

The background of the cover is a detailed microscopic cross-section of a plant stem. The central vascular cylinder is a large, circular, greenish-yellow structure with a distinct boundary. It is surrounded by a thick, multi-layered cortex of various cell types, including large, thick-walled cells and smaller, more densely packed cells. The overall appearance is that of a complex biological structure, likely a dicot stem, showing the intricate organization of its tissues.

Selective Reproduction in the 21st Century

Edited by
Ayo Wahlberg & Tine M. Gammeltoft



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Editors

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Foreword: The Egg Imaginary

Selective reproduction is ubiquitous today. As the chapters in this compendium point out, the “moral pioneers” who surfaced in my exploration of prenatal diagnosis in the greater metropolitan area of New York City in the late twentieth century have now morphed into “moral bearers” in Taiwan and “moral adherers” in Denmark in the twenty-first century as selective reproductive technologies (SRTs) have become routinized. Indeed, the underlying themes of this excellent volume are the explosive as well as selective globalization of reproductive technologies: here, you will find ethnographic case studies of sex selection in the USA and Vietnam, embryo selection in Spain, and surrogate selection in India. These analyses are drawn from the developing as well as the over-developed world, as the American philosopher Sandra Harding once dubbed such socioeconomic distinctions. And readers will also discover the rapid evolutionary trajectory on which reproductive technologies have embarked, from what Anglo-American anthropologist Sarah Franklin famously described as “giving nature a helping hand” to what our editors call “providing a guiding hand” that turns out to be a “vote of no confidence against nature, preventing certain kinds of children from being born”.

Our editors do a skillful job in reminding us how these rapid changes in the use of what they have long identified as “selective reproductive technologies” have become routinized. Beyond repro-tech in general, these

particular interventions aim to ensure that certain kinds of pregnancies will not be initiated nor their outcomes borne to fruition. As they tell us, and these case histories dramatically illustrate, selection is densely structured in the heterogeneous web of kinship, religious, legal-medical and bio-political relations within which it takes shape. Accounting for all this complexity and diversity is essential to understanding how a mistrust of nature and its biomedical modification have become routinized differently in different places. Yet, such scrutiny of structural differences in the deployment of SRTs should not occlude our analysis of some obvious commonalities. I would argue that these, too, are structural on at least three grounds.

First, selective repro-technologies have spread under conditions of lowered total fertility worldwide, based on diverse, regionally-specific processes: increasing education and labor-force participation of young women leading to an uptick in the age of first births and a reduction in completed family size. While there are significant regional and national differences in how such demographic forces play out, most of the world has experienced a version of these changes. Therefore, there are fewer helping hands within domestic arrangements and less intimate knowledge, ability, or willingness to nurture atypical dependencies and needs for caregiving, whatever these turn out to be.

Second, techno-belief in a controllable reproductive future has become widespread. What contributors to this volume label “the prevention paradigm”, articulated in the book’s Danish cases, increasingly prevails as a schema of early and thorough medical intervention to “nip problems in the bud” before they manifest in fiscally as well as social-emotional costly forms. Said differently, the acceptance of biomedical intervention into the intent of gods, ancestors, or statistical patterns has circulated widely if unevenly over the last few decades under the umbrella of robust medical care. In countries with both high literacy and high medical access, such interventions are increasingly accepted as a rational aspect of “the idiom of self-determination” (Heinsen, this volume). At the same time, Chinese and Israeli uses of selective screening are widely criticized as “too interventionist”. Many Western debates have denounced “sex selection” without necessarily interrogating the US uses of “gender balancing” as if it were the more rational response, individual but not patriarchal. How

are we to understand the politics and effect of market-driven versus state-selected shaping of reproductive selection?

Along with these technoprotocols and imaginaries has come greater specificity of what's imagined to be in the egg. Not only can many known hereditary and/or genetic disorders be prevented from transmission but also many potential consumers of selective repro-technologies increasingly believe that complex traits such as intelligence, height, beauty, musicality and more have become the objects of gamete selection. This is hardly the case: scientific technique works most effectively at selecting out undesirable traits, including sexed embryos. Yet, scientific evidence for selection of desirable traits is basically non-existent. What biomedical screening, diagnosis, and selection (through selective abortion or prenatal genetic diagnosis in conjunction with *in vitro* fertilization (IVF)) can accomplish should be understood along a medico-affective continuum: chromosomal disorders are easy to spot, and autosomal recessive conditions known to run at heightened risk in certain populations and families may be effectively identified through a series of tests. Yet, it is a leap from such medical interventions to the desire to curate complex phenotypes: since when did high SAT scores, collegiate athletic prowess, or even height run directly along the branches of family trees? This fantasy of bio-desire is potent and pervasive, however, and encouraged by many of the egg "donor" businesses that match buyers and sellers, a practice that is particularly prevalent in the US context.

Third, and densely attached to the first and second, market forces shaping medical-technological access are now and for the foreseeable future propulsive in their reach and reactivity. Whether arranging medical travel, advertising IVF vacations, promising religious adherence by surgical technicians, or offering parent/donor/surrogate "matches", the business of manufacturing and sorting maybe-babies is booming. One of the volume's authors labels these biotech selections "technologies of enchantment" (Stockey-Bridge, this volume). Of course, virtually all cultural groups have long used small-scale prayers, amulets, and food taboos as interventions into the liminality of pregnancy. Now, it is almost impossible to disentangle commercially driven enchantments from the sci-fi future to which reproducers with the literacy and wherewithal to engage them are subjected, when viewed through the lens of market

individualism. The label of healthcare thus veils a potent compound of escalating *techne* and biotech fantasy of control. And when positioned through the social optics of governmentality and its regulatory discipline, rationalities of cost-benefit analysis may call forth so-called responsible action on the part of citizens whose healthcare costs are publicly funded. There is no obvious pathway toward disentangling the individual from the social nor the costs from the benefits in this set of practices.

But whatever the national specificity through which such interventions are shaped and made more or less available, the flip side to reproductive selection is also well known: the normative discrimination against disability may focus on diverse impairing traits or disorders in different sociocultural and legal systems. Yet such selection against adds up to substantially the same ethical claims: certain embryos, fetuses, and potential family members bearing X, Y, or Z traits can now be barred from admission to the human community. Should they be? And how are such decisions shaped? Selective reproduction as a form of intimate, gendered, and kin-based control increasingly articulates with public discussions of neo-eugenic perfectibility, as scholars and activists in the fields of gender/sexuality and disability studies have long made clear.

This tension runs through the interstices of all chapters, sections, and the entire book. It cannot be otherwise: “we” readers, analysts, practitioners, and citizens drawn from many diverse locations are, willy-nilly, also participants in an ongoing public debate about the limits and liabilities—if any—that selective repro-tech entails. The volume you are about to read is thus a rich ethnographic contribution to the history of the re-present, as it passes across generations and through scholarly lineages. I recommend it with considerable enthusiasm as a fertile “donation” to a necessary, important conversation about the politics of reproduction in our immediate present and foreseeable future.

Rayna Rapp

Preface

In 2010, Tine was working on a long-term ethnographic study of prenatal screening in Vietnam, while Ayo received funding for an ethnographic work of sperm banking in China. Our common interests in social studies of how reproductive technologies were being routinized throughout the world led to numerous exchanges, not least since the use of reproductive technologies in these two countries was explicitly tied to governmental programmes aimed at improving “population quality”. At that time, assisted reproductive technologies (ARTs) had received substantial ethnographic attention globally. Yet, at the same time, we noted that increasing numbers of social studies were focused on another set of reproductive technologies often lumped together with ARTs under the rubric of new reproductive technologies or NRTs. These included social studies of prenatal screening and testing (which is often followed by late-term abortion) and preimplantation genetic diagnosis (PGD), technologies which were not being used by couples to overcome infertility. What these technologies did have in common were some form of deliberate, technologically aided selections regarding pregnancy outcome. During the course of our exchanges, we decided that the time was ripe to send out an international call to gather the growing group of social scientists who were studying what we ended up calling “selective reproductive technologies” or SRTs. The chapters that make up this book were originally written for this conference which was titled “Selective Reproductive Technologies—

Routes of Routinization and Globalization” and held in Copenhagen on 13–15 December 2012.

We are grateful to the nearly 100 scholars who participated in this conference, giving inspiring papers and contributing to lively discussions on the many questions that practices of selective reproduction raise across the globe. We are of course particularly grateful to those participating scholars who contributed findings from their research to this volume, and we thank the chapter authors for their engagement and commitment to the book project. We were thrilled and privileged to have Sarah Franklin, Lene Koch, Rayna Rapp and Margaret Sleeboom-Faulkner as keynote speakers, scholars who have led the way in social studies of selective reproduction in Europe, America and Asia. We thank them for their thought-provoking presentations which helped us develop the ideas and framework for this book. The conference was organized as a collaborative effort between the Department of Anthropology and the Centre for Medical Science and Technology Studies (Department of Public Health) at the University of Copenhagen, and we would like to extend a special thanks to Mette Nordahl Svendsen and Sebastian Mohr for their intellectual and organizational support. We would also like to thank the Danish Council for Independent Research for generously funding the conference (grant no. 10-094341) in a way that allowed us to support the travel of a number of scholars from less-resourced parts of the world. As a result, the conference benefited from empirical contributions from over 20 countries representing all 5 continents. This book attests to the importance of funding independent research.

We are grateful to Palgrave Macmillan’s Holly Tyler for receiving our book proposal with enthusiasm and to two anonymous reviewers for their constructive comments on the prospectus. We would also like to thank Joanna O’Neill for guiding us through the production process, as well as Charanya Manoharan and Dharaganath Ulaganathan.

Copenhagen
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List of Abbreviations

ART	Assisted reproductive technology
CNRHA	National Assisted Reproduction Committee (Spain)
CVS	Chorionic villus sampling
DCCR	Danish Central Cytogenetic Registry
DGP	diagnóstico genético pre-implantacional
DNA	Deoxyribonucleic acid
FISH	Fluorescence in situ hybridisation
FTPRA	First-trimester prenatal risk assessment
GIVF	Genetics & In Vitro Fertilisation Institute
HFEA	Human Fertilisation and Embryology Authority
HLA	Human leukocyte antigen
ICSI	Intracytoplasmic sperm injection
IP	Intended parent
IUI	Intrauterine insemination
IVF	In vitro fertilisation
PCR	Polymerase chain reaction
PGD	Preimplantation genetic diagnosis
PGS	Pre-implantation genetic screening
PND	Prenatal diagnosis
PST	Prenatal screening and testing
SRT	Selective reproductive technology
USDA	US Department of Agriculture

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1

Introduction: Kinds of Children

Ayo Wahlberg and Tine M. Gammeltoft

This book is about selective reproduction in the twenty-first century. Although selective reproductive practices have existed for a long time (Gammeltoft and Wahlberg 2014), twenty-first-century biomedicine provides historically unprecedented possibilities for technological interventions in childbearing processes. In the past 40 years, human reproduction has been technologically parcelled out into specialized fields of insemination, fertilization, implantation, gestation, termination and (preterm) birth. Such developments have separated reproduction from sex as well as genetics from gestation. As such, in the twenty-first century, selective reproduction increasingly takes place through decisions about which gametes to fertilize, which embryos to implant or which foetuses to abort. These new possibilities for decision-making and choice raise urgent questions for social scientists.

In this volume, we use the term *selective reproduction* to refer to practices that aim to prevent or promote the birth of particular kinds of

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Table 1.1 Major forms of selective reproduction in the twenty-first century

Objective of selection	Type of selection (SRT)	Scope
Selecting for desired sex (sex selection)	<ul style="list-style-type: none"> • Sex-selective abortion following prenatal determination of foetal sex • Sex-selective implantation of embryos following in vitro fertilization (IVF) and embryo biopsy (PGD) • Sex-selective fertilization of gametes following the MicroSorting® of sperm cells in a semen sample based on the chromosome they are carrying (can only influence sex of embryo) 	<p>Sex-selective abortion is legally prohibited in most countries of the world. Nevertheless, millions of especially female foetuses are aborted annually around the world. In countries like China, India and Vietnam, obstetric ultrasound has contributed to unprecedented sex ratios at birth as high as 120 boys for every 100 girls. While sex-selective abortion is often considered to be a problem of the so-called Global South linked to son preference, sex-selective fertilization of gametes or implantation of embryos (as opposed to abortion) is often described as ‘family balancing’ or ‘lifestyle’ sex selection in the Global North. While prohibited in some countries, thousands of cycles of MicroSort® insemination and PGD for sex-selective purposes are carried out each year globally</p> <p>Prenatal screening programmes have been routinized throughout the world covering millions of women (there are an estimated 213 million pregnancies globally every year, not all are screened) involving combinations of maternal serum screening, free foetal DNA screening, obstetric ultrasound scans and invasive prenatal diagnosis. Legislation varies with some countries allowing for late-term abortions if a ‘serious’ condition is detected. Such terminations remain controversial in many countries and there is no consensus as to what conditions (if any) are considered serious enough to warrant an abortion. Following the detection of foetal abnormalities, chromosomal disorders or genetic diseases/conditions, hundreds of thousands of pregnancies are terminated annually (legally and illegally) around the world (there are an estimated 45 million induced abortions globally every year; we estimate between 0.2 and 1 % of abortions are on grounds of substantial risk that the child would be seriously affected if the pregnancy is not terminated). Thousands of cycles of MicroSort® insemination and/or PGD are carried out around the world to prevent transmission of a genetic disease.</p>
Selecting for a healthy/normal child (prevention of disease/disability)	<ul style="list-style-type: none"> • Selective abortion of foetuses following detection of ‘serious’ foetal abnormality, chromosomal disorder or genetic disease • Selective implantation of only unaffected/healthy embryos following IVF and embryo biopsy (PGD) • Sex-selective fertilization of gametes following the MicroSorting® of sperm cells in a semen sample based on the chromosome they are carrying (can only influence sex of embryo) in order to avoid transmitting a sex-linked genetic disease • Selective fertilization of gametes following medical screening of gamete donors to prevent transmission of infectious or genetic disease 	<p>Prenatal screening programmes have been routinized throughout the world covering millions of women (there are an estimated 213 million pregnancies globally every year, not all are screened) involving combinations of maternal serum screening, free foetal DNA screening, obstetric ultrasound scans and invasive prenatal diagnosis. Legislation varies with some countries allowing for late-term abortions if a ‘serious’ condition is detected. Such terminations remain controversial in many countries and there is no consensus as to what conditions (if any) are considered serious enough to warrant an abortion. Following the detection of foetal abnormalities, chromosomal disorders or genetic diseases/conditions, hundreds of thousands of pregnancies are terminated annually (legally and illegally) around the world (there are an estimated 45 million induced abortions globally every year; we estimate between 0.2 and 1 % of abortions are on grounds of substantial risk that the child would be seriously affected if the pregnancy is not terminated). Thousands of cycles of MicroSort® insemination and/or PGD are carried out around the world to prevent transmission of a genetic disease.</p>

(continued)

Table 1.1 (continued)

Objective of selection	Type of selection (SRT)	Scope
Selecting for desired traits (donor selection)	<ul style="list-style-type: none"> • Selective fertilization of gametes following the choosing of a suitable gamete donor based on available information about donor health, eye colour, hair colour, blood type, height, intelligence, beauty, race/ethnicity, and so on • Selective implantation of embryos with disabilities by parents with disabilities (e.g., deafness or dwarfism) 	<p>Sperm banks and egg brokers screen thousands of potential gamete donors every year. Of these, between 10 and 20% are selected as qualified donors according to screening criteria. Legislation varies with some countries prohibiting all gamete donation and others allowing infertile couples, single women and/or lesbian and gay couples to access donor gametes. Studies have shown that infertile heterosexual couples are mostly concerned with health and less concerned with traits while gay couples, lesbian couples and single women often select for traits that are familiar to them and their families. Hundreds of thousands of donor babies have been born worldwide, the first major cohort of which (born in the 1980s) is now actively seeking out donor siblings and their biological fathers or mothers</p>
Selecting for saviour siblings (HLA matching)	<ul style="list-style-type: none"> • Selective implantation of histologically compatible embryos following IVF, embryo biopsy and HLA (human leukocyte antigen) typing (using PGD) in order to treat a sick sibling 	<p>Hundreds of saviour siblings have been created using PGD throughout the world starting in the USA in 2000. Using PGD to create saviour siblings remains controversial (because of concerns about the welfare and instrumentalization of the saviour child) and not all countries allow it</p>

See references in "Sources for Table 1.1"

children. What we collectively show in the following chapters is how selective reproductive technologies (SRTs) have been developed and routinized—which is to say taken up, practised and experienced—around the world over the last few decades. Selective reproduction is ubiquitous and not limited to any specific parts of the world, although the ways in which SRTs gain traction and stabilize are multiple. With the increasing availability of SRTs, selective reproduction is taking place on a historically unprecedented scale, through sex-selective abortion following ultrasound scans, abortion following detection of foetal anomalies during routinized prenatal screening and testing programmes, the development of preimplantation genetic diagnosis (PGD) techniques as well as the screening of potential gamete donors by egg agencies and sperm banks (see Table 1.1).¹

From ‘Helping Hand’ to ‘Guiding Hand’

Over the last three decades or so, social scientists have followed assisted reproductive technologies (ARTs) on routes of routinization and globalization, examining their development by clinicians and scientists as well as their impact on the daily lives of involuntarily childless couples in different cultural and socio-economic settings. Indeed, Marilyn Strathern’s reflections on such reproductive technologies as ‘nature assisted’ have provided an entire generation of social scientists with conceptual tools for analysing supposed nature-artifice divides in the field of human reproduction as well as for troubling separations of the natural from the social. ‘Nature assisted’, as she wrote in *Reproducing the Future*, ‘compromises the definition of nature as those conditions of life from which intervention is absent; what is given is no longer given by nature itself but is visibly circumscribed by technological capacity’ (1992: 57). Writing in the early years of reproductive technologies, Strathern was referring mostly to ARTs: ‘artificial insemination, in-vitro fertilisation, or other practices such as GIFT (gamete intra-fallopian transfer) simply stand in, so the justification goes, for natural body processes’ (Strathern 1998: 186). ‘If nature can’t deliver’, as one medical company put it in early 1990s

marketing material, then ‘nature sometimes needs a helping hand’ (Strathern 1992: 56, 57; see also Edwards et al. 1993).

Such technologies have become routine throughout the world, to an extent that the birth of the world’s 5-millionth IVF baby was celebrated by the European Society of Human Reproduction and Embryology in July 2012. A string of ethnographies over the last two decades have shown how IVF is construed as a solution to the disruptions of infertility and can become a way of a life for many involuntarily childless couples as treatment appointments, drug regimens, oocyte retrievals and embryo transfers take over their daily lives with many couples opting for multiple cycles in the face of repeated failure (Franklin 1997; Becker 2000; Thompson 2007). We have also seen how the development and practice of ART comes to be shaped by local moralities as well as national aspirations and programmes in so-called pro-natalist countries like Egypt, Israel, India and China (Inhorn 2003; Kahn 2000; Handwerker 2002; Bharadwaj 2016; Wahlberg 2016). Finally, as couples are increasingly prepared to travel in pursuit of conception, social scientists have turned their attention towards the phenomenon of ‘reproductive tourism’ or ‘reproductive travel’ as involuntarily childless couples—‘reproductive exiles’—cross international borders as a way to circumvent local restrictions, seek better quality care or more affordable treatment (Inhorn and Görtin 2011; Inhorn 2015; Stockey-Bridge, this volume).

In recent years, similar ethnographic attention has been directed at what we term selective reproductive technologies (SRTs) (Gammeltoft and Wahlberg 2014). It is important to distinguish between ARTs and SRTs, not least because of the differing objectives that are at stake. If ‘nature assisted’ is a fitting caption for ARTs, then SRTs might be summarized as ‘nature directed’. This is what Sarah Franklin and Celia Roberts were pointing to when contrasting IVF and PGD in *Born and Made*. While both involve in vitro fertilization (IVF), ‘the goal of IVF is a child, whereas the goal of PGD is, in a sense, the reverse, in that it is aimed at preventing some kinds of children being born’ (Franklin and Roberts 2006: 161).² The point being that SRTs involve a decision not just to seek a viable pregnancy and a birth but indeed to determine pregnancy

outcome in very specific ways, which is to say by preventing or promoting the birth of specific kinds of children. Indeed, SRTs can be thought of as a vote of no confidence against nature, as they do not so much stand in for natural biological processes as they seek to steer or obstruct these same processes. Social studies of ARTs have pointed to the importance of kinship and relatedness in explaining the uptake of such technologies as involuntarily childless couples go to great lengths to ensure that they have their own, genetically related children (Edwards et al. 1993). SRTs, on the other hand, are not primarily playing out in a context of infertility. Couples who pursue the use of SRTs are typically not negotiating an inability to conceive and as a result are not primarily concerned with ensuring succession through genetically related offspring or realizing a dream of having a family. Instead, they orient themselves towards the future living of their families. When making selective reproductive decisions, families invariably engage with their futures in terms of different kinds of living that they might wish to avoid (e.g., living with cystic fibrosis or living ‘only’ with girls) or achieve (e.g., living with healthy children, raising a son) (see Wahlberg 2009). In these cases, it is not that nature can’t deliver, it is rather that nature cannot be left to its own devices.

Having distinguished between the two, we know of course that any proposed dividing line between ARTs and SRTs will always be blurred not least since techniques often overlap and since it is difficult to imagine any reproductive process devoid of attempts to influence pregnancy outcomes. We see this in the case of transnational surrogacy involving egg donors (see Stockey-Bridge, this volume) or in the IVF clinics which now attract both couples seeking to overcome infertility and couples seeking to prevent transmission of a hereditary disease through embryo biopsies and PGD (see Pavone and Lafuente, this volume). Nevertheless, it is, as this book shows, analytically productive to distinguish between what might be thought of as two different reproductive schemas, namely, ‘helping hand’ or assisted reproduction which aims to technologically overcome biological obstacles to reproduction on the one hand, and ‘guiding hand’ or selective reproduction which aims to technologically prevent or promote the birth of certain kinds of children on the other, that is to say between nature assisted and nature directed.

Gametes, Embryos, Foetuses

As we have already pointed out, selective reproduction is nothing new. But if we look at this reproductive schema today, we can see how, until only relatively recently, selective reproduction mainly took place at the two poles: either before fertilization (think of partner selection or sterilization) or following birth (think of infanticide or selective neglect). We say mainly because pregnancy of course has been subject to all kinds of taboos and advices aimed at generically or specifically influencing pregnancy outcomes for a very long time, just as induced abortion has been used to prevent transmission of traits to offspring. Nonetheless, it is fair to say that since the 1970s, following the birth of Louise Brown, the development of increasingly sophisticated biomedical technologies has allowed for selective reproductive practices to become more targeted. Not only has human reproduction been separated from sex, as already noted, the entire reproductive process has been parcelled out and fragmented using ever more specialized techniques related to insemination, fertilization, implantation, gestation and birth. Gamete banks, medical/clinical genetics departments, IVF laboratories, prenatal clinics, abortion clinics, neonatal units and maternity wards are each involved in reproductive health care in different ways. Moreover, with the advent of cryopreservation in the latter half of the twentieth century, each reproductive segment can be realized in different places (indeed on opposite sides of the world), using gametes from partners and/or donors (at times in combination with gestational surrogates) and at varied intervals (the record with frozen sperm is 25 years and legal requests for posthumous use of frozen gametes or embryos are increasing around the world). Reproduction, it is safe to say, has become transbiological, transtemporal and transnational in hitherto unimagined ways while introducing possibilities of selection at each step.

At the same time, this fragmentation of the reproductive process has introduced new reproductive sites, techniques, forms of expertise and dilemmas. SRTs comprise specific laboratory and clinical techniques which facilitate the *selective* fertilization of gametes, implantation of embryos or abortion of foetuses (see Box 1.1). Decisions about which gametes to fertilize, which embryos to implant or which foetuses to abort are explicitly wound up in ideas about the kinds of children that are

desired or unwanted; ideas which in turn are inextricably bound to the kinds of societies within which selective reproduction is taking place. Prospective parents who engage with SRTs are not dealing with ways to overcome involuntary childlessness, rather they are involved in the planning of future family life.

In countries where gamete donation is allowed, sperm banks and egg agencies make selective decisions about which donors to accept by socially and medically screening them. Such screening practices are shaped by cultural values and social norms around notions of what a 'high quality' or 'good quality' donor might be, often times reifying eugenicist notions of positive selection (see Martin, this volume). These values and norms not only shape their recruitment and screening practices, they are also actively mobilized in marketing campaigns and information provided to prospective parents which include infertile couples, single women and lesbian couples (albeit with differential access in different countries depending on legislation) (see Stockey-Bridge, this volume). Moreover, couples with a known sex-linked genetic disease in their family may choose to MicroSort® their sperm prior to insemination or IVF as a means of sex selecting in order to avoid transmitting that disease. MicroSort® has also been marketed as a potential means for sex-selective 'family balancing' (see Bhatia, this volume). In selectively deciding which gametes to use, prospective parents are confronted with questions about which kinds of children are desired or unwanted for them as they go about planning their future family lives.

One of the consequences of routinized infertility treatment has been the bioavailability of embryos *in vitro* (cf. Cohen 2007). While these human embryos were initially produced in the clinic to identify those embryos considered to be the most viable for infertile couples seeking to achieve pregnancy, since 1990, increasing numbers of couples have chosen to pursue IVF cycles in order to allow embryologists to biopsy resulting embryos. Such biopsies provide geneticists with access to a potential child's DNA, allowing for genetic testing prior to implantation, which is known as preimplantation genetic diagnosis (PGD). PGD was developed to help families with a known hereditary disease to avoid commencing an affected pregnancy, thereby hopefully alleviating them of the difficult decision of whether or not to terminate a pregnancy. As such, PGD is a form of family planning that has become an option for some so-called

carriers of a genetic mutation who want to avoid passing on a disease that lies dormant in their genes. More recently, PGD has also been used as a means to secure the birth of a histologically compatible child (a so-called saviour sibling) who can provide blood and tissue samples for therapeutic use in a sick sibling suffering from, for example, sickle cell anaemia or β -thalassaemia (Dobson 2003). Finally, PGD has emerged as a technique to facilitate ‘lifestyle’ sex selection or ‘family balancing’ for some couples. And so, just like in the case of gamete sorting, couples who selectively decide which embryos to implant following embryo biopsies and genetic tests are confronted with questions about which kinds of children are desired (e.g., a girl or an HLA-match for a sick sibling) or unwanted (e.g., a child with cystic fibrosis or Huntington’s disease) as they attend to their current families while imagining their future family lives.

Box 1.1: Four important milestones in the development of SRTs globally

Seeing the foetus: Ever since *ultrasound technology* was first used for foetal head measurements in the 1960s, its ability to detect gender and physical abnormalities has propelled it to universal use in prenatal care. Sex selection is by far the most common form of selective reproduction today and the correlation between growing ultrasound availability and the skewing of sex ratios in countries like China, India and Vietnam is dramatic (UNFPA 2012). Moreover, foetal anomaly scans halfway through a pregnancy have become routine throughout the world to detect and confirm diagnoses of anencephaly, spina bifida, Edward’s syndrome and more, generating dilemmas for parents as they consider whether to continue or terminate a pregnancy.

Decoding the foetus: The development of reproductive genetics has had a profound effect on antenatal care. While ultrasound technologies are becoming ever better at seeing the foetus, they cannot tell parents anything about their foetus’s genetic makeup which is hidden away in its DNA. As such, ever since Fuchs and Riis in 1956 reported being able to determine the sex of a foetus after having collected amniotic fluid from pregnant women (Fuchs and Riis 1956), clinicians have been looking for safe and reliable ways of getting access to a foetus’s DNA. *Amniocentesis*, *chorionic villus sampling* and, most recently, *free foetal DNA testing* have each been developed for this purpose and have become standard offers for

women during antenatal care. Once samples of a foetus's DNA are available, they can be subject to a battery of genetic tests and screens to determine whether the foetus has a rare genetic disease, Down's syndrome or other chromosomal disorder. Concomitant screening procedures have also been developed to help identify those couples considered at risk who may then opt for an invasive procedure to get access to foetal DNA. Most recently, isolation of free foetal DNA from an expecting woman's serum has made non-invasive prenatal testing a reality.

Avoiding transmission: Family disease history has long played a role in reproductive decision-making as families have sought to avoid passing on debilitating conditions such as Huntington's disease or aggressive forms of cancer to their children. In the post-World War II period, *genetic counselling* emerged as a particular specialization in hospitals aimed at providing couples with a known (or suspected) hereditary disease with information about how inheritance works and what options they have when planning a pregnancy. Options may include carrier testing to see whether the man, woman or both carry a mutation of a genetic disease followed by gamete donation, preimplantation genetic diagnosis (PGD) of embryos or prenatal genetic testing of fetuses. Genetic counsellors are trained to be 'non-directive' as they encourage couples to make their own decisions about whether to begin, continue or terminate a pregnancy.

Sorting gametes and embryos: One of the important consequences of IVF technology has been displacement of the fertilization process from the womb to the laboratory. No longer only brought together through sexual intercourse, gametes can now be retrieved after which they can be prepared, sorted, cryopreserved and eventually fertilized. Once fertilized, clinicians are faced with the decision of which resulting embryos (and how many) to implant into the woman. A number of selective practices have emerged in the lab as a result, each of which is used to prevent or promote the birth of certain kinds of children. Developed in the 1970s, *MicroSort*[®] 'separates the sperm cells in a semen sample based on the chromosome they are carrying... result[ing] in samples containing significantly increased percentages of sperm that are carrying the desired (X or Y) chromosome' (MicroSort 2013). In this way, couples can significantly increase their chances of conceiving a boy or a girl or avoid transmitting a sex-linked genetic disease by inseminating sorted sperm or by using sorted sperm in conjunction with IVF. Similarly, *gamete banks and brokers* tend to select 'good quality' donor candidates with traits considered desirable by recipients. Since 1990, PGD clinics have carried out genetic tests on successfully fertilized embryos by taking a cell biopsy from each embryo as a way to decide: which affected (or mutation carrying) embryos should *not* be implanted in order to avoid transmission of hereditary disease; which histologically compatible embryos should be chosen for implantation to produce a so-called saviour sibling; or which embryo should be chosen for implantation to secure the birth of a boy or a girl.

Throughout the world, pregnancies have come to be the object of various forms of medicalized surveillance through routine prenatal care which can involve ultrasound scans, maternal serum tests as well as amniocentesis or chorionic villus sampling. The goal of this surveillance is to monitor the health of women and foetuses during gestation as a way to ensure safe and healthy births. With the global routinization of ultrasound scans as well as prenatal risk assessments in the closing decades of the twentieth century, one can say that the majority of pregnancies have become potentially selective—or ‘tentative’ in Barbara Rothman’s (1993) phrase—as prospective parents grapple with societal expectations and their own convictions about which kinds of children are desired (e.g., a son) or unwanted (e.g., a child with Down’s syndrome) as they prepare for an approaching birth. Termination of pregnancy—whether for sex-selective reasons (millions of pregnancies have been estimated to have been terminated to avoid the birth of a girl) or to prevent the birth of a child with a serious disease (thousands of pregnancies are terminated around the world each year following prenatal screening, testing and diagnosis)—is the most ubiquitous form of selective reproduction in the twenty-first century. The surveillance and, in some cases, ensuing terminations of pregnancies are, existing research shows, often shrouded in deep ambivalence, as pregnant women, relatives and health care providers agonize over the—potential or actual—life-and-death decisions that SRTs confront them with (see Rapp 1999; Gammeltoft 2014; Trần, this volume).

