective perspective, tobacco exposure creates a higher risk for preterm birth than alcohol or cocaine exposure, alcohol and drug use are treated more negatively from a social perspective. In the context of her work on anti-smoking campaigns and pregnancy, Oaks observes that drug and alcohol exposures are more stigmatized, possibly because all drug use and some levels of alcohol use are illegal. Cigarette smoking is considered the least of the three evils (Oaks 2000). As a further illustration of the normative nature of attributions of danger to characteristics or activities of pregnant women, O'Leary et al. (2007) point out that in Australia and Great Britain, where drinking is broadly socially acceptable, both governmental and medical authorities have been reluctant to advise pregnant women to avoid alcohol use, despite evidence that suggests that it is difficult to identify a safe threshold of alcohol exposure.[4] In contrast, in the U.S., where alcohol use is more stigmatized particularly during pregnancy (Armstrong 2003), authorities advise abstinence from alcohol. As will be discussed further in Chap. 4, cocaine use among pregnant women became the target of draconian legal sanctions in the U.S. in the 1980s. Enforcement authorities focused on women using the concentrated form of cocaine known as crack. These women were overwhelmingly Black, and the focus on poor pregnancy outcomes associated with cocaine use became a rhetorical counter point to a focus on other causes of racial disparities in preterm birth and infant mortality.

In all of the cases cited here: obesity, tobacco smoking, alcohol use and drug use, risks for increased rates of preterm birth exist. The level of risk depends on the extent of exposure (or in the case of obesity, the level of elevated body mass index)

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[4] The authors note that another concern cited by experts in Australia and Great Britain for not issuing advisories against moderate drinking for pregnant women is the fear that women who drink before they realize that they are pregnant might choose to abort their fetus out of guilt for the potential effects of alcohol exposure.

and is complicated by many co-occurring conditions and social and medical contextual features. In all cases, the attention paid to these risks fits a cultural narrative that locates responsibility for pregnancy outcomes in maternal behavior.

2.4 Poverty and Preterm Birth

2.4.1 Definitions and Measurement

Poverty can be thought of in relative terms, as the lowest end of a spectrum which social scientists often refer to as socioeconomic status, or position and rank within society. Socioeconomic status is associated with current income, ability to earn income in the future, and ability to access material and social resources in society. These in turn are structured by current income, wealth (accumulated resources), occupation, education, identity, and place of residence. Poverty can also be thought of in absolute terms, as the circumstance in which an individual's current material resources fall below a threshold that is deemed necessary for meeting their basic needs. This is the approach typically taken in the U.S., where individuals and families can be categorized as falling above or below the Federal Poverty Level (FPL), a dollar amount set to represent the amount of money needed to purchase enough food and to provide shelter on average in the U.S. In 2014, the FPL for a family of four was set at $ 23,850.

Because the amount of income needed for food and shelter actually varies across the U.S. and changes over time with more frequency than the official poverty threshold, many scholars as well as some public programs designed to assist individuals in poverty, apply a relative scale comparing income to the poverty threshold (Institute for Research on Poverty 2014). For example, the expansions of the Medicaid program in 1988 which extended health insurance coverage to low income pregnant women, set the minimum eligibility threshold at 133 % of the FPL, and many states expanded this threshold further to 150 % (Indiana, Kansas, Nebraska, Oklahoma, and West Virginia), 185 % (Connecticut, Delaware, Florida, Georgia, Iowa, Kentucky, Maine, Maryland, Massachusetts, Michigan, Mississippi, Missouri, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Pennsylvania, Tennessee, Texas, and Wisconsin) or even 200 % or more (California, Hawaii, Minnesota, Rhode Island, Vermont, and Washington) of the FPL (National Conference of State Legislatures 2002).

Population-based studies which include measures of socioeconomic status, such as income, education, occupation, and/or neighborhood poverty rates, consistently find that the poorest women have the worst pregnancy outcomes (Blumenshine et al. 2010). The first modern social welfare programs, as well as public health interventions such as improvements in sanitation and the urban food supply, were established in Europe and North America in the late nineteenth century in response to high infant mortality rates. These high death rates were a consequence of poverty that occurred in the context of the industrial revolution in these countries. This is discussed further in Chap. 4. Even as infant mortality rates declined over the twentieth century, with preterm birth accounting for the majority of infant deaths in the U.S. by the 1940s, disparities by socioeconomic status remained.

Despite broad acceptance of the premise that women in poverty or at the lowest end of the socioeconomic spectrum have higher preterm birth rates, in the U.S. it is difficult to identify population-based surveillance data to examine this relationship. As discussed in the beginning of this chapter, the view that the U.S. is an egalitarian society where social class is irrelevant means that measures which would capture such gradations are not available in population-based data. As statistician Joyce Martin of the National Center for Health Statistics notes in a government publication on preterm birth rates for 2007

> Racial/ethnic origin of the mother are self-reported. National gestational age data according to such attributes as educational attainment, income, and disability status are not available or not collected consistently in NVSS (National Vital Statistics System) and therefore were not analyzed for this report. (Martin 2011, p.78).

Table 2.4 shows data from a 1988 U.S. Maternal and Infant Health Survey that did report preterm birth rates separately for Black and White women, by gradations of their income to poverty ratio and also by maternal education. In addition, the table includes an analysis based on 1998–2000 combined U.S. vital statistics data, showing rates of preterm birth by maternal education, also separated by race, and a

Table 2.4 Preterm birth rates by indicators of socioeconomic status, based on Parker et al. (1994), Tables 2 and 3, Huynh et al. (2005), Table 5, Garn et al. (2015), Table 1

	White, non-Hispanic 1988 (%)	White, non-Hispanic 1998–2000 (%)	Black, non-Hispanic 1988 (%)	Black, non-Hispanic 1998–2000 (%)	Overall, 2005 (%)
<100 % FPL	3.5		12.2		
100–199 % FPL	4.7		9.4		
200 % + FPL	3.4		7.4		
Maternal Education less than high school	4.5	10.4	12.0	17.3	
High school grad	3.9	8.7	12.0	15.3	
Some college	3.8	7.9	7.5	13.9	
College grad	2.8	6.7	6.7	12.3	
Income lowest third					8.4
Income middle third					8.1
Income upper third					6.3

third analysis, based on the 2005 Pregnancy Risk Assessment Monitoring System surveys, that shows preterm birth rates by income ranking, not separated by race group. Educational achievement and income are two social measures often used to proxy or attempt to assess socioeconomic status, although neither captures completely the multiple dimensions of poverty or social ranking, and may actually have different meanings when applied to different ethnic groups or different historical time frames (Savitz et al. 2004).

Because the sources of data used in these three studies differ, it is not accurate to use these data to compare the absolute rates of preterm birth over time. What the table does illustrate is that, consistently over time and across groups, preterm birth rates are highest for women at the lowest end of the socioeconomic ranking, those with the lowest income or the least education. The table also illustrates that, across both the measure of income and the measure of education, preterm birth rates are higher for women identified as Black, compared to those identified as White. This suggests that while socioeconomic rank affects the preterm birth rates of both groups, factors in addition to socioeconomic status are associated with higher preterm birth rates among Black women.

A body of studies in the U.S. examines the association between residential neighborhood measures of poverty and preterm birth rates. Neighborhood measures of poverty include census-based estimates of median income or percent of households with incomes under the FPL in an area, unemployment rates, or average levels of educational achievement. These measures are used in two ways. They can substitute for individual measures of socioeconomic status when such individual measures are not available (Krieger et al. 2005). They can also be used to explore whether neighborhood deprivation has an impact on preterm birth rates over and above the impact of poverty at the household level. Neighborhood deprivation indicates a more global absence of resources that is difficult to overcome, even for individuals with relatively more advantage in the household (O’Campo et al. 2008). In either case, the majority of studies using neighborhood measures of low income or social deprivation also show that preterm births occur more commonly among women living in the most impoverished neighborhoods (Kim and Saada 2013).

2.4.2 *Understanding the Role of Poverty in Preterm Birth*

While there is no disagreement that preterm births occur more frequently among women living in poverty, it is clear that socioeconomic status does not fit well into the risk factor paradigm of individual diseases. One reason for this lack of fit is that material and social deprivation are multi-faceted and are poorly measured by single indicators, which can mean different things in different social contexts.[5] Yet studies

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[5] For example, in some eras in some communities, high school graduation could be an indicator of high socioeconomic status; in other contexts it is an indicator of relatively lower status.

following routine epidemiological research formats attempt to use statistical models to determine, for example, which of three measures, income, maternal education or paternal education best “explain” (correlate to) pregnancy outcomes (Blumenshine et al. 2011), or whether the extent of boarded up windows in a neighborhood has an effect on preterm birth rates that is distinct from the impact of median household income (Farley et al. 2006). Furthermore, the impact of deprivation unfolds over time, so women’s pregnancy outcomes can be affected by their experience of poverty as children, even if they are not poor when assessed during a particular pregnancy and thus are not likely to be categorized as having poverty as a risk factor (Currie and Moretti 2007; Love et al. 2010).

Finally and perhaps most importantly, many of the other circumstances or characteristics associated with preterm birth, including young age, short inter-pregnancy interval, stress, family strain, minimal social support and tobacco, alcohol and cocaine use, occur more frequently among women living in poverty. The more simplistic risk factor models attempt to take account of these characteristics, in order to assess whether poverty has an independent impact on pregnancy outcomes beyond these circumstances. This is challenging in statistical terms because the multiple factors are not randomly distributed. For example, it is difficult to find cases of White highly educated women living in low income, predominantly Black neighborhoods, but such cases would be needed, in statistical terms, to assess the separate influences of race, income, and neighborhood characteristics on pregnancy outcomes. In addition, if these co-occurring factors are parts of the pathway through which poverty and low socioeconomic status impact maternal health, it can be misleading to simply include all factors in a statistical model and control for them simultaneously. It may be that women in poverty have higher rates of preterm birth in part because they are more likely to be poorly nourished and have endemic infections, so attempting to take the pathway factors into account while examining the impact of poverty itself yields distorted results. (Kim and Saada 2013; Kramer et al. 2000).

As an example of a more phased, or hierarchical, approach that examines the interaction among poverty associated measures, Holzman et al. (2009) studied preterm birth rates across eight U.S. rural and urban areas, linking vital statistics to census data in order to measure neighborhood level social deprivation. They found that the relationship between older maternal age and preterm birth was strongest for Black women who reported being smokers and who lived in high poverty areas; White women who did not smoke and lived in low poverty areas showed no greater risk of preterm birth at older compared to younger ages. The association between older age and poor pregnancy outcomes in Black women has been termed “the weathering hypothesis”, and is thought to reflect the accumulated health effects of social inequality (Geronimus 1992). Holzman’s study suggests that weathering may apply across the board by social deprivation as well, since older White women in impoverished neighborhoods had worse pregnancy outcomes compared to younger women in those settings. However, this study still found that Black women in all circumstances were more likely to have a preterm birth.

In addition to examining the array of co-factors linked to poverty, analysts have also attempted to identify the way poverty may actually affect the physiological processes that are thought to trigger preterm birth. Kramer et al. (2000) note with some surprise that poverty is associated both with intrauterine growth retardation and preterm birth, even though the two phenomena seem to have different physiological pathways. They suggest four potential linkages between conditions associated with poverty and higher rates of preterm birth: chronic stress, the vaso-constrictive effects of tobacco and cocaine use, physically demanding employment that results in prolonged standing and heavy lifting, and higher rates of bacterial vaginosis.

The causes of cumulative chronic stress include financial insecurity, crowded substandard housing, unstable family relationships, and domestic violence. Exposure to chronic stress may stimulate the release of hormones that trigger spontaneous labor. Chronic stress is also the mechanism suggested as a linkage between social class and various manifestations of morbidity and early mortality (Isaacs and Schroeder 2004). This is sometimes conceptualized as having a “high allostatic load”, or having the combined physiological indications of elevated stress hormones, markers of metabolic syndrome such as high glucose and hemoglobin A1C, cardiovascular indicators such as elevated blood pressure, chronic inflammation and disrupted organ function, all of which can be a consequence of repeated stress and can reduce one’s ability to cope with additional stress (Geronimus et al. 2006; McEwan 2006; Szanton et al. 2005).

One subtext in the effort to identify the physiological mechanism linking poverty to poor health and poor pregnancy outcomes is that such a linkage might legitimize social efforts to alleviate poverty, because poverty would then constitute a medical or public health problem. This is discussed further in Chap. 4, in the context of examining the history of efforts to address infant mortality in the U.S. as the mode of legitimizing social efforts to ameliorate poverty. However, such a biologically oriented approach has limitations. In the 1980’s, British sociologist Ann Oakley (a noted critic of the medicalized approach to childbirth as it expanded markedly in the nineteenth and twentieth centuries (Oakley 1984)), led the Social Support and Pregnancy Outcomes (SSPO) study which randomized women who had previously had a low birth weight infant into two groups: a control group who received routine treatment, and an intervention group, who received supportive visits from nurse midwives. In her book recounting her experiences with the study, she objects to the practice of attempting to distinguish “social” risks such as poverty from “biological” risks such as stress, contending that in practice they are intimately intertwined. She writes:

> [T]he official statistical categories of perinatal mortality, low birthweight and social class are batted back and forth- now you see one of them, now the other. Behind the screen of the statistics which demonstrate that social deprivation, bodily deprivation and death are linked…something is known to be happening; but the discursive discourse of the social and medical – the relentless argument about which it is- gets in the way of understanding just what it is. The material poverty of the women who took part in the SSPO study emerges clearly in both the quantitative and the qualitative data drawn on in this book. Not only did

> many of them lack the material resources to provide for themselves and their families anything other than a health-denying quality of life, but the practical shortfalls were matched by the cultural under-resourcing of both gender and class. (Oakley 1992, pp. 314–315)

Like other studies of stress-reducing interventions, Oakley's study found that participants in the intervention appreciated the social support, were more satisfied and had fewer health problems, but did not deliver infants with appreciably higher birth weights than women in the control group. In defense of the findings, which her clinically oriented audience found disappointing, she comments:

> [T]he research midwives' perception of the difficulty of their task – how to overcome, by providing social support, the health-defeating effects of poor material conditions with their associated high levels of life stress – also proved correct. The space for effecting change in lives such as those of [the study participants] is small. This dilemma of social support interventions is perhaps best, albeit very painfully, illustrated in the story of Simone Churchill told in chapter 7. Simone's healthy baby (claimed as a 'success' by her research midwife) died at 4 months of a respiratory illness attributed by her mother to health-damaging housing. (Oakley 1992, p. 315)

It is difficult to fully insert a discussion of the impact of material deprivation into the epidemiological framework that dominates authoritative knowledge on the topic of preterm birth. Still, the efforts taken to obtain data on pregnant women's poverty or socioeconomic status have paid off by providing an important addition to the understanding of the population distribution patterns for preterm birth. The research described here, although limited in the ways material deprivation can be measured and bound to the conventions of causal models in medicine, offers a corrective both to the ideologically motivated overstatement of the role of stigmatized health behaviors in preterm birth and to the pull towards confounding the impact of poverty on preterm birth with the impact of race and ethnicity.

2.5 Preterm Birth, Race, and Ethnicity

2.5.1 Black-White Disparities in Preterm Birth Rates Over Time

The differences in birth outcomes for White and Black Americans have been observed since the start of vital statistics record keeping in the U.S. In 1922, when birth registry data were available only for major metropolitan areas, and neither gestational age at birth nor birth weight were recorded, the infant mortality rate for White infants was 73 per thousand; for Black infants the mortality rate was 127 per thousand, 74 % higher (Washington, 1925). In 1935, the U.S. infant mortality rate for White infants was 51.9 per thousand; the rate for Black infants was 81.9 per thousand, 58 % higher. In 2007, the mortality rate for White infants was 5.6 per thousand; the rate for Black infants was 13.2 per thousand, 136 % higher (Singh and van Dyck 2010). Singh and Van Dyck also note that Black infants had twice the risk of dying of conditions of the perinatal period (including prematurity, low birth weight and complications of delivery) compared to white infants in 1970, but 2.6 times the likelihood of dying of these causes in 2007. This suggests that, particularly over this most recent time period, preterm and low birth weight rate differences were increasingly the major explanation for racial differences in infant mortality. The National Center for Health Statistics reported that in 2001, preterm births accounted for 84 % of neonatal deaths among Black infants and 72–75 % of neonatal deaths among infants of White and other race or ethnicities (MMWR 2004)

Gortmarker and Wise (1997) point out that the infant mortality rate is driven by two components: the distribution of low birth weight (prematurity and growth restriction) in the population, and birth weight specific mortality (the mortality rate for premature and growth restricted newborns in each weight group). It is birth weight specific mortality that is influenced by advances in medical treatment in the prenatal and particularly the neonatal periods, as more and smaller babies are resuscitated and kept alive. Between 1960 and 1980, the time period bridging the establishment of Medicaid to finance medical care for low income families (as discussed in Chap. 4), infant mortality for White infants declined by 59 %, and infant mortality for Black infants declined by 49 %. In all, 85 % of the change in the White infant mortality rate could be attributed to changes in their birth weight specific mortality, or in other words, their access to medical interventions. In contrast, 100 % of the decline in Black infant mortality rates was due to improvements in birth weight specific mortality; without these improvements, the Black infant mortality rate would have risen by 3 % (Buehleret al. 1987; Gortmarker and Wise 1997). Improved medical technology is as helpful for Black newborns as for White newborns, but the underlying portion of White infants born prematurely or at low birth weights declined between 1960 and 1980, while the underlying portion of Black infants born prematurely or at low birth weights slightly increased.

Figure 2.1 shows the trend in preterm births between 1989 and 2012 for three groups, non-Hispanic Whites, non-Hispanic Blacks and Hispanics, based on vital statistics data. The race and ethnicity categories are derived from reporting on state birth certificates, and the category of Hispanic combines women reporting being of Mexican, Puerto Rican, Cuban, Central and South American or other Hispanic origin. As can be seen, the gap in preterm birth rates between Black and White pregnant women has narrowed slightly in the most recent decades, as preterm birth rates in the Black population have declined, while rates in the White population have increased. Thus it is preterm birth rates in the White population which have driven the overall population increases in preterm birth rates discussed in Chap. 1.

Kitaw Demissie and colleagues (2001) studied the vital records from the 1989 to 1997 period more closely, and noted that preterm birth rates for White infants increased by 15.6 % over that decade, while preterm birth rates for Black infants declined by 7.6 % (births to Hispanic women were combined with births to White or Black women, depending on whether Black or White race was recorded on the birth certificates). Rates of multiple births increased over the decade for both

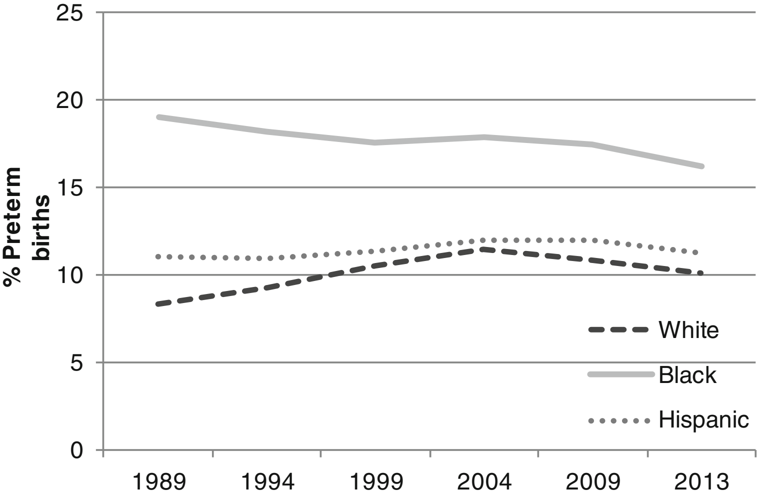

Fig. 2.1 Preterm birth rates by race/ethnicity, vital records 1989–2013, from, Martin et al. (2015), Table 24

groups, but the increase was greater (+27.4 %) for White women than for Black women (+14.7 %). The portion of births with preterm induction of labor increased by 148 % for White women and 102 % for Black women, while the portion with preterm cesarean section increased 30.8 % for White women and 21.6 % for Black women. Considering that Black women tend to have a higher prevalence of several of the conditions that trigger interventional preterm deliveries, including hypertension and diabetes, it is notable that they had lower rates of increase in preterm inductions and cesarean sections over this period. This differential points to the physician practice variation in preterm interventional deliveries noted in Chap. 1 and discussed further in Chap. 5.

In the Demissie and colleagues study, the increase in interventional deliveries accounted for nearly all of the increase in preterm birth rates among White women. When they were excluded, the (spontaneous) preterm birth rate among White women increased by only 0.5 % over the 1989–1997 time period. The (spontaneous) preterm birth rate for Black women decreased by 19.2 %. The differential in infant mortality for the two groups did not diminish. Rather, the authors note that the Black–White disparity in mortality for preterm infants actually widened over this period, as neonatal mortality rates for White preterm infants fell by 34 % for White infants and 24 % for Black infants ((Demissie et al. 2001) One explanation for this difference, as suggested in Chap. 1, is the lower morbidity profile for preterm infants born via interventional preterm deliveries. Even though the trends suggest that the differential between preterm birth rates among Black and White women is narrowing, in 2013 the preterm birth rate among Black women was still 60 % higher than the rate for White women.

2.5.2 Poverty as an Explanation for Racial Disparities

The two most common rationales offered to explain Black–White differences in preterm birth rates are the effects of poverty, and biological differences in the two groups. However, neither of these explanations is well supported by the scientific evidence. Larger portions of minority racial and ethnic groups in the U.S. have incomes below the Federal Poverty Level, compared to non-minority groups. An analysis of census data from the U.S. Census Bureau, combining the years 2007 through 2011, found that the group with the highest portion of members living in poverty was the Native American and Native Alaskan population with 27.0 %. The Black or African-American population had 25.8 % of individuals living in poverty, the Hispanic population had a poverty rate of 23.2 % and the White population had a poverty rate of 11.6 % (Macartney et al. 2013). Yet as noted in the previous section of this chapter, studies that have data available for both race/ethnicity and socioeconomic status have consistently shown that women categorized as Black have higher rates of preterm (and low birth weight) deliveries than women categorized as White, even when socioeconomic status, healthcare use, age, health behaviors, and other factors are taken into account (Giscombe and Lobel 2005). Such studies include ones where birth outcomes are assessed for the entire population, and studies where birth outcomes are assessed for strata of women who are assumed to be otherwise similar in education or social situation. As an example of the latter approach, social psychologists Cheryl Giscombe and Marci Lobel describe four studies comparing preterm birth rates for African-American and European-American (the authors' preferred designation) college graduates, and in one case, children and grandchildren of these college graduates. All four studies documented higher preterm birth rates among African-American women. The authors also describe two studies that compared birth outcomes between African-American and European-American enlisted military personnel and their families that similarly found racial differentials in preterm birth rates for these otherwise presumably similar women. Thus, racial categorization cannot be considered a measure of poverty. Black women of all income levels have higher rates of preterm birth than White women in comparable income levels.

2.5.3 Biology as an Explanation for Racial Disparities

As discussed in the Preface to this book, race is a social category that makes cultural sense as a way of dividing up a population. The way populations are divided varies cross-culturally and evolves over time.[6] However, there is a belief in Western societies that racial differences represent differences in human biology,

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[6] For example, in the U.S. in the nineteenth century, some immigrant groups, including those from Ireland and Greece, were considered to be non-white (Jacobson, 1999).

usually described as differences that are passed down over generations. There are a few genes that actually do vary based on continent of origin (e.g., Africa versus Europe), but they are neither numerous nor significant enough to influence the complex physiological processes. There is much more genetic variation within than among individuals categorized by race (Bhopal 1998; Cooper and David 1986; David and Collins 2007). Still, beliefs about the biological basis of racial differences persist. They are socially convenient, because they are a way of explaining some unfavorable circumstance experienced by Black people without implicating the existing U.S. social and cultural status quo. For example, scholars over the past several decades have periodically proposed a heredity-based explanation for differences between the average performance of Black and White children on standardized intelligence tests (Fryer and Levitt 2013; Hernstein and Murray 1994). Such an explanation allows policy makers to ignore the many aspects of the differences in social environment experienced by Black and White children that affects the way they respond to standardized tests. Biology can also be used to justify racial differences in the extent to which medical care ameliorates disease states. David and Collins note that racial disparities in preterm birth rates are used to justify a contemporary interest in identifying a “preterm birth gene”. They credit this interest in part to the effect of a political ideology which emphasizes individual over socially addressable causes of disease, and in part to commercial interests which could adapt such genetic findings to the production of lucrative patented therapies.

A body of studies has been used to challenge the rationale that higher preterm birth rates among Black women is related to their African heritage. All of these studies take a similar form: they analyze data from a population of women who self-report their race as “Black” and who delivered infants in the U.S., and then compare birth outcomes based on ancestry, that is, whether the women report their ancestry as “American”, “African”, or specific Caribbean or Latin American countries. Some studies also include data on nativity—whether the women were born in the U.S. or in other countries. These studies fairly consistently show that Black women who identify as American have statistically significantly higher rates of low birth weight or preterm birth than Black women identifying as African or Caribbean. For example, Howard and colleagues studied over 168,000 New York City birth records for the 1998–2002 period for women reporting their race as “Black”. Taking other characteristics (including insurance status as a measure of income) into account, U.S. born Black women had a relative risk of preterm delivery that was 9 % higher than Cuban-born Black women, 19 % higher than West Indian and Brazilian-born Black women, 24 % higher than Asian-born Black women, 25 % higher than Puerto Rican-born Black women, 36 % higher than European-born Black women, 39 % higher than African-born Black women, 45 % higher than South and Central American-born Black women and 60 % higher than non-Hispanic U.S.-born white women. Other individual studies (Acevedo-Garcia et al. 2005; David and Collins 1997; Palloto et al. 2000; Singh and Yu 1996) and a meta-analysis of the recent literature on birth outcomes for migrant versus U.S. born women (Urquia et al. 2010) report similar findings. There is thus no evidence to support the premise that higher rates of preterm birth among Black women are a consequence of any unique genetic profile for women with African heritage.

2.5.4 Stress, Racism, and the Life-Course Model

Pregnancy outcomes are far from the only area of morbidity and mortality in which Black people are at a disadvantage. In particular, non-Hispanic Black individuals have higher rates of hypertension and diabetes, and higher rates of death from coronary heart disease and strokes than non-Hispanic White individuals (Beckles and Chiu-Fong 2013; Gillespie and Hurwitz 2013; Gillespie et al. 2013). Coronary heart disease, hypertension and diabetes are all conditions associated with high allostatic loads, that is, with biological markers for the negative physiological impact of stress (McEwan 2006). In an analysis of the National Health and Nutrition Survey, Geronimus and colleagues found that Black respondents had significantly higher measures of allostatic load than white respondents, with disparities increasing as individuals aged. This held true across high and low poverty groups, and the racial disparity between Black and White women was greater than the disparity among men (Geronimus et al. 2006). Thus, differences in the extent of exposure to acute and long-term stress are a plausible explanation for racial disparities in general health in the same way that stress has been proposed as the primary explanation for poorer health among those in poverty. Both theoretical models and empirical studies (Paradies 2006; Pascoe and Smart Richman 2009) suggest that exposure to racism could account for higher rates of physiological indicators of stress and stress-related diseases among Black people born and raised in the U.S., compared to those born and raised in countries without the U.S. legacy of slavery, or where Black people comprise the majority rather than a minority of the population,

As noted in Chap. 1, stress is associated with premature delivery through a number of biological pathways. Higher rates of cortisol and other stress hormones can potentially trigger spontaneous early labor. They can exacerbate the inflammatory effects of infections which can also trigger membrane rupture and spontaneous early labor. Stress can affect the cardiovascular system, increasing rates of hypertension which can lead both to spontaneous early labor and to the medical decision to intervene in a pregnancy and deliver a baby before term (Giscombe and Lobel 2005).

Much attention has been paid to the experience of stress during pregnancy, and for Black women the experience of racism during pregnancy that can trigger stress; both stress and the experience of racism are associated with preterm delivery and the delivery of very low birth weight infants (preterm and growth restricted) (Collins et al. 2000; Dole et al. 2003, 2004; Lespinasse et al. 2004; Rosenberg et al. 2002). Of course, the high levels of stress experienced by African Americans in the U.S. are not limited to pregnancy, but accumulates over a lifetime. Lifetime stress levels are also associated with preterm delivery (Dole et al. 2003; Dominguez et al. 2008).

Still, Rosenthal and Lobel (2011) argue that Black women are subject to a unique level of racism-related stress during pregnancy, for three reasons: experience and beliefs related to discriminatory treatment in medical and particularly reproductive health settings, contradictory cultural pressures that both support and devalue motherhood for African-American women, and the pressure of negative stereotypes concerning African-American motherhood. On the latter, they write:

> Applying the stereotype threat paradigm, there is a strong basis to suggest that the stereotypical, degrading images associated with Black women's sexuality and motherhood result in a unique source of stress for these women throughout their lifetimes, and particularly during pregnancy. Black American women may be affected by stereotype threats throughout their lives, concerned about whether people are judging them or making assumptions about their sexual behavior (e.g., promiscuity) based on stereotype. These concerns are probably heightened during pregnancy, when Black American women may be distressed about others believing that they are fulfilling stereotypes like the "welfare mom". Pregnancy may be a time that elevates a Black American woman's awareness of and concern about others' stereotypes because her sexuality and impending motherhood are visible and displayed through the prominence of her pregnant body. This awareness may be a reflection of reality in that the pregnant body may prompt others' views about Black women's sexuality and motherhood and influence behavior toward them. (Rosenthal and Lobel 2011, p. 980, reprinted with permission from Elsevier)

In 2003, physicians Michael Lu and Neal Halfon published a seminal paper (Lu and Halfon 2003) that sorted through the research on racial and ethnic disparities in birth outcomes, intersecting as it does with birth outcome disparities associated with socioeconomic status. They proposed a paradigm that takes into account the way a range of risk factors in the context of protective factors, both experienced over a life time, contribute to different rates of preterm birth (and other birth outcomes) between Black and White women. Risk factors include poor nutrition, exposure to toxic and infectious agents, chronic and acute stress, physical exertion, cigarette smoking, etc., while protective factors include social support, continuous medical care, flexible employment and access to material resources. Life time includes time spans that are particularly sensitive to the impact of risks, such as the period of fetal development. Their diagram expressing this paradigm is shown in Fig. 2.2.

Lu and Halfon refer to their paradigm as the life-course perspective, and describe it as a synthesis between the cumulative stress or weathering model described above, and the early programming model, which emphasizes the way physiological factors such as nutrition and trauma experienced in the fetal period, infancy and early childhood impact individuals' health as adults, including stress reactivity and susceptibility to infections and inflammations. Their model reflects epidemiologist Nancy Krieger's suggestion that researchers move away from an undifferentiated, web-like way of expressing interconnections towards models that can reflect changes over time and integrate the impact of factors at various social and biological levels. The model also challenges the dominant approach in clinical medicine, which tends to look for risk factors and events occurring during pregnancy as influences and explanations for pregnancy outcomes, since those are the factors that are most likely to be influenced by clinical care. Instead of proposing a set of

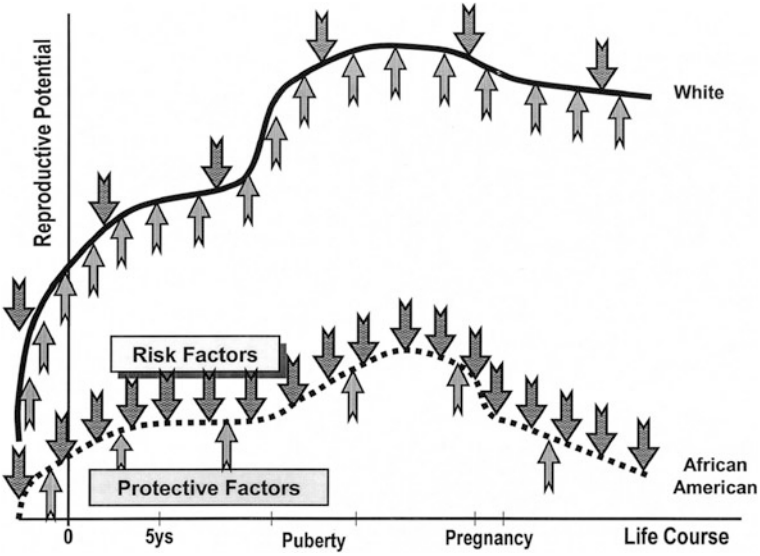

Fig. 2.2 The life-course perspective as diagrammed in Lu and Halfon (2003), reprinted with permission from Springer

interventions that could be applied in the prenatal period to improve birth outcomes, Lu and Halfon write:

> From the life-course perspective, eliminating racial-ethnic disparities in birth outcomes will require 1) closing the gap in one generation to give the next generation an equal start, 2) targeted interventions during sensitive developmental periods (e.g., in utero development, early childhood, puberty, pregnancy), and 3) risk reduction and health promotion strategies across the life span… Such strategies "pull up" the trajectory by mitigating risk factors, and "push up" the trajectory by promoting protective factors. It should be evident…that closing the gap between Black and White curves will require risk reduction and health promotion strategies to be not only applied during pregnancy, but sustained over the life-course, particularly during sensitive periods of development. (Lu and Halfon 2003, p.19, reprinted with permission from Springer)

As will be discussed in Chap. 4, the life-course approach to addressing infant mortality, preterm birth and other pregnancy outcomes has had a notable effect on programming and policy interventions, broadening the types of community development activities that are considered relevant to addressing these issues, particularly for low income and Black populations. As the framework has been integrated into the strategic planning approach for the federal Maternal and Child Health Bureau, it has influenced program funding and Maternal and Child health professional training programs. However, Halfon et al. (2014) note that an agenda and resources to integrate life-course theory into research on pregnancy outcomes and infant health is still in the early stages of development.

2.5.5 *The "Latina Epidemiologic Paradox" and Preterm Births in Other Ethnicity Populations*

Most women of Hispanic heritage in the U.S rank lower on conventional measures of socioeconomic status, income and education, than White women. Yet their perinatal outcomes—preterm birth, low birth weight and infant mortality—tend to be better than those of Black women, and only slightly worse than those of white women (Shiono and Klebanoff 1986). For example, vital records data for 2013 shows an overall preterm birth rate of 10.17 for White women, 16.27 for Black women and 11.31 for Hispanic women (Martin et al. 2015, Table 24).

However, the category of "Hispanic" is very general, grouping together women with a wide range of ethnicities (that is cultural heritages) including Mexican, Puerto Rican, Cuban, Central and South American and European-Spanish. In most studies, the birth outcomes for women of Mexican and Cuban heritage are actually better than those of White women. Puerto Rican women's rates of preterm and low birth weight births are similar to that of the U.S. Black population, and birth outcomes for women of Central and South American heritage vary depending on the U.S. population measured (Rosenberg et al. 2005). Furthermore, birth outcomes for women of Mexican heritage vary based on whether they are born in Mexico or the U.S. Fairly consistently, it is the women born in Mexico and delivering infants in the U.S. who have lower rates or preterm and low birth weight births than White women, while U.S.-born women of Mexican heritage tend to have relatively equivalent birth outcomes to White women (de la Rosa 2002; Flores et al. 2012).

This observation has been termed the Hispanic or Latina epidemiological paradox, because it challenges the expectation that women of lower socioeconomic status have worse birth outcomes. The paradox is not exclusive to birth outcomes, but is observed across many measures of adult morbidity and mortality, where Hispanic adults appear to be in better health than other U.S. sub-populations (Markides and Coreil 1986). Three rationales have been suggested to explain these findings. The first is that morbidity and mortality among Hispanics is under-reported, partly because individuals with health difficulties may return to their countries of origin, and therefore infant and adult deaths are not recorded in U. S. vital statistics. However, such under-reporting seems an unlikely primary explanation for the paradox, particularly for birth outcomes and infant deaths within the first week of life, both of which are well recorded in vital statistics data (de la Rosa 2002; Hummer et al. 2007).

The second explanation for better birth outcomes among women of Mexican heritage is what is termed the "healthy migrant effect". This is the premise that sub-populations who are geographically mobile, such as Mexican-born women who have migrated to the U.S., are healthier in perhaps unmeasurable ways than individuals who remain in their native regions. The healthy migrant effect may be one reason that, as discussed above, foreign born women of African heritage have lower rates of preterm birth than U.S.-born Black women. Wingate and Alexander (2006) used U.S. vital records to document not only that migrants from Mexico had lower preterm and low birth weight rates than U.S.-born women, but that women of Mexican ancestry who migrated within regions of the U.S. also had better birth outcomes than those who remained in one location. A similar healthy migrant effect is observable for non-Hispanic Black women who deliver in regions and states other than the ones where they were born (Wingate et al. 2009).

The third rationale, which may operate simultaneously, is that there are some components of traditional Mexican culture that are protective against health threats, including those that are linked to preterm births. Evidence to support the credibility of the cultural explanation include observations that the birth outcomes of individuals of Mexican origin appear to deteriorate the longer they live in the U.S. Birth outcomes are also worse the more that the individuals are acculturated into U.S. society, for example, by speaking English rather than Spanish (de la Rosa 2002). Guendelman and English (1995) studied women of Mexican origin in Los Angeles, and found that those who had resided in the U.S. for more than five years had more pregnancy complications and higher preterm birth rates than new immigrants. It is not clear what elements of traditional culture are protective against poor birth outcomes, but possibilities include better strategies for coping with stress (Farley et al. 2005), more social support and stronger social networks (Dyer et al. 2011), and a traditional orientation towards specific family roles for pregnant women, mothers, and their spouses and partners (Abdou et al. 2013).

As for other ethnic groups in the U.S., the National Center for Health Statistics reported in their analysis of 2012 birth records that women of Native American or Alaskan native ethnicity had a preterm birth rate of 13.25 %, compared to the rate of 16.26 % for Black women 11.58 % for Hispanic women, 10.29 % for White women and 10.15 % for Asian and Pacific Islanders (Hamilton et al. 2014, Table 7). By most comparisons, Native American women have higher rates of medical complications and other pregnancy risk factors, but taking those into account to the extent feasible with population-based data, they have about a one-third greater likelihood of having a preterm birth than White women (Alexander et al. 2008; Hwang et al. 2013; Shah et al. 2011b). A listing of possible factors explaining these higher rates, identified by Shah and colleagues in their review of studies on the issue, includes many familiar explanations. Native American women are often of short stature and obese, and are prone to diabetes and urogenital infections. They use less prenatal care and may encounter communication difficulties interacting with the health care system. They may have culturally associated differences in health behaviors, use more alcohol and tobacco, be more likely to have had multiple pregnancies, be of younger age and have less education. In addition, many Native American people live in extreme poverty. The census-based grouping of women as Asian or Pacific Islander is so broad that it is difficult to draw conclusions about their preterm birth rates.

In summary, data on preterm birth rates in ethnic and racial sub-groups in the U.S. is readily attainable, because the population-based vital statistics system includes these descriptors along with records of pregnancy outcome. It is much more difficult to understand the meaning of differences in rates by race and ethnicity, since many of the actual drivers for preterm birth are not measured in these data sources. In fact, if the life-course paradigm is taken as a guide, much more would need to be known about women then their race or ethnicity, including their exposures as fetuses and infants to a variety of risks and the stock of protective factors that they have accumulated, in order to predict each individual's likelihood of giving birth preterm. The value of examining variations and disparities in preterm birth rates by race/ethnicity is that it can challenge assumptions made about the causes of preterm birth. For example, understanding that preterm birth rates are high for Black women across socioeconomic statuses challenges the premise that racial disparities relate only to poverty, and causes observers to examine the potential impact of racism on health. Understanding that the birth outcome advantage accruing to women of Mexican heritage fades with time and acculturation draws attention to the impact of cultural practices on preterm birth. One downside of focusing on preterm birth rates for ethnic and racial sub-groups is that it can lead to stereotyping of women by race and ethnicity and diminish the likelihood that health care providers will attend to the unique needs of individuals.[7]

2.6 Comparisons with Canada, Great Britain, and Western Europe

An understanding of the distribution of preterm births across the population helps to explain why the U.S. rates of preterm birth are so much higher than rates in Canada, Great Britain and Western Europe. This section explores whether the child-bearing population in the U.S. includes more women with the characteristics associated with preterm birth than the child-bearing population of these other nations, or whether the same segments of the population have different preterm birth rates in different settings.

2.6.1 Features of Pregnancy

Data are available for international comparisons of four of the aspects of pregnancy associated with preterm birth discussed above: multiple births, assisted reproduction, maternal age, and pregnancy intendedness. Blondel and colleagues report that rates of twin pregnancies were similar across the U.S., Canada, England and Wales and France, both in 1981–1982 and in 1997, but rates of triplets in 1997 in the U.S. were somewhat higher (1.7 per 1000) than in the comparison countries (the next

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[7] For example, anthropologist Khiara Bridges recounts the experience of a fellow researcher who was present at a difficult labor experienced by a Mexican-American patient in New York City. Clinicians were slow to provide pain medication for the patient, because of their assumption that Mexican women were healthy and tended to have easy labors (Bridges, 2011).

Table 2.5 International comparison of age-specific fertility rates, 2009–2010, United nations department of economic and social affairs (2013), Table A5

Nation	Births per 1000 to women age 19 and Younger (% of total)	Births per 1000 to women age 20 to 34	Births per 1000 to women age 35 and Older (% of total)
Canada	14 (4.2 %)	310	9 (2.7 %)
Denmark	5 (1.3 %)	376	10 (2.6 %)
France	12 (2.9 %)	389	13 (3.1 %)
Germany	9 (3.3 %)	256	8 (2.9 %)
Netherlands	5 (1.4 %)	347	9 (2.5 %)
Norway	8 (2.0 %)	374	12 (3.0 %)
Sweden	6 (1.5 %)	376	14 (3.5 %)
United Kingdom	25 (6.4 %)	351	13 (3.3 %)
United States	41 (9.9 %)	364	11 (2.6 %)

highest was 1.4 per 1000 in England and Wales). Triplet rates may be higher in the U.S. because procedures involving multiple embryo implantation in assisted reproduction are more common in the U.S. than in other nations.[8] The likelihood that a twin or triplet pregnancy resulted in a preterm birth was similar across the nations compared (Blondel et al. 2002).

The discussion earlier in this chapter noted that pregnancies among women over age 34 and particularly among women under age 20 are more likely to end in a preterm delivery. As shown in Table 2.5, using 2009–2010 data selected from the United Nations Department of Economic and Social Affairs, Population Division, Fertility and Family Planning Section website, the U.S. has about the same portion of births occurring to women over age 34 as Canada, the United Kingdom and Western European nations, but has a larger portion of births occurring to women under age 20.

The factors related to teen births are consistent across nations; teens who initiate sexual intercourse at earlier ages, who do not use contraceptives and who have less access to abortion services are more likely to become pregnant. These same teens have parents with less educational attainment and lower incomes. They have less success in school and are more likely to take risks. An unknown but significant portion of teen pregnancies are the consequence of non-consensual sexual activity, particularly with older males. Several studies comparing teen pregnancy rates in

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[8] Use of ART occurs more frequently in European countries than in the U.S., but fewer procedures in Europe result in a live birth (17 % compared to 27 % in the U.S. in 2001). Because of regulatory restrictions and different practice patterns, fewer ART pregnancies in Europe involve the transfer of multiple embryos to a woman's uterus (36.3 % with three or more embryos, compared to 66.4 % in the U.S. in 2001) and fewer result in multiple births (25.5 % compared to 38.6 % in the U.S. in 2001) (Gleicher et al. 2006). This is discussed further in Chap. 6.

Europe and the U.S. have concluded that rates of sexual activity are fairly similar across these countries, but teens in Europe are more likely to use contraceptives, and thus are less likely to become pregnant compared to teens in the U.S. (Jones 1985; Santelli and Melnikas 2010; Advocates for Youth 2011). The larger representation of women under age 20 in the child-bearing population in the U.S. is another factor contributing to higher preterm birth rates.

The association between pregnancies that are unintended and poorer birth outcomes, including greater likelihood of preterm births, has been documented internationally (Gipson et al. 2008). Associations between preterm birth and births to unmarried women have also been described in Canada and Europe, as well as in the U.S. (Shah et al. 2011a; Zeitlin et al. 2002). Singh et al. (2010) used United Nations population data and multiple surveys on pregnancy planning, abortion and miscarriage rates to create global estimates of the portion of pregnancies in each world region that were unintended in 2008, along with the portion of these pregnancies that ended in a live birth. A summary of their findings is shown in Table 2.6. Data for the U.S. are combined here with data from Canada, and show that these countries together had a higher portion of unintended births than any of the regions of Europe. This was the case both because the portion of unplanned pregnancies was higher and because the portion of pregnancies that ended in abortion was lower in these countries. Clearly, attitudes towards sex and fertility differ between the U.S. and Europe, as does public policy towards birth control and abortion (Brown and Eisenberg 1995; David et al. 1990; Puffner 1993). International differences in the politics of fertility control are discussed further in Chaps. 3 and 4. Higher rates of births that are products of unintended pregnancies are yet another component of higher preterm birth rates in the U.S.

Table 2.6 International comparison of unintended pregnancy, birth and abortion rates, 2008, Singh et al. (2010), Table 1

Region	% Pregnancies unintended	% Unintended pregnancies ending in births	% Unintended pregnancies ending in abortions	% Unintended pregnancies ending in miscarriages
Northern Europe	41	17	18	5
Southern Europe	39	18	16	5
Eastern Europe	48	5	38	5
Western Europe	42	17	20	5
U.S. and Canada	48	23	18	7

2.6.2 *Health and Health-Related Behaviors*

Data are available to compare three of the four health and lifestyle characteristics described in this chapter as associated with preterm births: body mass index (underweight and overweight or obesity), heavy alcohol consumption, and smoking among pregnant women. These comparisons are shown in Table 2.7. For underweight, smoking and alcohol use, the U.S. is in about the mid-range of the countries shown. The U.S. is quite high for rates of obesity and overweight, however. Some European observers have suggested that higher rates of overweight and obesity in the U.S. are the primary explanation for the nation's higher rates of preterm birth (Cnattingus et al. 2013). However, as discussed above, obesity itself is not a risk factor for preterm birth, but is an indicator of maternal health problems such as hypertension which tend to trigger early interventional deliveries. As discussed in Chap. 1, other data such as maternal complication and mortality rates also suggest that prevalence of maternal co-morbidities and complications are in higher in the U.S. than in comparison countries.

2.6.3 *Poverty*

Poverty or low socioeconomic status, measured at the individual or neighborhood level, is associated with higher rates of preterm birth internationally. The number of studies documenting the association between poverty and poor birth outcomes in

Table 2.7 International comparisons of health and health behaviors, OECD (2014a) (obesity), World Health Organization (2012) (underweight), Zeitlin et al. (2013), Table 4.1 and Garn et al. (2015) (tobacco use), World Health Organization (2014) (alcohol use)

	% Women over age 15 overweight or obese, 2012	% Women over age 15 underweight (BMI < 18.5), 2002–2009	% Pregnant women report tobacco use, 2010	% Adult women reporting heavy drinking in past 30 days, 2010
Canada	24.6	2.6	10.5	10.9
Denmark	13.1	2.2	12.8	19.5
France	14.6	4.8	17.1	17.7
Germany	13.8	n/a	8.5	n/a
Netherlands	12.8	n/a	6.2	1.3
Norway	9.0	5.0	7.4	6.5
Sweden	11.8	2.0	4.9	14.5
United Kingdom	25.1	5.1	12.0	20.9
United States	36.6	2.4	11.7	10.9

Table 2.8 International comparisons of poverty rates, OECD (2014a, b)

	Poverty rates after taxes and transfers 2011–2012[a]	
	Age 18–25	Age 26–40
Canada	13.1	11.4
Denmark	21.5	5.8
France	13.1	7.8
Germany	12.7	8.8
Netherlands	20.0	8.1
Norway	28.9	8.5
Sweden	18.1	10.6
United Kingdom	11.5	8.1
United States	21.6	15.7

[a] Poverty is defined by the Organization for Economic Cooperation and Development (OECD) as 50 % of the median income in the country

Great Britain and Western European communities has increased in recent years (Kim and Saada 2013). Table 2.8 suggests that the adult population with income under the poverty level is larger in the U.S. than in the comparison countries. Thus it seems likely that another component of the difference in preterm birth rates between the U.S. and comparison Western countries is that more pregnancies in the U.S. occur among low income women.

2.6.4 Race and Ethnicity

Finally, it is clear as discussed above, that the lifetime and multi-generational stress and disadvantage of the Black and Native American populations in the U.S. are important drivers of high preterm birth rates. These two populations represent 16.1 and 1.2 % of all U.S. births respectively in 2013, while births to Hispanic women, also at higher risk except for recent immigrants, represented 22.9 % of all U.S. births in that year (Martin et al. 2015). It is difficult to identify sub-populations in other Western countries exposed to these same stresses, both because the migration of individuals of non-European heritage to Europe is relatively recent, and because ethnicity is not well documented in birth registries in European countries (Zeitlin et al. 2013).

Indications are, though, that the dynamics that increase preterm birth rates among ethnic minorities in other Western countries are similar to those in the U.S. For example, Garn et al. (2015) report that in Canada aboriginal (Native American and Eskimo) women composed 5.5 % of the child-bearing population in 2005–2006, and had preterm birth rates that were 38 % higher (6.9 % compared to 5.0 %) than non-aboriginal women. In Great Britain and Europe, a meta-analysis of studies indicated that the low birth weight rates of immigrants from sub-Saharan Africa, South Central Asia, East/Southeast Asia and Latin America and the Caribbean were 63, 70, 19 and 44 % higher, respectively, than the non-immigrant European low birth weight rate of 4.3 % (Urquia et al. 2010). Non-European immigrants constituted between 2.1 % (Netherlands) and 5.7 % (Germany) of the population in Western European countries in 2009 (Rogers 2010). If the portion of ethnic minorities in Canada, Great Britain or Western Europe approached the portion in the child-bearing population of the U.S., preterm birth rates in those countries would be higher than currently observed.

In sum, the composition of the child-bearing population in the U.S. differs in significant ways from the composition of the child-bearing population in Canada, Great Britain and Western Europe. Women who get pregnant in the U.S. are more likely to be younger, to have more higher order multiple births, to have unintended pregnancies which end in live births rather than abortions, to have lower incomes and to be of a racial/ethnic heritage that has exposed them to multiple generations of disadvantage. As noted in Chap. 1, they are also more likely to have chronic diseases that complicate pregnancy, indicated in part by their much greater likelihood to be overweight or obese. Higher rates of preterm birth in the U.S. compared to other countries is associated with the higher portion of women more likely to deliver preterm in the population.

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Chapter 3
The Cultural Dimension: How We Understand Preterm Birth

Culture is the set of shared understandings within a society that contain what the members need to know in order to communicate and interact with each other. Anthropologist Ward Goodenough draws a parallel to language, in the sense that the vocabulary of a language shapes what can be effectively communicated, while the grammar reflects the way phenomena are organized. Culture includes the criteria that members of a society use to categorize phenomena as meaningful; to decide what can be; to know how they feel about things, that is, their values and preferences; to decide what to do about things, and to decide how to go about doing things, as well as including the sets of skills needed to perform acceptably within the society (Goodenough 2003). Individuals within a single society may not hold exactly the same cultural understandings, and cultural understandings are dynamic, shifting over time. However, within a single society there is enough overlap across the cultural understandings held by members that they can usually interact successfully with each other. Cultural meanings are transmitted over time, so they have a historical trajectory. They also tend to be interconnected, so that, for example, understandings about the appropriate behavior of men and women within families may draw from the same body of themes, symbols, and principles used to make sense of the natural world and the desirable arrangements of the economy.

Beyond guiding individuals so that they can behave acceptably, both by articulating expectations and by structuring how people understand what choices of behavior are open to them, a shared culture reinforces social solidarity, or sense of cohesion and interconnection among culture holders (Ortner 1984). Simultaneously, a shared culture can legitimize existing power or economic arrangements by making it difficult to think about alternatives. For example, the U.S. cultural belief that social mobility derives from individual initiative (pulling oneself up by one's bootstraps) makes it difficult to discuss, think about, or even to notice structural circumstances such as the linkage between low-income neighborhoods and poor schools, which systematically disadvantage low-income children. Thus, the dialogue about the limited employment options for low-income young adults "naturally" turns into a discussion about their lack of individual initiative, rather than their limited access to educational opportunities.

J.M. Bronstein, *Preterm Birth in the United States*,
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In contemporary U.S. culture, the medical paradigm is used to understand all issues related to the body, including pregnancy and childbirth.[1] The medical paradigm sees pregnancy as a disease, a risky condition or an abnormal state that needs to be monitored and treated by medical authorities in order to assure a positive outcome. The occurrence of a preterm birth and the health problems of the preterm newborn validate the belief that all pregnancies are potentially threatening states that need to be managed by qualified professionals. The details of the way preterm birth is understood from a clinical perspective were discussed in Chap. 1 of this book.

However, pregnancy and childbirth are also about the continuity of a society across generations, so the medical paradigm of pregnancy is situated within a broader paradigm of social reproduction. The social reproduction paradigm sees pregnancy as a means for assuring the continuity of individual families, as well as the entire society over generations. Pregnant women in this context are the pathway for the production of children, and pregnancy is differentially valued, depending how reproduction is viewed for the particular woman who is pregnant. For example, there are differences in the social reactions to pregnancy for teenagers, for married women in their late-20s, and for unmarried women in their mid-40s, because of deeply held beliefs about who is fit to be a mother and what type of family situation is preferable for raising children.[2] The occurrence of a preterm birth is understood in the social reproduction context in two ways: as a marker of failed motherhood if a mother cannot nurture her fetus to term, and as an indicator of the potential power of technology (for example, interventional deliveries and neonatal intensive care) to substitute for mothers and assure successful reproduction.

The two nested sets of cultural beliefs, the medicalization of pregnancy and the expectations for mothers, as conditioned by the framework of social reproduction, are well illustrated by the testimony of Kelly Jordan, a Tennessee woman who spoke in support of more federal funding for research on preterm birth, at a Senate hearing in 2004:

> I had hoped and dreamed that they could do like the movies and hook me to all these machines and sustain my life and give my child a chance to go to 40 weeks of pregnancy,

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[1] The cross-cultural study of the ways that pregnancy and childbirth are understood is very revealing about the ways societies understand the relationship of humans and nature. Interpretations of pregnancy and childbirth also reflect power relationships and beliefs about reproduction (Ginsburg and Rapp 1991). For a discussion of the conflicts that arise when the understandings about pregnancy in a Western culture (in this case Canada) are imposed on pregnant women from an indigenous culture (in this case, the Inuit) with very different models of the meaning of reproduction, see O'Neil and Kaufert (1990). For a good illustration of the ways models of pregnancy weave into other aspects of cultural understandings, see Ivry (2010).

[2] Such beliefs form the basis of stratified reproduction. The designation of which women should or should not be encouraged to reproduce reflects the configuration of power relations in the society. Reproduction refers not only to conception and pregnancy but also to child rearing. The situation in which women of a certain ethnicity or race are hired as child care workers to take care of the children of more privileged groups, while confronting obstacles to their ability to take care of their own children, is also an example of stratified reproduction (Ginsburg and Rapp 1995).

> and they explained to me it's not how it happens. So I was taken to the labor and delivery room just shy of 26 weeks and forced into an emergency Caesarean section, and, for those of you who've never been part of it, it's not very pleasant. They took one arm and strapped it to one side of the table. They took another arm and strapped it to the other side. They took my feet, put them together, and strapped them down to the end of the table. I had very little clothes on, I was draped, and a gas mask was put over my face. And I'll tell you, at that moment, you feel like you have failed your child in some way because I was not able to have a full- term pregnancy. (U.S. Senate, Subcommittee on Children and Families, Education, Labor and Pensions Committee 2004)

This chapter examines first the U.S. cultural understandings of routine pregnancy and childbirth, as medical phenomena and as components of the system of social reproduction. It then explores how the interpretations of high-risk pregnancy, preterm birth and neonatal care unfold in these two contexts. Cultural understandings of preterm birth are important not only for the role they play in shaping responses when pregnancies end before term, but also because they reinforce the set of beliefs held in U.S. culture about all pregnancies.

3.1 The Medical Model of Routine Pregnancy and Childbirth

3.1.1 The Rise of Medicine as the Authoritative Domain for Childbirth

Birth and death are transitions into and out of human existence. They are made meaningful in particular social contexts, and are accompanied by what might be termed rites of passage, or a series of rituals (prescribed and patterned behaviors) that express the transformation of someone from one state to another.[3] The meanings ascribed to these transitions vary across cultures and change over time, and the rites of passage work to socialize individuals into the world view and acceptable power relationships of the particular society. The modern Western view of birth and death dates from the Scientific Revolution in seventeenth century Europe, when the dominant metaphor for understanding the universe began to shift from a view of the natural interconnectedness of organisms to the view that natural phenomena are like machines, composed of distinct parts which occasionally break down, but can be fixed by human intervention (Merchant 1983). Many social and cultural changes flowed from this shift, including the positioning of technology as the logical way to interact with the forces of nature, and the elevation of rationality

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[3] Davis Floyd includes the typical patterning of physician–patient interaction during prenatal care visits, the treasuring of ultrasound records as baby photographs, and the routines imposed on the delivery experience as examples of rites of passage rituals, and also notes that contemporary Western cultures seem to lack a ritual for reintegrating pregnant women, transformed into new mothers, back into society in a changed way (Davis Floyd 2003).

and efficiency as core positive characteristics of human behavior (Rothman 2000). Also with this shift to a mechanical world view, human agency replaced fate as the explanatory model for most events, raising expectations that humans, through technology, can control nature (Lupton 1996).

In this historical period, the shift toward a mechanized view of the universe coincided with and supported a social transition that replaced the authority of traditional institutions, such as the church and feudal landlords, with the authority of bureaucracies and commercial enterprises. This shift weakened the extent to which different social classes depended on each other for survival, and dependency became a negative status that contrasted with the increasingly highly valued state of social and economic independence (Fraser and Gordon 1994). Together, the shift of authority to bureaucracy and business, and the placement of rationality, efficiency and independence in lead cultural roles provided the cultural foundation for the development of modern capitalist systems (Weber 1996). The elaboration of the Western framework of disease, with its emphasis on individualism and naturalism, as opposed to social context and supernaturalism, as discussed in Chap. 1, fits these broader cultural trends.

As the body came to be viewed as a machine, medicine replaced religion as the primary domain responsible for interpreting, demonstrating, and communicating to others the dynamics of the natural world. Birth and death also were reframed as medical rather than spiritual events (De Vries 1981). Maintaining continuity with established religious views, in medicine, the male body is assumed to be the prototypical machine. Female bodies are seen as inherently abnormal, with the reproductive systems, the aspect of female bodies that is the most different from male bodies particularly subject to defects and vulnerabilities (Davis Floyd 1994, 2003; Martin 1987; Rothman 2007a). Lupton (1996) notes similarly that the post-seventeenth century Western cultural ideal de-emphasizes awareness of the body, but women in general are socialized to be more self-conscious of their bodies. Pregnant women in particular are encouraged to become intensely aware of their bodies. This is another way of emphasizing the premise that pregnancy deviates from normal or ideal states.

This shift to the cultural framework which views pregnancy as a deviation from the normal functioning of the body-machine led logically to a shift in the allocation of cultural authority for maintaining knowledge about childbirth, away from informal social networks and traditional midwives, and toward physicians who could claim to act based on science. In seventeenth century Britain and Western Europe, physicians began differentiating themselves from midwives as childbirth attendants by developing expertise in anatomy and in newly invented birthing technology such as forceps. Initially, they assumed the role of attending problematic births when called upon by midwives because surgical intervention was required. However, they soon broadened their scope of practice by convincing the public that all births are potentially dangerous and would benefit from expert technological intervention (Rothman 2007a).

Use of physicians rather than midwives as childbirth attendants became a mark of social prestige in the eighteenth and early nineteenth centuries, and physicians began training programs in obstetrics which were closed to midwives. The medical schools of the late nineteenth and early twentieth centuries in the U.S. provided childbirth services to immigrant and low-income women as a way to train students in childbirth techniques, so even women with fewer social resources soon no longer used midwives as birth attendants (Donnison 1977; Ehrenreich and English 1973; Starr 1990). Between 1900 and 1960 there was a public health movement that included formal training for the lay midwives still providing care to rural, and especially to Black women, but by the 1950s, scope of practice laws enacted by states severely restricted the ability of midwives to offer childbirth services to women, independently of supervising physicians.[4] The continuing competition between lay and nurse midwives, between midwives and physicians, and across various medical specialists and subspecialists to provide obstetrics services are discussed in Chap. 5.

3.1.2 The Medical Model and the Experience of Pregnancy and Childbirth

3.1.2.1 The Impact of Standardization

Typical of a technological orientation to any phenomenon, in a medically framed understanding of pregnancy and childbirth, the entire set of experiences are divided up into preestablished components. Standard or ideal characteristics of each component are identified, and then actual experiences are assessed to see if they align with the standards (Clarke et al. 2003). For example, it is common now to describe the experience of pregnancy in terms of what the fetus is experiencing at each week of gestation. These are imaginary experiences, based on two assumptions: that all fetuses mature at the same rate, and that fetuses have the same type of sensibilities that infants do after birth. The assumption that all fetuses mature at the same rate allows obstetrical care providers to make decisions about interventions based on gestational age, although it is clear, as noted in Chap. 1, that there are actually ranges in fetal maturity by age and that truly accurate gestational age is rarely known (Clark et al. 2009). The estimated length of gestation of the pregnancy, rather than the experience women are having in their pregnancies, becomes a key external measure for describing pregnancy-related phenomena, interpreting what they mean and taking action in response to these interpretations.

The extensive testing that is done during prenatal care is reassuring when metrics fit expected standards and when medical authorities can reassure women that their pregnancies are proceeding normally. When the metrics do not fit the standards

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[4] In Southern states, the drive to outlaw the practice of midwifery was promoted by associating the practice with stereotypes of the Black population as primitive and uneducated (Fraser 1995, 1998; Robinson 1984).

there is cause for anxiety, even when it is not clear that the metrics being employed are particularly meaningful. Anthropologist Khiara Bridges writes about the experience of pregnant women she studied who were clients of a public hospital clinic in New York City. Almost all of these women were covered by New York's Medicaid program, and many were foreign born. The care provided in the clinic, staffed by academic physicians and residents, was highly technical and included many testing protocols customized for a patient population predesignated as high risk. She writes

> I recall having a long, in-depth interview with one delightful patient while she waited over two hours for an ultrasound scan. After she was finally called and had completed her scan, I asked one of the nurses if the patient had left for home yet, as I wanted to exchange contact information with her. The nurse replied, 'No, she's talking to the doctor. They saw something with the baby's heart in the ultrasound.' I became distraught, imagining the patient's own distress at receiving the news of a problem with her fetus. In response, the nurse said 'No, no, no. Don't worry. It's no big deal. They see this all the time. It usually goes away.' I looked at her skeptically. She laughed. 'It's nothing to worry about. Really. It usually goes away.' Indeed, when I talked to the patient after the meeting with the doctor, she said. 'They want to run some sort of blood test. If it comes back negative, then there is really nothing to there. But if it comes back positive, then they would just have to monitor me to make sure that the heart thing goes away'. (Bridges 2011, p. 97, reprinted with permission from University of California Press)

Bridges makes the point here that one cultural subtext to extensive monitoring during pregnancy is that this natural process cannot be trusted to proceed successfully without the monitoring and potentially the intervention of medical authorities. It is in this way, as Davis Floyd and others contend, that medicalized childbirth expresses the transition to the post-enlightenment view of the need for technology to mediate the relationship between humanity and nature (Davis Floyd 1994).

As another example of standardization applied to pregnancy and childbirth, while the natural course of labor in women is highly variable, with contractions that speed up and slow down and cervical openings that dilate and contract, sometimes over several days (Gaskin 2003), the medical model divides labor into progressive stages, with specific numbers of hours allocated to each stage and technical interventions—drugs and ultimately surgery—applied if labor "fails to progress" from one stage to another as expected (Rothman 2007b). Aware of the increasingly high number of pregnancies receiving induction and cesarean sections because of labor that fails to progress (Declercq et al. 2013), in 2014 American College of Obstetrics and Gynecology (ACOG) issued a consensus opinion suggesting that the expected time frame for labor should be recalibrated. The opinion states

> [I]t may be necessary to revisit the definition of labor dystocia because recent data shows that contemporary labor progresses at a rate substantially slower than what was historically taught. (ACOG 2014, p. 693, published by the American College of Obstetricians and Gynecologists)

Here, experience with the lack of fit between standards for how long the cervix is expected to take to dilate during labor and the actual time it takes for women's cervixes to dilate has motivated the professional association of obstetricians to consider improving the standards. The lack of fit is not understood as challenging the idea that the labor process can and should be standardized. Neither is the lack of fit understood to suggest that the previous expectations for the speed of cervical dilation were inaccurate. Rather, the ACOG opinion suggests that the standard expectation for labor timing needs to be improved, because contemporary labor is slower than labor observed in the past.

Writing in the health policy journal *Health Affairs* in January 2015, physician Carla Keirns provides a personal example of the way such norms played out in her childbirth experience. Pregnant at age 40, high blood glucose levels which did not resolve with diet change caused her to be categorized as having a high-risk pregnancy. She switched to a specialist obstetrics group for care. She hoped to avoid the standard protocol for pregnant women with diabetes, which calls for labor to be induced at 38 weeks gestation, rather than allowing labor to begin naturally. However, at "39 weeks and 5 days gestation" (it is not clear how this estimate could be so apparently precise), her physicians convinced her to enter the hospital so that they could use medications to induce labor. She was hopeful that she could avoid a cesarean section and deliver her baby vaginally, but when her medication induced and enhanced labor had lasted over 18 hours and her amniotic sac had been manually broken, physicians began to discuss surgical intervention. She writes

> They said they'd give me a couple of more hours. If my cervix was not dilating more quickly, the on-call obstetrician said, 'We're going to talk about a cesarean. When things stop, there's usually a reason.' They'd said a 'couple of hours' so casually. I didn't remember until later that active labor is technically not considered 'arrested' until there has been no cervical change for two hours during adequately strong contractions, after the cervix is 4 cm dilated…
>
> At that point, I called three friends from medical school – a pediatrician, a family-practice physician who delivers babies, and an MFM [Maternal Fetal Medicine] specialist. I reviewed the situation with them as I lay in the delivery room, with an intravenous oxytocin drip running into one arm, magnesium into the other, an epidural infusing anesthetic around my spinal nerves, an intrauterine pressure catheter monitoring the strength of my uterine contractions, and a fetal scalp electrode monitoring my baby's heart rate. We all agreed that there didn't seem to be an urgent clinical reason for cesarean. My baby's heart rate tracings were described by the labor and delivery team as 'beautiful' and I was tolerating labor fine. My friends counseled patience and advised me to point to the objective data. I resolved to push for more time. My sister watched me open-mouthed. She was shocked by the debate. When I got off the phone with my friends, she said: 'I wouldn't know that was a debatable point.' (Keirns 2015, pp. 179–180, reprinted with permission from Project Hope/Health Affairs Journal, conveyed through Copyright Clearance Center)

Keirns learned later that at his point her case had become the subject of intense debate within the labor and delivery team. Her own physician argued for allowing her to continue labor, but other obstetricians staffing the labor and delivery unit pressed for surgical intervention. At that point, several other cases involving cesarean deliveries arose in the unit, and her case dropped to lower priority.