Tracking Routes of Routinization

Any attempt to empirically address the unfolding routinization of SRTs globally, as this book sets out to do, must attend to a multitude of problematics. As medical technologies, SRTs must traverse the continuum from experimental technology to standard of care to become routinized (Koenig 1988), a process that is unique to every country. SRTs have tended to go through variegated patterns of acceptance in different countries: from pioneering ‘breakthroughs’, at times followed by periods of concern and resistance, then regulation and eventually routinization as

particular procedures are rolled out and made available (Wahlberg 2016). Consequently, we propose four important empirical routes to studying SRTs in the twenty-first century. First of all, as we have seen, there are a range of *techniques*. SRTs comprise a plethora of specialized techniques—such as amniocentesis, ultrasound scans, sperm sorting, PGD and carrier testing—each of which zooms in on a particular segment of the reproductive process. Each technique can be (and indeed have been by many scholars) studied in terms of its history, social life and/or social impact (Rapp 2000; Franklin and Roberts 2006; Gammeltoft 2014). Once standardized, such techniques can be rolled out in the form of routine prenatal care or national screening programmes. Among the techniques that will be explored in the following chapters are sperm sorting, egg harvesting, PGD, maternal serum screening and ultrasound screening.

Secondly, as noted earlier, one of the consequences of the fragmentation of the reproductive process has been the emergence of specialized sites dealing with particular aspects of reproduction. It is in these *sites* that we as social scientists often must negotiate access and carry out our fieldwork and interviews, ranging from sperm banks to clinical genetics units, IVF labs, prenatal clinics, abortion clinics and labour wards, not to mention the homes and communities of all those couples who engage with SRTs. To understand routinization, we need to visit the places in which certain diagnostic and screening offers operate on a daily basis, witnessing the daily grind while analysing the interactions between professionals, techniques and couples. Contributors to this volume have carried out research in egg agencies, IVF clinics, prenatal care units, ultrasound clinics as well as pregnancy termination units.

Thirdly, it is arguably the *people* that engage with SRTs that are the most important constituents in understanding how SRTs come to be routinized and globally widespread. The field of SRTs is filled with a myriad of choreographies, decision-making processes, evaluations and deliberations. In researching SRTs, we meet its users in the form of ‘prospective parents’, ‘intending parents’, ‘expecting couples’, ‘pregnant women’ or ‘families’ who at times will choose to use a gamete donor or surrogate mother. To understand how SRTs are experienced and incorporated into individual family planning strategies—whether in accordance or in conflict with dominant cultural values and social norms—it is essential that social

scientists spend time with those who make use of SRTs. We also meet SRT practitioners such as clinicians, nurses, geneticists, sonographers, midwives, gamete brokers, gynaecologists, obstetricians, nurses and embryologists who go about ensuring that SRT services are provided to users, often in so-called resource poor settings. Perhaps inevitably, considering the controversies that surround selective reproduction, social scientists also often seek out policymakers, government officials, lawyers and ethicists in their countries of study as part of their efforts to understand how SRTs are normalized in particular places and at particular historical moments. It is these users, practitioners and regulation makers that each of us has talked to and spent time with when studying selective reproduction in the twenty-first century in different parts of the world.

Finally, empirical engagement with SRTs will almost always lead not only to regulation makers but also to the *laws, regulations and guidelines* (as documents) which circumscribe the availability and intended use of SRTs. Selective reproduction is an ethically and emotionally charged field of practice governed not only by national laws, such as the Embryo Protection Law in Germany or the Law on Maternal and Infant Health Care in China, but also by a host of procedures, guidelines, codes, contracts, forms, and so on aimed at ensuring acceptable ('appropriate' and 'lawful') use of SRTs in clinical settings through Good Clinical Practices, Good Laboratory Practices as well as ethical guidelines. Moreover, nation states invest heavily in the deployment of SRTs through screening programmes and health delivery systems, not least with the controversial (at times explicit, at others implicit) aim of reducing congenital malformations and hereditary disease. It is therefore virtually impossible, as we will see, to study SRTs today without familiarizing if not immersing ourselves into such regulatory debates and texts.

Taken together, these techniques, sites, people and regulations form selective reproductive assemblages, infrastructures or complexes (cf. Collier and Ong 2007; Inhorn 2015; Larkin 2013; Vertommen 2016; Wahlberg 2016) which are always particular to the different countries, economies, cultures and societies within which we study SRTs. As Wahlberg (2016) has argued, when it comes to medical technologies, routinization is a socio-historical process whereby certain forms of medical technology come to be (re)produced and entrenched within particular

juridical, medical, social, economic, cultural and institutional configurations. It also entails a daily grind of practices through which certain medical technologies are rolled out and become an established and habituated part of health delivery, which is to say a standard of care provided in a fixed setting. And finally, routinization suggests a gradual take up and acceptance of a medical technology such that it becomes a normalized part of daily life, in the sense that it is available to and used by its intended users in a routine manner, albeit surrounded by all manner of socio-economic or cultural barriers. In the chapters that follow, we will learn how SRTs came to be routinized in different parts of the world from Denmark to Spain, Vietnam, India, Taiwan, Australia and the USA.

Tracking the Economic and Political Forces Underpinning Routinization

Across the globe, SRTs are located at a convergence of political and economic forces. In some countries, national governments define SRTs as political tools, mobilizing new technologies for selective reproduction in overt efforts to enhance ‘population quality’ (see Shih, this volume). Seeking to prevent the birth of children with disabilities, the governments of China and Vietnam, for instance, are actively encouraging pregnant women to make use of prenatal screening and testing technologies. A strong and healthy population, government authorities inform people, is a precondition for national stability and welfare (Zhu 2013; Greenhalgh and Winckler 2005; Gammeltoft 2014). In other countries, most notably in Europe and the USA, the spectre of twentieth-century eugenics continues to haunt present-day reproductive policies, compelling state authorities to frame selective reproductive decisions as matters of personal preference and choice rather than as matters of demography. SRTs are *not*, government documents emphasize, introduced to serve demographic purposes; rather, they serve as medical means by which citizens’ capacities to make their own reproductive choices can be enhanced (Schwennesen and Koch 2009; Meskus 2009). As much research has shown, however, individual reproductive choices are always formed by the socio-political contexts within which they are made, guided by

powerful societal norms, values and expectations (see Heinsen, this volume; Shih, this volume; Trần, this volume; Rapp 1999). This is the case also in social settings where official health care practice guidelines emphasize balanced information and individual choice: such information provision tends to be carried by particular normative demands and expectations, pushing people in certain decision-making directions. Consequently, some critics have characterized twenty-first-century selective reproduction as a ‘laissez-faire’, ‘back-door’, ‘neo’ or ‘flexible’ eugenics (Duster 2003; Taussig et al. 2003; Lock 2007).

Besides political forces, economic forces also drive the introduction and routinization of SRTs. Within public health care systems, the introduction of state-funded programmes for pregnancy screening and testing are often based on cost-benefit calculations assessing the costs saved if fewer children are born with disabilities (Schwennesen et al. 2009). Some countries offer couples access to publicly funded carrier testing and, if a genetic disposition is found, access to publicly funded PGD. Yet these offers cover only certain selected conditions, and decisions regarding which prospective parents should be offered access to these technologies rely on calculations assessing the economic gains attained if the birth of a child with this particular condition is averted. The assumed societal resource implications are, in other words, often the subtle subtext when public sector SRTs are offered. Due to the sinister history of nineteenth-century eugenics, however, such underlying economic rationales are often downplayed in official documents and policy guidelines, perhaps particularly in Europe where the eugenics movement had the most disastrous consequences (cf. Erikson 2003; Koch 2006).

When selective reproduction takes place in the private health care sector, economic rationales play important roles too. The parcelling out of reproductive processes described above has entailed novel possibilities for commercialization and commodification: from being intimate and integral parts of individual bodies, human eggs and sperm have changed character and can now be extracted, stored and circulated in national and transnational capitalist circuits. In the reproductive markets that this has generated, some gametes hold higher value than others, offering the prospect of considerable economic profit (e.g., Martin, this volume; Pavone and Lafuente, this volume; Almeling 2009; Pollock 2003). It is probably

no coincidence that ‘sperm banks’ are described through metaphors derived from the financial world. As the bedrock of capitalism, banks facilitate markets, the notion of ‘sperm bank’ pointing us to the ways in which human bodies and their reproductive capacities are being turned into property in the twenty-first century. These processes are evident also in markets for babies. The increasing access to surrogacy services in countries around the world entails new possibilities for economic gain; cross-border surrogacy is by now a multi-billion dollar global industry (Deonandan 2015). As donor gamete selection is often involved in these arrangements, although surrogacy is primarily an assisted reproductive technology, it nonetheless can have its ‘selective moments’, as Stockey-Bridge shows us in Chap. 8. Further, in many countries with privatized health care systems, prenatal screening and testing are important sources of revenue for health care providers, and their economic interests may therefore fuel a technology’s routinization (cf. Gammeltoft and Nguyen 2007). Selective reproduction is, in short, lucrative business in many respects, and as such a focal point of numerous economic interests. The biomedical research and technological development that precedes the launch of new SRTs will, as Bhatia’s (this volume) work in a Euro-American context exemplifies, often take place in an orientation towards a given technology’s marketability and economic potential.

Economic calculations are, however, not restricted to the domains of states and markets; they are also made within domestic worlds. When individuals and couples resort to SRTs, personal assessments of the economic burdens and benefits that the birth of a particular kind of child will entail often contribute to shaping their motivations; users of SRTs are often engaged in active forms of planning or ‘reproductive accounting’ (Franklin and Roberts 2006: 164; Shih, this volume). In many cultures, a male child is expected to be of long-term economic gain to his parents, while a female child is considered as a cost (see Trần, this volume; Khanna 2010). The capacity to influence the sex of one’s children can therefore play an important role in domestic economic calculations, not least in low-income societies. Similarly, across the globe, prospective parents often express concern regarding the financial burdens that the birth of a disabled child can be expected to place on their household economy (Gammeltoft 2014; Kohrman 2005). Even in affluent welfare societies, parents-to-be must weigh the assumed needs of particular potential children against the

care that they expect to be able to provide given the economic means they have at hand. Fears and anxieties regarding their own capacities to care adequately for their child often seem to push prospective parents towards the uptake of SRTs (Rapp 1999; Gammeltoft 2014; Heinsen, this volume). As we will see in the chapters that follow, these various forms of reproductive accounting shape the ways in which SRTs come to be viewed, made available and used in specific countries and settings.

Possibilities for SRT uptake are, however, unevenly distributed. While some technologies—such as 2D ultrasounds—are relatively low cost and therefore generally accessible, access to other technologies, such as PGD, requires considerable economic means. Such uneven distributions are also evident in the moral separation of sex-selective abortion (associated most often with countries of the Global South) from PGD-enabled ‘lifestyle sex selection’ which is marketed by IVF clinics in the USA (cf. Trần, this volume; Bhatia, this volume). For most people in the contemporary world, access to SRTs is not a given. Economic stratification not only shapes people’s access to technology but also determines how they are positioned in relation to it: some individuals and couples are placed in economic positions that enhance their chances of realizing their reproductive desires, while others—such as women in low-income countries who carry other people’s children in their wombs in surrogacy arrangements—live in situations of economic vulnerability that expose them to considerable reproductive health risks.

Conclusion: Ethnographies of SRTs

The cultural, social and economic rationales that underlie the spread of SRTs have raised criticism from various quarters. Pointing to the alternative ways in which societal resources could be used, disability rights activists have argued that the promotion of SRTs tends to rest on and reinforce a reduction of the value of disabled lives. In Tom Shakespeare’s words:

The drive to use genetic and obstetric techniques to remove disabled people from the population fails to consider the millions of people developing impairments as a result of accident or disease during the life-course. Resources would be better spent on creating an inclusive and barrier-free

society, and promoting the civil rights and independent living of disabled people. Society should value disabled people, alongside all human life (1998: 678–679).

In a similar vein, women's health activists have criticized the subtle or not-so-subtle ways in which pregnant women are placed under pressure to conform to unspoken health systems expectations and opt for a pregnancy termination in case a child-to-be is found to be anomalous. Marsha Saxton, for instance, writes:

Those who advocate selective abortion to alleviate the suffering of children may often raise that cornerstone of contemporary political rhetoric, *cost benefit*. Of course, cost-benefit analysis is not woman-centered, yet women can be directly pressured or subtly intimidated by both arguments. It may be difficult for some to resist the argument that it is their duty to “save scarce health care dollars,” by eliminating expensive disabled children. But those who resist these arguments believe the value of a child's life cannot be measured in dollars (1998: 383; see also Lippman 1999).

Criticism has also been raised of the commercialization and manipulation of human childbearing that SRTs allow for. The concept of ‘designer baby’ captures ethical anxieties regarding what kind of society we are moving towards if increasing numbers of prospective parents are enabled to select for specific traits in their children, ‘buying’ the kinds of babies that they want. To date, however, such a brave new world of perfectly designed offspring still seems far away, as the contingencies involved in human childbearing appear to continue to surpass our capacities for technological manipulation (Franklin and Roberts 2006).

Against the backdrop of these important social and ethical debates, the task that we have set ourselves in this volume is empirical: What techniques have been developed to facilitate selective reproduction in recent decades? How are SRTs being rolled out and made available within different regulatory frameworks? How do people living in different cultural settings perceive, respond to and make use of the new possibilities for selective reproduction that they are offered? Addressing the social and ethical questions that selective reproduction raises requires, we believe, concrete and critical insights into the ways in which new technologies for selective reproduction operate on the ground as people weave these

technologies into family lives, clinical worlds and political imaginaries. Through ethnographic studies conducted across the world, this volume seeks to provide such insights, thereby offering new and research-based contributions to the ethical and political debates that selective reproduction will continue to generate in years to come.

Notes

1. It should be noted that developments in critical care of premature babies have in recent years raised numerous ethical questions around how decisions should be made about which (if any) premature babies doctors and parents should 'let die', not least because of concerns about the future health-related quality of life of the child if the baby is kept alive (Nuffield Council 2006; Svendsen 2014; see also Heinsen, this volume).
2. As Strathern has highlighted, there has been concern about the selective potentials of reproductive technologies from the very beginning as she showed how the authors of the Glover Report on Reproductive Technologies to the European Commission from 1989 suggested that in the future 'gene therapy and embryo research... will enable us to influence the kinds of people who are born' (Strathern 1992: 31).

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Part I

Sex Selection

2

Coping with Sex-Selective Abortions in Vietnam: An Ethnographic Study of Selective Reproduction as Emotional Experience

Trần Minh Hằng

The nurse gave Hiền¹ two tablets and asked her to take them immediately. Looking anxious, Hiền left the surgical room. Reeling, she sat down on the long bench at the corner of the corridor. Her sister gave her a cup of water. Hiền held the cup and prepared to put the tablets in her mouth, but she stopped suddenly and cried bitterly. After a while, she said that she wanted to check the sex of her foetus again. Although she had had six ultrasound scans, she still wanted to check one more time before taking the tablets.

Accompanied by her sister and me, Hiền went to a private clinic near the gate of the hospital to have a three-dimensional ultrasound scan. It was very easy to have ultrasound in a private clinic. Hiền and I went to the ultrasound room while her sister was waiting outside. The ultrasound room was gloomy and damp. In it, a sonographer was scanning a woman. We sat on a long bench next to the door to wait for Hiền's turn. On the wall, there was a large frame with many pictures of foetuses in a variety of gestations and postures. Some of the pictures focused on the genital

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organs of the foetus. These pictures seemed to be on display in order to prove the qualifications of the sonographers in the clinic. Hiền looked at a picture of a foetus at 14 weeks gestation. In a trembling voice, she said, "My foetus is the same age as that foetus over there. So it has a human form. I feel I am doing wrong towards my child." Hiền got the same ultrasound result as her previous ones. She called her husband by cell phone to tell him about the result and asked him again about the final decision on this abortion. Then she decided to go ahead with the abortion.

Hiền's face turned pale when the nurse in the surgical room called her name. She climbed tremblingly to the abortion bed with a mixture of fear and torment in her eyes. She put her legs in the stirrups, crossed her fingers and put her hands on her belly. In contrast to the noise in the corridors and waiting rooms outside, the atmosphere in the surgical room was quiet and filled with tension. I heard the clinking of surgical tools as the nurse prepared them for the abortion. Hiền looked around nervously then turned her eyes to the ceiling. The nurse gave her a pain medication injection without saying anything. Hiền winced and breathed in to calm down. With skilful movements, the doctor inserted a speculum into her vagina, cleaned the vagina and cervix with an antiseptic solution and grasped the cervix with an instrument to hold the uterus in place. The doctor inserted forceps into the uterus and grasped a piece of the foetus's body, which he removed. It was streaming with blood. Hiền curved her body in pain, but she tried to constrain her groan and her eyes were full of tears. When the doctor finished the procedure, Hiền was transferred to the post-abortion room which was crowded with women.

After Hiền's abortion, I visited her several times at home. She did not talk about her abortions much; rather, she seemed to try to keep silent and bear the pain on her own. The memories of this abortion were haunting her, she said, and they affected the couple's relation. "After the abortion, I have had a disinterest in sex. I pulled away from my husband. Whenever I had sex, I thought of my abortion. I feared becoming pregnant and having another abortion. We went three months without having sexual intercourse." Hiền sometimes went to the pagoda to pray for

her foetus and her family. The praying helped her recover sooner, she said, but the memories still remained.

This is the story of Hiên's abortion which she obtained in the summer of 2009. Her story provides insights into the many ways that sex-selective abortions can be painful for the women who undergo them. Besides the physical pain she experienced, Hiên also struggled with moral, social and spiritual suffering. Anxiety, guilt, distress and sorrow mingled with each other, blending into her physical pain.

While undertaking research in a hospital in Hanoi between January 2009 and February 2010, I had the opportunity to meet 35 women who were in the process of having a sex-selective abortion. The women accepted the invitation to take part in my research, and through our conversations and interactions I was able to explore their experiences in depth and gain insights into the circumstances, dilemmas and decision-making processes that led them to seek a sex-selective abortion. I came to understand the difficult emotional experiences that they went through, before, during and after the abortion (for details on research methodology, see Tran 2011).

Sex-Selective Abortion: Women's Emotional Reactions

Women's experiences of abortions are situationally specific. The relationship of abortion experiences to social, cultural and political conditions has been addressed in several studies (Andrews and Boyle 2003; McIntyre et al. 2001; Whittaker 2002). David (1992) finds that the incidence of abortion-related mental problems is negligible in the countries where abortion is legal and accessible for women. Boyle and McEnvoy (1998) conclude that women's perceptions of abortion and their ways of coping with stigma and guilt are affected by the anti-abortion climate around them. Peterman (1996), in a qualitative narrative analysis, demonstrates that women's abortion experiences are affected by social support systems, religious beliefs, desires for motherhood, opportunities and financial situations. Whittaker (2004) also argues that the religious and institutional pro-

scriptions against abortion in Thailand and the clash between biomedical and folk religious worldviews combine to make the experience of abortions in that country particularly traumatic and stigmatising.

Second- and third-trimester abortions are potentially more painful to women than earlier abortions. From a medical point of view, early abortions are generally agreed to be preferable to later abortions, for as the weeks go by abortion becomes riskier for the woman. Hadley (1996) argues that late abortions require more heart-searching than those performed early in pregnancy. A number of studies have investigated women's emotions after abortions performed in the second or third trimester (Rapp 1999; Gross 1999; Mitchell 2001; Gammeltoft 2002; Gammeltoft et al. 2008). These studies found that women and their partners usually had several emotional reactions after such abortions. They may have negative feelings, such as anxiety, grief, anger, loneliness, hopelessness and guilt. Looking at Vietnamese women's experiences after second-trimester abortion for foetal anomaly, Gammeltoft and colleagues observed that women usually felt very sad, cried a lot and kept thinking of the child they had lost. They had doubts about their way of life, their reproductive capacities, their worth as wives and mothers, and their present and future position in their kin group (Gammeltoft et al. 2008).

The existing research provides valuable insights into the moral dilemmas, psychological conflicts and social tensions experienced by women who undergo abortions. It also addresses the effects of prevailing ideological, institutional and cultural structures on women's abortion experiences. As yet, however, women's feelings after sex-selective abortions and the ways they cope with these experiences remain largely unknown territory. In this chapter, I focus on Vietnamese women's emotional experiences with sex-selective abortions. In Vietnam, what political, moral, cultural and religious frameworks shape the field in which sex-selective abortions take place? What moral dilemmas and emotional conflicts do women experience? To what extent do they experience shame, stigma, loneliness and other forms of social suffering? How do women cope with these tensions and what forms of support are available to them?

The Context of Sex Selection in Vietnam

The skewing of sex ratio at birth occurred later in Vietnam than in other Asian countries such as the Republic of Korea, India and China. Within a short period of time, however, the sex ratio at birth rose from an estimated 106 male births per 100 female births in the year 2000 to 110.5 in 2009 and 112.6 in 2013 (UNFPA 2014). Demographers and health researchers suggest that this imbalanced sex ratio at birth—an indicator of sex selection—is the result of numerous factors, including a small family size norm, recent reinforcement of the ‘one-to-two child’ family policy, son preference and easy access to antenatal ultrasound screening and abortion policies (Bélanger 2002; Guilmoto 2007; Guilmoto et al. 2009; Pham et al. 2008; UNFPA 2011). To date, very little is known about the circumstances and experiences of those who are engaged in these practices; the women who undergo sex-selective abortions, their husbands and other relatives, and their health care providers.

In 1988, the Vietnamese government launched a one-or-two child policy, aiming to limit family size through provision of family planning services including abortions. This policy placed childbearing couples under contradictory pressures: on the one hand, local authorities demanded that they keep within the two-child limit; on the other, relatives and peers expected them to have at least one son (Johansson et al. 1998). In contemporary Vietnam, son preference remains central to the reproductive desires and strategies of a substantial proportion of couples and families. A recent United Nations Population Fund (UNFPA) report suggested that the strong son preference found in Vietnam is rooted in a largely patrilineal and patrilocal kinship system that tends to place normative pressure on people to produce at least one son. The report also observed that family and community pressures play important roles in maintaining male dominance in general and son preference in particular. People prefer sons to daughters not only because of the ‘intrinsic’ value of male children but also because having a son improves a woman’s status in the family and confirms a man’s reputation in the community (UNFPA 2011). Through sex-selective abortions, then, people try to maintain moral status, while also securing old-age support and lineage continuity.

Abortion has been legal in Vietnam since 1954 and is currently legal until 22 weeks of pregnancy. According to the Ministry of Health's Health Statistic Yearbook, in 2013, the abortion rate was 17.45 per 100 live births (Ministry of Health 2014). These figures do not include private-sector abortions. Estimates suggest that abortions provided in the private health sector are equal in number to abortions performed in public hospitals (Hoang et al. 2008). Before 2002, only the Kovac's method—the use of a condom-covered catheter with saline solution introduced into the cavity of the uterus—was used to perform second-trimester abortions. In 2002, the Ministry of Health introduced new standards for second-trimester abortion in its National Guidelines for Reproductive Health Services (MOH 2002). New methods including Dilatation and Evacuation (D&E) and medical abortion (using mifepristone and misoprostol) were allowed at the provincial and national hospital levels. At present, abortion services are provided at three administrative levels of the health system: (1) abortions at 6–22 weeks gestation are provided at central and provincial hospitals; (2) abortions at 6–12 weeks gestation are provided at district health stations; and (3) abortions up to 6 weeks gestation are provided at communal health centres. Private clinics are allowed to perform abortions of up to six weeks gestation if they meet required criteria set out by the Provincial Health Services. The cost of abortion services varies by gestation period, abortion method and service site. In 2009, a manual vacuum aspiration case cost approximately 4–7 US dollars, while a dilatation and evacuation case cost 80–100 US dollars at public hospitals. The cost of abortion services in the private sector varied depending on gestational age and the specific clinic, ranging from 18 to 100 US dollars.

Ultrasound is one of the most common new reproductive technologies in Vietnam. Research indicates that the skewed sex ratio at birth arose at the same time as ultrasounds became widely available in Vietnam (Guilmoto 2007; UNFPA 2009). This technology was first introduced in Vietnam in the late 1980s and has become widespread in provincial hospitals since the mid-1990s. At present, use of ultrasound scanning in obstetrics and gynaecology is booming in Vietnam. Most district health centres, provincial and central-level hospitals currently have ultrasound machines. In urban areas, ultrasound machines are routinely used in

private clinics. The price for a two-dimensional ultrasound scan is 3–5 US dollars compared to a three-dimensional ultrasound scan which costs 8–10 US dollars. These prices are reasonable for most urban women, although they are prohibitive for the rural poor. In January 2003, the Standing Committee of the National Assembly passed a Population Ordinance forbidding sex-selective abortion. In 2006, the Ministry of Health issued the Decision number 3698/2006 forbidding foetal sex determination. In other words, sex determination and sex-selective abortion have been illegal in Vietnam for more than a decade.

When exploring the experiences of women involved in sex-selective abortions, I found it helpful to distinguish between different stages: abortion decision-making, the abortion procedure, and post-abortion consequences and care. In the remaining sections, I follow these stages, describing and analysing how women experienced and coped with their sex-selective abortions.

Deciding for a Sex-Selective Abortion: Emotional Ambivalence

Many people in Vietnam consider termination of pregnancy as a sin (*phâi tội*). Often, people distinguish morally between early and late abortions. Several of the women in this study who had sex-selective abortions told me that abortion early in the second trimester of pregnancy was acceptable. They would not have an abortion late in the second trimester of pregnancy because by then they felt that the foetus was too big and had the completed shape of a baby. Sex-selective abortion is, they said, considered more immoral than termination of unplanned pregnancies making the decision all the more difficult. Still, the women in this study decided to obtain a sex-selective abortion. Despite the fact that this kind of abortion is illegal and morally problematic, the women felt that it was necessary for them to terminate their pregnancies, in the hope that their next pregnancy might end in the birth of a son. The abortion decision was not an easy one for the women to make. Most couples discussed at length what to do, and in some cases the woman felt pressured by her husband to obtain the abortion. Huyen, for instance, said, “Indeed, I did not want

to have this abortion. I felt it is immoral. If my husband had not insisted, I would not have done this” (36 years old, cadre, 2 daughters). In other cases, it was the wife who insisted on the abortion. Thuong and Na, for instance, told me that they were afraid of losing face due to having many daughters. As Na said, “If I have another daughter, people will laugh at me instead of having compassion” (49 years old, worker, 2 daughters).

The women who underwent abortions for foetal sex told me that this process threw them into deep emotional turmoil (see also Gammeltoft 2002). The women’s pain seemed to have several dimensions—it involved the agony of ending the life of their own child-to-be; the loss of a months-long pregnancy; and the pain of separating mother and child-to-be. Since sex-selective abortion is not only illegal but also considered morally dubious by many people in Vietnam, the women strove to keep the abortion decision to themselves talking only to their husbands—and perhaps to a few other trusted individuals—about it. They had to cope with the anxiety, fear and grief that accompanied the abortion and the moral pain of shame and guilt without professional psychological support. In these circumstances, ritual activity seemed to serve as one means to cope with the feelings that they struggled with. Before undergoing the abortion, most women sought help and compassion from spiritual beings and powers. They burnt incense to pray for the abortion to proceed in a safe manner, thinking to themselves: “Có thờ có thiêng, có kiêng có lành” (Worshipping provides sanctity, abstaining provides goodness).

Many women undergoing sex-selective abortions observed ritual practices in order to seek forgiveness and find moral support and understanding. In this way, they found strength and consolation to endure the passage through an emotionally and morally difficult experience. Explaining women’s resort to ritual in the context of abortion, Tine M. Gammeltoft writes: “Ritual practice produces a social sphere where the personal suffering generated by the abortion can be expressed and recognised, and where youths can seek moral forgiveness and understanding for the actions they have had to undertake” (Gammeltoft 2003: 139). Existing studies of moral perceptions of abortion in Vietnam point out that there are widely varying attitudes to the ethics of abortion and that attitudes vary between different generations (Johansson et al. 1996; Gammeltoft 1999, 2002). For example, in a study on the side-effects of

the intra-uterine device among married rural women in Ha Tay province, Gammeltoft found that elders considered abortion at any stage of gestation a sin, while younger people found early pregnancy terminations morally acceptable (Gammeltoft 2016). Similar perceptions emerged in this study. For instance, the mother-in-law of one of the women said:

In the past, we did not dare to have abortions. When we got pregnant, we had the child. Throwing it away is a sin (*bỏ nó đi thì phải tội*). If we do an immoral thing, it [the foetus] might condemn our family. Young people now have a more relaxed attitude to abortion. Abortions are popular now. But it is still a big sin if abortions are conducted when foetuses have a human form. (Trang's mother-in-law, 68 years old)

Although younger people thought that early abortions are morally acceptable, they felt very uneasy about abortions performed later in pregnancy. Not only women but also men found that abortions that are obtained after the foetus has attained a human form are highly morally problematic.

If it is in an early stage of pregnancy and the foetus has no human form yet, having an abortion is simple. But I thought a lot when we had to decide to have an abortion when its body had been formed. Perhaps it would be injected with a toxic drug or cut into several parts before being expelled from the womb. I felt guilty when thinking that we killed our baby. (Hue's husband, 48 years old)

Doctors in this public hospital do not want to perform second-trimester abortions because, like many of their patients, they feel that such abortions are morally problematic. Lan, a 47-year-old doctor specialising in abortion provision described the abortion process as follows: "To conduct a second trimester abortion, the foetus is dismembered, crushed, destroyed, and torn apart." She considered this job as murder and as a brutal action. She said that in her opinion, sex-selective abortion is different from termination of unplanned pregnancies because this kind of abortion aims intentionally to eliminate a child who does not live up to its parents' expectations. Therefore, doctors do not want to do this job but they have to do it if the woman requests it. To cope with the negative

feelings that abortion provision generated in her, Dr. Lan strove to find psychological balance by turning to ritual practice. She said:

Actually, I always think about moral issues when I conduct this job, but I try to stay in balance between ‘practical matters’ (*duy vật*) and ‘spiritual matters’ (*duy tâm*) in order to avoid mental suffering. I do not want to do this job forever. After I have to perform a late-term abortion, I go to the pagoda to pray in order to balance my psychology. Most women have abortions following unplanned pregnancies, and I think it is normal. What happens if women have to give birth if their pregnancy is unplanned, and they are unintended? Who will help them to deal with this matter? However, it is different when they have the pregnancy intentionally, and have the abortion only because the little one is a girl. Killing a girl to have a boy, this is a brutal action.

Like this doctor, other doctors also found it morally and emotionally difficult to conduct second-trimester abortions. Similarly, the nurses I talked to often also said that they did not want to assist doctors in performing second-trimester abortion procedures. They were concerned about the moral and spiritual issues involved. Mai, a 35-year-old nurse, confided:

I do not want to do this job, but I have to do so. I always feel a chill when I have to perform a second trimester abortion. I feel great pity for these unfortunate babies. Their bodies are formed, but they are eliminated. Sometimes, I cannot sleep thinking about the babies’ images. I burn incense and pray for the little souls on the first and the fifteenth of the lunar month to relieve my anxiety or I go to the pagoda to restore my peace of mind.

Undergoing the Abortion: Physical and Emotional Suffering

This section explores the anxieties and psychological issues that women described in connection with the abortions they underwent. The case of Hiên whose story opened this chapter shows us her physical and emotional suffering during the abortion process. Although the abortion clients and

abortion providers uttered scarcely a word through this transaction, their facial and bodily expressions raise many questions. Why did Hiền seem fearful and nervous? What was the meaning of her tears? Did she cry only in pain or did she also feel anguish for her foetus?

Before going to the surgical room, abortion regulations stipulated that women should attend a counselling session. My observations showed, however, that little or no communication between health staff and clients took place before and during the abortion procedure or in the recovery room. This, the women told me, was not just a question of the providers being too busy but also a result of their attitude to their clients.