At 21 hours after her amniotic membrane rupture, she was almost fully dilated, and the physician on-call told her to signal when she was ready to deliver the baby. She continues

> I called the team at 11:30 AM. My cervix was completely open, but I was told not to start pushing until they 'got some things ready'. I called them back thirty minutes later; I didn't think I could wait much longer. The nurse coached me for the next hour and a half, as the baby descended steadily. It was hard going, and I was exhausted. When the nurse saw that my baby's head was visible, she went to get the obstetrician. The obstetrician did not even stop to examine me before she said: 'If you haven't delivered by 2:30, we'll have to go to the O.R.'.
>
> 'The hell with that,' I thought. And in seven minutes, she had the baby in her hands.
>
> But after all that, the medical team wasn't ready. The instrument tray was still in the hallway outside my room. The neonatology team should have been called for my delivery, but wasn't. My baby was blue and not breathing. As I lay there, feeling the warm blood flow down my legs, I blocked out all the rest of the sounds in the room, listening for crying. I didn't hear any crying. I barely heard the doctors say it was a boy.
>
> As the neonatal intensive care unit team was summoned to attend to my son, and my placenta was removed manually to slow the hemorrhaging, I was horrified that my physicians had been so unprepared for delivery. None of the delivery problems were unanticipated. Perhaps they really had already earmarked me for cesarean, and the delivery room simply wasn't ready for a vaginal birth. (Keirns 2015, p. 180–181, reprinted with permission from Project Hope/Health Affairs Journal, conveyed through Copyright Clearance Center)

In the end, Keirn's baby was healthy and she was happy to have had a vaginal delivery. But her experience illustrates the extent to which the standardized expectations of pregnancy and childbirth, incorporated into a medical model, frame interpretations and subsequent actions, even when they are debatable in their own terms (based on "objective data") and when the standards fail to align with actual experiences. She writes that her colleagues' consensus after the fact that was that in all likelihood she would have been delivered by cesarean section after 24 hours of labor if she had not been a physician herself, and that she would have agreed to the surgery if she had not known about high rates of unnecessary cesareans, had been advised to have one by a physician she trusted rather than one she did not like, or if she had been told that her baby's life or health was in jeopardy. Few U.S. women have the personal resources to resist actions based on the standardized expectations for their birthing experience.

3.1.2.2 Categorization by Level of Risk

In addition to the attempt to standardize actual experiences toward a predetermined set of meaningful components, another feature of the medical framing of pregnancy and childbirth is the categorization of pregnancies and pregnant women as low or high risk. In popular terminology there is no such thing as a "no risk" pregnancy (Fordyce 2009). Risk categorizations of pregnancy are part of a much broader trend in contemporary medicalization that frames states of health in terms of their likelihood or risk of becoming illnesses. Such "risk discourses" expand the authority of medicine (or what sociologist Adele Clarke and colleagues describe as the "biomedical technoservice complex" that encompasses physicians, public health entities, the pharmaceutical and medical device industries, medical information technology, and the biomedical research enterprise) to define and monitor appropriate behavior (Clarke et al. 2003). Risk categorization is also an attempt to predict and feel more in control of the future. The process of risk categorization mobilizes fear and blame, and can express trust or the lack of trust in authorities. Risk categorization provides a scientific language through which the deeper cultural practice of sorting pure from impure activities and objects, a practice which is universal across human cultures, can be discussed in the modern Western context. For example, scientific debates about whether genetically modified foods are safe to eat are a modern expression of an ancient practice of trying to make sense of the introduction of new foods into a society (Douglas and Wildavsky 1982; Kenan 1996; Nelkin 2003; Oaks and Harthorn 2003; Ruhl 1999).

In pregnancy, as in other health states, risk definitions are derived from a combination of epidemiological associations between population characteristics and outcomes, and individual assessment measures which fail to meet normative standards. Both sources of information have weaknesses. As discussed in Chap. 2, population-based associations are complex, and are often not meaningful at an individual level. For example, population level correlations between unintended pregnancies and poor birth outcomes do not mean that every woman who becomes pregnant unintentionally has a greater likelihood of a poor birth outcome than every woman who intended to become pregnant. Individual assessment measures, the second source of information for categorizing risk, are snapshots that occur at some point in pregnancy. Appropriate standards of normalcy may be inaccurate or may not reflect the true extent of normal variation. This is the standardization problem, discussed above.

In addition, as suggested in Chap. 1, a heterogeneous outcome such as preterm birth may not be predictable enough to assign a meaningful risk status. In the 1990s, the National Institutes of Health-sponsored Maternal-Fetal Medicine Units Network pooled the data from pregnant women who were patients in the ten member hospitals in an attempt to create a gradient risk score for spontaneous preterm birth, based on data available at 23 weeks gestation. More than 100 parameters were identified, including demographic and socioeconomic data, information on the home and work environments, drug and alcohol use, medical and obstetrical history, current symptoms, laboratory results, treatments during pregnancy, medications, hospitalizations, restrictions in activity, body mass index, and the results of pelvic exams. The women were followed to delivery, and 10 % had a preterm birth. The researchers used the information for 85 % of the nearly 3000 women in the sample to identify correlations between their prenatal parameters and the occurrence of a preterm birth. They then applied a formula calculated from their results to the data on the remaining 15 % of the women, to see whether they could predict the likelihood that their pregnancies would end in a preterm birth. The researchers concluded that the women identified as being at higher risk for preterm birth were indeed more likely to have a preterm birth than those who were not identified in that way. However, the risk score failed to identify the majority of women who had a preterm birth, while the majority of women scored as being at high risk ended up not having a preterm birth. The researchers concluded that the scores were not that useful in a clinical context (Mercer et al. 1997).

Despite these complexities and weaknesses, the practice of categorizing pregnancies by risk level is ubiquitous in U.S. clinical care and in popular conversation. Sociologist Barbara Rothman commented on this practice, observing

> Whenever I am talking about home birth or midwifery care, some woman speaks up wistfully: ' I'd have loved to have done that, but my pregnancy was high risk'. Everybody, it seems, is 'high risk'. Like the fabulous children of Lake Wobegon, all of whom are 'above average', the pregnancies of U.S. women all seem to be of above-average risk… Ever since the introduction of the 'risk' approach to pregnancy, obstetrics has broadened the 'high-risk' category. For example, a grand multipara is considered a high risk patient. Until the 1970s, obstetrics defined a woman as a grand multipara when she had five or more previous births. Once women started having fewer children, they redefined 'grand multipara' to mean having had three previous births. Presumably the objective and inherent risk of a fourth or a fifth pregnancy had not increased just because it became a less frequent occurrence, yet it was a newly defined 'high-risk' situation. Similarly, the age for amniocentesis for genetic disorders moved from 40 to 35, and in some locations 33 or even younger. As the categories expand, more and more pregnancies are subsumed under the heading of 'high risk,' until by now more pregnancies are high risk than are low risk. (Rothman 2007b, pp. 29, reprinted with permission from Taylor & Francis, conveyed through Copyright Clearance Center, Inc.)

In addition to changing over time, as Rothman suggests, each setting and information source has a slightly different set of criteria for determining whether a pregnancy is high risk. Table 3.1 shows the items listed as indicators of high-risk pregnancy on the four web sites which top the list of over 61,300,000 results of a Google search on the entry "How do I know if my pregnancy is high risk?" Each listing includes a slightly different list of chronic diseases, different framing of the impact of maternal age and health behaviors, and different symptoms in the current pregnancy.

In addition to the fact that each care setting (or as framed by the Web MD site cited above, each health insurance plan) selects different features drawn from epidemiology or clinical care to define high-risk status, there is variation in the way these features are actually used in different settings. Anthropologist Lisa Handwerker studied the prenatal care provided to low-income women in a public hospital setting in California in the early 1990s and observed

> For example, one Caucasian practitioner labeled two patients from different ethnic groups sharing the same risk factor inconsistently. While she considered a pregnant Black woman with a poor diet 'high risk', she did not consider a pregnant Asian patient with a poor diet 'at risk'. Instead, the health worker attributed the Asian woman's poor nutrition to cultural differences, stating 'she isn't used to eating foods from the four food groups'. The designation of 'high risk' groups has stigmatizing consequences, especially for Blacks. Conversely, labeling Asians as 'low risk' may mislead medical staff to overlook potential problems. (Handwerker 1994, p. 668, reprinted with permission from Elsevier)

Table 3.1 Popular web sites listings of indicators for high-risk pregnancy

Web MD[a]	National Institute of Child Health and Human Development[b]	BabyMed[c]	Mayo Clinic[d]
Diabetes	Diabetes	Diabetes	Diabetes
High blood pressure	High blood pressure	High blood pressure	High blood pressure
Kidney disease	Kidney disease	Kidney problems	Epilepsy
Cancer	Autoimmune disease	Cancer	Blood condition such as anemia
Epilepsy	Polycystic ovary syndrome	Autoimmune diseases	Underlying mental health condition
Lupus, rheumatoid arthritis	Thyroid disease	IVF pregnancies	Smoking cigarettes, drinking alcohol and using illegal drugs
Sickle cell disease	Infertility	Heart disease	Advanced maternal age
Asthma	Obesity	"The older a woman is, the more apt she will be to be termed high risk"	Multiple pregnancy
You use alcohol or illegal drugs, or you smoke	Alcohol use Cigarette smoking	Multiple pregnancy	Prior C-section
You are younger than 17 or older than 35	Teen pregnancy First time pregnancy after age 35	History of miscarriages	History of pregnancy loss or the death of a baby shortly after birth
You are pregnant with more than one baby (multiple pregnancy)	Multiple gestation	History of premature labor	Prior low birth weight baby or preterm birth
You have had three or more miscarriages	Gestational diabetes	History of low birth weight	Family history of genetic conditions
Your baby has been found to have a genetic condition, such as down syndrome, or a heart, lung, or kidney problem	Preeclampsia and eclampsia	Sexually transmitted disease, HIV for instance, or genital herpes	Infection
History of preterm labor	HIV/AIDS		Problems with the uterus, cervix, or placenta
History of preeclampsia or seizures (eclampsia)			Too much or too little amniotic fluid
History of a baby with a genetic problem, such as down syndrome			Restricted fetal growth

(continued)

Table 3.1 (continued)

Web MD[a]	National Institute of Child Health and Human Development[b]	BabyMed[c]	Mayo Clinic[d]
You have an infection, such as HIV or hepatitis C. Other infections that can cause a problem include cytomegalovirus (CMV), chickenpox, rubella, toxoplasmosis, and syphilis			Rh sensitization
You are taking certain medicines, such as lithium, phenytoin (such as dilantin), valproic acid (depakene), or carbamazepine (such as tegretol)			

[a] "High risk pregnancy overview" http://www.webmd.com/baby/guide/high-risk-pregnancy-overview

[b] "What are the factors that put a pregnancy and risk?" http://www.nichd.nih.gov/health/topics/high-risk/conditioninfo/pages/factors.aspx

[c] "How to find out if you are a high risk pregnancy in 12 steps" http://www.babymed.com/12-steps/how-find-out-if-you-are-high-risk-pregnancy-12-steps

[d] "High-risk pregnancy: know what to expect" http://www.mayoclinic.org/healthy-living/pregnancy-week-by-week/in-depth/high-risk-pregnancy/art-20047012

Handwerker also notes that in this setting there was a category for "medium risk" patients, but it was never clear how these were differentiated from high-risk patients, and the category was seldom used.

The flexibility of the systems for classifying pregnancies as high or low risk opens the way to conflation of the notion of pregnancy risk with the categories of women whose pregnancies generate disapproval for ideological reasons. In her ethnography, Bridges describes the way the entire patient population of her clinic study site was categorized as high risk because most of the women were covered by public insurance (Medicaid). The category of publicly insured was equated with being impoverished, which was further equated with the image of Black women on welfare, who purposely get pregnant outside of marriage in order to unfairly appropriate working peoples' tax money for their own benefit. This impression persisted despite the obvious circumstance that not all of the patients in the clinic were impoverished, a minority was Black, and a small minority received public income assistance. In this sense, the entire patient population was "racialized" in Bridges terms, and then stigmatized on that basis (Bridges 2011).

Although the categorization of pregnant women as high or low risk fails to consistently predict whether there will be difficulties with their birth outcomes, risk categorization serves several other social functions. In the clinical setting, risk categorization triggers heightened surveillance, additional diagnostic testing[5] and protocols for delivery intervention (as in Carla Keirn's case, described above). Categorization helps clinicians focus their resources and guide or rationalize their decision-making amidst a range of options for care which are sometimes contradictory and difficult to evaluate on the basis of scientific evidence. It also structures the options women have for their choice of care providers during pregnancy, because many categories of care providers, particularly midwives, nurse midwives and generalist physicians, are prohibited by license or insurance restrictions from providing care for women with high-risk pregnancies. These professional competition issues are discussed further in Chap. 5. At the societal level, the designation of poor women as an at-risk population in the 1980s justified the extension of public insurance coverage to them during pregnancy and six weeks after delivery. This was an exception to the historical reluctance within the U.S. to support universal health insurance for all citizens (Bridges 2011). This political dynamic is discussed further in Chap. 4.

In addition, categorizing individuals as being at high-risk shifts the burden of responsibility to them for modifying their behavior in particular ways, and for being especially scrupulous in following their care provider's instructions. This is true generically for health risk categorizations, and is part of the modern Western notion that individuals have a moral responsibility to seek a state of health (as discussed in Chap. 2, and see Clarke et al. 2003; Kenan 1996). In pregnancy, this is tied to mothers' responsibilities for social reproduction, as discussed in the next section of this chapter. The attitude manifests in the clinical setting, as Handwerker notes

> While practitioners' comments reflect varying degrees of accountability, they all placed the burden of blame on the pregnant woman. One practitioner said 'these women are responsible for everything. They should be able to control their life circumstances. If they decide to have a baby, then it is their responsibility to take care of themselves.' One nurse added 'if they put garbage in, out it comes. They get a 'geek' baby'. Additionally, a nursing assistant remarked, 'babies should be able to sue their moms for taking drugs while they are pregnant'. (Handwerker 1994, p. 671, reprinted with permission from Elsevier)

The shift of responsibility is sometimes framed as giving women the "gift of knowledge", for example, about an abnormal prenatal diagnostic test, or other indicator of risk status (Hunt and de Voogd 2003; Kenan 1996). Chapter 6 of this

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[5] Bridges observes that part of the Medicaid-prescribed protocol for care of the high-risk (that is Medicaid covered) women in her clinical setting included multiple (including post-pregnancy) tests for sexually transmitted diseases (STD), and early pregnancy screening for gestational diabetes. She interprets the enhanced STD surveillance as a reflection of the stereotyped view of the nature of the entire Medicaid covered population as sexually promiscuous. In the case of the gestational diabetes screening, she reports that clinicians she spoke with could not really explain the clinical value of the early test, because they knew of no other population with similar testing to use as a standard for what to expect. They were considering using the data from the practice in a scientific publication (Bridges 2011).

book discusses the ethics of conducting screening that is not associated with a meaningful diagnosis that alters clinical practice.

Being able to shift responsibility for pregnancy outcomes away from the medical care system and onto pregnant women relieves medical care providers of some of the responsibility that otherwise goes along with the status they have been allocated as the mediators between nature and culture. Handwerker notes that while women's risk status may be upgraded in the course of a pregnancy, they are never downgraded from being high to being low risk. The medicalized approach to pregnancy and childbirth is validated by the existence of a large group of women who were categorized as high risk, who adhere to the protocols prescribed for them as high-risk patients, and who subsequently carry their pregnancies to term and have newborns with no poor outcomes. Maintaining broad and vague systems for categorizing pregnancies as high risk has no obvious downside within the medical system.

3.1.3 Acceptance and Resistance to the Medical Model of Pregnancy and Childbirth

The historical trajectory of the medicalized approach to pregnancy and childbirth in Western Europe, Great Britain, Canada and the U.S. has been accompanied by a sequence of countering social movements; these have promoted natural, that is, less technologized, approaches to child birth. They include movements supporting use of less or no anesthesia during labor, supporting a reduction in the occurrence of cesarean sections, and supporting the broadening of access to and use of midwives as birth attendants and the home as the childbirth setting. However, there is an equally long history of these movements being either vilified [as is particularly the case with midwife attended home births (Craven 2005)] or absorbed into the mainstream technologized birthing approach. This has occurred, for example, through the addition of childbirth education, labor coaching and upgraded hospital labor and delivery settings (Davis Floyd 2003; De Vries and De Vries 2007; Rothman 2007a).

Ultimately, the medicalized approach to pregnancy and childbirth remains in place because it is embedded in the broader U.S. culture and incorporates components that are highly valued in this context. For example, researchers who have studied middle class and professional women's experiences of pregnancy and childbirth describe the value these women place on the cultural ideal of self-control and freedom of choice, the distinction they concur with and appreciate between their personal identities and their bodies, and their desire to avoid feeling dependent on others. The medical model of pregnancy and childbirth supports all of these values by offering numerous diagnostic and treatment interventions that are supposed to ensure positive pregnancy results, by ensuring pain relief during labor, by using language that frames pregnancy as a fetal rather than a maternal event, and by providing professional care in the immediate aftermath of delivery, so that these women do not need to rely on their sometimes meager informal social networks for support (Davis Floyd 1994; Fox and Worts 1999; Morton and Hsu 2007; Namey and Lyerly 2010).

Women who are members of more marginalized or stigmatized groups express support of the medical model of childbirth for other reasons. Sarah Brubaker interviewed pregnant Black teens in a Southern U.S. city, and reported that these teens accepted many features of the medical care setting and the treatment of their pregnancy as a medical condition. She writes

> In many ways, teens seemed to appreciate and value formal reproductive care. Medicalization's separation of the body and self - often a major point of criticism among feminists- allowed teens to focus on the physical issues related to their pregnancies and to avoid the moral issues. In stark contrast to the ways that the social problems discourse of teen pregnancy places blame on teen mothers and holds them responsible, medicalization allows teens to rely on medical authority and decision-making and place the responsibility for their pregnancy outcomes in physicians' hands. (Brubaker 2007, p. 543)

Anthropologist Gertrude Fraser found that the older, rural residing Black women whom she interviewed about traditional midwifery practice in their communities associated the demise of midwifery in earlier decades with access to better hospital and medical care, with desegregated hospital facilities, with the availability of anesthesia for childbirth, and simply with being included in the view of medical and public health authorities as a population with legitimate healthcare needs (Fraser 1995).[6]

Even when women resist some aspects of childbirth technology as intrusive or unnecessary, they are likely to accept some components as beneficial for themselves. Khiara Bridges describes the way some patients at the New York public hospital clinic carefully selected which intrusive clinical routines to cooperate with and which to refuse, in order to meet their overarching goal of acquiring the best clinical care for themselves and their babies (Bridges 2011). Alyshia Galvez describes the way the Mexican-born women she studied in the U.S. held to their own frame of pregnancy as a natural experience which they were innately able to successfully accomplish, in contrast to the medicalized frame which holds that success can only be guaranteed with technological intervention by experts. Yet, the women she studied expressed the belief that complicated pregnancies are better treated in New York, while normal ones are better treated in Mexico (Galvez 2012).

The medicalized vocabulary of pregnancy and childbirth is so well embedded into the larger worldview of how individuals relate to their environment and their bodies that it is nearly impossible to conceptualize the experience in alternative terms (Brubaker and Dillaway 2009; Davis Floyd 2003; Michie and Cahn 1997). The authoritative knowledge of medicine is incorporated into the way women

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[6] To avoid disparaging the midwives active in their youth, these informants held that something had changed in the biology of modern women which made it optimal for them to use modern health care.

perceive themselves. Browner and Press, who studied women at a prenatal clinic in Southern California in the 1990s observe

> Popular knowledge and the media insist that pregnant women must attend to their bodies to a degree that others need not. Some women therefore are disappointed when they receive what they consider scant biomedical information. Said Jennifer Lowe, “When I had my last child…I was kind of disappointed because I had a girlfriend who was pregnant at the same time and she said ‘I don’t do this and I don’t do that,’ and I thought, he didn’t tell me all that stuff.” Alicia Aguilar similarly remarked, “We [society] know more, but I don’t think the information is readily available…I want to hear specifically why am I feeling like that. [If the doctor says] ‘Oh, that’s normal.’ O.K., why?” Our informants, then, expected their prenatal providers to offer accurate interpretations of their sensations and bodily experiences while simultaneously providing reassurance that their pregnancies were proceeding as expected. (Browner and Press 1997, p. 117, proper names are pseudonyms)

These researchers go on to say that, in their observation, women do not agree with everything their physicians tell them about pregnancy and childbirth. They also seek other authoritative sources to legitimize their personal interpretations of subjective experiences (Browner and Press 1997). Brubaker (2007) also notes that some of the teens she studied selected behaviors such as taking vitamins which they could reject as a way of expressing autonomy and agency. Still, even autonomous decisions made by pregnant women that are not recommended by their prenatal care providers are rationalized and legitimized using medical language and concepts (Root and Browner 2001).

3.2 The Social Reproduction Model of Routine Pregnancy

3.2.1 *The Impact of Patriarchy*

While pregnancy and childbirth are always surrounded by diverse cultural meanings because they are transitions in states of existence, they are also always understood in cultural context because they are components of social reproduction, the set of activities crucial to the continuity of societies over time (Ginsburg and Rapp 1991; Laslett and Brenner 1989). The strategies, institutions, and ideologies of social reproduction include, for example, norms for sexual activity, the timing of family formation, household composition and processes for child rearing and integrating young adults into society. Laslett and Brenner suggest that social reproduction can be thought of as a kind of “work” within a society, and societies can be characterized by considering how this work is distributed across families, economic sectors, communities, and states, and between men and women within families. Robertson (1991) points out that social institutions are always involved in assuring reproductive success, even if the belief system in the society holds that reproduction is a personal or family issue. He also notes that in societies stratified by class, these social institutions may be structured to assure more successful reproduction by the class that exerts the most power in the society. In the U.S., for example, some women have access to flexible work schedules, parental leave and subsidized child care, which make it easier for them to raise children in stable environments. Others are paid hourly, with no flexibility or paid parental leave, and are forced to rely on less stable informal networks for child care. In this way, institutions of social reproduction create advantage for higher ranking individuals, thereby ensuring the replication of class structure over generations.

One of the ideologies that influence social reproduction in Western societies is patriarchy. In patriarchal systems, kinship and inheritance are determined on the basis of who fathers a child, and great emphasis is placed on genetic or "blood" relationships. Because paternity matters in Western societies, there are strategies and institutions that monitor the sexual behavior of girls and women, so that men can be sure they are the fathers of their partners' children. For example, Isaacson notes that the 1966 and 1971 editions of **Williams Obstetrics**, the authoritative textbook in obstetrics practice, state that establishing the gestational age of the fetus through accurate dating is important

> …primarily to establish paternity. "The upper limit of duration of pregnancy is of great medicolegal importance in cases in which the husband has been away for 10 months or more and the legitimacy of the child is in question." (Isaacson 1996, p.473, reprinted with permission from Springer)[7]

Other social reproduction practices create and enforce decisions about whether men have obligations to or rights over children they father. This depends in part on whether they are married to a child's mother, so regulating marriage is another aspect of enforcing patriarchal control over reproduction (Smart 1987).

Western interpretations of the process of reproduction reflect this orientation toward rationalizing patriarchy. The ancient Greeks thought of reproduction as occurring when men, through copulation, plant seeds in women's wombs which women then nurture through pregnancy until childbirth. The medieval Christian philosopher Thomas Aquinas wrote that men's semen is the active principal in generation, with the fetal matter provided by the woman.[8] Rothman (2000) suggests that these historical models privileging semen have been supplanted by a model that has men and women contributing equally to the genetic-kinship relationship. She contends that this is still patriarchal, in the sense that linkages across generations occur through copulation and fertilization.

As is typical of cultural beliefs, those brought up in the Western tradition take this patriarchal view of reproduction and the importance of establishing fatherhood

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[7] More recent editions of the textbook emphasize the importance of establishing gestational age or maturity of the fetus through functional measures in order to make treatment choices.

[8] Thomas Aquinas's Summa Theologica, Part II, Question 118, Article 1, Reply to Objection 4, reads in part: "*In perfect animals, generated by coition, the active force is in the semen of the male, as the Philosopher says (De Gener. Animal. ii, 3)*; *but the foetal matter is provided by the female* ... And after the sensitive soul, by the power of the active principle in the semen, has been produced in one of the principal parts of the thing generated, then it is that the sensitive soul of the offspring [=the foetus] begins to work towards the perfection of its own body, by nourishment and growth (Knight 2014).

for granted, as though they were natural phenomena. Yet there are matriarchal societies, for example, which trace descent through mothers only; a mother's male relatives rather than the child's father take the position of family authority (Pasternak et al. 1997). There are also societies with extensive fosterage arrangements, where continuity across generations is based on which adults assume the social role of parents to children rather than which parents are related to children through biology (Bledsoe 1990; Modell 1998).[9] Emphasizing fertilization as the key component of social continuity may be common, but it is not inevitable.

3.2.2 The Fetus as Baby

The current popular belief in the U.S. and other Western cultures is that women who are pregnant are "carrying babies" with unique individual characteristics such as personalities. These babies must sometimes be protected from the threats to their health originating from their mothers, and this is one of the roles and responsibilities of medical (and sometimes legal) authorities. This view of fetuses as babies is relatively recent, closely related to the development of ultrasounds and other diagnostic technology, and intertwined with debates about abortion. However, public interest in the status of the fetus has a long history in the Western tradition, with themes that clearly reflect the concerns of patriarchal systems. These include the need to link offspring with their fathers and to distinguish them from their mothers. The Justinian code of law, which replaced Roman law when the Roman Empire was Christianized in the sixth century, decreed that fetuses stood in for offspring even before birth, stating, for example, when considering who should inherit the property of condemned prisoners

> The fetus in the womb is held to be a full human being, whenever the question concerns advantages to him when born, even though, before birth, his existence is never assumed in favor of anyone else. (Watson 1998 Book 1, Chap. 5, p. 1.5.7., reprinted with permission from the University of Pennslvania Press)

Christian religious scholars debated for centuries over the point during a pregnancy when "ensoulment" of the fetus occurs. In early Christian law, abortion was considered a sin against the holiness of marriage, but in the thirteenth century, the Church redefined it as infanticide. In secular and some religious settings,

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[9] Anthropologist Sarah Franklin provides an extensive discussion of the way that Western beliefs about patriarchal descent made it difficult for early European and American anthropologists to understand the kinship systems they encountered, which did not always consider male–female intercourse to be the basis for reckoning relationships over generations. Contrary to original popular belief, this did not mean that individuals living in these cultures did not connect intercourse with pregnancy, and were therefore more primitive or less intelligent than those who did. Rather, it means that this understanding of the biology of conception is not the basis for assigning membership or describing relationships over generations in these non-Western societies (Franklin 1997).

a distinction was made between abortions that occurred before and after “quickening” (when pregnant women feel the movement of the fetus); only those occurring after quickening were considered crimes.

However, by the mid-nineteenth century, all abortions were criminalized in European countries and in the U.S. unless performed by physicians (not midwives) for the health of the mother (Duden 1993; Petchesky 1990). Other cultural practices and interpretations maintained the understanding that fetuses were distinct entities independent of their mothers, even if they were not considered “babies” until they were born. Legal precedent through the 1970s held that parents could receive damages if a fetus was injured during pregnancy, because injuring a pregnant woman was different from injuring a nonpregnant woman. Damages paid on behalf of a fetus accrued to the child, if the child was later born alive (Daniels 1993).

German historian Barbara Duden has found that, in texts from the ancient Greeks through the eighteenth century, the dominant metaphor for fetal development was fermentation, as in the ripening of cheese. Beginning in seventeenth century Europe, however, a succession of scientists used techniques of dissection and specimen examination to render sets of drawings of fetal maturation during pregnancy. By the early part of the twentieth century, several collections of fetuses at various points of reproduction were assembled, displayed, and studied in in order to understand and communicate the “fact” that the process of human development is biological rather than social or religious, thereby furthering the post-enlightenment view of the material nature of the universe (Duden 1999; Morgan 1999). According to anthropologist Lynn Morgan, these specimens were not considered to be persons or individuals, the collections were not controversial, and the way they were obtained (one set of physician-collectors encouraged their patients to have unprotected sex and become pregnant before their scheduled hysterectomies so their physicians could obtain fetal specimens) apparently did not offend the sensibilities of the era (Morgan 1999).

It was the publication and wide distribution of photographs of these fetal specimens which initiated the popular reframing of fetuses as infants before they were born. In 1962, Look Magazine published photographs from Geraldine Flanagan’s book entitled **The First Nine Months of Life** (Petchesky 1987) and in 1965, Life Magazine published excerpts from Swedish photographer Lennart Nilsson’s pregnancy and childbirth book **A Child is Born** (Duden 1993). That issue of Life magazine sold out its 8 million copies in 4 days. In 1968, one of Nilsson’s fetal images appeared as “the star child” at the conclusion of Stanley Kubrick’s popular movie **2001, a Space Odyssey**. In each case, the images were notable for their human appearance; aspects of the developing fetus which do not appear as human were de-emphasized. Furthermore, the fetuses appear to be free-floating, rather than being embedded in a maternal body.

At about the same time in the 1960s, the technology of ultrasonography, pioneered for submarine warfare, came into use in the field of obstetrics, making it possible to visualize a fetus within a pregnant woman’s uterus with photographic equipment that produced images out of sound waves. Ultrasound imaging was quickly adopted for use in fetal diagnosis, and for estimating the functional maturity of the fetus. Fetal monitoring made it possible to directly record the heartbeat and laboratory values of fetuses during labor. A subspecialty of physicians began exploring techniques for treating fetuses with surgical and pharmaceutical interventions before they were born (Casper 1996). Fetal monitoring helped to shift the attention of attendants during childbirth from the mother to the fetus (Banta and Thacker 1979). The potential for fetal diagnosis and treatment supported two sets of changes within obstetrics practice: the conceptualization of the fetus as a "patient" distinct from the pregnant woman, and the blurring of the distinction between a fetus and an infant. In a review of the implications of these technological changes, F.A. Manning identified both developments as consequences of the rapid dramatic expansions of the ability of physicians to visualize, monitor and treat fetuses directly, commenting first

> The fetus is now relegated from the status of a relatively intangible, but nonetheless most important entity, to the status of fetus as patient. (Manning 1989, p. 342, reprinted with permission from Elsevier)

and then at the conclusion to his article

> The psychological, physical and therapeutic barriers between the fetus and the newborn are sharply eroded now and may soon disappear. (Manning 1989, p. 350, reprinted with permission from Elsevier)

Manning himself uses the term "perinate" in some parts of the article to refer both to the fetus and the newborn infant.

In her examination of changes in **William's Obstetrics** in this regard, Nicole Isaacson (1996) notes that while the 1976 edition described the aim of the field as focused on pregnancy, with a healthy baby as the outcome, the 1989 edition describes the aim as being simultaneously concerned with two patients whose lives are interwoven, and the 1993 edition names these two patients as the mother and the fetus. She also contrasts the sharp distinction drawn in the 1966 edition, which stated that, in a sense, the fetus dies when the baby is born, to the language in the 1980 edition, which used the term "fetus-infant" to refer both to the developing fetus in utero and to the neonate at birth. The 1984 edition of the text actually uses the term "infant" in some places to describe the fetus in utero at 23 weeks gestation. Isaacson writes

> Close reading of these [obstetrics] texts suggests that two different dynamics of classification are occurring concurrently. First, the fetus is increasingly differentiated and "split apart" from the woman who "carries" it. This change in emphasis serves cognitively to separate the fetus from the pregnant woman. Secondly, the fetus in utero and the baby ex utero are blurred as a single category. Through this discursive construction of the fetus in obstetric texts, medical accounts are beginning to classify the fetus as an infant, contributing to a melding of two previously distinct mental entities-a fetus and an infant-into one new medical category: the fetus-infant. In the changing language of obstetrics, these textbooks are placing an ever-increasing emphasis upon the "infant" character of the unborn fetus while downplaying its morphological immaturity. (Isaacson 1996, p. 459, reprinted with permission from Springer)

The ethical dilemmas and challenges that arise from the view that during pregnancy and childbirth clinicians are providing care for two patients at the same time is discussed further in Chap. 6. Chapter 6 also includes a discussion of the view, developed in this same era, that fetuses have independent legal rights, and examines the practice of court-ordered interventions which mandate that pregnant women make specific medical treatment choices for the benefit of their fetuses.

Initially, photographic and ultrasound images of fetuses were a continuation of the push to medicalize, or frame in scientific terms, the story of human origins. Soon they became multivalent symbols, used to communicate about innocence and new possibilities (the star child in Kubrick's movie), about moral obligations to protect the vulnerable (Petchesky 1987), and about the inevitability of progress and development (Layne 2003). Barbara Rothman writes that by the early 2000s, when she asked audiences during speaking engagements to draw with their hands an image of a fetus, all could do so, placing the fetus in a head-upright position. When asked to place the navel of the pregnant woman on the image, audiences generally could not do so—the image of the fetus was very clear, but the pregnant woman who was carrying the fetus was very vague (Rothman 2007b).

As will be discussed further in Chap. 4, the images of independent fetuses were rapidly taken up by opponents of abortion, which was legalized in the U.S. in 1973, to illustrate graphically the contention that abortion is murder. Fetal-focused medical practices and the lowering of the gestational age threshold at which preterm newborns are resuscitated have also been incorporated into the ideology that holds that fetuses are persons from the moment of conception; this is a foundational premise of the anti-abortion movement. Although total opposition to abortion is not the majority view in the U.S., the imagery and the arguments of the movement are common features of the U.S. political landscape.

It is thus not surprising that women in contemporary U.S. and other Western societies think of themselves as carrying babies, not fetuses, while they are pregnant. It is increasingly common for parents to refer to fetuses in utero by name (Isaacson 1996) and to shop for gifts for them (Layne 1999). Ultrasounds recorded during pregnancy are referred to as "baby's first pictures", and are interpreted by ultrasound technicians in a way that emphasizes their child-like nature and individuality. Monitoring and visualizing techniques are used explicitly to encourage pregnant women to think of their fetuses as separate from themselves, to "bond" with them and to follow instructions from clinicians in shaping their behaviors (Mitchell 2001; Taylor 1992).[10] Prenatal education classes emphasize that women's actions during pregnancy have significant effects on their "babies". In reporting on women's understandings of nutrition, from the same study conducted in California

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[10] Interestingly, this use of ultrasound as a way of encouraging women to identify as mothers to their babies is particularly characteristic of contemporary Western societies. Mitchell and Georges contrast the use of ultrasound in Canada, where the technology is used to frame the fetus as a baby, and in Greece, where the technology is used to encourage traditional women to be more "modern" and European, see (Mitchell and Georges 1997).

in the 1990s described above, Markens, Browner and Press note the way their interviewees framed this idea for themselves

> Acting to assure the welfare of the fetus/baby was a globalized preoccupation in the minds of those interviewed. Asked why she made changes to her diet, Daphne Potter described how she believed that the responsibilities of motherhood begin with pregnancy: '[I]t makes me feel more responsible. Right off the bat I'm already being a mother. Granted, I'm the baby's mother but the baby isn't here yet, but I still feel responsible and I still feel the care is necessary.' (Markens et al. 1997, p. 359, proper names are pseudonyms)

The threat of harm to the baby is a concern that constrains a wide array of pregnant women's activities and the choices they make in the context of their medical care.

3.2.3 The Demands of Motherhood

If the fetus is a baby, then a pregnant woman is already a mother, and subject to the various role expectations that characterize motherhood in any given society. The discourse of maternalism reflects contemporary female socialization in general, with the contrasting themes of selfishness and responsibility, and the obligation to demonstrate caring and avoid hurting others (Chodorow 1978; Gilligan 1982; Petchesky 1990). The contemporary cultural model of motherhood is "intensive mothering" in which children are the central focus of a mother's time, activities and emotional investment (Arendell 2000; Hays 1996). Children are sacred, a scarce resource, and a reflection of parental achievement. Any flaws that are perceived in children are targets for intervention, preferably through prevention. Mothers have primary responsibility for maximizing the potential of their children, and it is assumed that they have the capacity to do so (Lupton 1996). Mothers who do not adhere to or who are perceived to have failed at this role are "bad mothers", a very flexible cultural category that can include any woman who does not live in the approved form of family or household, any mother who is not able to protect her child from harm (including mothers whose children die in infancy or before), and any mother whose child does not mature according to cultural ideals (Ladd-Taylor and Umansky 1998). Women who have abortions may be the ultimate "bad mothers" and by extension, discredited individuals, since mothering is a key component of female identity (Kumara et al. 2009).

But there is a marked contradiction between the ideal of intensive mothering and the competing contemporary expectation that women will participate fully in the market sphere as employees. Sociologists and historians suggest that intensive mothering is an outgrowth of what is known as the "cult of domesticity" that developed for middle class women in the nineteenth century, when the locus of economic activity moved out of the home into the workplace. In that era, men were paid a family wage, sufficient enough to support wives whose primary activity was housekeeping and raising children (Hays 1996; Laslett and Brenner 1989). Due to the labor demands of post-industrial capitalism, the family wage is no longer a standard in the workplace. Frequently now, all adult members of a household feel pressure to work as employees to support subsistence and to maintain their expected middle class standard of living. In the U.S. even government welfare programs, which were at one time designed to replace a family wage for women who were raising children but were not married, were reconstructed in the 1990s to require that recipients place their children in child care and seek and accept paid employment (Fraser 1994). The ideology of gender equity and individual achievement, along with the increased stigmatization of dependency, including the dependency of women on their husbands, raises the expectation that women are able to act just like men in the sphere of employment (Beck-Gernsheim 1996; Fraser and Gordon 1994). These economic and cultural changes contribute to the diminishing role of marriage as a basis for family formation (Bumpass 1990).

The shifts in norms for independent achievement of women in the market sphere have not been accompanied by parallel shifts in the ideology that calls for women to maintain the domestic sphere, and particularly to devote themselves to bearing and raising children. Rather, intensive mothering and domestic sphere activity in general have taken on added cultural significance as the last remaining realms that represent the significance of caring and emotional attachment. In contrast to the domestic sphere, market-based relationships are impersonal and commodified, based on rational self-interest rather than unselfish action. Psychoanalyst Adam Phillips and historian Barbara Taylor, in their social history of the emotions and practice of kindness, note that the realm in which kindness is an expected behavior has contracted over the centuries. Unlike in earlier periods, people now doubt whether kindness is a natural aspect of being a human being, although they would still like to think that this is true. The relationship between mothers and children are one of the few contexts in which it is still acceptable to express kindness and empathy (Phillips and Taylor 2009).

The competing pressures of the ideologies of motherhood and the marketplace raise the stakes for women to have positive birth outcomes when they do get pregnant. British sociologist Deborah Lupton writes

> The quest for the ‘perfect child’ means that any flaws perceived in children are viewed as targets for intervention, preferably to be prevented before they are even able to manifest themselves. Parents – and particularly mothers – are charged with the primary responsibility of maximizing the potential of their children. It is assumed that there is agency on the part of the parent to do so. The emphasis placed on reducing risk in pregnancy is part of the greater goal of creating the ‘best possible’ child.
>
> Changes in women’s opportunities for participation in the labor market and expectations about their societal role are also influencing the intensification of discourses of risk in relation to pregnancy. Many women, particularly those with high levels of education and professional satisfaction, no longer see their lives as solely devoted to the family. Rather, they position themselves as bourgeois, autonomous entrepreneurs, seeking to achieve success and recognition in the workplace. Because of the inherent structural and symbolic contradictions between paid labor and motherhood, however: ‘having children today is the structural risk of a female wage-earning biography: indeed it is a handicap, measured by the yardstick of a market society.’ (Beck-Gernsheim 1996: 146, original emphasis) If having a

> normal child is a handicap, then having a disabled child is even worse in terms of a woman's prospects in the paid workplace and capacity for autonomy and self- improvement. (Lupton 1996 pp. 67–68)

Considerable research documents the extensive time demands and resulting levels of stress and dissatisfaction experienced by employed mothers who are attempting to meet social expectations in both the employment and domestic spheres (Arendell 2000; Hays 1996; Laslett and Brenner 1989). Hays (1996) finds in her research that women who continue to work while mothering do not resist the ideology of intensive mothering, but find ways to justify their employment as contributing to intensive mothering or to manage their employment so they can fulfill the mothering role. A range of social constraints (for example, resistance to the use of child care) inhibit the expansion of the multifaceted mothering role out to social institutions beyond the family which could supplement or substitute for actual mothers.

3.3 Preterm Birth in U.S. Culture

How does the U.S. cultural understanding of preterm birth fit into the medical and social reproduction paradigms described in the first parts of this chapter? The occurrence of preterm births strengthens the persuasiveness of the medical-technological model by demonstrating that pregnancy must be a risky medical problem and not a normal function of a woman's body, because normally functioning machines do not produce flawed products (Layne 2003; Rothman 2000). The broader the definition of "high risk" in pregnancy, the more the disease metaphor becomes broadly applicable. As more women receive medical interventions during pregnancy, more women end up with a personal sense that pregnancy is a disease-like condition (Queniart 1992). The experience of medical interventions just in the delivery phase of the pregnancy experience is very widespread. The organization Childbirth Connections, which surveys U.S. women periodically to assess the current patterns of their childbirth experiences, reported in 2013 that 47 % of women surveyed with term deliveries had their labor induced with medication; 50 % of women who experienced labor induction went on to have cesarean section deliveries. Of the 53 % of women who did not have labor induction, 29 % had cesarean section deliveries, for a net cesarean section rate of 21 % (Declercq et al. 2013).

At the same time, the more persuasive the framing of pregnancy as a medical problem becomes, the greater the expectation is that medical intervention will prevent or at least successfully treat poor birth outcomes. This makes preterm birth a challenge for the medical system because, as indicated in Chap. 1, it is for the most part not preventable, and preterm newborns do not consistently survive, or survive without major disabilities. The drive to continually develop and apply technical interventions intended to prevent preterm birth and to assure preterm newborn survival thus has an impetus beyond simply providing benefit to affected newborns and their families. By preventing preterm birth and rescuing preterm newborns, medical authorities preserve their cultural role as critical intermediaries in all childbirth events.

In addition to reinforcing the importance of medical expertise and technology for the care of pregnancy and childbirth, preterm births reinforce the understanding of fetuses as individual, independent persons from the moment of conception. Preterm babies are a concrete representation of “fetus-babies” who look like fetuses, but are able to survive separately from their mothers with the help of medical technology (Isaacson 1996). The more visible they are, and the more publicity that hospitals receive for the miracle babies who survive premature birth, the more rational the supposition becomes that developing fetuses are miniature babies who simply have not left the womb yet. As noted above, the belief that fetuses are distinguishable from their mothers is an important part of the ideology of patriarchy, and the fact that the technological intervention of experts can keep them alive reinforces the message that societal authorities, not simply parents, are in control of the fate of the next generation.

Finally, the occurrence of preterm birth can also be interpreted as supporting beliefs about the responsibility of women as mothers for the outcome of their children. The threat of a possible preterm birth (or other poor outcomes such as death or disability) is used to regulate women’s behavior in socially desirable ways. Oaks (2001) and Armstrong (2003) describe how women have been blamed for preterm births and other poor birth outcomes by the anti-tobacco and anti-alcohol movements, respectively. Similarly, the panic that occurred in the 1980s and 1990s over the impact of cocaine use among Black women on birth outcomes, including preterm birth, blamed women to the point of criminalization and imprisonment for their drug using behavior.[11] This is discussed further in Chaps. 4 and 6.

On the other hand, some women receive credit after the delivery of preterm infants, if their social characteristics (race, age, marital status, socioeconomic status) are not stigmatized, and their behavior meets the approval of authorities. A story in the **Birmingham** (Alabama) **News** about the delivery of sextuplets at 28 week gestation following fertility treatment, illustrates this phenomenon

> All six babies were healthy, doctors said, and ranged from 1 pound, 10 ounces to 2 pounds 5 ounces. ‘All of them were born very healthy and that weight spread is a good sign that there was not one baby that was lagging behind, that all of them had grown and developed well,’ Bill McKenzie, Carroll’s OB/GYN said Saturday. ‘I’m extremely proud of Heather’….‘She’s a small girl with a big heart and a strong faith,’ her doctor said. ‘I think she and Mitchell were committed to this journey and her family and community have been very supportive and then God was faithful and that’s a good formula for success.’(Wolfson 2011, reprinted courtesy of Alabama Media Group)

Ultimately, the cultural function of placing the responsibility for preterm deliveries on mothers is to shift responsibility away from other entities.

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[11] Researchers later concluded that poor birth outcomes among these women, when they occurred, were probably related to the many other risk factors that they experienced, rather than to drug use itself (Daniels 1993; Flavin 2009; Michie and Cahn 1997; Pollitt 1998).

Anthropologist Anna Tsing examined the criminalization of women, often teenagers or women in extremely challenging social situations, who have preterm deliveries without medical treatment because they do not realize that they are pregnant until the delivery. She highlights the significance for society in placing blame for poor birth outcomes on maternal behavior.

> Criminalization gains its importance within a cultural setting in which the unsupervised death of a newborn is a public tragedy that cannot be resolved without a renewal of the state's civilizing authority. Unless blame is fixed and punishment is meted, society might be held to blame for not protecting human life. Thus, in a 1987 case in which the fetus of a nineteen year-old high school senior probably dies in utero before an unassisted premature birth, the liberal county attorney still insisted on the importance of criminal charges: "it just, just didn't get through to her, the significance of the act of human life…I wanted to show the community, to show her that indeed this isn't right". (Tsing 1991, p. 298)

Popular beliefs about these three themes, confidence in the ability of the medical profession to ameliorate the problem of preterm birth, the expectation that preterm babies are viable and able to survive outside of the womb, and the assumption that irresponsible behavior on the part of mothers is an important cause of preterm births, are expressed in opinion surveys, in the pregnancy advice literature, and in the narrative themes presented in popular media. Media coverage of preterm births also reflects a fourth theme: that caring for preterm infants is an act of compassion that contrasts with the typical commercial or financial logic that rationalizes most social activity in the U.S.

3.3.1 Popular Beliefs About Preterm Birth

Studies suggest that popular perceptions underemphasize the severity of preterm birth, overestimate the maturity and viability of developing fetuses, place responsibility for preterm birth on mothers, and express confidence in medicine to ameliorate the consequences of preterm birth. In 2002, the March of Dimes sponsored a national telephone survey of almost 2000 adults to gauge perceptions of premature births in the general public. These respondents, on average, defined a premature infant as one born seven weeks before its due date (in fact, infants are considered preterm if they are born more than three weeks before a term gestational period). Over half of respondents agreed both with the statement "most premature births are the result of the mother not taking care of herself during the pregnancy," and "most premature births can be prevented." Less than one third agreed that "if a baby is born prematurely, there's little the mother could have done about it". Over 80 % of respondents agreed that "lack of access to good health care during a pregnancy is the cause of many premature births," while 30 % of female and 41 % of male respondents agreed that "premature birth is not a big worry because today's medical technology is so good." The majority of respondents selected "educating pregnant women about what they can do to prevent premature birth" as their choice of actions that should receive public funding (Massett et al. 2003).[12]

A second survey, this one of insured women who had recently had uncomplicated deliveries, also found that most respondents believed that pregnancies reach term earlier than 39 weeks, and that it is safe to deliver babies at 34–36 weeks gestation (Goldenberg et al. 2009). The authors of this publication speculated that news coverage of the increased rates of survival of preterm infants in intensive care support this belief. They expressed concern that underestimates of the true length of a normal pregnancy may lead women to request or agree to a scheduled early delivery via cesarean section during an uncomplicated pregnancy, resulting in an unnecessary preterm birth. Along these same lines, a third survey, this one of women who had recently had babies and anticipated having additional children, found that perceptions of personal risk of preterm birth were associated with being underweight, having a personal or family history of preterm birth, smoking, and more use of medical care, but not with race/ethnicity, age, income or stress levels. Women who considered themselves more at risk for preterm birth were less concerned about the severity of the consequences than those who considered themselves lower at risk (Chuang et al. 2008).

In her ethnography of pregnancy loss in the United States, Linda Layne (2003) identifies a social taboo around acknowledging the occurrence of a poor outcome in pregnancy (including early miscarriage, stillbirth and death of a preterm baby). She associates this "culture of silence" with three factors. First, because birth is a rite of passage from one state of existence to another, incomplete pregnancies that do not result, as expected, in the birth of a healthy child leave both adults and fetuses in a liminal state, caught between two modes of existence. Universally across cultures and types of transitions, such liminal states present a challenge to established cultural categories (for example, did a woman really become a mother if her child did not survive, but is she still childless if she had at one point been pregnant?). It is as though there is no satisfying language to talk about the issue, and no clear set of roles for individuals to play in regards to pregnancy loss, so it is best not to mention it.[13] Second, acknowledging a pregnancy loss violates a modern Western interdiction on acknowledging the naturalness of death, in part because death is less familiar in the contemporary era than it was in the past, and in part because U.S. culture emphasizes a social obligation to be happy and to avoid sad experiences. Third, pregnancy loss forces people to confront the limits of medical technology, which normatively should enable individuals to avoid bad outcomes. Nursing

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[12] The researchers, writing in the discussion section of their publication, clearly thought that funding more research to find modes of prevention would be the preferable use of funds.

[13] Layne notes that in her experience obstetrics care providers abruptly stop providing care for former patients who miscarry and are no longer pregnant, transferring them to the care of other medical personnel. Friends and acquaintances are unsure what to say to parents whose pregnancies end in miscarriage or fetal loss, and often avoid the subject. One of her informants noted that there are even greeting cards to send to people whose pets die, but nothing for individuals experiencing pregnancy loss (Layne 2003).

researcher Anita Joy Caitlin confirms that the possibility of a preterm birth or other poor pregnancy outcome is almost never discussed in routine prenatal care (Caitlin 2005).

One of the consequences of this culture of silence is that parents are often unprepared for the likely health outcomes of their infants, and for the decisions about treatment that need to be made when a pregnant woman goes into labor at the point where a fetus is marginally viable. Physician William Grobman and colleagues (2010) conducted interviews with 40 pregnant women who suddenly faced a delivery at 21–26 weeks gestation. They also interviewed 14 partners of these women and 52 health care providers, all in the Chicago metropolitan area. They found that the majority of women and partners wanted clear information as quickly as possible, so that they could better understand the situation, because they had no knowledge about prematurity and its consequences. The researchers quote one interviewed father whose partner was in labor at 23 weeks gestation as stating

> I am thinking that nothing really could happen (and that my baby) is going to be just a little bit smaller than the average baby. (Grobman et al. 2010, p. 907, published by the American College of Obstetricians and Gynecologists)

At the same time, nearly a third of respondents asked that the information be provided with a sense of hope. As one woman interviewed stated

> Share everything … not just all of the gloomy stuff because you can imagine how a mother would feel [when she is] 23 weeks and [her] bag of waters breaks. (Grobman et al. 2010, p. 907, published by the American College of Obstetricians and Gynecologists)

The medical care providers interviewed for the study agreed that the provision of clear information was important, but disagreed that the information should be provided with an optimistic or hopeful approach, preferring instead to provide information in an “objective” manner to avoid giving parents a “false sense of hope”. The plea on the part of women and partners for hopeful narratives may reflect the desire to adhere to the cultural expectation of happiness and progress.

In her work, Layne also identifies the pervasive perception of women who have a pregnancy loss that their actions are to blame for this experience, reflecting again this common theme of social reproduction in modern Western societies. She writes

> Since in the United States we tend to understand moral stature and worldly success to be the result of purposeful, individual effort, a reproductive ‘failure’ like pregnancy loss is often understood by women to be somehow their fault. Although physicians routinely reassure women post facto that there was nothing they could have done to cause their loss, this message contradicts all of the morally laden messages they have received throughout their pregnancy regarding their personal responsibility for the well-being of their child. The women’s health movement has also contributed to the belief that women can and should control the outcome of their pregnancies. The doctrine of individual responsibility and culture of meritocracy that so infuses our society…, including orthodox and alternative obstetrics, exacerbates the experience of pregnancy loss by creating a double bind. Either women accept responsibility for the pregnancy loss and blame themselves for the death of their ‘baby’, or they must admit that the loss was a bodily event over which they had no control. This alternative is nearly as damning as self-blame. In fact, many North American women who experience pregnancy losses judge themselves on both of these counts- they

> tell of how upsetting it was to be ‘out of control’ and at the same time list ways that they may have been responsible. (Layne 2003, p. 19, reprinted with permission from Elsevier)

In other work, Layne has noted that pregnancy loss support group participants sometimes reported feeling that it was unfair that they had experienced a pregnancy loss, while other, “less morally deserving” women (those who used drugs or had not taken care of themselves) had not experienced such a loss (Layne 2006). The theme of self-blame in the birth of a preterm baby, along with the sense of disappointment that medical intervention failed to prevent the delivery, is expressed vividly in Kelly Jordan’s quote at the beginning of this chapter.

3.3.2 The Pregnancy Advice Literature and Preterm Birth

Examining themes in any type of advice literature, such as handbooks on child rearing or housekeeping, does not provide direct information on what the general population believes on a given topic, nor does it indicate what people actually do. Rather, analyses of advice literature are ways to understand the cultural ideology surrounding a topic (Siegel 2014). This is particularly true for topics where expert advice is valued over guidance from social networks, and where guidance from social networks is not readily available. Since the late nineteenth century, pregnancy, childbirth and child rearing have been topics for which expert advice is valued over informal advice. Social reform movements have explicitly worked to alter approaches to childbirth and child raising as a way to reform society. For example, the “scientific motherhood” movement of the first half of the twentieth century was intended to teach immigrant, Black and low-income women how to adhere to the norms of White middle class women in terms of family structure, gender role norms, child bearing and child rearing (Ladd-Taylor 1994; Litt 2000). Changing family patterns and patterns of time allocation also mean that new parents may have little exposure to informal advice on these topics from peers, and thus turn to experts for guidance (Hays 1996).

Michie and Cahn (1997) use an analysis of contemporary pregnancy and infertility advice books to explore the cultural messages communicated about these topics. They note that pregnancy advice books, and particularly the best-selling pregnancy advice book, **What to Expect When You Are Expecting** (Murkoff and Mazel 2008), universally assume a middle class subject and audience, the presence of a male partner with the mother, and few limitations on family resources. Pregnancy advice books often become advocates for the developing fetus, emphasizing ways that pregnant women need to alter their behavior for the fetuses’ benefit.

Table 3.2 shows selected components of a content analysis conducted on nine readily available childbirth advice books examining the presentation of advice on preterm birth.

One of the most striking findings of this analysis is the extremely limited amount of information included in pregnancy advice books on preterm birth, despite the

Table 3.2 Content analysis of pregnancy advice books on the topic of preterm birth

	What to expect when you are expecting (Murkoff and Mazel 2008)	The mother of all pregnancy books (Douglas 2002)	Our bodies, ourselves: pregnancy and birth (The Boston Women's Health Collective 2008)
Number (%) of pages in which preterm is discussed	6 (1.0 %)	11.75 (2.4 %)	7.25 (2.2 %)
Presence of a dedicated section on preterm	Risk factors, signs of preterm labor, PPROM and premature labor	Symptoms of premature labor Section on premature birth under—"when a pregnancy isn't perfect"	No
Level of concern expressed	Downplayed-the chances are pretty low; normal for twins to be born early	Downplayed—the vast majority of high-risk women give birth to healthy babies. Multiples are expected to be early	Relatively common—about one in 20
Portrayal of severity	The top notch medical care currently available gives even the smallest a good chance of surviving and growing up healthy	Higher than average risk of complications, quarter to half "will require special education"	At 22–24 weeks, low survival and serious complications. At 24 weeks, serious complications. After 34 weeks, usually just fine

	Your pregnancy-week by-week (Curtis and Schuler 2004)	You and your baby. pregnancy. The ultimate week-by-week pregnancy guide (Riley 2006)	The complete book of pregnancy and childbirth (Kitzinger 2004)
Number (%) of pages in which preterm is discussed	10.5 (2.4 %)	4.5 (1 %)	0.5 (0.1 %)
Presence of a dedicated section on preterm	In week 27	Week 25 – preterm labor and delivery	Preterm labor
Level of concern expressed	Downplayed—average length of pregnancy for twins is 37 weeks.	There are serious risks associated with premature birth, Leading cause of death	Not discussed, except special needs of low birth weight and preterm babies immediately at birth
Portrayal of severity	Survival better than 50 years ago. At lowest birth weight, survivors likely to have disabilities.	Serious risks—neurological impairments and death, more likely to need special education, Lifelong health problems	Not discussed for preterm

(continued)

Table 3.2 (continued)

	Your best birth, know all your options, discover the natural choices, and take back the birth experience (Lake and Epstein 2009)	The pregnancy Bible. your complete guide to pregnancy and early parenthood (Stone and Eddleman 2008)	Having a baby, naturally (O'Mara 2003)
Number (%) of pages in which preterm is discussed	0.75 (0.4 %)	2.25 (0.6 %)	8.5 (2.9 %)
Presence of a dedicated section on preterm	No	Quarter page on preterm labor	Chapter on prematurity and multiple births
Level of concern expressed	Not discussed	Listed as a reason not to use illicit drugs while pregnant. Otherwise reassuring	Matter-of-fact, acknowledging emotional reaction
Portrayal of severity	Not discussed	Early difficulties, but two-thirds grow up either completely normal or with mild to moderate problems	Treatment now available that helps most go on to live full and normal lives

fact that preterm births represent over 10 % of all births in the U.S. Layne (2003) observed the same thing regarding discussions of pregnancy loss in pregnancy advice books, which very frequently are structured around the inevitable progress of fetal development from one week to the next, but never suggest that a pregnancy may end at any week. She attributes this absence of discussion to the culture of silence described above.

The material that is included on preterm birth in pregnancy advice books reflects much of the optimistic tone of popular beliefs expressed in the March of Dimes survey, along with a very strong message that pregnant women should follow their physician's instructions in order to avoid poor birth outcomes. On the issue of preventability of preterm births, all of the books and additional web sites examined stated that in many cases (sometimes quantified as 40 % of cases) the causes of preterm birth are unknown, and, even when causes are known, not all are preventable. Several sources discourage women from blaming themselves for their "less than perfect" pregnancy outcomes, particularly miscarriage, although they note that self-blame is common. At the same time, several of the sources articulate the principle that a combination of self-discipline (adhering to a healthy lifestyle) and following the advice of one's health care practitioner can reduce the chances of giving birth prematurely. The best-selling pregnancy advice book, **What to Expect When You're Expecting**, includes a passage framed as a question from a woman who had a previous preterm delivery. She writes that she has eliminated all of her risk factors but is still worried about going into preterm labor with her current pregnancy. The answer provided in the book congratulates her on doing everything she can to make sure her current pregnancy is healthy, and then writes that there are probably even more steps she can take to minimize the chances of a repeat preterm delivery, which she can identify by working with her practitioner and gaining more knowledge (Murkoff and Mazel 2008, pp. 44–45). Elsewhere in the same book, the preventability of low birth weight births is framed as contingent on being conscientious about both medical care and self-care (Murkoff and Mazel 2008, p. 266).[14]

Historian Leslie Reagan notes a similar contradiction in the popular literature on miscarriages during pregnancy that was published in the 1940s and 1950s; women were assured that they were not to blame for their miscarriages, and also assured that if they scrupulously followed their physicians' instructions, they would, in all likelihood, soon have a healthy, full-term baby (Reagan 2003). As Layne suggested in the quoted section above, it seems that the ideology of self-determination and self-control is so powerful in U.S. culture that it is difficult to convincingly write about preterm birth without assuring readers that its occurrence can be prevented with appropriate individual action.

The need to follow physicians' instructions during pregnancy in order to prevent preterm birth, and more generally to assure a good pregnancy outcome, is emphasized to varying degrees in all sources of pregnancy advice. For example, one advice book comments on instructions for bed rest during pregnancy as follows

> Most of our discussion this week [pregnancy week 29] has been devoted to the premature infant and treatment of premature labor. If you are diagnosed as having premature labor and your doctor prescribes bed rest and medications to stop it, follow his or her advice! If you're concerned about your doctor's instructions, discuss them. If you're told not to work or advised to reduce your activities and you ignore the advice, you're taking chances with your well-being and your unborn baby's. It isn't worth taking risks. Don't be afraid to ask for another opinion or the opinion of a perinatologist if you experience premature labor. (Curtis and Schuler 2004, page 302, reprinted with permission from the Perseus Book Group)

As the review of bed rest as a preventive therapy for preterm birth in Chap. 1 indicated, there is no evidence that bed rest is an effective intervention, and a considerable amount of evidence that it has negative consequences for maternal health. One physician commentator has suggested that the continued prescription of bed rest, despite its counter indications, is a violation of clinical ethics (McCall et al. 2013), and journalist Alexandra Kleeman associates the prescription with the nineteenth century use of "rest cures" for women considered too active and independent (Kleeman 2015). Bed rest in pregnancy is popularly thought to be

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[14] Michie and Cahn (1997) note that this is a very common rhetorical device in **What to Expect When You're Expecting**, which often begins topics with a reassuring tone that supports autonomy, choice and diversity and minimizes the negative consequences of actions, and then moves on to seem to prescribe exacting maternal behavior to assure positive pregnancy outcomes.

important, but it is also difficult to adhere to, and assumes that families have resources to find substitutes for the social roles that pregnant women play as wage earners and caregivers. These two facets of bed rest use in high-risk pregnancies are discussed in Chap. 5. The ethics of prescribing (and sometimes legally mandating) bed rest are discussed in Chap. 6.

In a similar demonstration of respect for medical authority, most pregnancy advice sources describe interventional preterm births, those that occur because physicians intervene to deliver infants surgically before the pregnancy reaches term, as necessary and appropriate. They frame preterm induction as a decision that one's care provider makes when it is determined that this would be best for the baby. Natural childbirth advice sources are more skeptical about inductions and surgical interventions to deliver babies before labor begins, and encourage women to question and challenge this intervention, but also list several circumstances in which induction is appropriate. For example, the pregnancy advice book produced by the Boston Women's Health Collective lists placental abnormalities, multiple births, breech presentations, preeclampsia, maternal infections and certain maternal medical conditions as appropriate reasons for interventional deliveries.

Finally, many of the pregnancy advice sources downplay the individual likelihood of a preterm birth and reflect the optimism of the respondents to the March of Dimes telephone survey, stating that good medical care resolves many of the potential health problems of preterm births. For example, an advice book entitled **Your Pregnancy Bible** (Stone and Eddleman 2008) remarked that while there are early difficulties facing premature babies, "nearly two thirds of premature babies who survive will either grow up to be completely normal or will have only mild to moderate problems" (p. 373). This is accurate when applied to the majority of preterm infants, who are born after 34 weeks gestation, but it is not an accurate description for infants born at earlier gestational ages. Similarly, the web page Parenting.com presented 13 case histories of infants born before term in honor of Prematurity Awareness Month in 2006. Twelve of these case histories describe preterm births (including very early ones) where the children are now thriving and healthy. The thirteenth describes a child with health problems that are "quite manageable" and "correctible". None describes a situation where the child who was born preterm died or was permanently severely disabled.

3.3.3 Media Presentations of Preterm Birth

A review of the presentation of preterm birth in the news media provides a way to identify the stock of cultural narratives that are used to think and talk about preterm birth. Such narratives are referred to as frames, or ways to structure interpretations of reality in order to promote particular types of problem definitions, identify salient causes, provide a moral evaluation and stress acceptable courses of action (Entman 1993). Gamson et al. (1992) refer to framing as a mediating activity which links cognition to culture.

A cultures includes a sets of narratives that are used communally to interpret an events. These frames are sometimes contested, particularly in the context of a push for social reform on some issue. Seale (2003) notes that media narratives related to health have some rather typical cultural themes, for example, the dangers of modern life, villains, victimhood, and professional and lay heroes. He also notes that in a media context these narratives have entertainment value, so they are often presented in ways that are emotionally stimulating. They may be imaginary conversations with “people like me”, or a playing out of a narrative about human vulnerability. Commentators also note that media stories about health often involve idealizing the power of technology (Parrott and Condit 1996; Seale 2003).

For this chapter, a review was undertaken of 15 major U.S. newspapers included in the Lexis/Nexis data base over the period of January 1st 2010 to December 31st 2012. The review identified 135 articles containing the terms preterm, premature, low birth weight or tiny babies, or referred to NICU or neonatal intensive care units and focused on an issue related to preterm birth.[15] Content analysis applied to these articles identified eight primary themes; many articles touched on more than one theme. The eight content themes were: (1) risks or causes of preterm birth (19 articles), (2) outcomes of preterm birth for the infants or children (27 articles), (3) heroes who rescued or provided support for the preterm infants (14 articles), (4) technological interventions (30 articles), (5) parents’ experiences (28 articles), (6) the relative success or failure of states or the nation in preventing preterm birth (9 articles), (7) commercial activities involved in providing care (30 articles), and (8) miscellaneous policy or advocacy pieces (3 articles).

3.3.3.1 The Hero’s Journey

Three primary narratives, or frames, cut across these multiple content themes. The frame that appeared most frequently in these news articles is one that portrays a journey over time, filled with trials and tribulations, and ultimately triumph or resolution. This frame echoes the format of the “hero’s journey”, a pervasive theme in Western myth and literature (Bloom 2009; Campbell 1972). When applied to

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[15] Newspapers that yielded articles included The New York Times, The Washington Post, USA Today, The Chicago Sun Times, The New York Daily News, The St. Louis Post-Dispatch, The Minneapolis Star-Tribune, The Houston Chronicle, The St. Petersburg (FL) Times, The Atlanta Journal-Constitution, The Denver Post and the Philadelphia Inquirer.

stories featuring the outcomes of preterm birth, the journey narrative reinforces the cultural theme of the personhood of the preterm baby and the expectation that the baby will survive and progress to adulthood. These stories are emotionally evocative. They almost always begin with a description of a newborn preterm baby, its tiny size, the various health crises experienced and the medical skill and technology that is required to keep the baby alive. This example is from the **Philadelphia Inquirer** in August 2011.