Providers should ask about our situation and give us counselling. I was still indecisive and in doubt, but I was just urged to hurry up. The clinics are crowded with patients and staff have a heavy workload, but sometimes they act in a very authoritarian manner. (Hà, 39 years old, 15 weeks pregnant)

While empathic counselling is generally recommended, women in this study felt that they were judged by staff or that they were rarely offered the opportunity to share their feelings and discuss their difficult situation. Although the women faced a multitude of anxieties and psychological issues and, in some cases, had repeat sex-selective abortions, they rarely received any counselling. Similar limitations in terms of counselling in abortion care in Vietnam were found in recent qualitative studies (Trần 2005; Gammeltoft et al. 2007).

Prior to abortion, a cervical preparation procedure is performed. This usually takes place three or four hours before the abortion itself. Prostaglandins may be taken orally or inserted into the woman's vagina. At that time, women have to stay in the waiting room, where tension is palpable and the air seems to be filled with anxiety. I often sat and talked with women during their waiting time; this, I soon realised, was the most stressful time for them. One woman cried before going to operating room, saying, "Mommy doesn't want to do this, but I have no choice. Please forgive me." Some women asked themselves, "Am I doing the right thing?" Clearly, at this late stage, the women were still ambivalent about their abortions.

Also the husbands and other relatives who accompanied women seeking a sex-selective abortion seemed to find themselves in deep emotional turmoil. Men often seemed to experience their own personal crisis when their wives underwent abortion. Tuấn's case is an example:

As he sat outside the operating room, Tuấn looked exhausted. Behind the door, his wife was in pain. He told me that he could not sleep and that he had a terrible headache. This headache, he said, was caused by his struggles with his conscience. He did not want his wife to have this abortion. He felt sorry for his baby and he was worried for his wife's health. The couple had two daughters and he was eager to have a son "I want to have a boy because I think about my family line," he said.

After the Abortion: Silence, Suffering and Spiritual Relief

When I visited women after their pregnancy terminations, one of my most striking observations was that they tried to keep their abortion a secret. This raises questions about why women are silent about the matter, what the reality of abortion is in their lives and what they really think about this kind of abortion. Many women strove to bear the pain on their own: "I didn't tell anyone else, even my family or my friends, about my abortion because I was scared that they would look down on me for it. It [abortion] is perceived to be such a bad thing" (Phi, two months after her abortion). Similarly, Trybulski's study (2005) of 17 women's long-term post-abortion experiences showed that women concealed their abortions because of shame or fear of adverse reactions from family and friends. The secrecy in abortion, Trybulski found, led to an increase in intrusive thoughts.

The women in this study experienced a variety of post-abortion problems, with different emotional strands. Although each woman's experience was different, most expressed mixed feelings of guilt, distress, sorrow and relief. In Huyen's words: "I committed a serious sin. I terminated the life of my child-to-be. I felt ashamed when I taught my students about moral issues" (36 years old, teacher, 2 months after her abortion). Some

women felt that abortion is wrong and that they killed their babies. These thoughts seemed to severely impact their psychological health. Three days after her abortion, Thuan told me: "I feel guilty about my abortion. I regret that I did that. I feel pity for my child-to-be..., it was my blood. It had a human form and was healthy. It seems I killed my child" (34 years old, 14 weeks pregnant).

The women's feelings of sadness and doubt often seemed to affect their close relationships. Women who were highly ambivalent or confused about their abortion decision and had great difficulty making the decision often felt tense in their relationship with their husband and/or family-in-law. Loan (33 years old, cadre, 3 days after her abortion) said:

I had this abortion mainly because of my parents-in-law. My parents said if they [her parents-in-law] pressure me I should have an abortion. I felt that they did not feel compassionate towards me. All they needed was a male heir.

Having trouble sleeping was also a common experience among women who had sex-selective abortions. Sleep problems, including nightmares, often involved the return of the aborted foetus or something that had happened during their abortions.

In my dream, I saw a nurse strapping my legs into the stirrups. Then a doctor used some big forceps to pull out my baby. It was covered with blood. There was a lot of pain. Then the nurse wrapped the baby and took it away. I cried out and my husband came to untie me. We searched everywhere but could not find my baby. Then I heard crying coming from a bin, and I saw my baby. But when I held it in my arms, it disappeared.

Hue described her nightmare with eyes full of tears (43 years old, 5 days after her abortion). Huyen told me about her nightmares in these words: "I often saw a newborn baby in my nightmare. She was black and blue all over. She was naked and ants swarmed over her. I took her to a river to wash her, but I lost my grip and she sank and I could not find her" (36 years old, 7 days after her abortion). "The house was burning and I heard my daughter crying. I ran around looking for her. I could see and hear her but she was being consumed by the flames and I could not reach her," Lua (28 years old, 2 week after her abortion) recounted. I could

empathise with these women, as I experienced trouble sleeping or had vivid nightmares during my field research. I often saw the operating room and abortion procedures in my dreams. I most vividly recall the nightmare I had after observing the first abortion procedure. In this nightmare, I was helping a nurse to put a foetus in a fridge. After a while, I opened the fridge and saw the bloodied foetus stand up and cry. Some health staff also confided in me about their fears when they first began to work with abortion patients. On night duty at the hospital, they saw foetuses or heard stamping noises in their dreams, but this stopped when they woke up.

Despite the fact that women had to face emotional difficulties, most women found ways to cope with these negative feelings. As Goodwin and Ogden (2007) suggest, women who have abortions do not experience distress alone but also have emotions such as relief and a sense of return to normality. Although women experienced the negative effects of abortion, some of them felt that abortion was the best way to go under the circumstances: “This prevents suffering for the child-to-be and for me” (*đỡ khổ nó, đỡ khổ mình*). Thus, a sex-selective abortion is painful, but on another level it resolves problems associated with going ahead with the pregnancy. Given their circumstances, most women felt, an abortion was the best solution. This gave them the chance of having a son (in the future), while still living up to the state-promoted normative ideal of a two-child family. The women told me that abortion is “the best thing” rather than “the right thing.” As one woman comforted herself—“I feel pity for my child-to-be, but I think that abortion is the best thing in my situation” (Lua, 28 years old, 2 months after her abortion)—this way of thinking seemed to help them to control their negative feelings. Some studies have emphasised women’s experience of relief as a positive outcome over and above the negative outcomes in connection with abortion (Adler et al. 1990; Armsworth 1991). Feeling relief is a way of recovery. Women in this study also felt relief when having a safe abortion after a hard decision. “It was hard to decide to have an abortion. At the beginning I felt guilty, but then I thought that was good for me and the child-to-be,” Na said (49 years old, 1 week after her abortion).

One of the fundamental Buddhist beliefs is that by having an abortion, one kills a human life. As I described above, women often felt helpless and remorseful after abortion. Foetal rituals helped them to relieve a general

sense of guilt. Many women performed a foetal ritual to cope with their sense of guilt. While reproductive clinics are not concerned with psychological healing, the foetal ritual has an important role in the psychological healing process. It provides comfort to women who have had an abortion and allows women to express their grief for their aborted child.

Conclusions

This chapter has described the range of complex emotions that women experience during their journey through abortion. The women in this study had a great number of conflicting feelings before, during and after the abortion, going through feelings of guilt, distress, sorrow and relief. Sex-selective abortion was immensely painful for the women and for other people involved. Emotional attachment to the pregnancy, lack of social support and moral condemnation of abortion seemed to deepen such negative feelings. As Petchesky observes, “Women make their own reproductive choices, but they do not make them under conditions which they themselves create but under social conditions and constraints which they, as mere individuals, are powerless to change” (1980: 675). In a context of illegality, institutional channels through which abortion-seeking women might air their feelings were lacking, and public forums did not provide a safe environment in which women could express their complex emotions and thoughts without fear. Keeping their abortions secret, the women often received little support from their family, their community and health care system. In this situation of limited social support, ritual was often the preferred way of attaining some degree of psychological healing.

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Notes

1. Like all other personal names in this article, “Hiền” is a pseudonym.

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3

The Development of Sex-Selective Reproductive Technologies Within Fertility, Inc. and the Anticipation of Lifestyle Sex Selection

Rajani Bhatia

During the mid-1990s, declarations from the International Conference on Population and Development and the World Conference on Women defined prenatal sex selection as an “act of violence against women,” “a form of discrimination against the girl child,” and “unethical” (UNFPA 1995; UN Women 1996). The documents called upon nation states to prevent and eliminate prenatal sex selection. Ironically, at the very same moment in the Western Hemisphere, the Institutional Review Board (IRB) of the Genetics and IVF (GIVF) Institute in the USA approved the use of MicroSort, a preconception method of sex selection under trial for “family balancing.” The company introduced this new term to mean a practice by which married, heterosexual couples try to increase the probability of having an additional child of a sex less represented among their current children. In other words, just as the international community came together to condemn one form of sex selection (prenatal via abortion), a fertility clinic in the USA created

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an ethical opening for sex selection by other means (prepregnancy via reproductive technology).

In this chapter, I focus on the development of sex-selective reproductive technologies within Fertility, Inc.¹ and how the two technologies, preimplantation genetic diagnosis (PGD) and MicroSort, became acceptable in the fulfillment of a lifestyle desire for specifically sexed children. Scientists and clinicians particularly from the USA and UK played a very significant role in the science and practice of lifestyle sex selection. In conversation with one another, they articulated a justification to develop these techniques for application in Western medicine, first for therapeutic and then for lifestyle purposes. PGD is a broader diagnostic technology that can screen embryos for a number of chromosomal and genetic conditions, only a few of which may be sex linked (such as Duchenne's muscular dystrophy and hemophilia). Sex-selective PGD involves testing embryos produced through in vitro fertilization (IVF) for the characteristic of sex and then preselecting embryos for implantation based on sex preference. MicroSort involves sorting sperm based on the chromosomes determinative of sex and using the sorted samples either with IVF or intrauterine insemination (IUI). Since both PGD and MicroSort are applied before pregnancy in conjunction with assisted reproductive technology (ART), they could circumvent the politically contentious abortion issue in both the US and UK social contexts.

As *biomedicalized* interventions, MicroSort and PGD for sex selection fulfill a need based on a lifestyle desire, to transform parental and family identity and constitution. As opposed to what has been termed "gender-biased sex selection," *lifestyle sex selection* denotes a practice of imagining one's future self and family contingent upon the sex of future offspring and trying to realize that dream using technoscientific means. Constituted as benign and devoid of gender discrimination in a hierarchy of global sex selection practices, the practice runs parallel to other processes of biomedicalization that have since 1985 expanded medical jurisdiction to lifestyle wishes. American popular culture figures, top model Chrissy Teigen and musician John Legend, made headlines in 2016 for their use of PGD to select a girl. In an interview with *People Magazine*, Teigen expresses this desire: "I think I was most excited and allured by

the fact that John would be the best father to a little girl. That excited me,” she said. “It excited me to see ... just the thought of seeing him with a little girl. I think he deserves a little girl. I think he deserves that bond” (Kast 2016). Teigen imagines Legend in a paternal role that is not only “best” or most effective “with a little girl” but also most happy. She describes him as entitled to experiencing “that bond.” Indeed, among issues concerning life itself, the moral imperative to be healthy includes an imperative to be happy.

This is a story of not only how the technologies developed but also how they became acceptable for lifestyle sex selection. I argue that the “techno-social shaping” (Clarke et al. 2010: ix) of lifestyle sex selection took place through active disassociation by scientists with practices of sex selection that never biomedicalized, such as those involving abortion, “low” tech, or “unscientific” interventions and association with “high” technologies merging in the realm of assisted reproduction such as IUI, IVF, and ICSI, technologies that can be applied en route to establishing a pregnancy. Situated within the overlapping Western worlds of high-tech reproductive medicine and clinical genetics, the tools of lifestyle sex selection get charged by the “promissory capital” and “hope and hype” of fast-paced change in biotechnology (Thompson 2005; Adams et al. 2009: 252).

The Agriculture Industry: The Seedbed of Sex-Selective Reproductive Technologies

Just as the agricultural livestock industry provided the seedbed to all ARTs, so did it spur the development of sex-selective reproductive technologies (Clarke 1998). The ability to control for sex in the production of farm animals, especially cattle, swine, and sheep, has long been recognized as having the ability to bring an economic boon to commercial agriculture (Johnson and Welch 1997: 337; Theodosiou and Johnson 2011: 459). This industry drove the development of both embryo and sperm sexing technologies during the 1970s and 1980s, which manifested later in human medicine as PGD and MicroSort. David Karabinus, formerly the

scientific director of the MicroSort clinical trial, whose background also stems from the field of animal reproduction explains:

Dr. Johnson [US Department of Agriculture (USDA) scientist, Lawrence Johnson, who developed the sperm sexing technology that is MicroSort] developed the application in livestock, because male cattle don't give milk, females do. Male cattle don't bear more young, females do. So, you don't need as many males as you do females to keep the line going to make babies. Female livestock are easier to manage. Males are more physical, bigger, and tend to be more aggressive. (Interview by the author, 2010)

In their history of the commercialization of sperm sexing technologies within the cattle industry, Seidel and Garner also underline the long-standing industry interest in sex selection. Even though laws of 50:50 probability in the absence of sperm sexing would not make it unlikely for dairy farmers to get several male cattle in a row, the authors describe how farmers in the past interpret such an occurrence as bad luck, resorting to “folkloric” (read unscientific) ways to explain them (Seidel and Garner 2008: 886–887). Thus, dairy and meat farmers have sought ways to reliably control the sex of their cattle and the long-standing economic value of females in livestock reproduction spurred the development of both PGD and MicroSort. However, of the two technologies, MicroSort (or more accurately, its precursor, the Beltsville Sperm Sexing Technology) remains the preferred method within the industry because it can be applied with artificial insemination. PGD, on the other hand, requires IVF, a relatively complicated procedure, which cannot easily be applied en masse. Optimizing sex selection for livestock reproduction must contend with industry standards that involve inseminating many cows at one time with the sperm of just one superior bull. Although PGD's design does not fit with that standard, the industry nonetheless remained interested in its development, in part because the experimental demonstration of sexing sperm took place much later (Theodosiou and Johnson 2011; personal communication with Larry Johnson, March 24, 2011).

PGD's first experimental demonstration came as early as 1968 when Robert Edwards, today recognized with a Nobel prize for advancing

infertility medicine through the development of IVF, and Richard Gardner successfully biopsied cells from 119 rabbit embryos, sexed the embryos, and then transferred them back to rabbit does, which produced 18 offspring all correctly sexed. Lawrence Johnson's first experimental demonstration of the Beltsville Sperm Sexing Technology (precursor to MicroSort), also on rabbits, occurred in 1989, 21 years later. Yet, this gap closes considerably when comparing the first clinical application in humans of the two technologies, which occurred in 1990 for PGD and 1995 for MicroSort.

Theodosiou and Johnson explain the longer period between first experimental demonstration and first clinical application of PGD by a lack of explicit motivation to develop the method in humans. Although the early experimental development history of PGD is intertwined with that of IVF, IVF moved into the human clinical realm much earlier. Those in the UK, most famously Robert Edwards and Patrick Steptoe, who were involved with the advent of IVF, never envisioned IVF technology to only address infertility. In the experimental stages of IVF, long before the birth of the first IVF baby, Louise Brown in 1978, Edwards and Richard Gardner among others simultaneously developed the technique of embryo biopsy used in PGD. As Edwards has emphasized in retrospective accounts of his work, PGD was conceptualized along with the possibility of fertilizing eggs outside of the womb (Franklin and Roberts 2006: 42–43). Edwards applied for research funds to develop PGD in 1971, seven years before IVF was even successfully shown in humans. In the grant application, Edwards proposed that a first potential application of PGD in humans could control “sex-linked mutant genes in man” (cited in Theodosiou and Johnson 2011: 461). Yet, the UK Medical Research Council rejected the proposal, and it was not until 15 years later that UK scientists formed PROGRESS, a lobby to advocate for the realization of PGD successfully drumming up public support. Thus, PGD development during the 1970s through the mid-1980s remained relegated to the animal agricultural sector.

PGD was demonstrated for sexing of sheep in 1975 and cattle in 1976. The timing of biopsy (stage of embryo development when cells are removed) and mode of analysis used to identify sex varied in these studies, none of which pointed to a potential application in humans

(Theodosiou and Johnson 2011: 460). Similarly, the research that led to the development of MicroSort became technologically viable under the helm of the US Department of Agriculture, though the method was first conceptualized in a weapons laboratory through research funded by the US Department of Energy.

Scientists working at the Lawrence Livermore National Laboratory, a weapons lab in California, and the Max Planck Institute for Biochemistry in München among other institutions first theorized the potential of sperm sexing via flow cytometry (Van Dilla et al. 1977). Supported by the US Energy Research and Development Administration, a central aim of the research was to study the effects of radiation on human reproduction (Van Dilla et al. 1977; Seidel and Garner 2008; Pinkel et al. 1982). However, distinguishing between X- and Y-chromosome-bearing sperm appears to have been a secondary goal and by-product of their work. Scientists during the 1970s anticipated, but were not yet able to distinguish between the relative DNA content difference between X- and Y-chromosome-bearing sperm, and they certainly did not articulate a medical purpose to sexing human sperm, which only first appeared in the literature in the early 1990s.

In 1977, a team of German and American scientists published an article that described some specific problems in trying to measure sperm DNA content. By the early 1980s, the Livermore scientists detected relative DNA content differences between X and Y sperm populations based on fluorescence intensity after applying a DNA-binding fluorescing dye to tailless sperm. In 1982, they published their success in using flow cytometry to distinguish between X and Y sperm from bulls, rams, rabbits, and boars (Pinkel et al. 1982). Yet, these experiments did not yield live sorted sperm viable for reproduction as the tails of the sperm had to be removed in order to get them to smoothly pass through the cytometer. Furthermore, the research on sexing sperm may have ended altogether had it not been subsequently taken up and funded by the USDA prompted by a research proposal submitted by one of the Livermore scientists to the USDA while on sabbatical (Seidel and Garner 2008). The Department of Energy, would likely not have sustained ongoing research on sperm sorting for sexing purposes. Lawrence Johnson, lead scientist who helped move the endeavor forward in the 1980s, recalls:

So, I and Pinkel from Lawrence Livermore, which was a weapons laboratory, well, it still is, they had done some work with DNA and sperm, and they had demonstrated that if you stain the tailless sperm, the nuclei, what we call the heads, or whatever you want to call them, that you could demonstrate a DNA difference. And, so, but they had to get out of the business. They're Department of Energy, and they were looking initially at the effect of nuclear weapons on human sperm. So, that was the focus of their research when they got into the animals. (Interview by the author, 2010)

While the Livermore lab had the advantage of being able to tinker and improve various aspects of instrumentation (the USDA did not initially own a flow cytometer), the USDA had a clearer vested interest in pursuing research on sexing sperm.

Several major technological developments in the 1980s shaped the practice. Flow cytometry was demonstrably used not only to distinguish X- and Y-chromosome-bearing sperm in a number of different non-human mammal species but also to separate X from Y sperm populations. The instrumentation of flow cytometry was successfully perfected for use on sperm (Pinkel et al. 1982; Johnson and Pinkel 1986). A staining process that could allow sperm to go through the sorting process intact and remain viable for reproduction was found (Johnson et al. 1987), and flow cytometrically sorted sperm populations were combined with assisted reproductive methods to produce sexed offspring of non-human animals. The method was named the Beltsville Sperm Sexing Technology (Johnson et al. 1989).

Among the many technical obstacles was the standard cylindrical-shaped needle at the flow opening of the cytometer better suited to the round shape of blood cells, rather than the flat-shaped heads of mammalian sperm. Scientists at first tried to imitate that shape by removing the sperm tails, which meant the sperm had no prospect for remaining viable for reproduction. In 1986, Lawrence Johnson of the USDA and David Pinkel from the Livermore Lab described two major mechanical adjustments to standard flow cytometers, whose design had to be adapted for use with sperm cells. These changes were ultimately incorporated into commercially available flow cytometers intended for use with sperm (Johnson and Welch 1997: 345).

Alongside tinkering with mechanical elements related to the cytometer design, scientists sought ways to use intact sperm (sperm with their tails) and to change staining protocols because the dyes used in the early 1980s also compromised the viability of the sperm. As Lawrence Johnson recalls:

So, I said to Mary actually. Mary Look. She was working for me at that time. This was about 1986. I said we need to just try it with in-tact sperm. I got ahead of myself. The stain we were using in the heads was detrimental to living sperm. So, I found another stain, and that's the Hoechst 33342 that's still used. It's the only one that works. (Interview by the author, 2010)

Once Dr. Johnson's team succeeded in separating X- from Y-bearing viable sperm, they surgically inseminated that sperm in litter-bearing animals such as rabbits and pigs that rapidly produce a large number of offspring. The resulting proportions of sexed baby animals, they argued, could thereby prove that the method worked. In 1989, Dr. Johnson and two of his colleagues, put forth the results of a rabbit study in a paper headlined, "Exceptional Paper—Rapid Publication." This paper reported that rabbit does inseminated with X-bearing sperm samples had a litter that was 94% female, and those inseminated with Y-bearing sperm had a litter that was 81% male (Johnson et al. 1989).

The paper "made waves" Johnson recalls. "It was a scientific breakthrough of considerable proportion because it had never been done before" (Interview by the author, 2010). As a postdoctoral student at South Dakota State University, working in a flow cytometry lab, David Karabinus, who later became the scientific director of MicroSort, remembers his advisor first bringing Johnson's rabbit study to his attention, "To me that represented the epitome of science. It was a well thought out, well based study, and the results were good, credible results. I just thought it was, as I told my postdoc advisor, I thought it was a landmark paper" (Interview by the author, 2010). The paper also caught the attention of scientists working in human genetics, especially Edward Fugger at GIVE, who also had a background in animal reproduction. Fugger took the initiative to approach Johnson along with his colleagues Joseph

Schulman and Andrew Dorfman about the prospects of applying the method in humans. Reaction to the paper thus unleashed the kernels of a new collaboration between the USDA and GIVE, which would lead to the transfer of the method to human medicine. Scientific collaboration of concern in the history of MicroSort shifted from Livermore and the USDA to the USDA and GIVE. The purpose of the research shifted along with these institutional changes. By the end of the 1980s both PGD and MicroSort's antecedent in agriculture had been successfully shown to sex non-human mammals, and both technologies were poised to enter human medicine.

“A powerful approach to disease prevention”: The Transfer to Human Medicine

The drive to develop PGD among scientists in the UK arose in part as a means of demonstrating the medical importance of embryo research beyond the treatment of infertility. Within the situated context of mid-1980s Britain, proposed anti-abortion legislation began to widen its ambit from debates about shortening the timing of legal abortion during pregnancy to banning embryo research and IVF practice. Alarmed by what was at stake, UK scientists and clinicians organized to defend a publicly made case to support the clinical practice of IVF as well as the development of IVF-dependent technologies, including PGD. They recommended that research should be supported and proceed within the bounds of a responsible governing authority (what became Britain's highly acclaimed Human Fertilisation and Embryology Authority—HFEA), which would ensure their “proper” use. Therefore, scientists and clinicians took pains to associate PGD foremost with its medical indication (i.e., its application in the realm of clinical genetics as a preventive/therapeutic intervention) and avoid any relation of the technology to controversial and commercial uses, including as a means of improving IVF success rates much less as a means of lifestyle sex selection.

As Britain's scientists defined “proper” uses of PGD as a means of “minimizing public ‘discomfort’” with the new technology, it also, in making

the medical argument for PGD, highlighted the technology's ability to obviate abortion in reproductive genetics (Franklin and Roberts 2006: 98). Scientists, who pursued the development of PGD publicly and in active, direct response to anti-abortion legislation which threatened embryo research, emphasized the technology's ability to avoid repeat and late-term abortions associated with a positive amniocentesis result.

Within mid-1980s Britain, then, the normalization of prenatal diagnostic technologies (PND) and IVF on the one hand, and the encroachment of anti-abortion forces on embryology and IVF practice on the other, formed the contextual backdrop to public debates in which scientists articulated a need to pursue the development of PGD. In June 1985, an anti-abortion bill put forth by conservative MP Enoch Powell would have ended research on embryos in Britain if not for a narrow defeat. Members of the lobby called PROGRESS organized to defeat the bill began to persuasively advocate for PGD as an urgent need for inheritable genetic disease patients who have to contend with the "fear and anxiety" associated with pregnancies that get terminated after positive PND results. In a 1987 assessment of prospects for PGD, McLaren and Penketh highlight not the relative simplicity of PND vis-à-vis PGD as McLaren had done just two years earlier, but PND's associated "high physical and emotional price" necessitating tentative pregnancies and possible repeat abortions (Penketh and McLaren 1987: 747, cited in Franklin and Roberts 2006: 56; Rothman 1993). The UK parliamentary debate on timing of abortion and research on embryos thus helped to spur the first articulations of a medically justifiable need for PGD—a clearly spelled out *medical* problem (early childhood death and disease affliction) requiring a *medical* solution. As it turned out, this motivation served not only the development of PGD by instigating an increased pace in research but set the stage for MicroSort's entrée into human medicine just a few years later.

The work done by some UK scientists to *publicly* safeguard not only the practice of IVF but also a political climate supportive of their research on PGD against a growing threat from anti-abortion interests is highly significant. It imbued the technology with a social validity and paved the way for *disassociation* with abortion, which contemporary lifestyle sex selection has further underlined. Thus, for PGD, it was after 1986–1987,

that researchers, using techniques developed on animals, began to direct their efforts explicitly toward application in humans. The stated reason was medical: to avoid X-linked genetic disease with an eventual expansion to screen against other genetic conditions.

Initial technical obstacles facing PGD research for humans resolved over time through the concurrent development of requisite *in vitro* technologies such as IVF and PCR (polymerase chain reaction). IVF produced the raw material—human embryos, and PCR provided the initial diagnostic means to identify sex because it could quickly amplify (or reproduce) DNA, thus requiring only the removal of a single cell from the embryos. The first clinical application of PGD took place in 1990 by Alan Handside and Robert Winston. Using PCR to amplify Y-chromosome-specific DNA strands, the clinicians isolated female embryos for transfer. Once again, sex selection took place in this initial clinical instantiation as a means of avoiding the birth of male children, because females can carry but do not express the disease trait.

Since its first clinical use, the scope of PGD applications has broadened considerably. Although in the very first clinical application of PGD, PCR was used for embryo sex identification, in practice, fluorescence *in situ* hybridization (FISH) soon replaced PCR as the “diagnostic” technique of choice because it provided a simpler means to test for basic chromosomal characteristics of the embryo, such as sex, and was also well suited to checking chromosome numbers (Sermon et al. 2004, 1633). A method for detecting and mapping sequences of genes within chromosomes that came into being during the 1980s, FISH was among a number of new techniques that revolutionized the field of molecular genetics, providing an important diagnostic tool to check for chromosomal abnormalities and genetic mutations (Levsky and Singer 2003). FISH was already well integrated as a PND tool of analysis when its utility for PGD and MicroSort was first realized. While the utility of FISH allowed PGD sex and aneuploidy screening to become more widespread and accessible, the method, it turns out, also provided a critical key to the overall development of MicroSort, which has narrowly remained a sexing technology.

GIVF scientists who pursued an application of the Beltsville Sperm Sexing Technology in humans told Johnson that they were interested in the method’s potential to avoid sex-linked genetic disease in human

babies (Interview by the author, 2010). Johnson anticipated initial technical challenges. First, relative to other mammals, humans have a small difference in DNA content between X- and Y-bearing sperm. Initial experiments to sort X- from Y-bearing sperm were conducted on mammals with more easily distinguishable, large differences in the DNA content of their sex chromosomes such as in a vole (9%) or chinchilla (7.5%) as compared to bulls (3.8%) or humans (2.8%). Moreover, this smaller difference in DNA content between human sex chromosomes compromised the utility of Johnson's own method of determining sort purity (through a reanalysis of the sorted sperm populations which involved putting them again through the flow cytometer). The GIVF team had a solution to offer: FISH.

Founded by Joseph Schulman in 1984, GIVF uniquely provided under one institutional roof an IVF clinical facility, a molecular genetics lab that provided prenatal diagnostic services to pregnant women, and one of the largest sperm banks in the USA. FISH was one technique already in use in GIVF's genetic laboratory as a means to analyze fetal and placental tissues, and according to GIVF's website, Shulman realized its potential to serve as a reliable test of purity of the sorted sperm samples. Furthermore, GIVF through its sperm cryobank could readily supply the raw material needed for the experiments. While the USDA now had the flow cytometer and the expertise with the instrumentation needed to make adaptations for human sperm, GIVF supplied the human sperm itself and the test needed to check the proportions of X or Y sperm populations. The proximity of the two institutions (about 25 miles distance between Fairfax, Virginia, and Beltsville, Maryland) likely simplified the effort. Since the research was mainly conducted at the USDA lab, a USDA restriction that prohibited using the sperm for fertilization of human eggs effectively limited the study to determining only whether the Beltsville technology could reliably distinguish and separate X from Y viable human sperm.

In 1993, the USDA-GIVF collaboration published their findings. The article proposes the development of human sperm sexing as "a powerful approach to disease prevention" (Johnson et al. 1993: 1733) that "could in time reduce or eliminate the use of selective abortion as a means of decreasing the incidence of X-linked genetic disorders" (ibid: 1738).

The collaborators make no mention of sex selection as a lifestyle option, highlighting instead a medical purpose and a disassociation with selective abortion.

FISH results revealed enriched samples of X and Y sperm populations with an average 82 and 75% rate of purity, respectively, as opposed to their normal 50% presence in unsorted semen. Yet, the results stress the challenges posed by human sperm in comparison to livestock sperm, including their different morphology—more angular heads (rather than paddle-shaped as with bull sperm), smaller difference in DNA content as already mentioned, and sperm heterogeneity (lack of uniformity among sperm from a single individual and between individuals) (Johnson et al. 1993: 1735). These complicating material factors compromised the number of sperm retrieved after sorting and the sort sample purities.

Although the GIVF-USDA collaboration proved that the method could work in theory, in practice the safety and efficacy of the method ultimately to produce human babies of desired sex still had to be shown. *Institutionally*, the locus of research had to shift once more. In 1992, GIVF took over the task. The Office of Technology Transfer of the Agricultural Research Services of the USDA granted GIVF a 17-year exclusive license to develop the Beltsville Sperm Sexing Technology for commercial use in humans. Johnson claims to have at least in one aspect significant influence on that process since he insisted that the USDA issue separate licenses for the commercialization of the method in humans and animals (Interview by the author, 2010). In this way, this history of sperm sexing divided, with a boundary between human and non-human development sharply drawn. GIVF purchased two flow cytometers, secured IRB approval from Inova Fairfax Hospital (Wadman 2001), and in 1993 the human clinical trial was underway. GIVF named the human application “MicroSort.”

Anticipating Lifestyle Sex Selection

In a 1995 report of the first achieved MicroSort pregnancy published in the scientific journal *Human Reproduction* of the European Society of Human Reproduction and Embryology (ESHRE), trial scientists propose a material linkage between MicroSort and PGD in which MicroSort

would serve as an “adjunct” to PGD “for the prevention of X-linked disease” (Levinson et al. 1995: 979). The combination, the authors contend, raises the chance of pregnancy by increasing the number of female embryos (as identified by PGD) from which to choose for transfer. Further, they suggest MicroSort combined with PGD would simultaneously minimize the number of male embryos, the production of which pose a “dilemma” for patients as some may be unaffected by disease² (ibid: 979). In fact, the first human clinical instantiations of MicroSort did the reverse, by utilizing PGD as an adjunct of sorts, a backup and further test of validation—“purely a necessary precaution to check the sex ratio and to identify the rare male embryos conceived by the few Y spermatozoa which escaped X-sorting” (Edwards and Beard 1995: 978). In this way, at the very moment MicroSort is introduced to scientists in the field as a viable, sex-selective technology in human reproduction, the parallel histories of MicroSort and PGD converge within the framework of scientific discussions of sexing for medical purposes.

A directly preceding editorial co-authored by reproductive scientists, Robert Edwards and Helen K. Beard, reinforces that frame, while also anticipating the leap to lifestyle sex selection. Entitled, “Sexing human spermatozoa to control sex ratios at birth is now a reality,” the editorial first grants MicroSort a high level of scientific recognition—another form of validation—coming from some of Europe’s most esteemed scientists in the field. This editorial highlight granted to MicroSort’s first pregnancy may in no small part have been influenced by the enduring friendship and growing affinity between GIVF’s Schulman and Robert Edwards, which first began while Schulman attended Cambridge in the mid-1970s where he had the opportunity to observe early (unsuccessful) attempts to clinically apply IVF (Schulman 2010). Secondly, the editorial seals the material convergence of MicroSort and PGD as sexing technology alternatives (if not adjuncts) by discussing the two in relation to one another. The authors suggest:

Sperm sorting will be a valuable adjunct to other forms of very early prenatal diagnosis. It could well replace the use of preimplantation diagnosis which utilizes marker genes on the X and Y chromosomes for sexing. Preimplantation diagnosis offers a high degree of success, perhaps equal to

or greater than sperm sorting, but it is an expensive approach to diagnosis. Its great advantage is avoiding or reducing the need for abortion, but it involves an operation on the wife, IVF, and the rejection of the afflicted embryos. (Edwards and Beard 1995: 977–978)

Here, as in subsequent comparative assessments of the technologies, the authors not only presume heteronormative applications of both technologies but that MicroSort will most likely be combined with insemination procedures (unlike PGD, which necessitates IVF). Finally and most significantly, Edwards and Beard, foreshadow the immediately forthcoming move made by MicroSort to expand to non-medical uses. They condition the acceptability of using MicroSort for “sex choice” with its inherent capability (unlike PGD) to be combined with “artificial insemination.” They state, “The introduction of sex choice *using artificial insemination* with sorted spermatozoa would make the method highly acceptable for sexing for social purposes. Indeed, such an approach may be imminent” (ibid: 978, emphasis mine). In fact, the USDA license that extended MicroSort indications to what today is described as *family balancing* was deliberated and approved that very year. Edwards and Beard continue, “This prospect will rattle the skeletons in the cupboard for some observers as they contemplate the ethics of a further example of a rapidly advancing biotechnology” (ibid: 978). The anticipated move to lifestyle sex selection found even earlier expression in an opinion piece published in 1993 by GIVF founder, Joseph D. Schulman.

At the moment of its very inception into human medicine, even as MicroSort’s *medical* purpose was still being mobilized and the technology’s viability for human applications underwent its earliest testing, developers began to envision future human lifestyle applications. Schulman wrote in 1993 that in order “to achieve broad ethical acceptance,” MicroSort’s “initial applications” would be “limited” to avoid sex-linked disease and to prevent abortions or the destruction of embryos that might ensue following PND or PGD. He then foreshadows the “family balancing” policy later operationalized within GIVE.

What carefully defined conditions would permit more ethically acceptable gender preselection of healthy girls or boys? The ‘balancing’ of sex ratios in

families is certain to attract considerable discussion in this regard. Consider a family with its only children being three healthy boys. If a fourth child is desired, and a girl is preferred by the parents, why would sperm sorting to enhance the odds of a female not be ethical?

...In my opinion, many people will conclude that ethically acceptable guidelines for family balancing can and should be developed. One position to be considered might simply be that it is ethical to perform balancing to increase the less represented gender in any family that already has at least one child. (Schulman 1993: 1541)

Schulman's assertion of a medical need for MicroSort simultaneously looks ahead to the potential for lifestyle uses, long before such applications would also envelope PGD. His language asserting a non-medical iteration of sex selection within ART is enabled by material aspects of MicroSort's design, for example, its bias toward the more effective production of girls and its relative simplicity and lower risk profile than PGD (assumed as it was to be applied with IUI instead of IVF). Schulman's hypothetical family of three boys would likely not have been randomly chosen as it implicitly created distance to situations of son preference.

Thus, Schulman in 1993 and Edwards and Beard in 1995 highlight the comparative material and design advantages of MicroSort over PGD that, in their perspective, could enhance its ethical profile for non-medical sex selection. In addition, MicroSort's prominence in the field of reproductive genetics served to vet the technique and distinguish it from the "pseudoscience" of another method of sperm separation named after its founder, Ronald Ericsson. Unlike MicroSort, the Ericsson method could not be independently verified (Claassens et al. 1995; Flaherty et al. 1997; Rose and Wong 1998; Fugger et al. 1998). Indeed, after much tried but unproven low-tech methods such as the Shettles method on timing of conception or particular diets, mass print and television media hailed MicroSort and PGD as the answer to a long quest for scientifically proven methods for selecting the sex of a child.

Thus, a local US climate, in which the medicalization of abortion is tenuous at best combined with an international climate in the 1990s that began to recognize the scale of and condemn sex-selective abortion. As

a result, scientists developing PGD and MicroSort in the UK and USA within human medicine, stressed that their application could avoid abortion by establishing desired pregnancies based on characteristics in the resulting child. As already described, British reproductive scientists vested in the development of PGD, highlighted this feature to politically counter an anti-abortion bill that would have stopped research on embryos. In the USA, professional bioethicists tentatively approved MicroSort for non-medical sex selection, if it could be shown safe and effective, and justified this position precisely based on the technique's potential to avoid IVF and the creation and destruction of embryos (Ethics Committee 2004). *Not* abortion is a central feature of the material definition of both technologies. Boundaries drawn between ART and abortion, partially in response to local politics in their Western contexts of origin, initially drove a wedge between selective abortion on the one hand, and selective fertilization or implantation in the realm of reproductive genetics on the other. This wedge extends further into lifestyle applications, situating sex-selective reproductive technologies like MicroSort and PGD against sex-selective abortion. While the longer standing practice of sex-selective abortion can be historically traced to world regions associated with the imposition of population control such as in South and East Asia (Hvistendahl 2011), sex-selective reproductive technologies situate in the opposed regions of the “developed” Global North or West. The material-technological tools of contemporary lifestyle sex selection disassociate from the opposed reproductive biopolitical context of population control, its related technoscientific practices, such as sex-selective abortion, and world regions.

Conclusion

MicroSort and PGD became acceptable in the fulfillment of a lifestyle desire for specifically sexed children through a multi-staged process of biomedicalization. Developed for use in the livestock industry, scientists had to first articulate a justification for their development and application in human medicine as therapeutic interventions to prevent genetic disease and avoid abortion. A distinct geopolitical,

transatlantic connection, particularly among UK and US scientists in conversation with one another provided the springboard for the subsequent meaning-making shift that extended their application rather quickly to desire, lifestyle, and family composition as signified in “family balancing.”

These shifts took place within the overlapping domains of ART and reproductive genetics, which strongly associate with “high”³ science, the pioneering field of human biotechnology, and wealthy world regions. Not only does ART provide PGD and MicroSort with an *institutional* home but also associative meaning. As ART embedded technologies, PGD and MicroSort gained definition through belonging and situation on the privileged side in a dichotomized world of reproductive technologies alongside valued reproduction, conceptive technologies, and neoliberal, individual choice. While the local anti-abortion context in the USA and UK influenced the material-discursive development of both PGD and MicroSort, the international condemnation of sex-selective abortion in the mid-1990s, connected as it was to critiques of abusive global population control policies, amplified meaning-making transitions in the biomedicalization process via implicit disidentification. Later, professional bioethicists would make explicit that sex-selective PGD and MicroSort not only were not abortion but also not China, not India, not family limitation, not “son preference” and not a manifestation of sex bias. Here, I underline that requisite to the formation of lifestyle sex selection were countervailing ideas stemming from a globally stratified infrastructure of reproduction that gave rise to widespread practices of sex-selective abortion.

Notes

1. First termed by science writer, Gina Kolata, sociologist, Laura Mamo applies “Fertility, Inc.” to signify the competitive, for-profit, and relatively unregulated market of ART, especially as it manifests in the USA (Mamo 2010, 178).

2. The authors are suggesting that for patients trying to avoid having children afflicted with disease, the dilemma arises because the process may involve the destruction of healthy embryos.
3. As with “high culture,” I use “high” as a referent of taken-for-granted status indicating a more cultivated, advanced, complex, or developed form of science, whose truth and knowledge claims are generally less scrutinized.

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Part II

Preventing Disease and Disability

4

Moral Adherers: Pregnant Women Undergoing Routine Prenatal Screening in Denmark

Laura Louise Heinsen

Ida: I'm looking SO much forward to it [becoming a mother again]. It's insane how much I look forward to it. Very, very, very, very, very much. And I'm also really, really ready to become a mother again. I really want it to happen now, it's the perfect timing. Lots of things are perfect. I will go on maternity leave in February, which fits perfectly with Sonja's birthday coming up, I can't wait.

Laura: But still, you've decided to opt for the nuchal translucency scan?

Ida: Yes, and I also know that if we learn the baby has Down's syndrome, we would opt for an abortion. I'm one hundred percent sure of that.

In recent years, feminist medical anthropologists engaged in the study of human reproduction, particularly the medicalization of pregnancy and birth, have shifted attention away from earlier approaches that linked the control of women's bodies to male-dominated structures of medicalization and biopower (Oakley 1984; Petchesky 1987; Jordan and Davis-Floyd

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1993), toward documenting how women themselves actively engage with high-tech reproductive medicine in complex, culturally contingent and contradictory ways (Rapp 2000; Lock and Kaufert 1998). Within this tradition, wanted and unwanted pregnancies have often been explored as two disparate research fields, the first focusing particularly on the experience of assisted reproduction and miscarriage (Tjørnhøj-Thomsen 1999; Franklin 1992; Inhorn 2006; Layne 2003) and the latter on social, economic and gendered structures that lead to abortion and infanticide (Ginsburg 1998; Scheper-Hughes 1993). However, as prenatal screening and diagnostic technologies become routine around the globe, a wished-for-child may become unwanted in the process of the pregnancy, challenging in new and compelling ways the notion of 'intended pregnancy'. As argued by sociologist Barbara Katz Rothman, prenatal testing has rendered pregnancies 'tentative', as women hesitate to attach themselves to a fetus they might not want to keep (Rothman 1986). The line between a wanted and an unwanted child has become blurred amid this change, as the words of Ida, a mother expecting her second child, in this chapter's epigraph exemplify.

In her book about the social impact of amniocentesis (2000), medical anthropologist Rayna Rapp demonstrates the difficult decision-making process that women who are confronted with prenatal diagnosis and selective abortion face. Writing at a time when amniocentesis—an invasive diagnostic technology used to detect chromosomal and genetic anomalies in fetuses—was at the cutting edge of becoming normalized, Rapp argues that

the construction and routinization of this technology is turning the women to whom it is offered into moral pioneers: Situated on a research frontier of expanding capacity for prenatal genetic diagnosis, they are forced to judge the quality of their own fetuses, making concrete and embodied decisions about the standards for entry into the human community (Rapp 2000: 3).

However, while the notion of 'moral pioneering' captures women's responses to the burdens and benefits created by amniocentesis (*ibid*: 126), the then new and revolutionary reproductive technologies are today deeply routinized in many parts of the industrialized West and, in some cases, have been replaced by newer non-invasive screening technologies,

presented as ‘safe’ means by which women can gain more ‘certainty’ about the health of their fetuses (National Board of Health 2004b).

Denmark constitutes a unique case study for such nation-wide normalization. In Denmark, prenatal screening has been offered to all pregnant women, on a routine basis *and* free of charge, since the introduction of a new screening policy in 2004. Since then, Denmark has topped the statistics as the country with one of the highest uptake rates of both prenatal screening and selective abortion in Europe and North America. It is estimated that the overall current uptake of routine prenatal testing is at least 90% nationally and 98% in the Copenhagen area (Ekelund et al. 2008; Schwennesen 2010: 13). Since the implementation of the new regime of prenatal testing, the number of babies born with Down’s syndrome has dropped by more than 50%, giving Denmark a reputation among its Nordic neighbors as a ‘sorting society’ (Schwennesen and Koch 2009: 70; URL 1 n.d.). How has it come to be that so many pregnant women accept prenatal screening? And why has it become common to reject a fetus with Down’s syndrome? Does the notion of ‘moral pioneering’ capture present-day pregnancy experiences within a Danish context?

The aim of this chapter is to explore how selective reproductive technologies (SRTs), understood here as technologies used to *prevent* the birth of certain kinds of children, have become routinized among pregnant women in Denmark. Starting from Rapp’s work, I will argue that the routinization of prenatal screening has created a situation in which pregnant women have become what I term ‘moral adherers’ of SRTs. Furthermore, it is my argument that the highly institutionalized availability of pregnancy ‘opt-outs’ shapes women’s moral reasoning about termination, compelling them to see selective abortion as an acceptable choice and delegating the moral responsibility for fetal selection to the antenatal healthcare system rather than to pregnant women as individuals. In this moral optic, rather than an individual moral burden, selective reproduction becomes a collective responsibility.

In a study of Danish pregnant smokers, anthropologist Mette Bech Risør (2002, 2003) defines ‘reasoning’ as connected to everyday practice, life experiences and moral deliberations that involve weighing good and bad in an individually configured rather than universal way (Risør 2003: 73). Inspired by Risør, I take reasoning as a concept that captures both

the 'habituated' and the 'active' nature of moral deliberations and actions that are connected to the regime of prenatal testing and the historically shifting and culturally constructed moral landscape of selective reproduction in Denmark. The analysis thus takes as its starting point an understanding of women as agents in shaping their reproductive lives, but it also acknowledges that reproductive decisions, aspirations, fears and actions are enmeshed in and conditioned by social and cultural structures of a society, such as reproductive politics. As Rapp puts it, SRTs have 'enormous discursive and practical powers to define what it is to be normatively human' (Rapp 2000: 14). In other words, this chapter examines not only how women reason about prenatal screening but also how the use of these technologies influence the ways in which the pregnant women negotiate boundaries between fetal life and death, and between unwanted and wanted 'kinds of living' (Wahlberg 2009). The data on which this chapter is based stem mainly from interviews with 12 women and observations of 28 routine prenatal screening sessions at a hospital-based ultrasound clinic in Copenhagen. These research activities took place during eight months of 2011.

Prenatal Screening and Selective Abortion in a Danish Context

Within anthropology, the impact of new SRTs on the experience of pregnancy is well documented (Rothman 1986; Rapp 2000; Press and Browner 1997; Taylor 1998; Mitchell and Georges 1997; Saetnan et al. 2000; Gammeltoft 2014; Gammeltoft and Wahlberg 2014). However, few ethnographers have explored the social impact of routine prenatal screening in a Danish context.¹ This is rather surprising as Denmark stands out as one of the first countries in the world to roll out routine prenatal screening at a national level through a publicly financed health system (Ekelund et al. 2008; Schwennesen 2010: 116), and in comparison with other European countries with similar prenatal testing offers, Denmark is the country where most pregnant women undergo prenatal screening. For instance, England has a system equivalent to the Danish, however in 2011 only 68% of women accepted the offer (Morris and

Springett 2013), and in the Netherlands, where a national screening program was implemented in 2007, women below the age of 36 have to pay 150 Euros to get tested (Lichtenbelt et al. 2013), but despite the national policy, the overall uptake remains low (Engels et al. 2014).

In Denmark, routine prenatal screening was implemented, backed by the government, when the Danish Board of Health issued new guidelines for prenatal screening and diagnosis in 2004. The guidelines recommended that non-invasive prenatal screening, consisting of a first-trimester prenatal risk assessment (FTPPRA) for chromosomal anomalies, such as Down's syndrome,² and a second-trimester ultrasound scan for congenital malformations, should be offered to all pregnant women, regardless of age and risk profile (Danish Board of Health 2004a). In the guidelines, the board formulated a new criterion of success for the public health program of prenatal screening: 'informed choice'. This was formulated as a solution to what was considered a problematic past of the previous program, where only women aged 35 or older, or women who had a known increased risk of having a child with chromosomal diseases, were automatically given access to prenatal screening and testing. The Danish Board of Health argued that such a regime could be characterized as belonging to a 'paradigm of prevention' since access to services was organized around a pre-defined high-risk group. Instead, prenatal screening should be offered to all pregnant women, based on an ethics of individual choice, volition and self-determination.³ Furthermore, in order to prevent the new policy from being conflated with state-mandated eugenics, the Board accentuated that the offer should *not* be organized as a nationwide screening program that aimed to include all pregnant women (Danish Board of Health 2004a: 7). Rather, access to screening and testing services should only be given on the request of pregnant women themselves. Therefore, the national guidelines stipulate, women should not be directly invited to participate but are to be asked by their general practitioner (GP) if they want information about the services offered. If so, they should be provided with non-directive information, on the basis of which they then can decide whether or not to undergo prenatal screening. Thus, through this idiom of self-determination and free choice, the Danish Board of Health explicitly emphasized that the objective of the

new policy was to enhance the reproductive autonomy of prospective parents. The Danish Parliament issued the following statement:

The aim of prenatal testing is—within the juridical framework of Danish law—to assist a pregnant woman, if she wants such assistance, to make her capable of making her own decisions. Neutral and adequate information is a necessary condition to this end [...]. The aim of prenatal testing is not to prevent the birth of children with hereditary disease or handicap (Parliamentary Decision on Prenatal Diagnosis, May 15, 2003).

However, in spite of this anti-eugenic rhetoric, ‘therapeutic’ abortion is inextricably tied to prenatal screening, as it is the only biomedical solution to the conditions that can be prenatally diagnosed. Furthermore, since abortion is legal only until week 12 of pregnancy, second-trimester abortions must be approved by one of the country’s three ‘abortion commissions’ [Abortsamråd] whose members are legal, medical and psychiatric professionals. Thus, when prospective parents learn that their fetus has chromosome abnormalities, they are not alone in deciding whether or not this condition warrants an abortion.

According to the Danish Central Cytogenetic Registry (DCCR), 99% of prospective parents who receive a positive diagnosis for Down’s syndrome choose to terminate. In 2011, a total of 385⁴ late-term abortions were performed due to chromosomal anomalies, including trisomy 21, 18, 13, sex-chromosome disorders and other rare chromosomal diseases; 147 cases of Down’s syndrome were diagnosed prenatally; and 29 babies with Down’s syndrome were born. Twenty-four of the 29 babies were diagnosed postnatally, due to either no prenatal screening or non-detection in spite of prenatal screening. Five were born after prenatal diagnosis, out of which two were detected after the legal limit of abortion for fetal anomaly in week 24 of pregnancy. In other words, *only three couples* actively chose to give birth to their baby knowing that it had the syndrome (DCCR 2014).⁵ I find the relationship between the emphasis on informed choice in the official guidelines, on one side, and the state-sanctioned institutionalization of selective abortion, on the other, highly puzzling. This prompts me to ask how opting for an abortion seems to have become the conventional response when a fetal anomaly is found, and what role the routinization of prenatal screening

and selective abortion plays in pregnant women's moral reasoning about boundaries between fetuses that are regarded as 'rejectable' and those that are not.

Moral Adherers

We just assumed we would do it. That was just the next test we did. I don't know. It's the way it's presented; it just seemed safe to do and part of the process. And I was interested in seeing the baby, if it was on track.
(Mille, 26, Architect, 14 weeks along in her first pregnancy)

When a woman becomes pregnant in Denmark, she normally consults her GP, who initiates the woman's pregnancy health record and refers her to a midwife. At this initial consultation, the woman is informed of the possibility of undergoing routine prenatal screening (if she wants to be informed⁶) and also told that she has to book a time for the screening herself at the local hospital (Schwennesen et al. 2009: 195). In accordance with the dominant ideal of non-directive counseling that underpins clinical practice in Denmark⁷ (Koch and Svendsen 2005; Schwennesen 2010), the logic behind this organizing structure is to secure that women are not coerced into accepting prenatal screening but choose 'freely' whether or not to participate. When I began studying pregnant women who had opted for prenatal screening, I was struck by how little some of them knew about the tests and the conditions that can be diagnosed prenatally, the apparent conformity with which all of them approached prenatal screening, and how rarely they, at the outset, expressed moral ambivalence about undergoing screening. Most of the women defined prenatal screening as driven by a need to see the fetus in order to be reassured that it was alive and well, or to know 'the risk of Down's syndrome' and 'other birth defects'. Generally, they did not describe undertaking prenatal screening in terms of active choosing but rather assumed it to be 'a routine act'.⁸ None of the women had been given or had vigorously sought additional information about prenatal screening or the diseases and disabilities that they aimed to detect. Instead, the women radiated profound trust in the biomedical system and the medical judgment of healthcare professionals.⁹

When probed for her level of knowledge of prenatal screening, Randi, a 32-year-old academic and first-time mother, answered:

Whatever they test for, I find important. I have so much faith in this technology, this screening, so they only screen for things that, I mean, they've only offered me this screening, because they assess it to be useful.

When Rapp began her studies of prenatal diagnosis in the 1980s, amniocentesis was seen as a window of unprecedented opportunities for prospective parents to influence the quality of their own and their children's lives. Women submitted themselves to this new technology to reap its biomedical benefits, but in doing so they had to face the risks of reproduction. Not only did they risk miscarrying due to the invasiveness of amniocentesis, but they were also forced to judge the quality of their fetus in case of 'bad' news. However, subscribing to routine prenatal screening as it is perceived in Denmark does not necessarily imply making explicit the moral quandaries of selective reproduction. Rather, many of the women in this study took prenatal screening for granted as an inherent part of the pregnancy process, hardly considering the next step in case of receiving a high-risk assessment. All of the women stated that they would take things 'as they come' if the fetus turned out to be abnormal. For some of the women, the prospect of potentially learning that their fetus could be anomalous was not even within their mind-set prior to the nuchal translucency scan.¹⁰ For instance, Ida said the following when I met her at nine weeks pregnancy:

I'm convinced I'm not carrying a child with Down's syndrome. I couldn't imagine that. It's quite far out of my consciousness, you know, the odds of something being wrong. Mostly we are there to have a picture [laughing].

In an anthropological study of first-trimester screening for Down's syndrome in the UK, Williams et al. (2005) argue that women 'reported having thought carefully through their own moral beliefs and values prior to screening', concluding that women enacted 'moral pioneering' in this new setting of non-invasive technology (Williams et al. 2005: 1983). However, my findings suggest that in some social settings we have passed

the stage where we can speak of women who accept prenatal screening in terms of pioneering. Instead, I propose to conceptualize them as ‘moral adherers’. According to the Free Dictionary, ‘adhere’ means to stick to like glue, to be in support of something or to carry out a plan or scheme (URL 4 n.d.). The notion of ‘moral adhering’ designates both an individual and collective level; women submit themselves to prenatal screening to reap its *social* benefits; getting reassurance from seeing a moving fetus on the ultrasound monitor appeal powerfully to pregnant women. But they also submit themselves to prenatal screening because they perceive fetal quality control to be the recommended reproductive path. As Mille, a first-time mother, said: ‘I just did what I was told.’

When you have the offer, you take it: Collectivized Responsibility of Selection

Anthropologist Margaret Lock argues that reproductive technologies would be confined to the research laboratory without ‘the desire of “consumers” to cooperate’ (Lock 1998: 206). Danish women have adopted prenatal screening extensively, but as I see it, the high uptake rates are not indicators of active consumerism. Rather, they convey a habitual adherence to a screening program that is being interpreted as a technological and moral imperative, and has been conflated with and thus naturalized as standard antenatal health care (Browner and Press 1995; Press and Browner 1997: 984). 36-year-old Astrid for instance said: ‘It’s natural, when you have the offer, you take it.’ It could be argued that although the regime of prenatal screening officially has been framed as a free offer, the fact that it is offered at all implicitly sends a message to pregnant women that prenatal information is valuable. Prenatal screening is considered beneficial *because* it is offered by ‘the system’.

On a self-critical note, one could argue that because I was not present in the biomedical settings of health professional-client communication, I cannot verify the women’s representation of information transfer. As such, there is the possibility that what is practiced in the Danish antenatal healthcare system is a system of directive counseling that disregards

the ethos of non-directiveness. If this were the case, my arguments could be said to misrepresent a group of women who ought to be seen as victims of a paternalistic counseling system rather than adherers of a routinized prenatal screening regime.¹¹ However, anthropological studies¹² have demonstrated that the ways in which counseling is understood and practiced are too complex to be dichotomized into two opposing poles of directiveness versus non-directiveness. For instance, in a study of FTPRA in Denmark, Schwennesen et al. (2009) show that even though sonographers made great efforts to provide couples with non-directive counseling in the wake of a high-risk assessment, the couples had a hard time making sense of the risk figure and therefore experienced a need for more direct advice.¹³ My reading of the pregnant women in my study is more in line with Koch and Svendsen (2005), who argue that the concept of non-directiveness does not capture how decisions are actually made. As they argue in the context of genetic counseling, decisions of individual counselees made within a health-promoting medical setting are directed toward disease prevention 'by appeals to familial and social responsibility. This does not mean however that non-directiveness is an illusion but rather that the governmental processes, which take place, also functions by the voluntary choice of the counsellee' (Koch and Svendsen 2005: 828). The women I met told me that prenatal screening was never presented as a choice and many of them had not considered that it was possible to turn down the offer; however, prenatal screening was also never spoken of as coerced. Thus, in my interpretation, the regime is working (so well) precisely because it is perceived to benefit prospective parents, while simultaneously allowing the many women who are placed in low-risk categories to keep the moral and emotional predicaments of selective reproduction at arm's length. In the words of first-time mother Andrea:

Well, as long as all the tests have been negative, we haven't really been confronted with any ethical conflicts. We've kind of just gone along with it. So we haven't really discussed the pros and cons of all of this, or thought through the consequences.

Williams et al. (2005) describe how the women in their study considered the decision-making of prenatal testing and selective abortion a private

process, where they themselves had to take responsibility for their choice. However, when it came to the (hypothetical) question of opting for selective abortion, the women I met mostly framed this as an opportunity *given* to them by the biomedical system, thus essentially the Danish state. In my interpretation, this might explain the certainty with which they defined selective abortion as morally justifiable. The women kept stating: ‘if there’s a way out’ and ‘if I have the choice’ when reasoning about abortion. Charlotte, a woman in her 30s expecting her second child, said: ‘I’m not willing to carry on a child’s life with Down’s syndrome if I have the possibility to opt out. I guess we would survive it, but as I have the choice not to, I would rather not.’ And Marie said: ‘I think it’s brilliant that you have the opportunity to opt out and opt for an abortion. It’s a good service actually.’

Social Imaginaries

Even though the women seemed to perceive selective abortion in terms of ‘available opt-outs’ and outsourced the moral responsibility of rejecting defected fetuses to ‘the system’, this does not mean that they did not have their private reasons for wanting to identify a fetal anomaly. In fact, when pushing the women to explain and elaborate on why they perceived prenatal screening to be reasonable, a variety of social expectations and imaginaries about living with disability arose. These social imaginaries seemed to underpin the women’s take on selective abortion as morally acceptable. What it means then is of methodological importance in the sense that these social imaginaries, in most cases, were not articulated until I began probing for more elaborate explanations. It should be noted though that few of the women phrased their outlook on disability from the onset but most expressed that my probing questions made them reflect on things that they had not considered or put into words before. Susanne, a 36-year-old social worker expecting her first child, framed her intention to abort her fetus had it been diagnosed with Down’s syndrome in terms of care for the unborn child. Susanne had not only conceived with technological aid but she also suffered from pulmonary embolism, making the pregnancy potentially life threatening for both her fetus and

herself. Essentially, she had one shot at motherhood. Still, she reasoned that she would choose to abort because:

So few are born with Down's syndrome today, so a child like that is going to have a hard time getting a social network, whereas 10 or 15 years ago, they had plenty of options [...] I'm not doubting whether we as parents would love the child, but we would opt for an abortion out of concern for the social life it would have as Denmark is today. It's not a life I would want to offer. So, in reality, my choice is a consequence of the opportunity of choosing... and the choices made by all the others. So yeah, I cried when we received a good risk figure.

33-year-old Marie also stressed that Denmark is not 'geared for' children with disabilities. Unlike most of the women who had no personal experience with disability, Marie had worked several years with disabled people, having witnessed the predicaments of caring for a handicapped child:

Society is really not geared for children like that. They are not like normal kids. You can't say the same things to them. You risk losing your child earlier. They often have heart diseases, and you have to fight a lot with the system to get support. Of course there are some who are super cute, because they really are special. But there are also the ones that are really... cumbersome. And you can't know which one you're gonna get. You can't know that with a normal child either, but still, that part, the heavy part, I'm not up for that if I can opt out.

While many of the women framed abortion as a means to prevent suffering, both individually and collectively, a few of the women mostly worried about not having the kind of mother-child relationship they wished for if having a disabled child. Randi, for example, envisioned that a disabled child would not be able to engage in *emotional reciprocity*, leaving her trapped in an eternal state of responsibility for a dependent child:

I think, if I have a child with a physical or mental disability, I mean, depending on the condition and what kind of impairment we are talking about, but in reality I think it could be a good life for the handicapped child. I don't question that at all. But if I can prevent bringing it into the

world, I wouldn't hesitate, mostly for my own benefit. Because I think the child is going to have a great life no matter what. So some of the horror scenarios are, you know, that the kind of dependency that I presume an infant has, continues, so that when I am 80 years old, my child is depending on me instead of the other way around. That imagery is not part of the kind of egoistic vision that I've bought in to. I mean, you get children with the anticipation that they will repay your efforts [*på forventet efterbevilling*], that you get a repayment [*afbetaling*] for your children. And if I get a disabled child, then it's not certain that I'm going to get back anything.

Thus, these social imaginaries about what living with an impaired child entails fed into the women's perception of selective abortion as a feasible solution. These imaginaries were far from embedded in real-life worlds, as few of them had personal experience with what living with disease and disability actually implies. They reasoned mostly in a 'social vacuum', to paraphrase Rapp (Rapp 2000: 131). However, they did draw on other real-life experiences when reflecting on disabilities and selective abortion. For example, Ida spoke about the hardship of caring for a normal child as the backdrop against which the decision to terminate her pregnancy seemed morally just:

After having my daughter, I've kind of experienced my limit... for what I can cope with. I had a long birth, was diagnosed with preeclampsia during birth, and then my body just went into shock. My life was actually hanging in a thread, and it took three months before my body was normal again. And Sonja had colic, and I was not allowed to walk around much, and she just cried and cried, so it was just SO hard.

What all the women shared was the ways in which their thought processes circulated not around social and moral judgments regarding fetal life but rather around the prospective of good *quality of life* for the unborn baby and themselves as mothers. It was within the space of 'available opt-outs' and social imaginaries about a hoped-for future free of disease and disability that the women negotiated the criteria for wantedness of their potential child; a negotiation that took shape in relation to both the SRTs they were offered and the embodied and temporal process of growing more and more pregnant as the birth came closer.

Negotiating Wantedness

When I met Randi for the first time, she had recently undergone the nuchal translucency scan, receiving a low-risk assessment for chromosomal anomalies. Like most of the other women, she described the scan as marking a first milestone that enabled her pregnancy to progress. However, although she was expecting a highly wanted and planned-for child, the prospect of actually giving birth to this child was still hinging on the results of the malformation scan:

I look forward to seeing how big it is now, and to see those two legs cycling around. But I'm also like eh, because maybe we'll find out something's wrong, right? That's also one of the reasons why I'm not already buying baby clothes and stuff, because I'm like, it might be we're not having this child, maybe we're not having this child, maybe we'll have another child. [...] I want a child, but not at all costs.

Similarly, Marie said:

Sometimes I think, I've been waiting so long for this child, so shouldn't we just have it no matter what, but I don't think I would choose that. I wouldn't have a child at all costs.

A wanted pregnancy is only wanted *as long as* everything progresses uneventfully. The women awaited a medical 'quality control' of their baby-to-be before it could become *really* wanted (Rapp 2000: 126). Some of the women were quite clear about the preconditions for wantedness, others were more wavering about where to draw the line between wanted and unwanted. Randi and her boyfriend Jakob, who had conceived with the aid of donor sperm, expressed a zero tolerance of disease and disability. They couched this in a language of egotism; they were not having the child 'for the sake of the child, but for their own sake'. The following conversation took place at the hospital, immediately after the second-trimester scan:

Randi: Well, in reality, this malformation scan, and also the nuchal translucency scan, it's like an instrumental milestone of, you know like,

precluding certain risk factors, and when we're beyond those, yeah, how can I put it, it's like it does something to my process in the sense that it continues. Because if she [the sonographer] had looked at it and said 'uh, clubfoot or cleft lip and palate' and stuff like that, then we weren't gonna have this child

Laura: So if you had learned the baby had cleft lip and palate, then what?