> Eliahna Riley Silva was born at 10:50 a.m. April 18, weighing one pound and 3.7 ounces. Evan Edward Obert-Thorn arrived six hours later at a much more manly one pound, 4.7 ounces.
>
> They are at 114 days and counting in the Abington Memorial Hospital Neonatal Intensive Care Unit, side by side, reigning over the nursery as king and queen.
>
> An engagement between Evan and Eliahna might be considered premature, but their mothers joke that the wedding invitations could be adorned with a simple E, and nurse Sharon Houlihan noted, “It’s like an arranged marriage from the isolette.”
>
> Eliahna is a pink and portly six pounds now, and her mother, Andrea Silva of Doylestown, absolutely loves it when nurses walk by and gush, “She’s so huge.” The week Eliahna was born, her father, Josh Silva, slid his wedding ring over her foot and all the way up to her thigh.
>
> Evan, at five pounds, can now suck, swallow, and breathe with the best of babies, and has passed every test required for graduation. As soon as he gains seven ounces, enough for hernia surgery, he will spring this joint.
>
> Both babies should be heading home by week’s end, perhaps even on the same day - fitting, after all this time.
>
> These “micro-preemies” were born at the gestational ages of 23 weeks and five days for Eliahna, and 23 weeks and three days for Evan. A normal pregnancy is 40 weeks.
>
> At birth, their chance of survival was one in five, doctors say. Half of such babies that do survive, studies show, suffer lifelong disabilities, from retardation to blindness to lung and digestive problems.
>
> Doctors say that Evan and Eliahna have run the gauntlet comparatively well, surely in the healthier half, and that there’s nothing to indicate they can’t lead happy and healthy lives. Only time will tell.
>
> Doctors also say Evan’s and Eliahna’s chances of doing well are better than they would have been five years ago, maybe even five months ago. (Vitez 2011, reprinted with permission from the Philadelphia Inquirer)

Note the many references in this article to the potential adulthood of these preterm infants and the optimistic tone of the article, along with a celebration of the technical progress which kept them alive. Even media articles that portray preterm newborns with severe disabilities tend to sound an optimistic tone and describe the success of medical interventions.

The “hero’s journey” frame also structured the 28 articles that focused on parental coping with preterm birth. Here the frame served as a contrast to the cultural premise that mothers are responsible for their birth outcomes. Mothers of preterm babies have to prove their moral worth, and adhere to the cultural norms of unselfishness and self-discipline in order to avoid being stigmatized by this prevailing belief. Often this response involves reframing the experience of having a preterm baby as a blessing or miracle, as opposed to a tragedy or a burden.[16] For example, this is an excerpt from an article that appeared in the **St. Louis Post-Dispatch** on Mother’s Day, 2011:

> Julia and Thomas, now nearly 2, have made remarkable strides since their birth, but their days are still packed with various therapies and doctors’ appointments. Kandi Gregory calculated the cost of their birth, surgeries and five-month neonatal intensive care unit stay to be around $4 million (largely covered by their insurance, with state assistance making up the difference).
>
> “My life is about them, from the moment I get up until I go to sleep. We do therapy, we go to doctors’ appointments. Everything I do is solely so they can have the best chance in life. If you had told me this would be my life as a mom, I would never have believed you. It’s nothing like what I would have imagined.”
>
> But the rewards to having what she calls her “miracle babies” is not like anything the Gregorys could have imagined, either…
>
> “I am Thomas and Julia’s mom,” she said. “If you ask me what I do, that’s who I am.” She left a full-time job as an account manager because child care costs would have consumed the bulk of her paycheck. She’s established a rhythm to their days and their weeks. The babies have a team of specialists who make regular visits to the house. There are occupational, developmental, speech and physical therapists who come nearly weekly. There’s a nutritionist who visits twice a month. The state’s First Steps program has covered all their services since the babies came home.
>
> Kandi Gregory says she is lucky to have support from their families, church and a moms with twins group. But even while surrounded by this team, there are judgments she can’t escape.
>
> On a recent trip to Walmart, while shopping for groceries, a woman approached her.
>
> “What is that?” the stranger asked her, pointing to Julia’s feeding tube.
>
> “It’s a feeding tube,” Gregory said.
>
> “Is that because you’re too lazy to feed her?”
>
> Kandi Gregory walked away. She has overheard women say she must have been taking drugs to have children with special needs. (Sultan 2011, reprinted with permission from the St.Louis Post-Dispatch)

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[16] Linda Layne notes the same phenomenon applied to pregnancy loss, reframing the miscarried fetus, or stillborn baby as a gift (Layne 2003).

Several articles featured parents who stated that they felt they were given the burden of having a preterm baby because they knew they could handle it, and this was frequently coupled with expressions of faith in God.

Media coverage of parental experiences also expressed the contemporary expectation that parents can simultaneously be deeply devoted to their children and be independent, productive and able to handle challenges without complaint. Among the 28 articles identified in this content area, five described parents who were volunteering or fund-raising on behalf of hospitals, the March of Dimes or families of other preterm babies. Four described parents who were writing books about their experiences, and two described mothers who had started successful businesses while coping with preterm babies (one baby food business and one business manufacturing stuffed animals that can be used in NICU incubators). A **Washington Post** article covering Stephen Bowen, a defensive end on the Washington Redskins football team described his admirable ability to function well despite his personal concerns

> The last half-year of Stephen Bowen's life has gone something like this: Rush your wife, pregnant with twins, to the hospital. Stand by her as she gives birth to two boys, four months prematurely. Grieve the loss of one of those boys, Skyler, 10 days into his life. Keep the faith that Skyler's brother, Stephen III, would survive, then thrive.
>
> "I don't wish for anybody to go through none of the stuff I've been through," Bowen said.
>
> That was true last week, last month, even before he signed a free agent contract in July to move from the Dallas Cowboys to the Washington Redskins. It was true before the last five days of his life, which have gone like this: Go to bed at the team hotel prior to Sunday's game against the New York Jets. Awaken sometime after 4:30 a.m. to a message from security: Call home. Your mother-in-law has died.
>
> "Any time you deal with death, you just don't know," Redskins Coach Mike Shanahan said. "It's a question you can't even ask. You just got to let somebody do what he needs to do."
>
> What Bowen decided he needed to do Sunday - after the Redskins provided him a ride home, after he spoke with his wife Tiffany, after he considered his options—was play football….
>
> Still, it would seem natural for the weight of such a situation to trickle into Bowen's professional life. Players and coaches are emphatic that it hasn't.
>
> "I'll ask him every so often, 'How's your wife doing? How are you doing?'" defensive coordinator Jim Haslett said. "And he's kind of short with it. He doesn't let his business get out."
>
> [Redskins coach Mike] Shanahan said: "It's unbelievable that he has dealt with the situations that he's dealt with and really hasn't said anything to me. I've said a few things to him. But he just goes about his business."…
>
> "Your faith and family come first, and then football's after that," Haslett said. "He's a tough-minded guy, and he's one of those guys that he's not going to let his other family down, which is the football part of it." (Svrluga 2011, reprinted with permission from the Washington Post)

3.3.3.2 The Power of Technology

The second frame that cut across the content themes in media coverage of preterm birth concerned the power of technology to overcome natural phenomena such as infertility, serious maternal medical conditions, premature birth, and serious pediatric medical conditions. The many media stories about parent and child experiences in the neonatal intensive care unit reflected this narrative, with heroic and skillful medical personnel, equipped with the latest technology, saving lives, or minimizing the negative complications of medical crises. Stories of fertility treatments also reflect this theme, and the allure of this narrative may explain why such treatments, which account for only 1 % of preterm births, were the most frequently cited risk factor for preterm birth among the 19 articles primarily focused on risk. Absence of prenatal care was cited equally often, also reflecting the expectation that medical interventions can prevent preterm birth. The third and fourth most frequently cited risks were obesity and smoking, which, as discussed above and in Chap. 2, reflects the premise that irresponsible maternal behavior causes preterm birth.

At the same time, a substantial amount of the media coverage of technological or medical interventions stressed their potential dangers and/or high costs as well as their positive impacts. Seale (2003) suggests that this twist on an expected narrative is actually a common convention in media portrayals of health issues, and is a way of keeping readers engaged in a set of themes which are otherwise very predictable. Thus several of the articles covering fertility treatments noted the irony that this extremely costly intervention, while useful in overcoming natural fertility problems particularly for women who have postponed their pregnancies to later ages, often generates multiple and preterm births. Similarly, there was considerable media coverage during 2010 and 2011 about unnecessary cesarean section deliveries in late pregnancy which resulted in the birth of late preterm babies, who needed brief NICU hospitalizations and have medical complications. For example, this excerpt is from an article that appeared in the **St. Petersburg (FL) Times** in December 2010

> [n]ew data showing that delivery even a week or two early can lead to significant health problems are fueling efforts in Florida and around the nation to stop preterm births for the sake of convenience.
>
> “We’re correcting a problem,” said Dr. Robert Yelverton, chief medical officer of Women’s Care Florida, a Tampa-based group of more than 100 ob-gyns. “There should be justification for delivery before 39 weeks.”
>
> For years, many doctors have considered a pregnancy full term at 37 weeks. Indeed, most babies born at that point do just fine. But the new data are showing that babies born at 37 and even 38 weeks have much higher rates of respiratory problems, pulmonary hypertension and admissions to neonatal intensive care units than those born at 39 weeks. Florida’s rate of preterm births is so high - 14 percent - it recently earned its third-consecutive “F” from the March of Dimes.
>
> So the Florida Perinatal Quality Collaborative has just been created to work with the March of Dimes and six Florida hospitals, including St. Joseph’s Women’s in Tampa, on a yearlong project to reduce or eliminate the practice of elective early inductions.

> Given that 37 weeks has been the standard for years, changing to 39 weeks will be a challenge, said Dr. John Curran, a neonatologist and senior executive associate dean at the University of South Florida College of Medicine who is serving in the collaborative.
>
> “Physicians often practice as they were trained, which goes back a fair number of years,” Curran said.
>
> Yelverton, an ob-gyn for more than 30 years and a collaborative member, said medical textbooks still define full term as 37 weeks.
>
> But doctors are learning more about pregnancy and fetal development. Advances in ultrasound technology have led to more accurate gestational dating than the old method of counting back to the last menstrual cycle.
>
> “The practice of obstetrics should be dynamic and changing to reflect best practice,” Curran said. “We’re trying to move things forward to do better for mothers and children.”
>
> Many factors contribute to preterm births, including maternal smoking, obesity, lack of health insurance and poor or no prenatal care. Fetal distress, maternal high blood pressure, diabetes or other chronic conditions are a few of the compelling reasons for an early delivery. (Martin 2010, reprinted with permission from the Tampa Bay Times)

The expected narrative in the technology frame would emphasize the benefits of medical intervention. This article presents a twist on that frame, highlighting the problems created by excess intervention. Still, the article features physicians who are addressing the problem, provides a rationale that emphasizes the continued progress of technology, and emphasizes the ways in which preterm births, whether spontaneous or induced during late pregnancy, are related to the actions of the pregnant women themselves. Similarly nuanced or ambiguous coverage of neonatal intensive care use in Texas was reflected in this excerpt from an article in **The Texas Tribune**

> “When we look at the data, it indicates that, yes, there is overutilization of NICUs. More babies are being put in NICUs than need to be in NICUs,’” said Thomas M. Suehs, the commissioner of health and human services, adding that two of his own grandchildren were put in Texas hospital NICUs in the last two years, even though they were healthy and the deliveries were uncomplicated.
>
> Lawmakers are not ready to assert that Texas has an NICU overutilization problem, though their comments suggest it.
>
> “We are seeing some trends that are a bit troubling,” said State Representative Lois Kolkhorst, Republican of Brenham, who has filed legislation to create a commission to study NICU use. Senator Jane Nelson, Republican of Flower Mound, added, “We don’t want to reduce services, but we need to combat inefficient, unnecessary use.”
>
> Nor will most hospitals admit to a NICU problem. Combine Texas’ high birth rate, low health insurance coverage and limited prenatal care with the growth of in vitro fertilization, multiple baby births and so-called geriatric – past the age of 35 – pregnancies, hospital administrators say, and you have a full NICU. “The services exist because they fill a need,” said Amanda Engler, spokeswoman for the Texas Hospital Association. (Ramshaw 2011, reprinted with permission from the Texas Tribune)

Again in this example, there is a critique or concern expressed about the use of technology in preterm birth, but the criticism is muted by a rationale of the need for expanded facilities for care.

3.3.3.3 Expressions of Compassion

The third cross-cutting frame observed in media coverage of preterm births was compassion expressed toward preterm babies and their families. In most of the coverage, this compassion was associated with the medical care provided to pregnant women and preterm babies, and was thus another way of reinforcing the theme of the value of medical expertise, and by extension, the dependability and trustworthiness of other social institutions and individuals involved in providing care to preterm infants. In addition, emphasizing compassion reflects the linkage of preterm births to the domain of motherhood which, as noted above, is one of the few arenas where the values of caring and nurturing supersede values of rationality and independence that characterize market-based relationships.

The accounts of experiences with neonatal care units frequently included the statement that the medical staff, other families and volunteers there came to feel like "family". Several instances were noted where the families of preterm babies maintained relationship with the NICU nurses for several years after the children's birth. In addition to medical personnel, news articles described volunteers who provided comfort and support to parents in the units, a funeral director who arranged for burials for newborns of families without the means to pay the costs, and a volunteer photographer who takes pictures of preterm babies as memorials if they die. This example, from **The Washington Post**, is typical.

> It must have looked incongruous: a shackled man entering a hushed intensive care unit where an impossibly small baby labored to breathe.
>
> There was no hope for the baby, but maybe there would be for the man.
>
> "That was really important to me - that the father saw that child before he died," said Edie Mead, a social worker in the neonatal intensive-care unit at Children's Hospital. The man was in jail. The baby was dying. Edie had made a flurry of phone calls and worked with authorities to allow the man to come and see his child, for the first and last time.
>
> Two police officers stood nearby as the prisoner bent to look at the newborn. The baby had been born too early and too sick to have a chance at life. The fact that the newborn's father was in jail could have meant that he wouldn't be able to gaze upon the child during its brief time on this planet.
>
> But Edie wasn't going to let that happen.
>
> There are plenty of nonmedical people at Children's: chaplains, interpreters, child-life specialists, members of the Clown Care unit; and social workers such as Edie. Their presence is an acknowledgment that healing often depends on more than a scalpel. "Our role is to be here for whatever may come up," she said.
>
> For Edie, that means meeting with parents to be sure they understand the procedures the medical team is proposing. It means working with mothers suffering from postpartum

> depression, an affliction more common among women who have given birth prematurely. ("You didn't have the child you thought you'd have or the birthing experience you thought you'd have," Edie explained.)
>
> And it means writing letters, lots of letters: to fire departments letting them know a family in their neighborhood is coming home with a medically fragile child who may need 911, to the electric company requesting that an impoverished family's power not be shut off now that their newborn depends on a ventilator.
>
> Edie writes a lot of letters to employers, too. They are tricky ones to write. Edie isn't allowed to divulge personal medical information, but she has to get across the severity of the situation and make a heartfelt request. Can the employer please be understanding?
>
> Some bosses are. "They say, 'Take as much time as you need,' " Edie said. But even so, "some parents are in jobs where if you don't work, you don't get paid." (Kelly 2010, reprinted with permission from the Washington Post)

The frame of compassion was also expressed in the context of a story about KV Pharmaceuticals, a pharmaceutical company based in St. Louis that was granted an exclusive license to market a form of progesterone to reduce the risks of spontaneous preterm labor in a subset of pregnant women. As noted in Chap. 1 and discussed further in Chap. 5, the progesterone drug had been taken off the market by the time that clinical trials in the 1990s suggested it might be effective in reducing the risk of preterm delivery. When the data on the potential value of the treatment was published, some physicians began using a form of progesterone obtained from compounding pharmacies at a cost of $10 to $15 per dose. The March of Dimes and the National Institutes of Health helped to finance a study that was required before re-commercialization of the drug could be approved. When the Food and Drug Administration granted a license to KV Pharmaceuticals in 2011, the company announced that the new price for its progesterone formulation would be $1500 per dose. Although the initial media coverage, particularly in the local St. Louis paper, portrayed this as an admirable business opportunity for the struggling company, an uproar ensued over the impact that the high price would have on pregnant women and infants. The company later offered to reduce the price to $650 per dose and to offer subsidies to patients who could not afford it, but this did not reduce the negative reaction. This coverage in the **St. Louis Post-Dispatch** was typical

> The March of Dimes released a statement Friday saying that KV's price reduction and expansion of financial assistance to patients are "steps in the right direction" but not enough. In a letter to KV chief executive Greg Divis, March of Dimes President Jennifer Howse asked the company to "immediately cease and desist the use, distribution or publication of or reference to the March of Dimes name and/or logo on any materials or communications in connection with KV Pharmaceuticals," its marketing subsidiary, Ther-Rx Corp., and the drug, Makena.
>
> KV officials voiced disappointment with the March of Dimes' decision, saying in a statement that they had partnered with the nonprofit "because of our shared passion for advancing the health of women and infants." As for the price of Makena, the company said it would offer additional rebates to help reduce the cost of the drug for state Medicaid programs and also provide additional financial aid to patients, saying that "85 percent of

> patients will pay $20 or less per injection for FDA-approved Makena" with the balance to be picked up by insurance carriers, presuming they agree to pay.
>
> On Feb. 4, Hologic won FDA approval for a branded version of the drug, Makena, and transferred marketing rights of the drug to KV in a deal worth nearly $200 million. The federal blessing came with exclusive marketing rights to sell Makena under an FDA designation known as "orphan status," given to companies developing drugs for relatively small markets.
>
> But on Wednesday the FDA announced that - because of widespread concerns about KV's high price - it would not take enforcement action against so-called compounding pharmacies that continue to sell 17P. The FDA declined to comment through spokesman Jeff Ventura about KV's price reduction.
>
> Others said the new price hardly made the drug affordable.
>
> "At a time when rising prices for prescription drugs are stretching the budgets of middle-class families, we can't allow pharmaceutical companies to price gouge pregnant women when it comes to vital medicines," said Sen. Amy Klobuchar, D-Minn., who joined Sen. Sherrod Brown, D-Ohio, in recently asking the Federal Trade Commission for an investigation into Makena's pricing. (Doyle 2011, reprinted with permission from the St. Louis Post-Dispatch)

Both in the way that strangers can come to feel like family, and in the way a pharmaceutical company could experience public sanction simply for making sound business decisions, these narratives of compassion stand out as being unusual and unexpected within the norms of contemporary American life. As the discussion of the intensive mothering component of social reproduction indicates, care for vulnerable babies and parents in crisis are one of relatively few situations in U.S. society where the expression of compassion is viewed widely as appropriate, while commercial concerns and social distance between strangers are considered inappropriate.

3.4 Comparisons with Canada, Great Britain, and Western Europe

Chapter 1 stated that there was no strong evidence that the U.S. differs from other developed countries in terms of the causes of preterm birth or the therapies used to prevent its occurrence or treat newborn infants, with the possible exception of more support in other countries for pregnant women leaving the active workforce when they are close to delivery. Chapter 2 showed that, in terms of epidemiology, in Great Britain, Western Europe, and Canada fewer women are categorized as belonging to high-risk groups—fewer are low income, fewer are racial or ethnic minorities, fewer are very young, fewer have unintended pregnancies, fewer have higher order multiples related to assisted reproductive technology, and fewer have maternal health complications—some related to obesity—that trigger interventional preterm deliveries.

In terms of the cultural understanding of preterm birth as discussed in this chapter, there are many similarities between the U.S. and these comparison countries. The U. S. inherited from seventeenth century Great Britain and Europe a mechanized world view that places pregnancy in the medical domain, to be treated with physician-controlled technology. Until World War II, U.S. physicians and hospitals modeled their most sophisticated medical approaches to obstetrics and neonatology based on European practices, and modeled their approach to the regionalization of neonatal intensive on developments in Canada in the 1960s. Pregnancy is medicalized in the cultures of all of these societies, and midwives, where active, operate within the medical systems. Ultrasound technology is promoted in all of these maternity systems as part of modern childbirth (Mitchell and Georges 1997). As in the U.S., the criteria designating pregnant women as high or low risk are variable both across, and in most cases within, national systems, and the designation of pregnant women by risk level impacts the type and location of the care they receive, along with their personal perceptions of their pregnancies (Grytten et al. 2014; Marlow and Gil 2007; Stahl and Hundley 2003; Zeitlin et al. 2004).

However, there are some important differences between the U.S. and Canada, Great Britain, and Western Europe in terms of the cultural understandings of social reproduction, and these also have an impact on cultural understandings of preterm birth. All of these Western settings have patriarchal systems which place great emphasis on identifying the father of a child. All consider a fetus to have some independent existence during a woman's pregnancy. Western European restrictions on early and late term abortions predate those put in place in the U.S. in the late nineteenth century, and initially were also based on the identification of a fetus as a human life which needed protection by the state from actions of their mothers.

But as political pressure to liberalize abortion restrictions intensified in the twentieth century, the dialogue in the U.S. centered around the conflict between the individual rights of women and the individual rights of fetuses. Opponents to liberalizing abortion in the U.S. framed the problem as one of women who refused out of selfishness to accept the role of motherhood (Petchesky 1990). As noted above, this theme of personal maternal responsibility for the outcomes of pregnancy permeates views about preterm birth, supporting the cultural logic which holds that these births are preventable if women adhere to prescribed behaviors. This logic carries over to views about the high rates of preterm birth in specific categories of women, whose reproductive success is less highly valued in mainstream U.S. culture, including teens, poor women, Black women, and other ethnic minorities. In the U.S., the assumed high-risk status of these women and the designated high-risk status of other women is read as a mandate for them to be extra scrupulous in regulating their behavior. High-risk status provides an opportunity for physicians to shift responsibility to patients for poor birth outcomes.

In contrast, in Great Britain and Western Europe the dialogue around liberalizing abortion restrictions centered on concern for the plight of mothers, so distressed by their pregnancies in the midst of personal, social, and economic pressures that they would resort to the unnatural act of sacrificing their motherhood. In this context, easing restrictions on abortion and placing access to abortion in the context of access to the established medical and social systems was seen as a way to screen for and identify women with this level of distress. Distressed women could then be provided with counseling and economic support so that they could make more beneficial reproductive choices (Linders 1998). Law professor Mary Ann Glendon describes the French abortion legislation, crafted in the 1970s amidst public conflict over liberalizing the existing restrictive abortion policies as follows

> The legislation as a whole is pervaded with compassion for pregnant women, by concerns for fetal life, and by expression of commitment of society as a whole to help minimize occasions for tragic choices between them. The commitment is carried out by provision of birth control assistance, and by comparatively generous financial support for married as well as unwed mothers. (Glendon 1987, p. 18)

Differences in population policies between Great Britain, Western Europe, and the U.S. can be traced in part to differences in these society's experiences with population issues in the late nineteenth and early twentieth century. In this post-Civil War period in the U.S., successful reproduction among Black Americans went from being an asset, as it had been for slave owners during the slavery era, to being a threat to White dominance (Fraser 1998; Roberts 1997). The influx of immigrants and their perceived high birth rates were also seen as a challenge to the character of the nation. Restrictions on abortion and also on birth control were proposed as ways to prevent "race suicide", or the decline of the White, Western European-heritage middle class. Ambivalence about the benefits of pregnancy, successful childbirth and infant survival among specified subgroups is evident from these concerns.

In contrast, in Western Europe during this time period, nations faced a general decline in birth rates that threatened to create an overall decline in population. In both Britain and France, concerns were expressed that there would soon not be enough men available to serve in the military and protect the countries from foreign invasions (Cone 1985; Hyatt 1999). In Sweden there was a concern that there would not be enough native Swedes to support industrialization, and this would open the way to increased immigration from Russia and Poland. It was feared that this in turn would lead to the dilution of native culture (Linders 1998). These population concerns were one of the incentives for the development of robust social welfare programs in Great Britain, Western Europe, and Canada, in a manner that was quite different from the development of social welfare programs in the U.S. These differences are discussed further in Chap. 4. The contrasting history of population concerns in the U.S. and these other settings means that there is less stigmatization of pregnancy and childbirth among subgroups in these settings, compared to the U.S.

Glendon puts her comparative study of family law in Europe and the U.S. in the context of differing societal emphasis on the role of the family as well as differing governmental approaches to social welfare. She notes that European countries all have stricter enforcement of child support laws than the U.S. including, in the Nordic countries, a policy of governmental support for single women until fathers can be identified and required to financially support their children. Orloff (1996) notes similarly that in the Great Britain, social welfare laws enforce the expectation that fathers will support their children. In contrast in the U.S., the extent of enforcement of child support agreements among previously married parents varies across jurisdictions, and there is no policy of governmental income support to substitute for family support. Glendon relates the divergence between the U.S. and particularly continental Europe in part to differences in a culture that focuses on individualism, self-reliance and self-determination, versus ones that retain some elements of a more feudal system that emphasized social connection and interdependence. She summarizes

> Our [U.S.] law stresses autonomy, separation, and isolation in the war of all against all, in contrast to Sweden, where the laws emphasize sex equality and social solidarity, West Germany, where the message is pro-life and social solidarity, and France, where equality, life and solidarity are all sought to be promoted. The European laws not only tell pregnant women that abortion is a serious matter, they tell fathers that producing a child is serious too, and communicate to both that the welfare of each child is a matter in which the entire society is vitally interested. (Glendon 1987, p. 58)

One consequence of this cultural message, that reproduction is both a family and a societal concern, is a modification of the belief that women alone are responsible for their poor birth outcomes. Anthropologist Susan Hyatt relates that there is a belief in British culture that women must control their behavior in order to guarantee successful reproduction for the benefit of the society, but this is balanced by social welfare interventions that attempt to modify threats in the environment of women at risk (Hyatt 1999). Anthropologist Sociologist Kristina Orfali (2004) describes how, in the French context, the combination of societal investment in individual birth outcomes and the authority assumed by physicians as a component of pregnancy medicalization cause physicians to assume responsibility for birth outcomes, rather than placing responsibility on the parents. In her comparative study of decision-making in neonatal intensive care units in France and the U.S., she observed that, in France, decisions about resuscitation of preterm newborns in intensive care units were made to a large extent by physicians, without the level of parental consultation that she observed in intensive care units in the U.S. Referring to cases where newborn health status is extremely compromised, she writes

> The handicap is, in the eyes of the French neonatologists, viewed as an iatrogenic consequence of their own intervention (“the handicap is really the failure of what we do”). In this context, leaving the burden of decision to the parents is seen as an inappropriate, unethical and inappropriate way of ridding one’s duty as a physician. The professional duty of neonatologists is to give parents a child in good condition. “I have always thought we should limit treatment instead of giving (the parents) a handicapped child. Especially as we know very well what happens in the long run for a couple. Statistically, there are many divorces and things like that….” (pediatrician). Physicians thus act as if society had implicitly mandated them as gatekeepers for such selective treatment limitation. (Orfali 2004, p. 2019, reprinted with permission from Elsevier)

The parallels and contrasts in neonatal resuscitation decision-making between the U.S. and Canada, Great Britain, and Western Europe are discussed further in Chaps. 5 and 6.

In sum, cultural understandings of preterm birth in Western Europe, Great Britain, Canada, and the U.S. have many similarities. Where they diverge most dramatically is in the allocation of responsibility for the event. In the U.S., mothers are assumed to hold responsibility for their birth outcomes, and find themselves striving to prove that they are good mothers in spite of their apparent failures at motherhood. In the comparison settings, there is more of a sense that families, the medical system, and particularly the broader society bears some responsibility, and more public support is available to parents to reduce their individual burdens during pregnancy and after childbirth.

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Chapter 4
The Political Dimension: Solving the Preterm Birth Problem

Political systems are the arrangements within a society that regulate the distribution of resources, including both power and wealth (Lasswell 1936; Marvick 1977). Patterns of resource distribution, for example, the designation of who owns land, who is employed, and how leaders are selected, are characteristics of all societies. Each society has both historically established wealth and power distribution patterns, and historically established mechanisms for setting the rules that control these distribution patterns. Although the patterns and the rules both have established histories, they also change over time as social circumstances change. Sometimes these changes reflect shifts in the economic basis for creating wealth, or the relative influence of different groups. For example, when industrial development replaces agriculture as a source of wealth, and more recently as finance and information-based enterprises replace industry, new sources of wealth and patterns of wealth distribution are created. The established patterns of political power change accordingly. That is, the political influences of both landowners and organized labor have waned as the influence of financial institutions and large technology corporations have increased. Shifts in political power have an impact on which policies—rules for the distribution of resources—are enacted by government, and which policy proposals can be safely ignored.

There is another way that resource distribution and rulemaking change over time. Political observers note that sometimes these patterns change because a situation gains traction as a social problem, and rule-makers (politicians and government authorities) find themselves compelled to divert resources to problem resolution in order to maintain their legitimacy with the public. Not all troubling situations are defined as social problems, and not all social problems win a place on the political agenda as issues that require a redirection of societal resources. In political scientist John Kingdon's (1984) formulation, conditions become social problems when they are perceived to conflict with prevailing values, and when there is a belief that the problems can be ameliorated or solved. Conditions evolve into problems either when they change in magnitude, or when social expectations change so that the conditions are no longer accepted as normal. For example, the

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death of newborn infants was once considered an inevitable and personal experience. As families became smaller and the value placed on each child increased, and as public health conditions and medical interventions improved, it became both feasible and increasingly desirable to prevent infant deaths. At that point, social norms began to shift so that infant mortality was seen as a social problem as opposed to simply an individual misfortune (Meckel 1990).

In Kingdon's model, recognizing a circumstance as a social problem is not sufficient to ensure that it will generate political change. Problems reach the political agenda when they are accompanied by proposed solutions. These solutions are essentially proposals for social reform. Inevitably such changes benefit certain constituencies and are costly to others. Ultimately political action is taken on specific solutions to social problems when the political circumstances align so that it becomes more advantageous to provide benefits to the new constituency than to maintain the status quo. It is not unusual for this three part process—defining social problems, proposing solutions, and realigning political forces—to work in reverse: advocates of particular social changes look for social problems to link their proposals to, with the hope that political pressure galvanized to solve the problem will lead to the implementation of their favored policies (Kingdon 1984; Spector and Kitsuse 1977).

The discussion of the political dimension of preterm births in this chapter explores the way prematurity and infant mortality have become social problems linked to three political arenas in the U.S., that is, three domains of struggle for control over resource distribution: the domain of women's fertility, the domain of addressing poverty, and the domain of addressing racial inequality. In the arena of control over fertility, the claim that preterm births can and should be prevented is used both to justify public support for universal availability of contraception, and also to justify restrictions on abortion. In the domain that addresses poverty, the potential to prevent preterm births has been used to legitimize social programs for the poor, including the need for universal health insurance coverage. These programs would have been politically less acceptable if they had been framed as addressing the problems faced by poor adults. In the struggle over equality for Black Americans in the United States, the persistent disparity in rates of preterm birth between Black and White women serves as proof that racism has measurable negative consequences that matter to society. Framing racism as an issue that affects newborn infants adds traction to policy proposals that address the issue.

As will be discussed, the political debates in each of these three domains have their own dynamics, and these dynamics have a powerful influence over which policies are proposed to address preterm birth, and whether and how the policies are enacted and implemented. This chapter examines two aspects of the role of preterm births for each of these domains: the way the preterm birth problem is framed in order to fit the political dynamics within the domain, and the impact that policies enacted have had on preterm births in the U.S. The comparative section at the end of this chapter explores differences in the political dimension of preterm birth between the U.S. and Great Britain, Western Europe and Canada. Some issues that are politically salient in the U.S., such as contraception, abortion availability and racial inequality, do not reach the political agenda in the same way in these other countries. However, in these countries, broader social welfare issues and concerns about low fertility rates, which have a minimal role in political debates in the U.S., have been arenas for the creation of policies that have had an impact on birth outcomes.

4.1 Preterm Births and the Politics of Fertility Control

The use of contraception to control reproduction has been widely documented, both historically and globally. The extent to which contraception is used depends in part on the desirability of large or small families, and this depends primarily on the prevailing economic systems. In agricultural societies, large families are desirable to increase the potential labor pool, but in both nomadic and industrial societies, small families are preferred, although for different reasons. During times of economic transition, societies may include sub-groups with different preferences for family size. A society may have cultural norms that support one family size but that conflict with changing economic realities that make a different family size more advantageous. In these cases, there will be social conflict over fertility regulation, and consequently there will be political conflict over the availability of contraception and abortion (The Commission on Population Growth and the American Future 1972; Gordon 2002; Petchesky 1990).

There has been political conflict over the availability of contraception and abortion in the U.S. since at least the mid-nineteenth century. The demand for contraception has increased as the economic base of society moved away from agriculture towards industrialization, a change which advantaged smaller families and also households where women work outside the home. A cultural shift has occurred that increases both the value placed on women's independence and the value placed on sexual relations, independent of procreation. Finally, the demand for fertility control has increased out of concern about high fertility rates among poor people and racial and ethnic minorities, whose expansion in numbers has been seen as a threat to existing political and social arrangements. Support for the broader availability of abortion services has been driven primarily by the second force: adherence to the principle that women should be able to choose to limit their reproduction. Abortion is also seen as the unfortunate but sometimes necessary action that may need to be taken when other forms of contraception are not used or when they fail (Petchesky 1990).

On the other hand, opposition to the increased availability of contraception is driven in part by resistance to social changes that are perceived to de-value the centrality of reproduction and over-value the self-interest of adults, including adult enjoyment of sexual activity distinct from procreation. Such changes are, in fact, the consequences of the drive towards smaller families and the weakening of the distinction in economic and cultural roles between men and women. Opposition to abortion is also driven by resistance to the redefinition of women's roles that minimizes reproduction, and resistance to the expansion of sexual activity for reasons other than procreation (Ginsburg 1989; Luker 1984). In addition, there is a long history of opposition to abortion in the Western tradition because it is considered ending a human life, and because, when unregulated, it constitutes a danger to women's health.[1] Finally, particularly in the nineteenth century, there was opposition to the availability of contraception and abortion because of the potential for diminished influence of White people of British and Western European ancestry, if their reproductive rates declined with fertility control.

4.1.1 Preterm Birth and Support for Contraception

The advocates of birth control for different reasons—the economic advantage of smaller families, the independence of women, the enjoyment of non-procreative sex, and the shaping of demographic trends in desirable ways—have not always been natural allies. For example, in the late nineteenth century some advocates of increased contraceptive availability also supported free love as opposed to marriage, while others supported voluntary motherhood, which emphasized women's rights to remain abstinent even within marriage. Yet both groups, along with the advocates concerned about over-population with less desirable groups, believed that preventing unwanted reproduction or reproduction among the wrong types of people, would improve the physical and mental health of newborns.[2] It is at this juncture that the social problem of preterm birth intersects with the political dynamics that support the increased availability of contraception.

During the Progressive era in the U.S. (1910–1918), supporters of birth control aligned with advocates of women's rights, civil liberties, and the unionized labor movement. Birth control was seen as a key strategy for improving the lives of working and impoverished people. This alliance dissolved after World War I. Birth control advocacy then came to be shaped and led by a combination of health and welfare professionals and supporters of a eugenic approach to improving population health. The logic of the eugenic approach was to improve population health by reducing the levels of reproduction among those perceived to be unfit, while promoting greater reproduction rates among the fit or socially desirable segments of the

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[1] Feminist scholars generally contend that the argument that abortion ends a human life is relatively recent (Daniels 1993; Petchesky 1990). However as discussed in Chap. 3, other scholarly evidence indicates that social ambivalence around abortion has deeper historical roots, certainly related to ancient philosophical disagreements about whether fertilized ovum have souls (Mohr 1978; Burns 2005).

[2] Gordon relates this to the beliefs of that era that undesirable behaviors among parents could be inherited by their children; in addition, some advocates believed that infants have a right not to be born if they are not wanted or if they will be born into circumstances that will not promote their well-being (Gordon 2002).

population.[3] The involvement of health professionals was critical because, during this period, federal and state laws made public discussion of contraception illegal and restricted the distribution of contraception to physicians for use only with medical indications.[4] Advocates campaigned from the 1920s through World War II to remove these legal restrictions, framing their rationale on the basis that contraception improved birth spacing, reduced infant mortality and the extent of mental and physical deficiencies in the population. For example, a Birth Control Federation of America poster in the early 1940s was headlined “Proper Child Spacing Prevents Infant Deaths” and compared infant mortality rates for infants spaced one, two, three and four years apart. While these campaigns failed to change the restrictive legislation (Gordon 2002), birth control use became widely accepted over this period, and most restrictive laws were not actually enforced (Engelman 2011). Barrier methods, including condoms and diaphragms, were the most common contraceptive methods used in this period.

In 1942, the various contraceptive advocacy groups came together in an organization named the Planned Parenthood Federation of America, which both advocated for and provided family planning services, intended to strengthen society by promoting rational and planned child bearing. This was the same point at which the first community surveys were implemented to assess the prevalence of pregnancies that were unintended or unwanted. As discussed in Chap. 2, the initial motivation for these studies was to understand why birth rates were declining among middle class white families. During the next three decades, the studies reported that a surprisingly large portion of pregnancies in the U.S. were not fully intended (Campbell and Mosher 2000). An extensive literature developed that linked unintended births to poor birth outcomes, echoing the ideology of nineteenth century birth control supporters. Analyses also suggested that infant mortality rates were lower among populations with access to family planning. It was thought or assumed that family planning also lowered the portion of infants born at low birth weights or early gestational ages, and this could happen in three ways: by reducing the incidence of pregnancies among high-risk women (low income women, teenagers, high parity women, and those with chronic health issues), by increasing birth spacing, and by helping to assure that pregnant women would adhere to good health practices, including early use of prenatal care (Brown and Eisenberg 1995; MacDorman et al. 2008). In 1970, the Public Health Service Act was amended to

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[3] Burns (2005) refers to this as the medicalization of birth control, and considers that this more neutral, medical frame accounts for the eventual success of the movement in making birth control more available.

[4] The Comstock law, passed in 1873, prohibited the interstate mailing of obscene material, and explicitly listed information about birth control as obscene. Several state laws similarly banned distribution of information about birth control and birth control methods themselves. The application of the anti-obscenity laws to the distribution of contraceptive devices by doctors to patients was ruled unconstitutional in 1936, and various state laws were successfully challenged over the next decades. In 1965, the Supreme Court ruled in the case of Griswold v. Connecticut that use of contraception by married couples was protected by the right to privacy. Congress removed references to contraception in the Federal anti-obscenity laws in 1970.

establish a national set of subsidies for family planning, and in 1972 the new Medicaid program (which had been established in 1965 and financed health care for low income populations) increased federal subsidies for family planning services to 90 % of expenditures (Campbell and Mosher 2000; Gordon 2002; McFarlane and Meier 2001; Ward 1986).

Although federal support for family planning services has waxed and waned over the succeeding four decades with the shifting influence of interest groups supportive of and opposed to contraception (McFarlane and Meier 2001), the link between unintended pregnancies and poor birth outcomes, including preterm birth, low birth weight birth and infant mortality, has become an article of faith. Writing in the policy review journal of the Guttmacher Institute, a policy analysis and public education organization devoted to advancing sexual and reproductive health and rights,[5] Gold (2011) notes that reducing the rate of unintended pregnancies has been a stated goal of the federal *Healthy People* initiative since 1979, and expanded Medicaid coverage for contraception has been endorsed by the National Governor's Council and by the March of Dimes as strategies for the improvement of maternal and child health. The Affordable Care Act (ACA), which passed Congress in 2010, included a requirement that health insurance plans cover preventive services for individuals and fully finance. In early 2011, the Department of Health and Human Services asked the Institute of Medicine to assemble a panel of experts to advise them on the specific services for women which should be categorized as preventive. The intention of the request was clearly to try to avoid politicizing the definition of contraception as a health service by relying on experts to make the determination (Pear 2011).[6]

This IOM committee report, issued July 19, 2011, did include a recommendation that contraceptives be included as a preventive service under the ACA. The rationale was that contraceptives help to prevent unintended pregnancies, and unintended pregnancies are associated with late use of prenatal care, less breast feeding, more maternal depression and less happiness, higher odds of preterm and low birth weight births, and births to women for whom pregnancy is counter-indicated for health reasons. Contraceptives are shown to be effective in reducing the likelihood of unintended pregnancies, and requiring out-of-pocket payment for contraceptives is shown to discourage use (Committee on Preventive Services for Women 2011). In making this recommendation, the Institute of Medicine committee followed the approach that had proved to be successful since the 1970s in securing public policies that support more widespread availability of contraception: link the policy to the problem of unintended pregnancies, which

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[5] The Guttmacher Institute was founded in 1968 as the Center for Family Planning Program Development, and housed within the corporate structure of the Planned Parenthood Federation of America. It became an independent non-profit organization in 1977, and is named for Alan F. Guttmacher, an obstetrician-gynecologist who was president of Planned Parenthood in the late 1960s.

[6] In fact, several states already included coverage of contraception as a mandatory health benefit for health insurance policies offered in the state.

should be addressed because they can result in preterm births, among other undesirable outcomes. The image of preterm birth presented in this particular political context is that such births are often the consequence of a lack of rational planning around childbirth, and therefore that preterm birth is potentially preventable with contraception. Promoting contraception for health reasons is more effective in the political context than promoting contraception in order to allow women to control their entry into motherhood, or in order for couples to engage in sexual activity without concern about procreation.

4.1.2 Preterm Birth and Opposition to Abortion

Contraception opponents have not linked their advocacy to preterm births or other health issues. In fact, they have resisted the framing of contraception as a health issue. This is the basis for political resistance to the coverage of contraception under the Affordable Care Act. To birth control opponents, restricting the availability of contraception helps with the retention of reproduction as a primary role for women, while supporting the voluntary restriction of sexual activity outside of marriage out of fear of a resulting “illegitimate” pregnancy. There has been resistance within the Black community to the promotion of birth control because it is linked to the eugenic movement to suppress birth rates among minority populations (Roberts 1997; Ward 1986); this history is discussed in Sect. 4.4.1 of this chapter.

In contrast, opponents of abortion have explicitly framed their policy proposals as a way to assure the survival of preterm babies. Movement activists have also cited the improved survival of preterm babies as a rationale for opposing abortions. To briefly summarize the history of abortion provision in the U.S., the procedure was available in the early history of the country, but was criminalized in mid-nineteenth century, as it was across Europe, Great Britain and Canada. Abortion remained available from private physicians, if the physicians were willing to provide a therapeutic rationale for the procedure. Pressure to liberalize abortion laws began in the 1960s, primarily because some women who were perceived as justified in their request for therapeutic abortions were denied them by medical authorities.[7] Initially, the liberalization of abortion laws was supported by one group of professionals who wanted to retain the autonomy to decide whether a particular request for abortion was justified, along with a second group who wanted

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[7] Luker (1984) writes about the case of Sherry Finkbine, a mother of four who inadvertently took a large dose of thalidomide early in her 5th pregnancy and became concerned that her child would be born with multiple birth defects. She requested an abortion, which was at first approved and then later denied by the local public hospital because of media attention to the case. She eventually traveled to Sweden and received an abortion, but the case revealed the divisions within the medical community over whether abortions could legitimately be performed to ensure that a child was born healthy, in a setting where it could thrive, or whether abortions could only be performed if the life of the mother was threatened, and this threat was perceived to outweigh the interests of the fetus.

to eliminate the medical consequences of poorly conducted illegal abortions. These reformers were soon joined by individuals mobilized by the new women's liberation movement, who began to reframe access to abortion as a reproductive right for women. The liberalization of abortion laws was opposed by the Catholic Church, some conservative Protestant denominations and some physicians.

In 1973, the Supreme Court ruled in the *Roe v. Wade* decision that all state laws that restricted abortion before the point of viability of the fetus were unconstitutional invasions of privacy. Glendon (1987) notes that this framing of the abortion liberalization decision in the U.S. was unique, compared to the framing in Western European countries (which were also confronted with ambiguity around judgments about therapeutic abortion), because of its exclusive emphasis on the individual liberty rights of mothers, without the acknowledgement of concerns about the rights to survival of the fetuses. The Supreme Court decision surprised many people who believed that fetuses are persons from the moment of conception, and consequently that abortion is murder. The pro-life (anti-abortion) movement that expanded rapidly after the court decision included many people with the same beliefs as those articulated by opponents to contraception, as described above. In addition to the conviction that fetuses are individuals from the moment of conception, they felt that women and men are intrinsically different, that motherhood is the core activity of women, that interference in any way with the process of becoming a mother is wrong, and that the availability of abortion (and contraception) encourages sexual activity separate from procreation, which is immoral and destructive (Luker 1984).

Many authors have noted that images of fetuses in utero have been a powerful galvanizing component of pro-life campaigns (Georges and Mitchell 2000; Hartouni 1997; Mitchell 2001; Taylor 1992). The re-definition of the fetus as a patient distinct from the pregnant woman that began in the 1970s, as discussed in Chap. 3, is seen by the pro-life movement as proof that the view of fetuses as babies from the moment of conception is a scientific fact, as opposed to an ideological conviction (Duden 1993). Furthermore, developments in neonatal care which have lowered the threshold of viability to 22–23 weeks, is interpreted to mean that there is no limit to the viability threshold. That would mean that the Supreme Court's decision in *Roe v. Wade,* that abortion is a private matter until the point that the fetus is viable outside of the womb, is untenable. Legal scholar Cynthia Daniels notes that, in "1982", President Reagan stated (incorrectly) that premature infants had been born alive and survived at 3 months gestation, and in 1983 Supreme Court Justice O'Connor dissented in an abortion rights case because she believed fetal viability in the first trimester was an imminent possibility. Daniels writes:

> Images in the media of two-pound 'miracle' babies encourage the belief that the first- and second-trimester fetus is a smaller but physically complete version of the newborn infant. Anti-abortion activists such as Bernard Nathanson have encouraged this view: 'significant advances in science and technology in the past four years, such as real time ultrasound

> scanning, fetal medicine, intra-uterine surgery, and in vitro fertilization have all confirmed beyond a reasonable doubt that prenatality is just another passage in our lives.' Nathanson argues that abortion advocates have simply not come to grips with advances in modern technology, as they 'cling to their flat earth credo.' (Daniels 1993, p. 18).[8]

The supporters of restrictive abortion laws currently find two aspects of preterm birth in the U.S. useful for their advocacy efforts. First, the increasing ability of medical interventions to resuscitate and support the survival of extremely preterm infants has resulted in an overlap between the point in pregnancy when abortion is still legal (though relatively rare at less than 1.5 % of all abortions between 20 and 24 weeks gestation)[9] and the point where it is possible that a fetus will survive (approximately 50 % survival at 23–24 weeks). This overlap carries a powerful symbolic load, because it intensifies the contradiction between women's roles as mothers and as independent choice makers, unburdened by children. In theory, two women could reach the same point in pregnancy with these opposite intentions, and this point continues to be used rhetorically in political efforts to restrict abortion availability. In 2013, the political observer column PolitiFact reported:

> [Texas] Governor Rick Perry spoke up for restricting abortions earlier in pregnancy by saying that extremely premature births increasingly result in healthy children. To Democratic opposition and a sustained uproar in the Texas Senate gallery, a proposal intended to tighten the regulation of abortion in Texas perished at the end of the session that ran through June 25. Perry reacted by calling a fresh special session before telling the National Right to Life Convention in a June 27, 2013 speech: "We will ban abortion after 20 weeks" of pregnancy. "And you think about it," Perry said, "it makes sense considering the growing number of healthy, happy children who are born prematurely at the same early gestation that our laws allow abortion". (Selby 2013, reprinted with permission from the Austin American-Statesman)

PolitiFact rated this statement as "mostly true," based on contemporary studies that reported a 21 % survival rate for infants born after 22 weeks gestation.

Another rhetorical approach used to draw attention to the contradiction between the potential survival of infants born between 20 and 24 weeks gestation and the permissibility of abortion during this period is the collection and publicizing of stories of "abortion survivors." These stories point out that what are termed "failed" or "missed" abortions (where a fetus is not successfully removed during the abortion procedure) eventually result in childbirth. Many individuals described on the abortion survivors' web page survived missed abortions early in their mothers' pregnancies, in an era when the procedure was not routine, and failures to remove

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[8] Bernard Nathanson was an OB-GYN who advocated for liberalized abortion laws early in his career, but later became a leading opponent of abortions and leader of the pro-life movement. He died in 2011 at the age of 86.

[9] As of September 2012, 20 states had regulations banning abortions beyond 20 weeks gestation.

the fetus during a surgical abortion were more common than they are now.[10] Some survivors of missed abortions have become very effective anti-abortion advocates. A subset of these individuals are also survivors of a preterm birth, and the existence of surviving individuals whose mothers attempted to have abortions, and who were born prematurely, allows advocates to raise the possibility that a number of prematurely born infants are also the consequence of failed abortions (Carmon 2012). As will be discussed below, some proposed public policies and a few enacted policies have mandated resuscitation of preterm infants on the premise that they might otherwise be left to die, because parents and physicians meant to conduct an abortion rather than a live delivery when they were born. The linkage of abortion to preterm birth is a way of asserting that abortion is not different from the murder of a newborn child.

Another way that preterm birth plays a role in opposition to abortion is through the observation that women who have abortions are at increased risk for a subsequent preterm birth. One of the initial opposition advocacy responses to the *Roe v. Wade* decision was to lobby municipalities and states to pass laws that required physicians performing abortions to list a set of specific risks when obtaining patient consent for the procedure. This list included a claim that abortions were associated with subsequent miscarriages and subsequent deliveries of preterm or low birth weight infants (Kapp 1982). Within the medical community, one response to these proposed regulations was to review the scientific literature on abortions in order to assess whether such risks were verifiable. It seemed possible that the risks could have been exaggerated in order to discourage women from consenting to the abortion procedure (Cates 1979). Initial studies by the Centers for Disease Control (CDC) suggested that the risks were exaggerated; subsequent pregnancy complications were related more to surgical abortions than to the saline injections used for abortions in early pregnancy (AMA Council on Scientific Affairs 1992).[11]

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[10] For example, the following is posted on an abortion survivor web site, referring to an abortion that took place in 1970: "…My mother decided to have an abortion. At the time, she was pregnant with twins, but nobody knew this, not even her doctor. My tiny brother and I were both there growing in her womb, until that dreadful day. Before the abortion, we were both alive. Moments later, I was alone. It's frightening to think I was almost aborted when my mom had a D&C abortion. Somehow, miraculously, I survived! My twin brother wasn't so lucky. Andrew was aborted and we lost him forever. Several weeks later, my mother was shocked to feel me kicking in her womb. She already had five children and she knew what it felt like when a baby kicked in the womb. She instantly knew that somehow she was still pregnant. She went back to the doctor and told him she was still pregnant…that she had made a big mistake and that she wanted to keep this baby." (http://theabortionsurvivors.com/abortion-survivors-their-stories/sarah-smith/).

[11] In 1983 Dr. Willard Cates, head of the Division of Reproductive Health at CDC which produced the review that found no negative medical effect of abortions, was demoted and transferred to the Division of Sexually Transmitted Diseases at the request of the White House. Allegedly this was because of his perceived pro-choice advocacy and bias (Anonymous 1990).

In 1987 the Reagan Administration, at the urging of pro-life activists, directed Surgeon General Everett Koop to conduct a study of the medical and psychological impact on abortion. To the disappointment of these activists, Koop reported publicly in 1989 that the data were inconclusive on the negative medical impacts of abortion. While the final report was never publicly released, a draft obtained by Congress in 1989 actually reported no evidence of a negative medical impact of abortion (Anonymous 1990).

Perhaps because of this legacy of politicization, or perhaps to avoid providing support for the anti-abortion movement, the 2007 comprehensive Institute of Medicine study on preterm birth included no discussion of the relationship of abortion to subsequent preterm birth, and included no index entry for abortion (Behrman and Butler 2007). Prior first trimester induced abortion is listed as an "immutable risk" in an appendix to the report (Alexander 2007) but is not discussed in the text of the appendix. However, the association between induced abortion and subsequent preterm birth has continued to be researched, particularly in Western Europe (Papiernik 2006). Accumulating evidence suggests that induced abortion does in fact elevate the subsequent likelihood that women will have a preterm delivery (Bhattacharya et al. 2012; Shah and Zao 2009; Swingle et al. 2009; Thorp et al. 2003).

The perception that experts on preterm birth downplay the risks of abortion and abortion's role in elevating preterm birth rates has resulted in efforts by pro-life activists to challenge the integrity and expertise of authorities in the field of high-risk obstetrics. For example, in a summary of recent research on the association between preterm birth and induced abortion, published by the Catholic Family & Human Rights Institute, physician and abortion opponent Byron Calhoun writes:

> The most remarkable evidence at the time are the 127 published peer review articles all documenting an increased risk of preterm birth associated with induced abortion (see appendix A). Yet, the leading medical organizations for women's healthcare, including the American College of Obstetricians and Gynecologists (ACOG) in their on-line Compendium for 2011, refuse to acknowledge the increased associated risk of preterm labor or the substantial body of literature raising this concern……Few seem to acknowledge the link between abortion and preterm birth. Liao et al. (2011) is but one example of reporting bias that pervades the study of abortion and preterm birth. Who are the victims here? The victims are not researchers. Researchers will continue to actively study this topic, whether or not they choose to acknowledge the implications of the data. The victims of this irresponsible journalism are the millions of women, who have not been able to move beyond their abortion(s), suffered a preterm birth, and found very little assistance from the medical community. Continued efforts to deny the significant risk of preterm birth after only a single abortion are dishonest, disingenuous, and disrespectful. Moreover, such efforts have, and will become even less effective as more women who experience preterm birth after an abortion begin to come forward. These women are everywhere and their voices echo in honestly collected and reported data. (Calhoun 2012)

4.1.3 The Impact of Fertility Control Policies on Preterm Births

Following Kingdon's model of the way perceived social problems interact with political dynamics, advocates for more contraception availability and advocates for restrictions on abortion both identify their preferred policies as solutions to the problem of preterm birth. At the same time, because their policy proposals are driven by other social forces such as the changing roles of women in society and patterns of population growth, their proposed solutions may or may not have a direct influence on preterm births. This appears to be the case for policies that increase the availability of contraceptives and legalized abortions: it is difficult to document their association with lower preterm birth rates. In part this is because policies that have officially legalized abortion and have subsidized family planning have not reduced the rates of unintended pregnancies across the board. Between 1994 and 2001, unintended pregnancy rates declined for more affluent and better educated women and for teens, but not for lower income and less educated women (Finer and Henshaw 2006). Between 2001 and 2006, rates of unintended pregnancies increased slightly overall, but declined among teens. The portion of unintended pregnancies resulting in abortion rather than miscarriage or delivery also declined (Finer and Zolna 2011). Legal abortions are not universally available and contraceptives have to be acquired and used effectively in order to prevent pregnancies (Brown and Eisenberg 1995; Santelli et al. 2007). Policies to limit the availability of abortions, such as parental consent policies and standards for abortion clinics, have reduced the availability, use and timing of abortions (Bitler and Zavodny 2001; Blank et al. 1996; Colman and Joyce 2011; Ellertson 1997; Haas-Wilson 1996; Joyce and Kaestner 1996), but have not been shown to directly affect the preterm birth rate (Currie et al. 1996).

However, anti-abortion advocacy has been instrumental in the passage of a set of federal laws and statutory interpretations which impact decisions about the resuscitation of infants born very early with marginal viability. Serious discussion among clinicians and ethicists about the provision of life sustaining treatment to newborns of marginal viability began in the 1970s. Early on, the discussion shifted from debating an absolutist view that all levels of treatment should be provided when a newborn has any possibility of surviving, towards ways to make such decisions that would be in the best interests of the newborn. A "best interests" view recognizes that there are times when the death of a newborn might be preferable to survival with severe disabilities, but what criteria should be used to determine this, how the interests of the newborn can be distinguished from the interests of its parents and society, and who should make these decisions remain areas of debate. While the "best interests" view is widely accepted in clinical medicine and ethics, it stands in contrast to the "sanctity of life" ideology of the pro-life movement, which holds instead that all life is sacred and must be protected, and that fetuses have the equivalent status of any other persons from the moment of conception (Kopelman 2005; Placencia and McCullough 2011; Sayeed 2005).

Beginning in the early 1980s, three federal policies were established which reflect the “sanctity of life” ideology. All were established under circumstances in which the pro-life movement wielded strong political influence.[12] The first policy was an interpretation of the anti-discrimination component of the federal Rehabilitation Act; the interpretation held that withholding medical treatment from severely handicapped newborns constituted a civil rights violation. This policy (the first Baby Doe rule) was struck down by the Supreme Court in 1986 on the grounds that it failed to respect the rights of parents to make decisions that they deemed to be in the best interests of their newborns. However, a similar set of rules had already been passed by Congress in 1984 as amendments to the Child Abuse Prevention and Treatment Act (CAPTA). These defined withholding any life sustaining medical treatment to newborns as child abuse unless that treatment could be considered futile. These rules remain in force.

A third statute, enacted in 2002, states that all acts of Congress or administrative rules or interpretations that refer to persons should be interpreted as applying to any infant born alive at any stage of gestation. Born alive is defined as:

> the complete expulsion or extraction from his or her mother of that member [of the species homo sapien], at any stage of development, who after such expulsion or extraction breathes or has a beating heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, regardless of whether the expulsion or extraction occurs as a result of natural or induced labor, cesarean section or induced abortion. (Sayeed 2005, p. e577)

This law, the Born Alive Infant’s Protection Act (BAIPA) was passed in part to support a Nebraska state law that outlawed partial-birth abortions, a medical procedure used for late term abortions of severely defective fetuses. The law had been overturned by the Nebraska Supreme Court. In 2005, the Secretary of the U.S. Health and Human Services Department issued a statement indicating that the Department would enforce the BAIPA law through the existing federal child abuse laws, and also through the existing laws requiring hospitals to treat critically ill individuals rather than transferring or refusing to treat them. In both cases, physicians and hospitals would be subject to sanctions if they did not provide life-saving treatment to newborn who could be identified as having been “born alive” by the definition in the statute.

The initial Baby Doe rule occasioned a formal statement from the American Academy of Pediatrics opposing the rule and supporting the “best interests” standard for decision making for marginally viable infants. The Academy, along with the American Medical Association, sued the Secretary of Health and Human Services in 1983 to block the rules from implementation (Placencia and McCullough 2011). Formal response was less negative to the interpretations of the child abuse statutes and to the BAIPA law. Both have been interpreted by medical

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[12] The movement gained such influence as a consequence of strategic decisions made in the 1970’s by the Republican Party to endorse anti-abortion policies in order both to gain support among conservative religious voters and to weaken the traditional alignment of Catholic voters with the Democratic party (Gordon 2002; Petchesky 1990).

organizations as still allowing for "best interests" decision making. However, some in the neonatology and ethics community still express concerns about the existence of these statutes. They believe that the statutes are perceived by practicing clinicians as restricting their choices of treatment when infants are born at the cusp of viability, and they worry that the rules impact state judicial rulings in cases that come to trial because parties disagree about the decisions made about these infants (Kopelman 2005; Sayeed 2005).

In sum, preterm births have played a role in contemporary U.S. political conflicts over policies related to fertility regulation. However, it is not clear that fertility policies, including either the increased or the decreased availability of contraception and abortion, have had a major impact on the occurrence of preterm birth. On the other hand, policies concerning newborn resuscitation, enacted with the support of anti-abortion activists because they validate beliefs about the legal status of fetuses as persons, have had an impact on decisions made about preterm infants after they are born. These impacts are discussed further in Chap. 6 of this book.

4.2 Preterm Births and the Politics of Poverty

As discussed in Chap. 2, there is a strong correlation in the U.S. and internationally between maternal poverty and higher rates of preterm birth, low birth weight and infant mortality. Within the medical and public health dimensions, this association raises the challenge of identifying the precise mechanisms that link poverty to the biological processes of fetal growth, timing of delivery and survival. In these science-based paradigms, it is assumed that identifying the way poverty "causes" biological responses will lead to tailored interventions that can alter the relationship and thus improve infant outcomes.

In contrast, within the political dimension, the association between poverty and poor pregnancy outcomes provides an opportunity to use the most sympathetic and broadly supportable cause of "saving babies" to garner public support for social reforms to address broader and more controversial issues. These larger issues include the causes and consequences of poverty and the demand for universal access to health care. However, because the problems of impoverished populations are framed primarily as health-related, and the emphasis in the political arena is placed primarily on pregnant women and infants, the anti-poverty policy solutions are often also constrained to the health arena and to these target populations. Baby-saving has not been able to bear the political burden of ameliorating the full impact of poverty on the U.S. population.

4.2.1 Baby-Saving and the Establishment of Social Welfare Systems

The roots of the political linkage between preterm birth and poverty lie in the dramatic social changes that occurred with industrialization in Europe and North America in the nineteenth century. With industrialization, mechanization of agriculture, changes in the ownership of land and other resources, and the shift from domestic production to the purchase of consumer goods, the majority of individuals in these societies at this time began to make a living through employment, rather than through independent production as small farmers and artisans. As employees, their subsistence was a function of the availability of jobs and the wages these jobs paid. Job availability was a function of where new industries were located, and wages were a function of the availability of a labor force. By necessity, employees moved to places where jobs were available, and the nineteenth century saw large-scale relocation of individuals from rural to urban areas. As enterprises came and went, and wages declined with greater labor availability due to mass immigration, substantial segments of the population saw their resources decline, sometimes below the level where they could afford adequate food and housing. Urban congestion overwhelmed existing sanitation and water supply arrangements and housing stock deteriorated.

Beginning in the mid-nineteenth century, both European and North American nations responded to these social changes by creating both welfare systems, which combined private charity and government organized efforts (Katz 1986), and public health systems which began to regulate the urban infrastructure. One of the major political catalysts for these reforms was the publication of statistics showing that the growing cities were the sites of large numbers of infant deaths, as well as infant and child abandonments, particularly among the poor and ethnic minorities or immigrants. In the prevailing sentiment of the day, these deaths were considered tragic and socially unacceptable. Historian Richard Meckel writes:

> On July 19, 1876, the New York Times sadly editorialized: 'There is no more depressing feature about our American cities than the annual slaughter of little children of which they are the scene'. The editorial was in direct response to a health department bulletin reporting that each day during the preceding week more than a hundred infants under the age of one year had died in the city. But it was not the first time the Times had felt compelled to comment on infant mortality. For almost two decades, it had been lamenting that each summer, with unfailing regularity, an already high urban infant death rate climbed to catastrophic levels. Indeed, by 1876 it had become almost impossible for any observer of the urban scene not to conclude that whatever else American cities happened to be, they were for infants, and especially the infants of the immigrant poor, giant abattoirs in which a large proportion of all those born were destined to be slaughtered before they could celebrate their first birthday. (Meckel 1990, p. 11)

Infant mortality rates came to be seen as measures of livability or even morality for localities. Sara Josephine Baker, the first director of the New York City Bureau of Child Hygiene, wrote in 1908 that "the infant mortality rate is the most sensitive index of municipal housekeeping of a community. It is more than that; it is an index of civic interest, cooperation, consciousness and worth" (Katz 1986).

The public welfare systems that were established to respond to the growing issue of poverty in the U.S., Great Britain and European societies initially focused on removing children from impoverished homes and supporting them in state-run orphanages. In later decades, welfare policy preferences evolved towards support of pension or welfare payments that helped poor mothers maintain housing and food for their families while they continued to seek employment (Katz 1986; Ladd-Taylor 1994). Early public health activists used infant mortality statistics to campaign for improved sanitation systems in urban centers, and in later decades to overcome considerable resistance in the drive to mandate the pasteurization of milk (Hargreaves and Thomas 1993; Meckel 1990).

In the first decades of the twentieth century, infant mortality was redefined as a consequence of inadequate mothering, rather than a problem caused by environmental threats such as poor housing or by poverty in general. Diverse interests were then able to come together in an effort to "save children." Broader economic reforms that might have addressed poverty more globally, for example by mandating higher wages, creating welfare systems for the elderly and unemployed, and subsidizing health services, divided these interest groups, and thus had insufficient political support (Katz 1986; Skocpol 1992). Major public and private campaigns were launched to address the problem of inadequate mothering, and to promote modern childrearing practices. These campaigns, sometimes called "scientific motherhood" campaigns, became a vehicle for promoting the assimilation of immigrants and Black Americans into white middle class culture, while re-framing issues of poverty and social class as issues of aberrant individual behavior, such as not understanding the correct way to feed babies (Litt 2000).

The federal Children's Bureau was established in 1912, an action strongly supported by an increasingly organized sector representing women's interests. Shortly after women gained the right to vote, Congress passed the Sheppard-Towner Act of 1921, notable as the first federal grant-in-aid program.[13] The Act provided federal funds to states to establish educational programs and to operate prenatal and well-child clinics, intended to improve pregnancy outcomes and infant survival.

Political opposition from the organized medical community, concerned that the activities of non-physician government employees would reduce demand for physician care, and opposition by fiscal conservatives concerned about government expenditures, forced the repeal of the Sheppard-Towner Act in 1929. However, many of its provisions for aid to states to provide education and maternal and child health (MCH) services were inserted in Title V of the Social Security Act, which was passed in 1935 as part of a package of social reforms in response to the

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[13] Grant-in-Aid programs are now the most common mechanism in the U.S. for passing federal legislation to promote social welfare programs, which constitutionally are state and local functions. In this mechanism, federal funds are offered to states to conduct social programs, providing these programs meet specified federal guidelines.

Depression (Ladd-Taylor 1994; Skocpol 1992). Interestingly though, while the Sheppard-Towner Act-supported prenatal and well-child services and educational campaigns had been oriented to the general population, the statute establishing Title V required that these services be targeted to "economically depressed areas". The Children's Bureau, which administered the program, allowed local and state medical societies the right to approve or disapprove state plans for use of the funds (Meckel 1990). The history of these public health initiatives has a two-fold legacy. First, issues related to sub-optimal infant survival have been framed politically as being individualized health concerns, and consequently as having primarily individualized, medically oriented solutions. Second, public health campaigns concerning sub-optimal infant survival have been linked in the political arena to programs for the poor (Barker 2003; Ladd-Taylor 1994; Meckel 1990; Rinehart 1987).

4.2.2 Poverty and Infant Mortality in an Affluent Society

Political support for federal programs that actively addressed maternal and infant health problems waned in the 1940s and 1950s, but infant mortality was re-discovered as a problem in the U.S. in the early 1960s. Richard Meckel writes:

> The leveling off of infant mortality rates during the 1950s and early 1960s presented American health analysts with a paradox. In a period when per capita income was rising sharply, when medical science and practice continued to improve, when the medical sophistication of the average American increased significantly, and when there was a mass migration from rural areas with poor health facilities to urban areas with excellent ones, infant mortality should have declined dramatically rather than leveled off. For the liberal analysts who helped shape national health policy during the Kennedy and Johnson administrations, there could be only one answer: a significant proportion of the population had been excluded from the benefits of economic and medical advance. Providing these "other Americans" with access to those benefits thus became a central part of the 1960s federal program to renew the downward trend of infant mortality. (Meckel 1990, p. 228)

One policy response to the higher rates of infant mortality in this era—framed as the problem that some segments of the population were being excluded from the promise of affluence that Americans were expected to be able to enjoy—was direct funding of prenatal, delivery and post-partum care to high-risk women in low income areas. A second was the establishment of the Medicaid program in 1965, providing health insurance for low income pregnant women and infants so that they could have access to the private medical care system. A third policy response was the establishment of Women Infant and Children (WIC) food supplementation program through the federal Department of Agriculture in 1972. Even this third program, which addresses hunger and malnutrition as a likely causal linkage between poverty and poor pregnancy outcomes (Hughes and Simpson 1995), was initially proposed as a health initiative. Physicians in community health clinics wrote prescriptions for nutritional foods, which were available in food pantries located at the health clinics. Currently the WIC program, which enjoys broad political support, provides vouchers to pregnant women and mothers of young infants that are exchanged for a set of pre-specified foods; beneficiaries also receive nutritional counseling and health care referrals (Oliveira et al. 2002).