Jakob: Then it would probably have ended in an abortion

Laura: Ok?

Randi: Yeah, because, in reality, if a health professional tells me, it has disease X or condition X, and if they assessed that this is some kind of disease.

Jakob: But a clubfoot is not really...

Randi: No, but it is a condition, right? It's a symptom or syndrome, I don't know what they call it. But I'm not having that child. I want a healthy child.

Laura: But is cleft lip and palate a disease?

Jakob: It's a really huge problem

Laura: Why?

Jakob: Eh, because it's a regular handicap, it's a regular speech disorder you get out of it, as far as I remember.

Laura: Because you'll lisp or what?

Jakob: I'm not sure, it's not certain they can operate it, and children get teased and... it's not just cosmetic.

Randi: No, it's not just cosmetic, things haven't grown properly together. But again, I'm still thinking that if someone told me that something is wrong with my child, and I can do something about it, like as in not having this child, but having another, then I'm going to do that.

This extended quote not only reveals how I as an ethnographer sometimes had difficulties maintaining a neutral stance, it also demonstrates how this particular couple came to agree upon the conditions for the continued wantedness of their unborn child, defined vaguely as 'healthy'. But the excerpt also illustrates another common feature in the women's reasoning about selective abortion: none of the women expressed concern about whether they would get permission to obtain a second-trimester abortion, neither in apparently 'severe' nor 'mild' cases. Randi and Jakob assumed that *they* held the mandate for deciding what kind of a life they wanted to bring into the world. However,

as already mentioned, second-trimester abortions must be approved by one of the commissions of legal, medical and psychiatric professionals. While abortion for Down's syndrome is always approved, conditions such as clubfoot and cleft lip and palate are subject to interpretation and handled differently depending on the committee¹⁴ (Politiken 2012). None of the women (and partners) whom I interviewed spoke about these commissions, and only one¹⁵ spoke about the emotional turmoil of possibly having to give birth to the aborted fetus. Whether the lack of reflection over second-trimester abortion procedures is due to a general gap of knowledge or rather reflects women's unease with reasoning about abortion on a more practical level is hard to tell. However, in my interpretation, it does reflect the (perceived) orthodoxy regarding selective abortion in Danish society. It seems to be the general perception that an abortion is granted, if wanted, which—by all means—is not far from the truth.

Negotiating Fetal Living

Ever since Marcel Mauss' pioneering book, *A Category of the Human Mind: The Notion of Person, the Notion of Self* (1985 [1938]), anthropologists have been interested in the social dimensions of personhood. Generally, anthropologists agree that personhood is a social status granted—in varying degrees—to members of society (Morgan and Conklin 1996: 662). For instance, a study conducted in North America has shown how fetuses are ascribed personhood and agency as a result of the visualization of the unborn baby through ultrasound scanning (Mitchell 2001), while studies of prenatal diagnosis and disability have shown how fetal and neonate personhood is called into question¹⁶ (Landsman 1998; Rapp 2000). I knew after a dozen interviews that the women saw screening as an opportunity to prevent disease and disability which they all depicted as threatening the quality of their lives. But I wondered if these imaginaries, and the premises on which the women reasoned about wantedness, were stable through the course of pregnancy? I asked the women to reflect on whether or not the choice of

abortion had an expiration date, and if so, when? I met Charlotte when she was nine weeks pregnant. She explained:

You could say that I am choosing in relation to the prerequisites I want to offer my child *before* life has begun. But when life has begun [after birth], then it's as it is. Then we would just have to take it as it is.

Marie, ten weeks along, put it in similar terms:

Something could go wrong during birth, or after, you can't guarantee that won't happen. And you could say that if the baby has come out, then you have to be in it. Then you can't return it. You can't do that. But that's the possibility you have now, you could say.

When Charlotte and Marie were in the beginning of their pregnancies, *biological* birth marked a clear dividing line between 'rejectable' and 'non-rejectable' life. The majority of the women shared this understanding. But the women who I had the opportunity to follow through their entire pregnancy loosened the dividing line between pre- and post-birth as the symbolic marker of non-rejectable fetuses. Marie continued to talk of abortion as a possibility; both prior to and after the malformation scan in week 20. However, when we met for the third time when she had entered week 25 of pregnancy, she spoke of abortion in a different way, though not precluding rejecting the child-to-be entirely either:

Marie: In the beginning everything was quite unreal. I was like, let's see what happens. But now as the pregnancy has progressed I'm also growing closer to the child inside of me.

Laura: So I would like to return to the question about your thoughts on abortion?

Marie: Yeah, I don't know really. Of course it would be more and more difficult, because you are getting closer to your child, but still I'm also thinking a lot about what it would do to your child's life and your own life, and I'm also thinking that if I were to give birth to the baby today, well, how much should you help this child to live?

Laura: You mean, if you went into preterm labor?

Marie: Yes. Because I had a lot of Braxton Hicks contractions, and they [the hospital] said I might be in labor, and so I thought to myself that I might choose to opt-out [on the neonate] then. I don't know if I would, but I mean, they are not completed in any sense at this stage, and I've worked with a lot of premature kids, who had lots of problems.

Though I met several of the women at different stages of their pregnancies, the status of the growing child-to-be continued to be open to negotiation. Even when faced with the risk of preterm birth, Marie reasoned, to my surprise, that her potential child possibly could be 'left to die' as she envisioned potential long-term effects of prematurity as causing suffering. While I was not surprised that women spoke about growing more aware of the unborn child as the pregnancy progressed, I was struck by learning that the negotiation of fetal living did not circulate around questions of their personal moral feelings regarding second-trimester abortion. The negotiation happened mainly in response to the (perceived) *availability* of opt-outs. However, even though Marie envisioned having the choice to leave a premature neonate to die, some of the women closed the 'window of opt-outs' earlier. Meeting Cecilie just days before her child was due underscored the temporality of selective abortion in a quite compelling way. Like the other women, Cecilie was sure that she would opt for an abortion in case her unborn child had had Down's syndrome, but the upcoming birth of her son-to-be brought every prior consideration into a new light:

I wouldn't care if he were a *Mongol* [child with Down's syndrome] now. With him. I would love him no less. I would have eternal love for him [...] Just the thought of not having him now, it's unbearable.¹⁷

Or as expressed by Andrea when she was in the third trimester of her pregnancy:

It has changed in the direction of 'now we just have to figure things out', whereas there was more selection in the beginning. And it's true that the damages can be even more severe later without ending in an abortion. So

it's still important to me to have a healthy child, but now I'm so far in the pregnancy that an abortion is no longer an option.

Conclusion: Structural Directiveness in Danish Antenatal Care

In this chapter, I have provided an ethnographic exploration of the ways in which 12 women reasoned about, gave meaning to and acted within the regime of non-invasive routine prenatal screening as it is practiced in contemporary Denmark. I have argued that the women in this study did not make active, informed decisions to opt for prenatal screening, and did not perceive screening to be riddled with moral conflict. Rather, all of the women took the screening for granted as part of standard antenatal health care and, as such, adhered to it—uncritically. Based on this, I argue that even though Rapp's concept of women as moral pioneers has its pertinence in the context of prenatal diagnosis, it is not apt for women undertaking routine prenatal screening in a Danish context today. It has not been my aim to criticize in any normative sense the current offer of routine prenatal screening. Rather, I have set out to problematize, by way of inquiring about pregnant women's experiences and thought processes, some aspects of the prenatal screening program by pointing to some inconsistencies between *principle* and *practice*. The current prenatal screening program became normalized under the banner of informed choice and self-determination. By arguing that prenatal screening aimed only to enhance prospective couple's reproductive choices and autonomy, not to prevent disabled infants from being born, the Danish state has been able to distance itself from a problematic eugenic past—seemingly with great success. However, though the women reasoned about abortion in relation to their individual everyday lives, social relations and imaginaries about family life, thinking about terminating a pregnancy for medical reasons would simply not make sense if selective abortion was not available. The mere fact that the Danish government has sanctioned and institutionalized prenatal screening and selective abortion indirectly encourages pregnant women

to regard their child-to-be as a fluid, negotiable and contested entity that is potentially 'rejectable'.

Notes

1. The studies by Schwennesen (2010), Schwennesen et al. (2008, 2009) and Niklasson (2014) are exceptions.
2. FTPRA, consisting of a blood test from the mother, and a nuchal translucency screening of the fetus detect Down's syndrome (trisomy 21), Edward's syndrome (trisomy 18) and Patau's syndrome (trisomy 13); however, Down's syndrome has become the prototypical image of 'serious disease' connected to prenatal screening and diagnosis (Meskur 2009). However, this is perhaps no surprise since the official information pamphlet on prenatal screening, routinely handed out to pregnant women at the GPs' office, only mentions detection of Down's syndrome and 'serious malformations' as its aim (Danish Board of Health 2004b: 3). During the 21 nuchal translucency scans that I observed during fieldwork, all the sonographers only gave information about Down's syndrome. It took several months before I realized that screening also concerns other chromosome aberrations.
3. From a medical point of view, the main advantages of implementing FTPRA into Danish antenatal care was argued to be its higher predictive value compared to the previous regime and an expected reduction of the number of invasive tests carried out and the number of miscarriages caused by invasive testing, which is about 1% (Schwennesen 2010: 13).
4. According to my research, there are great inconsistencies between the statistical data provided by the Danish Board of Health and DCCR, meaning that a precise overview of the total number of abortions due to fetal aberrations is currently non-existing. In the statistical data, which I have collected from the Danish Board of Health, 660 second-trimester abortions were performed in 2011, out of which 290 were performed on social indication and 339 due to fetal aberrations. This contradicts the 385 abortions performed *singlehandedly* on the grounds of chromosomal anomalies, as listed by DCCR. Second, there are 31 abortions that have been performed but with reason unknown (Danish Board of Health, personal communication). Consequently, it is unknown precisely how many abortions are performed due to congenital malformations, such as

neural tube defects and structural malformations. Taking into account how routinized the regime of selective reproduction is in Denmark, I find this lack of follow-up knowledge quite disturbing.

5. One can only speculate, but taking the statistical evidence into consideration, it is not unlikely that the birth rate of children with Down's syndrome will drop even further, when non-invasive prenatal diagnostic technologies are made accessible in the near future. Non-invasive prenatal diagnosis (NIPD) is an early blood test that yields chromosome information on 'conditions' like sex and trisomies within a few weeks of the establishment of a pregnancy. As Rapp notes, this type of test is high likely to make trait selection via early medical abortion easier and more plausible (Rapp 2011: 16). See also Etisk råd [Ethical Council] (2009).
6. As already mentioned, prenatal screening is to be initiated on the basis of 'informed choice', where the women are asked if they want information about the services offered. However, as the initial quotes demonstrate, the impression I got from my informants was that their doctors mostly took for granted that they wanted to take part. No one asked the women if they wanted information, and only few women expressed that their doctor had explicitly verbalized it as an offer they could choose to accept or refuse, as they recalled it.
7. As Schwennesen (2010) describes, non-directiveness is defined by several bioethicists as the ethical gold standard and as a presumption for the realization of a truly autonomous choice in prenatal counseling (Schwennesen 2010: 15) Non-directiveness, defined as providing complete unbiased information and restraining from giving practical advice (Rehmann-Sutter 2009: 235), is thus seen as a tool to avert a potential powerful and authoritarian paternalistic doctor from determining what is right and wrong and dictating subsequent decisions. Questions have been raised in the Danish debate whether or not the policy of autonomous decisions in prenatal testing works as intended and whether pregnant women and their partners are well informed (Dahl et al. 2006a, b; Bangsgaard and Tabor 2007).
8. See also Schwennesen (2010) for similar findings.
9. This is similar to the Finnish experience as described by Meskus (2009). Schwennesen et al. (2008) also experienced that Danish couples reinstalled profound authority in the healthcare professionals when interpreting risk calculations in the context of FTPRA.

10. This point gets support from the study conducted by Schwennesen (2010) on Danish pregnant women's experience with decision-making in the aftermath of a high-risk assessment of Down's syndrome. Many women reported feeling 'unprepared to deal with this knowledge' (Schwennesen et al. 2009: 200).
11. Let me emphasize that I aim to problematize some aspects of the ways in which routine prenatal screening works, but in doing this I do not intend my criticism to reflect negatively on the women who have undergone screening; criticism of the moral and social impacts of the regime of prenatal screening is not criticism of them.
12. See, for example, Williams et al. (2002).
13. In fact, they write: 'The pregnant women and their partners were unwilling to give up the health professionals as the paternalistic expert' (Schwennesen et al. 2009: 201).
14. In an article published by the Danish newspaper, *Politiken*, a story is told about how the committees in some cases have allowed prospective parents to abort due to cleft lip and palate, while in other cases have declined the request (Politiken 2012).
15. The conversation with this woman took place after she had been both to the nuchal translucency scan and the malformations scan, receiving news that her fetus looked healthy (she subsequently gave birth to a healthy boy). She did not speak about the scenario of having to give birth to the aborted fetus until my probing about her thoughts on that issue.
16. Gail Landsman, for example, describes how American mothers of disabled children insist on the personhood of their children in spite of society's devaluation of impaired children as 'defected merchandise' (Landsman 1998). Anthropologist Elaine Gale Gerber argues that pregnancy must be understood as a 'reproductive continuum' that transcends a binary understanding of pregnancy as present or non-present (Gerber 2002). Gerber shows how French women in early, unwanted pregnancies depict the life growing inside of them as 'eggs', not fetuses. On the other end of the continuum, Danish anthropologist Tine Tjørnhøj-Thomsen has shown how infertile childless women personified unfertilized eggs as 'potential babies' even though they were far from an actual pregnancy in biological terms (Tjørnhøj-Thomsen 1999).
17. On the language used in Denmark to denote disability, see Kulick and Rydström (2015).

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5

Moral Bearing: The Paradox of Choice, Anxiety and Responsibility in Taiwan

Li-Wen Shih

Because you can't see it [the foetus], it [the process of pregnancy] is very stressful. Because it is uncontrollable, you worry about its [the foetus'] condition. It is as if you had paranoia. (Mu-En Yo, 34 years old, second pregnancy)

Prenatal screening and testing (PST) is a generic term that refers to a set of medical procedures that test the health of the foetus and pregnant women.¹ It is, for example, routine that pregnant women undergo several ultrasound scans in many parts of the world. The words *screening* and *testing* are used in different situations. Screening is for those who do not have a history of family disease and is used to see if they or their foetus nonetheless might carry certain kinds of genetic disease or congenital malformations. Techniques of screening include maternal serum screening (MSS) and the nuchal translucency scan. Testing, on the other hand, is

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for those who are suspected of or known to be carrying a specific genetic disease as well as for those who have come out with a screening result that indicates high risk. Prenatal testing can be performed by either invasive or non-invasive methods, with [amniocentesis](#) being one of the most widely used invasive methods requiring the insertion of a needle into the [uterus](#) to extract amniotic fluid at around 15–17 weeks gestation.

In Chinese, “chan qian jian cha” (產前檢查) means prenatal examination or check-up, and this term includes both screening and testing. In Taiwan, people usually use “chan jian” (產檢) as an abbreviation and both “chan qian jian cha” and “chan jian” are used to refer to both screening and testing. As such, prenatal examination in Taiwan can be either screening or testing and includes a range of different medical procedures that pregnant women undergo. It does not refer to a woman’s specific health condition or family genetic disease history. Moreover, it indicates that both screening and testing are implicated in prenatal examinations, and many pregnant women are actually not aware of this ambiguity and the differences it masks. To emphasise this blurriness, I use the term “PST” in this chapter not simply as an abbreviation but also to reflect its medical and social practice in Taiwan.

In Taiwan, when women become pregnant, they routinely have PST which is sponsored by the National Health Insurance (NHI) system and regulated by the *you sheng bao jian fa* (優生保健法) or “Eugenic Protection Law”. They are entitled to have ten free sessions of PST. According to an official survey, 97.21% of Taiwanese pregnant women underwent PST in 2008 (Department of Health, Executive Yuan 2009: 49), and in 2013 around 90.9% of pregnant women had ten sessions of PST (Ministry of Health and Welfare 2013: 23). It seems to be “natural” for most pregnant women to undergo a series of PST procedures as the pregnancy advances. But what is the significance of PST? As I will show, the experiences of pregnant women in Taiwan provide us with a particular answer to this question which is shaped by the kind of society they live in.

When conducting fieldwork to investigate women’s experience of PST in Taiwan in 2008 and 2009, I had an impression that my participants worried a lot. On average, the participants in my ethnographic study underwent around 13–15 sessions of PST—more than what the

Department of Health recommends. There were particular issues that concerned them. The health of the foetus was one of them. Their worries led me to investigate further how women in Taiwan experience PST through observations in prenatal care hospitals and clinics, by interviewing 35 women (in some cases their husbands as well) and also by asking them to make a drawing of PST which was then discussed during interviews. As I will argue, their anxiety is related not only to technological and medical practice but also to the social construction of responsibility for prospective mothers in Taiwan. In particular, the construction and routinisation of PST technologies as selective reproductive technologies (SRTs) compel women to judge their own foetus, turning them into the kind of moral philosophers that North American anthropologist Rayna Rapp described as “moral pioneers” to highlight how developing PST technologies produce new ethical decisions for pregnant women. In her book *Testing Women, Testing the Foetus*, Rapp (2000) suggests that women act like moral philosophers when faced with decisions about whether to accept further testing or refuse it during routine prenatal care. As Laura Heinsen (this volume) also discusses, Rapp argues that the women she interviewed in New York who were using or refusing amniocentesis can be seen as moral pioneers because they are historically the first generation to face moral decisions about whether to terminate a pregnancy depending on the health condition of the foetus; a decision previous generations did not have to face. When women are constituted as subjects at the intersection of either choosing to have a disabled child or terminating their pregnancy they are “culturally” positioned as moral philosophers who have to judge what kind of child can enter our community.

Since Rapp’s pioneering study which was carried out in the 1990s, SRTs have advanced globally, and women throughout the world cross moral frontiers during the course of prenatal care. As Danish Anthropologist Tine M. Gammeltoft (2014: 18) observes, “in China and Vietnam, present-day population policies focus on the improvement of population quality”, so to improve pregnancy outcomes through enhanced prenatal care becomes an important issue in those countries. In Vietnam, Gammeltoft observes that this brings women anxiety and uncertainty, particularly those women who receive PST results indicating that their foetus has an abnormality. In a country haunted by images of malformed

and disabled children blamed on Agent Orange which circulate through media reports and television programmes, Gammeltoft shows how pregnant women actively tried to avoid seeing such images for fear that the images would stay in their mind thereby negatively impacting their foetus (Gammeltoft 2014: 95). Even in a country like Denmark, which emphasises the importance of individual choice, eugenic orientation is still embedded in the prenatal care system. Laura Heinsen (this volume) uses the term “moral adherers” to illustrate how routinised prenatal care practices in the Danish welfare state implicates a “collectivized responsibility of selection” that has integrated into individual/reproductive choice, and that this results in Danish women taking PST for granted as part of routine prenatal care, uncritically adhering to the tests. Choice is never only personal, and that is because it reflects one’s social belonging (Gammeltoft 2014). In Tsipy Ivry’s (2010) book *Embodying Culture: Pregnancy in Japan and Israel*, Ivry uses two prenatal care models: “environmentalism” and “geneticism” to discuss women’s experience of PST in Japan and Israel. In Japan, Ivry shows how physicians emphasise pregnant women’s roles as the “makers’ [through weight control and proper nutrition during pregnancy] of their babies rather than the receptacles of genetically determined, ‘ready-made’ babies” (Ivry 2006: 459), which helps explain some of the resistance to routinised PST she met among doctors. The point being that no matter which prenatal care model women experience, these models are always connected to their social-cultural settings.

During my fieldwork in Taiwan, I observed that almost all of my participants persistently worried about the health of the foetus throughout the whole pregnancy, not just when they had to decide about amniocentesis or other tests. Significantly, as I will show, most of the women in my study are concerned about the burden to society when imagining a disabled child. Because of the health care system, medical practices as well as social and family values in Taiwan, women in my study encounter different difficulties than those in America or Europe. To highlight the specific Taiwanese social and cultural context, I use the term “moral bearing” to indicate Taiwanese women’s situatedness at a moral frontier in Taiwan. The idea of “bearing” is, according to Merriam-Webster online dictionary,² the way in which a person moves, stands or behaves; and it also means *to bear* from its verb which is “to accept or endure (something)” or

“to support the weight of”. In addition, a bearing can also be a machine part that makes it possible for one part of a machine to support another. In this chapter, I take these meanings to imply women’s moral enacting in PST in a context where societal expectations and personal desires are often conjoined. Because they bear concerns about their foetus’s health and the burden to society when imagining a disabled child, pregnant women actively undergo different routine prenatal checks and these checks bring them anxiety. In the following sections, I use my participants’ experiences of PST to illustrate how their anxiety is triggered by their sense of responsibility of having a genetically healthy child which is based on the notion of *you sheng* (優生) or “superior birth”, and also how their decisions, in return, help to reshape this moral terrain.

Prenatal Care in Taiwan: *Maternal Health Handbook and You Sheng*

In Taiwan, after ten weeks of confirmed pregnancy, a woman will receive a copy of the *Maternal Health Handbook* (*yun fu jian kang shou ce*, 孕婦健康手冊) from their obstetric clinic or hospital (Fig. 5.1). Its purpose is to introduce the different stages of pregnancy and to provide information on different kinds of genetic diseases to pregnant women. It is also a documentary record for obstetricians to keep track of the health of both the foetus and the woman. As noted earlier, pregnant women can have ten free sessions of PST by showing their *Maternal Health Handbook* when visiting an obstetrician. With this handbook, women will be referred to different scheduled PST programmes, including ultrasound scans and MSS. Therefore, in Taiwan, the *Maternal Health Handbook* is seen as both an identification of the woman and a document for medical records.

The *Maternal Health Handbook* is published by the Taiwanese government and is informed by the “Eugenic Protection Law” (literally “superior birth protection health law”). This law was passed in 1984, regulating birth control, including fertility, prenatal care and abortion. *You sheng* is often translated from the English term “eugenics”, which has a stigmatised association with ethnic superiority. In Chinese, *you* (優) means “the best” or “superior”, and *sheng* (生) as a verb means to give birth or to produce,



Fig. 5.1 The front cover of the *Maternal Health Handbook* (Chinese version)³

while as a noun it means “production” depending on the semiotic context. Hence, the term *you sheng* in Chinese means “superior birth” and has a positive meaning in Taiwan. However, as historian Yueh-Tsen Chung (2002: 11) suggests, when this term is used in the context of PST, it seems to be strongly related to the option of terminating an undesired pregnancy, for example, following the discovery that a foetus is carrying a genetic disease or congenital malformation. This connection has perhaps surprisingly not resulted in the term *you sheng* being viewed negatively in the general public. Different public opinion investigations (Discovery Channel 2003; Fu 2004: 245; 2005: 125) have shown that the public generally is positive towards the development of this type of selection. Without entering a discussion on foetal rights (which is relevant but not within the scope of this chapter), but instead with a focus on pregnant women’s experiences, this chapter shows that choosing a child from a *you sheng* perspective is far from unproblematic as it turns women into what we might think of as “moral bearers” during their pregnancies amidst considerable gestational anxiety.

Tracing Taiwanese Women’s Experience of PST

Sunny Days and Rainy Days

On 27 February 2009, a television news report about an infant born without a right hand described the parents accusing the obstetrician of medical carelessness because it was not discovered during ultrasound scans (Fan 2009). Although the news media reported this for only two days, it significantly affected pregnant women at the time of my study. It shocked couples who feared that it might happen to them and also affected obstetricians who were flooded with enquiries from couples seeking reassurance on this matter. During my observations in prenatal care hospitals and clinics, many couples were concerned about this issue. Obstetricians responded by trying to show pregnant couples where their foetus’ hands were and even counting the foetal fingers carefully, making sure the couples saw what they were being shown. Whilst conducting interviews with pregnant women, interviewees would ask me if I knew the news. What made the biggest impression on me was that whilst my participants told

me it would be really terrible and unbelievable if it happened to them, it was not the obstetrician's medical error per se, rather it was the possibility of having a child with this kind of problem that seemed to trigger their anxiety, underlining how pregnant couples in Taiwan fear anything that might be wrong with the foetus. For pregnant women, as Hong-Lan Din described it in her drawing, it is like experiencing a rainy day.

Hong-Lan has a very creative reflection on her experience of undergoing PST. She drew a woman standing in both a sunny day and a rainy day (Fig. 5.2). When we afterwards talked about her drawing, she explained:

In general, having PST for me is always full of happiness and fears. It is sometimes like a rainy day, but also sometimes like a sunny day. As a pregnant woman, the feelings are always very complicated, because you expect to have a check [ultrasound scan] to see the baby, but you also worry about hearing bad news. So it is always like that (Hong-Lan Din, 29 years old, first pregnancy).

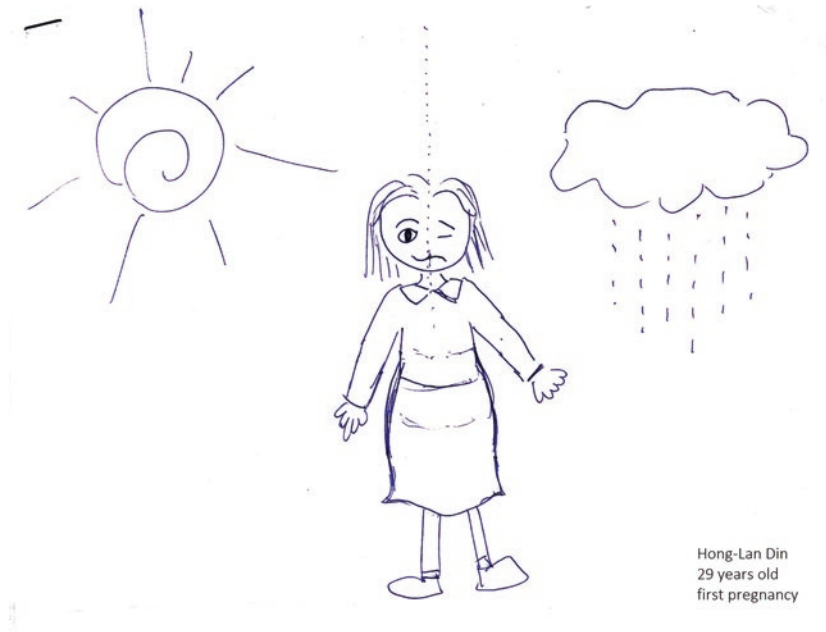


Fig. 5.2 Hong-Lan Din's drawing: Sunny days and rainy days

Having PST enables women to see the foetus on the ultrasound monitor and to know its health condition. That pleases them, but it also makes them anxious, as most of my participants' narratives suggest. Hong-Lan's drawing and description illustrates both her pleasure and anxiety in PST. She drew a woman who has two different faces and stands in two different weathers because she is not sure which one she is going to have; but these feelings are not opposite to each other, they always come together as her drawing shows. This kind of uncertainty, as another of my informants Mu-En Yo describes, is like a lucky dip.

A Lucky Dip

Mu-En drew a lucky dip (Fig. 5.3) to describe how PST makes her feel uncertain and anxious. She told me:

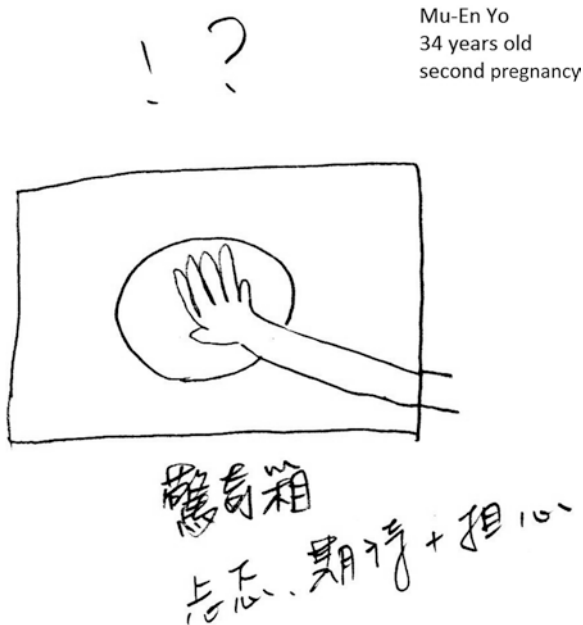


Fig. 5.3 Mu-En Yo's drawing: A lucky dip

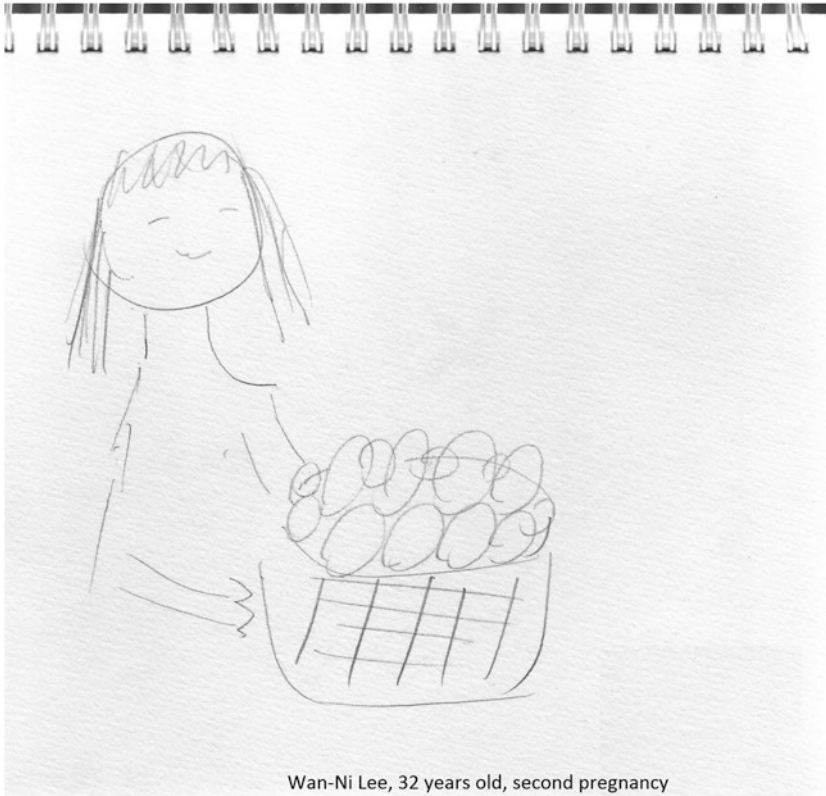
It is as if you put your hand into a lucky dip. And you will never know what you are going to get from the black box. So for me having PST is full of anxiety, expectation and worries. Because during each visit you don't know what your obstetrician is going to tell you. ... Therefore you are full of anxiety when you go into the clinic. I always look forward to visiting the clinic, but I also worry a lot (Mu-En Yo, 34 years old, second pregnancy).