When the Medicaid program was implemented in 1965, eligibility was linked to eligibility for Aid to Families with Dependent Children (AFDC, popularly known as welfare). These direct cash supplements had their origins in the Mothers' Pensions of the early 1900s, supplemented with federal payments to states as established in Title IV of the 1935 Social Security Act. States had the prerogative to determine income thresholds for qualifying for these welfare benefits, and thus for coverage for medical costs. Enrollment in the Medicaid program expanded in the 1970s, and by 1980 there was pressure to control costs. In response, the Reagan administration encouraged states to restrict AFDC and Medicaid eligibility. Simultaneously, the funding mechanism for Title V, the state maternal and child health grants, shifted in format from grants-in-aid to block grants. This reduced the amount of funds allocated for MCH services, and allowed the states more flexibility to spend their reduced amount of funds on a wider variety of programs.

A broad coalition of public health, maternal and child health, and political advocacy groups such as the Children's Defense Fund, banded together to object to these changes. A slowdown in the decrease in infant mortality rates in 1983 was used as evidence in the political context to claim that the welfare and Medicaid reforms were "being paid for with the lives of nation's babies." These claims were countered in the political arena with alternative interpretations of the data, which suggested that infant mortality rates had probably plateaued, with the remaining deaths being due to demographic and behavioral characteristics of pregnant women, not to cutbacks in payment for medical services or welfare payments. Opponents to the cutbacks then countered by re-framing the infant mortality problem as a problem of high rates of low birth weight infants. Their argument was as follows. By this period, the majority of infant deaths were occurring among low birth weight infants. Rates of low birth weight births were higher among low income and Black infants. The low birth weight birthrate was higher in the U.S. than in other developed countries with stronger welfare systems. Thus, maintaining, if not expanding social welfare programs and Medicaid was necessary in order to save babies' lives by reducing the number of babies born prematurely or at low birth weights in disadvantaged populations (Budiansky 1986; IOM 1985; Meckel 1990).

Ultimately, the objection that low birth weight and infant mortality rates were being misinterpreted to justify continued expansion of government activity failed to stop the drive to expand Medicaid. Between 1986 and 1990, a series of policy reforms de-linked eligibility for Medicaid from eligibility for AFDC, allowing coverage to be provided to low income women who were not poor enough to qualify for welfare in their home states. Since 1990, states have been required to provide Medicaid coverage to pregnant women and children through age 18 with incomes at 133 % of the Federal Poverty Level (FPL). Many states set the Medicaid eligibility threshold for maternity coverage at an even higher level, and in many states Medicaid programs now cover almost half of all pregnancies (Markus et al. 2013).

The threshold for expanding Medicaid under the terms of the Affordable Care Act is 138 % of the FPL.

Analyst Alice Sardell (1991) identifies the political consensus for this Medicaid expansion as part of a continuum that began in the early 1900s when, as discussed above, baby-saving successfully became part of the political agenda while other welfare reforms did not. She describes five reasons why preventing infant mortality and improving infant health emerged as a high consensus issue in the political context. An examination of these issues helps to illuminate the linkage between the cultural construction of preterm birth and the U.S. ideology concerning poverty.

First, she writes, infant mortality and other childhood disabilities are considered to be preventable, and thus problems which are amenable to solutions. This is significant in Kingdon's model of how issues become established on the political agenda; political attention is only sustained for social problems that are believed to be solvable. The authoritative report from the Institute of Medicine on preventing low birth weight deliveries, issued in 1985 at the height of the political activity surrounding the initial Medicaid expansion, identified early, high quality prenatal care as the primary vehicle for delivering interventions to prevent low birth weight births. Access to contraception and risk reduction activities before pregnancy were also identified as potentially successful interventions to prevent low birth weight births (IOM 1985). Thus, it was expected that solutions to the problem of infant mortality would arise, for the most part, from the field of medicine, and would not need to involve major structural reforms of the economic system.[14]

The second reason cited by Sardell for the high consensus around the expansion of government support for services to low income pregnant women was the belief that provision of these services in the present would save larger costs later on. She cites Senator Lawton Chiles of Florida as remarking "It is not often that a person in public life gets to say, 'I know how to save the lives of American children and save taxpayer money at the same time." This economic rationality helped to frame expenditures to reduce infant mortality as investments, rather than aspects of charity.

Sardell's third reason for the political consensus around efforts to reduce infant mortality was the expressed belief that investment in young children is an investment in the future of the American work force. Many historians who have examined U.S. welfare policies note that these policies have been tailored to meet the labor needs of U.S. employers. For example, for many decades agriculture and domestic workers could not qualify for welfare benefits. This allowed their employers to pay extremely low wages, because potential employees had no foreseeable other sources of income. The 1990s era welfare reforms, which required recipients to look for work and to accept government-arranged low paying jobs if necessary, have been analyzed in a similar way (Fraser 1994; Katz 1986; Marchevsky and Theoharis 2000; Morgen and Maskovsky 2003). Reducing infant mortality is not a

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[14] The IOM committee did note that other interventions outside of the medical arena may have promise in reducing low birthweight. The report mentions expanded income support programs and early childhood education for children, which may reduce low birthweight because graduates of such programs are less likely to become pregnant as teenagers (IOM 1985).

contradiction, but a continuation of the use of government subsidies in support of employer interests.

The fourth and fifth reason Sardell cites for the political success of the child health frame are, in her words:

> Because babies and young children, unlike other 'disadvantaged groups,' are viewed as innocents and morally blameless for their condition. In addition, since they are young, their lives can be changed and their problems are more 'fixable' that those of adults. (Sardell 1991, p. 31)

These rationales reflect the way poverty has long been framed in U.S. society. Poverty is considered to be a consequence either of negative characteristics of individuals or of particular barriers that individuals face in achieving the fundamental American expectation that everyone will be prosperous (Katz 1986; Meckel 1990; O'Connor 2001). Ideologically, there is a concern that supporting impoverished individuals directly is useless or dangerous, either because it discourages them from changing their behaviors so they can help themselves out of poverty or because it insulates them from the competitive "survival of the fittest" pressure that is needed to maintain the prosperity of the overall society (Murray 1985; Sklansky 1999). Impoverished individuals are dependent on others, and dependency is highly stigmatized, especially in a country founded by religious sects that left Europe because they did not want to live in hierarchical dependent relationships within the established society (Fraser and Gordon 1994). However, welfare policies directed towards improving the health of poor children avoid these ideological pitfalls because children are not considered morally culpable for their poverty. Since poverty is conceptualized in U.S. society as a negative individual trait, intergenerational poverty is understood as a consequence of parents passing the trait of poverty on to their children. Interrupting the cycle of poverty by providing benefits to infants and children is thus potentially a policy solution for the entire issue of impoverished populations in the U.S.

4.2.3 Infant Health and Universal Health Insurance

As noted above, the final pregnancy expansion of Medicaid in April 1990 required states to cover all women with incomes up to 133 % of the Federal poverty level for maternity care services through 60 days post-delivery (Hill 1992). Shortly thereafter, advocates began pressing Congress for an additional expansion of publicly funded health insurance to cover uninsured children whose family incomes were too high to qualify for Medicaid benefits. The State Children's Health Insurance Program (CHIP), enacted in 1997 under a Democratic president with a majority Republican Congress, provided federally funded grants to states to either expand their Medicaid program to cover more children, or to sponsor a separate insurance program open to low income children. States had flexibility to define the eligibility criteria and the structure of the programs.

The CHIP programs were immediately politically popular, and were successful in reducing the number of uninsured children (Ryan 2003). In the early 2000s, a coalition of Republican and Democratic members of Congress began to craft legislation designed to amend the statute to include pregnant women. The amendment was framed as providing children who would be covered by CHIP programs upon birth, the healthiest start in life, by covering prenatal care for their mothers. Maternal coverage would be structured, as in the Medicaid program, to include a 60 day postpartum period. Before the legislation was fully drafted, however, the Bush administration announced that the Department of Health and Human Services would pre-empt Congressional action by issuing rules deeming fetuses to be children for the purposes of CHIP coverage, thus allowing states to cover prenatal care through the federally financed CHIP program.

This action by the Administration was widely seen as an effort to establish a legal basis for eventually prohibiting abortions, on the basis that fetuses are not different from children already born. The CHIP reform was promoted in the political context of a set of pro-life activities, such as the Baby Doe legislation discussed above, that occurred early in the Bush Administration. Women's health advocates expressed concern that expanding prenatal care through CHIP would mean that care needed by women during pregnancy or immediately after delivery would not be covered, because it would benefit mothers, but not fetuses.[15] On the other hand, as the Administration pointed out, this mode of CHIP expansion would allow states to cover prenatal care costs for undocumented immigrants, because their fetuses, if born in the United States, would be U.S. citizens. Medicaid does not cover prenatal care for non-citizens (Dailard 2002). As of 2009, 15 states had employed the "unborn child" option to cover pregnant women under CHIP programs. Another 6 states had waivers approved to include comprehensive maternity benefits for women who were not U.S. citizens, but whose children would qualify for CHIP upon delivery (Parisi and Klein 2009).

The expansion of CHIP to include prenatal care illustrates again the capacity of the "saving babies" approach to support the passage of policies that would otherwise have powerful political opposition. In the case of the unborn child CHIP expansion, the approach even unites reproductive health supporters, immigrant rights supporters and anti-abortion activists.[16] At the same time, it reinforces the patriarchal orientation discussed in Chap. 3, which emphasizes the reproductive

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[15] The ACOG Committee on Ethics notes that CHIP expansion prenatal care covers anesthesia during labor because mothers' pain may affect the newborn. Coverage is not required to include the costs for treatment of post-partum depression, for maternal injuries that do not affect the fetus, or for molar pregnancies (abnormal embryo implantations that do not mature into fetuses) (ACOG 2005).

[16] For example, in April 2012 the Nebraska legislature over-rode the governor's veto of a proposed expansion of the state's SCHIP program to cover unborn children. The governor stated he thought it was unfair to use state funds to provide health care to undocumented immigrants, but the legislature viewed the expansion as a pro-life vote. Nebraska Right to Life, Nebraska Catholic Conference, Planned Parenthood and anti-poverty activist group Nebraska Appleseed all lobbied in support of the expansion (Hoy 2012).

role of women, while diminishing the distinction between a developing fetus and a child.

One way to think about the establishment of Medicaid, the Medicaid expansions of the 1980s and the CHIP amendments in the early 2000s is that they are a continuation of efforts to address the negative impacts of poverty, without actually altering the economic structure of society. A second way to look at these policies is as aspects of incremental reforms towards establishing universal health insurance as a social benefit in the United States (Gruber 1997). By 2009–2010, when the much broader Affordable Care Act was being debated in Congress, the relatively high U. S. infant mortality rate came to be interpreted as an indication of the failure of the U.S. health care system. As Murray and Frenk (2010) framed it in the **New England Journal of Medicine**:

> It is hard to ignore that in 2006, the United States was number 1 in terms of health care spending per capita, but ranked 39th for infant mortality, 43rd for adult female mortality, 42nd for adult male mortality and 36th for life expectancy. These facts have fueled a question now being discussed in academic circles, as well as by government and the public. Why do we spend so much and get so little? (Murray and Frenk 2010, p. 98, reprinted with permission from Massachusetts Medical Society)

At this point, most experienced health care lobbyists understood that the infant mortality rate in the U.S. is not really driven by factors that are easily affected by changing the health care system (Daniels and Roberts 2008), a point quickly made by critics of health care reform whenever this argument was raised (Chapman 2009; Frech et al. 2012). Still the linkage between poor pregnancy outcomes and flaws in the medical system resonated with the public and with journalists, as the **New York Times**' coverage of the release of the November 2009 report on international infant mortality rankings from the National Center for Health Statistics (MacDorman and Mathews 2009) illustrates:

> Dr. Alan R. Fleischman, medical director for the March of Dimes, said the new report was "an indictment of the U.S. health care system" and the poor job it had done in taking care of women and children. The report, Dr. Fleischman added, "puts together two very important issues, both of which we knew about but hadn't linked tightly."
>
> Infant mortality is widely used as a way to gauge the health of a nation, and the relatively high rates in the United States have long dismayed health officials. Most European countries – as well as Australia, Canada, Hong Kong, Israel, Japan, New Zealand and Singapore – have lower rates of infant death than the United States.
>
> Premature infants in the United States are more likely to survive than those born elsewhere. Yet they are still more likely to die than full-term babies, and the sheer numbers born prematurely in the United States – more than 540,000 per year – drive up infant mortality.
>
> The high levels of prematurity in the United States have various causes.

> Dr. Fleischman said the smallest, earliest and most fragile babies were often born to poor and minority women who lacked health care and social support. The highest rates of infant mortality occur in non-Hispanic black, American Indian, Alaska Native and Puerto Rican women. (Grady 2009, reprinted with permission from The New York Times)

4.2.4 The Impact of Poverty-Related Policies on Preterm Births

Framing the health and survival of infants born into poverty as a social problem that demands a policy solution has successfully galvanized political decision makers into the implementation of a range of public programs. The scope of these programs has been limited by the political infeasibility of making massive changes to the U.S. economic system in a way that might eliminate poverty over generations, and by the logic of focusing on infant health, which leads to policies that support health care-oriented action. Hughes and Simpson (1995) identify two primary policy strategies that have been implemented to address the health of low income newborns: policies that improve access to medical care, and policies that mitigate the effect of economic disadvantage during a woman's pregnancy.

The impact on pregnancy outcomes of the establishment and expansion of Medicaid, as a means for increasing access to health care, has been well studied, and findings are very consistent across studies. The early establishment of Medicaid, and the expansion of eligibility to very low income women by expanding the eligibility criteria for welfare, was associated with reduced infant mortality and reduced incidence of low birth weight births (Currie and Gruber 1996). The later expansions to women with incomes just above the poverty level had a positive effect on prenatal care use, but minimal impact on actual birth outcomes (Currie and Gruber 1996; Gruber 1997; Hughes and Simpson 1995; Piper et al. 1990, 1994). The working explanation for the difference in impact between the initial establishment of Medicaid and the broader income-based expansions is that Medicaid initially was targeted to a more vulnerable and needy group, who benefited the most through receiving Medicaid coverage. Among the women affected by the broader income-based expansions, many did not take advantage of Medicaid coverage because of stigma attached to participating in the program. This low participation rate was thought to weaken the expected relationship between program expansion and improved population birth outcomes (Currie and Gruber 1996).

Early experiments with direct income supplementation (that is, welfare-type payments) to low income pregnant women were also found to be associated with increases in birth weights of infants (Kehrer and Wolin 1979). A careful study that took into account the differences between low income welfare recipients and those who did not receive welfare found that welfare benefits were associated with higher birth weights for infants born to low income White women (Currie and Cole 1993). A later study, also by economist Janet Currie, found that welfare expansions were associated with reduced fetal deaths (but not with changes in birth weight), a finding that the authors suggest is due to easier access to Medicaid coverage with welfare expansions (Currie and Grogger 2002). Two more studies examined the impact of the earned income tax credit, a component of the 1990s-era welfare reforms that increased incomes for low-income working families by reducing their tax liability. Strully et al. (2010) found that the program was associated with increases in birth weights for newborns, and Hoynes et al. (2012) found that the program reduced the incidence of low birth weight births and increased average birth weights. Leonard and Mas (2008) found that the phasing in of time limits on AFDC eligibility, another component of the welfare reform of the 1990s, was associated with increases in infant mortality. Thus, the evidence suggests that direct income supplementation to families can improve birth outcomes for pregnant women, while reductions in welfare benefits can have a negative effect.

In-kind benefits programs that provide food assistance to low income families have also been associated with improvements in infant health. The phasing in of the food stamp program[17] in the 1960s and 1970s was associated with reductions in low birth weight births and increases in birth weights for newborns in participating families (Almond et al. 2011). Early studies of the WIC program found higher birth weights among the newborns of program participants (Avruch and Cackley 1995; Devaney et al. 1992). Similar findings have been documented when statistical approaches that take into account which women enroll in WIC are used in the evaluation (Kowaleski-Jones and Duncan 2002). In general, studies of the impact of Medicaid, income supplementation and food supplementation programs have found associations between use of these programs, modest increases in birth weights and improvements in infant mortality.

Do these programs that address the effects of poverty reduce the likelihood of preterm births as well as lowering the incidence of low birth weight births? Preterm birth rates are often not studied directly in policy evaluations, either because the data on gestational age as reported in large databases such as vital records are not clinically confirmed, and thus some analysts do not consider them to be reliable, or because birth weight is considered a more comprehensive measure of birth outcomes. However, it is possible that these social programs really do impact birth weight and not the preterm birth rate. They may lower maternal stress and improve nutrition, which could reduce the incidence of growth restriction during development, without altering the physiological processes that trigger early labor. As discussed in Chap. 1, however, growth restriction is increasingly interpreted as an indication for early interventional delivery. If these income supplementation programs do reduce the prevalence of growth restriction during pregnancy, they would also have the effect of reducing the occurrence of these types of preterm birth.

In sum, numerous scholars of social welfare programs in the U.S. note that the reforms that have garnered the most political support, dating back to the

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[17] The food stamp program provides coupons to low income participants which can be exchanged for food at grocery stores.

mid-nineteenth century, are those that claimed to be able to save the lives and improve the health of newborns. This framing has restricted the scope of these reforms, and the U.S. has a weaker and less universal set of social welfare policies than most other developed nations. The reforms that have been put in place, including income support, food supplementation and health insurance coverage, have had a positive impact on the health of newborns in low income families. The generosity and consistency of these social welfare programs vary markedly over time, with changes in the policy agenda and the resources available at the federal and state government levels.

4.3 Preterm Births and the Politics of Race

The legacy of slavery in the U.S., which began in 1605 and persisted until 1866, continues to affect the cultural understandings of the meaning of race and the pattern of distribution of power and wealth in this nation. These cultural interpretations and established resource distribution patterns leave many Black Americans exposed to stressful experiences of racism, and isolated in specific neighborhoods, with minimal access to employment, good quality education, advantageous social networks or political influence over laws and government policies that influence their well-being. As discussed in Chap. 2, these factors, as they unfold over the life course, have a negative impact on the birth outcomes of Black women: preterm birth rates among Black women are one and a half times the rates for the rest of the U.S. population.

This section of this chapter examines how racial disparities in preterm birth rates and in infant mortality rates have played out within the politics of fertility control and the politics of poverty in the U.S. In addition, this section explores how racial disparities in preterm birth rates have become part of efforts to place the overall situation of Black Americans directly on the political agenda. As in the case of the baby-saving movement discussed above, expressing the impact of racial discrimination in terms of infant lives damaged or lost has served as a powerful way to frame the issue and gain momentum for social change. At the same time, shifting the discussion of racial inequities towards health and childhood issues has limited the nature of the policies that could be adopted as solutions to broader racial inequity issues.

4.3.1 Race and Fertility Control

As discussed in the Preface to this book and in Chap. 2, the dominant model of "race" in Western culture is that observable differences in human appearances, such as those that differentiate "Blacks" from "Whites" represent biological differences. Bhopal (1998) cites the ancient Greek physician Hippocrates as believing that human races differ because their ancestors originated in different geographical locations with differing conditions, particularly climate. Hippocrates viewed some races as superior to others, a belief that was also strongly held in nineteenth century Europe and the United States, serving as a rationale for a range of public policies including slavery, immigration restriction and fertility control. The eugenics movement had its roots in British and American philosophies of this era. Subscribers held that negative traits are inherited and that populations would be improved if individuals with undesirable characteristics did not reproduce. Immigrants from countries outside of Western Europe, Black Americans, impoverished populations and individuals with physical and mental disabilities were all targets for restrictions on reproduction.

The eugenics movement was most influential in the United States between 1910 and the mid-1940s. During this era, foundations sponsored population-based genetics research, federal immigration restrictions were put in place for selected countries of origin, and many states passed laws allowing compulsory sterilization for the "mentally unfit" (Kevles 1995; Ladd-Taylor 1997; Washington 2006, Chap. 8). Historian Molly Ladd-Taylor (1997) contrasts eugenics with the ideology of the baby-saving movement, which idealized motherhood and viewed the welfare state as the entity that could protect mothers, thereby improving the health of their newborns. She writes:

> Public funding for child health care thus challenged the more orthodox eugenicist view that saw infant death as part of a natural order which allowed the fittest to survive – and considered high death rates among blacks and immigrants as evidence of their inferiority. In the words of Paul Popenoe and Roswell Johnson, authors of the popular textbook Applied Eugenics, baby-saving was not a "fundamental piece of race betterment" but a means of "race impairment" instead. Conceding that infant health services did keep babies alive, Popenoe and Johnson asserted that the gain was "temporary and illusory"; babies who lived to adulthood as a result of welfare work would undoubtedly transmit their weak constitutions to their offspring. (Ladd-Taylor 1997, reprinted with permission from Oxford University Press)

Thus, the eugenics framework provided the apparently scientific modern language of genetics to rationalize existing beliefs of racial physiological inferiority. In this context, disparities in the prematurity and infant mortality rates for Black and White newborns were explained as biological differences related to the relative inferiority of the Black population. Negative characteristics of Black mothers, particularly sexual behaviors, were also associated with poor birth outcomes (Roberts 1997).

Although the many state compulsory sterilization laws enforced in this era targeted institutionalized men and women and were intended primarily to reduce welfare costs, several reviews indicate that a disproportionate number of individuals who were sterilized were Black or other ethnic minorities (Ladd-Taylor 1997; Roberts 1997; Washington 2006). In addition, beginning in 1939 and led by the state of North Carolina, first state and then federal funds began to be used to support family planning activities, particularly for low income and Black women. Among the reproduction control methods made available in these settings was female surgical sterilization. There is a very mixed record concerning how many of these procedures were requested by and consented to by the recipients, how many were performed under pressure by welfare authorities, and how many were performed without consent (Schoen 1997, 2005; Washington 2006).[18]

Also in this era, pioneering birth control advocate Margaret Sanger forged an alliance with the eugenics movement to gain public support for increasing the availability of birth control. Biographers disagree as to whether this was simply a strategic necessity for the movement to expand access to contraceptives, or if in fact Sanger endorsed the notion of selective control of reproduction for targeted populations (Baker 2011; Franks 2005). In 1939, Sanger's organization, the American Birth Control League, merged with the Clinical Research Bureau to form the Birth Control Federation of America, later re-named Planned Parenthood. The same year, the new organization launched an effort termed "The Negro Project" to make family planning clinics staffed by Black physicians and nurses available in selected Black communities, including Harlem in New York City and Tuskegee in rural Alabama. Prominent Black leaders of the time supported these activities.[19]

Through the early 1930s, eugenics organizations in the U.S. shared warm relationships with eugenicists in Germany, but the genocidal policies of the Nazi era cast a pall over the movement in the U.S. Carnegie Foundation funding for eugenics research was withdrawn in 1939 and overt efforts to control the racial composition of the U.S. population fell out of favor after World War II. Eugenics supporters merged quietly into the international family planning movement (Gordon 2002). By the 1960s, Margaret Sanger's Negro Project and publicly supported birth control activities joined the list of civil rights grievances, with some activists contending that they met the definition of genocide as specified in the 1948 U.N. charter. Ethicist Harriet Washington points out, however, that many Black women appreciated having the availability of birth control methods, even though they often distrusted the intention behind the provision of family planning services in Black communities. She comments:

> Considering these social complexities, is the term genocide an accurate description of the birth control initiatives directed at African Americans? The proliferation of birth control clinics that were clearly aimed at an African American population falls neatly within the U.N. definitions – they were intended to selectively reduce births within the group. Also, these

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[18] Civil Rights leader Fannie Lou Hamer was sterilized without her consent in 1961 at the age of 44 during a medical procedure; she credited her rage about this experience as one force that propelled her into national leadership in the Civil Rights movement (Washington 2006).

[19] These early Planned Parenthood activities of expanding access to birth control in Black communities is now framed by anti-abortion as a racist activity, and is used to galvanize support for campaigns to eliminate funding for the organization.

> clinics were numerous and well- funded at a time when health advocates failed to address more pressing African American health issues, such as abysmal nutrition, poor control of infectious disease, high infant mortality, low life expectancy, poor quality health care, scare mental health care and even a lack of access to hospitals and physicians. This medical myopia cripples any argument that birth control clinics were erected with the health of African Americans in mind. But although the proliferation of birth control clinics was unethical, the general rise of reproductive clinics in black neighborhoods did not constitute genocide because, whatever the intent of the whites who introduced them, such measures were widely embraced by black women. They welcomed contraceptive choice, however warily they eyed those who offered it. (Washington 2006, pp. 200–201, reprinted with permission from Penguin Random House)

With the beginning of the Civil Rights era in the 1950s, the framing of high preterm or infant mortality rates among Black newborns as a consequence of racial biological inferiority lost salience as a vehicle for garnering political support. Instead, high preterm birth rates in the Black population came to be viewed first as evidence of the need to address poverty issues, and later as evidence of the need to address racism in society. Discussions around the linkage between race, biology, and negative population characteristics such as lower intelligence have not disappeared (Fryer and Levitt 2013; Hernstein and Murray 1994), and there is current interest in identifying a “preterm birth gene” that would offer an inherent biological explanation for racial disparities in preterm birth rates (David and Collins 2007). However, the biologically based arguments do not seem to have broad enough appeal now to justify policy interventions such as the targeted population control activities that were common in the early to mid-twentieth century.

4.3.2 Racial Disparities and Poverty

High rates of infant mortality have long been a concern within Black communities. Needless to say, explanations of racial disparities within these communities are not premised on a belief in racial biological inferiority. Historically in these contexts, racial disparities in infant mortality have been seen as a function of high rates of poverty and poor living conditions, particularly among the poorest segments of the Black population (DuBois 1902). At the turn of the twentieth century in several cities with large Black populations, including Atlanta, Philadelphia and Chicago, middle class Black women’s organizations conducted health education and hygiene campaigns designed to improve child survival and health. One of the motivations for these campaigns was that White Americans did not distinguish between poor and non-poor Black Americans, so that improving conditions among the poorest segments of Black communities would have a positive impact on the public image of the entire community (Hargreaves and Thomas 1993; Smith 1995).

In 1915, building on the work of these women’s organizations, Booker T. Washington, president of Tuskegee University, launched the National Health Improvement Week movement, and later called the National Negro Health Week (NNHW). The movement called for Black communities to set aside a week in April of every year to promote sanitation, healthy behaviors, health education and use of clinical services within the community. From early on, leaders saw the movement as having the potential to unite Black and White people around the cause of improving health within the Black population. Leaders argued that the health of the White population would benefit directly from health improvements in the Black population, because “germs know no boundaries.” They also argued that economic productivity for the overall economy, and particularly the economy of Southern states, would improve with reductions in disease, disability and preventable deaths in the Black population (Brown 1937; Smith 1995). Improved health was also seen as the basis for improved economic and educational progress for Black individuals, and this was seen in turn as a key to increasing their acceptance into mainstream American society (Quinn and Thomas 1996). Finally, poor health indicators in the Black community became an argument against residential segregation, because segregated communities had worse infrastructure and sanitary conditions that contributed to poor health (Brown 1937).

National Negro Health Week had the endorsement of local public health officials from early on. In 1921, then Tuskegee Institute president Robert Moton requested material support from the U.S. Public Health Service (USPHS), and the USPHS began publishing material and otherwise assisting in the planning activities for the movement. In the New Deal era, the federal government established the Office of Negro Health Work, and the activities of National Negro Health Week were absorbed into a year round effort called the National Negro Health Movement (Quinn 2001; Smith 1995). The same era saw the authorization of a set of maternal and child health programs through the Children’s Bureau. This federal agency compiled statistics on racial disparities in infant mortality, infant health and maternal mortality, sponsored advanced training for health professionals serving Black communities, such as midwives, and attempted to direct federal resources into services to improve health (Lenroot 1937; Tandy 1937). All of these federal activities built on the efforts of existing public health activities within Black communities, and all generally articulated the view that poverty and associated environmental conditions were the primary cause of poor health among Black Americans. These conditions could be ameliorated and health status improved once environmental conditions could be altered and access to medical care could be expanded. As suggested above, this view contrasted with the eugenics-related view that biological inferiority of Black Americans was the cause of poor health, including infant health, in the population.

The Office of Negro Health Work was dissolved in 1950, as the views of Black leaders and the federal government shifted towards integration and away from the maintenance of separate institutional structures that addressed the needs of the Black population (Smith 1995). Meanwhile, the understanding of poverty in general was shifting towards a paradigm which viewed impoverished individuals as living in a so-called “culture of poverty” which perpetuated over generations because of dysfunctional family structures and poor behavioral choices. The fact that many poor people in the U.S. were also Black helped to reinforce the view that poverty was a characteristic of people who were not like most (White) Americans. It was thought that those Black Americans who were not poor were those whose family structures and lifestyles were more like middle class White people. This conflation of race and socioeconomic status was discussed in Chap. 2 of this book, while the stigmatizing of poverty as a negative individual trait was discussed above. Racism was seen in this paradigm as a set of attitudes which, when reduced, would open the way towards lifestyle change in the Black community. Lifestyle change in the Black community would then lead to racial equality and reductions in poverty. In the "culture of poverty" view, the problem was not considered to be a set of structural divides across race and class in the U.S., but a vicious cycle that kept poor people (who often happened to be Black people) isolated, maladjusted and politically passive. The solutions that were called for were not ones that required major political or economic restructuring, but ones that altered the attitudes and behaviors of poor people so that they could enter the cultural mainstream of the affluent society (O'Connor 2001).

In the same historical period that the culture of poverty paradigm was being adopted to explain poverty without challenging existing economic and political arrangements, public concern began to grow about apparent increases in the number or rate of teen pregnancies. Furstenburg (2007) and Luker (1997) among others argue persuasively that there actually was not a crisis around an increase in teen pregnancies. Rather, the U.S. has always had a relatively young age-specific fertility rate relative to Western European countries. What happened in the 1950s and 1960s was that fewer of the young women who became pregnant outside of marriage chose to marry before giving birth. Black teens were among the first to make this choice, which occurs primarily because changing social conditions mean that marriage is not economically advantageous for single mothers. Eventually women of all ages, backgrounds and economic circumstances began to have children outside of marriage. Research also suggests that unfavorable life outcomes for low income teen mothers occur because they are poor, and not because of teen pregnancy itself (Edin and Kefalas 2005; Furstenburg 2007). Still, high non-marital birth rates among Black teens fit so neatly into the ideological construct that attributed racial disparities in health to poverty, and attributed poverty to the racial composition (and consequently the lifestyles) of low income populations, that it was very difficult to dislodge.

The rationale that equated poverty to race and to family structure waned briefly in the 1960s, in response to objections around the framing of family structure patterns and other characteristics of the Black population in negative terms, and in response to race riots in major American cities. Policy reform shifted towards improving welfare payments and modifying welfare rules, expanding health care coverage, and increasing jobs and education programs. It was hoped these might actually shift social and economic circumstances for low income populations (Katz 1986). But backlash towards these government allocations, beginning in the 1970s and continuing through the welfare reforms of the 1990s resulted in the resurgence of the ideological paradigm that held that the problem of poverty in the U.S. was located in a Black (or sometimes also Latino) "underclass," which was characterized by absent fathers, teen mothers, drug use and urban decay. Historians Alejandra Marchevsky and Jeanne Theoharis write:

> Tapping into the white conservatism fomented by Nixon's "Silent Majority" campaign, Reagan's war on welfare flourished through a strategy of racial division and homilies about hard work and family values. The president and his administration accused the "liberal" programs of the 1960s, and their black and Latina clients, of undermining the American tradition of individualism and self-reliance. AFDC s shortcomings went beyond its fiscal cost to honest, hard-working (read "white") American taxpayers. In his 1986 State of the Union address, Reagan openly blamed the AFDC system for propagating a "welfare culture" of "female and child poverty, child abandonment, horrible crimes, and deteriorating schools." Drawing on a centuries-old culturalist discourse on poverty, Reagan targeted the "welfare state" and its undeserving clientele as the primary cause for America's social and economic problems. (Marchevsky and Theoharis 2000, p. 240)

As discussed in Chap. 3, a major theme in the cultural interpretation of preterm births and other poor birth outcomes in the U.S. is that the behavior of mothers is to blame. The "crack baby epidemic" of the 1980s and 1990s played on this theme by identifying poor birth outcomes among pregnant Black women as caused by use of the particular form of cocaine that was more common in inner city settings. Observers note that the "crack baby epidemic" was publicized first in the popular press and soon entered the political agenda at the federal and state levels, both as a way to justify reductions in social welfare spending and a way to empower prosecutors to arrest women for drug dealing if they used drugs while pregnant (Gomez 1997). Sociologists Sheigla Murphy and Marsha Rosenbaum summarize this era as follows:

> Beginning in 1988, a new social problem, crack, captivated the nation's attention. The image of poor inner city African Americans, whose mothering instincts had been destroyed by crack, was highly publicized and widely accepted. Numerous media stories reported that the coming generation would comprise untold numbers of permanently impaired crack babies. Journalists predicted that these impaired infants would topple the health care delivery and educational systems due to their expensive and lifelong problems….In 1991, findings began to emerge contradicting previous predictions about pregnant crack users who were creating a "bio-underclass," or generation of permanently impaired children. It now appeared that the relationship between maternal crack smoking and fetal morbidity was far from clear. Poverty and lack of prenatal care were, in all probability, more significant contributing factors for the symptoms attributed to maternal crack smoking. Other important work was done on crack-exposed children indicating that, with proper care and parenting, by school age they developed on par with their unexposed peers. During the same time, there was no political move to jail tobacco-smoking pregnant women, force them to go to treatment, or take away their children. Tobacco smoking was viewed as a habit that pregnant women should try to avoid. By contrast, crack-smoking pregnant women and mothers were jailed or sentenced to treatment, or they lost custody of their children…There are ideological explanations for why these infants continued to be labeled as "crack babies" rather than, in light of scientific findings, "poverty babies." In an era of fiscal retrenchment, the notion of poverty babies might engender public sympathy and interfere with the conservative drive to demolish social welfare programs. (Murphy and Rosenbaum 1999, pp. 140–141)

The "crack baby" scare has been extensively examined by sociologists because it so clearly displays the overlap of ideologies around motherhood, poverty, race, drug use, abortion and fetal rights (Daniels 1997; Flavin 2009; Gomez 1997; Murphy and Rosenbaum 1999; Pollitt 1998; Springer 2010). Yet the counter-dialogue, articulated above, re-iterating the idea that racial disparities in birth outcomes are caused by poverty, even if the mechanism is not irresponsible maternal behavior, has two important political limitations as well. First, as discussed in Chap. 2, it is not well supported by population-based data, which show that even Black women who are not impoverished tend to have higher rates of preterm and low birth weight infants than White women. Second, the poverty paradigm is not as supportive of a broader civil rights agenda as an alternative paradigm, which is that Black–White disparities in birth outcomes illustrate the dramatic negative consequences of continuing racial discrimination.

4.3.3 Racial Disparities and Civil Rights

As the mainstream political establishment was shifting from biology to poverty as the explanation for poorer pregnancy and other health outcomes among Black Americans, the Black community was moving from poverty to the public articulation of a different explanation for disadvantage among its members: racial discrimination and its consequences. The story of Juliette Derricote, the Dean of Women at (historically Black) Fisk College in Nashville, who died in 1931 after being refused treatment at a hospital in Georgia following a traffic accident, came to embody the belief that racial discrimination in medical care facilities is a fundamental explanation for health problems among Black Americans. In the early 1960s, following the precedent set by the Supreme Court's public school desegregation decision in *Brown v. the Topeka Board of Education*, a series of suits were filed challenging the practices of racial discrimination in both hospital patient admissions and in the granting of staff privileges to Black health professionals. In 1963, overt racial segregation was ruled illegal for hospitals receiving federal Hill-Burton funds, and in 1964 it was ruled illegal for all non-profit hospitals. In 1964 Congress passed the Civil Rights Act which included, in Title VI, a prohibition against federal funds being dispersed to segregated institutions, including hospitals. This statute became more enforceable with the establishment of the Medicare program in 1965; the federal government operated a vigorous inspection program to certify that Medicare-participating hospitals were desegregated (Gamble and Stone 2006; Smith 2005).

Twenty-one years later, the same mechanism—threat of withdrawal of Medicare funds—was included in the 1986 Emergency Medical Treatment and Active Labor Act (EMTALA, or anti-dumping legislation) to enforce a prohibition against hospitals' refusals to treat patients needing acute care, including refusals to accept women in active labor for deliveries. One of the widely cited lawsuits stimulating the passage of EMTALA was the story of a Black woman in Mississippi who was refused care at a local hospital, one that received federal support from the Hill-Burton program, while in active labor:

> On March 21, 1974, Hattie Mae Campbell gave birth to her third child in a parking lot outside the Marshall County Hospital. When Ms. Campbell unexpectedly went into labor early that morning, she and her sister asked a neighbor to take them to the nearest hospital. Upon arriving at the emergency room, a nurse informed Ms. Campbell that she should travel some thirty miles to a hospital in Oxford Mississippi, where she had received prenatal care, and deliver the baby there. An emergency room doctor who never examined Ms. Campbell agreed with the nurse's directive. Ms. Campbell left the emergency room and proceeded to the parking lot, where she gave birth to her son in the front seat of her neighbor's car. When Ms. Campbell's sister returned to the emergency room and asked the nurse to admit Ms. Campbell and her newborn son, the nurse refused. The doctor was never notified of the birth, and Ms. Campbell and her son were not provided any postnatal care. (Schaffner 2005, pp. 1021–1022)[20]

Although EMTALA was intended primarily to prevent hospitals from shifting uninsured patients needing immediate care to other providers, it was also considered a policy lever to be used to enforce civil rights and to reduce racial disparities in health status (Chin et al. 2007; Schaffner 2005).

The passage of the 1964 Civil Rights Act helped to establish the principle that any observed racial disparity in health or life opportunities is an indicator of the presence of racial discrimination in some form, and that a fundamental aspiration in the United States is the elimination of such discrimination. Gamble and Stone (2006) term this the civil rights approach to racial disparities in health care, and identify a pair of government reports, one commissioned by the Office of Civil Rights in the Department of Health and Human Services in 1981 (Stevens 1981) and one by the U.S. Commission on Civil Rights in 1999 (U.S. Commission on Civil Rights 1999) which articulated this view. The same view is apparent in introductory statements by President Reagan's Secretary of Health and Human Services, Margaret Heckler, to a volume she commissioned in 1985 examining racial disparities in health status:

> In January 1984 – ten months after becoming Secretary of Health and Human Services – I sent Health, United States, 1983 to the Congress. It was the annual report card on the health status of the American people. That report – like its predecessors – documented significant progress: Americans were living longer, infant mortality had continued to decline – the overall American health picture showed almost uniform improvement. But, and that "but" signaled a sad and significant fact; there was a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans as compared with our nation's population as a whole. That disparity has existed ever since accurate federal record keeping began – more than a generation ago. And although our health charts do itemize steady gains in the health status of minority Americans, the stubborn disparity remained – an affront both to our ideals and to the ongoing genius of American medicine. I felt – passionately – that it was time to decipher the message inherent in that disparity. (Malone 1985, p. x, emphasis in original)

Continuing this aspirational theme, one goal of Healthy People 2000, the continuation of the Public Health Service and Department of Health and Human

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[20] This case was also cited in the Institute of Medicine report on racial disparities in health care, commissioned by the Office of Civil Rights, Department of Health and Human Services in 1981 (Stevens 1981).

Services decennial articulation of national health goals which began in 1979, was to reduce racial and ethnic disparities in health among Americans. A goal of Healthy People 2010 was to eliminate health disparities, while a goal of Healthy People 2020 is to achieve health equity, eliminate disparities, and improve the health of all groups (see www.healthypeople.gov). Examining racial disparities in health status through a civil rights paradigm leads to the suggestion that the root of such disparities is racial discrimination in the provision of health care. This conclusion is extremely challenging for the medical profession because it implies a violation of the established professional values of responding compassionately and dispassionately to all patients according to their needs (Bhopal 1998).

Research on racial disparities in health status, including racial disparities in birth outcomes such as the preterm birth rate, expanded rapidly beginning in the 1980s. At first there was concern about the negative political consequences of data analyses which disentangled race from poverty as causes of health problems. Pediatrician Paul Wise warned that such research might re-invigorate the discredited argument that health disparities between Black and White people are caused by biological differences (Wise 1993). Epidemiologist Arline Geronimus faced withering criticism, professional isolation and even death threats when she presented work showing that, while pregnancy outcomes are worse for White teenagers than for White women in their 20s, they are actually better for Black teenagers than for Black women in their 20s. As discussed in Chap. 2, this was related to the notably worse outcomes for older Black women compared to older white women, but her critique was interpreted as downplaying concerns about pregnancy among Black teenagers (Blitstein 2009; Geronimus 1992; Geronimus and Korenman 1992).

Chapter 2 of this book described the life-course perspective, which frames racial disparities in birth outcomes as a consequence of both long-term exposures to stressors such as racism, and health and social disadvantages that unfold over a lifetime. At one level, life-course is a paradigm that can help researchers identify how the accumulation of risks or protective factors over a lifetime impacts pregnancy outcomes. The life-course approach can be used to set a meaningful agenda for future research, for example, by encouraging scientists to expand the time frame they use to link exposures with outcomes (Halfon et al. 2014). At another level though, the life-course paradigm presents the scientific literature on the epidemiology of preterm birth and other birth outcomes in a way that can be used in a political context. Michael Lu and Neal Halfon's original paper includes a laundry list of social reforms that are justifiable as mechanisms to address the phenomenon. They write:

> The life-course perspective has far-reaching policy implications for eliminating disparities in birth outcomes. As a first step, it calls for greater investments in women's health. Presently many women, particularly low-income women and women of color, lack access to women's health care….Ultimately a more unified approach toward universal coverage (e.g., universal health insurance) is needed…Second, the life-course perspective calls for greater investments in community health. As long as African American women continue to grow up and reside in neighborhoods and communities that put them at early life disadvantages and under greater cumulative allostatic loads, racial disparities in birth outcomes

> will persist, even with the best pregnancy care, or women's health care…Building healthy communities requires investments in infrastructure, such as affordable and decent housing, safe neighborhoods, accessible parks and recreation, clean air and water, and competent health care. It also requires community collaborations….Lastly, the life-course perspective calls for greater investments in improving social conditions, with the goal of reducing allostatic load over the life course of women. This requires policymakers to pay attention to issues that disproportionately impact women's lives, such as domestic violence and child care….Prolonged working hours, shift work, high stress, low control or reward, inflexibility of work schedule or responsibilities, and gender discrimination can add to the accumulation of allostatic load. For women of color and particularly for African American women, internalized, personally mediated, and institutional racism contribute to further wear and tear on their body's physiologic systems. By improving social conditions, public policy can help eliminate racial disparities in birth outcomes by protecting women, particularly African American women, against the damaging effects of cumulative allostatic load over the life course on their reproductive health. (Lu and Halfon 2003, pp. 25–26, reprinted with permission from Springer)

This statement illustrates the extremely broad scope of policy proposals that can be plausibly linked to racial disparities in preterm birth and other birth outcomes. It is reminiscent of the use of baby-saving in the early 1900s as a way to galvanize political support for social welfare programs that challenged the economic status quo.

On the other hand, there is resistance in mainstream U.S. political discourse to the assertion that racism is widespread (Graham 2015). One way this resistance is expressed is by interpreting disparities and other phenomena related to racism as occurring only in isolated parts of the U.S. For example, Cosby and Jones (2010) examine an article published in the **New York Times** in 2007 that described in alarming terms a spike in infant mortality rates that occurred in Mississippi in 2005. The **New York Times** article gained widespread national and international coverage, with the subtext of the coverage suggesting that racial disparities in birth outcomes were increasing in states in the Deep South. This was in line with the commonly accepted beliefs about poor race relations and the legacy of slavery in this region. Subsequent analysis of infant mortality rates in Mississippi revealed that the spike in infant mortality in the state was in fact a one-year aberration in the small number of deaths involved. Infant mortality rates are high in Mississippi for both Black and White infants, while racial disparities in infant mortality are actually larger in other regions of the United States. Another manifestation of this resistance is the argument that the U.S. should end the use of racial categories to measure population phenomena such as infant mortality rates. It has been suggested that racial categories could be replaced by ethnic categories which might give more indication of the sociocultural or behavioral factors influencing population statistics. However, such an approach has embedded in it an assumption that racial differences are explained by culture, behavior or socioeconomic status. Losing the traditional racial categorizations in counts of the U.S. population would make it difficult to document racism-related population patterns (Thomas 2001).

4.3.4 The Impact of Race-Related Policies on Preterm Births

In the early twentieth century, advocates within the Black community used racial disparities in birth outcomes to point out the need for improved employment opportunities in order to reduce poverty, and the end of housing segregation in order to improve sanitation and adequate environmental conditions for the Black population. These social changes did not occur in that era. Disparities in pregnancy outcomes were also part of the justification for targeting health and family planning programs to Black women in the 1940s and 1950s. These programs did result in some improvements in health status and child survival, although they also eroded established midwifery practices and catered to eugenic philosophies about population control (Litt 2000; Schoen 1997; Smith 1995).

In 1963, in the context of the civil rights movement, the push to desegregate hospitals and the rediscovery of poverty amid affluence, Congress amended the maternal and child health (MCH) provisions (Title V) of the 1935 Social Security Act. A portion of the funds that had historically flowed directly to states were diverted into special projects designed to enhance the availability of prenatal care services for women in communities with high infant mortality rates. The rationale for this diversion, and subsequent expansion of Title V funding, was that some state officials were reluctant to provide services to these low income and often majority Black communities (Klerman 1981). Rural locations in Southern states and inner city neighborhoods in most major U.S. urban centers were funded directly by the federal government for these Maternal and Infant Care (MIC) projects, and fifty of these projects were established in the 1960s.

Although these funds were later combined back into the state-level programs, in 1976 another set of 34 states with the highest infant mortality rates were awarded Improving Pregnancy Outcomes (IPO) projects. These IPO projects were funded through a different federal program, the Bureau of Community Health, which also funds direct health care services by supporting community health centers. The IPO projects were intended to allow states to reconfigure their maternal and child health systems in order to improve access to services. In 1978, the Bureau of Community Health funded an additional 31 target areas in 11 states and the District of Columbia with Improved Child Health (ICH) funds, also to improve comprehensive services for high-risk mothers and infants (Clarke et al. 1993; GAO 1980; Klerman 1981; Peoples et al. 1984; Peoples and Siegal 1983). In 1979, the Robert Wood Johnson Foundation funded projects in 10 rural states to support cooperation between medical schools, local health professionals and state health departments to improve perinatal health care systems for populations with high infant mortality rates. As in most communities targeted by all of these programs, the populations served included a high proportion of Black women and infants (Gortmaker et al. 1987).

The evaluation of the impact of these various programs is mixed in terms of comprehensiveness and quality. The actual interventions were diverse, they were established quickly in response to political pressure to address racial and income disparities in infant health, and it was difficult to identify areas that were not affected by the interventions to use for comparisons (GAO 1980; Peoples and Siegal 1983; Strobino 1984). Also, as will be discussed in Chap. 5, the establishment of these programs coincided with improvements in the technical capacity of neonatal intensive care units, the drive to expand their availability and to organize services for high-risk infants into regionalized systems of care, so it is difficult to determine any independent impact of the subsidized programs themselves. The evidence suggests that these programs improved access to medical care and reduced infant mortality, but did not lead to a reduction in preterm birth rates in the population, or to a significant reduction in the disparity between these rates across race or ethnicity groups (Clarke et al. 1993; Gortmaker et al. 1987; Peoples et al. 1984; Peoples and Siegal 1983).

In the 1980s, policy preferences shifted away from direct government funding of health care services towards improvements in insurance coverage through Medicaid expansions. It was thought that if more individuals had insurance, the private sector would respond by increasing the provision of medical services to low income individuals (Schlesinger and Kronebusch 1990). However, as discussed above, improvements in infant mortality rates actually plateaued over the decade. Furthermore, racial disparities persisted. At the end of the 1980s the White House Task Force on Infant Mortality compiled a report that highlighted these racial disparities in infant mortality rates and called on the federal government to commit funds to expand prenatal care availability and set uniform policies for state Medicaid programs. The report was never officially published, but was provided to the media by task force members who supported the recommendations (Pear 1990).

In response to this expressed concern over racial disparities in infant mortality, Congress designated a stream of funding within the Health Resources and Services Administration (HRSA), to establish the Healthy Start program. The program began in 1991 in an initial set of 15 sites, all with a majority Black population except for a site on the Northern Plains, which was predominantly Native American (Howell et al. 1998). By 2010 the Healthy Start initiative had 104 sites in 38 states. The program is intended to reduce disparities in infant mortality and other birth outcomes. Its focus, as prescribed in the funding guidelines, includes five individual level components—outreach, case management, health education, perinatal depression screening, and maternal care between pregnancies—and four systems level components—partnership across organizations, local health systems planning, collaboration with state Title V programs, and sustainability planning (Brand et al. 2010).

Throughout its 30 year operation, evaluations of the Healthy Start initiative have consistently shown that the program is associated with improvements in use of and satisfaction with prenatal care, along with some improvements in health behaviors associated with better pregnancy outcomes (Brand et al. 2010; McCormick et al. 2001; Rosenbach et al. 2010). Early on, evaluations of some of the Healthy Start sites suggested that preterm and low birth weight rates were lower among program participants than in comparison population. This was because rates of these outcomes for program participants had remained stable since before the start of the programs, while outcomes in comparison areas deteriorated (Moreno et al. 2000). Infant mortality rates declined across both program and comparison areas. More recent evaluations have not shown a difference in pregnancy outcomes associated with the Healthy Start program, but instead continue to document more preterm and low birth weight births in the Black population. Commenting on these findings, public health physician and researcher Milton Kotelchuck notes:

> Perhaps in the early initiation of Healthy Start, the expectation was established that the Program could and should directly reduce birth outcome disparities. Healthy Start was initially announced as an initiative that would "reduce infant mortality by 50 % in 5 years", reflecting the then widely held view that access to comprehensive prenatal care would improve birth outcomes. Today we know that this optimistic thinking is not accurate. MCH life course models suggest that the life time experiences and exposures women (and populations of women) bring to their pregnancies strongly determine their differential pregnancy outcomes….As currently conceived, Healthy Start alone will unlikely be a major source of reduction of birth outcomes or disparities in America. Healthy Start is not a silver bullet. Rather, Healthy Start must be part of a broader, more comprehensive set of longitudinal initiatives throughout high-risk communities to enhance birth outcomes and subsequent maternal and infant health. That is, Healthy Start is a necessary, but not a sufficient program, to address the perinatal impacts of racial/ethnic and social class disparities in America. (Kotelchuck 2010, p. 651, reprinted with permission from Springer)

The shift away from a medical model towards a more broadly based approach that seeks overall improvement of conditions in communities is beginning to be apparent in the Healthy Start program. Local Healthy Start programs have created linkages with community development, housing improvement and other public health activities in their target neighborhoods (Gray 2011). The National Healthy Start Association, which still describes Healthy Start programs as an organized effort to improve and enhance the delivery of services for women and children, lists as its strategic goal the practical application of the life-course concept within vulnerable communities (NHSA 2011).

4.4 Comparisons with Canada, Great Britain, and Western Europe

As discussed at the conclusion of Chap. 3, the extent of medicalization of pregnancy and childbirth is similar across the U.S., Canada, Great Britain, and Western Europe, but there are differences in the cultural understanding of social reproduction across these settings. In general, successful reproduction in the U.S. is considered an individual responsibility; while in these other settings, there is more of a sense that successful reproduction is a society-wide endeavor. In addition to these cultural differences, there are differences in political arrangements—traditions, competing concerns and arrays of interest groups—in these different countries. Consequently, preterm birth as a social issue has a different set of dynamics in these different settings.

4.4.1 Fertility Control

As in the U.S., fertility control became an issue in Britain, Western Europe and Canada with industrialization in the late nineteenth century, which contributed to changing preferences for the optimal size of families. Social tensions were similar in all of these countries. Changing social roles for women and children and concerns about population growth stimulated interest in increasing the availability of contraception, while concerns about declines in birth rates for desirable segments of the population, along with resistance to birth control linked to religious institutions, stimulated opposition to family planning. As in the case of the Comstock laws in the U.S., both Canada and France had statutes criminalizing the distribution of information about birth control, and Canada and Britain both had pioneering women physicians who established clinics in the 1920s and 1930s to distribute contraception despite public opposition (Canadian Public Health Association 2015; Family Planning Association (Britain) 2011; Pavard n.d.).

Still, general attitudes towards sexuality tend to be more permissive in European countries than in the U.S. In Germany in the 1920s, there was political pressure to expand the availability of contraception as part of a movement to liberalize sexuality (Grossman 1995). The movement in France to decriminalize contraception, which began in the 1950s, was framed as a way to respect the dignity of married women by allowing them to control their own bodies and their pregnancies (Pavard n.d.). As modern methods of contraception, such as birth control pills, became available in the 1960’s, limitations on discussion of birth control and restrictions on the distribution of contraceptives, such as the requirement that recipients be married, were overturned. Because Great Britain, Western European countries and Canada all have some form of national health care or universal health insurance, the distribution of contraception, once it was decriminalized, was not problematic.

Currently more than 80 % of women in Europe and Canada regularly use contraception, and European countries have the lowest fertility rates in the world (Ulrich 2001). As discussed in Chap. 2, rates of unintended pregnancies are also lower in these countries, while abortion rates are higher. Sex education for teens is more extensive and more explicit in Europe than in the U.S. (Advocates for Youth 2011). In general sexuality, rather than the health of newborns, has been the primary political driver of expansion of contraception availability in countries other than the U.S.

Also, as noted in Chap. 3, abortion laws are actually more restrictive in these other settings than in the U.S., and late term abortions must have a documented reason and be approved through an established governmental process. This means that debates over abortion policies in these countries do not hinge on the issue of fetal viability as they often do in the U.S., and are thus not intertwined with approaches to preventing preterm deliveries or providing care for preterm infants. Furthermore, abortion practices in Canada, Great Britain and the Western European countries were set by statutes after a process of negotiation across interest groups. This is in contrast to the U.S., where abortion practices were set by court decisions, and debate about the issue came afterwards (Fentiman 2009). Because U.S. abortion practices can more easily be changed by court decisions, and also are not set nationally but are subject to alteration across 50 states, politicized debates about this aspect of fertility control is a continuing feature of discussions about the care of preterm newborns. This is discussed further in Chap. 6.

4.4.2 Addressing Poverty

Canada, Great Britain and the Western European countries all have social welfare systems that were established earlier and are broader in scope than the system in the U.S. As in the U.S., the political interest in social welfare was mobilized initially out of concern for high infant mortality rates. Governments took more active roles in funding old age pensions, unemployment insurance, maternity and general health care benefits, as well as minimum wage rules and workplace regulations in these other countries, in part as a response to organized labor interests, which were more politically powerful in these contexts in the early twentieth century than they were in the U.S. Other explanations for this activist government role include the relatively less stigmatization of poverty in these settings, and a political tradition that includes the expectations that government, rather than individuals or private markets, act for the benefit of public welfare (Fraser and Gordon 1994; Katz 1986; Skocpol 1992). In addition, Gornick and Meyers, in their work on comparative social policies related to family welfare, note the importance of relative homogeneity of the population in supporting social welfare programs. They comment:

> The extent of racial, ethnic, and national diversity strikes many as the most important dimension on which the United States differs from other wealthy industrialized countries. The population of the United States is remarkably diverse in terms of race and ethnicity, nearly 10 percent of residents are foreign born, and just over one-quarter are African American, Hispanic, Asian or Pacific Islander, or Native American. Critics often portray this as an insurmountable barrier to lesson-drawing from abroad, arguing that the generosity of the European welfare states, in particular, is possible only because the populations of these countries are so homogeneous.
>
> This caution deserves to be taken seriously. Our comparative study of policies in other countries suggests that the most successful and resilient policies are broadly inclusive, providing similar options to all families and creating strong and broad-based support for their continuation. The United States does not have a similar history of inclusive social provision. Welfare state scholars have frequently explained this exceptionalism in terms of deep racial and ethnic cleavages and resistance to policies that redistribute across these divides. In recent years, fissures have grown increasingly wide when social programs are seen to benefit recent immigrants. (Gornick and Meyers 2003, p. 269)

Following World War II, Canada and most European nations developed a package of public policies which were framed as explicitly supporting families. This generally meant encouraging women's labor force participation while simultaneously preserving practices that supported child-bearing and child-raising. According to French economist Olivier Thevenon, modern family policies in these settings include six aims, which each receive different emphasis in different national settings. These six aims are poverty reduction (through cash benefits directed universally or to low income families); direct compensation for the costs of children (payments to equalize income between families with and without children); labor laws to foster parental employment in ways that benefit children (including maternity and paternity leave, publicly supported child care and tax incentives); gender equity (equal benefits to mothers and fathers, no workplace gender discrimination); support for early childhood development (restrictions on parental work hours and preschool education); and support to raise fertility rates (Thevenon 2011).

In contrast to Great Britain, Western Europe and Canada, the U.S. does not combine these types of policies or frame them as being related to families (Glendon 1987). Instead, as noted in this chapter, policies intended to ameliorate poverty are tied to the demands for labor participation, with cash welfare support eligibility set at the state level, available for limited time periods, and contingent on adults continuing to seek employment. There is no policy of directly compensating families with children with cash benefits, although there are tax benefits available to families with children (Wennemo 1992). There is very limited public support for child care services, and availability varies markedly across states and localities. The Family and Medical Leave Act of 1993 (FMLA) guarantees employees access to 12 weeks of family-related leave from work with job reinstatement if they work for employers with more than 50 employees, but this leave is unpaid (although some states and employers have more generous policies). The U.S. is currently the only developed country that does not guarantee paid leave related to childbirth (Gornick and Meyers 2006; Human Rights Watch 2011). Comparative studies of family-related policies across the U.S., Europe and other developed nations rank the U.S. well on gender equity policies, but relatively poorly on other policies (Gornick and Meyers 2006; Thevenon 2011). As discussed in Chap. 2, European countries and Canada have a smaller portion of women of child-bearing age living in poverty, compared to the U.S.

As discussed in Chap. 1, French physician Emile Papiernik credited the European policies of providing work leave for pregnant women for lower preterm birth rates in those countries, compared to the U.S. (Papiernik 2007). Such labor policies date to the early twentieth century and were mandatory (and not always paid) in some countries. Following World War II, leave during pregnancy as well as parental leave following childbirth were adopted as part of family or population support policies, with job protection and wage replacement guarantees added in the 1960s and 1970s. Pregnancy leave remains mandatory in some nations (Ruhm and Teague 1995). In contrast, in the U.S., two policies address employee leave during pregnancy. The FMLA guarantees 12 weeks of unpaid leave, but leave taken during pregnancy reduces the amount of leave available to parents to take care of newborns after delivery. Women with access only to this level of maternity benefit will often continue to work until delivery in order to have paid time off to care for newborns after childbirth (Human Rights Watch 2011).

The second policy that affects leave during pregnancy predates the FMLA. The Pregnancy Discrimination Act (PDA) of 1978 was an amendment to Title VII of the

Civil Rights Act of 1964. It prohibits employers from discriminating on the basis of sex, and thereby requires that all sick leave, temporary disability and job modification policies that apply to employees in a given setting also apply to women requesting leave or job modifications due to pregnancy (EEOC 2015).[21] In essence, the PDA functions to guarantee the right to work while pregnant, rather than guaranteeing the right to reduce or stop work in order to promote a woman's well-being during pregnancy. The nature of these pregnancy and parental leave policies in the U.S. reflect the tendency for public policies in the U.S. to protect the interest of employers (and employees wanting to continue on their jobs) rather than the general interests of employees wanting to balance their personal and employment interests. As Gornick and Meyers (2006) note, it also reflects a split in political influence between those advocating for gender equity in employment—which includes protecting the rights of pregnant women to work—and advocates oriented to family and child well-being, who may advocate for special benefits for working women when pregnant.

4.4.3 Addressing Racial or Ethnic Inequities

This chapter has discussed the way that racial disparities in preterm births, low birth weight births and infant mortality rates helped to put the need to address racial inequities in the U.S. on the political agenda. Several public programs, mostly providing support for improved health and social services, have been created to address this issue. Racial disparities also stimulated broader enforcement of civil rights laws such as guaranteed access to hospitals.

Canada, Great Britain, and Western Europe do not have the same legacy of racism and racial inequality as the U.S., but they do have increasingly large segments of non-Western (African, Caribbean, South American, and Asian) first and second generation immigrant women in their child-bearing populations. As indicated in Chap. 2, although systematic surveillance is hindered by a lack of indicators of ethnicity or immigrant status in population databases in some countries, non-Western ethnicity women in Europe and Canada have less favorable birth outcomes compared to European natives of those countries. While part of the explanation for these disparities is higher rates of risk factors among these women, several studies have also suggested that some non-Western or immigrant women

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[21] In December 2014, the U.S. Supreme Court heard the case of Peggy Young versus United Parcel Service, in which Ms. Young sued her employer for placing her on mandatory unpaid work leave while she was pregnant when she requested, on physician orders, to be relieved of the requirement to lift heavy packages. Lower courts had determined that she was not eligible to sue under the PDA because, at the time, United Parcel Service did not accommodate all requests for reduced work requirements, only those which arose from on the job injuries. In March 2015, the Supreme Court ruled that she did have the right to sue under the PDA, because her employer had singled out pregnancy as a condition which it did not have to accommodate (Sneed 2015).

receive prenatal and delivery medical care that does not meet expected quality standards. While it does not seem that these women are purposely treated differently than native women in the health care setting, there is evidence that they tend to start prenatal care later, do not report pregnancy problems promptly to their caregivers, have language barriers that cause lack of communication, have economic difficulties in accessing care (lack of transportation, inability to leave work), and have cultural practices such as preference for remaining covered, for limiting food intake to keep fetuses smaller, and avoiding recommended cesarean sections. All of these factors could contribute to poor birth outcomes (Alderliestan et al. 2008; Boerleider et al. 2013; Essen et al. 2002).

At least one set of researchers has explicitly suggested that public action would be appropriate to improve use of care by immigrant groups:

> The Swedish antenatal care programme has, until now, lacked appropriate measures to meet the pregnancy strategies of this immigrant group. As a matter of public policy, it would appear to be important that ESE [Ethiopian, Somali and Eritrean] women in Sweden be informed about perinatal health issues, be encouraged to book for antenatal care early, attend clinical sessions regularly and be trained to seek immediate health care when certain symptoms appear. (Essen et al. 2002, p. 681, reprinted with permission from Elsevier)

However, given contemporary concerns across Europe about the lack of assimilation among immigrants, particularly Muslim immigrants (Hamid 2011), it is not clear how politically feasible it would be for governments to invest in such modifications of their health systems to meet the needs of immigrants.

In sum, the perception of preterm births as a solvable social problem has not been incorporated into political debates about contraception, abortion or the treatment of minorities in the population in Great Britain, Western European countries or Canada as it has in the U.S. On the other hand, concern about successful reproduction and the well-being of children is an important facet of income redistribution policies and workplace requirements in these countries to a much greater extent than in the U.S.

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Chapter 5
The Health Care Dimension: Delivering Care for High-Risk Pregnant Women and Preterm Infants

Health care systems are the social arrangements—organizations, institutional practices, and role assignments—that a society makes in order to distribute therapeutic services to the population. The health care systems in the U.S., Great Britain, Canada, and Western Europe are similar in many ways. They rely on a global body of scientific knowledge and technology; they hold similar ideals about the efficiency, efficacy, and equity of their systems; they face similar challenges in terms of disease patterns and aging populations; and they have similar standards for training health professionals. At the same time, each society's health care system is shaped by its unique history, cultural values, ideology, and the structure of companion social arrangements such as legal and social welfare systems. This leads to different practices that impact which therapeutic services are delivered, how and to whom. In particular, health care systems such as those in Europe, Britain, Canada, and the U.S., can be distinguished by the roles that governments play in the social arrangements. For example, governments may be involved to a greater or lesser extent in credentialing and monitoring health professionals, negotiating prices, managing financial systems, or directly providing services through government organizations. The relative role of governments in healthcare systems is in turn influenced by the mix and relative political influence of the organized private interests, including health professionals, industries such as hospitals and pharmaceuticals, and financiers such as health insurers and large employers (Mechanic and Rochefort 1996).

The U.S. health care system is notable for the relatively weak role that the government plays as a regulator and a direct service provider. On the whole, the balance of power in the U.S. system is held by private sector therapeutic service providers—physicians and hospitals—and the organizations, such as health insurance companies, that have been created to manage the distribution of resources.[1] Among the interests of health care providers, like any producers when considered in economic terms, are the desires to maximize the demand for the services they

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[1] Even the public financing systems of Medicare and Medicaid and the insurance regulatory role of the Affordable Care Act are greatly influenced by the powerful political role of insurers and providers, and the rules and pricing approaches in these systems reflect the interests of these parties.

J.M. Bronstein, *Preterm Birth in the United States*,
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provide, maximize the revenue they earn and minimize competition. This does not mean that health care providers do not care about providing benefit to patients, but they do not view their care mission as being in conflict with maximizing their financial well-being. The U.S. system is unique because the interests of other parties, including the population using services and those responsible for allocating resources to healthcare or other enterprises (for example, employers who must choose whether to offer health insurance or to increase wages) are marginalized in decision-making. The consequence is that the U.S. health care system in general, relative to comparable systems, is highly technically focused, higher priced, and for the most part, missing enforceable social obligations to assure the universal distribution of therapeutic services (Squires 2012).[2]

This chapter examines the organization and operation of those components of the U.S. health care system which have the most impact on the pregnant women who have preterm infants, and on the infants themselves. As Chap. 1 discussed, there have been many attempts to identify therapeutic interventions to prevent spontaneous preterm birth. While none so far have been consistently successful, demand for such interventions is strong, leading to opportunities to research, test, market, and provide them to a significant segment of the population. Another set of diagnostic and monitoring interventions has contributed to an increase in interventional preterm births, when assessments are interpreted to mean that fetuses and mothers will be better off if deliveries occur before the infant reaches term. Therapeutic interventions that improve the chances of survival for neonates delivered before term have been more successful than prenatal preventive interventions and, as Chap. 3 discussed, have become iconic of the power of modern technology to defeat death. Demand for these neonatal interventions is also robust, and extensive private and public resources have been committed to supporting and expanding them.

Because in the U.S. healthcare is a provider-dominated system, preventive and rescue interventions tend to be distributed widely and priced as high as possible. In some circumstances this has meant that a broader group of women and sometimes infants receive high-risk oriented interventions than actually need or can benefit from them. Many critiques of contemporary childbirth practices have discussed the consequences of over-intervention on normal pregnancies and deliveries (Davis Floyd 2003; Perkins 2008; Simonds et al. 2007). There is also concern about extraordinary measures used to keep marginally viable newborns alive (Harrison 2008; Peabody 1998), and over-use of neonatal intensive care units (NICUs) for routine surveillance and for infants with minimal complications (Perkins 2008).

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[2] The Affordable Care Act of 2010 includes provisions that move towards enforcing a social obligation for universal access through incentivizing states to expand Medicaid programs, mandating that individuals purchase health insurance and requiring that large employers offer health insurance to employees, while providing subsidies to individuals to reduce the costs of insurance plans. These are generally understood as individual benefits, rather than social obligations that one segment of U.S. society owes to another.