The word in Chinese 驚奇箱 (*jing chi xiang*) that Yo puts on the top of the drawing means “surprise box” and translates into “lucky dip” in English. Lucky dip is “a game in which people choose a present from a container of presents without knowing what it is going to be” (Oxford Advanced Learner's Dictionary 2000: 800). This opacity brings uncertainty; it is unpredictable. To express her complicated feelings towards having PST Mu-En Yo uses three words: “tan te” (忐忑, anxieties), “qi dai” (期待, expectations) and “dan xin” (擔心, worries). In this way, Mu-En's experience of ambivalence corresponds to Hong-Lan's sunny and rainy days. But what is it that triggers women's anxiety? According to Mu-En “You will start to worry whether or not you will pass the prenatal screening and testing after you received the Maternal Health Handbook.” Mu-En started to worry after receiving the handbook, not when she discovered she was pregnant. For Mu-En, the handbook stirred her anxiety. Two of my other study participants, Yi-Zheng Hsu and Hsiao-Huei Chen, also shared this experience: “the more I know the more anxious I am” (Hsiao-Huei Chen, 33 years old, second pregnancy). Knowing more information may trigger women's anxiety but taking part in testing maintains this constant disquiet. It is as if women are carrying a heavy basket of eggs, as Wan-Ni Lee's drawing (Fig. 5.4) illustrates.

A Heavy Basket of Eggs

To explain her drawing, Wan-Ni said:

For me, having PST feels like I am caring for these eggs. It is like caring for this basket of eggs, and it is not easy. [...] When undergoing the procedure, I feel lots of expectations and anxieties. I worry I won't be able to hold the basket well, or that maybe there is a problem with the basket, and the eggs will fall out. I mean if there is any problem with it. My feeling is totally like that.



Wan-Ni Lee, 32 years old, second pregnancy

Fig. 5.4 Wan-Ni Lee's drawing: Holding a basket of eggs

Because I think what makes pregnant women worry is that there might be some problems detected with the baby. Therefore I felt cold during every PST, especially around my feet and hands because I was so afraid that the obstetrician would tell me there is any problem with my baby (Wan-Ni Lee, 32 years old, second pregnancy).

At first glance, Wan-Ni's drawing looks like a happy woman who is holding a basket of eggs. However, after hearing Wan-Ni's description, this does not seem to be the case. During our conversation, I could see from her body language that she was very worried and anxious about the health of the foetus. Wan-Ni described her anxiety as stemming from her own uncertainty about her capacity to hold and protect the basket.

When I asked further about what makes her feel so nervous during PST, she explained:

Sometimes I think about ...hmm...what would I do if anything happened to baby or if the baby was detected with some defect? [...] Many friends told me that I was thinking too much. I understand that many things are not controllable so I feel anxious and helpless in every PSTTherefore every time when I look at the monitor, I always just do a quick scan of the image of the foetus. Then I turned my head and tried to avoid seeing more of it. So when the obstetrician was showing the foetus, I always did a quick scan only. So for me, PST is like having to care for this basket of eggs, but it is actually not easy (Wan-Ni Lee, 32 years old, second pregnancy).

Even though Wan-Ni successfully gave birth to a child in her last pregnancy, she still experienced a lot of anxiety. When talking about her fear and uncertainty in PST her eyes welled with tears. It is clear that her anxiety is associated with uncertainty and lack of control concerning the health of her foetus: “I understand that many things are not controllable so I feel anxious and helpless in every PST.” This triggers her anxiety because she is afraid of having to decide between a termination or having a disabled child. Whilst she agrees with her friends that she is overthinking the risks, this doesn’t allay her fears. As Wan-Ni points out “once it happens to you, it is something that can’t be changed back for the rest of your life”.

In contrast to Wan-Ni’s anxiety, her husband Chi-Jie Shih sees PST as a “good thing”:

I don’t feel that PST is very troublesome. I do think it is necessary to have. It is good for the baby. If the result of PST shows abnormality, if the baby is anomalous, we would know earlier and therefore make the decision earlier (Chi-Jie Shih, 31 years old).

I interviewed the couple separately, Chi-Jie first, then Wan-Ni. When interviewing Chi-Jie, his positive attitude towards PST was clear; he saw it as a helping hand. He did not appear to be emotionally burdened by the experience, taking a more practical perspective: for Chi-Jie, PST could help him to make a decision earlier if the foetus is “anomalous”.

The decision-making that Chi-Jie talked about is the same thing that concerned Wan-Ni: “what would I do if anything happened to the baby or if the baby was detected with some defect?” However, imagining making this decision upsets Wan-Ni a great deal, whereas Chi-Jie seems to remain calm.

To understand how Chi-Jie experienced PST, I also asked him to draw a picture that answered the question: “What is PST for you?” Chi-Jie drew a pregnant woman undergoing an ultrasound scan done by one obstetrician (Fig. 5.5). He did not put himself in the drawing. Interestingly, I found that almost all my male participants drew only the PST technology, the obstetrician and the woman. They position themselves as outsiders in the course of PST. This echoes other studies which show that women usually do more and take more responsibility than men when engaging in reproductive technologies (Wu 2000, 2001; Franklin and Roberts 2006; Throsby 2004; Rapp 2000). This means women experience more

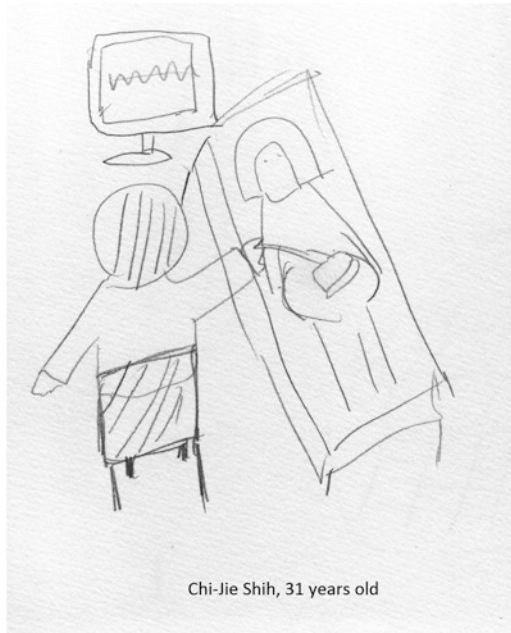


Fig. 5.5 Chi-Jie Shih’s drawing: A woman with an ultrasound scan

pressure than men, as shown by studies in both the USA and Taiwan (Rapp 2000; Wu 2000, 2001). As Rapp (2000: 127) explains:

Most of the technological augmentation of anxiety is expressed by women, not only because pregnancies happen inside of women's bodies, but because most (perhaps all) cultural constituencies in contemporary America assign the benefits and burdens of making and raising babies to women.

Rapp suggests that the American women in her study are often the ones who disproportionately bear the burden of rearing children. Even though men's involvement in childrearing may be a social goal, women do the hard work of living with pregnancy and facing PST. She sees this as an instance of "male privilege" (Rapp 2000: 182). In a similar vein, Celia Roberts (2006) suggests that men's role in reproductive process is gendered through social and medical practices which constitute women within an uneven distribution of responsibility for decision-making. In Vietnam, decisions arising from PST are often taken not by women alone, rather following consultations with extended family members. Yet, even in such situations of collective decision-making, Gammeltoft has argued that it was the women who alone struggled with the "dilemmas of conscience" surrounding selective abortion (Gammeltoft 2014: 223). In my study, the main reason that makes Hong-Lan, Mu-En and Wan-Ni worry is not only the burden that they bear, but also the moral decisions they may have to make. As Wan-Ni asks, "what should I do if anything happened to the baby or if the baby is detected with some defect?" This difficult question positions them as "moral pioneers", yet as we will see, not necessarily in the same manner as women in America or Europe might be.

Amniocentesis: Accounting for PST

According to a national survey from 2008, there were 330,000 pregnant women who underwent amniocentesis, an increase of 95.9% from 1998 (National Statistic ROC, Taiwan 2009: 49). However, this number represents pregnant women who were sponsored by NHI only. If counting those paying the examination fees themselves, the number would

be higher. While conducting my fieldwork, I found that many young women requested to have amniocentesis. Many of them were less than 30 years old, and thus not within established risk categories, and therefore had to pay the examination fee of 8000 NT dollars (around 170 British pounds). Without clinical indication, some women still decided to have amniocentesis even if it is one of the more expensive self-pay medical examinations in Taiwan and increases the risk of miscarriage.

Shu-Lan Hua told me the reason that she engaged with amniocentesis:

The purpose of amniocentesis is to see if the baby carries some possible disease. And the accuracy for maternal serum screening is only 50–60% reliable for seeing if the baby has the problem. However, amniocentesis is 99% reliable for seeing if the baby carries Down's syndrome. Therefore we of course chose the latter one even if it is a bit scary. I heard that most Down's syndrome children were born by young women. Especially when I heard a story from one of my friend's wife, I had decided to have amniocentesis. She gave birth to a Down's syndrome child when she was 22. Her maternal blood screening is very low, so she didn't have further testing. After hearing this, I wanted to have amniocentesis straight away. I had it in my last pregnancy, so I did it again this time (Shu-Lan Hua, 26 years old, second pregnancy).

Learning from a friend's experience and other sources of information, Shu-Lan was convinced that MSS is not reliable enough, so she decided to have amniocentesis in her first pregnancy even though she was only 23 years old and had no family history of Down's syndrome or any genetic diseases. As she emphasised, the reliability of MSS is about 50–60% compared to 99% in amniocentesis. For Shu-Lan, MSS does not provide a certain answer. In contrast, she thinks that amniocentesis does. This "technological accountability" implies a certain kind of purpose (Franklin and Roberts 2006: 228). Clearly for her it is important to know whether the foetus has Down's syndrome or not, as she does not want a Down's syndrome baby, as she told me, "we can make the decision earlier if we know the result earlier", which was similar to Chi-Jie's ideas. Like some of my other participants, Shu-Lan explains why she made the decision to have amniocentesis: to know for certain whether the foetus has Down's syndrome (and other genetic defects) or not.

Many of my participants were keen to know the health condition of the foetus. To ascertain a definite answer, they all chose to have amniocentesis, as Yi-Ling Sue suggested, “PST can ease your anxiety” (Sue, 29 years old, first pregnancy). However, although some women think that PST can ease their worries about the health of the foetus, at the same time, it can also produce more anxiety as I learnt from Wan-Ni’s and Hong-Lan’s experience.⁴ In the next section, I use Hsue-Juan Zhang’s description of PST to illustrate how decision-making about whether or not to have amniocentesis is an anxious process.

To Do or Not to Do: Visiting Four Obstetricians in Five Days

As already noted, within Taiwan’s health care system, pregnant women are entitled to have ten free sessions of PST, and they can choose to visit any clinic or obstetrician for these. During my fieldwork, I found that many of the participants in my study engaged with a form of prenatal care “shopping” when they were anxious and seeking a second opinion.

They told me it [the white spot] could be detected as Down’s syndrome because my baby is big enough that time, so they could find it through ultrasound screening. I think the obstetrician checked very carefully. I didn’t know that the cyst in the brain could cause Down’s syndrome. Through last Friday, Saturday, and Sunday, I suffered a lot. It was really difficult for me because every obstetrician had a different opinion. It was the holidays and we went back to our home town of Yi-Lan. On the Friday night, we went back to Yi-Lan after visiting Wu’s clinic, and we discussed with in-laws. All the family came and discussed about how to sort it out together. My in-laws worried a lot. [...] They suggested I visit an obstetrician in Yi-Lan. The obstetrician thought that it is alright and I shouldn’t worry so much. [...] After I visited that obstetrician, they worried a lot. They worried if having amniocentesis would hurt the baby. They decided that I should have a maternal blood test first. Therefore we decided to have a maternal blood test (Hsue-Juan Zhang, 30 years old, second pregnancy).

Hsue-Juan recalled the days when the obstetrician revealed a cyst in the brain of her foetus, and how it worried her and her family. To get a second opinion, she was advised to visit another obstetrician. To avoid miscarriage, she was advised by her in-laws to have a MSS. In Hsue-Juan's case, her family was involved with the decision-making.⁵ However, Hsue-Juan was so upset that she fainted after the blood sampling. She told me "I worry it [amniocentesis] might hurt the baby or cause a miscarriage. I also worried about if the result is positive."

Hsue-Juan's anxiety is twofold: firstly, the foetus may have Down's syndrome; secondly, amniocentesis may cause a miscarriage. Even though the obstetrician in Yi-Lan city advised her not to worry too much, she was still anxious. Two previous obstetricians had advised MSS, but it seems their efforts did not comfort her. However, she made her mind up after consulting a third one.

So after two days, on the morning of 6th of April, we went to visit Wu's clinic again, to visit another obstetrician, Dr. Wu, to have another check again. During the course, he knew my situation and asked us what we want to know. He said 'Do you want to know if the risk [of having a Down's syndrome child] is high or low? Or do you prefer to know if you can pass this test?' In other words, he meant that having amniocentesis is very common nowadays. So his suggestion was we could go straight to have an amniocentesis. That's the reason we visited Ke clinic after seeing him at the same day.

(Interviewer: Really? Did he say having amniocentesis nowadays is very common?)

Yes. He said it is very common, and it is not a big deal. He told us that his wife and many nurses in his clinic, who are under 30 years old, all had amniocentesis. He thought it was absolutely fine. He also thought that miscarriage is rarely caused by it. He meant that the percentage of miscarriage after having amniocentesis is not high. He also told me that he has nothing to do with it if finally the result of amniocentesis is positive. He meant that it is not his responsibility if it does happen like that (Hsue-Juan Zhang, 30 years old, second pregnancy).

Hsue-Juan finally decided to have amniocentesis after visiting Dr Wu, the third obstetrician. She seemed to be convinced because the obstetrician

gave her direct advice. What is more, Dr Wu spoke to Hsue-Juan's anxiety more directly and asked her what she was actually looking for: "Do you want to know if the risk [of having a Down's syndrome child] is high or low? Or do you prefer to know if you can pass this test?" It is clear that Hsue-Juan seeks the latter but that this is also what triggers her anxiety because this "test" embodies both medical and social discourses. Dr. Wu's emphasis on Hsue-Juan's responsibility if an undesired result were to occur raises a question: what kind of responsibility is this? I would argue that Dr. Wu's account of responsibility is misleading, and that in fact this responsibility is unevenly distributed to Hsue-Juan. When Dr. Wu told Hsue-Juan about the health of the foetus, he participated in a moral judgment about it. Dr. Wu told Hsue-Juan that "it is common to have amniocentesis" which implies selection and termination, but he deflects the responsibility for this onto Hsue-Juan. This is what triggers Hsue-Juan's anxiety; she is made to feel responsible for the result whatever it is.

Moreover, I also want to argue that women's anxiety and decision-making imply their responsibility for *you sheng*. The women I interviewed are influenced by *you sheng*, a discourse and policy which places emphasis on having a healthy child, and this involves women's responsibility for having further genetic testing, even though this includes judging the quality of their own foetus and the possibility of termination. This is what puts women at a moral threshold as all the women in my study made their decision by referring to *you sheng*.⁶ As such, I use the term "moral bearing" to indicate that Taiwanese pregnant women are positioned in ways unique to Taiwan especially as a result of the wide acceptance of the idea of *you sheng*—an idea that contributes to Taiwanese pregnant women constantly imagining and worrying about their child becoming a burden to society. In addition, as I will argue, in the Taiwanese context PST places pregnant women in a paradoxical position.

Paradox: The Responsibility and the Choice

In Hsue-Juan's story, Dr. Wu sees PST as an examination of a pregnant woman. So his directive suggestion is to have amniocentesis to see whether Hsue-Juan will pass or not. This conceptualisation is also

expressed by Mu-En, Hsiao-Huei and Pei-Yian. As Pei-Yian said, “PST is like an exam, and it matters whether you pass it or not” (Pei-Yian Tsai, 31 years old, second pregnancy). Seeing PST as an exam could certainly trigger anxiety in women because no one likes to fail an exam. For me, this “exam” implies a negative attitude towards the foetus and the woman. So, what if they fail it? When I asked Pei-Yian about this, she said:

If it is confirmed that it [the foetus] does not develop well [with Down’s syndrome], it is better to terminate within 24 weeks. So it is very difficult for women (Pei-Yian Tzai, 31 years old, second pregnancy).

Pei-Yian’s suggestion that when the foetus is confirmed with high risk of Down’s syndrome, “it is better to terminate within 24 weeks” is based on termination law in Taiwan. According to Article 9 of the “Eugenic Protection Law”, women are allowed to terminate a pregnancy when the foetus is diagnosed with a malformation based on medical evidence; or when women are mentally or physically affected by the pregnancy in a negative manner. However, in Pei-Yian’s statement, what “is very difficult for women” is their failure of the “exam”, imagining having a disabled child and undergoing a termination.

I worried about my baby with Down’s syndrome; of course I worried about it. I was afraid of having a kid with Down’s syndrome since it will bring more burdens for our country (Hsue-Juan Zhang, 30 years old, the second pregnancy).

Seeing one’s own child as a burden to society could be difficult. Hsue-Juan is not alone in conceiving of disabled children as a burden to society. Other participants, like Chi-Jie, Wan-Ni, Hong-Lan and Chiao-Wong Lian, also expressed this to me during interviews:

[Chiao-Wong Lian:]Once you give birth to him/her, you need to take the responsibility. You need to take care of him/her through your whole life. This is your responsibility, and you can’t abandon him/her. [...] But people will ask why you gave birth to this kind of child and they probably will discriminate against the child.

The earlier you undergo the test the better decision you can make about the foetus. My obstetrician also suggested we engage with CVS [chorionic villus sampling] since it is the part of the prenatal checks we can have in the early stage. Then we can make a decision if there is a problem with the foetus. [What decision?] I meant terminating the pregnancy. You know, I shouldn't deliver it if my baby carries thalassemia. It will bring lots of social costs and be a burden to the whole society (Yi-Zheng Hsu, 31 years old, first pregnancy).

When seeing disabled children as a burden to society, my participants' attitude towards termination is clear. It seems as if they are not concerned about disability rights or abortion. As I will discuss later, this kind of impression could mislead us when probing the paradox of PST.

Only 2 out of 35 participants who participated in my research said that they would not terminate the pregnancy if the foetus was detected with Down's syndrome. The rest all said that "the earlier you make the decision the better it is" (Tzi-Xing Huang, 34 years old, second pregnancy). Wen-Feng Tu was one of the outliers in the group, she described her determination not to terminate her pregnancy:

I had maternal blood testing, and the data was higher than average. So my obstetrician suggested I have amniocentesis....I asked my obstetrician what is the purpose of doing this. My obstetrician answered that it is a kind of testing which has higher accuracy to detect if the foetus has Down syndrome. He said that we [my husband and I] can consider terminating the pregnancy if the result of amniocentesis is positive. I told my obstetrician that there is no difference for me because my decision will never change no matter whether the foetus has Down syndrome or not (Wen-Feng Tu, 32 years old, first pregnancy).

Wen-Feng told me that she saw many friends and colleagues experience anxiety and pressure "because they all want to avoid having a disabled child". As she suggests:

This kind of decision is the result of bringing hospitals and pregnancy together. It is also because of *you sheng* expectation of pregnant women and their family, they together construct this kind of idea (Wen-Feng Tu, 32 years old, first pregnancy).

As Taiwanese scholars Chiang et al. (2005, 2006) suggest, the routine checks of PST help to construct a specific life attitude of *you sheng* (some women they interviewed explicitly emphasised *you sheng*). As they argue, not only does this kind of routine check shape ordinary people's attitude to disability, the idea of *you sheng* is also implicit in the *Maternal Health Handbook* (Chiang et al. 2005). "When women are encouraged to have amniocentesis, they also internalize discriminatory beliefs concerning disabled people" (Chiang et al. 2005: 74). What is more, because of this *you sheng* attitude, most women see disabled children as a burden to society. When women are imagining disability and facing reproductive decisions, they found that *you sheng* becomes one of the important factors that helps them to make their decision (Chiang et al. 2005). Chiang et al.'s research resonates with my observation that most of my participants use *you sheng* to justify their decision as morally sound. As Mei-Hua Lee suggested to me, "[a]s you know about *you sheng*, we shouldn't give birth that is not *you sheng*" (Mei-Hua Lee, 34 years old, first pregnancy).

From Wen-Feng's and Hsue-Juan's experience of PST, it is clear that their obstetricians delineated their choices; obstetricians are actively involved in pregnant women's decisions during the course of their prenatal testing. In this case, the choices available to pregnant women are not as free and open as the medical establishment suggests. Tom Shakespeare (1998: 676) contends that genetic testing technologies are never neutral "because the possibility of obtaining prenatal genetic information inevitably creates new problems and dilemmas". Testing and selection are made desirable through PST.

Although PST makes women anxious, they still rely on it. "PST is one of the things I like the most in my pregnancy, but it is also the one I am most scared about" (Wan-Ni Lee, 32 years old, second pregnancy). This paradox corresponds to Hong-Lan's drawing; it is like sunny days and rainy days coming to women together. This paradox demonstrates the complex intertwinements of *you sheng*, morality, technoscience and women's reproductive choice. It also illustrates how women, as moral bearers, are constituted in morality and choice in Taiwan. Another paradox, as I have argued earlier, is that having PST appears to be an individual choice where women are themselves responsible for their decision-making; however, this idea of PST is in fact socio-technically

constructed through *you sheng*, medical professionals and technological practice, and it can therefore be questioned to what extent we are actually dealing with individual choices.

Conclusion

The choices of the pregnant women who participated in my study are shaped by the medical, social and moral terrains within which they are situated. However, once made, these decisions, in turn, reshape the social and moral terrain. What is more, participants' decisions are informed by moral debates concerning the health of the foetus and avoiding bearing a child who will burden society. Their anxiety indicates that making this decision is difficult because it involves collective values. Rapp uses the term "moral pioneers" to indicate that both accepting or resisting having testing involves participating in a set of values and reshaping the social and moral terrain. I found this to be the same in my research. Yet, by extending Rapp's discussion on moral pioneers, I use the term moral bearing to identify the difference between the women in Rapp's study and my work. Almost all my participants participate in articulating the moral value that a disabled child is a burden to society, and in return, their decision helps to confirm that value. Prenatal decision-making embodies those distributed actions and enacts biomedical and social values. My participants' decision-making and also their anxieties demonstrate the context of moral bearing that they are constituted in. Most women in my research chose to have further testing and indicated that they might terminate the foetus if the result is positive, but this attitude is not only an expression of individual moral, it is interwoven with the idea of *you sheng*, medical practices and family relations (particularly important is pressure from in-laws). All of those factors together push women to the intersection of a moral frontier to judge their unborn foetus during PST. More specifically, women act as moral bearers, their decision-making does not only intertwine with medical professionals, technoscientific practices and social values, but also enact moral judgements of women's reproduction.

However, as we have learnt from these women, their choices usually also reflect their individual experiences and religion. As Wen-Feng

suggests, having a disabled child is a challenge for parents. To some extent, Taiwanese women's attitude to terminating the pregnancy seems to stem from a practical approach which is similar to that Gammeltoft found in Vietnam and different from the women in Rapp's study who seem to be pushed at the intersection of abortion and disability rights. Women's choices may be constituted in social and biomedical practices, but women are not passively participating in the process. Instead, their choices and positions as moral pioneers indicate the material-semiotic relations in which they are embedded in. One significant paradox in my findings is that Taiwanese women seem to rely more on technologies and medical professionals to ease their anxieties even as their anxieties are triggered by these same practices. It seems as if women's anxieties cannot be stopped once they are constituted in Taiwan's routinised PST programme.

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Notes

1. This chapter is part of my PhD thesis. A version of it appeared in Chinese in the Taiwanese Journal: *Taiwanese Journal for Studies of Science, Technology and Medicine* 21: 77–134.
2. Please see the website: <http://www.merriam-webster.com/dictionary/bearing> (last accessed 15/9/2016).
3. Please see Bureau of Health Promotion, Department of Health (2008).
4. This is similar to what Gammeltoft found in her study in Vietnam: "Although many women said that they found ultrasounds anxiety-relieving, their stories indicated that fetal images were also anxiety-producing" (Gammeltoft 2014: 90).
5. As some studies show, a woman's pregnancy is not just a personal issue in Taiwan, particularly because it embodies patrilineal reproduction (Stafford

1992; Chen 1990; see also Gammeltoft 2014 on Vietnam). It is a family issue. The sex of the foetus concerns the family, so does its health. This imposed lots of pressure on women in my study. In particular, when the in-laws participated in decision-making, it both made women stressed and made them feel like the foetus was more important than them. For example, Wei-Lun Wu (33 years old, first pregnancy) said that “they only care about the foetus not me”.

6. See Zhu (2013) for a discussion of how maternal serum screening has become a part of a “quality assurance regime” which enlists pregnant women to take active measures of self-assurance in the People’s Republic of China, not least with direct reference to *you sheng* discourses.

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6

Selecting What? Pre-implantation Genetic Diagnosis and Screening Trajectories in Spain

Vincenzo Pavone and Sara Lafuente Funes

Genetic testing is one of the few biomedical sectors in which significant advances have been made in the past 20 years. Over this period of time, new genetic testing technologies have made their way into healthcare practices. Interestingly, the field in which most new genetic testing technologies have been introduced is human reproduction, especially assisted reproduction (Overall 2012; Rothman 2001).

Among these technologies, pre-implantation genetic diagnosis (PGD) and pre-implantation genetic screening (PGS) have raised enormous expectations due to both their ability to prevent the transmission of hereditary genetic diseases and their promise to improve success rates of in vitro fertilization (IVF) (Mastenbroek et al. 2007; Pehlivan et al. 2003). Often singled out as a paradigmatic example of soft eugenics, PGD has been criticized as yet another instance of the medicalization of reproduction, health and life (Ehrich and Williams 2010; Holm 2009;

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Krahn and Wong 2009). It has also been suggested that genetic testing, in general, and PGD, in particular, contribute to the commercialization and commodification of bodies, tissues and reproductive practices, in the context of a neoliberal strategy of individualization of medical risk and marketization of healthcare (Bunton and Petersen 2005). Experiences and imaginaries of patients undergoing PGD/PGS have also been explored (Ehrich et al. 2007; Lavery et al. 2002; Roberts and Franklin 2004), just as their political economy dynamics have been studied (Pavone and Arias 2012). However, most of these social studies have focused on PGD for molecular diseases while little work has been done on PGS.

This chapter aims at contributing to these debates by addressing what it means to go through pre-implantation genetic testing in Spain today. Spain alone performs almost half of all the PGD and PGS in Europe (Kupka et al. 2014). In Spain, however, PGS is, by far, the most implemented practice, representing more than 80 percent of the tests performed, according to a national registry that collects data from about 67 percent of the Spanish IVF centers (SEF 2013). Moreover, Spain has a very permissive legislation, which allows PGS to be performed without specific authorization, and adopts a set of very flexible criteria to grant permission to perform PGD. Finally, Spain has become a worldwide hub for assisted reproduction-related travel, both for PGD/PGS and egg donation, and possesses a remarkable IVF private sector, which features among the most technologically advanced in the Western world (Bergmann 2014; Salama 2014). Consequently, and contrary to the situation described in several other studies on PGD, the Spanish pre-implantation landscape is characterized by an unrestrained, massive use of PGS directed at increasing IVF success rates and a limited, stable recourse to PGD to positively select embryos free from specific genetic mutations or histologically compatible to their siblings for therapeutic reasons.

Drawing from interviews with patients undergoing PGD or PGS in different regions and clinics in Spain, we show that there is a significant difference in the experiences of women undergoing PGD and PGS. The experiences of women undergoing PGD with chromosome translocations—whose knowledge of their genetic condition followed their attempt to have children—lay somewhere between PGD and PGS, but are closer to the experiences of women undergoing PGS. These differences are not

(only) due to the different techniques, they are rather due to the different trajectories that the two techniques often entail. Many factors account for these differences, such as the clinical setting, referral routes and the actual health conditions. Though selection is at work in both cases, what is being selected and for what purpose is different for PGD and PGS, and so is the related experience. As such, examining how couples reflect on and experience embryo selection prior to implantation in Spain provides important insights into the material and conceptual intersections, convergences and blurring of assisted and selective reproduction in the twenty-first century.

Selecting What? PGD, Reproductive Autonomy and Genetic Reductionism

Within reproductive medicine, pre-implantation genetic testing constitutes the technological core of the reprognetics sector. It has been argued that it is a sociotechnical practice developed as part of a broader process re-configuring health, kinship and reproduction into increasingly medicalized practices within a general neoliberal strategy of market-based provision and regulation (Pownall 2013; Ruckert et al. 2015). Many studies addressing pre-implantation genetic testing wonder what it is that is actually being selected through genetic testing; what kind of biological characteristics are being given priority and what kind of social expectations, values and visions of life are being, thus, selected and reproduced. Indeed, pre-implantation genetic testing might be considered, in many ways, a family planning practice. As a consequence, it sparks questions about what kind of family types and relationships are being reproduced and what kind of society, and economy, is ultimately being endorsed. In order to answer these questions, different approaches to the study of genetics, health and society have been developed.

Some scholars have approached PGD and PGS from a perspective of biomedicalization of health, disease and identities (Clarke 2003; Clarke et al. 2010). From this perspective, PGD is seen as contributing to the ongoing transition from medicalization to biomedicalization, shifting the emphasis from enhanced control over external nature to the harnessing

and transformation of our internal nature (Ehrich and Williams 2010). Inspired by these studies, some have argued that pre-implantation genetic testing may be promoting a gradual shift from a complex, sociobiological view of human life to a narrow, reductionist approach where differences among individuals would be increasingly reduced to their genetic characteristics (Arribas-Ayllon et al. 2013; Bumiller 2009; Finkler 2011).

Other scholars have focused on the role played by genetic testing in a European context of increasingly privatized healthcare, constructed around patient choice models and inspired by new public management approaches. In this context, the increasing availability of genetic information is allegedly transforming the governance of population's health and encouraging an active participation of citizens constituted as "pre-patients", because of the genetic risk they carry, and as "potential consumers", for all the treatments they may have access to (Castiel et al. 2006). From this point of view, PGD emerges as yet another selective technique reinforcing the societal transition toward genetic welfare while consolidating an existing trend toward an individualization of health and care responsibilities.

Many studies have addressed the motivations of women and couples undergoing PGD. Some authors highlight the importance of reproductive choice, the desire to avoid abortion and the welfare of the future child as the main factors driving them to use PGD (Ormondroyd et al. 2012). Kalfoglou et al. (2005), for instance, argued that the use of PGD to avoid severe, life-threatening genetic illness or to select embryos that are a tissue match for a sick sibling was strongly supported, while its use to avoid adult-onset genetic disease, to select for sex, or to select for other non-medical characteristics was rather controversial. While these scholars have insisted that PGD for hereditary, life-threatening, genetic diseases increases reproductive choice and fosters individual autonomy, others have shown how this increase of choice opens a variety of more complex decisional scenarios (Järvholm et al. 2014). For instance, it has been observed that a history of miscarriages and infertility increases the willingness to undergo PGD, while the existence of an already affected child rather reduces couples' determination to use PGD (van Rij et al. 2011). It has also been argued that the increase of choice offered by PGD can actually hamper couples' choice (Zeiler 2004).

From a slightly different point of view, Hershberger and colleagues have focused on the importance of the individual psychosocial journey in the decision-making process (Hershberger et al. 2012). Similarly, Drazba et al. (2014) suggested that economic incentives and constraints play a crucial role in the decisional process. Others have rather stressed the importance of the IVF-stem cell interface (Franklin 2006), emphasising the higher propensity of women undergoing PGD or PGS to donate their “spare”, genetically discarded embryos to research (Franklin et al. 2005; Svendsen and Koch 2008).

Finally, some scholars have studied the impact of national regulations, bringing to the fore how restrictive legislation may reduce the prescription of PGD in a particular national setting, while simultaneously encouraging a growing flow of affected couples going abroad to achieve it (Gianaroli et al. 2014), a phenomenon also known as reproductive tourism (Pennings 2002). It has also been argued that women undergoing PGD converge at the IVF clinic from a diverse range of reproductive and genetic trajectories, under very different psychosocial circumstances and with remarkably different worldviews (Karatas 2010). As already noted, the large majority of these studies have essentially focused on PGD for hereditary genetic disorders, while little is known about couples undergoing PGS.