Market related concerns—provider competition and commercial interests—also influence the choice of procedures provided to pregnant women at risk for preterm birth.

There are few parties in the health care system in the U.S. who can legitimately argue against the huge outlay of resources devoted to rescuing preterm infants with marginal viability. The social reproduction system described in Chap. 3 supports the premise that all fetuses and babies should be treated as individuals and given every opportunity to survive. The legal restrictions put in place on resuscitation decisions in the context of the political debate over abortion, as described in Chap. 4, limit parental and physician choices about the care of preterm infants. The authoritative parties in treatment setting are the physicians and hospital personnel, and they have both a professional and a financial interest in the survival of preterm infants. Neonatologist and ethicist John Lantos described this situation in an opinion piece in a health policy journal, writing:

> We may imagine that we are working to protect premature babies because they need us, but it turns out that preemies are also working for us. They perform an important altruistic function for our medical centers. We are supported by the rewards that doctors and hospitals claim for meeting the obligations that we've taken on ourselves. Pediatrics departments and children's hospitals are now financially dependent on NICU preemies. At the University of Chicago, for example, over the past three years, the NICU has had the highest revenue to expenses of any unit in the entire hospital. Recognizing this fact, the new University of Chicago Children's Hospital, like most new children's hospitals, will have more NICU beds than the current one, but will not have room left over for a new emergency department, new outpatient clinics, or an auditorium for public gatherings. (Lantos 2001, p. 239, reprinted with permission from Johns Hopkins University Press)

Provider dominance of the health U.S. health care system is the main reason why there are limited countervailing pressures to restrict the use of resources in the care of high-risk pregnant women and preterm infants. However, as discussed in Chap. 4, medical care is also the form in which the broader U.S. society expresses its interest in addressing the consequences of political tensions over fertility control, ameliorating poverty, and addressing racial inequities. Providing maximal treatment during pregnancy and exercising extreme caution in decisions not to resuscitate and provide care for preterm newborns while they are in the hospital, are the ways that the healthcare system is able to fulfill this conflict-mediating social role.

5.1 The Content of Prenatal Care for High-Risk Pregnancies

As discussed in Chap. 1, the idealized view of medical interventions holds that they are based on a thorough understanding of the conditions being treated, and that they are targeted to patients who have these conditions. In reality, sometimes medical interventions are used, even though there is no direct evidence of their effectiveness, because it is believed that they should or could work. Also, if interventions do seem to work for a patient, this implies that the patient probably had the condition being treated. However, it may be the case that an ineffective intervention seems successful because it was given to a patient who did not have a condition that needed treatment. For example, preterm labor often resolves by itself in the natural course of a pregnancy, but an ineffective treatment to stop preterm labor might appear to be effective if this is not taken into account. As discussed in Chap. 1, no intervention currently meets the criteria of effectiveness in preventing preterm birth across most women at risk, although some, notably progesterone treatments and cerclage, are used with modest success in specific subpopulations of pregnant women. Part of the difficulty in identifying a widely effective intervention is that preterm birth itself is a pregnancy outcome that occurs in a wide variety of circumstances, so it is unlikely that a single set of treatments would be broadly preventative.

Another aspect of the idealized view of medical interventions is that they are provided in an unbiased way, based purely on whether they are needed. In fact, interventions are provided in the social and economic context of particular healthcare settings, and providers have differing beliefs about their appropriateness under different circumstances. This section explores three contextual factors that have an influence on patterns of provision of obstetrics interventions in the U.S.: competition among providers, with advantage accruing to those providers who have the capacity to offer the broadest range of prenatal interventions; perceived pressure to actively intervene when problems arise in pregnancies, due to fear of seeming negligent if a potentially helpful intervention is not recommended; and commercial interests, which identify revenue opportunities when new interventions are adopted as standards of care.

5.1.1 The Impact of Provider Competition

Advice and instructions for care during pregnancy, what we now call prenatal care, were traditionally part of the role of birth attendants. Physicians took on this practice as they moved to become the primary providers of maternity services in the late nineteenth century. As discussed in Chap. 1, for decades there was a belief that prenatal care itself could prevent preterm birth. However, contemporary thinking on prenatal care is that the association between receiving a greater quantity of prenatal care and being less likely to have a preterm delivery is driven primarily by two measurement problems: women whose pregnancies go to term have a longer time period in which to receive more prenatal care, and women who use more prenatal care have other characteristics that make them less likely to have a preterm delivery. Although prenatal care itself has not been shown to prevent poor birth outcomes, it has been proposed that prenatal care is important because contact with the medical system creates an opportunity to monitor women's risk levels, to provide health education, and to intervene with a variety of potentially beneficial procedures. Observers have expressed concern that overly strong critiques of the effectiveness of prenatal care might lead to diminished support for public financing of these services (Alexander and Kotelchuck 2001).

While the beliefs within the medical community about the clinical value of prenatal care itself are not supported by scientific evidence, the organizational value of prenatal care to obstetrics care providers is very clear. Prenatal care is the primary venue within which women are socialized into accepting the authority of medical professionals as experts in childbirth, as opposed to relying primarily on their own experience or informal social networks; this socialization makes it more likely that pregnant women will comply with their clinicians' instructions (Browner and Press 1997; Oakley 1982; Rothman 2007). From the providers' point of view, prenatal care is the mechanism by which medical professionals link themselves to pregnant women and secure what might be termed their customer base for the provision of maternity delivery services.[3] Such linkages are important because the provision of delivery services is a competitive enterprise with limited demand (only pregnant women need these services, and the number of pregnant women in a society is limited by demographics and fertility trends) and a flexible supply of providers (because a variety of medical professionals can offer maternity care). In addition, the provision of delivery services is an important revenue stream for hospitals, so hospitals compete with each other both directly for maternity patients and indirectly for obstetrics professionals who can maintain a stream of patients (Gray 1988; Perkins 2008).

Competition for potential patients occurs across all types of childbirth professionals, including lay and nurse midwives, family and general physicians, and general and specialized obstetricians. Some types of child birth professionals, particularly midwives, are formally excluded from providing care to women with pregnancies that have been labeled as high risk (Simonds et al. 2007). Goodman (2007) relates the case of a university-based health science center which restricted the scope of its long-established midwifery practice, after an audit by the state Medicaid program ended the obstetrics group's practice of billing for physician services on behalf of the midwifery service's patients. The rationale for the midwifery service's closure was that the patients were "too high risk" to remain in the midwives' care, but Goodman suggests that the primary motivation was to recapture the revenue from prenatal and delivery care to these patients for the physician practice.

Among physicians there has been competition dating from the early twentieth century, and continuing through the development of the family practice specialty in the 1970s, between medical generalists and obstetric specialists for the provision of maternity services (Arney 1982; Baldwin et al. 1991; Franks and Elsinger 1987; Onion and Mockapetris 1988; Perkins 2008). Although formal guidelines in the U.S. for assigning patients to one set of physicians or another do not exist, the

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[3] Perkins (2008, p. 44) cites a Children's Bureau report from 1926 which quotes the Director of Obstetrics at the University of Chicago as stating that the purpose of prenatal care was to get pregnant women away from midwives and into the medical system.

tendency is to limit maternity practice of family physicians to the care of low-risk women (Goldstein 2015). The Childbirth Connection web site, a popular source of information about childbirth practices in the U.S., states:

> The great majority of childbearing women in the U.S. are well and healthy, and can consider choosing from among the full range of maternity caregivers. If you have a serious medical condition are at high-risk for developing such a condition, you will probably want to (1) be in the care of a doctor who has completed a residency and is board-certified in obstetrics, and (2) plan to give birth in a hospital. Maternity caregivers understand and can advise you about situations that may call for more specialized care. (Childbirth Connections 2015)

The 1990s saw the establishment of maternal-fetal medicine as a subspecialty within obstetrics, vying for authority with general obstetrics over the care of high-risk pregnancies (Cain and Jonsen 1992; Eden et al. 2005; Vintzileos et al. 2001). In these cases, as in the case of midwifery, the premise that all pregnancies can potentially lead to abnormal childbirth experiences, which must be managed with complex technologies, became the basis for justifying limiting the provision of maternity care to specialized medical personnel. The flexible criteria used to label pregnancies as high risk, as discussed in Chap. 3, plays into the ambiguity of which specialist is appropriate to use for obstetrics treatment.

A related pathway to securing a competitive advantage over alternative practitioners in obstetrics is to specify services or interventions which can only be provided by certain specialized practitioners, and/or with expensive equipment as standard modes of practice. Having the resources to offer all of the recommended technical interventions then becomes a way of demonstrating competence, and demonstrating competence is a key component of the culture of American medicine (Good 1995). The specialty of obstetrics has been characterized historically by a stream of innovations that have steadily increased the quantity of technologically oriented interventions provided during the prenatal period and at delivery. Some of these interventions have been adopted without sound evidence that they are beneficial, or even safe, for example, medications to treat nausea or prevent miscarriages (Chalmers 1986; Perkins 2008; Rothman 2007; Thompson et al. 1990). One interpretation of the reason for such an interventionist approach is that it is an aspect of the heritage of obstetrics as a surgical specialty; interventional procedures are a means for status and revenue enhancement in surgical specialties (Perkins 2008; Williams and Mackey 1999). The importance of being able to provide care for women with high-risk pregnancies supports this trend toward defining only those obstetrics practices with significant technological capabilities are being competent to deliver maternity care.

Electronic fetal monitoring (EFM) is one example of the way that expanded use of technologies has had an impact on provider competition in obstetrics. Although it was introduced in the 1960s as a way of monitoring high-risk women for fetal distress during labor, within the decade it was used in the majority of deliveries. This required hospitals to purchase elaborate equipment and reorganize their labor and delivery unit staffing. Randomized clinical trials and technology assessments critiqued the effectiveness of such widespread use and pointed out the potentially negative side effects of EFM, including increased likelihood of infection from the insertion of monitoring equipment into the fetus's scalp during labor, and non-indicated cesarean section occurring because of misidentification of fetal distress. These assessments in turn were the subject of vigorous critiques by obstetrics professionals. EFM remains in wide use, while the skill of auscultation, which allowed women in labor to be monitored by stethoscope without additional equipment, is no longer practiced (Banta and Thacker 2001; Kunisch 1989; Perkins 2008).

Another example of the impact on provider competition of recommended standard of care for pregnant women is the proposal to create a universal standard for transvaginal ultrasound screening. This type of screening measures the length of women's cervical opening, which can indicate the likelihood of an imminent early delivery. Short cervical length is currently an indicator for the provision of weekly progesterone treatments to delay spontaneous preterm labor. The ACOG practice guidelines on the prevention of preterm delivery note:

> Proponents of universal cervical length screening of women without a prior preterm birth cite the following points in support of this practice: it has the potential to reduce the preterm birth rate; higher quality evidence exists to support efficacy of treatment for positive test results (i.e., cervical length of 20 mm or less); and it is cost effective, safe, accepted by patients, and widely available. Opponents of this approach raise the following concerns: quality assurance of the screening test; lack of availability of screening and of patient access to qualified imaging centers in some areas; and the potential for patients to receive unnecessary or unproven interventions.
>
> The American College of Obstetricians and Gynecologists recognizes that both sides of this debate raise valid issues. Although this document does not mandate universal cervical length screening in women without a prior preterm birth, this screening strategy may be considered. Practitioners who decide to implement universal cervical length screening should follow one of the protocols for trans-vaginal measurement of cervical length from the clinical trials on this subject. (ACOG 2012b, p. 968, published by the American College of Obstetricians and Gynecologists)

If this type of screening were to become the standard of care for all pregnant women, it would require that maternity providers have ready access to particular types of ultrasound equipment and the expertise to interpret the findings. This will again support the competitive advantage of maternity care providers with the capital to expand their care technology.

5.1.2 The Urge to Action

Maternity care providers experience powerful pressure to deliver perfect babies. They fear that they will be held accountable for birth outcomes if they do not use all of the interventions which appear to be promising, as ways of preventing or ameliorating the consequences of a problematic delivery. This results in an urge to act, even when the effectiveness of the action is unknown. Family medicine physician William Hueston termed this “bandwagon medicine” and commented that even obstetric interventions with scant proof of efficacy are adopted because of the narrow room for error (or perceived error) when two lives, the mother’s and the newborn’s, are involved (Hueston 1992).

This view is often framed as the malpractice problem or the liability crisis in obstetrics. There are legal precedents in the U.S. malpractice arena that allow parents to sue for negligence if a baby is born with health problems and the appropriate standards of care were not followed. The medical specialty of obstetrics and gynecology experienced a rapid increase in the number of malpractice suits and in the costs of malpractice insurance coverage in the 1980s, and obstetrics still ranks seventh out of the top 25 physician specialties most frequently sued for malpractice (Jena et al. 2011). It is difficult to lower the expectations that medical intervention will produce perfect babies in every pregnancy, and thereby reduce high rates of malpractice suits, without acknowledging the limits of the medicalized model of pregnancy and childbirth.

Malpractice concerns can reduce competition among maternity care providers by limiting the number of practitioners and the range of specialties that can afford to maintain the appropriate level of obstetrical malpractice insurance (Good 1995). This limits high-risk pregnant women’s choices for providers, since some physicians avoid providing high-risk prenatal care in order to limit their exposure to lawsuits (Rostow et al. 1989). Additionally, malpractice concerns may increase the number of interventions that become standard during prenatal care, because such protocols can help physicians avoid liability for poor birth outcomes (Perkins 2008).

Malpractice concerns of physicians aside, demand for interventions may come directly from patients. The culturally based expectation that medical interventions can resolve most health problems makes a request for action seem a rational and responsible approach. Awareness of practice variation across physicians and knowledge about the care provided to other women with high-risk pregnancies, easily available now with online forums, provide women with information about a repertoire of interventions which can be requested. Clearly, it can be difficult for physicians to avoid providing even marginally or noneffective interventions in the face of patient demands. Table 5.1 shows a paraphrase of an exchange on an online forum for pregnant women that occurred in October 2008, illustrating patients’ quests for high-risk pregnancy interventions, despite the ambivalence of their obstetrics care providers.

The urge to action helps to explain the persistent tendency to prescribe bed rest for women with pregnancy complications (Bigelow and Stone 2011; Biggio 2013), despite the absence of evidence that bed rest is effective and the presence of evidence that it is both physically harmful, as noted in Chap. 1 (Goldenberg et al. 1994; Maloni 2011), and difficult for patients to accomplish (Bigelow and Stone 2011; Maloni 2010; Sciscione 2010). Another prenatal intervention that continues to be used despite its lack of endorsement in professional practice guidelines is long-term tocolytic therapy, the use of medications to relax uterine contractions and thus halt preterm labor. Current practice guidelines advise that tocolytics should be

Table 5.1 Blog exchange entitled "High Risk OB says no Cerclage?? Help!" from BabyCenter.com (2008)

Initial inquiry	Responses
[following a stillbirth at 18 weeks, all pregnancies involve fertility treatment] Specialist after stillbirth suggested she had an incompetent cervix, and she could have a cerclage [stitches to keep cervix closed] during her next pregnancy. Has had two more miscarriages and is now 11 weeks pregnant. Her current OB is not planning to do a cerclage, but prefers to monitor with ultrasound and administer progesterone injections instead. Suggests an underlying infection is primary reason for preterm delivery. She is scared and confused, and can't imagine not carrying this pregnancy to term. HELP!!!!! Any suggestions? (10/6/08)	(R1) Suggests getting a second opinion. Cerclages have higher rates of delivering full term babies (10/6/08) (R2) Get a second opinion if you choose, but definitely do BEDREST! She started dilating at 23 weeks, no cerclage but strict bed rest until 36 weeks. Then induced at 37 weeks (10/06/08) (R3) Definitely get a second opinion (10/06/08) (R4) Agrees. Sounds like she has both incompetent cervix and preterm labor. She would get a second and third opinion. Respondent lost three pregnancies, and is thankful now that she has a cerclage, is on progesterone, taking terbutaline pills and on bed rest. She and her husband did not want to "experiment" so are using every type of intervention. "I wish you the best of luck and if you need anything send me a note, I'm always on[line]…nothing much else to do for me sadly!" Lol (10/06/08) (R5) At 20 weeks, cervix dilated, she spent three weeks on hospitalized bed rest, but dilation did not resolve. Received many different opinions, some suggested cerclage, others did not, some said baby would survive at 24 weeks, others said no. One offered to do a cervical stitch if contractions stopped, although these are usually done earlier. She credits the cerclage with having kept her pregnancy through 30 weeks. She found younger doctors more discouraging than older ones, suggests getting another opinion (10/06/08)
Thanks to all responders. Her regular OB says a second opinion never hurts. Scheduling her to see a different high-risk OB, before she is out of the cerclage period (Something like 13–16 weeks before cervical mucus changes) (10/07/08)	(R6) Also had trouble conceiving, then pregnant and diagnosed with short and funneling cervix. Put on bedrest, no cerclage. Knows the research on cerclage is not conclusive, this is why physicians are indecisive. When transferred hospitals at 24 weeks, new physicians were upset that the previous ones had not done a cerclage. She was given Indocin, refused terbutaline, two hospitalizations, including one a month long. She delivered at 38 weeks. Always get a second opinion, she was uncomfortable with her indecisive physicians (10/07/08)

(continued)

Table 5.1 (continued)

Initial inquiry	Responses
	(R7) She should change physicians (R8) Also had fertility issues, now pregnant with twins. Had an emergency cerclage at 20 weeks, and is now 35 weeks. Although her high-risk OB said there is no solid evidence that cerclage works, she knows they help. She was 90 % effaced and 2 cm dilated when they put it cerclage in. Bedrest is a MUST. Trust me on that. A stitch would not keep the babies in if she was upright too much. It is a combination (10/07/08) (R6) She agrees…the cerclage and bedrest especially done late go hand in hand (10/07/08) (R8) She agrees, get a second and possibly third opinion. She had preterm labor with first pregnancy and a cerclage with the second. Doctor had no idea why preterm labor, but placed the cerclage when she was 15 weeks. Now newly pregnant and will be seeing a new doctor because of change in insurance. Hopes to get another cerclage (11/06/08)

used only in cases of preterm labor occurring after neonatal viability and before 34 weeks gestation, and only when preterm labor is accompanied by cervical dilatation, suggesting that a delivery is imminent (ACOG 2012a). Physicians critical of this cautious approach have referred to it as "therapeutic nihilism." They believe that aggressive use of tocolytics earlier in pregnancy can reduce the likelihood of preterm birth, and that the reasons that research has failed to show the effectiveness of tocolytic therapy are that women have not started tocolytics at an early enough stage in preterm labor, and/or that women do not adhere to long-term tocolytic therapy because of negative side effects (Morrison and Chauhan 2003). At least one set of proponents of long-term use of terbutaline (a drug used to treat bronchospasms but used off-label as a tocolytic) discounted the Food and Drug Administration's 2011 warning against such use, arguing that the few maternal deaths observed with use of this treatment were not a great concern, given the extent to which the drug had been used to halt preterm labor over the preceding 30 years (Elliott and Morrison 2013).

There is also considerable practice variation in the decision to intervene during a pregnancy in response to apparent pregnancy complications, and to deliver a fetus before term. Studies suggest that considerations other than strictly medical diagnosis are associated with interventional deliveries. One study conducted at a large hospital found that elective deliveries with no documented indications of risk accounted for 8.2 % of all late preterm deliveries in 2007–2008. An additional 8.8 % of late preterm period deliveries were interventions performed in response to maternal complications that the authors characterize as manageable without delivery, including mild pre-eclampsia and routine findings from fetal diagnostic tests. In both of these categories, the indicated deliveries were more common among privately insured women with nonfaculty physicians (Holland et al. 2009). Another study of ten years of birth certificate data in Illinois showed higher rates of inductions in the late preterm period in communities with higher malpractice insurance premiums. The authors of this study suggest that obstetricians concerned about malpractice suits perform more tests on pregnant women. They then choose to intervene to deliver infants preterm, reasoning that managing the complications of preterm birth in all cases would be less risky than facing the possibility that one of the cases might go to term with a catastrophic outcome such as a fetal death (Murthy et al. 2009).

As noted in Chap. 2, one population-based study of racial disparities in preterm birth rates observed that Black women are less likely to receive interventional preterm deliveries than White women (Demissie et al. 2001). In contrast, it appears that Black women are more likely to receive cesarean section deliveries at term than White women and women of other ethnicities (Getahun et al. 2009; Roth and Henley 2012). Other studies have shown that, at least in some time periods in some clinical settings, Black women have been less likely to receive counseling about tobacco and alcohol use during pregnancy (Kogan et al. 1994), and less likely to receive tocolytic (Brett et al. 1994) and corticosteroid therapy (Bronstein and Goldenberg 1995). Variations in the use of medical interventions among Black patients compared to White patients with similar same clinical indications is part of a broader pattern of disparities in healthcare use, with multiple causes, including delayed presentation in clinical settings, the failure of clinicians to recognize the clinical indications in Black patients, lack of trust in the patient–physician relationship, and preferences on the part of some Black patients for less aggressive treatments (Smedley et al. 2003). Other studies suggest that Black patients are often concentrated in healthcare settings that provide substandard quality of care, possibly because of limitations on staffing and infrastructure in settings that serve less affluent populations (Baicker et al. 2005; Lake et al. 2015).

The trend toward increasing rates of interventional deliveries, particularly those with ambiguous indications, has come under scrutiny. In recent years, major campaigns have been launched by public health agencies, the March of Dimes, hospital licensing organizations and health insurers to encourage pregnant women, physicians, and hospitals to avoid early interventional deliveries unless there are clear indications of maternal or fetal risk (Oshiro et al. 2013). In February 2011, the National Institute of Child Health and Human Development (NICHD) and the Society for Maternal-Fetal Medicine held a workshop intended to produce consensus recommendations on the appropriate timing of an indicated delivery for specific maternal and fetal conditions. The consensus recommendations recognized that early indicated deliveries can be beneficial, but also noted that in some cases the decision to deliver early involves weighing maternal against fetal risks. The recommendations list several conditions where delivery could be delayed until at least 37 weeks, barring indications of imminent threat to the mother or fetus. These included placenta previa, uncomplicated fetal growth restriction, controlled chronic maternal hypertension, mild pre-eclampsia, and diabetes (Spong et al. 2011).

The alternative to interventional delivery is expectant management, which involves monitoring pregnant women, treating their conditions, such as hypertension, where possible, and waiting as late as possible in the pregnancy before initiating an indicated delivery (Wong and Grobman 2011). Possible organizational factors that affect physicians' choice of interventional delivery over expectant management—the relative availability of neonatal intensive care units in many hospitals, along with the relative lack of availability of maternal-fetal medicine specialists with experience managing pregnancy complications—is discussed in Sect. 5.3.3 of this chapter.

5.1.3 Commercial Interests

Because the U.S. health care system operates as a marketplace, with health professionals essentially selling goods and services to patients (who are sometimes thought of as consumers), decisions about the content of prenatal care offer opportunities for revenue gains or losses for a range of commercial enterprises. Commercial interests are evident in discussions about recommended practices in high-risk obstetrics. For example, one of the arguments made in support of long-term tocolytic therapy during pregnancy is that it might be more effective if it could be started at the earliest point in a pregnancy when a woman experiences preterm labor. In the 1990s and early 2000s, a series of studies were conducted to test whether monitoring uterine activity at home could enable women to reach care and begin therapy with tocolysis at an earlier stage of labor then would likely occur without monitoring. The intervention proposed to accomplish home monitoring was a portable electronic appliance that transmitted records of contractions over a telephone or modem line to a high-risk nursing service. The nursing service in turn examined the recorded contractions and provided daily counseling to women about their preterm labor symptoms. Many of the studies of this intervention were financially supported by the manufacturers of home uterine activity monitoring devices themselves (Williams and Mackey 1999). Other studies were supported by insurance companies that had to decide whether or not the intervention was effective enough to warrant reimbursement if it was used (Morrison and Chauhan 2003). None of these studies showed strong support for home monitoring devices as a preventive intervention for most pregnant women, primarily because, while women who deliver preterm have early contractions that can be identified by monitoring, many women who do not deliver preterm also have early contractions. Furthermore, none of the studies identified an impact of the electronic device itself that was distinguishable from the impact of daily counseling by obstetrics personnel, combined with training pregnant women to identify early contractions.

However, the interpretation of studies of home uterine monitoring was hotly debated, particularly in the context of a 2001 U.S. Food and Drug Administration

(FDA) review for marketing approval for the monitoring devices. The devices were approved at that point for a relatively narrow indication: monitoring women who have had a previous spontaneous preterm birth. However, they continue to be marketed for “off label” use to monitor women with preterm labor in the current pregnancy whether or not she has a history of preterm birth (Reichmann 2008).[4] Many insurance companies currently specify that they do not cover home uterine monitoring systems because they are deemed to be “not medically necessary,”[5] and current reviews and practice guidelines do not recommend use (Urquhart et al. 2012).

The commercial interests involved in supporting the availability of progesterone for use in the third trimester for women with a history of preterm birth are also illustrative of the link between high-risk prenatal care interventions and commercial interests. As noted in Chaps. 1 and 3, Delalutin, a form of the treatment which clinical trials showed to be effective in reducing the likelihood of a preterm delivery by about 30 % among women with a prior preterm delivery, was taken off the market by its manufacturer, Squibb Pharmaceuticals, in 1999. While the FDA had reported no safety problems from the drug, anecdotal reports were accumulating about the relationship between Delalutin administration and congenital abnormalities, a small study of mice yielded some concerns, and at least one law firm reported an accumulation of lawsuits concerning the effects of the drug (Gray 2002). Certainly the damaging long-term outcomes from pregnancies where women had been treated with another hormone supplement, Diethylsilbesterol (DES), likely had an impact on the pharmaceutical company’s decision to withdraw the drug from the market. Progesterone was still available for clinical use because it could be compounded in local pharmacies, but after the Delalutin withdrawal it was not commercially available.

In 2004, the National Institutes of Health (NIH) Maternal-Fetal Network (a consortium of academic hospitals with large obstetric and neonatology practices) undertook a study to follow up the children of mothers included in their earlier progesterone trial, explicitly to provide safety evidence in support of the re-commercialization of the drug (NICHD 2006, p. 21). In 2006, with the endorsement of the March of Dimes, the pharmaceutical company Adeza submitted a New Drug Application for the Delalutin formulation for use in preventing preterm birth. This was approved, and the FDA granted orphan drug status for the drug. Based on the 1983 Orphan Drug Act, orphan drug status is granted to companies developing treatments for rare conditions, defined as conditions affecting fewer than 200,000 people total in the United States, or affecting more than this number, but with no reasonable expectation that the company can make a profit marketing the treatment. The appropriateness of the designation of treatment for preterm birth as

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[4] James P. Reichmann, the author of this critical commentary of Home Uterine Activity Monitoring, is identified in the publication as having a Masters of Business Administration and being a former employee of Matria Healthcare, one of the HUAM manufacturers.

[5] As stated on the web pages of Blue Cross and Blue Shield of North Carolina and Mississippi, Premera Blue Cross of the Pacific Northwest, and Cigna Health.

an orphan drug has been debated in the clinical community, given that it is estimated that progesterone treatments might be appropriate for 139,000 women per year, a far larger number than the threshold for orphan drug designation (Armstrong 2011). The FDA decision to grant orphan drug status allowed Adeza seven years of patent protection for the formulation (even though the drug had long been available), pending the completion of further safety studies.

In 2009, the rights to the drug were purchased by a small, St. Louis-based company named KV/Ther-RX, and in early 2011, this formulation of the drug, now named Makena, was approved for use by the FDA for women with singleton pregnancies who had a previous preterm birth. Once the commercial product was approved, FDA regulations require that compounding pharmacies stop providing the drug. Physicians and insurance companies soon found that the price of progesterone, typically $15 per injection from the compounding pharmacy, was now set at $1500 per injection, or $25,000 for a full course of treatment. The pricing, while initially generating great interest from investors because of the perceived enhanced financial value of KV/Ther-Rx, was immediately the subject of protest from physicians and insurers, as noted in Chap. 3. The March of Dimes ended its relationship with the company, which had been a major charitable donor to the organization. Promises by the company to arrange charitable accommodations for patients who could not afford the treatment did not appease these parties, and hearings were arranged both in Congress and by the Federal Trade Commission.

Within weeks of the initial approval of the drug, the FDA announced that it would not enforce the policy prohibiting compounding pharmacies from providing the drug, and KV announced that it would lower the price to $690 per injection (Armstrong 2011; Cohen et al. 2011; Doyle 2011; Silver and Cunningham 2011). In October 2011, KV provided samples of compounded progesterone to the FDA, and raised concerns about the purity and potency of the noncommercial formulation of the product. In June 2012, the FDA announced that, while it found no safety concerns with the compounded product, it would subsequently extend enforcement of the ban on compounding patented drugs to the progesterone formulation. In July 2012, KV filed suit against the FDA for failing to enforce the policy of banning a compounded formulation of a patented drug. The suit was dismissed in September 2012 but reinstated in January 2014, in light of subsequent court decisions and statutes which suggest that the FDA does not have the discretion to choose not to enforce its policies (Hinckle et al. 2014; Patel and Rumore 2012).

In the meantime, KV pharmaceuticals declared and emerged from bankruptcy and renamed its women’s health division Lumara. Lumara was acquired by Boston-based AMAG Pharmaceuticals in 2014. Currently, Lumara markets Makena to patients and physicians, controls the distribution of the drug directly, negotiates prices with insurers, and provides a patient assistance program to help patients afford the treatment.

Effective treatment with progesterone requires that women at high risk for preterm birth be identified relatively early in pregnancy so that they can be treated with injections weekly. This has raised questions about the public health effectiveness of this treatment for the high-risk population, who do not always use prenatal care this consistently (Hogan et al. 2011). The current American College of Obstetrics and Gynecology (ACOG) practice guidelines recommend that women with a prior history of a spontaneous preterm birth should be offered progesterone treatment beginning at 16–20 weeks gestation (ACOG 2012b). There is some interest within the obstetrics practice community in offering progesterone treatment to women who do not have a prior history of spontaneous preterm birth, if a transvaginal ultrasound screening identifies them as having a short cervical length, often an indicator of imminent delivery. As noted above, some physicians advocate universal screening for short cervical length, although the condition is quite rare, so that all pregnant women who are potential candidates for progesterone treatment can be identified. Thus, despite the initial controversy over the pricing of the product, AMAG Pharmaceuticals has secured an expanding, lucrative, and—until expiration of the patent in 2018—competitor-free market for a medication that has actually been available in one form or another for decades.

While the commercial interests involved in the promotion of home uterine activity monitoring devices and progesterone treatments for high-risk women are obvious, in fact, in every practice decision made during prenatal care has financial implications. In contemporary health care, research, practice standards, legal guidelines, clinical practice, and product marketing are all intertwined (Clarke et al. 2003). One of the consequences of medicalization, not just of pregnancy and childbirth but of a range of conditions that were once considered normal or natural circumstances (such as aging-related physiological changes), is that the redefinitions expand the potential markets for pharmaceuticals and other medical technologies (Conrad 2005).

5.2 Rescuing Preterm Newborns

5.2.1 History of Preterm Neonatal Care

The occasional survival of a preterm infant has been documented since ancient times (Cone 1985; Obladen 2011). In the nineteenth century, British and, to a lesser extent, U.S. obstetricians, described cases where preterm infants were revived by stimulating their breathing reflexes. The ability to save such infants was considered to be an advantage of using physicians rather than midwives for delivery. Furthermore, when early induced labor became popular as a way to ease difficult labors related to narrow or deformed pelvises, delivering physicians considered it their responsibility to try to resuscitate the resulting preterm infant. However in this historical era, the survival and subsequent care of such infants after delivery was considered to be the province of mothers and the domestic setting rather than a medical concern (Baker 1996).

Incubators, or cradles equipped with a technology that could keep a preterm infant warm, were introduced into maternity hospitals in France in the 1880s as discussed in Chap. 1, and were used in conjunction with mothers and, if necessary, wet nurses, to prolong survival of these infants. This approach to hospital-based intensive resuscitation was not widely adopted in the United States in this time period, for two reasons. First, the political contexts in the two nations were quite different. The obstetrics innovators in France enjoyed wide public support and financing because improving survival of infants addressed a perceived national crisis: lower birthrates among French women were resulting in depopulation, which threatened the ability of the French to raise armies to defend themselves against Germany and other military threats. In contrast, as discussed in Chap. 4, the demographic threat in the U.S. was perceived to be a high birth rate among immigrant women, which threatened to overwhelm the native Anglo-Saxon population. Efforts to improve the survival of weak, often poor, and immigrant infants were thought to conflict both with a social Darwinist philosophy of survival of the fittest, and a conservative philosophy that held that the domestic setting was the appropriate context for infant care (Baker 1996). Second, the U.S. initially lacked the large maternity hospitals present in the large cities of Great Britain and Europe. The newer children's hospitals were not organized to accept newborns, so there was no obvious setting in which to place incubator technology.

Incubators did catch the attention of inventors and entrepreneurs in the U.S. however, and in the early twentieth century they were displayed, complete with preterm infant occupants, as sideshows at Coney Island and other fairs and expositions (Cone 1985). When pioneering obstetricians such as Joseph DeLee of Chicago tried to integrate incubators and the intensive nursing care needed to prolong the survival of infants born preterm into maternity settings, they found the financing to maintain such a setting was simply not available. Historian Jeffrey Baker writes:

> Despite the strident efforts of [the Chicago Lying-In Hospital's] directing physician, nurse, and their staff, its incubator station required more financial support than was possible in a hospital that attracted few paying patients. DeLee's dilemma was not unique. Before large numbers of middle-class women began to deliver their infants in the hospital after 1910, obstetricians remained heavily dependent on philanthropy for financial support. Public assistance, moreover, was far too meager to be of value. It is not clear whether even middle-class private patients could afford the kind of prolonged and intensive care required by premature infants without the assistance of third-party insurance coverage. By the time that the rise of hospitalized childbirth changed this reality, obstetricians were becoming increasingly preoccupied with the care of the mother. Neonatal medicine in the process shifted from an obstetric to a pediatric specialty. (Baker 1996, p. 122, reprinted with permission from Johns Hopkins University Press)

After World War I, the specialty of pediatrics took over from obstetrics in providing care to newborn infants. With their expertise in infants, pediatricians were much more aware than obstetricians had been of the extensive challenges that preterm infants presented to those who wished to intervene to support their survival. As discussed in Chap. 1, preterm respiratory and digestive systems are underdeveloped, making it extremely difficult for them to breathe unassisted, to take in nutrition by mouth or to digest even breast milk, not to mention the various experimental substitute formulas being proposed by physicians. They cannot adequately regulate their body temperature, and their circulations are fragile and immature, increasing the likelihood of cerebral hemorrhage and cardiac failure (Philip 2005). Still, across Europe, Great Britain, Canada, and the U.S., a select group of hospitals, led by academically oriented pediatricians, opened special units that offered care to preterm infants, while conducting and publishing research on their physiology and interventions proposed to prolong their survival (Obladen 2012).[6] One prominent example was the Sarah Morris Hospital in Chicago, with care led by pediatrician Julius Hess, who opened an incubator-equipped unit in 1922. Pediatrician Murdina Desmond writes that initially there were few referrals to the Chicago unit, given the pervasive view that very premature infants were unlikely to survive initial treatment. Hess documented that survivors of this early treatment could become healthy, functioning children, although many others did not survive initial treatment (Desmond 1991).

Robertson (2003a) refers to the period of the 1920s through the 1940s as the "hands-off" era in the treatment of preterm babies, because of observations made that handling of fragile infants seemed to trigger breathing difficulties. Preterm infants were kept warm, fed, and isolated from exposure to infection. Toward the latter part of this period, nurseries began experimenting with adding supplemental oxygen to incubators, but by the early 1950s it was recognized that, in fact, too much supplemental oxygen caused retrolental fibroplasia, resulting in blindness.

Public policy interest in the survival of preterm infants grew in the 1940s, as it became clear that, by this time, early neonatal deaths of preterm infants were a primary driver of infant mortality rates. In the 1940s, the Children's Bureau supported a newborn transport system in Chicago that mandated the reporting of all premature births to the Department of Health within an hour of delivery; public health nurses and ambulances were dispatched to transport the infants to specialized hospital units in an attempt to prevent their deaths. Survival rates were reported to be 70 %, and the program, supported by local and federal funds, became a model for other cities (Desmond 1991). The Children's Bureau also published a manual on the care of preterm infants (Dunham 1948).

By many accounts, a turning point in the survival and subsequent care of preterm infants occurred in the early 1950s when obstetric anesthesiologist Virginia Apgar pioneered a scoring system for newborns based on five signs that anesthesiologists use to measure patient responsiveness: heart rate, promptness and vigor of respiration, reflex response to stimulus, muscle tone, and color. The measures were to be taken one minute after delivery. A perfect score added up to ten. Early on, she reported that she had found most obstetricians wanted to score the babies whom they had delivered a 10 or even 12, so she recommended that someone other than the obstetrician evaluate the newborn. The consequences were first, that newborns

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[6] Obladen (2012) and Keirse (2004) both note that developments in high risk obstetrics and neonatology stalled in Europe between World War I and World War II, in part because many of the leading physicians involved were Jewish and were barred from professional positions, and because the Nazi ideology did not support the rescue of marginally viable infants.

received immediate attention by a dedicated caregiver at delivery, and second, that there was an objective indicator (Apgar score of 4 or less) for when a newborn required resuscitation to survive (Apgar et al. 1959; Desmond 1991; James 1975; Philip 2002). Apgar, the first female member of the faculty at the Columbia University School of Medicine and a highly energetic and charismatic figure, went on to earn a degree in public health and become Vice President for Medical Affairs at the March of Dimes. In that role she helped the organization expand its focus from birth defects (the cause chosen after the successful development of the polio vaccine in the 1950s) to outcomes of preterm delivery (March of Dimes 2011).

Robertson terms the period between 1950 and 1970 "the heroic years" in neonatology, when "All treatments were new, untested, and we marched on without fear!" (Robertson 2003b, p. 154). Equipment innovations supported pediatricians in developing resuscitation techniques, laboratory testing to monitor blood gases and other physiological measures, and intravenous lines to facilitate nutrition and the administration of medications. Public attention was heightened in 1963, when President Kennedy's third child was delivered five weeks prematurely and died shortly thereafter from respiratory distress; research funding became available to address this condition in preterm newborns. Innovations in ventilation and eventually the development of artificial surfactant helped infants with immature lungs transition to breathing on their own. The pediatric subspecialty of neonatology was founded, and the number of neonatal intensive care units expanded. Physicians directing these units tried numerous interventions, some helpful and some eventually found to be harmful. Once interventions appeared to be effective, they were trialed with neonates at younger and younger gestational ages. There was no attempt to conduct formal clinical trials to assess interventions before they were widely introduced, and any iatrogenic effects were not discussed until replacement therapies became available. The focus of interest was on whether the interventions increased short term survival, and in fact, birth weight-specific mortality for preterm infants declined across the U.S. population in this period. Generally, the long-term impact of the interventions on the health status and development of surviving infants were not taken into account as the technologies developed (Budetti and McManus 1982; Jain and Vidyasagar 1989; Kirby 1999; Philip 2005; Robertson 2003b).

Robertson terms the period between 1970 and 2000 as the "experienced years" in neonatology, when treatments were refined, guidelines and recommendations were issued in an attempt to systemize treatment across neonatal intensive care settings, new innovations were more likely to be subject to research, including randomized clinical trials, and research ethics review boards wielded more authority (Robertson 2003c). As one example of some limitation of technology in this period, extracorporeal membrane oxygenation (ECMO), a rescue therapy that involves circulating a neonate's blood through an oxygenation machine outside of the body if attempts at ventilation fail, rose and then fell in popularity, as research identified its neurologically damaging side effects (Perkins 2008). Two research networks of NICUs, the Vermont-Oxford network and the National Institute of Health (NIH)'s Neonatal Research Network, were established and survival rates and outcomes at different gestational ages were reported across hospital members (Lucey et al. 2004; Vohr et al. 2005). It became obvious that there were wide variations in neonatal management practices and outcomes across settings. The ethics of providing untested therapies to patients in clinical practice came under question (Tyson 1995). In the mid-1980s, British physicians and researchers developed easily accessible databases that pooled information from multiple clinical trials to inform physicians about the scientific evidence base for therapies. Obstetric and neonatal care were the first topics to be treated in-depth in the Chochrane database, because there seemed to be the most disagreement in these disciplines about the value of different therapies (Starr et al. 2009).

5.2.2 The Resuscitation Decision

As neonatal intervention practices became more established, attention shifted toward the critical decision about whether to always initiate resuscitation for extremely preterm infants. This initiation decision was particularly important because, once neonates start treatment in a neonatal intensive care unit, it becomes more difficult to shift from aggressive to palliative care. Palliative care allows infants to die in comfort, often in the arms of their parents, without extensive medical interventions. In their ethnography of NICUs conducted in the late 1970s through the early 1980s, sociologists Jeanne Guellemin and Lynda Holmstrom observed that multiple rationales coincide to justify aggressive treatment: preterm and marginally viable newborns enter the unit as referrals from in-hospital or out-of-hospital obstetric units, so they automatically take on the status of critically ill patients appearing to be requesting therapeutic care. Most are observed to be responsive to this care, at least in the short term, and with much invested in this care, it is difficult for the medical professionals to admit "defeat" and stop interventions, even when it appears that a newborn is not going to survive. Physician leaders of these units have a sense of mission that includes advancing the clinical frontier of treatment, so every aggressively treated case is an opportunity to learn something new about neonatology, even if it is unlikely that any particular treated infant will survive. In the hospitals they observed, medical staff worked as a team, and consensus of the entire team was required for decisions to halt treatment. Ethical lines of thinking (to be discussed in Chap. 6) seemed to favor life-saving treatment. As one example of the pressures of this type of decision-making, the authors write:

> One intervention leads to another, often not by any dramatic process of decision making, but in small steps. As one resident said, "You get into the morass bit by bit". A theme often heard at Northeast Pediatric was that it is hard to intervene halfway. The case of an infant with a fatal condition led to this discussion:
>
> Social worker: "Once you start, can you morally, ethically stop?"
>
> Fellow: "It's hard. It's all or none. That's why it's so important to make the decision about whether to put the baby on the respirator. Once you put the infant on the respirator, then

> you're into it. Then if he needs a chest tube, you do a chest tube; if one, you do the second tube. One thing leads to another. There is no [definitive] evidence yet about the brain. So it makes it difficult to find a reason to turn [the respirator] off, except our experience. (Guillemin and Holmstrom 1986, p. 130, brackets in the original, reprinted with permission from Oxford University Press. Northeast Pediatric is a pseudonym for "a Level III nursery in a large pediatric hospital in the eastern U.S.")

Guillemin and Holmstrom state that medical personnel in this NICU believed that funds would be available to support the care of the newborns, and did not consider financial issues in their treatment decisions.

By the early 1990s, a consensus opinion had developed which held that neonates born at or after 25 or 26 weeks gestation could likely be supported through survival to discharge (average estimated survival rate was reported to be 59 % in 1990, and about 76 % a decade later). Neonates born earlier than 23 weeks gestation, or smaller than 500 g, were not likely to survive, or to survive only with major disabilities (survival rates estimated at 15 % in 1990, 30 % a decade later). Between 23 and 25 weeks there was a "gray zone" of viability. Formal recommendations of the American Academy of Pediatrics (APA), which have been relatively continuous since first articulated in 1995 (APP and ACOG 1995; Batton 2009; MacDonald 2002), are that informed parent decisions should guide care for infants in this period:

> Although it is not feasible to have specific criteria for when the initiation of resuscitation should or should not be offered, the following general guidelines are suggested. If the physicians involved believe there is no chance for survival, resuscitation is not indicated and should not be initiated. When a good outcome is considered very unlikely, the parents should be given the choice of whether resuscitation should be initiated, and clinicians should respect their preference. Finally, if a good outcome is considered reasonably likely, clinicians should initiate resuscitation and, together with the parents, continually reevaluate whether intensive care should be continued. (Batton 2009, p. 422)

It should be noted that these resuscitation guidelines are based on the likelihood of short term survival, not the likelihood of long-term disability among surviving preterm infants.

Despite popular critiques of neonatal care because of the pain experienced by treated neonates, the stress on parents, uncertain outcomes, and community pressure for more conservative care, the actual resuscitation practices of neonatologists remain more aggressive than the guidelines prescribe (Harrison 2008). Neonatologist Jaideep Singh and colleagues conducted two surveys of the resuscitation practices of neonatologists, one in 1996 and one in 2003, and combined the findings because there was no significant difference in reported practices between the two years. Table 5.2 summarizes their findings.

The survey researchers were struck by the fact that nearly half of the respondents to their survey added a comment indicating that they would wait to "see how the baby looked" before deciding on resuscitation, a practice sometimes referred to as allowing the infants to "declare themselves." The researchers used data from their own NICU in Chicago to test whether a preterm infant's Apgar measures at birth,

Table 5.2 Neonatologists' reported resuscitation practices, 1996–2003, from Singh et al. (2007), and actual resuscitation practices, NIH neonatal network 2006–2011, from Rysavy et al. (2015)

	22 weeks gestation	23 weeks gestation (or less than 500 g)	24 weeks gestation (or 500–600 g)	25 weeks gestation (or 600–750 g)	26 weeks gestation (or 750+ g)
1996–2003 neonatologist survey responses					
Would provide full resuscitation (%)	4		59	91	99
Would provide comfort care (%)	52		2	1	–
Would defer to parent's wishes (%)	36		37	8	–
2006–2011 NICU practices					
Full active treatment (%)	22	72	97	100	100
Survival for actively treated infants[a] (%)	23	33	57	72	82
Survival without major impairment for actively treated infants[a] (%)	9	16	31	44	59

[a] Survival and disability rates measured and 18 months of age

including heart rate, appearance and respiration, were predictive of eventual survival, and found that they were not. They concluded that the practice of making decisions about resuscitation based on an infant's appearance is not evidence-based (Singh et al. 2007).

A study published in 2015 describing neonatal resuscitation practices from 2006 to 2011 among the 24 hospitals in the NIH Neonatal Research Network found a generally more aggressive approach to treatment than even that documented in the earlier Singh et al. study, which was already more aggressive than the professional practice guidelines. These are also shown in Table 5.2, and demonstrate the lowering of the gestational age threshold for resuscitation over the preceding decade. Variation in the decision of whether or not to initiate treatment at a given gestational age was observed at the hospital level; that is, some hospitals had more aggressive resuscitation policies than others (Rysavy et al. 2015). News coverage of this study illustrated this variation:

> At Iowa, Dr. Bell said, treatment is offered to most 22-week-olds, and he considers 22 weeks a new marker of viability. 'That's what we think, but this is a pretty controversial area, Dr. Bell said. 'I guess we would say that these babies deserve a chance.'

> Dr. Jeffrey M. Perlman, medical director of neonatal intensive care at New York-Presbyterian Hospital-Weill Cornell Medical Center, takes a different view. He said it was important to consider that long months in neonatal units can be 'like riding an obstacle course or flying in a plane with bad turbulence, and each of these down spirals can have an impact on the brain.'
>
> At his hospital, 'we go after the 24-weekers,' he said. 'If it's 23, we will talk to the family and explain to them that for us it's an unknown pathway. At 22 weeks, in my opinion, the outcomes are so dismal that I don't recommend any interventions.' (Belluck 2015, p. 18, reprinted with permission from The New York Times).

The news coverage also suggested that this study could contribute to a discussion about lowering the consensus gestational age at which treatment is recommended, and that this would affect the threshold of viability that is incorporated into many state regulations concerning abortion. This illustrates again, as discussed in Chap. 4, the way the issue of preterm infant resuscitation is intertwined with abortion policy.

5.3 The Organization and Financing of Perinatal Care

The preventive and rescue technologies applied to preterm birth in the U.S. are closely connected to the organization of obstetric and neonatal care. In some ways, the organization and financing of obstetrics and neonatology are complementary, and in some ways they are in conflict. Neonatologists and their NICUs[7] depend on referrals from delivering obstetricians (or other types of physicians or nurse midwives) for their patient flow. Actions taken by these personnel, either immediately before or at the point of delivery, impact the health status of neonates and consequently the eventual outcome of intensive care. In turn, the rescue technology of NICUs is one of the only really effective treatments that obstetrics personnel can offer women if they end up experiencing a preterm or complicated delivery. However, the ready availability of neonatologists and NICUs encourages obstetricians to deliver preterm infants in local settings, rather than transferring high-risk pregnant women to hospitals where they can be treated by obstetrics specialists, who may be more prepared to delay delivery until the fetus matures.

5.3.1 Practice Models in Obstetrics

In contrast to U.S. medicine in general, which sociologist Paul Starr characterized as retaining its cottage industry form of independent solo or group physician

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[7] The term "neonatal intensive care" is used here to refer to all levels of these services. Some hospitals offer "special care" units with less immediately available technology and expertise, for use in cases where the newborn is relatively less compromised.

practices into the 1980s (Starr 1982), Perkins (2008) observes that, led by academically based practices in the early 1900s, the delivery component of obstetrics practice is organized more like a factory. There are different specialists performing different tasks at different locations, pressure to move women through the labor process at a particular pace, and arrangements devoted to ensuring that physicians can minimize the time spent on each patient at delivery. This format for organizing delivery care has allowed physicians to manage high volumes of maternity patients, assuring a flow of revenue for themselves and the hospitals where they practice, while avoiding the tedium that might arise from providing the same relatively uncomplicated service, during the majority of their practice time. Academic practices set the form for community-based obstetrics practices, and the federally financed boom in hospital construction after World War II created hospital settings similarly organized for factory-style delivery services. As noted above, technology in obstetrics has been prized because of its prestige, potential for revenue generation and value in competition with other specialties that provide maternity services. As technology became more complex and expensive, obstetrics became more capital-intensive, closing out competitors and requiring those who remained in practice to serve large volumes of patients in order to stay financially viable.

Another organizational feature of obstetrics, dating from the early part of the twentieth century, is the way different delivery settings and medical personnel specialize in serving women of different social classes, or financial means. Early on, medical students and trainees provided care for low-income women, while specialists provided care to wealthier, private patients (Perkins 2008). In the 1960s, two intersecting trends promoted the academic leaders of the obstetrics profession to propose a reorganization of the entire specialty into regional systems. Under the proposed reorganization, obstetrics personnel (preferably teams of nurses and support professionals led by board certified obstetricians) would be located in feeder hospitals assigned to geographic areas. Feeder hospitals would be linked to medical schools, which could treat the most complicated cases.

The first trend, supporting the reorganization as discussed in Chap. 4, was the public financing that became available to improve maternity care for low-income women, both through direct funding of state and local health departments and other grantees, and through Medicaid insurance to cover maternity care for women on public assistance. In his inaugural address as president of the American College of Obstetricians and Gynecologists (ACOG) in 1967, Duncan Reid of Harvard Medical School expressed the belief that a federally funded system could not support the continuing stratification of maternity patient care by income, and that federal funds should be used to support “quality care.” He remarked:

> It is a personal view, based on considerable first hand observation, that government programs of medical care involving large numbers of patients should and indeed must be integrated with the private sector of medicine at both physician and hospital levels. Any program that avoids this arrangement will lose the advantages of the total medical skills this country has to offer, else short of a National Health Act, it is doubtful that qualified obstetrician-gynecologists can be secured in sufficient numbers to afford quality care and give permanence to the “urban” programs. It is no longer acceptable to have two kinds of

> patient care and two kinds of hospitals, one for the carriage trade or private patient and another for the poor or nonprivate patient. (Reid 1967, pp. 272–273, published by the American College of Obstetricians and Gynecologists)

In Reid's opinion, regionalization of obstetrical care would solve this and two other problems facing the profession. First, placing obstetricians into the role of captains of a team of personnel would help to resolve the profession's difficulty in recruiting the highest quality of residents into OB-Gyn residency programs, which was believed to occur because obstetrics work is often routine. Second, organizing obstetrics care into regional catchment areas would reduce the need to staff multiple small obstetrics units that were not offering a full set of services (for e.g., anesthesia so women could have emergency cesarean sections, if necessary). Staffing fewer hospitals with a team of providers would thereby solve the physician shortage problem without actually training more obstetricians, who would eventually be competitors to those already in practice.

This latter point represents health scholar Charlotte Bridgeman Perkin's view, which is that the idea of obstetrics regionalization came about in this era because of a second social trend: the U.S. in the 1960s and 1970s experienced a marked decline in the birth rate, after the high volume experienced during the post-World War II baby boom. With birth rates declining, there would rapidly be a surplus, rather than a shortage, of obstetricians and hospital obstetrics units. Furthermore, a survey of maternity care conducted after Reid assumed the presidency of ACOG revealed that medical school affiliated hospitals were providing maternity care for only 20 % of the nation's patients, which was a concern for the revenue base of academic specialists. The academic physicians would benefit the most from a regionalized maternity system (Perkins 2008).

5.3.2 Toward Perinatal Regionalization

Also in the 1960s, while obstetricians were concerned about reduced birth rates and the impact of expanded government involvement in financing on their practices, pediatricians were rapidly expanding the range of therapies that could be offered to improve the survival of preterm newborns. Early reports of improved survival and reduced neurological damage for preterm infants receiving specialty care suggested that the expansion of NICUs was a possible pathway to improving the U.S. infant mortality rates. As discussed in Chap. 4, infant mortality rates had become a political issue with the antipoverty and civil rights movements of the decade, and also because of the U.S.'s relatively low international ranking on infant survival. Yet the new hospital NICUs were expensive to operate, and there were relatively few trained physicians and nurses available to staff them. Furthermore, the units were dependent on linkages to relatively large numbers of hospital maternity units, and on an efficient transportation system to transport newborns needing care quickly to the specialty setting.

The Children's Bureau/City of Chicago funded regionalized neonatal system begun in the 1940s offered one solution, and the idea of regionalizing other highly specialized medical services for cardiac diseases and cancer, was beginning to take hold and to receive federal financial support. In 1967, the Title V program, which provides federal support for state and local maternal and child health programs, and had expanded in 1963 to allow direct federal funding of prenatal care services, was amended again to allow for direct funding of selected NICUs. Other philanthropic resources and federal research and facility funds were directed toward developing units linked to major university affiliated medical centers. Models for integrating the new NICUs into some kind of regional system began to be formulated, with regionalized systems in Canada in particular serving as a model (Cone 1985; Holloway 2001; Lesser 1985; Meyer 1980).

These early approaches to regionalization focused primarily on developing systems to transport sick newborns to intensive care centers. Depending on the area, these arrangements could be voluntary and informal, could involve state regulatory agencies, or could intersect with the federal health planning legislation, which was in place in the United States between 1966 and 1987.[8] This type of regionalization was generally not controversial, since obstetrics services remained in place, the sick newborns were not already the patients of local pediatricians, and few community hospitals had the resources to create their own NICUs. Financing for newborn intensive care was limited, so providing this type of care was not perceived, in these early years, as a revenue generating activity (McCormick and Richardson 1995; Meyer 1980).

Still, the American Medical Association (AMA) and the other medical professional organizations involved held a vision for consolidating and regionalizing obstetrics care as well as newborn intensive care, so that high-risk obstetrics patients could be identified before delivery and transferred to the care of specialized obstetrics centers, and obstetric care in general could be upgraded (with more technology made available). In 1970, after a series of professional conferences focused on the issue (Meyer 1980), the AMA Committee on Maternal and Child Care had the following statement included in the conference proceedings of the decennial White House Conference on Children[9]:

> National standards should be developed for perinatal care, including standards for newborn intensive care units. Hospitals unable to meet such standards should be required to close

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[8] The health planning movement was an effort to rationalize the distribution of health services in the United States by establishing local health planning agencies that would approve or disapprove the expansion of (primarily) hospital services based on documented population needs. Initially the activities were voluntary, but local planning was federally mandated in 1966. The federal mandate expired in the early 1980s with the ideological shift towards allowing market forces to determine the distribution of health care resources (Melhado 2006).

[9] The White House Conference on Children was held decennially beginning in 1909. The first conference, in 1909, marked the founding of the U.S. Children's Bureau and federal government involvement in the field of maternal and child health. The 1970 conference was the last one convened.

> their obstetrical and neonatal services. They should be provided incentives to remodel this space for other uses.
>
> Regional perinatal centers should be established, equipped and supported by Federal funds, and means should be developed to transport babies with special needs from outlying hospitals to these regional centers. (Hess 1971, p. 172)

In 1971, the entire governing board of the AMA endorsed the idea of perinatal regionalization, and in 1972 the APA, the Academy of Family Practice, the AMA, and ACOG requested the March of Dimes Foundation to finance and organize a committee which would set guidelines for regionalized perinatal systems.

While the March of Dimes committee was deliberating on a scheme for broader perinatal regionalization, several components fell into place that supported the expansion of neonatal intensive care and its linkages to obstetrics systems. At the currently operating NICUs in the United States, Canada, Great Britain, and Europe, the data were showing improved survival rates for treated infants, but also showing that infants born in hospitals with such units had better survival rates than those born at hospitals without these specialized services and transported in after delivery (Desmond 1991).[10] Furthermore, one promising neonatal intervention, the testing of lung maturity for fetuses in utero and the provision of steroids to a pregnant women before a preterm delivery to hasten lung maturity, was found to be difficult to implement because of a lack of coordination between obstetrics and neonatology (Philip 2005).[11] At the policy level, the federal Health Resources and Services Administration informed states that their plans for use of federal Title V funds would require a plan for perinatal regionalization by 1975 (Lesser 1985). The APA and the Health Insurance Association of America collaborated on model state statutes to mandate that private health insurance companies include newborn care in their coverage, and these were widely adopted, helping to ease the financial burden for hospitals providing neonatal intensive care. The Medicaid program, established in 1967, provided payment for newborn hospital care for the lowest income segment of the population. In 1972, ACOG established a subspecialty board for maternal-fetal medicine, for obstetricians focusing on the care of high-risk pregnancies. In 1973, the APA established a neonatology-perinatology specialization, with board certification in the specialty becoming available in 1975 (Holloway 2001).

In 1974, Irwin Merkatz, a specialist in high-risk obstetrics at Case Western Reserve University in Cleveland, convinced the Robert Wood Johnson Foundation to fund a demonstration project in which eight regions of the country would

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[10] In fact, this had been observed by the obstetricians who developed the first incubators in Paris in the nineteenth century as well (Baker 1996).

[11] Philips writes that successful reports of prenatal steroid use were available in 1972, but “possibly because it was published in a pediatric journal, but also because a subsequent collaborative study published in an obstetrics journal provided a less conclusive response, it was several more years before the body of evidence convinced obstetricians to sign on to this remarkably beneficial adjunct in the care of a preterm infant” (Philip 2005, p. 804). The obstetrics consensus conference that recommended prenatal steroid use occurred in 1994.

establish perinatal regionalization schemes that would involve assessing risk in pregnant women and planning for their referral to specialty centers, along with establishing a transportation system to bring women in labor and their preterm infants if born in local hospitals to specialty centers for care (Holloway 2001).[12] Survival data for low birth weight infants born in these test regions over the following five years would be compared to survival of the same weight infants in comparison areas without perinatal regionalization. Both the Robert Wood Johnson group and the members of the March of Dimes committee were aware of the obstacles to perinatal regionalization within the U.S. health care system (Merkatz and Johnson 1976; Ryan 1975). One of the biggest obstacles was the reluctance of obstetrics care providers to refer pregnant women to higher levels of care, when the limitation on their practice was not their own expertise, but the capacity of their hospitals to care for high-risk women, and particularly for the newborns (Merkatz and Johnson 1976).

The March of Dimes committee's report, entitled **Toward Improving the Outcome of Pregnancy** (TIOP), was issued in 1976. The committee advised that hospitals with obstetric or newborn services be ranked as "Level I," "Level II," or "Level III" depending on the range of specialty services they provided. Level I hospitals would be able to provide prenatal care, maternal risk assessments, uncomplicated labor and delivery services, newborn resuscitation and uncomplicated neonatal care; they should have the capacity to provide cesarean sections within 30 minutes of an identified need, 24 hours a day, 24 hour availability of anesthesia, radiology, laboratory, blood transfusions, and the capability to initiate IV therapy for newborns. Level II hospitals would offer all of these services plus inpatient care for prenatal complications, the capability to provide cesarean sections within 15 minutes, inpatient postpartum care, a special care nursery and the ability to provide short term assisted ventilation. Level II units should have at least one obstetrician with "special interest, training and experience" in high-risk obstetrics, and at least one pediatrician with the same for neonatology, who could serve as coordinators for the maternity services.

According to the TIOP, level III units would offer all of these services, plus full time personnel to manage complicated maternity problems and provide care for the most fragile newborns in the region. These units would also manage the transport system, provide consultation and continuing education and collect and evaluate data on the system's results. Obstetrics and neonatal personnel should have extensive training and experience in high-risk care, and a full complement of subspecialists in pediatrics, maternal medicine, genetics and surgery should be available for consultation. The TIOP anticipated that some public funding source would be identified to support perinatal systems, and that "effective utilization in a society with limited resources" would require restriction of the number of highly specialized units in an

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[12] 34 regions applied for Robert Wood Johnson funds to organize as perinatal regions, and the eight demonstration areas selected for funding in 1975 included Arizona, Cleveland, Dallas, parts of Los Angeles, the Upper West Side of Manhattan, and a 15 county area around Syracuse, New York.

area, to avoid wasteful duplication. It was also anticipated that multiple Level I units in an area could consolidate into a single, larger, Level II unit, which was envisioned to be the type of hospital that provided the majority of obstetrical care (Ryan 1975). Both Level II and Level III designated hospitals were expected to have at least 2000 deliveries per year, although only 10 % of units operating at the time had this volume of deliveries. The March of Dimes' TIOP report was widely disseminated, and the guidelines were adopted by national and regional health planning agencies and state health departments.

Early on, many communities organized themselves into cooperating networks of hospitals for the care of preterm and other high-risk infants, supported to various extents by local health planning agencies and state level healthcare regulation (Staebler 2011). When the Robert Wood Johnson demonstration project was evaluated after 5 years of operation (1974–1979), evaluators found that there was actually no difference in neonatal mortality between the regions financed to create regionalization systems and their comparison regions. The explanation seemed to be that both the demonstration and the comparison regions had an increase in the portion of very low birth weight infants born in tertiary level hospitals (hospitals with more than 1000 deliveries a year and reporting having an NICU), and this had been continuing since the early 1970s (McCormick et al. 1985). After Robert Wood Johnson Foundation funding ended in 1980, however, regionalization in two of the sites, Los Angeles and Dallas, collapsed. Regionalization continued in other sites, but hospitals were no longer able to maintain the shared data system that facilitated risk assessment and transfer of maternity cases (Holloway 2001). The experience of these sites foreshadowed some of the later challenges experienced by regionalized systems. In the absence of shared or public financing, hospitals receiving referrals for specialty care would themselves have to bear the costs of maintaining communication, professional education, and patient transport.

One impact anticipated by the advocates of regionalization was the closure of small obstetrics units in hospitals that could not meet even Level I criteria. This phenomenon was observed, for example, in Massachusetts with the initiation of their licensing and regionalization program in the early 1970s (Meyer 1980). While the birth volume expectation articulated by the March of Dimes committee as 2000 deliveries per year was controversial, was never enforced, and was not included in later revisions of TIOP or professional guidelines on levels of care, the technological requirements for licensure, along with declining birth rates and the resulting financial pressures, contributed to the closing of many smaller obstetrics units. Table 5.3 shows that overall in the U.S., the number of hospitals with obstetrics units and deliveries declined 32 %, from 3188 to 2588 between 1985 and 2010. Smaller hospital units had more of a decline than larger units. The portion of all U. S. counties with obstetrics hospitals declined from 78 to 60 % of all counties over this time period.

Critics suggest that this aspect of perinatal regionalization has the negative effects both of reducing geographic access to maternity care and shifting the type of obstetrics care available to women with low-risk pregnancies toward the type of care provided in larger and more technologically oriented obstetrics settings

Table 5.3 Change in hospitals with deliveries in the U.S., 1985–2010, based on American Hospital Association annual survey data

Year	1985	1990	1997	2000	2006	2010	% change
Hospitals by annual delivery volume	N	N	N	N	N	N	N
<250	1163	907	730	631	524	456	−60.8
250–500	692	593	551	506	427	436	−37.0
501–1000	786	749	664	633	567	552	−29.8
1001–2000	695	655	587	588	585	549	−21.0
2000+	482	604	483	534	596	595	+23.4
Total	3818	3508	3015	2892	2699	2588	−32.2
% with NICU							
<250 (%)	0.3	0.1	0.5	0.5	0.6	0.9	+155.0
250–500 (%)	1.0	2.0	3.6	3.2	1.6	2.3	+126.7
501–1000 (%)	7.5	8.4	14.5	11.8	13.8	16.1	+114.8
1001–2000 (%)	25.8	29.0	39.9	38.9	38.6	41.9	+62.7
2000+ (%)	63.5	69.9	76.2	78.1	80.9	84.2	+32.6
Total (%)	14.4	19.6	23.8	25.6	29.5	32.2	+123.7
% Counties with OB hospitals	77.6	72.2	68.8	69.3	63.3	60.4	−22.2

(Perkins 1994). Others emphasize the value of preserving Level I obstetrics facilities, particularly in rural areas, because obstetrics unit closures require women in labor to travel long distances for delivery care (Rosenblatt et al. 1988).

Another important impact of the TIOP report was the creation of an authoritative set of norms for the facilities required to care for high-risk pregnant women and infants. The Level II perinatal hospital care described in the report became essentially the standard of care for high- risk women (Holloway 2001; McCormick and Richardson 1995; Perkins 1994). This soon became relevant to the expanding malpractice crisis in obstetrics, because, as noted in Sect. 5.1.2, failure to provide the agreed upon standard of care, when there are negative consequences such as infant death or permanent injury, is grounds for a malpractice suit. While a claimant would still need to show that failure to provide appropriate care or to refer a woman to a Level II hospital in the specific instance caused the injury, and that the situation was not an emergency but could have been anticipated in time to take appropriate action, experts contended that it was legally risky for obstetricians to provide high-risk care without access to appropriate specialists and in hospitals without the capability for neonatal resuscitation. The accumulating data suggested that the delivery should take place in such a hospital; transfer of the newborn after delivery was not the recommended standard of care. While in theory, such access to delivery services would be available with a well-functioning perinatal regionalization system, in practice there were many obstacles to such care, including difficulty predicting when the need would occur, reluctance of local obstetrics providers to recognize when the boundaries of their expertise were being exceeded, desire to follow obstetrics patients through to delivery, and desire to retain patients in the local hospital setting (Richardson et al. 1985).

Thus, as the 1980s unfolded, hospitals were under increasing pressure to upgrade their maternity facilities to the standards at least of Level II hospitals; this would allow them both to retain their obstetrics staff who were concerned about malpractice suits, and to continue to attract adult female patients, who were perceived to make healthcare decisions for families and were thought to value state-of-the-art obstetrics care. Another factor supporting the addition of neonatal intensive care units into hospitals with obstetrics services was a concern that new forms of health insurance coverage, ones that more aggressively managed care and costs than traditional forms, would seek to selectively contract with providers as a way to reduce costs. Hospitals without NICUs feared they would be excluded from such contracts (McCormick and Richardson 1995; Richardson et al. 1995).

Fortunately for these community hospitals, the early restriction on expansion of such NICUs because of a shortage of neonatologists and similarly trained personnel had eroded quickly after training programs were established in the mid-1970s. By 1983, by some estimates, there were already enough neonatologists in practice to meet the needs of the low birth weight infants born in the U.S., and training programs were continuing to produce about 300 additional neonatologists per year (Merenstein et al. 1985). Concerns about the availability of reimbursement to hospitals for providing neonatal intensive care also decreased. The mid-1980s Medicaid expansion of maternity and child coverage to at least 133 % of the federal poverty level, regardless of whether women were eligible for welfare benefits, increased the portion of women and newborns whose care would be reimbursed by insurance. A further expansion offered Medicaid coverage to infants with catastrophic medical problems, with less stringent low-income requirements for parents, and this also provided some guarantee for financial reimbursement of neonatal intensive care (McCormick and Richardson 1995). Also, resuscitation and the technology for neonatal intensive care improved over this period and became easier to use by less experienced personnel.

The number of hospitals with NICUs expanded after 1980. Table 5.3 shows that the portion of obstetrics hospitals with NICUs more than doubled between 1985 and 2010, and hospitals with the most births were most likely to have NICUs. Table 5.4 shows a 47 % increase in the number of hospitals with NICUs, from 604 in 1985 to 886 in 2010. The net increase in numbers occurred only among NICUs co-located with obstetrics units, with the most increase occurring in the largest units. The count of stand-alone NICUs did not change, although the unit size of these also increased. The geographic spread of hospitals with NICUs was not as large as the geographic shrinkage of available obstetrics hospitals shown in Table 5.3; the portion of U.S. counties with hospitals with NICUs increased from 12.2 % in 1985 to 16 % in 2010.

Table 5.4 Change in hospitals with neonatal intensive care units in the United States, 1985–2010, based on American Hospital Association annual survey data

Hospital type	NICU bed size	1985	1990	1997	2000	2006	2010	% change
With OB units	<10	250	290	302	282	271	264	5.6
	15-Oct	100	117	109	113	123	134	34.0
	16–20	82	106	110	111	112	106	29.3
	21–30	71	100	104	102	127	135	90.1
	30+	49	75	93	132	163	195	298.0
Total		552	688	718	740	796	834	51.1
Without OB units	<10	15	12	13	2	4	3	−80.0
	15-Oct	3	4	5	3	4	2	−33.3
	16–20	7	9	8	4	5	5	−28.6
	21–30	15	12	10	12	12	5	−66.7
	30+	12	18	22	21	31	37	208.3
Total		52	55	58	42	56	52	0.0
Overall total		604	743	776	782	852	886	46.7
Counties with NICU hospitals (%)		12.2	13.7	14.9	15.1	15.7	16.0	31.1

Observing only the time period through the mid-1990s, Howell et al. (2002) reported a 99 % increase in hospitals with NICUs since 1980, along with a 140 % increase in NICU beds and a 268 % increase in the number of neonatologists. The increase occurred across all metropolitan areas, regardless of size, but the largest metropolitan areas, particularly in the Northeast, had more small units. The pattern noted by Howell et al. suggests what many observers reported: that the pressure to add neonatal intensive care units generated the most response in suburban areas where hospital competition was fiercest and patients were most likely to have private insurance. In that sense, the expansion of specialized care for preterm infants replicated the social stratification of obstetrics care observed since the beginning of the twentieth century. Specialized care was available to low-income women when they were patients of academic medical centers, and to higher income women more generally in their communities. Charlotte Perkins, who worked in the health planning office in Oakland California in the early 1980s recalled:

> Perinatal planners for Oakland CA, for example, identified larger voluntary hospitals as the most suitable facilities for Level II services. Yet the voluntary hospitals were not located where most of the low-income, high-risk population lived; the county hospital was located there. Despite the fact that half of the county's neonatal deaths and 85 percent of its black neonatal deaths occurred among Oakland residents, the county hospital serving the high-risk population had a hard time getting funds for neonatal intensive care. (Perkins 2008, p. 91, reprinted with permission from Taylor & Francis, http://www.informaworld.com)

The county hospital was considered less suitable than private hospitals for expansion because it did not have as many appropriate physician specialists.

5.3.3 Away from Perinatal Regionalization

There was broad agreement by the 1990s that the expansion of NICU facilities had resulted in a supply of both units and neonatologists which exceeded actual need as estimated by the rate of preterm births, even when improved survival of the newborns and the consequent need for more care were taken into account (Goodman et al. 2001; Goodman and Little 1998; Howell et al. 2002; Schwartz 1996). A benefit of this expansion was that it increased the likelihood that preterm or low birth weight infants would be born in better equipped settings as opposed to Level I or primary care obstetrics settings. This improved their likelihood of survival, even in the absence of organized regionalization systems (Gould et al. 2002). A perceived problem with the ample supply of these units was that it drew neonatal patients away from the largest, most specialized centers (Haberland et al. 2006; Phibbs et al. 2007). These specialized types of hospitals were redesignated as "quaternary" (that is, Level IV) centers in revisions of the March of Dimes' TIOP, while the expansion of the number of NICU units, in the absence of a plan for coordinating resources, was termed "de-regionalization." Under de-regionalization, the largest and most specialized centers provided care to the most complex neonatal cases, but had too few cases to financially support a transport system or the professional education efforts required for an organized system. A related perceived problem with the ample NICU supply was that it allowed many preterm infants to be treated in relatively low volume units, where they might fail to benefit from care by the most experienced personnel.[13]

By the year 2000, neonatology had become numerically the largest subspecialty within pediatrics. Research on neonatology dominated pediatric journals and academic conferences, and neonatologists served as journal editors and professional leaders (Lantos 2001; Philip 2005). By 2010, estimates were that about half of the approximately 4000 neonatologists in practice worked in academic medical centers, about 38 % worked in community hospitals, and the remainder was in private practice. This robust demand for neonatologists was due in part to the continuing revenue that NICUs provided to physicians and hospitals, as the quote from John Lantos at the beginning of this chapter suggests (Freed et al. 2011; Lantos 2001). The continuing value that NICUs represent to hospitals also created a market for inventors and manufacturers of NICU technologies, since NICUs must continually upgrade their facilities in order to remain competitive.

The demand to maintain a patient count in the many hospital NICUs available in the U.S. inevitably creates a tension with efforts to enforce perinatal regionalization schemes, which are premised on transporting women in labor so that they can deliver at higher level centers (Staebler 2011). While neonatologists are increasingly available in community settings, obstetricians specializing in high-risk pregnancies (maternal-fetal medicine physicians, or MFMs) are almost always located in the highest level perinatology settings. They depend on perinatal regionalization for patient flow. There are one-third as many MFMs as neonatologists, about 1355 in 2010, and specialty training programs in the field have difficulty filling their residency positions (Rayburn et al. 2012a, b).

Early on in the development of this subspecialty of obstetrics practice, it was clear that the most practical mode of MFM practice was to serve as a consultant to other obstetricians. There was no way to concentrate on serving women with high-risk pregnancies without receiving referrals from other physicians, and specialists were unlikely to receive such referrals if they also competed with these same obstetricians for low-risk maternity patients (Blanco 1989; Sokol 1989). Contemporary MFMs have expressed a sense of marginalization as a consequence of this arrangement, as Eden et al. remark:

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[13] Most studies show that the most seriously compromised neonates have better survival rates when born in higher volume, more specialized settings (Chung et al. 2010; Cifuentes et al. 2002; Phibbs et al. 2007). However the threshold for this differentiation is difficult to identify and may change over time as neonatal technology improves. It is difficult to use observational data to examine neonatal outcomes by hospital characteristics, in part because such research must take into account the fact that more seriously compromised cases are selectively referred to larger centers. Some studies show that the quality of care provided in an NICU has more impact on birth outcomes than simply the patient volume in a unit (Lorch et al. 2010).

> The MFM is supposed to supervise and coordinate basic and specialty care. This includes performing fetal diagnoses (targeted ultrasound, fetal echocardiography), advanced fetal therapy (e.g. intrauterine fetal transfusion and treatment of cardiac arrhythmias), medical, surgical, neonatal and genetic consultation, and management of severe maternal complications. Instead, the MFM sub-specialties may find themselves waiting to be consulted by individuals with less training or excluded from the peer review process or coordination of regionalization of care. (Eden et al. 2005, p. 253, reprinted with permission from Taylor & Francis, http://www.informaworld.com)

The consequence of this situation is that a minority of women who might benefit from subspecialty obstetrics care actually receive such care, or they see MFMs later in pregnancy when it may be more difficult to manage their health issues (Britt et al. 2006). Obstetrics care providers in community settings have more ready access to neonatology expertise and NICU capacity than to highly specialized MFM care. This creates a set of circumstances that may tip the balance in deciding whether to perform an interventional delivery before term in the face of pregnancy complications, rather than providing expectant management and delaying delivery. Some MFMs have suggested that the limited availability of high-risk specialty maternity care, in contrast to the widespread availability of specialized neonatal care, is partly responsible for maternal morbidity and mortality rates which have increased in the U.S. in recent decades (Hankins et al. 2012).

Finally, although in many communities dedicated high-risk obstetrics practices are relatively scarce, particularly compared to the availability of NICUs, their services may still be stratified by social class. This is accomplished by sorting women with different types of health insurance, public (Medicaid) versus private, into the care of different groups of providers, or even into the care of the same providers practicing in different physical settings. Participation as a provider in the Medicaid program is optional for physician practices, and decisions of providers not to participate results in an uneven distribution of Medicaid patients across available providers (Decker 2013; Fossett et al. 1990). Anthropologist Khiara Bridges quotes one of her study participants who had a previous experience delivering preterm twins at a private hospital in New York City which accepted Medicaid patients. The woman ended up settling a malpractice suit with the hospital, after one of the twins died and the other was diagnosed with cerebral palsy.

> I don’t want to say that it’s a racist thing because you know what? Black, White, whatever, we all go through the same thing. Who knows? There was a White woman that was suing Theta [hospital pseudonym] too. So I can’t say that it’s a color thing. I think it was more of a Medicaid thing. Because they did have separate areas for us. There was a clinic for the Medicaid women. And then there was the pretty lounge over here. You know? And they were, you know, they call them perinatologists, you know? They had the “Perinatology Suite”. Right here. And they had the little Jewish ladies, with the wigs, White ladies, all that- upscale Black ladies. All up in there. And I’m like, “Well, damn! Let me go get on my mama’s insurance or get on my daddy’s insurance. “You know? I’m like, “Damn!” They were looking good. They had beautiful comfy chairs. The lighting was nice. It was beautiful. It was a suite. Meanwhile, “Y’all [Medicaid recipients are] over there.” After I had my son, for some reason, I don’t know why, I went back on my job’s [private] insurance. Which is crazy. I don’t know if the hospital messed up, but I used it. I was a HIP patient. I was in the pretty area. Over here. All the Medicaid patients were in the crazy area

> over there. Yelling and screaming and carrying on. I was on this side. (Bridges 2011, p. 234, reprinted with permission from University of California Press)

5.3.4 Expenditures on Preterm Birth

Expenditures on health care in the U.S. are far higher than expenditures in other developed countries. The Organization for Economic Cooperation and Development (OECD) reports that per capita spending on healthcare in the U.S. in 2012 was $8745, compared to $4802 in Canada, $3289 in the United Kingdom, $4281 in Germany and $4288 in France (OECD 2014). There are two major reasons for this situation: the costs of purchasing care (i.e., prices) are higher in the U.S., and there are few limits on the intensity of the technology applied to healthcare problems. Prices for care are higher in part because healthcare competes with other lucrative economic sectors for talent, so physicians and administrators must be paid enough to retain them in the field. In addition, prices for care are higher because the administrative processes for billing and paying for care in the U.S. are extremely complex, requiring the support of extensive overhead for both providers and payers which is not required in other countries. Also, as suggested at the beginning of this chapter, prices are high in the U.S. because suppliers of care have more market power than payers, and have generally arranged systems so that they do not need to compete with each other on the basis of price. Providers also control entry into the profession, so, for example, the number of physicians trained in U.S. medical schools has remained relatively constant since the 1970s. These relatively low supplies of personnel and hospital capacity limit the ability of payers (public and private insurance companies) to negotiate lower prices (Reinhardt et al. 2004).

In terms of limits on the intensity of care, all countries face the dilemma of deciding how much additional expenditure on healthcare per benefit received (for example, per additional year of life) should be allocated, given potential other uses of these resources. While countries with national budgets for healthcare have systems in place to make such choices, for example by limiting reimbursements for certain health conditions or interventions, in the U.S. there has been political resistance toward acknowledging the need for such a discussion, much less setting explicit criteria for limiting the array of services provided.[14] Along the same lines, technological advances in medicine can decrease or increase costs, depending on their value in improving health and whether they substitute for or are used in addition to other therapies. Again, the U.S. has no systematic mechanism for evaluating or limiting the adoption of technology in healthcare, and healthcare

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[14] Both legislation regulating the Medicare program and the Affordable Care Act of 2010 bar the U.S. government from evaluating the relative costs of different therapies or taking costs into account when making coverage decisions.

technology is viewed more frequently from the business perspective of the innovators and sellers than from the perspective of the purchasers and users of care (Baker et al. 2003; Chandra and Skinner 2011).

The average costs of prenatal and childbirth care in the U.S. is much higher than the costs in other countries. In one estimate in 2012, the average cost for a vaginal delivery in the U.S. was $9775, compared to $4039 in Switzerland and $2641 in Britain (Rosenthal 2013). In the same year, expenditures on pregnancies and newborns constituted 26 % of all hospital charges paid by Medicaid (approximately $54 billion) and 14 % of all hospital costs paid by private insurers (approximately $50 billion)(Childbirth Connections, 2012).

These expenditures are not equally distributed across all pregnancies and newborns; rather, expenditures on complicated cases account for a large portion of the expenditures. In one study of expenditures on pregnancy and newborns within private insurance coverage, using 1996 data, researchers found that the 24 % of newborns in their sample born with some health problem accounted for 82 % of the total newborn expenditures, and the 4 % of newborns born at extreme prematurity accounted for 45 % of the total expenditures. Maternity care costs for mothers with preterm infants averaged 30 % higher than costs of care for mothers of infants born without health problems. On net in this study, mean maternity payments for deliveries of full term infants was $7451, while maternity costs for the delivery of preterm infants ranged from $10,626 (“normal” preterm) to $11,508 (extreme preterm) and $13,707 (preterm with other complications). Mean infant care payments through three months postdelivery were $1139 for full term infants, $10,417 (normal preterm), $49,933 (extreme preterm) and $21,514 (preterm with other complications) (Adams et al. 2003). Similarly, a 2006 study in California found that the 6 % of newborns born at less than 2500 g accounted for 57 % of newborn hospital expenditures, while total hospital costs for the mothers of low birth weight infants were on average more than double the costs for mothers of infants over this weight threshold (Schmitt et al. 2006). Longer lengths of stay in hospitals and more technological interventions were the primary drivers of these higher costs for preterm and other complicated births. Medicaid pays for slightly less than half of all births in the U.S. (the portion varies across states), but more than half of all complicated deliveries, including preterm births, in part because uninsured infants are moved into Medicaid coverage if their hospital costs are large (Markus et al. 2013). The remainder the costs of complicated deliveries is covered by private insurance.

The parties that pay for and finance health care in the U.S. are aware of the high and escalating costs of medical care in general, but their ability to contain costs is limited. There are two common strategies for cost containment for medical care in general in the U.S.: selective contracting and utilization review. Selective contracting allows insurers to select one set of care providers who will be used for all enrollees. The insurers negotiate discounted prices for care, in return for guaranteeing a high volume of patients to their providers of choice. Utilization review allows insurers to monitor and restrict providers' choices of services to provide to patients, if service restrictions can be justified as having either a positive or a neutral impact on the patients' health.

In the U.S. neither selective contracting nor utilization review has been vigorously applied to pregnancy and newborn care. There are several reasons for this. Friedman et al. (2002) found in a study of New Jersey data from the 1990s that the extent of penetration of managed care in communities was unrelated to whether or not hospitals in those communities had NICUs. They note that young couples who are the consumers of maternity services are attractive enrollees for health insurance plans, because they are generally cost less to insure, relative to older enrollees. They speculate that insurers are unwilling to exclude high cost hospitals with NICUs from their managed care plans, because these attractive potential enrollees are known to prefer hospitals with NICU services as sources of maternity care. Schulman (2003) observed that in some communities, the neonatologists staffing all the NICUs in all of the hospitals belong to the same practice group. This makes it difficult to exclude any single setting from coverage, and impossible to use an offer of selective contracting to negotiate price discounts for neonatology care.

In terms of utilization review, while Richardson (Richardson et al., 2001) and Schulman both identify opportunities for cost efficiencies in neonatal intensive care, Schulman notes that limited expertise in this practice area makes insurers "squeamish" about managing costs. She also notes attitudinal barriers that make it difficult to restrict NICU care on the basis of its costs. She refers to NICU management as a "persistent taboo," and a "political third rail" and notes that such care is viewed "paternalistically" by employers, despite awareness of its huge costs. A contrasting case illustrates this point. In late January, 2014, the CEO of AOL, a large media company, announced to employees that their pension benefits were being reduced because healthcare costs in the company's self-insured insurance plan had been unusually high in the previous year. Tim Armstrong, the CEO of AOL, blamed these high costs on two employees who had "distressed babies" that cost a "million dollars each"[15] to care for. Within a day, after a barrage of criticism in high-profile media outlets, Armstrong was forced to retract the statement and apologize. Among the issues raised by critics was his selection of care for newborn babies, as opposed to other high medical costs, as the object of his complaint, and the framing of employee benefit costs (health insurance and pensions) as a zero-sum situation, where costs in one category had to balance costs in the other, and not be counted against the company's record profits or the CEO's 12 million dollar salary. Once Armstrong's statement was publicized, it became clear that this was not an isolated case in which women with high-risk pregnancies or poor birth outcomes were blamed for threatening the solvency of employee benefit plans, but it was an unusually overt complaint about the issue (Davidson 2014; Fei 2014, 2015).

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[15] Deanna Fei, mother of one of the infants in question, estimated based on insurance bills that she received for the three month NICU stay, that the costs were closer to $550,000 (Fei 2015, p. 274).

From the physician perspective, neonatologist Joyce Peabody recounts an exhaustive process of utilization review occurring during NICU rounds, during which $7421 in savings were identified through short reductions in hospital lengths of stay and deferrals of some laboratory testing. She writes:

> I was proud of the results of our efforts and our contribution to the continuing efforts to control healthcare cost…until…until the telephone rang and a reporter from the LA Times requested that I comment on the Baby K case. The event that triggered the call was that Baby K., an anencephalic infant from Virginia, had just died following 2½ years of life, during which time she consumed health care services costing several million dollars. These costs resulted from repeated re-admissions to the hospital, days on mechanical ventilation and several surgeries, including a tracheotomy to support chronic ventilator support, all in response to the demands placed on the health care team by her mother, supported by the local and appellate courts. Suddenly, the contrast of what was saved by the painstaking cost-containment efforts of my team on rounds and what was spent to prolong the dying of an infant who never knew, to the best of neuro-scientific knowledge, let alone enjoyed, her life on this earth was painfully evident. (Peabody 1998, p. S24, reprinted with permission from Macmillan Publishers Ltd.)

Peabody refers to the pressure generated by the federal Baby Doe legislation, described in Chap. 4, that requires physicians and hospitals to resuscitate all infants born alive, along with the debates within medical ethics about whether physicians have a “duty to treat” all infants, as factors that make it difficult to address the largest component of potentially unnecessary expenditures on futile care for non-viable infants. Peabody’s other concern, as implied above, is that expenditures on futile care are partly driven by parental demands arising from unrealistic expectations. This belief, commonly articulated by medical personnel, is examined in later in this chapter.

The most viable approach to containing NICU costs may be shortening the length of stay in the NICU, and shifting the site of care for fragile surviving preterm infants to less intensive hospital settings, or to care at home when they are stable. Historically, preterm infants were considered to be ready for intensive care discharge when they reached 2000 g in weight. However, more recent studies suggest that an alternative approach is to allow discharge when these infants can successfully feed orally, maintain their body temperature and have respiratory control. Shortened lengths of stay also reduce the extent of parent–child separation and reduces exposure to hospital acquired health problems such as infections. Still, early discharge from the NICU can result in multiple health problems for the newborn, and the discharge of infants with ongoing needs, such as dependence on technology for survival, places major burdens on families (AAP Committee on Fetus and Newborn 2008). The experiences of parents are discussed later in this chapter. Although there are anecdotal reports of reduced NICU stays in hospitals, there is no strong evidence of a trend toward shortened stays across the population (Merritt et al. 2003; Ounpraseuth et al. 2015).

5.4 High-Risk Pregnant Women's Experiences with Medical Care

Every woman's experience of her high-risk pregnancy or preterm delivery is unique. It is influenced by her physiological events, the meaning of her pregnancy to her, her family situation and level of resources, background, psychological state, and the medical care she receives. At the same time, the experience of high-risk pregnancy is conditioned by shared cultural understandings of preterm birth, and significantly affected by the dynamics of the healthcare delivery system as discussed in this chapter. The next two sections of this chapter explore common themes in the experience of pregnant women and of parents of preterm infants in relation to the healthcare delivery system.

Although, as discussed in Chap. 3, pregnancy and childbirth are framed in the U. S. and other Western settings in medical terms, normal pregnancies have never fit well into the expectations that these cultures hold for people who are sick (McKinlay 1972; Meyers and Grasmick 1990). The paradigm of the sick role, articulated initially by sociologist Talcott Parsons in the 1950s, delineates four social expectations that U.S. culture holds for people who perceive that they have a physiologic abnormality. These components are that sick people (1) are exempt from their normal roles and responsibilities, (2) are not held to be personally responsible for their conditions, (3) are obliged to try to get well, and (4) are obliged to seek technically competent help and to cooperate with physicians. Parsons suggested that the social functions of these four expectations are to regulate the circumstances and length of time that individuals can be excused from social obligations (particularly work), and to delineate a category of deviance from social norms that differs from crime or sin, because the causes are understood to be beyond the individual's control. From the point of view of this framework, the health care system is an agent of social control because of its role in legitimizing when people can assume the sick role, enforcing adherence to treatments and determining when an individual is cured (Cockerham 2007; Levine and Kozloff 1978).[16]

Whether or not pregnancy exempts women from other social roles is complicated in U.S. culture and society. Pregnancy is a transition to or an intensification of the role of motherhood. Because pregnancy is a component of domestic expectations for women, and more broadly of the social reproduction system of society, pregnant women are not exempt from child care and housekeeping responsibilities. Pregnancy is a deficit in most employment contexts, since pregnancy confirms that women employees are different from men, and can serve as a rationale for limiting women's access to certain jobs, to promotions and higher pay (Huckle 1981).

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[16] In the latter half of the twentieth century, the paradigm of healthy lifestyle regulation restored some sense of individual culpability for sickness, and the adoption of identity politics and a consumerist model of patient empowerment modified somewhat the expectation that sick people would passively adhere to all physician instructions (Burnham 2012; Tomes 2006).

As discussed in Chap. 4, in the U.S. there are no special sick leave benefits for pregnancy, so it is in the best financial interests of most women not to seek exemption from their employment role during pregnancy. Even in settings where pregnancy sick leave is available, it is often still in the employed pregnant woman's interest to remain at work (Gatrell 2011a, b). Culturally, as discussed in Chap. 3, women are held to be responsible for their pregnancy outcomes, so the sick role expectation that one is not to blame for one's condition also does not hold. Finally, it is difficult to apply the sick role expectation that sick people are obliged to want to "become well" to pregnancy, which always ends at some point whether or not the pregnant woman wants this to happen.

On the other hand, when women transition from being pregnant to having a high-risk pregnancy, where there is some indication that the pregnancy will end before term or have some other undesirable outcome, the process does bear similarities to a shift into the sick role, or, as British sociologist Hilary Thomas conceptualizes it, as the assumption of the additional "career" of illness along with the "career" of pregnancy (Thomas 2003). Analyses of interviews with women experiencing high-risk pregnancies describe attempts to sort through a variety of ambiguous symptoms, trying to determine which ones are abnormal and signals of danger, with resulting delays in seeking treatment for preterm labor, for example, as women rationalize symptoms such as abdominal heaviness, low back pain and minor bleeding as normal (Coster-Shulz and Mackey 1998; MacDonald and Jonas-Simpson 2009; Mackey and Coster-Shulz 1992; Mackey and Tiller 1998; Rubarth et al. 2012; Stark and Brinkley 2007; Weiss et al. 2002). When there are no symptoms, but screening tests or clinical findings suggest the presence of a pregnancy complication, it may be even more challenging to transition into the role of someone with a high-risk pregnancy.

Observers describe women's typical initial responses to receiving a designation that their pregnancies are high-risk as fear and anxiety. This transforms into stress, as treatments are initiated and time passes. Some women describe a loss of self-confidence, as their sense of control over their lives diminishes. They question their ability to be mothers, having failed, in the words of one woman experiencing preterm labor, at the "work of keeping the baby in" (Mackinnon 2006). As one participant in an online forum on pregnancy, discussing her experience managing high blood pressure and diabetes, and being scheduled for labor induction once amniotic fluid tests indicated her fetus's lungs had reached maturity, remarked, "My goal was to have one good contraction. I felt that to truly be a member of the mommyhood sorority, I needed to feel just one." (Goehring-Harris 2014).

Commenting on a talk she heard that emphasized the naturalness of the pregnancy experience, health educator Darline Turner-Lee commented on her own blog, which focuses on information for women with high-risk pregnancies:

> For those of us who have had complications during our pregnancies or childbirths, these types of talks can be difficult to hear. As the speaker was talking about 'trusting her body, her body knew what to do', what do those of us who had preterm labor say? 'my body wanted to deliver my baby early (sometimes way too early!!) but it knew what to do? I had

> tremendous feelings of inadequacy following the birth of my daughter. She arrived in respiratory distress and I hemorrhaged. Is that my body knowing what is best? (Turner-Lee 2014)

In a sense, the transition to the sick role in a pregnancy involves a process of grieving for the loss of the experience of a normal pregnancy, in addition to anxiety about the future.

5.4.1 Personal Responsibility for High-Risk Pregnancy

Following Parson's model, women who shift into the role of having a high-risk pregnancy should at some level be relieved of personal responsibility for becoming sick. Research interviews with women experiencing high-risk pregnancies often describe their attempts to determine whether they are to blame for their own pregnancy complications. Most women can identify some areas of personal responsibility, often related to overexertion, stress, intense emotions, conflict at home, or ambivalence about being pregnant, that might have triggered early labor or other complications. At the same time, these interviews reveal a tendency among some women to feel that the exertion or stress was unavoidable, or that "preterm labor runs in the family," and that there was nothing particularly that could have been done to avoid the complications (Coster-Shulz and Mackey 1998; Mackey and Coster-Shulz 1992; Mackinnon 2006; May 2001; Rubarth et al. 2012; Weiss et al. 2002). This aspect of relief from blame seems to bring a sense of reassurance, and it is a marked contrast to the responsibility for children's outcomes ascribed to the standard social roles of pregnancy and motherhood, as discussed in Chap. 3. One participant in sociologist Ann Oakley's study in Britain of low-income high-risk women remarked:

> It may sound a little strange, but it was somehow comforting to have another small baby – this combined with the very plausible theory about the heart-shaped uterus has eradicated the guilt I have felt since the birth of my first daughter. I now know for sure I have done nothing wrong. (Rajan and Oakley 1990, p. 83, reprinted with permission from Elsevier)

Still, the potential to be blamed and to accept blame for having a high-risk pregnancy is always present. In another post on her blog for high-risk pregnant women, Turner-Lee commented on participating in a dialogue with members of ACOG concerning the role of counseling before pregnancy as a way of improving pregnancy outcomes:

> They seemed to be saying that when pregnancy complications arise, It's because of something mamas haven't addressed prior to getting pregnant, a sort of negligence. In my experience with mamas on bed rest, that simply isn't true. For many mamas, there is no rhyme or reason that they have the complications they have. (Turner-Lee 2013)

5.4.2 Exemption from Social Obligations

Exemption from other social roles is supposed to be a privilege of assuming the sick role, but its application to high-risk pregnancy is inconsistent. Gatrell describes the choice by some pregnant women with managerial jobs whom she interviewed to ignore their pregnancy complications, in order not to compromise their performance in their work roles (Gatrell 2011b). Many women find it extremely difficult to adhere to prescriptions for activity restriction during a high-risk pregnancy, because their ability to default on their social obligations depends on the range of other social roles that they occupy, and on their access to resources. Edmonds and colleagues (2014) describe a study of records of prenatal hospital admissions for diabetes, hypertension, preterm labor, preterm membrane rupture, and bleeding in California between 1995 and 2005. The researchers examined the characteristics of the small number of women who left the hospital against medical advice, presumably because their life situations could not support exemption from their other social roles. Women who left the hospital were more frequently Black, publicly insured or uninsured, higher parity, and between the ages of 18 and 35, rather than younger or older.

In interviews, women who were prescribed activity restriction for high-risk pregnancies reported feeling a loss of control, feeling like a burden, and feeling the need to balance the expectations that they fully assume a sick role with other expectations held for them as income providers and as mothers of their other children. Their ability to fully adhere to activity restriction depended on the availability of other adults who could take on their other responsibilities, and was also modified both by the meaning of the current pregnancy in their lives and their belief in the efficacy of the prescription of bed rest for reducing the likelihood of a preterm delivery (Coster-Shulz and Mackey 1998; Mackey and Coster-Shulz 1992; Mackinnon 2006; May 2001; Rubarth et al. 2012; Schroeder 1996).

5.4.3 Obligations to Try to Get Well and to Seek and Adhere to Treatment

The third and fourth components of Talcott Parsons' sick role model are that legitimately sick people are obliged to try to get well, to seek competent therapy and to cooperate with their physicians. In contemporary medical practice, these obligations are supposed to be balanced by the principle that patients should give informed consent for treatment, and have a right to refuse treatment. This principle, along with the obligation to seek competent treatment, aligns with the contemporary framing of patients as rational consumers of care.

However, the rational consumer model is difficult to enact in practice. The patient-as-consumer framework assumes that patients have full access to information about their conditions and alternative treatments, and that they are in a position to freely choose across treatments. In general, neither of these circumstances are characteristic of individuals experiencing acute and serious illnesses (Burnham 2012; Tomes 2006). Having full access to information and being in a position to freely choose across alternative therapies is even rarer in the context of high-risk pregnancy. As one example, Darline Turner Lee posted on her online blog the text of a comment she received in response to a dialogue about the FDA warning against the use of terbutaline as a long-term tocolytic.

> I had cramping (contractions) from about 9 weeks till I delivered at 31 weeks after pprom [premature membrane rupture]. I was first given terb at 23 weeks. 5 shots, no dilation, contractions started immediately upon leaving the hospital again. I was sent back that afternoon, given terb every 3 hours for about 24 hours straight along with constant IV fluids and some other medications for contractions. Wasn't even told what it was, it was just injected in my IV. I was given a cerclage for cervical incompetence…..which is funny, because I understood that cervical incompetence was characterized by dilation absent contractions…anyway. The cerclage seemed to cause even greater uterine irritability. Literally every week from 23 to 31 weeks I was back in Labor and Delivery and every time I was given 3 to 5 shots of terb and eventually procardia and indomethacin combined. I was also given torodol in my IV, and had to freak out on the nurse and make her call the doctor to find out what the hell they were injecting into me!!!
>
> So in total, I probably received between 30 and 40 shots of terb along with torodol, procardia, indo, and one or two drugs I never even knew the name of. At 29 weeks the perinatologist ordered a terb pump for me. I flat out refused it. My OB said he understood my reasoning, but recommended it anyway. The on-call doctor laughed in my face and refused to let me leave the hospital without it. I had to sign an AMA [Against Medical Advice] form. The perinatologist told me my insurance wouldn't cover it anyway, but then marked me as a noncompliant patient!! The only person who was reasonable was a nurse who discussed the terb pump in depth with me and agreed that I shouldn't be a candidate for it. I had side effects completely ignored and was treated like I was a monster. No one wanted to discuss risks or efficacy, it was their way or the highway.
>
> Not only did I have to deal with this from the hospital, but now my refusal of the terb pump is even being used against me in a custody case…even after the FDA warning. This is all just nuts to me, and women need to start educating themselves and their doctors if need be. (Turner-Lee 2012)

The issue of high-risk pregnant women's cooperation with or adherence to physician instructions and prescribed therapies is more complex than even the challenges of fully enacting the rational consumer model of patient care. Obstetrics care providers think of themselves as having two patients, both the pregnant woman and her fetus. If pediatric fetal care providers are involved in care, they are often focused primarily on the fetus as patient, and the pregnant woman becomes the consenting parent (Rink 2012). In the medical ideal, therapeutic choices that benefit pregnant women with health difficulties would also benefit the fetus, but in many cases there are trade-offs. For example, medications to lower high blood pressure in women or to end a pregnancy surgically before term can negatively affect the fetus or preterm newborn, while medications to halt contractions and prescriptions of total bed rest can negatively affect pregnant women.

The general approach to such trade-offs is to assume that pregnant women want the best for their fetuses and are generally willing to accept risks on their behalf.

Women in such situations frequently report that they are willing to make these choices, but also that they experience social pressure to accept risky or uncomfortable therapies on the premise that their fetuses will benefit. Summarizing across the responses of women she interviewed who had been prescribed activity restriction in high-risk pregnancies, Kathryn May observed:

> In some cases, women and their partners received punitive messages from health care providers about the consequences of non-adherence to the regimen, and took those messages to heart. Several women were told [by] physicians that 'if you don't get with the program, your baby will be born early and born sick'. In cases where women accepted those messages as valid warnings yet were unable to maintain activity restriction, it generated considerable emotional distress. (May 2001, p. 42, reprinted with permission from Taylor & Francis, http://www.informaworld.com)

For health care providers, the ultimate recourse in situations where they are unable to convince pregnant women to accept or adhere to treatments that they believe to be beneficial for fetuses is to secure court orders mandating that pregnant women comply, or to threaten to terminate parental rights in favor of fetal guardians appointed by the court. The most common situations where this occurs are in term pregnancies when women refuse cesarean section deliveries that physicians believe are necessary to save the life of the fetus, and in cases where maternal and fetal blood types are incompatible and the fetus can be treated by a blood transfusion. However, there are cases where treatments advised to prevent preterm birth are mandated by courts against maternal wishes. For example, in March 2009, the Circuit Court of Leon County (Tallahassee Florida) was alerted by a physician that his patient, Samantha Burton, was refusing to stay on bed rest at Tallahassee Memorial Hospital, as he had advised when she showed signs of a miscarriage in her 25th week of pregnancy. She stated that she had a job and two toddlers to care for, and wished to get a second medical opinion. The court ordered her to remain in the hospital and denied her request to transfer to a different hospital. After three days in the hospital, she underwent a cesarean section, but the fetus was deceased.

The court order was appealed, and the Appeals Court found in favor of Ms. Burton, ruling that her right to refuse medical treatment was violated both because the state did not show evidence that the fetus was viable, and because the mandated treatment was more intrusive than absolutely necessary to save the life of the fetus. The decision was in line with most court precedents which favor the rights of pregnant women to determine their medical care. In particular it echoed a landmark case in 1990, where an appellate court overturned a lower court decision to allow a hospital to perform a cesarean section at 26 weeks gestation for Angela Carder, a pregnant woman with terminal cancer who had clearly articulated a preference that no extraordinary measures be taken for her fetus before it reached 28 weeks (Minkoff and Lyerly 2010; Belkin 2010). The fact that these cases of coerced treatment for pregnant women for the benefit of their fetuses continue to occur[17]

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[17] In January 2014, a Texas case drew national attention when a hospital maintained a pregnant woman on life support for 8 weeks after she collapsed from a fatal blood clot. Texas law mandates

indicate that they express an important conflict in U.S. culture, between the autonomy of adult individuals and the right of society to intervene on behalf of children (Samuels et al. 2007). This is discussed further in Chap. 6.

5.5 The Experience of Parents of Preterm Infants

Becoming the parent of a child born before term is a traumatic event. It is a disruption of the cultural, social, and psychological transition into parenthood; one becomes a parent, but one does not bring a baby home from the hospital. The disruption is intensified, as suggested in Chap. 3, because the narratives of pregnancy emphasize the gradual stages of fetal development and de-emphasize the likelihood that anything will go wrong. If the mother has been treated as having a high-risk pregnancy, premature delivery represents a failure of those therapies to prevent the preterm birth. The reality of the frailty of the preterm infant may be a surprise, given the belief (widely held and reinforced in the political struggles over abortion regulation) that fetuses are like babies from the moment of conception. In addition, as previously discussed, there is a tendency to try to fix blame for imperfect birth outcomes.

5.5.1 Parental Participation in the Decision to Resuscitate at Delivery

One of the first events that occur when an infant is born very preterm is that a decision is made about whether to attempt resuscitation. As discussed above in Sect. 5.2.2, professional guidelines advise physicians to attempt resuscitation if infant survival is likely, usually if the infant is 25 weeks gestation or older; to not attempt resuscitation if the infant is younger than 23 weeks gestation, or not viable, and to support parental choice about resuscitation in the gray area between 23 and 25 weeks (Batton 2009). Yet neonatologists report and are observed to practice resuscitation at gestational ages younger than these guidelines indicate, and the decision is not consistently left to the parents even at the youngest ages (Bastek et al. 2005; Rysavy et al. 2015; Singh et al. 2007; Tyson 1995).

Physicians report that it is very difficult to provide parents with the type of information that they feel parents need to make resuscitation decisions, while

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(Footnote 17 continued)

that hospitals and physicians are prohibited from suspending "life sustaining treatment" for pregnant women, no matter what the patient or the family requests. In this case, the judge ordered the treatment terminated because it was determined not to be life sustaining, and the 22 week old fetus was documented as having severe developmental abnormalities (Morin 2014).

parents report that it is difficult to cope with the weight of the immediate resuscitation decision, particularly in the context of the medical providers' preferred approach of objectivity and neutrality, rather than emotional support and guidance (Grobman et al. 2010; Payot et al. 2007). Not surprisingly, a default decision may be made by the parents to ask physicians to attempt resuscitation. Such a decision seems rational in the face of uncertainty about the newborn's prognosis, and it also has the advantage of allowing time for the parents to process their emotional reactions to the event.

Journalist Kelley Benham described her experience with her pregnancy, as she began to miscarry at 20 weeks gestation. Tocolytic therapy delayed delivery through 23 weeks. Late one evening, when it appeared that delivery could not be delayed any longer, she received counseling from the hospital's neonatologist on the likely outcomes for her newborn when she was delivered. The choice about resuscitation was left to her and her husband, but they found it difficult to decide. A nurse practitioner from the neonatology unit arrived the next day, and explained that, while for decades it was assumed that 23 week old newborns would not survive, neonatal care had advanced, raising new questions. Benham relates that the nurse told her:

> When it came to babies born at 23 weeks, research showed, there was little consensus from one hospital to the next or even among doctors working the same shift in the same unit.
>
> Some were born limp and blue, and some came out pink and crying. In those first few hours and days, much could be revealed. And there was a window of time, while the baby was on a ventilator and still very fragile, when doctors and families could reverse course and withdraw life support.
>
> "You don't have to decide right now", she said. "It's a process".
>
> She seemed to be offering an escape from the torment we had suffered all night. Enough of the unbearable coin toss. We could let them intervene and see how it went. If our baby was born too weak, we could decide later to let her go.
>
> "We don't want her to suffer", Tom said. "But we want our baby to have a chance."
>
> As Diane headed back to the NICU, she told me later, she knew she had changed everything. She also knew that once a mother had seen her baby for the first time, there often was no turning back. She hoped we wouldn't blame her for the rest of our lives. (Benham 2012, p. 5, reprinted with permission from the Tampa Bay Times)

Benham's daughter ultimately survived after 196 days of NICU treatment, and at age 2, appeared to be developing normally.

While the common understanding among professionals is that parental choice is appropriate in the gray zone when outcomes are uncertain, it is up to the professionals to determine the boundaries of this zone. Kristina Orfali conducted comparative work in neonatal intensive care units in the U.S. and in France, and found that, while the U.S. practice was to report more uncertainty about preterm neonatal outcomes than was observed in France for infants with the same characteristics, the uncertainty was always directed toward the assumption that outcomes might be better than they appeared. As Singh et al. observed as well, Orfali found that U.S. medical personnel often rely on what they observe in terms of infant movement to make decisions about resuscitation. If physicians feel that the outcome for a preterm newborn might be positive, they then conclude that the decision about whether to resuscitate should not be left to the parents (Orfali 2004; Orfali and Gordon 2004).

As an example of this dynamic, neonatologist Gautham Suresh recounted in a health policy journal in 2013 an incident that had occurred in 2004, when a 14 year old Black teenager came into the hospital in labor at 22 or 23 weeks of pregnancy. She had not known she was pregnant, and had gone to the doctor that morning because of abdominal pain. He explained in his article that it was too late to halt delivery with tocolytics, or to provide extensive counseling to let the family decide about resuscitation. The obstetrician told the family that the neonatology team would determine whether the baby was viable. The support team indicated that they did not approve of resuscitation under the circumstances, but Suresh recounts:

> With the whole team assembled, I explained that if the mother wasn't sure of her "dates," twenty-three weeks was just a guess. We could always withdraw life support after we initiated it, but it would be a catastrophic mistake to let a baby die on a mistaken assumption of her gestational age.
>
> My team did not seem convinced. I know they felt that they were being forced to do something that they did not agree with. They knew my experience in my previous hospital had been with a quite different patient population. "You know, Black patients almost never agree to withdraw life support". Ron told me. Mary agreed – both of them warning that if we resuscitated this baby, we were committed to treating it until the very end, whatever complex form that treatment might take. (Suresh 2013, p. 1843, reprinted with permission from Project Hope/Health Affairs, permission conveyed through Copyright Clearance Center, Inc.)

At delivery, the infant seemed to weigh less than 500 g, and be possibly 22 weeks gestation. Suresh ordered the team to intubate the infant and begin ventilation. An obstetric resident entered the resuscitation room and told the team that the family did not want heroic measures performed for the baby—if it was going to suffer, they would rather let it go. The infant began to respond to ventilation, opened her eyes and moved her limbs. Her maturity scores suggested she might be 25 or 26 weeks old, and she weighed 650 g. Suresh continues:

> My visual estimate had been wildly inaccurate, and I was glad I had not used it or any other immediate impression to make a snap decision about resuscitation. As the team prepared to move the baby to the NICU for further care, I went to talk to the baby's mother and grandmother. I congratulated them on the birth of the baby girl, and explained that she was stable after our resuscitation. We would bring the baby to the mother so she could see her, before transferring her to the NICU. The teenager seemed tired, and she did not reply to me, turning her face away from me. Her mother thanked me but did not smile. Her face was impassive.
>
> The next day I met Dr. Carver [the obstetrician] in the cafeteria. "How's that kid from yesterday doing?" he asked. She was improving and being weaned off her ventilator support, I reported. He nodded. "I wouldn't have thought she'd make it, at twenty-three weeks, but I guess she turned out to be older," he said. (Suresh 2013, pp. 1843–1844,

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Suresh concludes his narrative by expressing concern about the unwarranted pessimism of health professionals about the outcomes for preterm births, the potential for counselors to overtly or implicitly encourage parents to choose non-intervention, and for decisions about resuscitation to be based on "how the baby looks" rather than on objective measures. He writes that the best solution lies in preventing premature births and avoiding such difficult ethical situations. He does not express concerns about the long-term outcomes for the infant, the impact of her birth on the mother or the family unit, or the lack of involvement of the family in the resuscitation decision.

5.5.2 Parental Experiences of Infants in NICUs

The next event in the life of preterm infants and their parents after resuscitation in the delivery room is admission into a NICU. As Table 5.5 shows, the vast majority of early and moderately preterm infants experience such an admission, although the length of the stay varies markedly by gestational age at delivery. Some very preterm infants delivered at ages younger than 28 weeks gestation have stays longer than six months, but this is a small percentage of all preterm newborns.

Nursing professor Lisa Cleveland (2008) summarized 60 studies of parents with infants in NICUs that were conducted between 1998 and 2008. She found that a common theme across studies was the challenge for parents in developing and expressing their normative parental roles with hospitalized preterm infants; they could not hold, care for or protect their infants and could not share their experiences of parenting with other family members whose children were born at term. She identified seven needs of parents with infants in the NICU as reported in these studies: the need for accurate information and inclusion in care and

Table 5.5 NICU admission rates and lengths of stay by gestational age, 2009–2010, based on Matthews and MacDorman (2013), Table 5.1 and NPIC (2011)

Gestational age	% all live births (based on U.S. vital records)	% all Preterm Births (based on U.S. vital records)	% admitted to NICU (based on National Perinatal Information Center data)	Average length of NICU stay in days (based on National Perinatal Information Center data)	% mortality at one year (based on U.S. vital records)
<32 weeks	1.96	16.38	88.5	46.2	16.56
32–33 weeks	1.53	12.77	95.3	20.3	1.57
34–36 weeks	8.48	68.75	47.8	9.8	0.71
37–38 weeks	26.85	–	10.5	5.9	0.30

decision-making; the need to vigilantly protect their infants from unwanted medical procedures, the need to address perceived lack of attention and poor continuity of care; the need for contact with their infants; the need to be positively perceived by the staff of the NICU; the need for individualized care; and the need for reassurance and a collaborative relationship with the NICU staff.

Interestingly, most of these needs had been clearly documented more than a decade earlier, in the early 1990s, when activist Helen Harrison, author of one of the very first manuals for parents of premature infants (Harrison 1983), gathered a group of parents, disability rights activists, attorneys, ethicists, physicians and nurses and proposed 10 principles for family-centered care in NICUs. Their proposal came in response to several published accounts of parents whose preterm infants experienced lengthy, painful hospitalizations with poor outcomes, legal precedents that promoted care for children with special healthcare needs, and the passage of the federal anti-child abuse (Baby Doe) legislation in the mid-1980s, which was interpreted as requiring resuscitation of any potentially viable newborn. The 10 principles are shown in Table 5.6.

Table 5.6 Principles of family-centered care for infants in neonatal intensive care, Harrison (1993)

1. Family-centered neonatal care should be based on open and honest communication between parents and professionals on medical and ethical issues
2. To work with professionals in making informed treatment choices, parents must have available to them the same facts and interpretation of those facts as the professionals, including medical information presented in meaningful formats, information about uncertainties surrounding treatments, information from parents whose children have been in similar medical situations, and access to the chart and rounds discussions
3. In medical situations involving very high mortality and morbidity, great suffering, and/or significant medical controversy, fully informed parents should have the right to make decisions regarding aggressive treatment for their infants
4. Expectant parents should be offered information about adverse pregnancy outcomes and be given the opportunity to state in advance their treatment preferences if their baby is born extremely prematurely and/or critically ill
5. Parents and professionals must work together to acknowledge and alleviate the pain of infants in intensive care
6. Parents and professionals must work together to ensure an appropriate environment for babies in the NICU
7. Parents and professionals should work together to ensure the safety and efficacy of neonatal treatments
8. Parents and professionals should work together to develop nursery practices and programs that promote parenting skills and encourage maximum involvement of families with their hospitalized infant
9. Parents and professionals must work together to promote meaningful long-term follow-up for all high-risk NICU survivors
10. Parents and professionals must acknowledge that critically ill newborns can be harmed by overtreatment as well as by undertreatment, and we must insist that our laws and treatment policies be based on compassion. We must work together to promote awareness of the needs of NICU survivors with disabilities to ensure adequate support for them and their families. We must work together to decrease disability through universal prenatal care

Cleveland notes that family-centered care in NICUs is well accepted as an ideal, but is difficult to actually implement. Substantiating this, Moore et al. reported in 2003 about a care quality improvement project in which 11 hospitals in the Vermont Oxford Network of NICUs attempted to implement family-centered care. For the project, family-centered care was defined as framing the needs of each infant in the context of its family, and reshaping the relationship between family and medical personnel to be one of information sharing and collaboration. The benefits of family-centered care were considered to be lowered parental stress and improved satisfaction, shortened NICU length of stay, increased parental comfort and competence in caring for their infants after discharge and improved staff satisfaction (Saunders et al. 2003). Although not acknowledged in this study, this definition is a shift from the tone of rights and ethical decision-making expressed in the family-centered care principles shown in Table 5.6. Moore et al. report that integrating parents as collaborators in the care of their infants in the NICU was the most challenging aspect of the project. Proponents encountered barriers including the need to disrupt nursing routines and opposition from infection control staff in the hospital. The authors report that involving parents who previously had infants in the NICU on advisory committees and as peer supporters was not as challenging. In fact, two hospitals found that this type of parent involvement was helpful in hospital fundraising. The authors concluded that "family-centered care is more of a journey than a destination" (Moore et al. 2003, p. e457).

In 2007, a combined group of parent advocates and professionals from the National Premature Infant Health Coalition commissioned a survey of families who had a preterm infant in a NICU (Berns et al. 2007). They defined family-centered care as including the treatment of family members with dignity and respect, sharing information, encouraging family collaboration and facilitating family participation in newborn care, and they described family-centered care as the emerging standard of care in NICUs. The group reported that 85 % of survey respondents had been encouraged to be involved in their infant's care, and 78 % had been as involved as they wanted to be. However, 20 % had not been able to talk to caregivers as much as they wanted and 39 % were less than very satisfied with their involvement with their infants' care. These authors concluded that, while progress had been made toward family-centered care in the NICU, there was still room for improvement.

In tandem with the shift toward support of family-centered NICU care, the number and the visibility of organizations of "parents of preemies" expanded in the 1990s and 2000s. These began as local support groups for parents with preterm infants, but were soon connected with each other, often online, to form umbrella parent networks with national visibility. Professional organizations such as the Healthy Mothers Healthy Babies Coalition, a collaboration of physician, nursing and public health associations, also began to incorporate parent representatives. Anthropologist Kyra Landzelius (2006) observed that these parent groups generally have two goals: to empower parents to be able to participate more extensively in neonatal care, and to reshape the representation of preterm infants in the public domain. She notes that while some organized patient movements challenge the medical domain, in this case both of these aims support the interests of neonatal professionals. By publicizing, normalizing, and in a sense claiming personhood for preterm infants being kept alive by life support technology, the movement helps to deflect criticism of the appropriateness of aggressive resuscitation. The activity of these organizations also creates a type of parental identity that these parents can claim ("NICU Moms"), to help to compensate for their inability to occupy the normative parent role. By encouraging parents to become involved in minor caregiving activities, the movement facilitates the use of parents as ancillary care providers in the NICU, and helps to make early discharge of infants more feasible. Peer support also provides parents with opportunities to express their emotional responses to the circumstances of having a preterm infant, thus relieving the burden on professionals to serve this quasi-counseling role. Still, Landzelius observes, the cultural norms of these support groups encourage parents to express positive emotions, rather than despair, and to express gratitude rather than resentment of NICU staff, particularly for their decisions to provide life support for marginally viable infants.

The actual burdens on parents of participating in NICU care and living up to the expectations set by family-centered care are rarely addressed in the research literature, but are clearly enormous. Some parents have infants hospitalized far from home, some have very limited financial resources to cushion the disruption of their established activities such as work or living and eating at home, and some have multiple other obligations and minimal family support. NICU personnel tend to expect that parents will demonstrate emotional investment in the infant, participate in care in appropriate ways, and manage their reactions to the situation in order to exhibit relative stability. Since patient turnover in NICUs is relatively rapid for most cases, NICU personnel are primarily focused on whether parents will be able to care for their infants at home, and whether they will exhibit enough investment in their infants to help assure better long-term outcomes.

Although parental involvement in the routine care of preterm infants is encouraged, the circumstances under which parents are actively involved in medical decision-making in the NICU remain relatively limited. Observers indicate that the decision to stop intervening in the care of a preterm infant tends to be made only when infant prospects for survival are very slim; otherwise neonatal intensive care and the related range of rescue procedures tends to continue (Baer and Nelson 2007). Although parents will be asked to sign consent forms for all procedures, they often have the most involvement only in situations where infant survival appears unlikely. Orfali gives the following example from her study comparing NICU decision-making in the U.S. and France. In contrast to France, the belief system in the U.S. is that parents have the autonomy to make medical decisions:

> This, however, does not mean that in the U.S., the critical decisions will systematically be left to the parents. The following example shows how the physician will construct his prognosis and by doing so will in fact limit parents' choices despite the prevailing autonomy model. Little John has an IVH grade IV [a severe bleeding in the brain], but the attending physician explains why he will not broach the subject of any treatment limitation: "I told the mother he has a bad bleed and that he could have some developmental delays but the mother didn't say anything. I did not offer any limitation because I do not think she would have wanted any, anyway."

> “You think it is better not to offer?” (Sociologist)
>
> “I think it would not be appropriate. The parents wanted this kid badly. The other reason is that he moves along quite well. If the mom had said something when I talked about the sequelae sand said we should not continue….well I would have probably said it’s an option. But that would have been a problem for us…because we think that the baby looks quite fine.” (Orfali 2004, p. 2017, reprinted with permission from Elsevier)

Under these circumstances, it is not surprising that the neonatologists seem hyperaware of situations in which parents object to the withdrawal of life support for a moribund child. For the most part the only situations in which parents are actually given decision-making authority are those in which the clinicians have already determined that treatment withdrawal is appropriate. In other situations it is more difficult for parents to express disagreement with aggressive treatment (Orfali and Gordon 2004).

5.5.3 *Parental Experiences After NICU Discharge*

After surviving infants are discharged from neonatal intensive care, their parents have the opportunity to assume a parenting role that fits more with cultural and social expectations. They become primary caregivers for their newborns, have them at home, and assume the responsibility of protecting them from harm. Still, they face many constraints that differentiate their experience from that of parents of infants delivered at term. Their experience of the earliest period of their infants’ lives is traumatic, they must cope with grief over the loss of an ideal pregnancy and delivery, and they must gradually adjust their time horizons for their newborns, from immediate survival to their children’s future. Apprehension, anxiety and fear are common, and are intensified by the increasingly common expectation that parents will take over many of the medical functions previously performed by NICU personnel (Jackson et al. 2003; Murdoch and Frack 2012; Phillips-Pula et al. 2013).

As noted in Sect. 5.3.4, the common criteria now used for judging a preterm newborn’s readiness for NICU discharge is physiological maturity—the ability to feed orally, maintain adequate body temperature, and control respiration. This can leave a considerable number of medical conditions unresolved, and may involve discharging infants who continue to be dependent on technology for feeding and breathing. The APA policy indicates that not all parents are ready to provide care for these newborns at home, but that there are increasing “social and economic” pressures to discharge preterm infants as early as possible. The policy holds that parents should be able to feed an infant, perform basic care such as bathing, provide cardiopulmonary resuscitation and other emergency interventions, assess the clinical status of the child, be aware of infant safety precautions such as sleep position and use of a car seat, know how to take care of airway tubes, feeding tubes, and other mechanical and prosthetic devices, operate and troubleshoot equipment, change dressings, suction airways and do physical therapy. In addition, a comprehensive home plan for the discharged infants should include a plan for nutritional care, equipment and supplies, assessment of the home physical facilities, an emergency transport plan and an assessment of the availability of financial resources to finance the costs of home care (AAP Committee on Fetus and Newborn 2008). While this type of preparation is ideally part of the family-centered care standards for neonatal intensive care, the extent of parental preparation is highly variable. The National Preterm Infant Health Coalition's parent survey found that one-third of parents reported receiving information on care of their infants at home less than one week before hospital discharge (Berns et al. 2007)

The AAP policy includes an extensive discussion of the need to link the family to a primary care physician who has experience taking care of high-risk infants and some experience with NICU care. However, 44 % of surveyed parents reported that their primary care physicians had no communication with their neonatal care personnel (Berns et al. 2007). Readmission of preterm infants to NICUs after discharge is relatively common. In one recent California study, 16 % of infants born before 33 weeks gestation and 12.5 % of those born between 33 and 37 weeks gestation had been rehospitalized at least once in their first year of life (Ray and Lorch 2013). Poor quality of care provided in outpatient settings has been shown to be associated with the likelihood of a NICU re-admission (Lorch et al. 2010), so the fragmented nature of pediatric care for preterm newborns has negative health consequences.

Over time, parental apprehension and anxiety over the care of preterm infants often resolves into a sense of competence or mastery. Other typical experiences reported for parents with preterm infants after hospital discharge include isolation and exhaustion, especially if they are constantly attending to breathing monitors and other technology. There is a tendency to compare the preterm infants' developmental milestones with that of term infants, in order to assess a child's relative normalcy (Jackson et al. 2003; Murdoch and Frack 2012) Phillips-Pula reports a sense of determination on the part of mothers whom she interviewed to do everything they could to assure the best outcomes for their infants. The demands on mothers varied, depending on their resources:

> Each mother in the study stated that her infant would not be "held back" because of preterm birth. They decided while in the NICU their infants would have the best possible care, regardless of the time or energy needed to ensure it. One of the younger mothers who lacked personal transportation reported riding 90 minutes 1-way to get her son to the required medical visits. Mothers who worked full time before giving birth tried to rework their maternity leave so that they could use most of it when their infants were discharges. One mother, an ICU nurse, returned to work 2 weeks after her cesarean section to save leave for when her daughter would be discharged.
>
> Mothers also discussed their plans for meeting future challenges, which included that their infants not only prospered but achieved. They spoke about goals and overall outcomes they wanted for their infants and concluded each statement with an expression of determination, that everything would be "fine," that "everything is going to be OK", or "She'll be fine". (Phillips-Pula et al. 2013, p. 340)

These themes echo the premises of social reproduction, discussed in Chap. 3, which holds that mothers are responsible for the outcomes of their infants, and can influence those outcomes by being good mothers. A summary analysis of multiple studies comparing the stress levels of parents of preterm infants to parents of infants born at term identified several studies which found no difference in stress levels between the two groups. This may be because of enhanced social support, lower expectations, or a purposeful strategy of being optimistic on the part of parents of preterm infants. Also, many of these studies exclude parents of extremely compromised preterm newborns (Schappin et al. 2013).

As discussed in Chap. 1, rates of disability for preterm infants vary markedly within as well as across gestational age at delivery. Some disabilities resolve over time, and others appear only as children develop. Eventually, the experiences of parents of preterm infants may evolve into the experiences of parents of children with special healthcare needs and disabilities. Seriously disabled preterm infants in families with limited financial resources may qualify for federally subsidized early intervention services, which support a range of therapeutic interventions for children through age three. Between ages three and 18, children qualify for school-based services. Low-income families with disabled children may also qualify for income supports, as well as continued eligibility for Medicaid. Legal and social services may be required over the long term to ensure that families gain and retain access to these services (Andrews et al. 2014). On the other hand, the experience of parents whose preterm infants develop without disabilities will eventually assume more normative forms.

5.6 Comparisons with Canada, Great Britain, and Western Europe

As discussed in the beginning of this chapter, the health care systems of the U.S., Canada, Great Britain, and Western Europe share and contribute to the same body of scientific information regarding the causes and treatments for high-risk pregnancies and preterm infants. Thus, there is little cross-national disagreement about effective medical approaches to these conditions. However, the organization of the health care systems in these countries is quite different from that of the U.S., and this difference has an impact on the nature and intensity of treatments received by pregnant women and preterm infants. Treatment decisions in high-risk pregnancies and preterm newborns in turn have an impact on preterm infant survival rates.

5.6.1 Public Financing and Ownership

Canadian, British, and Western European health care systems have more government involvement than the U.S. system, and all have a commitment to assuring universal access to healthcare for citizens and legal immigrants. In Canada, France, Germany, the Netherlands, and Switzerland, governments collect funds through income taxes and purchase health insurance plans for citizens. There are a limited number of health insurance plans in each country, and insurers do not compete with each other on the basis of price. In Canada and in part in Switzerland, hospitals are publicly owned and supported by government funds; in the other countries, hospital care is paid through the insurance plans, and hospitals can be public or private. In Canada, France, and the Netherlands, specialists are salaried employees of the hospitals, while in Germany and Switzerland, specialists maintain private practices, as in the U.S. In contrast to this government-sponsored insurance model, in Great Britain, Denmark, Italy, Norway, and Sweden, hospitals and ambulatory care clinics are publicly owned and operated. Specialist physicians are salaried employees of the hospitals, and general practitioner physicians are paid under contract with the government to provide primary care. In most of these settings, direct access to specialty medical care is limited. The systems are set up so that patients see a general practitioner first and receive a referral to a specialist if necessary. In most of these settings, general practitioners represent about 50 % of all physicians; in the U.S. they represent about 38 %. In all of these settings, individuals can purchase supplemental private insurance which in many cases will allow them direct access to healthcare services without going through the public systems (Mosialos et al. 2015).

The availability of public insurance or a publicly supported maternity care system impacts parents' experiences of having a preterm newborn. In her book describing the effort by AOL CEO Tim Armstrong to blame company changes in the employee pension plan on the costs of caring for her preterm infant, Deanna Fei writes:

> Health care reform has never been a cause that ignited my personal passions, but I'm struck by the frank bewilderment in the notes I receive from well-wishers in Canada, the United Kingdom, the Netherlands, Finland and New Zealand: bewilderment about why anyone would begrudge my baby's hospital bills, and why the bills for that care, which seems to be relatively routine in NICUs around the world, are so staggeringly expensive in the United States.
>
> Indeed, among my fellow Americans, even those who describe themselves as fortunate to have compassionate employers also describe carrying feelings of guilt, failure and shame for the medical bills of their babies. This group includes a pediatrician who spent years caring for premature infants and never imagined that she would have one of her own. She writes "the next year, premiums skyrocketed, placing health insurance beyond the reach of many of my husband's fellow employees. It was heartbreaking to think that our little boy's life was causing others so much financial burden.

> You don’t need to have socialist leanings to notice that such fallout would be nonexistent in a country with universal health coverage— which is to say ever other industrialized nation…
>
> Single-payer systems certainly have their own perils: bureaucracy, inefficiency, the entire population’s health data in the hands of the government. But they also have a noticeable advantage beyond the obvious ones of lower costs and universal coverage: No one’s boss is motivated to assess employees according to their medical expenses. (Fei 2015, pp. 282–283, reprinted with permission from Bloomsbury Publishing)

5.6.2 Organization of Maternity Care

Maternity care systems in Canada, Great Britain, and Western Europe are varied, particularly in the extent to which midwives are involved as direct providers of maternity care. Midwives play a limited role in Canada and Germany, but deliver over 70 % of newborns in the Britain, France, Italy, the Netherlands, and the Scandinavian countries. Ideally, the midwife-based settings have referral systems in place that allow midwives and general practitioners to refer complicated pregnancy cases to physicians for care, although the referral protocols vary in their specificity and the degree to which they are followed. In some countries, midwives, general practitioners, and obstetricians work cooperatively to sort high-risk pregnant women into specialty settings for prenatal and delivery care, while retaining low-risk pregnant women in primary care settings. In other countries there is competition between midwives and obstetricians for maternity patients. In some countries, laws require that women are able to choose the specialty of their maternity care provider, while others require, at least in the publicly financed system, that midwives or general practitioners be used unless there is a documented reason for a medical referral (Benoit et al. 2005; Emons and Luiten 2001). Benoit and colleagues observe that midwifery-focused maternity systems are found more commonly where there are concerns about the high costs of care, and this is more likely to occur in publicly operated as opposed to market-based systems. They report an increasing interest in Canada in shifting more maternity care toward midwives because of the increasing costs of maternity care in public budgets. Blondel and colleagues, who maintain a set of 10 study sites across Europe for which they track maternity care systems and outcomes for preterm births (the MOSAIC study), reported for 2004 that in sites in Belgium, the Netherlands, and Great Britain, fewer than a quarter of all maternity units had on-site obstetricians with 24/7 availability (Blondel et al. 2009).

The British health care system has long involved midwives and general practitioners in low-risk maternity care. In December 2014, the National Institute for Health and Care Excellence (NICE), the British government agency that evaluates medical technology and issues practice guidelines, advised primary care maternity providers to suggest to their patients that they consider the benefits of a home rather than a hospital-based delivery, if their pregnancies are proceeding without complications (NICE 2014). The response in the U.S. to this advisory indicates the (somewhat idealized) view held by U.S. maternity care providers about the differences in the British and American health care systems. Writing in the **New England Journal of Medicine**, obstetrician Neel Shah observed that British health care authorities were rightly concerned about the complications that can occur in hospital-based maternity care, which is often far too intensive than is required for routine deliveries. However, the U.S. medical community is more concerned about the risks of undertreatment, that pregnancy complications will not be identified promptly enough to intervene with the medical treatment that is required. He writes:

> One reason the risks associated with physician-led hospital birth appear starker in Britain is that under-intervention is less likely there than it is in the United States. Access to care is a given. British women who give birth outside the hospital receive focused, one-on-one attention from a qualified midwife. When more intense care is needed, there are clear protocols and mechanisms to facilitate transfer to a hospital. The fact that nearly half of first-time mothers who initially intend to have a home birth are transferred to hospitals may be a sign of a working system rather than a failing one. In this context, particularly for multiparous women, who have lower transfer rates, giving birth in the comfort and privacy of home not only seems reasonable – it seems preferable.
>
> In the United States, access to obstetric care that is coordinated among homes, birthing centers, and hospitals is both unreliable and uncommon. Nearly half of all U.S. counties have no practicing obstetricians or midwives, so women are often forced to drive to distant facilities offering needlessly complex care. Lower-level care facilities that could potentially fill this gap—such as midwifery-led birthing units—are few and far between. As a first step, ACOG and the Society for Maternal-Fetal Medicine released a consensus statement in February 2015 providing definitions for facility-based levels of maternal care. Unlike our British counterparts, however, U.S. obstetricians lack clear protocols for determining when and how to transfer patients to risk-appropriate facilities. Moreover, U.S. facilities often lack formal referral relationships and may face financial disincentives to transfer patients. (Shah 2015, p. 2183)

Limited hospital capacity is another characteristic of the primary care-focused and publicly financed health care systems in Canada, Great Britain, and Western Europe. While, as discussed above, there is broad consensus that there are more NICU facilities in the U.S. than necessary, given the volume of preterm births, there are probably fewer facilities, at least in some regions of some European countries, than would be preferable to provide immediate care to all preterm newborns. Emons and Luiten (2001) report that in 2001, Dutch midwives commented that in the Netherlands there was a shortage of Level III NICU units for the number of infants born preterm. Reviewing data collected in the late 1990s from the ten MOSAIC study regions in Belgium, Denmark, France, Germany, Italy, the Netherlands, Poland, Portugal, and the United Kingdom, Zeitlin et al. (2004) report that there was wide variation in the scale of delivery settings and their number relative to the size of the population. The rates of Level III NICU units per 10,000 births ranged from 0.25 in Poland and 0.50 in eastern and central Netherlands to 2.04 in Germany and 2.44 in Italy. In contrast, Howell and colleagues noted that, in the mid-1990s, the U.S. had an average of 2.17 units per 10,000 births (Howell et al. 2002). Using data from the late 1990s, physician Lindsay Thompson and colleagues reported that the U.S. had 8.0 neonatologists and 67.1 intensive and intermediate NICU beds per 1000 low birth weight infants delivered, while Canada had 5.5 neonatologists and 44.8 intensive and intermediate NICU beds and Britain had 3.7 neonatologists and 9.3 intensive NICU beds per 1000 low birth weight infants (Thompson et al. 2002).