Aims and Methodology

This chapter aims at exploring and analyzing what it means to undergo both PGD *and* PGS in Spain today. Paying a special attention to the different *routinization* trajectories that PGD and PGS follow, the chapter collects and analyzes different experiences and perspectives of PGD and PGS patients.¹ What these two groups have in common is that embryo biopsies following IVF are used to select those embryos that will be implanted. This similarity notwithstanding, this chapter specifically addresses the following three main research questions: What are the motivations, expectations, doubts and concerns of women undergoing PGD and PGS? Are there relevant variations between PGD and PGS experiences? And what are the main factors that may account for these variations?

In order to address these questions, we conducted 21 semi-structured interviews with women undergoing PGD or PGS in private and public hospitals across different regions in Spain between 2010 and 2012. Originally gathered to investigate the articulation of PGD and PGS in Spain from the perspective of the women involved, these interviews were part of a broader data-gathering endeavor, which included interviews to policy-makers and medical professionals. Interviews were collected following the principle of maximum variation sampling (Creswell 2013) in order to ensure access to different experiences with regard to the technique, regional diversity and the type of healthcare setting (public, private or private with public subsidy). All women interviewed had undergone either PGD or PGS, or were considering doing it at the time of the interview. The interviews, organized around open-ended questions, explored different issues around PGD and PGS, such as personal experiences, choice of IVF center, level of information, access to the tests, psychological and genetic counseling, embryo donation, public versus private IVF settings and future prospects of the technique. The interviews lasted between 45 and 60 minutes, were recorded, transcribed and, finally, analyzed through a combination of *thematic data analysis* and *discourse analysis*. The former was employed to identify the most recurrent topics and to reconstruct the various organizational, medical and social steps of the PGD/PGS journey (Marshall and Rossman 2011). Discourse analysis, on the other hand, was used to identify, analyze and interpret the emotional, discursive and representational tools adopted by the interviewees to make sense of their experiences and to frame and communicate them to themselves and to others, including the interviewer (Potter 1997).

Regulating Pre-implantation Genetic Testing in Spain

Although Spain's public healthcare system is well developed and highly valued by its citizens, assisted reproductive technologies (ARTs) and genetic testing are mostly accessed through the private sector (Pavone and Arias 2012). Indeed, the private sector has historically played a leading role in shaping the way in which ARTs developed in Spain, setting the agenda,

defining the problems that were likely to be addressed as well as the ways in which those were to be resolved (González 2014).² As a result, legal regulations followed, and were adjusted to, already existing practices, accommodating the needs and priorities of private clinics (Pavone and Arias 2012).

PGD was first regulated in 1988, when it was still an experimental technique (McClaren 1987). The 1988 Act considered pre-implantation genetic testing both as a tool to improve the success rate of assisted reproduction techniques and as a diagnostic tool for the detection of hereditary diseases. Given the experimental stage of PGD, the actual regulation was left to future legislative interventions based on three measures: the licensing and monitoring of authorized assisted reproduction centers; the setting-up of a consultative body to assess the government on the elaboration of appropriate legislative measures; and the creation of a National Registry, in which assisted reproduction activities could be recorded and stored (Alonso 2005).

In 1996, the law attributed the authority to license IVF centers to the regional governments but did not establish any specific authorization procedures for PGD and PGS. By then, private clinics had been performing these techniques without any specific regulation and control. The 1996 Bill, thus, entrusted the National Assisted Reproduction Committee (CNRHA) the regulation of PGD and PGS. Established in 1997, the CNRHA could not regulate the matter until 2006, when a specific bill introduced clear regulation criteria for PGD and PGS. The 2006 Act, however, did not establish a closed list of genetic conditions, introducing a more flexible regulatory regime to accommodate future technological advances without the need to modify the regulation. More specifically, the 2006 Act permitted the use of PGD for all the genetic hereditary conditions that could be considered “serious, early-onset and for which no treatment exist” and approved the use of PGD and PGS “to detect the alterations that may affect negatively the viability of the embryos”. In all the cases that met these criteria, IVF centers and hospitals were expected to inform, through their regional authority, the CNRHA, from which no further authorization was required. All other cases required a specific authorization from the CNRHA (Muñoz 2012).

Nowadays, access to PGD is usually granted through public healthcare. Strict conditions apply to access the three cycles covered by the

social security system, and those are only available to women under 40. Recently, access to IVF treatments in the public healthcare system has been denied to single women and lesbian couples because “the absence of a male partner is not a medical condition”³ (El País, July 18 and 23, 2013). Yet, some regions contested this measure, refusing to implement it. The public healthcare system, however, implies long waiting lists of more than two years, depending on the regions (Adeces 2015). While in a traditional IVF, couples with living offspring are prevented from accessing subsidized assisted reproduction; this condition does not apply to couples undergoing PGD to avoid transmission of hereditary diseases. Finally, being a controversial technique, whose effective ability to improve success rates has been extensively criticized (Hardarson et al. 2008), PGS has not been included in the social security system. While it has never been at the center of any public debate or controversy in Spain, PGS remains accessible only in private clinics where it is generally offered as an extra service enhancing the chances of success of the IVF cycle, which very much reveals the intense commercialized approach in the Spanish political economy of ARTs (Pavone and Arias 2012).⁴

Main Findings: Pre-implantation Trajectories

In 2014, Sociedad Española de Fertilidad (Spanish Fertility Society) (SEF) reported 2890 PGDs and PGSs. Of these, about 1000 were PGD performed on molecular diseases, cytogenetic diseases or specific chromosome translocations associated to miscarriages, while the rest were PGS performed in relation to advanced maternal age (almost half of all the tests performed), and repeated implantation failures (see Table 6.1).

Table 6.1 PGD and PGS distribution—Spain 2013

Molecular diseases (PGD)	340
Cytogenetic diseases (PGD)	373
Miscarriages (PGD)	340
Advanced maternal age (PGS)	1194
Implantation failure (PGS)	222
Others	305
Total	2890

Source: SEF 2014

A key finding of our study is that the experiences and trajectories of the women interviewed vary significantly depending on whether they have undergone PGD or PGS. This variation is partially related to the fact that the two techniques are very different and pursue different purposes. Both PGS and PGD are used in efforts to overcome biological obstacles to reproduction (assisted reproduction), while only PGD is used in efforts to avoid transmission of a known hereditary disease or to create a so-called savior sibling (selective reproduction) (cf. Gammeltoft and Wahlberg 2014). Whilst some PGDs are performed to look for specific chromosomal translocations, most of them look for specific genetic mutations in alleles, mostly through PCR (Polymerase Chain Reaction). PGS, in contrast, usually consists of a karyotype, mostly performed through a FISH study (fluorescence in situ hybridization), looking for both chromosome numerical and structural abnormalities. The variation is also due to the fact that PGS is only offered and accessed in the private sector, while PGD can be accessed in both healthcare settings. Finally, part of the variation is due to the different trajectories women using PGD and PGS follow, as they converge at the IVF clinic from different journeys, under different circumstances and for different purposes.

Importantly, we found a high degree of confusion between the two techniques in patient narratives. The two techniques, known as *diagnóstico genético pre-implantacional* (PGD) and *cribado genético pre-implantatorio* (PGS) in the clinics are both translated as DGP, *diagnóstico genético pre-implantacional*, that is, both are identified by the same name, blurring the differences between the two. For instance, women often wondered why for some people it was more *difficult* to get access to a technique that seems rather easy to access for others. They also wondered why it was covered by the public system in some cases but not in others, suggesting that they were not aware of the existence of two different techniques, both named “DGP”.

I never actually got to understand, because in all the websites, in the media, everywhere it is written that PGD can only be accessed if certain requirements are fulfilled and after the authorization of the Ministry... but we were having PGD without any authorization or any special requirements... you see what I mean? [...] I never understood this. I don't understand why

some couples need authorization, other couples who did not get authorization went to other countries... the fact is that I was having PGD without going to the public hospital, and without having to ask for permission...I was confused, but given that the only thing I wanted was to have a child, I ultimately did not care. [P16]

In spite of this blurred distinction between the techniques, the interviews reveal the existence of three different experiential trajectories: one for PGS and two for PGD. Of these latter two, women who had PGD performed for chromosomal translocation show an experience quite similar to the women undergoing PGS, as both groups were pursuing assisted reproduction. These women were, in fact, offered PGD without having previous knowledge of their genetic conditions: their journeys to IVF, and consequently to PGD, were linked to recurrent miscarriages, eventually diagnosed as linked to chromosome translocations. The experiences of women undergoing PGD as selective reproduction to avoid transmission of molecular, hereditary diseases, in contrast, are very different from the previous two. Consequently, our full account of these differences in the following will show how PGS women have experiences very similar to those identified in the literature about ART patients' trajectories (Cussins 1996; Friese et al. 2006), while women undergoing PGD for genetic disorders have experiences more similar to the ones discussed in the literature on selective reproductive technologies (SRTs) and on PGD elsewhere in Europe (Franklin and Roberts 2006). Interestingly, even if women undergoing PGD for chromosomal translocations are pursuing assisted reproduction, their experiences contain key elements from both of the other two trajectories (Table 6.2).

Women Undergoing PGS

The journey of the women undergoing PGS begins with a fertility problem: they cannot get pregnant or the pregnancy does not get to term (either the embryo does not implant or ends up with a miscarriage):

Table 6.2 Three different pre-implantation trajectories

Issues	PGS	PGD ct	PGD md
Main trigger to IVF	Infertility	Miscarriages or implantation failures	Hereditary genetic condition
Frame of the technique	Tool to improve IVF success rate	Only way to get pregnant	Prevent birth of affected offspring
Clinical setting	Private clinics	Both private and public hospitals	Both private and public hospitals
Level of prior information	Low	Medium-low	High
How they get to know about the technique	Offered by the clinic	Previous diagnosis	Previous diagnosis or affected offspring
Alternative to abortion	No	Occasionally	Yes
Main purpose	Getting pregnant	Have a successful pregnancy	Have a child free from a specific disease

Whenever I got pregnant I had some problems and it never worked out in the end... there was a genetic problem... not one affecting the egg, rather one proceeding from the assemblage of the egg and the sperm. I wanted to go for a safer and more effective option because my womb was being damaged... and you know I need my womb to become a mother [P12].

These patients are usually offered PGS as a tool to increase the chances of success of IVF, using embryo biopsy to choose among embryos. Framed as an effective technique to enhance success, some women suggested that the public sector should include it to improve cost-effectiveness: “*The public healthcare system would be better off because maybe with one cycle only [IVF with PGS]*” or “*you can have more success than with three normal cycles [without PGS]*” [P12]. Nonetheless, the relatively low success rate often generates second thoughts, disappointments and frustration.

We thought it was something almost foolproof, but then, once in the clinic, we realized that, with so many people there, it wasn't so foolproof, it is just one more option, that gives you much more opportunities with high

technology, but clearly it is not foolproof and clearly that came to me as a disappointment [P6].

Both patients and professionals are aware that PGS is a tool for selecting better embryos but “better” is understood in several, ambiguous ways. It is said to refer to a *correct* chromosome profile of the embryo, but it also implies the idea of “good quality” and “healthiness”:

PGD [in this case PGS] analyses each and every embryo in order to detect the ones that are perfect from a chromosome point of view and can survive better. Sure, it is also true that PGD can negatively affect the embryos but, then, those embryos that survive PGD are the ones that are most likely to continue to term. [P9]

I know that [PGS] analyses some chromosomes and then helps selecting those that are healthy, genetically healthy [...] given it was our last chance, we thought that selecting a healthy embryo would give us more chances. [P8]

These women associated higher chances of success with selection of “health(ier)” embryos, referring to them in abstract terms or understanding “healthy” as “endowed with ability to develop to term”. It is precisely this encouraged conflation between “chromosome normality” and “ability to develop to term” what moves patients into undergoing PGS, expecting it to raise their chances of success in the assisted reproduction journey.

As it was our last opportunity, to select a healthy embryo to have more chances... to be honest, well, the doctor told us that with two healthy embryos there is 50 per cent of likelihood, which is not much if you consider the cost, but well... [P8]

In one case, PGS is mentioned as a tool to get rid of “bad” embryos due to potential genetic conditions. Here, the genetic quality of the embryo was used by the clinic to persuade the patient to try IVF with PGS.

I had to go for IVF with PGD in order to get rid of the embryos that were “bad”, so to speak [...] they told me that, well, that it had to be done with pre-implantation diagnosis to, well, to... to put the healthy embryo

because there were not healthy ones, so they explained a little bit of the technique to me, well, they explained everything to me. [P12]

In the PGS trajectory, selection procedures are not framed in terms of specific alterations or mutations but in terms of a quality assessment procedure identifying and separating—on the basis of chromosome characteristics—“good” embryos from “bad” embryos. Health is geneticized: embryos are considered healthy or unhealthy on the basis of their genetic profile, interpreted by pre-implantation screening.

In our first clinic, they told us ‘well, you have high chances of having children with anomalies’ like Down syndrome, Turner syndrome ... Then obviously with this technique in principle before being implanted they analyzed the embryos before and they would only place on you the “good ones”, I mean, the ones that were genetically healthy. [P16]

The fact that these women end up in PGS is entangled in a longer history of being immersed in ARTs, blurring once again the differences between ARTs and SRTs as long as their trajectories come to matter. The experiences these women told us were highly framed by their need for *assistance* on their reproductive endeavor and selection *per se* only came to be relevant as long as genetic factors were used as an explanation to their reproductive problems. Thus, these women were having their embryos selected as a way of increasing their chance of having an actual baby, and even if selection was linked to genetics and took place at the embryo level, their experiences seem not to be that different to those of other women undergoing ARTs without pre-implantation genetic testing, whose embryos are selected on the basis of the visible, morphological features of the developing embryos rather than on their chromosomal configuration.

Women Undergoing PGD with Chromosome Translocation

The trajectory of women undergoing PGD for chromosome translocations stands somewhere in between those related to genetic PGD and those related to PGS. In this case, PGD targets specific chromosome

translocations and anomalies, focusing on previously identified hereditary chromosome alterations. Women undergoing have a degree of information, awareness and knowledge that is generally higher than the one observed in the PGS group and they do not frame PGD as a tool to boost their chances to get pregnant, but rather as “the only alternative” to achieve their desired motherhood.

The repetition of miscarriages was somehow due to the inversion of the chromosome, and so for us to achieve a pregnancy we had to do an in vitro fertilization and, after that, we have to do an embryo selection [...]. There was not much alternative. [P10]

Women in this group both use and resist the narrative of selection. They do so by re-framing the idea of selection, insisting that they are not selecting embryos on the basis of personal criteria and emphasizing that they are giving a chance for healthy children to be born. Thus, selection is considered legitimate under a discourse of health and pregnancy success but rejected on the basis of any other criteria (e.g., choosing gender or any other characteristics of the phenotype).

You don't look to see if it is a boy or girl, you are not looking for sex selection or discarding healthy embryos...it is more... more like the opposite, as long as they are healthy...[everything is good]. [P7]

Women undergoing PGD for chromosome alterations converge at IVF clinics mostly because their pregnancies cannot develop to term. In their case, the genetic component is both relevant and specific, and encourages them to further “geneticize” their reproduction experience, reducing their fertility problems to chromosome translocations.

Women Undergoing PGD for Molecular Diseases

The third group of women accessed PGD as a result of hereditary genetic conditions. They do not have fertility problems, but many have lived with a close relative affected by a genetic disease and opted for PGD as

a particular way to become parents. PGD is their fundamental reason to choose IVF because they want to prevent their progeny from developing the same disease affecting them or their close relatives. Some have already had children who have inherited the disease. In fact, two out of three kids born to these women before the interview were deceased at the moment of the interview, while the third one was under chemotherapy treatment. Clearly, in such cases, PGD is framed as a selective device enabling parents to have offspring free from hereditary diseases.

Both my husband and I, we are carriers of a genetic disease. We had a baby who developed the disease and died when he was five months old. Then, we decided that we wanted to have our second baby through PGD. [P23]

In these cases, women actively seek PGD, and often they get to the clinics with a deep and extended knowledge about their disease, the techniques, risk of transmission and the chances of success.

When I went to the gynecologist, I already knew that they offered this technique, I knew that I had to go through it ... in other words, it wasn't the doctor, it was me who already knew because I had seen it in the internet and in the press, when the first cases of children free from the disease were announced. [P19]

We had a fifty per cent chance that the baby would be born with the disease, so we decided to go the clinic. [P25]

In their narratives, healthy is no generic term: it means free from a specific hereditary disease.

I... well I have a genetic problem, a genetic disease that I share with nearly all the women in my family, it is inherited from my father [...] Given that I wish to have children, I would like to have them healthy...free from this disease, I mean. [P27]

PGD is more often framed as a medical tool helping children to come to life free from a disease, rather than as a tool to help parents to have kids free from it, even if both forms of reasoning are present. In other words, PGD is presented more in relation to the child than to the parents.

My mother has got a neurodegenerative disease, and this is hereditary so, a few years ago, the whole family was tested and it turned out I was a carrier [...] if I have children there is 50 per cent chance that they develop the disease, which is a fatal disease for children [...] Therefore, for me this is clear, that if there is anything I can do to ensure that my children will be healthy, I will do it. [P26]

As a result of this unique connection with the health of the prospected children, PGD is endowed with a special moral and social status, making it the only acceptable way of fulfilling their reproductive project:

My father and my son have a hypertrophic myocardial pathology and when I went for a genetic test and it came out positive, the doctors suggested I should go for pre-implantation genetic diagnosis [...] when this was suggested to me, I no longer considered having a child in a different way. [P13]

These women generally considered PGD an alternative to abortion. Indeed, some turn to PGD after difficult experiences trying to have children through regular pregnancies in combination with prenatal testing, as recommended by their doctors.

The geneticist in the Hospital [omitted] had no idea, he just suggested I should get pregnant in a normal way and, then, if the retinoblastoma would be detected in the fetus, I could always interrupt the pregnancy, which was legal to do. He never mentioned the possibility of selecting the embryos, which would have been way less painful. [P22]

While their medicalization dynamics are different, these women adopt patient logics more than the women in the two other groups. They present themselves as willing to undergo a medicalized reproductive process so as to prevent their children from going through the kind of medical journey their relatives have experienced. Thus, they accept becoming patients to avoid their children doing so. In their narratives, the experience of being close to patients is the key factor determining their reproductive trajectory:

If we had to have a child again, we would run the risk of going through this again, because both my husband and I, we have a mutated gene so... [...], after I had my son sick from this disease, I know this disease, it is atrocious [...] I do not want to have another child going through this again... this is a terrible disease. [P20]

The technique is not framed in individual terms nor is it linked to the desire of having children, as they are not going through PGD to become parents. Instead, PGD is framed in generational terms, for they are going through it to ensure that the next generation will be free from a disease that has haunted their family.

The fundamental reason to opt for PGD was that I have seen my father and my brother, and I know the quality of life they have, and I guess that all the people who share this kind of disease know how it dramatically affects the quality of life of those who are closer to you, and then... you don't even think this could be a possibility. [P13]

The logic of selection adopted is articulated around two main elements: on the one hand, preventing their children from suffering (or dying) and, on the other hand, preventing themselves from having to go (again) through the suffering they experienced with their affected relatives.

I believe that [PGD] offers an opportunity to get rid of diseases that have been devastating the quality of life of many people till now... it would be great if PGD would also give this opportunity in relation to more diseases... but at least it allows us to avoid some diseases... It would be nonsense not to take advantage of this opportunity. [P13]

Ultimately, the trajectories of these women are significantly built around the issue of selection, confirming thus many of the findings discussed elsewhere in the literature on PGD. Here, the fact that their reproductive processes are assisted technically is a means to one particular end: enabling the selection of embryos free from specific and known diseases. Interestingly, this specifically medicalized reproduction route is framed as a temporary way of escaping medicalization in the long run (for their potential children).

Conclusion

This chapter has focused on how PGD and PGS are experienced in Spain today. While most of the studies on PGD tend to focus on the individual experiences of women undergoing PGD for hereditary molecular diseases, we have included in this study women undergoing PGD for cytogenetic diseases and chromosomal abnormalities as well as women undergoing PGS. We interviewed 21 women undergoing PGD and PGS in public and private hospitals across different regions in Spain, with the aim of casting light on the differences and commonalities in the experiences and trajectories of the women undergoing these techniques.

Our analysis shows that there exist relevant differences between the experiences associated with these techniques and the approaches to selection by the related patients. Women undergoing PGS and PGD for chromosome translocations consider the technique a tool to boost their chances to achieve a successful pregnancy, seen as their only chance to become mothers. In that sense, the techniques seem to engender experiences similar to those recorded and discussed in previous studies of women undergoing IVF (Cussins 1996; Friese et al. 2006). The medicalization process, however, differs: PGS targets broader infertility while PGD addresses specific types of chromosomal translocations only. The selection logic in both cases is applied to discard “bad” embryos, understood as those which would not develop further, and select “healthy” embryos that are expected to be able to survive until birth. In contrast to those two trajectories, women undergoing PGD for molecular diseases accept to undergo medicalized reproductive processes to prevent their offspring from developing a disease that has been haunting their families. These women have vivid experiences of the disease, either because their first child developed it or because close relatives are affected. As a result, the selection logic is different: they do want to select “healthy” embryos, but healthy does not mean “fittest” but rather “free from a specific disease”. Following the distinction between assisted reproduction and selective reproduction made in this volume, we can now clearly speak of an SRT trajectory, in which selective reproduction is the key force driving these women to undergo the whole procedure.

Importantly, the information these women possess and receive is different. Often those undergoing PGS do not have information about the kind of selection their embryos are subjected to. They know that their embryos go through a process of genetic selection but they might not know how this process works exactly. Indeed, some are not aware that there are two different techniques, both abbreviated as DGP in Spanish. They are not that interested in knowing which kind of chromosomal issues are being screened out, as long as the selected embryo has more chances to result into a baby. They distinguish between healthy and unhealthy embryos assuming unhealthy to be “not likely to live to birth”. In PGS, selection is, thus, a means to an end, another assisted reproduction technique meant to help traditional IVF to succeed. The trajectory of women undergoing PGD for translocations or miscarriages is, in many ways, similar to this PGS trajectory. Some of them are more aware of the particular genetic problems they may have and may also be more informed about the techniques, but they look for PGD for the same purpose: a successful pregnancy. In contrast, women who access PGD in order to have offspring free of a specific genetic condition follow a different trajectory. They arrive informed; they have been through either selective abortion(s) or they live, or have lived, with family members affected by a disease, and they know pretty well what kind of selection procedure they need and for what specific mutation. Thus, PGD is the actual end, and IVF is the means to it. Their narratives differ from those of women with fertility problems, even if their genetic conditions bring them to the same clinic (which is not always the case, as PGD is offered by private as well as public hospitals).

These results suggest that selection is always at work but that the experience of selection is different. They also suggest that there is no clear boundary between ARTs and SRTs, and that PGD/PGS contribute to the further blurring of a boundary that has always been blurred. IVF, and ARTs in general, might have always been about selection and PGS works here as yet another example of it. In IVF, selection of gametes and embryos is done by using the technology of the informed, trained and selective gaze of the embryologist who either chooses gametes or ranks embryos in A, B or C quality according to their (observable) ability to multiply and survive. PGS is lived by these women, in a way, as a

technique extending the scope and power of this selective gaze into the chromosomal domain of the embryos but maintaining the same purpose. PGD extends it further down into the gene's structure and, allegedly, maintains and extends this purpose, too, by screening out specific genetic mutations to prevent the birth of individuals carrying (the risk of) specific genetic diseases. The experience of the women, nevertheless, showed that *selection*, in this second sense, is the real driving force in very few specific cases, which represent the minority of the PGD that takes place in the Spanish context.

This chapter makes a contribution to the existing literature by showing that these two techniques in Spain are embedded in different medical contexts and trajectories. The differences in the experiences we have collected are not (only) due to the technique per se, but rather to the different trajectories within which they develop. Many factors account for these differences such as the clinical setting, the actual health conditions of couples and also their previous reproductive trajectories. What we would like to emphasize is that two different types of selections are at stake in PGD and PGS: what is being selected and for which purposes is different, and the trajectories of the women may have more of an impact on what selection means than the technique itself, as the experiences of the second group of women show. While our results are consistent with many other studies on PGD for genetic mutations and diseases, we do need to emphasize that PGD for molecular disease is not what effectively characterizes the Spanish PGD landscape. The latter is rather characterized by an unrestrained, massive use of PGS as an assisted reproduction technique whose primary aim is an increase of the success rate, and by a limited, stable recourse to PGD to positively select embryos free from specific genetic mutations or histologically compatible to their siblings for therapeutic reasons.

Notes

1. Routinization has been defined as a “socio-historical process whereby certain forms of medical technology come to be (re)produced and entrenched within particular juridical, medical, social, economic, cultural and institutional configurations” (Wahlberg 2016: 98).

2. While in the late 1980s, there were only 14 IVF centers, today 200 IVF centers exist in Spain, 165 of which are private and 35 of which are public SEF. 2013. *Registro de la Sociedad Española de Fertilidad: Técnicas de reproducción asistida (IA y FIV/ICSI)*, 1–41. Madrid: Sociedad Española de Fertilidad.
3. El País Website, http://sociedad.elpais.com/sociedad/2013/07/18/actualidad/1374178125_262676.html, last accessed 20 May 2015, and http://sociedad.elpais.com/sociedad/2013/07/23/actualidad/1374575386_841886.html
4. In our previous round of interviews (2008), some embryologists and gynecologists admitted that new evidences was clearly showing a reduction of success rates associated with PGS and forecasted a decrease in the use of this technique. However, the most recent data (2013) show no sign of decline but rather a marked increase. In 2009, 1037 PGS were performed over a total of 1683 PGD/PGS and 40,704 IVF cycles. In 2013, 2064 PGS were performed over a total of 2890 PGD/PGS and 46,911 IVF cycles. While in 2009, PGS for advanced maternal age accounted for 26 percent of all PGD/PGS, this percentage rose to 41 percent in 2013.

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Part III

Selecting Traits

7

They Don't Just Take a Random Egg: Egg Selection in the United States

Lauren Jade Martin

In the science fiction film *Gattaca*, a eugenic dystopia is portrayed, in which parents select and pay for the desirable traits they wish to appear in their future offspring. While the scenario of parents selecting height, mathematical ability, and athletic prowess for their children has obviously not come to reality, the US fertility industry trades on the latent and explicit desires of intended parents to influence their children's destinies. This chapter examines how US fertility industry providers rely upon the ideology of "selection" and racialized and eugenic ideas about the genetic capacity of gametes to market their services to a domestic and international clientele. This is exemplified in the practices by which industry employees recruit, screen, and select egg "donors," carefully managing egg donor pools as a marketing device to appeal to intended parents worldwide who desire children of a particular racial-ethnic background, physical appearance, or personality trait. Because the use of third-party eggs is a market transaction rather than a gift economy in the US context,

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I herein use the phrase egg transfer rather than egg donation, and egg provider or vendor rather than donor, except in the context of direct quotes (see also Cooper and Waldby 2014).

Scholars have made comparisons between contemporary practices involving genetics and assisted reproductive technologies (ARTs) with older eugenic practices from the early twentieth century (Duster 2003; Fujimura et al. 2008; Roberts 2011; Rothman 2001). During the eugenics era, traits such as intelligence, promiscuity, poverty, and criminality were believed to be heritable qualities passed down through one's genes; this belief was linked with biological determinism and the idea that biology is destiny (Kevles 1995). In contrast, ARTs were developed as seemingly innocuous practices that help the infertile to have biological children, with no concrete relationship to the last century's state-sanctioned eugenics movement involving large populations. Third-party egg transfer, for example, was initially developed as an assistive technology by enabling infertile women to conceive using another woman's eggs. Furthermore, unlike old-fashioned eugenics, ARTs today involve market-oriented transactions mediated not by the state but by private agencies and medical clinics, in order to facilitate the birth of individual children rather than populations.

Yet, ARTs may become selective reproductive technologies (SRTs) when genetic determinist ideologies and the desire to manipulate the outcome of offspring motivate and contribute to third-party egg transfer and other technologies. SRTs are linked to the power to facilitate the birth of children to certain classes of women—and thus its arguable linkage with new forms of positive eugenics (Davis 1993). The decision to parent always involves risk, whether that is through “natural” or assisted conception, or by fostering/adoption. SRTs, such as third-party egg transfer, sperm sorting and pre-implantation genetic diagnosis (PGD), however, may be used to mitigate risks and give intended parents some modicum of control over the “product” by assessing, ranking, and selecting gametes and embryos. This screening and assessing is taking place on a global scale, enabled by reproductive tourism for selective purposes (Martin 2014).

In what follows, I show how US fertility industry providers inadvertently reify eugenic ideas about genetic “fitness” through their processes of

recruiting, screening, selecting, and marketing of gamete providers. The presentation of a pre-screened and diverse pool of egg providers becomes a marketing device to appeal to intended parents worldwide who desire children of a particular racial-ethnic background, physical appearance, or personality trait. Given the size and pluralism of the United States, as well as the fact that commercial third-party egg transfer is legal, its egg market is larger and more diverse than other countries'. By appealing to intended parents to come to the United States as a means to "select" traits in their future offspring by way of third-party egg transfer, American fertility industry practices may serve to undermine officially sanctioned norms and values regarding eugenics and selective technologies in those intended parents' own countries.

Methods and Background

New York City, Los Angeles, and San Francisco are three of the largest nodes of the fertility industry in the United States. This chapter is based on a larger research project in which I conducted multi-sited fieldwork and in-depth interviews in these 3 cities with 20 people employed in the fertility industry as physicians, egg and surrogate brokers, and family law attorneys, among other occupations (Martin 2015). Pseudonyms are used for all participants, and their places of work have been kept confidential. In addition, I conducted an analysis of US fertility clinic websites and Craigslist postings for their recruiting and marketing content, and examined public and professional policies regarding the uses and applications of reproductive technologies.

Fertility clinics and agencies in dozens of countries compete for clients on a global basis, offering such services as surrogacy, in vitro fertilization (IVF), egg transfer, PGD, and sex selection (Hudson et al. 2011; Inhorn and Gurtin 2011; Spar 2006). Countries such as India, the Czech Republic, Spain, and the United States, among others, have emerged as destinations for individuals seeking assisted fertility services and SRTs (Nygren et al. 2010). Although it does not provide bargain prices for expensive fertility services, the United States has become an ideal marketplace for "reproductive tourists" seeking out reproductive technologies

that are illegal, inaccessible, and/or of limited quantity and quality in their own countries (Twine 2011). Specifically, a more laissez-faire orientation regarding reproductive technologies makes the United States a favorable place for those intended parents, globally, who wish to use such SRTs as commercial egg transfer, PGD, and sex selection (Martin 2015).

Ideas about genetic heritability and consumer choice are embedded in the US fertility industry, the attitudes of its workers, and regional norms and practices. Fostering the illusion to intended parents that they can “select” traits in their egg provider (and, it follows, in their future offspring) is an appealing marketing device, particularly to foreign nationals who are unable to acquire the same technologies in their own countries. Despite other nations’ laws and policies that may restrict eugenic or selective technologies, they become available to those willing to travel to the United States.

Buying and selling eggs is outlawed in many countries, including Australia, Belgium, Canada, and France, and non-commercial egg transfer is prohibited in Germany, Italy, Norway, and Switzerland (Jones et al. 2010). Third-party egg transfer in the United States, on the other hand, is largely a commercial, rather than an altruistic, enterprise (Almeling 2011). In the US egg market, young women may legally sell their ova for any agreed-upon price, with \$5000–8000 per cycle being a typical amount for compensation. Without any federal- or state-level policies regulating the sale of eggs for reproductive purposes (as opposed to for stem cell research), the fertility industry attempts to self-regulate the market through its own practice guidelines (Ethics Committee of the American Society for Reproductive Medicine 2007).