5.6.3 Impact of Maternity Systems on Care for High-Risk Pregnancies and Preterm Infants

As Neel Shah noted in his New England Journal editorial cited above, primary care-focused maternity systems can provide appropriate care to preterm and other high-risk deliveries if referral systems are in place and if protocols are clear and are followed. Such protocols and regionalization schemes are varied across Europe, and have been slower to evolve there than in either Canada or the U.S. (Zeitlin et al. 2004). A study conducted by the MOSAIC researchers in 2003 concluded that three obstetrics procedures known to be effective in improving survival for preterm infants—administration of corticosteroids to mothers before delivery, transport of mothers to hospitals with NICU before delivery and cesarean sections for fetal distress—were systematically less likely to be provided to women delivering babies at 22–25 weeks compared to 28 weeks in some countries, but likely to be provided for all preterm deliveries in other countries (Kollee et al. 2009). Similarly, Blondel et al. describe a policy in the Netherlands that discouraged the referral of women in labor at gestational periods earlier than 26 weeks to hospitals with Level III facilities (Blondel et al. 2009). However, guidelines issued in 2005 lowered that threshold to 24 weeks (Verloove-Vanhorick 2006).

A report of a quality improvement project in one British National Health Service (NHS) region noted deviations from the established protocols for treating women with multiple pregnancies, primarily due to the primary care focus of the maternity system:

> In more than 90 % of NHS maternity hospitals, women with multiple pregnancy are not looked after by a specialist multiple pregnancy team. The women are often seen by non-specialists, who might lack the knowledge and experience required…. Our recent survey has shown that the level of awareness of the NICE guidance on “Antenatal Management of Multiple Pregnancy” among healthcare professionals was poor. These included midwives and doctors of varying grades, both consultants and trainees. Almost 60 % were unable to identify the correct indications for referral to a tertiary care unit. Approximately one-third did not know the correct method for screening for Down’s syndrome in multiple pregnancy. Half of the respondents did not realize that antenatal interventions such as bed rest, progesterone, cervical cerclage and oral tocolytics, are ineffective in reducing the risk of preterm delivery. Similarly, 50 % failed to specify the correct timing of birth. (NICE 2013)

In general, the issues with the maternity care system in at least some of the comparison countries is the mirror image of the United States, in the sense that pregnant women in the U.S. tend to receive the most intensive prenatal care, even when it is not necessary, while pregnant women in these other settings receive care that is less specialized than that which is thought to promote the best birth outcomes for women with pregnancy complications.

In any given region or country, preterm infants may be born in hospitals with higher level NICUs because there is an effective procedure for referring women in preterm labor, because women are referred to these settings during the prenatal period when they met the screening criteria for a high-risk pregnancy, or simply because the hospitals with NICUs are the only delivery settings in the area (Blondel et al. 2009; Zeitlin et al. 2004). Even where prenatal and delivery transfer protocols are in place and support the transport of all women who are about to deliver preterm, some portion of preterm births occur as emergencies without time to transfer the mother to a higher level of care. The 2010 European Perinatal Health Report found that the portion of preterm infants less than 32 weeks gestation that was delivered in hospitals equipped with NICUs was 66 % in the Netherlands, 69 % in Norway, 70 % in France, 83 % in Italy and 55 % in Scotland, and varied from 78 to 94 % in different regions of Belgium (Zeitlin et al. 2012). Data from the MOSAIC study a few years earlier put this portion of deliveries of preterm infants in hospitals with NICU in study regions in Germany at 85 % and in Northern England at 71 % (Blondel et al. 2009). Another study in Britain indicated that 56 % of infants born at 22–26 weeks gestation in 2006 were delivered in hospitals with appropriate level NICU facilities (Marlow et al. 2014). In contrast in California, a state with a large number of hospitals with Level III units but a lack of formal regionalization protocols, the portion of very low birth weight infants (usually less than 30 weeks gestation) born in hospitals with level III NICUs was 80 % in the period between 1997 and 2002 (Chung et al. 2010).

As discussed in previous chapters of this book, international comparisons indicate that the U.S. has a higher preterm birth rate than Canada, Great Britain and Western European countries, but also a higher survival rate for each gestational age category. Chapter 1 suggested that differences in the reasons that infants are born prematurely may be part of the explanation for better survival rates. That is, the U.S. has more preterm births, but the infants may be generally less compromised than those born in other countries and are thus are less likely to die. This chapter suggests that another part of the explanation for poorer survival rates in some other countries is that the treatment of women in preterm labor and infants born preterm is less aggressive these settings. The trend toward less intervention is certainly related to the marked differences in the healthcare systems in these countries. Publicly supported systems that are oriented more toward primary care have less immediately available specialty care for high-risk pregnant women, and particularly for preterm newborns. Additional differences in the way decisions are made about preterm newborn resuscitation in different countries is discussed in Chap. 6.

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Chapter 6
The Ethical Dimension: Moral Decision-Making About Preterm Birth

The last dimension to be examined in this book is the dimension of ethics. Ethics are the guidelines for conduct and decision-making based on morality. Morality is the principles, ideals, images, and values related to what a society defines as being "good." As such, ethics and morality are a subset of culture, defined in Chap. 3 as the shared understandings within a society that contain what members need to know in order to communicate and interact with each other. Morality is only one of many bases for conduct—others, for example, are expediency, personal gain, and social approval. Not all actions that people take within a society are expected to be based on morality. However, all human cultures have beliefs about morality, mechanisms to evaluate whether a given action is ethical, and guidelines for determining agency, or who has the responsibility for making ethical decisions in any given situation (Laidlaw 2014).

Definitions of morality change over time, as values evolve with other social changes and as novel situations require new sets of decisions. For example, there are a set of beliefs now shared in Western cultures about the moral way to conduct scientific research involving human subjects. A key component of these research ethics is the requirement that subjects give their informed consent before they are entered into a study. Once it was clear that this should be required, a conclusion crystallized after World War II when the research conducted by Nazi scientists on subjects in concentration camps became public, it was possible to look back in time and identify studies that did not adhere to this principle. The U.S. Public Health Service's Tuskegee syphilis study, begun in 1932 and involving study subjects who thought they were receiving treatment rather than participating in research, is now cited as a preeminent example of unethical research in this regard, even though the concept of informed consent was not really formulated until the 1950s (Benedek and Erlen 1999).[1] Definitions of morality also vary across cultures. For example,

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[1] Several other aspects of the Tuskegee study, including its persistence after the immorality of conducting research without subject consent was acknowledged, continued deception of participants and attempts to restrict their access to syphilis treatment, lead most observers to the conclusion that the study violated research ethics other than the expectation of informed consent at entry (Parker and Alvarez 2003).

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while researchers who study in non-Western settings are expected to adhere to the principle of informed consent, members of their study populations do not always hold the same definition of consent or prioritize consent in the same way (Marshall 2006). The fact that definitions of morality change over time and vary across societies does not mean that all moral systems are equally acceptable and should be immune from criticism, but critics must be sensitive to the moral orientation of those with whom they interact (Macklin 1998).

Several institutions within a society, in particular those with political, legal, and religious authority, can be recruited to enforce ethical behavior. However, this does not always occur, and ethics is not identical to law, government action, or religious dogma. It seems most useful from a sociocultural perspective to consider self-governance as the primary mode for enforcing morality. Individuals use the vocabulary of culture to create a self-image of being good, and then regulate their conduct so that it reflects this self-image (Laidlaw 2002; Robbins 2013). This analytic approach follows the theoretical framework of French anthropologist Michel Foucault, who was very interested in the ways that modern societies enforce social norms (Laidlaw 2014).[2]

Individuals face some challenges when trying to adhere to their moral self-image. They need to determine whether ideals about being a good person will be brought into play in any given act of decision-making. The decision to employ criteria other than morality to make decisions is sometimes made overtly; one knows an action violates morality, but one engages in it anyway. However, there are also ways that decisions are evaluated that allow ethical criteria to fade into the background, as other concerns, such as the drive for self-gratification, the preservation of social relationships, unconscious biases, and difficulties projecting into the future, take precedence (Bazerman and Tenbrunsel 2011). Another challenge involves selecting between principles and virtues that comprise morality, when they are perceived to be in conflict. The classic example given in philosophy for this situation is the “Heinz dilemma” which asks whether a man is justified in stealing a drug that could save his wife’s life, if he has no other way to obtain it. As will be discussed in this chapter, the persistent problem of choosing between respecting a woman’s right to self-determination, and acting for the perceived well-being of her fetus is an example of a conflict between values which are both components of a moral clinician, as defined by the ethical guidelines of the medical profession.

A third type of challenge occurs when there is more than one party involved in making a decision on a course of action, and the parties hold different definitions of morality. Definitions of agency—who is entitled to make a given decision—are critical in this situation, although sometimes the outcome fails to satisfy anyone’s definition of the fulfillment of a moral ideal. As discussed in Chap. 5, part of the decision-making process around prolonging the life of marginally viable infants involves structuring the circumstances under which parents will be presented with

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[2] The self-governance paradigm is most compatible with the framework of virtue ethics in philosophy.

options for their infants' treatment. The authority and resources of clinicians are used to enforce one set of understandings about the appropriate agency of parents, that is, the point at which they should be given the opportunity to decide whether to continue or withdraw treatment from their infant. When there are conflicts over which party has the right to decide about the newborn's treatment, as well as conflicts over what is a moral choice in the care of the infant, one or the other party may resort to legal action; this is an example of recruiting the legal system to attempt to enforce a moral choice.

Some sets of ethical decisions attract the interests of third parties, who represent some facet of society's interest in enforcing moral views. As discussed in Chap. 4, in the 1980s antiabortion advocates became involved in the decision-making around the care of very preterm infants, and used the political system to create a set of constraints (the Baby Doe rules) on parent and clinician choices. Ethicist Loretta Kopelman recalled one such situation that was influenced by these third-party views:

> A family was faced with a decision about how to respond compassionately to their extremely premature and severely impaired newborn. In attendance were members of the parents' extended family, including an aunt who was a hospice nurse and a cousin who was an adult pulmonologist. These two family members had extensive experience in caring for dying adults. The entire family agreed that given the infant's poor prognosis and suffering intrinsic to his illness and treatments, it was in his best interests to have comfort care and to forgo aggressive life-sustaining treatments. The three neonatologists present also agreed that this plan would be in the infant's best interests, but said that they were constrained by the Baby Doe rules and would have to continue maximal treatments because the treatments for the infant's condition were not virtually futile in terms of survival, the infant was not dying, and the infant was not in a chronic and irreversible coma. The hospice nurse and pulmonologist were shocked that the best interests standard could not be used for infants in the way it was routinely used for incompetent adults lacking advanced directives. (Kopelman 2005, p. 798)

6.1 Ethical Decisions in High-Risk Pregnancies

In general terms, the moral view of pregnant women in the U.S. is that they are supposed to be fulfilling the cultural ideal of being or becoming good parents. Good parents unselfishly put concerns for their children's well-being above their own, take action to nurture their children, and protect them from harm. This view of morality sometimes supports and sometimes is in conflict with a second moral principle: that adult women and men have the right to make their own procreative choices, to control what happens to their bodies and to determine how they are treated in a therapeutic context. The moral view of clinicians is that they act competently to bring benefit and not harm to their patients, that they act in the interests of these patients, and not in the interests of themselves or some third party, and that they respect the autonomy of their patients to make their own decisions about their treatment. Strong social norms in the U.S. about the medicalized nature of pregnancy set the expectation that the therapeutic relationship between clinicians and their patients will be the primary venue for decision-making in this context, so the ethics of clinicians and patients should be the dominant basis for cultural interpretations of the morality of decisions during pregnancy, that is, the way societies continue over generations. However, because pregnancy is also the venue for social reproduction, there are circumstances where third-party views of morality become involved in ethical decision-making. These third-party views are sometimes framed as representing society's interests, for example, for efficient use of resources, and are sometimes framed as representing the interests of the fetus, and in that sense the interests of future generations.

6.1.1 Multiple Embryo Transfers in In Vitro Fertilization

One of the situations that challenges parental, clinical, and societal definitions of morality occurs during the process of in vitro fertilization (IVF), a form of assisted reproduction in which oocytes (eggs) are fertilized with sperm outside of the body, allowed to mature into embryos, and then manually implanted in a woman's uterus. Medications are used to boost oocyte production so that there are multiple eggs to fertilize at any given time, and to regulate the fertility cycle so that the uterus is ready for implantation when the embryos reach the appropriate stage. The oocytes used may be from the woman undergoing IVF, or they may have been donated by another woman. In the process of implantation, a decision must be made about how many of the resulting embryos to implant in the uterus.

The implantation of multiple embryos increases the likelihood that one or more will mature into a viable fetus. However, if they all implant and mature, the resulting multiple gestation pregnancy is more likely to involve complications and to result in the delivery of preterm infants. This is particularly the case with multiple gestations greater than two. During the IVF procedure it is possible to implant multiple embryos. As noted in Chap. 2, multiple pregnancies resulting from assisted reproduction are part of the reason that preterm birth rates are increasing in the U.S. and in other countries, although the contribution of this phenomenon to the overall preterm birth rate has been relatively minor to date. As noted in Chap. 3, preterm births resulting from assisted reproduction receive considerable media coverage, in part because of the irony that this is a problem caused by technological intervention, while technological intervention is usually seen as a solution to the problems caused by preterm birth.

The issue of high-order multiple pregnancies in IVF has been discussed since the intervention was pioneered in the 1980s. Current practice guidelines of both the Society for Assisted Reproductive Technology and the American Society for Reproductive Medicine (ASRM) recommend against multiple implantation, stating:

> Clinicians have a professional and ethical obligation to optimize the chance of a singleton birth for prospective parents whose preferences and choices may be clouded by feelings of desperation to achieve a pregnancy (ASRM 2012, p. 838, reprinted with permission from Elsevier).

However, the practice of multiple implantation persists.[3] A 2008 survey of ASRM members found that, while 94 % of respondents reported following the ASRM practice guidelines, only 37 % routinely discussed single embryo transfer with all patients. Nearly all reported discussing the risks of multiple pregnancy, but 75 % reported that they would implant multiple embryos if the patient had previous failed IVF cycles, 55 % would do so on patient request, 55 % would do so if previously frozen embryos were used (because there is a lower likelihood of successful implantation), and 35 % reported routinely transferring two embryos for younger women with favorable IVF prognoses (who are prime candidates for single embryo transfer) (Jungheim et al. 2008).

These findings suggest either that the ethical obligation of optimizing a healthy singleton birth referred to in the professional guidelines is not actually a defining feature of morality, as perceived by physicians providing fertility services, or that other considerations displace morality when the decisions about embryo transfer are made. One other consideration that has been suggested as a motivation for the decision to implant multiple embryos is the desire to report high rates of pregnancy achievement at the clinic level, in order to improve the clinic's ability to compete for fertility treatment patients. The survey cited above found that 49 % of respondents said that they would be more likely to practice single embryo transfer if pregnancy rates from these procedures were reported separately and not factored into overall clinic pregnancy rates, which are reported nationally and published by the Centers for Disease Control. The survey also found that clinics were more likely to agree to patient requests for multiple embryo transfers in settings where more patients have fertility treatment insurance coverage. The researchers offer the interpretation that settings where more patients have insurance coverage probably have more competition from other clinics, so agreeing to patient requests is a way of increasing customer recruitment (Jungheim et al. 2008).

Another way that moral considerations in multiple embryo transfer are displaced is by discounting the true risks of multiple gestation pregnancies. Journalist Sara Elizabeth Richards writes:

> [D]octors tend to point out that mothers carrying twins suffer from more hypertension, gestational diabetes, heart stress and placental problems than those pregnant with singletons, and twin babies have higher rates of severe premature birth, handicaps, low birth weight and infant mortality.
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> Those risks would make twins seem like a terrible idea, *if* they applied to IVF patients and [IVF clinic medical director Norbert] Gleicher insists that they don't.

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[3] For example, in January 2015, 36 year-old Erica Morales, a Phoenix woman who was pregnant with quadruplets after undergoing IVF, died of blood loss after an emergency cesarean section. The procedure was conducted when she was 31 weeks pregnant and experiencing extreme blood pressure elevation (Campbell 2015). Her four preterm infants survived, and are under the care of their widowed father (Keating 2015).

> He says that IVF patients actually contend with a much lower set of risks than do other mothers of multiples, since they are closely monitored and managed from the moment of conception. Twin mothers in the general population, by contrast, might not know they are having twins until later in their pregnancies, and don't receive proper prenatal care. (Richards 2011, p. 2)

Here, physician confidence in the ability of prenatal monitoring and management to control the occurrence of preterm birth allows this physician, and the readers of the article, to minimize the ethically problematic nature of the multiple embryo implant decision.

However, there are at least two reasons why clinicians may proceed with multiple implantation despite the risk of preterm birth, and still maintain that this is an ethical decision. First, the primary responsibility of a physician is to provide benefit to patients by addressing their health concerns. To the extent that transferring multiple embryos increases the likelihood that a previously infertile woman will become pregnant, this action will be considered more aligned with physician morality than transferring a single embryo. Second, it is widely observed that IVF patients prefer multiple embryo transfer, because it maximizes their chances of becoming pregnant and minimizes the number of treatment cycles they will be required to undergo to complete their families. Although the professional practice guidelines suggest that patients can be educated to change their minds about this preference, clinicians can cite respect for patient autonomy and self-determination as reasons to agree to multiple embryo transfers (ASRM 2012; Campbell 2015).

Philosopher of science Charis Thompson notes that over two decades of studying (and personally experiencing) IVF, she has seen its cultural framing shift from being a procedure parallel to adoption, carried out in the best interests of the future child and thus provided only to the most appropriate parents (healthy, wealthy, heterosexual, and married), to being thought of as a private reproductive choice, like sexual activity and child spacing, which women can choose to engage in freely. She refers to this as “making parents,” as opposed to “making children” (Thompson 2005). Referring to the decision to transfer single or multiple embryos, she comments:

> Patients who cannot easily get pregnant typically have enthusiasm for any kind of pregnancy, fantasize about the “instant family” that multiple births seem to provide, and often do not want to jinx themselves by making judgements about the best number of embryos to transfer. Likewise they cannot easily get pregnant again, and so the high miscarriage rate associated with selective reduction [where multiple embryos are implanted but some are later removed] is not acceptable to many. (Thompson 2005, p. 261)

From this point of view, women undergoing IVF fulfill their moral ideals as parents by becoming pregnant, so anything that increases that likelihood would be considered an ethical action. Familiarity with the potential health risks to a child of multiple embryo transfer can cause that issue to be factored into moral decision-making, if these risks are communicated effectively (ASRM 2012). Research suggests that women with insurance coverage for fertility treatments are more likely to choose to transfer single rather than multiple embryos, apparently because they do not have costs as a reason to avoid repeat IVF procedures (Stillman et al. 2009). Cost, a consideration separate from morality, thus seems to help shift the balance between two moral principles—the drive to become a parent and the imperative to act in the best interests of the child.

The observation about the impact of health insurance coverage on the multiple embryo transfer decision leads bioethicist David Orentlicher (2010) to conclude that increased availability of insurance coverage for fertility, along with patient education and possibly legal restrictions (which are in place in other countries, as will be discussed Sect. 6.3.1), would be helpful in reducing the incidence of multiple embryo transfer. He believes such a reduction would be in society's interest, because of the high monetary and health costs of multiple gestations pregnancies. But, echoing Thompson's observation of the contemporary framing of IVF issues, bioethicist Maxwell Smith replied to Orentlicher's proposal by arguing that the advantages of single embryo transfer are not large or consistent enough to justify such a limitation of "procreative liberty" (Smith 2011).

Complicating the morality of the decision to implant single or multiple embryos is the question of what to do with embryos that are not implanted during an IVF cycle. The vast majority of these are frozen for potential future use, but are not actually used in this way. As a consequence, the U.S. has hundreds of thousands of embryos in frozen storage, with little agreement about their disposition. Examining the factors associated with the disposition decision reveals that many IVF patients think of their embryos as akin to "us" (adult human beings) in moral status. In one study, the closer to full human beings that IVF patients considered their unused embryos to be, the more likely they were to choose to use them in a future pregnancy, to donate them to an infertile couple, to have them re-implanted at a time when they know they would not get pregnant (thus generating a miscarriage, or an apparently natural fetal loss) or to have a ceremony upon disposal of frozen embryos. They were less likely to choose to thaw and dispose of the embryos or donate them for research. Interestingly, those who thought of their embryos as most like full human beings were least likely to want to donate them to other infertile couples, out of concern that they would not be able to control the fitness of the couple raising their children.[4] This is another aspect of the way that, from a parent's point of view, the morality of becoming a parent through IVF may support multiple embryonic implantation, despite the risks of preterm birth to the implanted fetus (Bell 2011; Lyerly et al. 2010).

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[4] These options were proposed as hypothetical choices in a large study of couples who underwent IVF. Many of these options are not actually offered to IVF patients, due to legal restrictions (e.g., prohibitions against stem cell research with embryos) and fertility clinic practices. The primary option for most IVF patients is freezing of embryos, and most respondents simply prolonged freezing because of few desirable alternative options (Lyerly et al. 2010).

6.1.2 Prenatal Screening

6.1.2.1 Clinician Views

Screening in the context of clinical care is the practice of searching for a disease or physical problem in the absence of symptoms. In general terms, medical ethics hold that such screening should be based on sound evidence that the practice will lead to the identification of a treatable condition. In other words, appropriate screening should have a benefit that outweighs any potential burden or harm caused by the screening itself (Malm 1999). Screening is an important component of prenatal care, in part because it can lead to the identification of treatable conditions, such as anemia or asymptomatic infections, but also in part because it allows pregnancies to be sorted into categories of risk, for example, blood glucose testing as an indicator of gestational diabetes. As discussed in Chap. 3, it is not clear how well these risk categories function as predictors of pregnancy complications, but they are useful to clinicians for reducing their sense of uncertainty about the outcomes of the pregnancy, and for deciding which clinical protocols to apply to the patient. Being categorized by risk status is an important feature of the contemporary experience of pregnancy.

The Committee on Ethics of the American Congress of Obstetrics and Gynecology (ACOG) identifies five principles that should guide the ordering of diagnostic testing (ACOG Committee on Ethics 2007b). The first is actually a dual principle, with a component for physicians and a component for patients. Physicians have responsibilities both to be guided by scientific knowledge in ordering tests, and to promote trusting and honest relationships with patients. Patients have the responsibility to provide accurate information about their "lifestyle, health habits, sexual practices and religious and cultural beliefs" when these may affect medical decisions. The second principle is that testing should be performed primarily for the benefit of the patient. If testing is requested by third parties, such as family members, employers, other health care providers or insurers, the patient should be informed about the risks and benefits of testing and give their consent.

The third ethical principle of screening is that the decision to offer or withhold a test should not be made on the basis of an assumption about the expected response of a patient to the test results. This is relevant, for example, in the case of prenatal genetic screening that is used to identify the likelihood that a fetus carries a disabling or fatal chromosomal abnormality. There is considerable debate about whether it is appropriate to offer such genetic testing to patients who have already determined that they would not terminate their pregnancies under these circumstances, since termination is the primary clinical action that is the outcome of such testing. Conversely, clinicians who are opposed to pregnancy termination might be reluctant to offer such testing if they think that the patient will decide to terminate the pregnancy. Following this principle articulated by the ACOG Committee on Ethics, it should be left up to the patient, in consultation with the physician, to decide whether or not to undergo this type of screening (Allyse et al. 2015; Chervenak et al. 2008).[5]

The fourth ethical principle proposed to guide obstetrician's decisions about screening is that patients should be informed ahead of time which parties will have access to the results of the screening. The fifth and final principle is that physicians and patients should discuss issues of costs, cost containment, and reimbursement for testing. The Committee indicates that this principle was included because both physicians and patients worry that useful testing might be constrained because of insurance rules about what tests are covered. Also patients may mistrust the intentions of physician recommendations, suspicious that they might be driven by economic concerns. Along these lines, the opinion states:

> Testing done with low probability of improving patient diagnosis, or testing solely for the sake of professional liability concerns should be avoided. (ACOG Committee on Ethics 2007b, p. 2, published by the American Congress of Obstetricians and Gynecologists)

It is difficult to know how much screening during pregnancy is driven by interests such as financial gain or legal protection for the care provider, particularly given (as discussed in Chap. 5) the way commercial concerns and interests and the urge to action are interwoven with the contemporary practice of medicine. However, in the context of prenatal screening there are clearly examples of the second type of ethical challenge described above, the need to choose between conflicting sets of values that all describe what it means to be a moral physician. The ACOG principles require that screening have a scientific basis and a direct benefit for the patient, but some screening is done to reduce uncertainty for clinicians, even though there is no specific action that can be taken based on the results. Reducing uncertainty allows physicians to feel more competent, and competence is a key feature of the self-definition of a good physician (Good 1995). Even if the results of a screening test will not lead to any meaningful change in how a pregnant woman is treated during prenatal care, there can be a powerful urge to conduct the test in order to provide reassurance to patients or clinicians, or to alter expectations for the outcome of the pregnancy. Khiara Bridges observed this phenomenon in the context of the standard screening protocols applied to women in the public hospital prenatal clinic she studied; repeated screenings for gestational diabetes and for sexually transmitted diseases were ways of confirming expectations about the level of pregnancy risk (and beliefs about sexual promiscuity) in the population, although clinicians themselves could not explain the meaning of these repeated screenings for their approach to care, and treatment protocols were not altered by the findings

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[5] The ethics of prenatal genetic screening has been extensively scrutinized because it raises so many issues, including the impact of expanding technology, the balance of risks and benefits of screening, whether termination of an affected pregnancy can be considered a benefit, how clinical personnel can reasonably adopt a position of ethical neutrality when advising patients on prenatal genetic screening, and whether having the "gift of knowledge" about fetal abnormalities actually enhances a pregnant woman's autonomy in decision-making, see (Allyse et al. 2015; Chervenak et al. 2008; Farsides et al. 2004; Kenan 1996).

(Bridges 2011). The drive to convince women to consent to prenatal genetic screening is another example of a practice that can improve clinicians' sense of competence but may not meet the ethical standard that screening needs to have a specified benefit for the patient (Fordyce 2012; Kenan 1996).

Another example of conflict between moral principles in the context of prenatal screening is the decision about whether to override the principle of respecting a woman's autonomy and right to refuse screening, in order to provide her or her fetus with care that the clinician believes will be beneficial. ACOG's Committee on Ethics considered this issue in a separate opinion, and noted that this perceived conflict between benefiting a patient and respecting her decisions is exacerbated by the view that a pregnant woman's fetus is also a patient, with health concerns that can be in conflict with those of the mother. As discussed in Chap. 3, the increased use of ultrasound and other diagnostic techniques beginning in the 1970s supported a shift within medicine toward thinking of the fetus as distinct from the pregnant woman. However, within contemporary clinical practice, fetuses are generally not thought of as separate patients with equivalent standing to the pregnant women who carries them, but more as intertwined lives that affect and are affected by care provided to the mother (Lyerly et al. 2008; Mattingly 1992). The ACOG committee advised that neither concern for the fetus nor concern about the refusal of screening on the part of pregnant woman justifies performing screening in the absence of the pregnant woman's consent. In part this is because outcomes in obstetrics are really not that foreseeable, so there is no real assurance that the clinician is correct about the likely negative effect of the woman's choice not to be screened. In part this is because screening without consent has the potential to cause harm, for example, by causing women to avoid future prenatal care visits and disrupting the therapeutic relationship (ACOG Committee on Ethics 2005). This ethical stance underlies the obstetrics profession's endorsement of the requirement that HIV screening during pregnancy, while important for clinical care of women and preventive care for their fetuses, still requires consent by the patient before it is included in her clinical care (ACOG Committee on Ethics 2007a).

6.1.2.2 Third-Party Views

The third type of challenge described at the beginning of this chapter occurs when other parties with different notions of morality enter the decision-making process. This has occurred most dramatically in the U.S. around the issue of screening for substance use during pregnancy. As discussed in Chap. 2, alcohol, tobacco, and cocaine use during pregnancy have all been associated with the occurrence of preterm birth. In theory, screening for substance use during pregnancy could lead to treatment that could reduce exposure, thus potentially improving a pregnancy outcome. ACOG's Ethics Committee recommends that clinicians provide routine screening for alcohol, licit, and illicit drug use. Tobacco use is considered to be "beyond the scope" of its opinion on substance abuse, although it is arguably the risk most closely associated with preterm delivery. Clinicians should establish a therapeutic alliance with patients, educate them on the consequences of these behaviors for fetal health, and provide risk mediating interventions (ACOG Committee on Ethics 2015).

Based on the ACOG guidelines and other statements of ethical principles of medical care, there is an expectation that results of substance use screening will be confidential and will be used only in a therapeutic context. However, the 2015 ACOG opinion notes that some clinicians practice in one of the 15 states which require the reporting of positive screens for substance abuse by pregnant women to government agencies, usually to agencies responsible for child protective services. A subset of four of these states have mandates that require providers to test their patients for specific substances. In addition to violating confidentiality, mandated reporting creates the potential for this type of screening to cause direct harm to patients, because some states define substance use during pregnancy as child abuse which can be punished as a crime resulting in incarceration. Reported positive screens for substance use can also trigger the loss of child custody (Dailard and Nash 2000; Guttmacher Institute 2015).

From the clinicians' point of view, involvement of the government as a third party threatens the trust relationship between patients and providers, which is essential for good care. Respecting women's autonomy and their choice to accept or refuse substance use screening is thought to increase the likelihood that women will cooperate with screening and treatment. The ACOG Committee on Ethics advises clinicians to inform patients if their screening results will be reported to a government agency, to advocate against punitive action such as the separation of mothers from children, and to work in the public policy arena to substitute policies that respect "autonomy and beneficence" for punitive policies concerning substance use during pregnancy (ACOG Committee on Ethics 2015; ACOG Committee on Health Care for Underserved Women 2011).

However, as in the case of multiple implantation of embryos in IVF as discussed above, in practice it is not clear how consistently physicians endorse the ethical stance of their professional associations on the drug and alcohol use screening issue. A survey of Michigan physicians reported in 2002 that 43 % of obstetricians, 49 % of family physicians, and 55 % of pediatricians favored mandatory screening for illicit drug use during pregnancy, with the majority also favoring the inclusion of mandatory screening for alcohol abuse (Abel and Kruger 2002). Furthermore, the majority of respondents favored defining substance abuse during pregnancy as reportable child abuse, and favored mandatory treatment for pregnant women found to be using drugs. The authors of the study describe the stance of those disagreeing with the ACOG ethics guidance and supporting mandatory screening and the incarceration of pregnant women found to be using drugs as feeling "morally outraged that unborn children are being exposed to drugs and alcohol by seemingly irresponsible mothers" (p. 768). Nearly all physician responding to the survey believed that pregnant women had a moral responsibility to ensure that they had healthy babies, and the majority thought that these women also had a legal duty to do so.

A similar sense of moral outrage has animated lawmakers and law enforcement personnel who have supported mandatory screening, reporting, treatment, and punishment for pregnant women found to be using drugs. Some of these government actions were triggered initially by public responses to the media attention focused on the issue of cocaine-exposed infants in the 1980s. Concerns about the costs to state government of care for drug-using women and their infants has been cited as a legitimate reason for state intervention (Steinberg and Gehsham 2000). The rhetoric surrounding these laws and prosecutions reflect the belief that substance use represents a moral failure on the part of these women, rather than a biological and behavioral disorder with a possible genetic component, as one of the ACOG committees described it (ACOG Committee on Health Care for Underserved Women 2011). Policy analysts Cynthia Dailard and Elizabeth Nash cite a Wisconsin statute as an example of this approach:

> The Wisconsin children's code, as amended in 1998, goes so far as to grant the state's juvenile court "exclusive jurisdiction" over an unborn child when a pregnant woman "habitually lacks self-control" with regard to alcohol or controlled substances. Because the statute defines an "unborn child" as a "human being from the time of fertilization to the time of birth", the state may intervene and detain a woman throughout her pregnancy if she poses a "substantial risk to the physical health" of her fetus. (Dailard and Nash 2000, p. 5)

The legal rationale for state involvement in prenatal screening for substance use hinges on the belief that the laws and their enforcement are an appropriate expression of society's interest in protecting the welfare of children, before they are born, from dangers posed by the actions of their mothers. Building this legal rationale has required accepting the premise that fetuses have interests that are different from, and potentially in conflict with, the interests of their mothers. The complexity and nuance that characterizes the clinical ethics approach to the maternal-fetal dyad is missing from this legal approach. Instead, the legal and governmental framework holds that maternal liberties, such as the autonomy to make decisions about receiving treatment for substance use during pregnancy, may be appropriately limited if these liberties have a negative impact on the fetus. For example, law professor Janet Stevenson laid out one policy proposal in 1994, using the terms fetus, unborn child and child interchangeably, as she called for policies that would mandate screening, mandate substance abuse treatment and mandate contraceptive use to avoid exposing future fetuses to dangerous substances until substance abuse treatment for the woman is successful. She compares these restrictions to the sanctions placed on drunk drivers, who are punished for their dangerous behavior even if they demonstrate that they are addicted to alcohol (Stevenson 1994, p. 340).

The view that fetuses have rights independent of their mothers did not arise in a vacuum. Until the 1970s the established legal view was that any rights that a fetus had would only accrue after birth; for example, a child would be entitled to an inheritance after birth if the father died while the mother was pregnant. The Supreme Court's 1973 *Roe v. Wade* decision was built on the premise that, before they are viable outside of the womb, fetuses do not have independent rights which override the privacy rights of a mother to make a choice about abortion. After viability, states may restrict the use of abortion unless it is necessary to save the life or health of the mother. Since the Supreme Court decision, efforts have been made in many legal venues, including courts, Congress, federal administrative agencies, and state legislatures, to establish the legal basis for fetal rights and for defining fetuses as persons under existing laws. Some scholars contend that these efforts are intended to rebalance legal precedents and to offer pregnant women some additional legal protections. At the same time, it is clear that the fetal rights initiatives are a major component of efforts to reverse the *Roe v Wade* decision and to re-criminalize abortions. Successful use of the fetal rights premise to mandate drug and alcohol screening and the reporting of the results of these screenings without the consent of the pregnant woman help to advance this broader agenda (Johnsen 1986; Roth 2000; Schroedel 2000). The fetal rights orientation also plays a role in discussions about mandated interventions during pregnancy, and in discussions about limiting the decisions of clinicians and parents regarding preterm infant resuscitation. These issues are discussed later in this chapter.

6.1.2.3 Parent Views

Pregnant women who use drugs and alcohol are often portrayed as selfish and uncaring about the health of their fetuses. However in interviews with researchers, pregnant women and mothers who used drugs or alcohol while pregnant consistently report that they share the view that substance use during pregnancy is morally wrong. They describe experiencing guilt at the thought of how they have hurt their fetuses, and shame about violating the social expectations of motherhood. Many attempt to stop or reduce use, substitute substances that they consider to be less dangerous, and engage in other behaviors such as eating well or taking vitamins that they hope will protect their fetuses. For physical reasons because of addiction, for social reasons including the influence of partners and friends, and for psychological reasons such as the perceived need for substances to cope with loneliness or stress, women report that stopping substance use during pregnancy is extremely difficult to do. Treatment resources are limited, and prenatal care providers do not always refer women to treatment (Barnwell and Bammer 2006; Flavin 2002; Leppo 2012; Murphy and Rosenbaum 1999; Roberts and Nuru-Jeter 2010, 2012).

Yet, although they agree with clinicians and third-party advocates that substance use during pregnancy is wrong, women do not always agree that they have a moral obligation to undergo drug and alcohol screening, or to otherwise inform their prenatal care providers about aspects of their behavior that could affect their fetuses. Sociologists Sheigla Murphy and Marsha Rosenbaum contrast the views of different women they interviewed in their study of pregnant women who used drugs about disclosure of their use:

> In her seventh month of pregnancy, Maria recalled the following conversation with her doctor: "I told my doctor, I said, 'Please have all your important instruments near you because I used [crack] with my baby."
>
> Amanda disclosed her crack use as a way of alerting her doctor to her high risk pregnancy. In addition to relying on technological advances, she felt her providers could give her valuable information. She characterized her doctor- patient relationship "When I go to my prenatal care appointment, I'll tell the doctor, 'I fucked up. I smoked. Is my baby OK? 'I don't want nothing to happen to my baby. I'm learning and wanting to know all these things so it'll help me further help my baby."
>
> For Amanda and the other women who disclosed, telling providers about their drug use during pregnancy was viewed as a way to open doors to important resources. While the women knew that prenatal caregivers could not erase crack-related harms, they believed that prenatal care was an essential step in monitoring and managing risk.
>
> Unfortunately, the women's attempts to improve their health through traditional health care was problematic. Crack users often found that after disclosing their drug-using status they suffered harsh judgements from health care professionals. When we interviewed her, Jessie had just given birth to her first crack-exposed child. The uncomfortable memories of her hospital experiences were still fresh in her mind. During Jessie's first two pregnancies, she had not smoked crack, nor had she missed a single prenatal appointment. At delivery, her doctors and nurses were very supportive. Jessie's crack-involved pregnancy was a markedly different experience. She had smoked crack almost continuously, and only managed to attend two prenatal care appointments. During labor and delivery, the doctors and nurses treated her like "a dirty little crack addict." Looking back at her own experiences and those of others, Jessie explained to her interviewer why women in her position fail to get prenatal care.
>
> "I know a lot of mothers say that they don't get prenatal care 'cause they feel like as soon as they walk through the door, they will be judged. "Oh, you're a crackhead. Why the hell did you get pregnant anyway!" So they don't get prenatal care. They have those commercials about addicts that don't get prenatal care because they just don't give a shit. They do give a shit, but they are thinking about how they gonna be looked at when they walk in the hospital door, like they were not good enough to be pregnant". (Murphy and Rosenbaum 1999, pp. 89–90)

A study conducted nearly 15 years after the Murphy and Rosenbaum study cited above (Roberts and Nuru-Jeter 2010) found similarly that some women who used drugs during their pregnancies disclosed drug use to their prenatal care providers. However many did not, and instead found ways to avoid drug screening or to invalidate the screening results. Many described the experience of being confronted by their prenatal care providers with the results of screening tests that showed drug use, although they had not given consent for testing and were unaware that they were being screened.[6] The decision to disclose drug use to a prenatal care provider

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[6] In 2001, the Supreme Court ruled in favor of 10 South Carolina women who sued their prenatal care provider, the Medical University of South Carolina in Charleston, for screening them for drug use without their explicit consent and turning the positive results over to local law enforcement authorities. The basis of the ruling was that the screening constituted illegal search and seizure because it was used for legal and not therapeutic purposes; it is not clear whether the expectation for explicit patient consent for prenatal drug screening, if it is used for therapeutic purposes, has the force of law (Gostin 2001; Sikich 2005).

depended on whether or not the prenatal care provider could be trusted not to turn the results of the screening over to child protective service agencies. As one women interviewed in the more recent study explained:

> With me being pregnant, obviously, you can't trust, you don't know who you can trust, you've heard other people going through their pregnancy and hearing horrible stories about the doctors turning on them and then you hear, I've had people in my life who've been to the doctor while they were using and they've had …experiences where the doctors have helped them, but us as users, we don't know who we can trust and we're not willing to take that chance. (Roberts and Nuru-Jeter 2010, p. 197, reprinted with permission from Springer)

Attempts to avoid prenatal drug screening could be thought of as situations in which selfish considerations take precedence over the moral obligation to do what is best for the health of the fetus. In that framework, the personal costs to women of experiencing stigma, being identified by legal authorities, and experiencing sanctions including loss of child custody or prosecution for a crime, would be in conflict with the moral concerns of being a good parent. However, based on interviews with women who have experienced these situations, it seems possible that attempts to avoid screening are ways to fulfill the perceived obligation for parents to take care of their children, rather than having them placed in some other care setting. In addition, by failing to offer or refer women for substance abuse treatment, and by violating expectations for informed consent and respect for confidentiality, prenatal care providers fail to uphold their role in the therapeutic relationship. From the women's point of view, this may remove their obligation as patients to reciprocate by providing accurate medical histories and agreeing to screening.

There are other situations during prenatal care in which women decide not to accept their care providers' recommendation that they undergo screening, but they are not that common. Diagnostic testing tends to be routinized, with limited opportunities to refuse specific tests (cf Press and Browner 1997 on prenatal genetic screening). Reasons for refusing screening include not understanding or accepting care providers' definitions of their level of risk for a poor pregnancy outcome, not believing that screening will lead to an effective intervention, and having concern that the risks or discomforts associated with a screening test outweigh the potential benefits (Carusi et al. 1998; Fordyce 2012; Press and Browner 1998). For example, in her book on the content of prenatal care advice, communications professor Marika Siegel recounts an exchange she identified on a forum for pregnant women within a prenatal advice web site. A participant in the forum asked others about refusing a glucose challenge test because of side effects; several respondents advised her that she could refuse, or suggested that she ask for a different type of test, while other respondents encouraged her to take the test anyway, that she could not refuse it or would be selfish if she did so (Siegel 2014). In these cases, women are not using different moral principles than their clinicians when making screening decisions, but they are applying those principles differently, based on their interpretations of the facts at hand, for example, identifying a different harm to benefit ratio than their clinicians.

There are some situations where the monetary costs of a given screening test are weighed against the ethical obligation to undertake screening in order to do what is best for the fetus. Sociologist Megan Allyse and colleagues conducted a national survey in 2012, asking respondents whether they would want a loved one to receive one of three prenatal genetic screening tests, which varied in cost, invasiveness and risk, and level of accuracy. Respondents were then asked to justify their choice. The researchers report that many respondents factored cost into their decisions, but then go on to observe:

> The second subtheme included a rejection of cost as a relevant factor in making testing choices. This subtheme was more frequently used to justify the selection of NIPT [the more expensive but more accurate diagnostic test] over traditional screening.
>
> "If I felt so strongly that I needed to know, cost would not be an issue. I think the higher accuracy rate is very important. Having the experience of having an amnio to detect downs [sic] syndrome in one of my twins was very stressful" (female, 35–44 years).
>
> "Accuracy is more important than money. A 15 % failure rate [for serum screening] is unacceptable". (female, 65 or over)
>
> Another aspect of this subtheme was an assertion that cost considerations are inappropriate in pregnancy, linking the inherent value of the anticipated child to the perceived duty to do "whatever it take" in the prenatal stage.This attitude was frequently associated with an insistence that the potential child (and, by extension, any information about his/her health) is valuable beyond any financial considerations (Allyse et al. 2015, p. 10, reprinted with permission from Taylor & Francis, www.informaworld.com).
>
> "Babies are important no matter what the cost! [NPTI] is more accurate! If I were to take the other one and it came back neg. I wouldn't feel right without taking the other one anyway". (Male, 25–34 years)

In fact, patients may over-estimate the value of screening, both in the prenatal context and more broadly, in part because of the pervasiveness of the medical model of risk categorization. If initial screening suggests that a pregnancy could be categorized as high risk, women may feel obliged to undergo further screening, either to alter the designation—to return the pregnancy back to normal—or to reassure themselves and their prenatal care providers that they will do anything that is required to protect the health of their fetus (Hunt and de Voogd 2003; Kenan 1996). Dutch bioethicist Tjeerd Tymstra (2007) refers to this decision-making approach as the drive to avoid "anticipated regret," so that if a pregnancy has a poor outcome, the parents can feel that at least they did everything that they could to prevent it. He suggests that because this view has such a strong potential to distort rational decision-making about diagnostic screening on the part of patients, there is a strong ethical obligation on the part of policy makers and clinicians to limit use of screens that are not linked to effective treatments.

6.1.3 Interventions for High-Risk Pregnancies

6.1.3.1 Clinician Views

As noted in the beginning of this chapter, core elements of morality for U.S. physicians include the commitment to offer benefit and not harm to patients, to act in patients' interests, to be competent, and to respect patient autonomy and patients' rights to refuse treatment. One reason for concern about the adoption of obstetrics practices in the absence of sound evidence that they are effective (Chalmers 1986; Hueston 1992; Starr et al. 2009), is that having an evidence base for clinical practice is a way to assure patient benefit and thus fulfill that ethical obligation (Culpepper and Gilbert 1999). For example, the practice of prescribing bed rest for women with high-risk pregnancies has been labeled unethical by some commentators, primarily because there is no scientific evidence of benefit, but there is evidence of harm. Physician Christina McCall and colleagues write:

> Some health care providers may believe that the absence of evidence proving an intervention's benefit is not sufficient to change long-standing practice. Moreover, an intervention that appears to pose little to no risk to the fetus may be deemed acceptable. However, three problems are evident with this view. First, it reflects a "risk distortion" common to reasoning regarding pregnancy. Namely, it attends to fetal risk and works toward its elimination without due regard for risks or burden to pregnant women. Indeed, women are often expected (and willing) to accept such burden if it has the potential to benefit the fetus. Secondly, this view conceptualizes the woman and fetus as distinct entities, as two separate patients. Yet the serious risks of bed rest, such as venous thrombosis, maternal depression, and deconditioning are not, in fact, just "maternal" risks. All risks have implications for both the woman and her fetus. And third, this view reflects an impulse toward control of birth, the tendency toward intervention, and a fear of stepping aside regardless of the harms an intervention may bring (McCall et al. 2013, p. 1307, published by the American College of Obstetricians and Gynecologists).[7]

Along the same lines, one British commentary suggested that there are ethical concerns about the provision of both tocolytic and corticosteroid therapy under some clinical circumstances because both can potentially cause harm, and neither are always beneficial (Steer 2005).

McCall and colleagues note two other ethical concerns with the continuing widespread recommendation for bed rest for high-risk pregnant women. The first is that prescribing such an intervention, which is difficult to fully adhere to, sets women up to blame themselves if they have a poor pregnancy outcome. The second is that it is difficult to know whether patients have been fully informed and offered the option to decline a recommendation of bed rest, or whether they feel pressured to comply. Such pressure would be a violation of the principle of patient autonomy,

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[7] This comment is also interesting because it indicates how the clinical reasoning around prescribing bed rest during high-risk pregnancies reflects beliefs about medicine—that action is preferable to no action—and social reproduction—that fetuses are separable from mothers and that the health of the mother can appropriately be sacrificed for the benefit of the fetus.

which holds that fully informed and competent adults have the right to refuse medical treatment. Yet, as described in Chaps. 3 and 5, pressure to comply with physician recommendations is a core component of the medicalization of pregnancy in the U.S. In acute situations such as a threatened preterm birth, fully informed consent for any procedure is an ideal which is seldom completely fulfilled. In her book The Rhetoric of Pregnancy, Marika Siegel describes her experience after going into labor five weeks before term with her first pregnancy:

> I was compliant. I followed the rules, had the tests, gained the recommended amount of weight, and so-on. In spite of this functional engagement, I still went into labor early (as thousands of women do, for unexplained reasons). When I was in the midst of preterm labor and in a high risk position, I did not know how and when I could question the system. I did not know what my rights were or which procedures I could and could not refuse, or about which I could ask for more information before making a decision. Learning how to question the experts, how and when to disengage from the system, and what one's rights are should be routine prenatal care instructions for both pregnant women and their partners. Although there are certainly procedures that I would, in retrospect, have agreed to again, there are others I could have, and probably should have, questioned or refused and still others I should have demanded that were not offered. (Siegel 2014, pp. 3–4, reprinted with permission from University of Chicago Press)

As long as clinicians feel confident that the interventions they propose are beneficial and not harmful, and as long as they believe that the patient—in this case the pregnant woman—has agreed to the intervention, they are unlikely to perceive any challenges to the morality of the their actions in providing treatments. The prompt endorsement of obstetric interventions as standards of care, the practice of minimizing the potential for maternal harm and exaggerating the potential for fetal harm, as McCall et al. (2013) discuss for bed rest and Casper (1996) discusses for fetal surgery, along with the structuring of interactions to limit opportunities for women to refuse interventions, all facilitate the perception that most interventions can proceed without ethical challenges.

However, there are situations in which women refuse obstetric interventions. As suggested in the previous section, the nuanced view of such situations is that the fetus and the mother are so closely interrelated that no intervention which a mother refuses for the sake of her own well-being is likely to ultimately contribute to fetal well-being (Harris 2000). The ACOG Committee on Ethics endorses this paradigm, and points out also that there is rarely enough certainty about the benefit of an intervention and the absence of maternal or fetal harm to justify overriding the ethical principle of respecting a pregnant woman's right to refuse treatment. The Committee recommends:

> Pregnant women's autonomous decisions should be respected. Concerns about the impact of maternal decisions on fetal well-being should be discussed in the context of medical evidence and understood within the context of each woman's broad social network, cultural beliefs and values. In the absence of extraordinary circumstances, circumstances that in fact the Committee on Ethics cannot currently imagine, judicial authority should not be used to implement treatment regimens aimed at protecting the fetus, for such actions violate the pregnant woman's autonomy. (ACOG Committee on Ethics 2005, p. 1135, published by the American College of Obstetricians and Gynecologists)

However, as noted in Chap. 5, there are situations in the U.S., where obstetrics providers seek court orders to require pregnant women to undergo interventions that they initially refuse. Primarily these interventions have been cesarean sections recommended by physicians concerned about potential or observed fetal distress, but court orders have also been issued for mandatory prenatal care visits, for bed rest to address preterm labor or high blood pressure, and for treatment of substance abuse, including mandatory inpatient hospital commitment (Cantor 2012; Kolder et al. 1987; Matevosyan 2012; Townsend 2012). Separately, but for similar reasons, maternal decisions to refuse treatments, along with maternal behaviors thought to represent pregnancy risks, have been subject to criminal penalties, including incarceration (Jos et al. 1995; Paltrow and Flavin 2013). Often in these circumstances a judge will approve an initial request for such a court order, in part because hearings are done in emergency situations, and the women refusing the intervention do not have legal counsel. When court orders or prosecutions are appealed they are frequently invalidated, because the weight of judicial precedent supports the ability of pregnant women to refuse treatment (Cantor 2012).

Still, a survey of obstetricians and healthcare lawyers conducted in 2005 found that over half agreed that a court order should be sought if a healthy mother refused a cesarean section that a physician felt would preserve the life of a fetus, although fewer agreed if the scenario included a provison that the mother would be at elevated risk of death if the surgery was conducted (Samuels et al. 2007). A survey of high-risk obstetric and pediatric specialists conducted in 2009–2010 similarly found that about one third of obstetricians and two thirds of pediatricians agreed with seeking a court order to force women into substance abuse treatment for cocaine use, force them to accept treatment for HIV infection, and force them to accept blood transfusions in the case of RH isoimmunization (maternal-fetal blood type incompatibility) (Brown et al. 2012). Both sets of researchers expressed surprise at their respondents' views, given that clinical ethics guidelines and legal precedents discourage the use of court orders mandating prenatal interventions without maternal consent.

The moral rationale for requesting such legal interventions is that they are necessary to protect the life of the fetus. Some of these rationales use the language of fetal rights and maternal-fetal conflict found in the legal and political campaigns intended to set precedents for the reversal of the Supreme Court's *Roe v Wade* decision banning abortion restrictions. For example, in their discussion of the ethical dilemma posed for physicians when women refuse recommended cesarean sections, physicians Neha Deshpande and Corrina Oxford cite three sources as evidence of a social mandate to protect fetal life: the language of *Roe v Wade*, the recognition in law in 36 states that "unborn fetuses" can be victims of violence, and the redefinition of fetuses as children so that prenatal care can be covered under the federally funded State Children's Health Insurance Program (Deshpande and Oxford 2012). Other rationales frame the problem differently, but also conclude that physicians sometimes have a moral obligation to favor the concerns of the fetus over those of the mother. Physician Frank Chervenak and ethicist Laurence McCullough frame the conflict as being between two physician roles, physician to the mother and physician to the fetus, and suggest that physicians should honor the “weightier” of the two sets of obligations in any given decision (Chervenak and McCullough 1985).

Framed in this way, clinicians’ decisions to proceed with medical interventions despite maternal refusal could be thought of as responses to conflicts between two aspects of the definition of a moral clinician, beneficence toward the pregnant woman and beneficence toward the fetus. On the other hand, there is some evidence that concerns other than morality play a role in the decision to seek a court order or to sanction women who refuse to follow physician recommendations for care. Deshpande and Oxford note that some physicians believe that a court order will protect them from liability in the case of a poor fetal outcome if a recommended intervention is not performed.[8] Both of the physician surveys cited above (Brown et al. 2012; Samuels et al. 2007) found that respondents with more conservative political views, those who were more religious, and, in the Samuels et al. study, those who considered themselves to be pro-life (opposed to abortion) were more likely to approve of seeking court orders to override maternal decisions to refuse interventions. While these ideologies may entail moral views, they are not views about what makes one a moral clinician, and thus are impositions of clinicians’ personal beliefs on to patients (Samuels et al. 2007).

6.1.3.2 Third-Party Views

Clinicians who seek court orders to protect fetuses from maternal decisions about care, and those who report women to legal authorities if they decline to follow physician recommendations, become participants in third-party efforts to regulate maternal behavior for the benefit of future generations. Legal advocates Lynne Paltrow and Jeanne Flavin, in their review of 400 cases of legal intervention during pregnancy between 1973 and 2005 (Paltrow and Flavin 2013), found that 20 % of prosecutions involved women who refused medical interventions. Clinicians were also involved in the reporting of pregnant women for other behaviors deemed subject to legal sanctions, but were more likely to report these women if they were also perceived to be refusing to follow medical instructions for their care. In many of the cases where legal proceedings included medical records, these records had been released by the prenatal care providers without patient consent.

Suspected illegal drug use in particular seems to justify decisions to override maternal choices to refuse treatment and to compromise patient confidentiality. Fully 84 % of the cases of legal proceedings against pregnant women identified by

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[8] In fact, they note, physicians would not be liable if they failed to seek a court order for a recommended intervention, but would be liable if they proceeded with surgery without maternal consent.

Paltrow and Flavin involved the use of illegal drugs. In the 2005 survey of physicians and lawyers described above, respondents were almost twice as likely to support seeking a court order for a cesarean section in a hypothetical case if the woman in question was described as "high on drugs and did not understand counseling" (Samuels et al. 2007). In a review of the Interagency Program put in place in the late 1980s at the Medical University of South Carolina (MUSC), in which prenatal care providers reported patients to local legal authorities if they screened positive for drug use and did not attend substance abuse treatment, Jos and colleagues note that the local solicitor (prosecutor) was interested in a broader definition of harmful behavior during pregnancy, but was unable to enforce that level of intervention. They write:

> The fact that conventional standards for health care were so quickly overridden needs further explanation. Concern for the well-being of the fetus, while significant, is not enough to account for the policy, or for the swiftness of its execution. Fetal well-being would have led to a broader conception of the problem. First, it would have included testing and treatment protocols for all obstetric patients, not just [public insurance] clinic patients. Second, the Interagency Policy would have included tobacco, alcohol, or other impediments to a healthy pregnancy; it would not have been restricted to illegal substances. The solicitor was well aware that the scope of the policy enhanced its political and public appeal. As he explained, "[t]here's not enough political will to move after pregnant women who use alcohol or cigarettes. There is, though, a political basis for this Interagency Program. (Jos et al. 1995, pp. 122–123)

The MUSC program applied only to the clinic where low-income patients were seen, not to the patients of private providers. Consequently, most of the affected women were Black, and civil rights violations were the basis of some of the complaints filed about the program. Jos and colleagues suggest that the moral outrage felt by clinicians and policy makers about drug use by pregnant women caused them to disregard the racially discriminatory aspects of the program. About the same time, physician Ira Chasnoff and colleagues (Chasnoff et al. 1990) reported that universal drug screening among pregnant women in Pinellas County Florida (St. Petersburg) found that an equal proportion of Black and White women had positive drug screens, but Black women were much more likely to be reported to authorities. Nearly 20 years later, Sarah Roberts and Amani Nuru-Jeter (Roberts and Nuru-Jeter 2012) observed a similar racial bias in California, with positive drug screening findings occurring at similar rates across racial and ethnic groups, but Black women more frequently reported to Child Protective Services. Paltrow and Flavin also report that criminal prosecutions in general, and prosecutions that were initially reported by healthcare providers in particular, were observed more frequently for Black than for White women. Physician Lisa Harris commented about the observation that Black women are disproportionately targets for prosecution or court orders while pregnant:

> Although those findings can be attributed to racism and not to the maternal-fetal conflict scheme, per se, the conflict-based scheme is particularly vulnerable to racism. When we separate the moral obligations owed to the pregnant woman and fetus, racism might

> become masked as fetal protection. Racial and social prejudices might find their way into identification of fetal interests and so-called conflicts. (Harris 2000, p. 788, published by the American College of Obstetricians and Gynecologists)

6.1.3.3 Parent Views

With the exception of rare instances of psychotic or suicidal behavior on the part of pregnant women (Dragatsi et al. 2013; Paltrow and Flavin 2013), refusal to follow physician advice or to accept recommended treatment generally does not indicate that pregnant women have a moral view of their obligations during pregnancy that differs radically from that of their clinicians. As in the case of screening, described above, when pregnant women disagree with their clinicians, it is usually because they have a different evaluation of the benefits and harms of the recommended interventions. For example Samantha Burton, who was the subject of a Florida court order for hospitalized bed rest in 2011 (as discussed in Chap. 5), had small children at home who needed care; her requests to rest at home or to transfer to another more conveniently located hospital were denied (Cantor 2012).

As an example of the aspects of women's experiences that contribute to the consideration of refusal of treatment during preterm labor, Table 6.1 shows a paraphrase of an exchange that took place on a community forum section of the web page BabyCenter.com, when one member requested advice from other pregnant women about refusing tocolytic injections to halt early labor contractions. All postings except the last two were made on October 10, 2013; the last two were posted on October 11.

In this sequence, it appears that the decision of the inquiring forum participant to refuse terbutaline for the treatment of contractions was made because the treatment did not seem to be working, and she believed that the contractions signaled that she was about to have a preterm delivery. It may have been that the expectation that the drug would stop the contractions was unrealistic, and it may have been that the woman was not actually about to deliver, but she had no information from the treating physicians to inform or reassure her about this. Her peer group of pregnant women had a wide variety of experiences both with tocolytics and with cervical examinations. Some advised the inquiring participant to seek another physician; some advised her to demand a cervical exam and alternate tocolytic treatment; others thought she should accede to the medical advice she did receive, which they believed was likely to be best for the fetus. The discussion suggests that patient refusal of obstetric interventions is more likely to be a consequence of miscommunication and differential expectations for treatment, than a consequence of markedly different moral views about ethical behavior by pregnant women. Given variations in the use of obstetric interventions across physician and hospital settings, it can be difficult for pregnant women in this situation to ascertain which decision represents the most ethical choices—to be compliant with physicians' instructions or to seek other advice in order to better protect the fetus.

Table 6.1 Blog exchange entitled “refusing terbutaline,” from BabyCenter.com (2013)

Original inquiry	Responses
In the hospital with contractions for last 4 h. Started 1½ min apart, now 5 min apart, with shots of terbutaline and Procardia, very painful. They want to give more, but she feels full of drugs and is afraid that the drugs will just space the contractions out so she can be sent home. “Would it be completely horrible to decline future shots?” They have refused to check her cervix, so she does not know if she is dilated. She is afraid that her water will break when she is home alone	(R1)—Have a doctor explain what is going on. Do not refuse drugs that might stop labor. Have they considered magnesium?
No magnesium, no IV. Fourth time since her 28th week of pregnancy, now she is 32 weeks. Between this pregnancy and the last, had 7 shots of terbutaline. They temporarily slow contractions, but she has to return a few hours later. “I guess I feel like they use it as a way to get me outta here without really giving me any answers or solutions.” Will not check cervix until 36 weeks	(R1) Why refuse cervical checks? Responder had one at 23 weeks. Demand the MD to give answers and ask if there are any other meds to try. Explain to them that she is not comfortable going home until checked
Went home after refusing the terbutaline, supposed to call own Dr. when office opens, hopes she can sleep	(R2) Weird no cervical checks. She has had one at every visit. (R3) Where is she? Since she is obviously contracting, they should check her cervix. (R1) Aggravating. (R4) Cervical checks this early can do more harm than good. Responder let them check her cervix last week, and now she is in labor, has been in Labor and Delivery since yesterday, has not delivered, will not let anyone check her cervix. Previous child was 3 months preterm. She should scream and yell if she has to. (R5) Had preterm labor with all 3 pregnancies. Had Procardia, and magnesium if Procardia did not work. With contractions, responder had her cervix checked and not sent home. Glad she will see own MD
Reasoning for not checking cervix was not wanting to make things worse. In a lot of pain. Plan to insist on cervical check. Her MD does not like to, but another she consulted a few days earlier did a check. Slept and then called MD, who did not want to see her. Advised rest, fluids, and call tomorrow. “I guess none of this fucking matters unless my water breaks, then there will be nothing we can do to prevent her from coming. I am so beyond frustrated.”	(R6) Is there a different hospital or MD she can go to? Responder had cervical checks at 30–32 weeks due to contractions/pain. (R7) When responder fell yesterday, had no contractions, they wanted to check her cervix, but her own MD advised no. (R1) Call a different MD. (R8) Responder respects decision not to do cervical checks, but “terb is such a joke,” should try magnesium

(continued)

Table 6.1 (continued)

Original inquiry	Responses
This is the only hospital in the area with NICU. No other MD will see her without getting a complete medical history. Does not see how contractions 5 min apart are OK	(R9) Sounds like irritable cervix, not true contractions that cause cervical change. If she has already been treated 4 times, labor is not progressing. Cervical checks could introduce infection. Probably not getting magnesium because not really in labor. Suggest looking up irritable cervix/prodromal labor. Responder had with last baby—awful and uncomfortable, but not truly at-risk. (R10) Is there another MD at the hospital who could see her? Tell them that she is refusing to see own MD
Has explored switching MDs and hospitals before, but nearest hospital is 90 miles away, and other MD could not see her for a few weeks	(R11) Astounded by lack of care. Not doing cervical check is understandable, but why refuse to see her?
Re-irritable cervix—makes sense, but how do they know if they will not check?	(R12) Suggests using ultrasound to check cervix. (R13) Suggests ultrasound, and to keep going to the hospital until something is done, (R14) Responder had cervical check twice after going to the emergency dept with regular contractions, was still closed. Went a few days ago, and was dilated to 3 cm, is 28 weeks and 5 days gestation with twins, so started on magnesium and given steroids for fetal lung maturation. She is now in a hospital with NICU and will stay until delivering. (R15) Similar experience in last pregnancy, preterm at 32 weeks. No cervical check, but received terbutaline, Procardia and magnesium. Advises tocolytics, because too many contractions bad for fetus. (R16) In last pregnancy, believes she had too many cervical checks. Was dilated at 3 cm for 4 weeks, went into labor at 37 weeks, not a coincidence it occurred right after a cervical check. Told MD for current pregnancy that she wanted fewer cervical checks, and MD agreed. (R17) Difference between being checked too much and not at all. Responder is glad she has 5 hospitals with NICUs close by

(continued)

Table 6.1 (continued)

Original inquiry	Responses
Home, contractions slowed. MD said to call and let him know how she feels, but she does not see the point. Was told she would get steroids if water broke, so may as well wait. Does not seem to make sense, since she is supposed to have a cesarean section (had one previously, and hospital does not allow vaginal delivery after c-section)	(R18) Can she request a fetal fibronectin test? If it is negative, delivery is not imminent. (R19) Responder's cervix has been soft since 20 weeks, normal for those with previous pregnancy. MD knows what he is doing
Doing OK, fewer contractions, but pretty intense with pressure, Will call MD later and ask for guidelines on when she should go to the hospital	

6.2 Ethical Decisions in Delivery and Treatment of Preterm Infants

As discussed in Chap. 5, the field of neonatology changed rapidly in the period between the 1950s and the 1970s. The development of assisted ventilation and central line intravenous feeding innovations, the establishment of specialized hospital units and the creation of a new pediatric medical specialty enabled life to be prolonged for preterm infants who were otherwise too immature to survive on their own. Pioneering neonatologists were aware that their innovations raised ethical questions, even beyond the fact that they were employing what were essentially experimental treatments in a therapeutic as opposed to a research context, without scientifically sound research designs or the informed consent of the parents of treated infants (Lantos and Meadow 2006; Tyson 1995). Chicago neonatologists John Lantos and William Meadow list these ethical issues as including whether success in treatment with a new technology could be defined in physiologic terms, for example by the maintenance of respiration over a certain number of days, even if the neonate ultimately died; deciding when an experimental treatment should become the standard of care and thus a moral entitlement for all preterm babies; and rationalizing the universal provision of a treatment, even when it was not possible to predict which infants will ultimately benefit (Lantos and Meadow 2006).

This first generation of neonatologists began including theologians, philosophers, and ethicists in their discussions and added some additional concerns, including the tension between saving newborns' lives without curing their underlying health problems, and the question of whether some newborns should simply not be treated. They wondered who should decide which newborns should not be rescued with the new technology, how the decision should be made, and whether the primary decision makers should be parents, rather than physicians. In 1974, a group of these concerned individuals met and compiled a consensus statement that identified the circumstances under which rescue treatment for newborns should be avoided, because it constituted a harm as opposed to a benefit, and would thus violate core clinical ethical principles. They defined this as occurring when a newborn would not survive infancy, when a newborn would live with intractable pain, and when a newborn would never participate, even minimally, in the human experience. The group agreed that every baby has moral value and is entitled to the medical and social care necessary for its well-being. They agreed that parents have principle moral responsibility for their newborns, but that physicians could act on the parents' behalf if the parents trust them. They also noted that neonatology should not operate in a vacuum. Newborns treated in NICUs who survive with permanent disabilities should have access to the ongoing medical and social support that they would need to function optimally throughout their lives (Jonsen 2012; Jonsen et al. 1975).

In 1983, The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research included a discussion of the treatment of very low birth weight and preterm infants, as well as infants with severe handicapping conditions, in its broader examination of decisions to forego life-sustaining treatment. The Commission's basic orientation was that competent individuals have the right to forego such treatments, but that this right could potentially be limited on moral or legal grounds. For newborns, the Commission identified parents as the appropriate decision makers unless they were incompetent, in disagreement with each other, or were clearly making decisions that were not in the best interests of the child. Such determinations about parents should be made by legal authorities. The Commission recommended that newborns receive all treatments that are clearly beneficial, but need not receive treatments that are expected to be futile. When the benefits of treatment are ambiguous, the choices of parents should prevail. The fact that a newborn might end up being permanently handicapped did not justify a decision not to provide beneficial care, unless the child's existence would not be a net benefit to the child. This needed to be evaluated from the child's perspective, not the perspective of the family or society. The Commission saw the need for improved communication between physicians—who bear primary responsibility for assuring that moral choices are made—and parents, whom the Commission believed had more capacity to make sound decisions than they were sometimes given credit for. It recommended that the state avoid intrusion into family decision-making on these issues (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983).

The Commission's report was issued the same month that the federal Department of Health and Human Services issued the initial version of the Baby Doe rule, an executive level re-interpretation of the antidiscrimination section of the 1973 Rehabilitation Act as discussed in Chap. 4 of this book. At President Reagan's direction, the Secretary of Health and Human Services interpreted the Rehabilitation Act to mean that it would be illegal to withhold nutritional, medical, or surgical treatment from newborns with disabling medical conditions. The rule came in response to a judicial decision in Indiana (one of a line of similar decisions made in other states), in which the courts refused a hospital's request to override parental and physician decisions not to provide nutrition and surgical treatment for a newborn with Down Syndrome.

Concern that some parents, sometimes with the support of physicians, withheld lifesaving treatment from newborns with disabilities such as Down Syndrome, spina bifida, and mental retardation, had long troubled advocates for individuals with disabilities. In the early 1980s, the political influence of this advocacy effort was strengthened when the issue was taken up by the pro-life movement. Establishing legal protection for the care of all newborns reflected a sanctity-of-life ideology which pro-life advocates hoped to extend to fetuses, by reinstituting bans on abortion. The Baby Doe rule set a legal precedent for limiting the autonomy of parents to make decisions about their children (Merrick 1992; Placencia and McCullough 2011).

The Baby Doe Rule required that notices be placed in hospitals stating that withholding care to newborns was prohibited, and providing a phone number to call to report such actions. Physician groups formally opposed the rule, although Lantos and Meadow note that the response was nuanced:

> For pediatricians, the Reagan regulations were a mixed signal. On the one hand, they seemed to represent an unprecedented endorsement of medical intervention for critically ill newborns. Neonatologists had been arguing for years that newborns had a right to medical care equivalent to that of other citizens. The Baby Doe regulations enshrined that right in federal law. Thus, it would be no small thing to oppose the regulations. Nevertheless, the regulations represented an unprecedented intrusion of the federal government into the doctor–patient relationship. Many pediatricians opposed the regulations on those grounds, even as they sympathized with the moral impetus behind them. A spokesman for the American Academy of Pediatrics wrote “I don’t really oppose proper intervention for any child, but I do have a deep concern about the propriety of the kind of federal involvement that has taken place so far, such as hotlines, the posting of signs in hospitals, and Baby Doe squads that go rushing into hospitals to check on cases. Such methods are an insult to the intelligence of professional people and a serious threat to the privacy and confidentiality of families in agonizing circumstances.” (Lantos and Meadow 2006, p. 70, reprinted with permission from Johns Hopkins University Press)

In 1986, the Supreme Court ruled that the initial executive branch Baby Doe rule was an invalid over-extension of the 1973 Rehabilitation Act. In the meantime, however, Congress had worked with disability and pro-life advocates and the organized medical community to craft a jointly acceptable piece of legislation which became part of federal child abuse statutes. This legislation removed federal funding for state child protective agencies that failed to enforce rules restricting the withholding or withdrawing of life support treatment to circumstances in which an infant was irreversibly comatose, in which treatment would merely prolong dying or be futile for survival, or in which treatment would be virtually futile, and under those circumstances would be inhumane. Nutrition, hydration, and pain medication could never be withheld. A proposed exception that would exempt preterm and low birth weight infants from coverage under the rules was rejected, as was any suggestion that decisions to withhold treatment could be made because the infant’s resulting quality of life would be poor if it did survive (Bopp and Nimz 1992).

Some medical groups viewed the compromise legislation as essentially reflecting the prevailing consensus on the care of preterm infants, since it would be possible to withhold futile treatment if it was in the best interest of the infants. Others felt that the compromise mandated more aggressive treatment of marginally viable infants than many physicians would have provided on their own (Kopelman 2005; Sayeed 2005). The premise expressed in the President's Commission report on foregoing life-sustaining treatment, that parents were the key parties who should make decisions on behalf of their newborns about treatment, were not reflected in these anti-child abuse rules. The advocates' main concern about the legislation was that the enforcement mechanisms for the rules were relatively weak, since they sanctioned only state child protection agencies after the fact, and only if the apparent violation was reported. Others felt the lax enforcement allowed the opportunity to resolve the issues privately, by consensus between physicians, hospitals, and families, as was most appropriate (Lantos and Meadow 2006).

6.2.1 Clinical Approaches to Defining Futility

Since the compromise Baby Doe rules were established in the 1980s, the primary ethical task facing clinicians has been to decide when treatment of preterm newborns can be considered futile. This involves applying general definitions of futility to specific cases and requires some way to estimate the likely outcomes of treatment for newborns born at different gestational ages and conditions. Initially, because techniques in neonatology had been changing so rapidly over the previous decades, there was not enough information available to estimate the long-term outcomes for very preterm infants resuscitated and treated using contemporary approaches. (That is, there were no surviving adults who had been born at very early gestational ages.) In the mid-1980s, two networks of hospitals with NICUs, the National Institutes of Health (NIH) Neonatal Research Network and the Vermont Oxford Network, began to collect and pool data on preterm infant treatments and outcomes. By the end of the 1990s it was observed that mortality rates and rates of certain severe complications had stabilized, suggesting that the limits of advancement in the field had essentially been reached. At that point, most clinicians were comfortable using the available outcomes data to set 25 weeks gestation as the threshold above which treatment was likely to be successful and newborns were likely to survive, and 22–23 weeks gestation as the threshold below which treatments were likely to be futile and infants were not likely to survive (Lantos and Meadow 2006).

Because deliveries at less than 28 weeks represented only 6.5 % of all preterm births in 2013 (Martin et al. 2015), those born between 22 and 25 weeks are a small portion of all preterm births. Most infants born preterm survive with NICU treatment. Within the 22–25 week parameter, however, there is a great deal of uncertainty about the potential effectiveness of NICU treatment. Singleton infants and those whose mothers received corticosteroids before delivery have better outcomes within each gestational age range (Tyson et al. 2008).[9] Survival rates may be higher in more recent years, particularly in institutions that typically provide more aggressive care, but outcomes still represent a range, and survival without complications is not the experience in the majority of cases (Cummings 2015; Kyser et al. 2012). As noted in Chap. 1, factors such as the triggering cause of the preterm delivery, the timing, and complications experienced by the mother while the fetus was in utero probably help to explain some of this variability, but these data are generally not known or not linked in studies of neonatal outcomes.

Lantos and Meadow report that one humbling outcome of the debate over the Baby Doe regulations was that physicians began to realize that some parents were much more willing to accept and care for a child with disabilities than they had anticipated. Some research with individuals with disabilities and with their families also suggested that clinicians and even parents might be unduly pessimistic about the acceptability of a disability, compared to those who actually live with such a disability (Hack et al. 2011; Saigal et al. 2000; Watts and Saigal 2006). Families of preterm infants do not consistently report more stress than families of term infants, although families of the most severely compromised children are often excluded from these studies (Schappin et al. 2013). At least one study has suggested that prevailing cultural attitudes undervalue survival for extremely preterm infants relative to other patients needing resuscitation, perhaps because they are not thought to have the same level of personhood. The authors warn that physicians should be aware of any overly negative biases they hold in this regard (Janvier et al. 2008). However, families of infants who were born prematurely and have profound handicaps have objected to these studies as underestimating the burden of ongoing care for surviving infants born at extremely young gestational ages (Culver et al. 2000).

Much of the well-documented variation across NICU hospitals in survival rates at the very youngest gestational ages occurs because of variations in decisions about whether to initiate resuscitation (Rysavy et al. 2015; Tyson and Stoll 2003). In the mid-1990s, neonatologists at the University of Chicago reported that survival rates for very preterm infants are more predictable after the first few days of treatment than they are at delivery. They observed that most deaths occurred within the first week of life, and some newborns remain unresponsive to ventilation and other aggressive treatments from the time of delivery. The implication of these observations was that very preterm newborns could be consistently resuscitated and offered a brief "trial of therapy"; interventions could later be halted if they appeared to be futile because a particular newborn was unlikely to survive. The trial of therapy approach would thus increase the certainty of the prognosis and ease decisions about continued NICU treatment (Meadow et al. 1996). An approach that supports nearly universal resuscitation on very preterm newborns, while postponing

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[9] Data from this study was used to create a web-based tool for estimating survival ranges with and without impairment, given gestational age, birth weight, sex, singleton or multiple status, and use of corticosteroids. This tool is available at www.nichd.nih.gov/about/org/der/branches/ppb/programs/bepo/Pages/epbo_case.aspx.

decisions about continuation of treatment until later in an infant's course of NICU care, also generally fits better with most physicians' perceived sense of themselves as active rescuers for struggling patients (Caitlin 1999; Guillemin and Holmstrom 1986).

As some critics had suggested when the Chicago findings were first published, however (Ellington et al. 1997), when the same researchers updated their study a few years later, they found that changes over time in care provided in NICUs meant that the time to death for preterm newborns of questionable viability had been prolonged. They write:

> These epidemiologic observations carry uncomfortable ethical consequences. A trial of therapy in the NICU takes longer than it used to. When the median day of NICU death was DOL [Day of Life]2, we were able to counsel NICU parents, even parents of infants born at 500 or 600 g, that if they could just "hold their breaths" for 2 or 3 days, we would have much different prognostic news to give them. Now we must ask them to hold their breaths for almost a week and a half to get the same news. Although the specific numbers almost certainly vary from NICU to NICU, the larger phenomenon of increased LOS [length of stay] for doomed infants seems to be widespread, a not-so-desirable side effect of improved survival rates for infants in this weight group. (Meadow et al. 2004, pp. 1226–1227)

Still, these neonatologists find it preferable to recommend a delay in making the final decision about continuing aggressive NICU treatment until the likelihood of death or survival is more certain.

Another type of delay in decision-making occurs at delivery, because some physicians prefer to evaluate the status of a newborn before making a resuscitation decision. This type of delay is not currently recommended, because assessments at delivery are inconsistent and not very predictive of long-term outcomes (Cummings 2015; Singh et al. 2007), but it is the practice of neonatologists in some NICUs. Both of these approaches, delaying resuscitation decisions until the baby is delivered and automatically commencing resuscitation with the view that treatment can be stopped later if it is not effective, limit, or eliminate the role of advance directives or any decisions that parents might make in the context of counseling before the delivery occurs (Kavanaugh et al. 2005). The trial of therapy delay also shifts the actions required to allow the newborn to die, from a decision not to actively intervene at delivery, to a decision either to stop actively intervening or to actively withdraw life supporting treatments. At both an abstract philosophical level and in a legal context, withholding and withdrawing life-sustaining treatment might be thought of as equivalent. In a care context, however, it is generally more difficult for care providers and family members to withdraw treatment from patients who have received care, than it is to decide not to initiate care (Lantos and Meadow 2006). Such difficulties undoubtedly delay decisions to declare NICU treatment to be futile, since these decisions are made by consensus within a medical team in conjunction with an infant's family. The default choice is to continue treatment until everyone agrees to stop (Carter and Rosenkrantz 2015).

Critics of the trial of therapy approach point out that the approach has at least two negative consequences: it requires an additional expenditure of resources and it causes suffering for the infant (Tyson and Stoll 2003). On the other hand, some contend that the delay allows families and care providers to adjust to the circumstances of the infants' condition and to consult with others who can support them in their choices. In that sense, they feel that the trial of therapy approach leads to better NICU decision-making (Lantos and Meadow 2006; Singh et al. 2004).

6.2.2 Parental Involvement

As discussed at the beginning of this chapter, prevailing beliefs are that good parents protect and nurture their children and make decisions that are in their best interests. U.S. culture also places a high value on adult autonomy. Given these principles, it is somewhat surprising that the role of parents in decision-making about the care of very preterm infants in the U.S. is actually quite limited. Neonatologist Frank Placencia and ethicist Laurence McCullough write:

> Despite the long-standing tradition of parental autonomy, the effect of the Baby Doe controversy has been to identify the government as the ultimate authority in its role as *parens patrie* in protecting the best interests of the infant. There are 3 categories of decision-making cases. In those where treatment is clearly in the best interests of the child, the physician, acting as the infant's advocate, must provide that treatment, turning to state intervention when parents fail in their duty to authorize such treatments. As described by the AAP [American Academy of Pediatricians] in 1995, parents are not asked for consent, but for permission, and treatment will be provided regardless of the parental response. When treatment is not indicated, as in the Sun Hudson [court] case, there is no ethical obligation to provide it, a position that some state courts have supported. The only category wherein parents can truly exercise an autonomous, meaningful choice is when the outcome of therapy is truly unknown and a good outcome is unlikely, as is often the case with periviable infants. It is only in these situations where they are allowed to consider other influences on their decision-making outside of the best interests of their child. (Placencia and McCullough 2011, p. 382)

The surprise of family members when they realize the limitations placed on their ability to make decisions about withdrawing life support care for preterm newborns with severe disabilities is reflected in the quote from ethicist Loretta Kopelman at the beginning of this chapter. The insistence of some neonatologists (Lorenz 2004) and ethicists (Paris et al. 2007) that the AAP guidelines provide for parental autonomy, when they clearly do not, may also be explained by this unusual contradiction of the more typical view of the morality of parenthood and adult personhood in the U.S.

As described in Chap. 5, clinicians have been observed to structure the transmission of information to parents of preterm infants in such a way that parents only become aware of their role in treatment decisions when the likelihood of a positive outcome is very low. The AAP has long recommended that parents be involved in resuscitation and ongoing care decisions when treatment outcomes are uncertain. However, as discussed in the previous section, there is clearly variability across physicians and hospitals in the determination of when outcomes are sufficiently uncertain to require this level of parental involvement. A 2013 conference hosted by NIH proposed formally narrowing the parameters of uncertainty to 22–23 weeks gestation (Raju et al. 2014). In September 2015, the AAP's Committee on the Fetus and Newborn recommended a set of standards or considerations for counseling families who are about to experience deliveries at 22–24 weeks gestation. The counseling is intended to prepare the families to make informed treatment decisions after delivery. The statement acknowledged the 2013 NIH conference, with its narrower recommendations about the gestational age at which the impact of resuscitation is uncertain, but maintained the broader window of 22–24 weeks, both because fetal maturation rates are variable in this period and the precise gestational age is rarely known, and because of the high risk of moderate or severe neurological damage in newborns born younger than 25 weeks. The recommendation states:

> [I]f survival were the only consideration, it would seem reasonable to offer resuscitation and intensive care to all infants born at or beyond 22 weeks gestation. However, parents and health care providers have to struggle with other considerations, including the fact that most surviving preterm infants born before 25 weeks gestation will have some degree of neurodevelopmental impairment and possibly long-term problems involving other organ systems. Infants born at 22 weeks gestation have reported rates of moderate to severe neurodevelopmental impairment of 85 % to 90 %; for infants born at 23 weeks gestation, these rates are not significantly lower. The risk of permanent, severe, neurodevelopmental damage and other special health care needs affect both the infant and the family and, for some parents, may outweigh the benefit of survival alone. (Cummings 2015, p. 589).

The willingness to recognize that families can legitimately consider quality of life concerns for their infant, and the broader impact of their child's survival on the family, represents something of a deviation from a strict interpretation of the Baby Doe rules, under which only survival and only concerns of the infant, not the family, were supposed to be taken into account.

The 2015 AAP recommendation does not suggest that the parents have sole autonomy to make the decision about care for a preterm newborn in this gestational age range, but it does hold that parental values and family concerns should be recognized as part of the process of shared decision-making in this window of marked uncertainty about treatment outcomes. The balance of power between parents and caregivers in this decision-making process has long been a point of contention in NICU care. In the 1970s, there were some providers who adhered to the principle of allowing parents to make the decision, but some physicians and ethical commentators objected, out of concern that the interests of the parents and families would outweigh the direct interests of the newborn. With the Baby Doe regulations in the 1980s, the situation was reversed, medical teams assumed more authority, and the expectation was that resuscitation and care would proceed unless it was deemed to be absolutely futile. Some state court decisions, rendered in cases where parents sued or took other action to end life support care over the objections of physicians and hospitals, seemed to validate the view that parents could not end life support if the physicians and hospitals disapproved (Lantos and Meadow 2006; Paris et al. 2007; Placencia and McCullough 2011).

In 1992 a group of parents, activists, attorneys, ethicists, and physicians proposed a set of principles for family-centered care of infants in the NICU (shown in

Chap. 5 of this book in Table 5.6) which included the principle that "fully informed parents should have the right to make decisions regarding aggressive treatment for their infants" (Harrison 1993). This principle has never been incorporated into formal clinical recommendations, which describe an ideal process in which parents participate, but physicians are ultimately responsible for assuring the best interests of the newborn (Bell 2007). Neither is a parental right to decision-making in the treatment of neonates broadly evident in reports of clinical practices. One survey conducted in New England in 2002 found that 11 % of neonatologists thought that parents should make the final decision about withholding resuscitation in the delivery room, 13 % thought neonatologists should do so, and 77 % endorsed shared decision-making. Even so, only 40 % reported that shared decision-making usually occurred; 50 % reported that decisions were most often made by neonatologists alone, while 9 % reported that the decision was most often made by parents (Bastek et al. 2005).

Helen Harrison, convener of the family-centered care group, commented in 2008 about the continued challenges to the meaningful involvement of parents in decisions about withholding or withdrawing NICU care. She observed that neonatologists often claim that they are responding to the demands of parents when they initiate and maintain aggressive care at the margins of viability, and suggested that, to the extent this occurs and is not a projection on the part of the physicians, it may be because of unrealistically high expectations on the part of parents that NICU care results in positive outcomes. These high expectations are at least in part a consequence of consistently positive news coverage about the survival of newborns treated in NICUs, augmented by claims of success used in public relations material by hospitals. As discussed in this book in Chap. 3, this optimistic narrative reflects beliefs about the power of medicine, coupled with technology, to overcome negative circumstances that have come to be defined as diseases.

Harrison (2008) describes two other obstacles to parental involvement in care decisions for their preterm infants. The first is a mismatch of communication styles between physicians and parents. Physicians are most comfortable in roles that call for them to neutrally and realistically transmit information about the status of the pregnancy, the newborn and the likely outcomes of birth at different gestational ages, while families state that they would prefer interactions in which physicians express emotions that can be interpreted as empathy (Boss et al. 2008; Gaucher and Payot 2011; Grobman et al. 2010). Without that type of emotional interaction and a sense that medical personnel are engaged with the parents in weighing the impact of different decisions, Harrison believes that it is difficult for parents to feel that they are sharing decision-making. Other studies indicate that a lack of trust of physicians by families help to create situations where families feel that it is necessary to resist or object to physician recommendations (Moro et al. 2011). The second obstacle that Harrison describes is a "turf" effect, in which it is difficult for parents to express independent opinions when they are in the medical setting, but when interviewed at home they tend to express a preference for less aggressive care than they actually received.

Clearly these obstacles to shared decision-making do not describe the experiences of all parents of extremely preterm infants. However, as noted in Chap. 3 (and see Caitlin 2005), since discussion of the limits of viability are almost never an aspect of routine prenatal care, pregnant women, and their partners can be confronted suddenly with large amounts of very unfamiliar information which is difficult to process. They may be interacting with physicians whom they have not previously met, and are likely to be dealing simultaneously with obstetric health crises. Observers of these situations find that parents often do not recall conversations about treatment alternatives and do not perceive that they had an opportunity to participate in treatment decisions, even when medical personnel recall and have documented that these conversations occurred and that options were presented. Parents may not recall, or they may recall and resent discussions of potentially poor neonatal outcomes, because of beliefs about the viability of very early fetuses and their expectations of medical care (Boss et al. 2008; Gaucher and Payot 2011; Grobman et al. 2010; Keenan et al. 2005; Moro et al. 2011; Zupancic et al. 2002). One consequence of these communication challenges is that medical care providers sometimes perceive that parents prefer not to participate in resuscitation and care withdrawal decisions, and that care providers are doing families a favor by taking on the decision-making burden (Lantos and Meadow 2006). However, the research literature suggests that parents almost always do want to be involved in decision-making (Moro et al. 2011).

Beyond these communication challenges, there is evidence that some families employ a set of moral beliefs and values about withholding and withdrawing intensive care for neonates which differ from those focused on health outcomes, as held by medical care providers. A relatively commonly expressed belief on the part of some families in the U.S. is that decisions about ending life support should not ever be made explicitly, because they are not within the appropriate scope of human action. Rather, humans should let God or nature take its course. This was expressed in one study of family responses as follows:

> Regardless of the medical information, parents maintained hope that everything would be fine. They were encouraged by friends and family members to pray for miracles, to transfer to a hospital thought capable of miracles, or to trust that a miracle would happen despite the physicians. Some parents felt that there were no decisions to make regarding the delivery room resuscitation; they wanted the physicians to do everything they could and the rest was 'in God's hands'. …'You know, everyone told me don't worry about what [the doctors] say, she will make it, she's a miracle. And so that's pretty much all I heard.' (Boss et al. 2008)

Anthropologist Cheryl Mattingly, in her long-term study of Black families' moral views of their children with disabilities, remarks similarly that she observed a family whose views about prolonging life support in a neonatal intensive care unit were based on a belief that their child was a miraculous gift whose life had a spiritual purpose which needed to be understood and attended to. This view draws from an evangelical Christian belief system, and also holds that the clinicians' assumption that people can take action to end life is an expression of a lack of faith in God. They believed it was more appropriate for clinicians to do God's will by continuing to vigorously treat their severely compromised newborn, while all parties waited to see what the child's eventual outcome would be (Mattingly 2014).

Other factors besides the prospect of a negative long-term outcome that matter for parents making resuscitation decisions are the amount of suffering their child is enduring, and whether a child appears to want to survive (Moro et al. 2011; Sharman et al. 2005). For example, Deanna Fei notes that she initially interpreted her 23 week-old newborn's physical reactions to NICU treatment as indicators of pain, which made her wonder whether the decision to resuscitate the newborn had been appropriate. Later, she reframed her daughter's responses to be indications that the child was fighting to survive, and this helped to justify the care decisions (Fei 2015). The goal of protecting a child from suffering and of rescuing a child who wants to survive are clearly in line with the moral expectations of parents.

Parents whose newborns do not survive NICU treatment, and those whose children survive with severe long-term impairments, sometimes express frustration or bewilderment about the course of treatment, the motives of the physicians involved, and their own inability to influence whether treatment continued. They are unsure whether the treatments their newborns received were in the newborns' best interests, or were part of their care provider's interest in financial reimbursements or the desire to "experiment" and to learn more about the care of neonates in general. In her comparative study of decision-making in NICUs in the U.S. and France, Orfali observes about a parent of preterm twins in a U.S. unit:

> Sometimes parents will express anger or become suspicious regarding choices that were made at the beginning of the NICU stay or even in the delivery room: "(…) I always wondered and never dared ask the physicians: did they really believe that he would pull through? At 25 weeks? It was such a threshold. Should they have done all this? And what if we had not resuscitated them?…I am haunted by that and I think I never really dared to hope. But the physicians, (…) I never knew what they really expected… Well, in a sense I believe that they would not have resuscitated them if they didn't believe they could do something. They don't do that, do they? They wouldn't have done all that to my son if they didn't believe he would pull through, would they? They wouldn't have gone through such things …they are professionals, they have other things to do than experiment on newborns" (mother of deceased twins, born at 25 weeks, unit A). (Orfali and Gordon 2004, p. 342, elipses in original, reprinted with permission from Springer)

Such divergence in the moral views of caregivers and families are indications of the moral ambiguities that surround care for extremely preterm infants. To the extent that parents feel alienated from the moral decision-making engaged in by physicians, they are likely to raise concerns that the decisions are made for reasons other than morality, e.g., for monetary gain or for increased knowledge (Fallon 2004; Vila 2004), or were not guided by the morally appropriate sense of humility about their role (Mattingly 2014). Similarly, physicians and the activists who negotiated the Baby Doe rules express concern that parents might equally make resuscitation and withdrawal decisions for reasons other than morality, including their own resource limitations and disappointment in their pregnancy outcomes. However, the ethical dilemmas around neonatal decision-making are more accurately characterized as a set of disagreements between the moral principles of saving or prolonging life and of making decisions that maximize well-being and minimize harm (Kopelman 2009), combined with disagreements over which party has the agency to make decisions for newborns (Harrison 1993), rather than conflicts between moral views and non-moral considerations.

6.2.3 Third-Party Views

The dominant third-party view discussed in this chapter so far is the view represented by pro-life activists. This view combines two features. The first is a distrust of parental decision-making during pregnancy and at delivery for at-risk infants, sometimes conceptualized as maternal-fetal conflict or the need to defend the legal rights of fetuses. The second is the belief that all life should be preserved, and that it is wrong to make the decision to withhold or withdraw treatment because a newborn's life does not meet others' criteria for its worth. This fetal rights/sanctity-of-life view supports the conduct of prenatal screening and the provision of treatments such as cesarean sections in the absence of consent by pregnant women, on the basis that these interventions are necessary to preserve the life or health of the fetus. This view is also the basis of the Baby Doe regulations, which set both the framework for defining the extent and circumstances under which parental involvement in neonatal treatment decisions is considered appropriate, and the guidelines for deciding when neonatal treatment is harmful or futile.

Another type of third-party view represents the concerns of society about appropriate use of resources. As noted in Sect. 6.1.1, this issue has been raised as a rationale for limiting multiple implantation of embryos during IVF, since this could be considered a poor use of societal resources that also has the undesirable outcome of increasing the delivery of preterm infants. Given the costs of providing neonatal intensive care to preterm infants, which is up to 50 times the cost of providing care to a term infant (Schmitt et al. 2006) it is understandable that questions have been raised about whether these expenditures are appropriate or worthwhile.

In the U.S., the most morally acceptable basis for limiting expenditures on medical care is the claim that such medical care does not yield sufficient value for the money spent (Caplan et al. 1999). This can be measured by estimating the dollar value for each year of life added by a treatment and using a reduced monetary value if the survivor has a disabling condition. Another type of assessment is whether the money spent on a treatment could be invested in an alternative intervention that would yield even more value.

A few studies have attempted to quantify expenditures per life-year gained for NICU treatment (Doyle and The Victorian Infant Collaborative Study Group 2004; Stolz and McCormick 1998). Using a cut-off value of $100,000 per quality adjusted life year, a 2014 U.S. study found that both universal and selective resuscitation of preterm infants born at 23 weeks gestation is cost effective, if the interests of the newborn and the mother are considered together. If only the quality adjusted life years of the mother are taken into account, such resuscitation is not cost effective, unless it is assumed that the mothers' life is severely impacted by the neonatal death (Partridge et al. 2014). Studies also suggest that NICU care is a better use of resources than other types of intensive care treatments, primarily because most resources are used in caring for survivors (nonviable newborns die relatively quickly), and patients are saved at the beginning rather than at the end of life (Cutler and Meara 2000; Lantos et al. 1997).

There are critics who argue that, given high mortality rates and high rates of survival with complications among very preterm infants, it would be preferable to invest in interventions that would prevent preterm delivery. They suggest that this could be comprehensive prenatal care for pregnant women or interventions to directly reduce the impact of poverty (Kliegman 1995; Silverman 1989). Other analysts have demonstrated that interventions which would reduce the rates of extremely preterm or low birth weight infants would reduce the resources expended on NICU care, although they do not offer suggestions for the interventions nor do they propose that NICU care should be forgone (Rogowski 1998; Schmitt et al. 2006). One problem with these arguments, as discussed in previous chapters of this book, is that it is not clear what alternative interventions could be financed instead of NICU care that would lead to a meaningful reduction in the preterm birth rate or the infant mortality rate (Leviton 1995).

A second problem with the argument that the resources devoted to rescuing preterm newborns could be better spent on prevention is that, due to the way health care in the United States is financed, it is never clear whether any given healthcare expenditure is really reducing the resources available for another. Public and private health insurance covers both NICU care and prenatal care. Lantos and Meadow take this as a signal that society is willing to pay for both types of care, and there is therefore no need to make a choice between prevention of preterm birth and NICU treatment of preterm infants. While rising costs for any type of medical care results in the expansion of public medical care budgets and increases in the price of health insurance premiums, attributing either of these increases directly to NICU care for preterm infants as opposed to other healthcare expenditure trends is both problematic and contentious. Occasional extremely high expenditures within health insurance plans, such as the expenditures for the care of a few very preterm infants, are often covered by secondary insurance, and thus should not contribute to increases in premiums to the same extent as general inflationary trends in prices and intensity of care use (Fei 2014, 2015).

A broader problem with the value for money approach to making ethical decisions about neonatal care is that such proposals conflict with other deeply held moral beliefs, such as the importance of saving lives, population well-being as measured by infant mortality rates, equity in outcomes across the population, and the need to consider the interests of infants as distinct from the interests of their families. On the latter point, pediatrician John Partridge and colleagues noted, in their analysis of the cost effectiveness of care for infants born at 23 weeks gestation, that the decision about whether to consider the outcomes of care for only the mother or for the mother and the newborn combined is an ethical decision that must be made before hand and separately from the assessment of the value of treatment expenditures

Table 6.2 Estimated savings and lives lost by withholding treatment using birth weight thresholds, based on Stolz and McCormick (1998), Table 2

Weight threshold for withholding treatment (g)	Percent of total NICU costs saved (%)	Local survival rate for infants born below weight threshold	Estimated number of infant lives lost in the U.S. in 1992 if threshold applied
Below 500	0.8	0.15	136
Below 600	3.2	0.20	575
Below 700	10.3	0.38	2689
Below 800	18.7	0.49	6126

(Partridge et al. 2014). On the former points, pediatricians Jeffery Stolz and Marie McCormick conducted a study of the costs and outcomes of limiting resuscitation and continued care to infants born above the birth weight thresholds of 500, 600, 700, and 800 g. The analysis was a response to commentators within and outside of the field of neonatology who proposed such thresholds as a way of limiting resource expenditures for newborns with relatively poor outcomes. The researchers used data from their own hospital in Boston on very low birth weight (VLBW) infants delivered and treated aggressively per the local protocols, between 1988 and 1992. A summary of their findings is shown in Table 6.2.

Stolz and McCormick conclude from their analysis that the cost savings of withholding treatment at specific birth weight categories would be minimal, and would not meet the moral criteria of being wasteful or futile, while the cost in lives of such actions is not morally tolerable. They write:

> This study finds that premature infants at the threshold of viability consume only a tiny portion of NICU resources. Furthermore, the vast majority of NICU resources spent on VLBW infants pays for care of infants who ultimately survive to be discharged. Because nonsurvivors consume so few NICU resources, it is difficult to consider rationing schemes aimed at trimming the fat spent on futile care. As demonstrated in Table 2 (the data shown here in Table 6.2), rationing schemes targeted in achieving even modest savings require restrictions at birth weights that now would be considered unethical. (Stolz and McCormick 1998, p. 346)

While the authors acknowledge that NICU costs constitute only a small portion of lifetime care and education costs for surviving preterm infants, they hold that VLBW infants account for “a relatively tiny fraction” of resources spent in these arenas. Furthermore, because many of these children come from families in poverty, they may have consumed these resources anyway, even if they had been born at term. This is another way of arguing, as above, that resources spent on NICU care do not really substitute for resources spent on other services, and therefore do not have a preferable use. Their other argument against the value for money approach to the ethics of resuscitation and neonatal care is twofold: failure to make these expenditures harms societal well-being by increasing infant mortality rates, and exacerbates social injustice by increasing racial disparities in infant survival rates. The latter occurs because more Black infants are born at low birth weights, and more survive because of NICU treatment; Black infants would thus be disproportionately harmed if resuscitation was restricted by birth weight or gestational age categories.

In general then, the third-party views on sanctity-of-life and the morality of protecting infants from potentially inappropriate decisions made by their parents have had a significant impact on the ethics of neonatal care in the U.S. Concerns about the value of neonatal care relative to the resources expended has not achieved the moral status of a convincing argument that would change decision-making in this arena. As neonatologists Lantos and Meadow conclude in their overview of the economic arguments regarding the ethics of neonatal care:

> After the Baby Doe controversy, in which the federal government tried to mandate treatment of almost all newborns, it became difficult to imagine a public policy in the United States that would allow care to be systematically limited. Instead the opposite happened. Public policies were enacted that generously reimbursed NICUs….. [T]he success of neonatology seems to be widely understood and broadly supported. This has led to a system of supports for NICUs that essentially make access to neonatal intensive care a right for every baby born in the United States and most developed countries without regard to the patient's insurance status or ability to pay. This reflects the uncontroversial medical success for neonatal care. Neonatology saves lives. In the United States as well as throughout the world, this success creates a moral, political and economic imperative to find a way to provide such care to all babies who will benefit. (Lantos and Meadow 2006, p. 129, p. 135, reprinted with permission from Johns Hopkins University Press)

Another way to think about the absence of persuasive moral concern at the societal level about the resources used for NICU care is that it is a reflection of the structure of the U.S. healthcare system. As discussed in Chap. 5, the U.S. system is unique, compared with the systems in Canada, Great Britain, and Western Europe, because of the dominance of the influence of healthcare providers and private financiers, and the relatively weak role of government in expressing the interests of the broader society. As Lantos and Meadow describe it, neonatal intensive care is a revenue generator, not a cost burden, for hospitals and physicians. This constrains the types of moral arguments that are made about the provision of care to marginally viable preterm newborns. Parties that have been able to mobilize political influence in support of a sanctity-of-life agenda have had a powerful role in framing which moral questions around neonatal resuscitation can be discussed. Parties in a position to examine the broader issues of resource allocation for medical care versus other social activities have little standing in the policy venues where societal interests are considered.

6.3 Comparisons with Canada, Great Britain, and Western Europe

The U.S., Canada, Britain, and Western European countries all draw from and contribute to the same body of medical knowledge regarding high-risk pregnancies and preterm deliveries. Professionals in these nations are held to parallel standards, and these societies share many of the same core notions of morality regarding the obligations of parents and clinicians. Thus, the contrasts in ethical decision-making for high-risk pregnancies and preterm births across these societies reveal aspects of the unique dynamics of preterm birth in the U.S. Previous chapters of this book have already noted some relevant differences across the U.S., Canada, Britain, and Western Europe in regards to high-risk pregnancies and preterm birth. Chapter 3 discussed the fact that, in European societies in particular, issues related to abortion tend not to be framed as examples of conflict between maternal and fetal interests, but as tragic choices for parents that can be ameliorated by better social and economic support for pregnant women; abortion is more available but also more strictly regulated in these countries compared to the U.S. Chapter 4 discussed the strong interest observed in these other societies in maintaining or increasing birth rates, and the family-oriented welfare systems and labor force policies in place to create such support. Chapter 5 described the divergence between the health care systems of the U.S. and those of Canada, Great Britain, and Western Europe. Although financing arrangements differ, systems in Canada, Great Britain and the European countries involve a much more explicit role of government in financing and organizing health care services. In general then, these other societies have more policies, institutions and belief systems that express communal support for health care, child birth and child rearing. Thus there is a more obvious role for societal views of morality in decisions about preterm birth in these societies, but these views are less entangled with the politics surrounding the regulation of abortion compared to the U.S.

6.3.1 Assisted Reproduction

Assisted reproduction, and particularly IVF procedures, occurs more frequently in other countries than in the U.S. However, the procedures tend to result in fewer pregnancies and fewer multiple births, in part because the practice of multiple embryo transfer is less common in these settings (Gleicher et al. 2006). Fewer multiple births related to assisted reproduction results in fewer preterm births related to fertility interventions, contributing to the lower rates of preterm birth found in these other countries. Australian fertility specialist Abha Maheshwari and colleagues conducted a literature review to examine the reasons behind the international variation in the use of single versus multiple embryo transfer. They describe sharp differences in the perceptions of health professionals cross-nationally about the balance between the risks of multiple births and the value of helping infertile women become pregnant. The authors credit these differences in perceptions, rather than strict guidelines about the permissibility of multiple embryo transfers, as a driving factor behind cross-national differences in multiple transfer rates (Maheshwari et al. 2011).

Stillman and colleagues characterize the differences in perceptions as related, at least in part, to differences in moral views. Supporters of multiple embryo transfer cite parental autonomy, that is, the rights of patients to make their own decisions about fertility procedures, as a guiding principle, while opponents cite beneficence toward future children, and avoidance of any harm that might occur from the delivery of preterm multiple infants with serious medical complications as their moral rationale (Stillman et al. 2013).

Maheshwari and colleagues also observe that, in general, families undergoing procedures to increase fertility have a preference for multiple embryo implantation. Multiple implantation reduces the number of IVF cycles that women must undergo and increases their chances of conceiving. Patient pressure for multiple implantation is intensified when families must pay for fertility treatment, and lessened in setting where treatment is provided in publicly funded systems or covered by publicly funded health insurance. Canadian fertility specialist Francois Bissonnette and colleagues, describing the impact of expanded insurance coverage for fertility treatment in Quebec in 2010 on reducing the rate of multiple embryo transfers, hypothesized that lessened financial pressure on families is associated with lessened pressure on physicians from patients desiring multiple embryo implantation. Lessened pressure makes it easier for physicians to adhere to professional guidelines which recommend single embryo transfer (Bissonnette et al. 2011).

Expanded education of families about the risks of multiple births also shifts the preference for multiple embryo transfers, particularly if concerns about higher costs are modified by the availability of insurance coverage. As discussed in Sect. 6.1.1, shifts in parents' preferences for multiple embryo transfer alleviates the ethical conflict that physicians experience between respecting parental autonomy and adhering to recommended medical practices. Public financing of assisted reproduction is available at least in some circumstances in some provinces of Canada, in Britain, Portugal, Greece, Belgium, Switzerland, Austria, Hungary, Germany, Italy, Sweden, and France (Stillman et al. 2013).

Another impact of public financing for IVF is that it allows an authority, the government or a financing entity, to enforce guidelines on single versus multiple embryo transfer, and to create consistent parameters for reporting pregnancy success rates and complications. These restrictions reduce the likelihood that any subset of fertility service providers can enhance their share of the business of assisted reproduction by responding more liberally to patient demand for multiple transfers, or by artificially enhancing their apparent success rate. This removes some of the competitive concerns that in the U.S. make it more difficult for fertility service providers to follow single embryo transfer guidelines (Bissonnette et al. 2011; De Neubourg et al. 2013).

Public financing of IVF allows a third party to have a meaningful voice in the decision about multiple embryo transfer, and this also shifts the dynamics of the ethical debate. The involvement of governments in financing has two primary rationales, in addition to providing a desired benefit to constituents: improving the quality and distribution of fertility services in the nation and reducing the rates of neonatal complications associated with assisted reproduction. As Bissonnette and colleagues report for Quebec:

> The costs associated with the ongoing care of multiple pregnancies, both during the pregnancy itself and for the care of premature infants, possibly with lifetime increased health costs, can be exorbitant. By reducing the number of multiple pregnancies and multiple births, the subsequent reduction in health costs can be used to pay for the assisted reproduction treatment. This appears to be a more positive use of provincial health funds since it is aimed at producing healthy babies, rather than needing to support babies with health issues. (Bissonnette et al. 2011 p. 503, reprinted with permission from Elsevier)

This value for dollars argument is easier to make in the context of a public health care financing system such as the Canadian system, because the trade-off between the two types of expenditures, coverage of fertility services and care of preterm newborns, is easier to track than it is in the complex system of U.S. health care financing. This in turn elevates the status of the societal-level argument about resource use so that it is influential in these contexts, in a way that this view is not influential in the U.S. (Orentlicher 2010; Smith 2011).

6.3.2 The Right to Refuse Screening and Treatment

As in the case of clinical ethical guidelines in the U.S., both ethical guidelines and legal precedents in Canada, Great Britain, and Western Europe support the right of pregnant women to decline medical interventions, even if clinicians believe this puts fetuses at risk (Lemmens 2010). The European Convention on Human Rights, signed in 1950 in the wake of World War II and in the then- contemporary political context of asserting the values of democracy in the face of the expansion of communism, has several articles that are interpreted as defending the right to refuse treatment as an aspect of individual autonomy (Wicks 2001). In a controversial case in Britain in the early 1990s, a lower court decision to approve a court-ordered cesarean section over the refusal of a pregnant woman was overturned, establishing a practice of accepting women's decisions about their medical treatment, even while acknowledging a moral basis for protecting fetal interests (Draper 1996; Dyer 1998). Similarly in Canada, higher courts overturned one court order for an enforced cesarean section and one for incarceration until delivery for a pregnant woman working as a prostitute, both on the grounds that the orders violated women's rights to autonomy, even if their decisions were believed to threaten the well-being of their fetuses (Dawson 1990).

Dutch legal scholar Christophe Lemmens believes that European and U.S. legal traditions are generally similar in their emphasis on pregnant women's rights to refuse treatment, although he notes that, in some U.S. states, fetuses are considered children for the purpose of enforcing child abuse laws. For the most part fetuses do not have this legal status under European laws (Lemmens 2010). American legal scholar Linda Fentiman agrees that legislation and court decisions in Canada, Britain and Europe do not distinguish fetuses as separate entities from their mothers, and this generally protects women from interventions performed without consent (Fentiman 2009a). In contrast but along the same lines, Irish legal scholar

Katherine Wade comments that, although no requests for court orders enforcing cesarean sections without patient consent had yet been brought in Ireland at the time of her publication, the fact that the Irish constitution explicitly protects the life of the unborn makes it possible that the courts would rule differently in Ireland than they have in England and Wales, and support the legality of treatment without consent for pregnant women (Wade 2013).

Despite these legal precedents, clinicians, activists, ethicists and legal scholars have similar debates in Canada, Great Britain, and Europe as they have in the U.S. about the balance between maternal and fetal interests. It is difficult for clinicians not to intervene when they believe a fetus's life is threatened by a pregnant woman's treatment decisions. In Britain, physicians sometimes find ways to declare pregnant women incompetent in decision-making so that they can justify interventions without consent (Wade 2013). In France, a different legal tradition puts less emphasis on individual consent, compared both to the traditions in Britain and in Germany. Instead, long accepted practice allows physicians to make decisions on behalf of patients, with the expectation that they are acting with beneficence for ultimate therapeutic benefit (Maio 2002).

A pair of studies surveyed obstetricians in eight European countries, and found consistently that, despite similar legal precedents and policies that protect patient autonomy, physicians' national settings predicted decisions about whether they would request court orders for cesarean sections and whether they would accede to patients' requests for the procedure in the absence of medical indications. The authors consider these two uses of cesarean section to be proxies for the range of treatments that can be provided during pregnancy, with and without patient consent. Physicians in Britain, Sweden, and the Netherlands were very unlikely to request court orders (4, 10, and 6 % respectively stated they would do so), while those in Italy, Spain, and France were more likely to request them if they believed fetal outcomes were at stake (33, 48, and 48 % respectively). Separate interviews with physicians in France revealed that some physicians considered sedating pregnant women so that procedures thought to be necessary could be carried out without consent (Cuttini et al. 2006). In several cases, in the places where physician groups were more likely to request court orders, they were less likely to agree to patient requests for elective cesarean sections (15 % in Spain and 19 % in France), while those less likely to request court orders were more likely to agree to patient requests (79 % in Britain and 49 % in France). This suggests that there are national biases in favor of or opposed to prioritizing autonomy over physician judgement. There was considerable variation across physicians within countries, and the structure of the different health care delivery systems also played in role in the likely choices that physicians' made (Habiba et al. 2006).

6.3.3 Substance Use During Pregnancy

As discussed previously in this chapter, legal action taken in the U.S. against pregnant women who use illicit substances reflects a more general belief that society sometimes needs to enforce the moral expectation that women should sacrifice their own interests for the benefit of their children. Minority and poor women, whose pregnancies are not as valued in the broader scheme of social reproduction in the U.S. as discussed in Chaps. 2 and 3, are much more likely to experience legal sanctions for their behavior than White women who are not low income. Also as discussed above, successful prosecution of women using the legal argument that they are harming their fetuses has been part of the broader advocacy effort of establishing legal precedents for the protection of fetal rights. This effort is part of building the legal case for eventually overturning the Supreme Court's 1973 *Roe v. Wade* decision that legalized abortion.

As in the U.S., officials in Canada, Great Britain, and Western European countries all have concerns about alcohol, tobacco, and prescribed and illicit drug use among pregnant women. While there are certainly parties in these countries who blame substance abusing women for harming their newborns, who target socially marginalized women in particular, who view fetuses as persons and who oppose abortion, unlike in the U.S. they do not have the opportunity to pass local laws or to interpret existing laws in ways that criminalize substance use during pregnancy. In the late 1990s, the Canadian Supreme Court ruled that a court in Manitoba erred in approving a court order for the forced detention of a pregnant woman for substance abuse treatment. She was a First Nations (Native American) woman with other children and a history of failed substance use interventions; the case was brought by the provincial social services agency. The court cited four reasons for its decision: fetuses have no independent legal rights in Canada, so there is no basis to hold a pregnant woman accountable for her actions toward a fetus; allowing provinces to force pregnant women to undergo substance abuse treatment could discourage them from seeking any kind of prenatal care; forced substance abuse treatment violates the principle of women's autonomy and equality; and if the court allowed substance abuse treatment to be required, there would be no legitimate way to stop governments from prohibiting a range of other lifestyle choices that could be said to harm a fetus. All of these concerns have also been raised by legal scholars opposed to fetal rights arguments in the U.S., but the arguments have not prevailed at the highest court levels.

Linda Fentiman suggests several reasons for the difference in criminalization of drug use by pregnant women cross-nationally. First, the fetal rights movement is not as politically influential in non-U.S. settings, because abortion policies in these settings have been created through legislation rather than judicial decisions, and thus cannot be overturned by establishing new legal precedents concerning the definition of personhood. Also, abortion services are routinely available in government financed health care systems, so the issue is not as publicly visible as it is in the U.S. Second, more centralized governmental systems in Canada, Britain, and Europe limit the venues for meaningful policy making at the local level. Third and perhaps most importantly, other legal systems are not structured to allow a broad scope of decision-making by elected local prosecutors. It is local prosecutors in various U.S. jurisdictions who decide to charge substance-using women with crimes. While these charges are most often dismissed upon appeal to the courts, the local prosecutors still benefit politically by appearing to support family values and to be tough on "bad" mothers. In these other societies, by contrast, local prosecutors are appointed based on merit and are monitored to be sure their actions fit with existing judicial interpretations of the law. Prosecutors who bring charges that are consistently overturned by higher courts as invalid would not be retained in these systems (Fentiman 2009a, b).

The approach to screening and providing treatment for pregnant women with substance abuse issues is also different in the U.S. compared to other countries. Appropriate treatment settings are not always available for pregnant women in the U.S. They are generally not integrated into prenatal care systems and protocols for referring women with positive drug or alcohol screenings for treatment are not always followed. As discussed previously in this chapter, informed consent for screening and treatment is not always required, and in some instances clinicians are expected to perform screening and report the results to government authorities, although this violates recommended professional guidelines for informed consent and confidentiality. As a consequence, it can be difficult for clinicians to form therapeutic alliances with pregnant patients who are using drugs, and this lack of trust is considered to be a detriment to the provision of good quality prenatal care.

In Britain and in most Western European countries, substance abuse treatment is integrated into prenatal care. A harm reduction approach to treatment is followed, which means that the focus of treatment is on limiting the immediate negative health consequences of substance use, rather than on ending addiction. Both behavior change and substitute medication therapies are employed, and healthcare systems operate separately from criminal justice and child protection authorities. In France, official documents put an emphasis on the detection and treatment of substance use early in prenatal care (Collin 2001). In Finland, treatment facilities take family circumstances into account (Leppo 2012). In Germany, treatment settings are available, and pregnant women are prioritized because they are thought to be more motivated to seek treatment than individuals who are not pregnant (Drug Commissioner of the Federal Government (Germany), 2012). In Britain, primary maternity care providers are expected to provide substance abuse treatment, with the support of multi-disciplinary teams who can create a fast track for women into substance abuse treatment. Confidentiality and consent criteria are clearly laid out (Department of Health (England) and the Devolved Administrations 2007). Substance abuse treatment in Canada is publicly financed, although treatment capacity varies across the provinces and facilities are not explicitly integrated into maternity care systems (Canada FASD Research Network 2014). Even if the approaches to substance abuse in pregnancy in these countries do not work as well in practice as the government goals and documents suggest, they still protect clinicians from conflicts between their roles as beneficent care providers and societal expectations about the need to enforce moral behavior for pregnant women.

6.3.4 Withholding and Withdrawing Neonatal Intensive Care

As discussed in Chap. 5, the publicly financed health care systems in Canada, Britain, and Western Europe emphasize primary care, and have fewer NICUs than most areas of the U.S. However, the technical quality of care in the systems is equivalent to that of the U.S., and innovations that have been shown to be effective for care are adopted cross-nationally. Official guidelines for neonatal resuscitation and life support care are relatively similar across the U.S., Canada, Great Britain and Western Europe, with care limited for infants younger than 22 weeks gestation, and care expected for infants born at 25 weeks gestation or later. In the gray zone area in between, it is expected that decisions will be made on an individualized basis in consultation with parents. Guidelines describe the decision-making role of parents differently in different countries (Pignotti and Donzelli 2008).

Actual practice tends to deviate somewhat from official guidelines, and resuscitation approaches vary across NICUs, within and across countries (Verhagen et al. 2010). However, in many of these other national settings, fewer marginally viable newborns are resuscitated than is customary in the U.S. A study of deliveries in the 1980s comparing treatment of births at 23–26 weeks gestation in the Netherlands and New Jersey found less use of cesarean sections and less use of assisted ventilation in the Netherlands, along with a lower survival rate but also a lower rate of cerebral palsy among survivors in the Netherlands (Lorenz et al. 2001). A survey of NICU staff in seven Western European countries in 1996–1997 found that the majority of respondents would set limits hypothetically (DeLeeuw et al. 2000) and had actually set limits in practice (Cuttini et al. 2000) on intensive interventions for newborns with poor prognoses. Setting limits includes withholding any intensive care, continuing treatment but not intensifying interventions if complications arise, withholding emergency treatment, withdrawing ventilation once it is begun, and even (reported only in the Netherlands and France) administering doses of pain medication high enough to end a newborn's life when it is believed that the infant's ultimate outcome would be poor.

Companion questions to the survey of NICU staff decisions about limiting care, described above, explored policies on parental involvement in newborn care and in ethical decision-making (Cuttini et al. 1999), and examined the values that staff members expressed concerning end-of-life decisions (Rebagliato et al. 2000). A selection of the findings from this survey is shown in Table 6.3.

As the table shows, there was marked variation across countries in survey responses, indicating that cultural, medical system and policy factors were major influences on these decisions. In general, decisions to limit care were more common in countries where respondents disagreed with an extreme sanctity-of-life argument and disagreed that family burden of care is irrelevant; parents also tended to be more involved in decision-making in these settings. Evaluation of the costs argument was more varied across countries: respondents in Italy and France were most likely to agree that costs limited the amount of care that should be provided,

Table 6.3 Survey findings on NICU Care limitations cross-nationally in Britain and Europe, from Cuttini et al. (2000), Table 2, Rebagliato et al. (2000), Table 2 and Cuttini et al. (1999), Table 2

	Italy (%)	Spain (%)	France (%)	Germany (%)	Netherlands (%)	United Kingdom (%)	Sweden (%)
Decisions limiting care							
Has set limits on interventions due to fatal condition	61	75	85	86	81	77	96
Has set limits on intervention due to poor neurological prognosis	46	61	85	69	78	74	90
Values expressed about neonatal resuscitation and life support							
Agrees that because human life is sacred, everything should be done to ensure a neonate's survival, no matter the prognosis	33	33	10	6	1	3	8
Agrees that limiting intensive care is a slippery slope that will lead to abuses	29	61	34	48	9	16	18
Agrees the burden that a disabled child will place on the family is not relevant to decision-making	87	53	52	60	45	14	32
Agrees costs of health care for disabled and preterm newborns do not allow us to treat patients regardless of outcome	50	29	57	18	21	26	23
NICU policies on parental involvement in ethical decisions							
They may choose the course of action for their baby	0	0	0	0	0	11	0
They may take part in the decision	19	35	0	54	50	78	26
Their wishes are indirectly sounded out and taken into account	48	47	100	44	50	11	68
They do not take part in the decision but are informed about it	22	12	0	2	0	0	6

although Italian respondents were the least likely to limit care, and French respondents were more likely. Respondents in Germany and the Netherlands were least likely to agree that costs should limit care, although respondents in both countries were more likely to have limited care. These findings suggest that quality of life arguments and value for dollar arguments operate separately in decisions to withhold or withdraw neonatal intensive care. With the exception of some NICU units in Britain, parents did not have the autonomy to make resuscitation decisions alone, and in Italy, Spain, and France, parents participated in the decision in fewer than half of the responding NICU units.

An update to this survey reviewed policy changes in the care of marginally viable newborns in the European countries and Britain in the early 2000s. Researchers reported that, for the most part, then-contemporary policies reflected the practices documented in the initial survey. Active euthanasia in the neonatal intensive care unit was still allowed in the Netherlands once the decision is reviewed, and was still practiced occasionally in France, although it is prohibited there by legislation (Cuttini et al. 2009).

The guidelines of the Canadian Pediatric Society recommend that physicians not resuscitate preterm newborns younger than 23 weeks gestation. Writing in 2014, Edmonton neonatologist Linda Maghroub and colleagues observed that they had long held to the policy of offering only comfort care to preterm newborns born before 24 weeks gestation. However, they recently re-evaluated this policy based on reports of successful resuscitation of newborns delivered at younger ages, and based on the practices of more newly trained neonatologists, who were familiar with resuscitation and treatment of younger neonates. To establish a consistent approach to resuscitation, the Edmonton neonatologists formed a working group to create local guidelines. They included parents who had experience in NICU settings, and observed:

> Parents from FACT [Family Advisory Care Team] expressed strong feelings toward the supportive management of infants born at 23 weeks' gestation, and that counseling leaning heavily towards compassionate care was not appropriate. They specifically stated that hope should not be taken away from families at 23 weeks' gestation before birth despite the possibilities of death and/or disability. Parents strongly felt that the option of resuscitation at birth with NICU admission and life supporting treatment should be offered but not mandated, and that family decisions should be supported whenever possible. (Mahgroub et al. 2014, pp. 1407–1408)

Subsequent to these discussions, the hospital policy was changed to encourage parental consultation before delivery about resuscitation at early gestational ages, and to encourage professional support for parental decisions that determine whether resuscitation is provided. The authors remark that it has been challenging to implement this policy, and some work has to be done with NICU staff, who must learn to cope with their distress when parental decisions "collide" with their own moral frameworks.

In summary, ethical dilemmas in the care of high-risk pregnant women and preterm infants are similar across the U.S., Canada, Great Britain, and Western Europe. Participants in decision-making must sort out issues of resource use, parental autonomy, respect for life, and concerns about quality of life. There is much individual variation in decisions that are made, but there are also national-level variations in patterns of decision-making. In general, societal-level concerns, particularly about resource use, figure more prominently in ethical discussions in countries other than the U.S. Arguments citing fetal rights figure less prominently in these settings.

In terms of decision-making around assisted reproduction, and particularly whether to accept the increased likelihood of preterm delivery related to multiple embryo transfer, the dominant trend in the U.S. is to respect parental decisions regardless of the potential increased risk for the fetus. The trend in countries where assisted reproduction is publicly financed is to limit multiple embryo transfer in order to reduce the likelihood of preterm birth. Once the pregnancy is in process and after the delivery, however, the trend in the U.S. is to override patient or parent autonomy and to act to preserve a fetus or newborn's life, with limited consideration for quality of life concerns and little overt discussion of the costs of neonatal and subsequent care. This reflects a sanctity-of-life philosophy that has historically had considerable political influence, and also reflects the absence of a unified societal-level influence on healthcare resource use that is distinct from the interests of health care providers. In Canada, Britain, Germany, and Scandinavia, patient autonomy during pregnancy is more deeply entrenched, while in France, Italy and Spain, physicians have more authority to act as they feel is therapeutically appropriate. In terms of neonatal care for very preterm newborns, adherence to the values of parental autonomy, effective resource use, and a nuanced view of life support in the context of expected quality of life of the newborn create a dynamic context in which resuscitation decisions are made slightly differently across NICUs and across countries.

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Epilogue

Preterm Birth and U.S. Culture and Society

The underlying premise of the sociocultural approach to preterm birth presented in this book is that features of social structure and culture shape the way the phenomenon manifests and is understood in the U.S. By the same token, examining the way preterm birth manifests and is understood in the U.S. offers a way to view more general themes in U.S. social structure and culture. In this epilogue, I will briefly suggest aspects of U.S. culture and society which I think are illuminated by the preceding examination of preterm births in this society.

E.1. The Framework of Disease and the Authority of the Medical Domain

First, it is clear that the mechanistic and problem-oriented paradigm of Western medicine is deeply rooted, because attempts to apply the paradigm to preterm births persist, although infant delivery before term is too heterogeneous and multi-factorial a situation to logically categorize as though it were a singular disease or health problem. Also preterm birth involves an interaction between two people, mothers and newborns, and this reality challenges diagnostic practices, research approaches, and ethical decision-making in clinical care, which are all oriented towards health problems as events that occur to individual patients.

The Western medical paradigm reflects themes that thread through many other aspects of U.S. culture, which is one reason it is hard to modify the framing to take account of preterm birth. Anthropologist Deborah Gordon (1988) notes that the individualism reflected in Western medicine reinforces core values that emphasize the independence of individuals from social context, relationships and emotional ties. Ultimately, she concludes, this type of individualism is associated with the belief that society is a means for individuals to achieve their own ends; there is no such thing as common good, and society is potentially a threat to individual liberty.

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Belief in the individualized nature of diseases lends itself to an ideology that emphasizes the impact of behaviors that deviate from accepted social norms, along with demonstrations of poor self-control, as causes of health problems. The association of poor pregnancy outcomes with the supposed negative actions of socially stigmatized groups—poor women, Black women, women who have sex without planning for childbirth, obese women, users of illegal substances—is an example of the application of this ideology to preterm birth. The emphasis on the risks of individual behavior, rooted in a theological framework that views disease as punishment, but coinciding with modern formulations that emphasize the obligations of individuals to be healthy so that they can function well as consumers in the marketplace, downplays any obligations on the part of society to assure the health of its members (Ayo 2012). In the body of research on preterm birth, paradigms that seek individualized causes for the early ending of pregnancies become ways of obscuring the multi-faceted relationship between social disadvantage and poor health, and this is important for preserving an ideology that favors consumption and the importance of free markets over organized social reforms.

The medical framing of preterm births helps to reinforce the medicalization of all pregnancies and childbirth, since the occurrence of a preterm birth can be presented as a cautionary tale showing that pregnancies can have undesirable outcomes if pregnant women fail to follow medical advice. The medicalization of pregnancy and childbirth in turn supports the authority of medical specialists in their role as mediators between humans and the natural world. The fact that there is little that can be done from a medical interventional aspect to prevent preterm birth is culturally obscured in order to preserve the authoritative role of medicine. Thus the popular belief, reinforced by many general pregnancy advice sources, is that preterm birth is preventable, and that when it occurs it is most likely because mothers made some kind of unintentional mistake or behaved in a selfish or inappropriate way.

The preservation of medical authority and the belief in the power of the medical domain to mediate between humanity and nature is very important in U.S. society more generally. The medical domain supplements and often substitutes for the legal domain in the control of undesirable behavior, including addictions, some forms of sexual activity and some criminal behavior thought to be related to mental illness. It is difficult to identify what types of social institutions could handle these issues on behalf of U.S. society, if doubt about the ability of medicine to control undesirable situations became widespread (Conrad and Barker 2010; Conrad and Schneider 1992). In addition, expansion of the natural states that can be addressed through medicine, starting with pregnancy but including aging and hyper-active behavior in children, for example, has opened up new opportunities to market technological innovations, such as pharmaceuticals, to the financial benefit of an important set of producers in the U.S. economy (Clarke 2003; Conrad 2007). These would also be threatened if the cultural authority of the medical domain came under question.

E.2. Preterm Birth and Social Reproduction

A particularly important second function of the medicalization of pregnancy and childbirth is to provide a legitimate cultural context for the preservation and enactment of the U.S. system of social reproduction. Social reproduction includes the beliefs, institutions and practices that shape how a society continues over generations. Among the principles that are important for societal continuity in the U.S. is the belief that fetuses are individuals who are distinct from their mothers, even during pregnancy (a component of the ideology of patriarchy which exists across all Western cultures); a belief that mothers are responsible for their children's outcomes; and a belief that the domestic sphere encompassing mothers and children is one of the few arenas where it is appropriate to act out of selflessness and compassion (Phillips and Taylor 2009).

In contrast with the social reproduction systems in comparable countries, including Canada, Great Britain, and those in Western Europe, the system in the U. S. considers successful reproduction an individual responsibility. There are fewer protective laws, labor policies, social welfare benefits, or supportive contraception and abortion policies in the U.S. than elsewhere. In part this is because of the racial and ethnic diversity of the U.S. population—not everyone feels invested in the reproduction of everyone else in the society—and in part because overall low fertility rates have not been framed as a political and social problem in the U.S. as they have elsewhere.

Medicalizing pregnancy and childbirth puts medical expertise and the medical care delivery system in charge of enforcing norms for maternal behavior, and for signaling that fetuses and newborn children are societal members, not simply family members or members of a dyad with their mothers (Davis Floyd 2003). The use of population data on the frequency of preterm birth to identify maternal characteristics—age, marital status, sexual activity (expressed as pregnancy intendedness), race, poverty, obesity, alcohol, tobacco and drug use—as indicating high-risk status overlaps with the enforcement of norms about which types of women should be encouraged to reproduce, and how these women should behave. The fact that clinicians are allowed to determine whether newborns will fare better if they are delivered prematurely through intervention, and are credited with keeping preterm newborns alive through medical technology, are also public demonstrations of medicine's authoritative role in social reproduction. The observation that fetuses who are delivered up to four months before they reach term are treated as infants, and can sometimes be kept alive through medical intervention, is seen culturally as illustrating the unacceptability of permitting women to choose whether to terminate their pregnancies through abortion.

E.3. Social Stratification

As noted, the child-bearing population in the U.S.is more diverse than the populations in Canada, Great Britain, and Western Europe: a larger portion of the U.S. population lives in poverty than is true in these other countries, and the U.S. is divided into more racial and ethnic groups than the populations in these other countries. Racial and ethnic groups are social categorizations related to ancestry that are meaningful in U.S. culture. Racial distinctions—the differentiation of Black Americans from others—is a particularly loaded social categorization that impacts many dimensions of peoples' lives and ultimately affects the course of women's pregnancies. Social stratification in the U.S. occurs at the intersection of race/ethnicity, socioeconomic status and gender. Dividing the population along one dimension without taking the others into account gives only a partial sense of the underlying patterns of power distribution which structure peoples' social opportunities (Landry 2006; Pascale 2007).

This is particulary well illustrated by population data on preterm births in the U. S., which show that race and poverty are not interchangeable, and both are associated with a greater likelihood that pregnancies will end before term. Another ideological function of framing preterm births as health problems is that the emphasis on negative behaviors and poor individual health states helps to obscure the negative impacts of social disadvantage. This in turn helps the U.S. avoid acknowledging the dissonance between its egalitarian principles and beliefs and the realities of racial and socioeconomic inequality.

E.4. Privatization of the Societal Response to Social Issues

Although generally preterm births are considered individual health problems, high rates of preterm birth in the U.S. are thought to require some type of social response. This is because these high rates contradict two overarching themes in U. S. culture: the assumption that problematic events should diminish with social progress (preterm birth rates should go down, not up over time as our society becomes more complex and technologically oriented), and the expectation of American exceptionalism, that the U.S. is a model of moral correctness, and should be superior in all measurable ways to other societies (Madsden 1998) (preterm birth rates should be lower, not higher, in the U.S. compared to other countries). These concerns give the problem of preterm birth the potential to galvanize political action for solutions, and this type of political traction means that preterm births can serve as "problem streams" in political agenda setting (Kingdon 1984).

Because preterm births are an aspect of social reproduction and are interwoven with the ways U.S. society is stratified, it is not surprising that, constructed as a social problem, preterm birth plays a role in political conflicts over control of fertility, addressing poverty, and addressing racial inequities. Because preterm birth is also constructed as a medical problem, the politically acceptable solutions to fertility control, poverty, and racial inequity have also taken on a medical framing. Framing fertility control, poverty and racial inequity as child and health-related issues has enabled reformers in these arenas to avoid ideological and interest group opposition that otherwise would assure the maintenance of the societal status quo. This opposition to reform includes resistance to fertility control approaches that are intended to allow people to have sexual relations without the intent of procreation, resistance to social reforms that might redistribute wealth to impoverished segments of the population, and resistance to fundamentally altering the situation of Black Americans in relation to the broader society.

Framing the social efforts to cope with the social tensions around fertility control, poverty and racial inequity as a social commitment to solve the medicalized problem of preterm birth places medical expertise and the healthcare system in the role of problem solvers for these broad and pervasive issues. As problem solvers, health care entities receive a considerable amount of societal resources. On behalf of preterm birth, these resources include direct financial subsidies for hospitals and physicians, and public and private insurance coverage for pregnant women and preterm newborns. There are public sources of financial support and producer-friendly regulations for technology innovations, and relatively little pressure to demonstrate the value of the medical care provided or to moderate prices. There is also a social environment that favors rescue interventions for fetuses, and favors sustained life support for all but the least viable newborns. Such an supporting environment maximizes the flow of patients into the system, which in turn generates revenue by support an expanded number of providers such as neonatologists and hospital NICUs.

The fact that all of these resources are invested in a sector that operates, not in the broad public interest, but as a set of interlocking business enterprises, is another telling feature of U.S. society. Rooted in the American Revolution, political rhetoric in the U.S. has stressed the importance of protecting people from government over the value of using government to protect people from disadvantage. Structurally, the legal traditions of limited government have created barriers to extensive public involvement in many sectors of activity. In recent decades, as political scientist Wendy Brown has pointed out, the neoconservative movement, which resists large scale redistribution of public resources and the neoliberal movement, which favors private market solutions over organized public actions, have intersected in a way that further diminishes societal capacity to organize a public response to social problems. Brown writes:

> As neoliberalism converts every political or social problem into market terms, it converts them to individual problems with market solutions. Examples in the United States are legion: bottled water as a response to contamination of the water table; private schools, charter schools and voucher systems as a response to quality public education; anti-theft devices, private security guards, and gated communities (and nations) as a response to the production of a throwaway class and intensifying economic inequality; boutique medicine

> as a response to crumbling health care provision………This conversion of socially, economically, and politically produced problems into consumer items depoliticizes what has been historically produced, and it especially depoliticizes capitalism itself. (Brown 2006, p. 704)

Although there are other reasons why preterm births are framed as medical problems and allocated politically to the domain of health care to resolve, the net result parallels Brown's other examples of the depoliticization of social issues. Thus, the increasingly common practice of converting public problems into opportunities for private sector gain is another feature of U.S. culture and society illuminated by the way it addresses the occurrence of preterm births.

The Preface of this book presented the metaphor of the six blind men confronting an elephant: each man knows the part of the elephant that he experiences, but no one is aware of the elephant as a whole. Likewise, obstetrics providers caring for women in preterm labor know the physiological complications of each case, but have no way to act on the diversity of cases that exist in the population; neonatologists can rescue individual infants but have no way to alter the flow of cases they see; political scientists can see the restrictions placed on broad social action that exist when the narrow but politically attractive frame of health is placed on a phenomenon that occurs in relation to deep societal conflicts in the U.S.; and the list goes on. I hope that this book, by introducing readers to the dynamics of the many dimensions of pregnancies that end before they reach term, can contribute to a holistic view that supports beneficial actions around pregnancy and the health of newborns, for the sake of future generations.

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