Recruiting Egg Vendors

In the United States, an industry of brokers and agencies work to locate egg vendors by advertising on college campuses and Craigslist, recruiting via their own websites, and by word of mouth. Brokers spoke to me about how they are constantly recruiting to find what they perceive to be the “best” egg providers. This was ironically revealed to me during the course of my research, as I was on more than one occasion solicited for

my eggs. The president of a Los Angeles egg agency, who remarked that she is “always recruiting donors,” attempted to recruit me at the end of our interview. When I informed her that I was “too old,” at least according to her agency’s age limit, she suggested I ask my younger friends to consider selling their eggs. Another broker I met at a fertility conference unsuccessfully attempted to recruit me when she found out that I was, at the time, a PhD candidate.

Craigslist in New York City, Los Angeles, and the San Francisco Bay Area offers a daily snapshot of the recruiting tactics of clinics and agencies. A search for the term “egg donor” in the jobs section on May 29, 2015, yielded 171 recent posts in New York, 70 in Los Angeles, and 84 in the San Francisco Bay Area. Although Craigslist New York had the highest number of advertisements, these included multiple postings by the same 16 fertility clinics and agencies. Nineteen clinics, agencies, and individual recruiters (including a couple conducting a search for themselves) accounted for 70 postings in Los Angeles, and in San Francisco, 13 clinics, agencies, and recruiters accounted for 84 postings (Table 7.1).

Given the size and pluralism of the United States, its egg market is potentially larger and more heterogeneous than in other countries. However, all ova are not interchangeable or equally desired. Craigslist advertisements list preferred qualities such as race/ethnicity, SAT scores, hair color, and talents. Almost three quarters (73.7%) of the recruiting posts on New York’s Craigslist specify race or ethnicity. These include African American, Armenian, Asian, Brazilian, Caribbean, Caucasian, Ethiopian, Greek, Indian, Italian, Jewish, Lebanese, Mediterranean, Puerto Rican, Scandinavian, and South American. Stating a desired race or ethnicity in the subject heading is prevalent but not as common in California. In Los Angeles, 37% of posts indicate race or ethnicity (Asian, Caucasian, East

Table 7.1 Craigslist “egg donor” recruiting posts in three cities

	New York	Los Angeles	SF Bay Area
Number of posts	171	70	84
Number of unique recruiters	16	18	13
Number of races/ethnicities requested	16	4	3
Posts requesting specific ethnicity in subject line	74% (<i>n</i> = 126)	37% (<i>n</i> = 26)	35% (<i>n</i> = 29)

Indian, and Middle Eastern), and in San Francisco, 35% of posts request specific races/ethnicities (Asian, Caucasian, Chinese, and Jewish). At least two of the race-/ethnicity-specific advertisements were posted by race-/ethnicity-specific companies, Asian Egg Donor Agency and A Jewish Blessing. In all three US egg markets, the ova of white and Asian women are the most requested, but many advertisements also overtly state that they welcome applications from women from all ethnicities; non-white and non-Asian women may be included in a broker's pool of potential egg providers even if they never get matched with intended parents.

Screening Candidates

Agencies and clinics are selective about their egg providers, usually stating minimum criteria on their websites and advertisements. For example, an advertisement posted by the PAMF Fertility Physicians of Northern California states that women should apply if they are “between 21 and 28 years old, healthy and within a normal weight range, have a healthy family history, non-smoker and drug-free, and able to reliably attend up to 10 appointments in San Jose, CA” (PAMF Fertility Physicians of Northern California 2015). Once they have applied, the women are further screened via extensive and exhaustive applications. These may require applicants to supply detailed information about their physical appearance, occupation, and medical history, as well as that of their parents, grandparents, siblings, and children. Some agencies and clinics require applicants to supply SAT scores and grade point averages, rate their mechanical, mathematical, literary, scientific, athletic, musical, and artistic abilities, list their special talents, include a community service record, and describe their personality and goals in life. They are asked to quantify their ancestors' countries of origin, disclose information about their relationship status, and provide psychological, menstrual, sexual, and pregnancy histories (see also Almeling 2011).

Applicants are subject to medical and psychological screening by fertility clinics prior to selection. According to Liz, program coordinator at a New York clinic, “We do quite a lot of screening on the donors here. We go well over what is recommended and required by state and federal law.

So if they have an abnormal pap smear, if they have HPV ... that will delay our process, because we will ... make sure that everything is fine, and we won't cycle anyone unless they're okay, or checked out. ... And we do genetics, we do psych, we do the physical exams, and the blood work. That whole thing." They do not accept as vendors women who "have alcoholism in the family, or if they were taking anxiety medications, for depression or something like that."

Some medical screenings and selection criteria are arguably used to reduce the risks of disease transmission as regulated by the US Food and Drug Administration or to gauge the viability of an individual woman's ova (U.S. Department of Health and Human Services 2007). But women are also recruited and selected on the basis of socially determined criteria, such as height or education, that have nothing to do with disease risk or egg viability. Women who wish to sell their eggs via the agency A Perfect Match must provide official transcripts and standardized test scores (A Perfect Match 2008b). A post that appears on all three Craigslist offers up to \$50,000 for "an Attractive Caucasian Candidate who attends/has attended an Ivy League School ... This specific couple is looking to find a candidate who looks similar to them, so a light eye color, 5'7 or over in height, and any particular hair color" (Caucasian, Educated Donor Needed! **\$50,000 a Cycle** n.d.).

The holistic screening process results in the creation of a biography that includes physical description, social history, medical history, family background, and, most importantly, race/ethnicity, enabling clinics and agencies to place women in their roster as both an advertising tool and to be potentially matched with specific sets of intended parents. During the eugenics movement of the late nineteenth and early twentieth centuries, the "fitness" of individuals determined whether or not they were worthy of propagating their gene pool (Kevles 1995). This belief about the fitness of individuals—and of entire populations—influenced by theories of heritability of traits resulted in both positive and negative eugenic practices. Almost a century later, the screening of egg vendor applicants implies similar distinctions between fit and unfit egg vendors—that is, by who is fit enough to sell genetic material—and similar beliefs in the heritability of traits such as race, intelligence, and beauty. By eliminating or including applicants based on their genetic, medical, familial, and social

information, brokers “pre-select” the types of women judged to be fit to reproduce not on the physical quality of their eggs but on their biographical details.

Through my interviews with egg brokers, I came to the realization that the most important criterion for an egg vendor to be added to an agency’s roster was her marketability, based on the brokers’ assessment of the likelihood of her being a good match with the intended parents they sought as clients. Megan, marketing director at a Los Angeles agency, informed me, “A lot of the times they’ll [intended parents] want somebody who’s bright. And we work with a lot of models and actresses, and they get chosen all the time. So basically, we look for candidates that people would really choose.” Beautiful women with high grade point averages and classical music training are assumed to be desirable candidates, whereas those who are overweight, have a history of mental illness, or lack a high school diploma are disqualified. Through recruiting and screening, egg brokers create and manage a pool of potential egg providers based on what the brokers themselves believe to be attractive and marketable qualities, reifying normative standards of beauty, intelligence, and markers of cultural capital (Martin 2014).

Marketing Eggs

Using marketability as the basis for vendor recruitment and selection is especially important in the global fertility marketplace. Egg brokers repeatedly remarked upon the “quality” of their egg providers as reasons for why their clients—especially those coming from abroad—choose to work with them, implying that they or their agencies are particularly adept at assessing and evaluating the genetic potential of young women. Websites are one tool used by clinics and agencies to signal the quality of their egg vendors. Megan tells me that as part of her responsibilities as marketing director, “I put all the donors up on our website, and make sure they look really appealing. Correct any spelling mistakes or anything like that.” Robin believes that it is the advertised quality of her donors that draws clients to want to work with her, but acknowledges “the bar is not super high.”

Some agencies are even more transparent about egg transfer as an SRT. The website of A Perfect Match Egg Donation and Gestational Surrogacy Agency, based out of La Mesa, California, uses the language of heritability to market the superiority of their egg providers. Their Egg Donation page states that the agency “actively recruits intelligent women ... who are also very accomplished in their personal lives in the areas of sports, arts, business, medicine, law and politics.” Further, without actually citing any studies, the page continues:

Many people do not understand or agree that personality or intelligence matters when it comes to choosing an egg donor yet there are many studies that show both personality and intelligence are very heritable traits. The majority of our intended parents select an egg donor based on a combination of factors which include the donor's accomplishments, personal appearance and her personality because they are truly trying to match themselves in as many ways possible. (A Perfect Match 2008a)

Intended parents who use clinics and agencies that allow them to select their own egg providers typically have access to photographs and other information from their applications that have been cataloged and made accessible over the Internet. The agency Egg Donation, Inc. provides photographs and detailed information about their egg providers for anyone with an Internet connection to see. Their profile of Jodi (#57540), for example, includes her SAT score (960), history of pregnancies (two, no complications), ancestry (French, English, Welsh, Scottish), and favorite color (purple), among other intimate information (Egg Donation Inc. 2015). Other agencies are not so transparent and require users to register before gaining access to their databases. At West Coast Egg Donation, the publically available database is searchable by blood type, race, ethnicity, eye color, hair color, and education level. Users need to register in order to view the full profiles and photographs (West Coast Egg Donation 2015).

The attitudes of brokers indicate a contradictory stance, in which they market the qualities of their egg vendors and, at the same time, they understand that scientifically speaking, traits such as musical talent and SAT scores are not necessarily heritable qualities (Martin 2014). Yet, claims by fertility industry professionals about the high qualities of their

egg vendors construct third-party egg transfer as a selective technology. Not only does one have to assume that intelligence or behavioral traits are passed down from the genetic parent to child, but that an egg vendor's genetic potential can be revealed by looking at her test scores or where she attended college. While some intended parents may seek vendors who resemble them in hopes of having children they can pass off as their own genetic progeny, others may use this technology for expressly selective purposes.

Matching Eggs in New York and California

In addition to the legal status of selling eggs as a marketable commodity, another distinguishing characteristic of the US fertility industry is the process in which eggs are selected by or for intended parents. Just as recruiting and screening egg providers rely upon socially determined criteria, so does this selection process. Because so much value is placed in the qualities of egg providers, and the implicit understanding that these qualities can be transmitted through their gametes, egg providers are individually matched with intended parents. In the cities studied for this field research, I have surmised two distinct patterns: clinics and agencies in Los Angeles and San Francisco allow the intended parents to play a significant role in choosing their own egg providers, sometimes even giving them the opportunity to meet them in person or over Skype, whereas in New York City, the clinics tend to do the matching on behalf of the intended parents, keeping the identity (and even adult photographs) of the egg providers completely anonymous.

Anonymity does not eliminate the selective nature of third-party gamete transfer but rather puts it in the hands of the professionals doing the selecting on behalf of the intended parents. Dr. Bradley, in New York, lauded this practice of anonymous gamete donation, as long as the intended parents are able to have certain information about the donor. "Like if you want sperm. You don't know the person. But you know that he was, you know, six foot one with blond hair and green eyes, and he was of Scandinavian background, and he's an engineer, and his hobbies are this, and he doesn't have any diseases, and he has a picture ...I think

that's cool. And it should be exactly the same on the female side. That's anonymous, in the sense they don't know the person, but they had a say in choosing the gamete. I think that's totally good and appropriate."

Liz, also in New York, acknowledges that by selecting the egg vendors for their clients, intended parents must trust the clinic's matching skills. She describes a time when a Chinese patient doubted that the clinic employees would be able to find someone appropriate:

Because we don't show adult photos—we have an anonymous program...—the whole team matches the donors with the recipients, and so she said, 'But you guys, you Caucasians, just think that we all look the same, so how can you match me with someone that looks like me?' And I'm like, 'Well, I see that you have, you know, a single eyelid,' and this and this... But, I said 'If there are certain traits or certain features that you absolutely do not want your donor to have, if you feel more comfortable doing so, send me photos of what you don't want.'

Again, the selection process at her clinic is quite robust and geared toward choosing the "correct" gamete for the client.

Regional norms of selection and matching differ in California. Although brokers and professionals in New York are satisfied with the regional norms of their field, some of their counterparts in California find their more transparent methods to be superior. Dr. Randolph, based in San Francisco, describes the matching process in New York much the same way that Dr. Bradley and Liz did in the above passages. Yet, Dr. Randolph sounds disconcerted that the fertility clinics "make the choice themselves. They look at the characteristics of the person, they say, 'This would be a good match for them, so we'll pick this.' So you never know who it is, their background, or anything else."

Rebekah, co-owner of a surrogacy agency in Los Angeles, describes clinics on the East Coast as having "in-house" egg programs where "there's usually a long waiting list, and they don't get as much information with an egg donor. They get maybe a baby picture, if that, and they're usually matched by somebody else. There's a limited number of choices. Here [in Los Angeles], there's loads of agencies. Adult pictures. You can have potential contact, if that's what you want." Rather than recruiting egg

vendors herself, she and her business partner help their clients find suitable egg agencies to work with and help them pre-screen and narrow down possible matches.

Megan described for me the matching process that is typical of California agencies, in which the broker works with clients to select a specific egg provider seen as uniquely appropriate. She says of her co-worker who works with clients to select an egg vendor: “[She] has worked at a couple different agencies, and has been doing this a long while. She’s a donor herself. She actually works with the couples in matching them. So she sits with them, and says, ‘Oh, you know, she has your same bone structure.’ Or, ‘Oh, you might want to try this donor.’” According to Megan, some clients will give her agencies photographs of family members and ask them to find young women who look like them.

Despite these differences in East and West Coast selection processes, what US clinics and agencies have in common is the selection itself. That is, no matter whether the clinic selects an anonymous egg provider for the client or if the client makes the selection herself, the very act of selection involves drawing from a pool of pre-screened women and then matching a specific woman to a specific intended parent, based on the collected biographical data I described in the above section. The US brokers and professionals I interviewed viewed this matching process—choosing a particular egg vendor for a particular client—as a uniquely American practice, superior to the matching process used by clinics and agencies in other countries.

Fertility industry professionals’ views of their counterparts abroad are shaped by stories that their clients share with them. For example, Liz described a clinic in Spain where she had heard they have an almost assembly-line process for egg donation, with egg providers constantly being stimulated. “You know,” she says, “I was talking with one woman, and she said, basically, they constantly stimulate donors. They just don’t stop. So they, you know, and they have however many donors stimulating at the same time, and then the patients just kind of come in and, I don’t think there’s much matching that goes on.” Notwithstanding this account heard by Liz, according to Spanish law, egg providers are assured absolute anonymity and confidentiality, recipients may not personally select their own providers, and medical professionals are urged to “provide the most

similar phenotypic and immunological match to the receptor woman from all samples available” (European Society of Human Reproduction and Embryology 2006). Regardless of how egg transfer is actually practiced in Spain, the requirements of the law, at least, do not sound all that different from how Liz’s own program selects egg vendors on behalf of clients, in part by matching phenotype.

Similarly, Dr. Randolph dismisses the protocols that he had heard about in an Italian clinic before egg transfer had been outlawed. According to some of his patients, the clinics would call clients whenever some eggs had become available, regardless of any particular matching process. This goes against the culture of California fertility clinics, where the client plays a role in selecting their egg provider and may even meet her. From Dr. Randolph’s perspective, the California method is more trustworthy because “They don’t just take a random egg or any egg is okay.”

Although both Liz and Dr. Randolph relied upon rumors and hearsay about how Spanish and Italian clinics operated, it is significant that fertility industry employees in the United States hold these perceptions of European practices because it influences how they market their own services. Within the cultural orientation of US fertility clinics and agencies, where egg providers are recruited, screened, and marketed for their social and genetic qualities, it is only logical that brokers would want to ensure that their clients are being matched with the “right” eggs rather than “random” ones.

Race and the US Gamete Market

Researchers studying gamete selling in the United States have shown how particular traits, such as race, are used to recruit and select egg and sperm providers (Almeling 2011; Moore 2007; Roberts 2011). This kind of selection extends beyond American consumers, enabled by globalization and the ability of US clinics and agencies to market the quality of their egg vendors to intended parents worldwide (Martin 2014). The website of Donor Concierge, based in California, has a special page for “International Services,” advertising their ability to help “intended parents from around the world find an egg donor and/or surrogate in

the United States to help create their family. ... We have access to more U.S. egg donor and surrogate databases than anyone in the world. Donor Concierge is your best bet for finding the donor or surrogate who most closely fits your requirements” (Donor Concierge 2013). The website of a fertility clinic in Florida (another destination for reproduction tourism) lists “Unique benefits for patients from other countries” including the “ability to provide an anonymous egg donor where the patients can view photos and extensive background profiles. Many countries limit the information available to patients. In addition, we have a large pool of egg donors because in Florida donors can be compensated for their time and efforts” (Fertility Center and Applied Genetics of Florida 2013).

The US gamete market offers intended parents around the globe access to a large, diverse, and highly curated pool of eggs to select from. An administrator at a Los Angeles clinic informed me that they work with a lot of intended parents flying in from East Asia and have thus established a special relationship with a local agency that specifically recruits Asian American egg vendors. Another egg broker described recruiting women of specific ethnicities in order to appeal to intended parents of that background. The “constant” recruiting by egg brokers described above enables brokers to offer an ethnically and phenotypically diverse pool of gametes.

Working with the assumption that eggs available in, say, the Czech Republic or in Spain would be more homogeneous, the sheer diversity of the US egg market is one of its biggest draws. Agencies such as Donor Concierge explicitly use this for both recruiting and marketing purposes. As indicated by the number of Craigslist recruiting posts seeking young women of specific races and ethnicities, matching by race/ethnicity is prominent in the selection process, along with physical resemblance. Liz sees the matching process as a way for the intended parent to “connect” with the egg vendor, since they match not only according to race but also according to “shape, size, color, body type, skin tone, and I mean there are just a million little factors, personality, mannerisms, similar interests.” Megan tells me about different traits that international clients request that she sees as culturally and phenotypically specific: “But specific cultures seem to have different things that they look for that’s kind of the same in each cultures. Usually when we get East Indian recipients, they’ll

say, 'We don't want anybody with blue eyes in our family.' It's a dead give-away (*laughs*)."

Matching by race/ethnicity and by phenotype may be used as a cover for people wishing to hide their use of an egg provider or who want the offspring to more closely resemble the rest of the family. Robin spoke of clients who wanted to pretend—to their child and to themselves—that they did not use another woman's eggs to conceive. In countries that ban anonymous donation, require donor registries, and uphold the right of offspring to know about their genetic parentage, hiding the origin story of children would be much more difficult, if not impossible. Hiding a child's origins is not always the motivation for matching by physical appearance, obviously, but emphasizing how imperative it is to match clients with familiar-looking egg providers hints at approximating phenotypical—if not genetic—continuity within a family.

Embedded in this racial/ethnic matching is the assumption that there is some genetic basis of race and ethnicity (Roberts 2011) or by a desire for gametes that come from a gene pool similar to the intended parents. The drive for genetic continuity is not merely an individualized phenomenon but is bound up with notions of nationhood, culture, race, ethnicity, and religion. In Benedict Anderson's (1991) famous formulation, there is an "imagined" quality to people's conceptions of themselves as members of nations and other communities, and part of the myth-making involved in the creation of nationalist sentiments is about the relatedness of its people. What is not clear is if this desire for race/ethnicity matching is more driven by consumer demand or by the brokers and professionals' own beliefs. Megan described working at another egg agency where workers were dismayed that an African American woman might select a white egg provider. "And I'm going, 'If she wants to, why not? You know, who cares?'" This type of matching by race or ethnicity may be an attempt to approximate finding egg vendors who physically resemble the intended parents, yet embedded in the request is the very assumption that a woman of similar race/ethnicity would be phenotypically similar.

American clinics and agencies use their unique practice of matching one egg vendor to one recipient as a competitive advantage in the global marketplace. In addition to their differences in matching vendors with

clients, the United States is exceptional in its lack of federal regulation of the buying and selling of gametes. In the United States, the only limits on compensation for eggs come from unenforceable guidelines by the American Society for Reproductive Medicine, whereas the prices of eggs in the United Kingdom are capped by regulatory authorities (Human Fertilisation and Embryology Authority 2011a). In addition, anonymous gamete donation is prohibited in the United Kingdom, contributing to a gamete shortage (Human Fertilisation and Embryology Authority 2011b). Eggs from US vendors cost about four to six times more than eggs in the United Kingdom, but what the intended parents get for those additional dollars is access to a larger, more diverse, and pre-screened assortment of potential egg vendors. Because there are no requirements for gamete providers to be tracked in a registry or enforceable caps on how much they may be compensated, there are many more gametes available in the United States for intended parents to choose from than in countries where gamete transfer is highly regulated.

The desire for a child (and, by proxy, an egg vendor) who resembles or exceeds the intended parents in appearance, educational background, personality, or hobbies is not unique to Americans. Intended parents come to the United States to work with agencies and clinics that cater to these desires for a particular kind of child/vendor—desires that many government and clinic policies regarding third-party egg transfer abroad make difficult to fulfill. Moreover, the United States' heterogeneous population is advantageous for those seeking a specific race/ethnicity or physical appearance.

The generally *laissez-faire* attitude of the US federal government toward reproductive technologies and the fertility industry benefits intended parents worldwide who seek selective technologies to increase their chances of having (or avoiding having) children with particular genetic qualities or traits (Martin 2015). As described above, it is standard practice in the United States to use selective criteria to recruit, screen, and match egg vendors. Most informants did not verbalize any major problem or concern with this practice and in fact saw the American way of matching egg vendors with clients as superior to third-party egg transfer practices abroad.

Conclusion: Selling Eggs on the International Market

Egg transfer in the United States functions not only as an assistive technology, but also as a selective one. Before the first “test tube baby” was ever born via IVF, historian Mark Haller (1963: 189) wrote of the ways in which advances in the study of genetics was leading to a revived interest in eugenics: “[While] eugenicists [*sic*] generally recognize that their movement currently has only minor influence and importance, they look forward to the day when man can, by bringing his genetic future under control, do much to make human life healthier and happier.” It is not quite accurate to state that eugenics as it was practiced in the nineteenth and twentieth centuries is being revived in the practice of egg transfer today. Unlike eugenics, third-party egg transfer is not compulsory nor is it being enforced by the state. As a quite expensive infertility treatment, IVF using third-party eggs is available only to the few who can afford it, and thus its material consequences are not widespread.

Yet, as a selective technology, third-party egg transfer reinforces genetic determinist ideas about the production of children with desirable and superior qualities while screening out less than desirable traits. The recruiting, screening, marketing, and matching process used by brokers is based on their ideas about what constitutes fitness, desirability, and marketability. The technology becomes both the instrument and justification for the practice. By assessing the qualities of the prospective genetic parent (i.e., the egg provider), brokers translate this information into a biographical tool for intended parents who want to determine, predict, or influence their future offspring’s race/ethnicity, appearance, temperament, abilities, and behavior (Martin 2014).

While the buying and selling of eggs, and the associated selective practices that attend these commercial transactions, is perfectly legal in the United States, other nations enforce much more regulation (if not outright prohibitions) on commercial egg transfer. Intended parents whose desires align with US fertility industry practices may travel to New York, Los Angeles, San Francisco, or elsewhere to find brokers and clinics that will meet their reproductive needs. As long as the policies in the United

States remain favorable toward technologies that other countries ban or highly regulate, New York and California will continue to be destinations for intended parents wanting to wager on SRTs. Designing one's own children is still merely science fiction, but the way that brokers and professionals recruit, screen, and match egg vendors with intended parents supports, rather than quells, the idea that the superior qualities of their egg vendors are transmissible—and worth paying a hefty fee for.

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8

Technologies of Enchantment: Commercial Surrogacy and Egg Donation in India

Michaela Stockey-Bridge

Transnational surrogacy is commonly portrayed in news reports as a phenomenon in which children born through such arrangements are ‘designer babies’ (Desai 2012) bought from a ‘supermarket of reproductive alternatives’ (Gupta 2006). In this chapter, I draw on parents’ narratives of selection in transnational surrogacy and egg donation and demonstrate that the experience of having children through surrogacy involves more emotional investment than the term shopping implies. Although there are certainly similarities with shopping, parents’ experiences are not wholly comparable to shopping; such a comparison does not do justice to the experience. I focus on intending parents (IPs) narrative accounts of their experiences of surrogacy in India. Selection and rationale for selective decisions emerge naturally in these accounts.

In vitro fertilisation (IVF) and surrogacy follow the regular format of assisted reproductive technologies (ARTs) (Inhorn and Tremayne 2016), including oocyte retrieval and embryo transfer. Sperm and ova

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are graded according to quality as are any resulting embryos. Sex selection¹ was illegal in India while I was conducting field work in 2011 (and remained so at the time of writing), and my informants did not describe the use of preimplantation genetic diagnosis (PGD). However, prenatal testing was performed without fail. Blood and urine tests alongside frequent ultrasound scans were produced, mainly for IPs to track the (healthy) development of their child. Prenatal testing is imbued with both hope for a certain kind of child (Gammeltoft 2013) and bonding with that child (Georges 1996; Kroløkke 2011), along with the fear of what these tests may reveal (Gammeltoft 2013). In addition to the selective reproductive technologies (SRTs) just described, my informants described non-technological selection in their narratives of family formation.

I describe IPs' selective decisions as 'selective moments', placing emphasis on selection as a temporal aspect in IPs' experience of family formation through cross-border reproduction rather than a motivating force. IPs describe 'falling in love' with a specific egg donor as their potential child's genetic donor and their 'heart break' when the donor is unavailable. The term shopping may imply a selfishness that overrides other drives and emotions that flow through the surrogacy process, perhaps more comparable to online dating (Bokek-Cohen 2015) than shopping for products. I draw on IP narratives as a means of illustrating the emotional aspects of selecting egg donors and surrogates in transnational commercial surrogacy arrangements.

While surrogacy involves both ARTs and SRTs, this mode of family formation blurs the boundaries of ARTs and SRTs (Wahlberg and Gammeltoft, this volume). I follow Wahlberg and Gammeltoft's definition of SRTs as those 'used to prevent or promote the birth of certain kinds of children' (this volume; Gammeltoft and Wahlberg 2014) in an exploration of third- (and fourth-) party reproduction and the selective moments involved therein. In doing so, I examine the emotional investment IPs describe in their narratives of selecting gamete donors and surrogate mothers and examine how these selective moments differ for gay men and heterosexual couples not so much comparing gay and heterosexual experiences but drawing on data from two different groups

of participants. The thread that connects all the instances I discuss is the emotion embedded in the selective processes involved in commercial surrogacy in India as conveyed by Australian IPs.

Previous studies of gamete donation have documented that what people seek is not a super child but an ordinary child (e.g., see Gammeltoft 2013; Whyte and Torgler 2015; Whyte et al. 2016; Millbank 2014; Blyth and Frith 2009). There is a dimension of this selection process that has been overlooked in the literature to date and this is the intuitive sense of connection with the third party in this reproductive process. In documenting the role that intuition or gut feeling plays, I highlight the ‘magic’ features of kinship as an aspect of third-party reproduction that has been overlooked in the literature to date and needs more attention.

Methods

I draw on multi-sited (Marcus 1995) ethnographic fieldwork in India and Australia among Australian IPs. My ethnographic fieldwork included participant observation carried out in clinics and social gatherings in India and IPs houses and consumer conferences in Australia and online. It also involved in-depth interviews with directors of 3 clinics in India, 14 IPs and 14 surrogate mothers, some of whom had also acted as egg donors, 3 surrogate agents and 3 IP recruiters from 2010 to 2013. The majority of the primary research this chapter draws upon took place in India in 2011 in IPs’ hotel rooms, IVF clinic waiting rooms and offices, as well as via Skype. I interviewed heterosexual couples and same-sex male couples as well as single same-sex-attracted men.

The next section briefly summarises key points in the social and legal history of surrogacy in Australia. This section creates context in terms of both understanding the kind of families recognised in Australia and the motivating forces that have led to the particular version of family formation and the related selective reproduction I go on to discuss.

A Very Brief Summary of Surrogacy in Australia

The first known² case of surrogacy in Australia, in 1988, was between sisters Linda and Maggie Kirkman. With the assistance of Professor John Leeton, Maggie supplied the egg, sperm was supplied by a sperm donor and Linda Kirkman acted as the gestational mother. Linda Kirkman is clear in her preference for the term 'gestational mother' and rejects the term 'surrogate mother' or 'surrogate' because, she says, 'I do not see myself as a substitute for anything' (2010: 20). This arrangement was difficult to organise; the first hospital's ethics committee rejected the arrangement, refusing to enable a surrogate pregnancy. Leeton found a hospital that did not have an ethics committee and assisted the Kirkman sisters' surrogacy arrangement (Rowland 1992). In 1990, just two years after Linda Kirkman birthed her sister's baby, the Australian ethics committee ruled that surrogacy should not be prohibited in Australia, under strict conditions (Swan 1990). A minority of committee members were concerned that personal autonomy was not possible, effectively, that women choosing to be a surrogate could not possibly give informed consent. They argued that surrogates could not know how they would feel after the birth and that they would suffer upon relinquishment of the child (Swan 1990). Proponents argued that surrogacy should be allowed, under special circumstances and strict guidelines, fearing that prohibiting surrogacy would force these arrangements 'underground'.

Furthermore, proponents contended that as long as the surrogate's gametes were not used and the genetic parentage was clear, the surrogate would not become attached to the child (Yovich 1988) and, therefore, not suffer upon relinquishment. Australian legislation defined (and, to date, still defines) the birth mother and her husband as the legal parents of a child born through genetic surrogacy (Millbank 2011). Regulation is precautionary in this context; although legislators believe that the lack of genetic connection also means a lack of surrogate attachment to the child, the birth mother's right to the child is protected. The belief that the genetic tie is paramount to claims of kinship, while legislation considers the birth mother's claim to kinship as primary, highlights a

ension³ between genetic parentage and the birth mother's claim to parentage. However, while the genetic tie is secondary to the birth tie under Australian law, the genetic claim to kinship is central to a new baby's claim to Australian citizenship. Children born to Australian parents overseas gain Australian citizenship by descent (Sifris 2015). Proof of citizenship by descent is achieved with a DNA test that must demonstrate that the child is the genetic offspring of at least one of the parents.

As a result of the challenges surrogacy poses to existing concepts of kinship, both payment and contracts were (and remain) problematic in regulating surrogacy in Australia. Both proponents and opponents of surrogacy in Australia excluded paid surrogacy as an option (Millbank 2011: 177) and contracts in surrogacy arrangements could not be legally enforceable, and this is still the case to date. Although it is very rare for a surrogate to change her mind and opt to keep the child, the lack of a contract is described as undesirable for IPs.

Currently, altruistic surrogacy is allowed in Australia, and commercial surrogacy is banned in all states and in New South Wales (NSW), this ban extends to overseas arrangements. Clinics follow the guidelines of the National Health and Medical Research Council (NHMRC) as well as the state-by-state legislation. The birth mother is considered to be the parent of the child she births and same-sex marriages are not recognised. Therefore, foreign birth certificates that include both parents in a same-sex relationship, such as those issued in Canada, for example, are not accepted in Australia. Australia thus allows for certain kinds of families and excludes others.

A Certain Kind of Society: Laws Without Teeth

Australian IPs sought commercial surrogacy outside of Australia's borders because they believed they had no alternative route into parenthood. More often than not, IPs had waited on adoption and fostering registers, or had undergone many IVF cycles, suffered multiple miscarriages and failed pregnancy attempts before considering cross-border commercial surrogacy. They chose to circumvent the laws in Australia because they did not offer what they considered to be a valid pathway

into parenthood. Aleardo Zanghellini's (2010) analysis of the 2008 law reforms in England/NSW and Australia governing non-coital procreation and parental responsibility is pertinent here. Zanghellini identifies that reforms tended to discourage family formation that challenge the hetero-normative nuclear kinship structure, in particular, regulation of parental responsibility discourages cooperative parenting arrangements. Like McCandless (2005), Zanghellini establishes that the 'sexual family' is the normative form of kinship regulated and recognised in Australia and the UK.

Each of my informants described the difficult system in Australia as hard to navigate and therefore off-putting. They preferred to follow the reproductive trails of other parents who had successfully formed their families with the help of transnational surrogacy. India was a desirable reproductive destination because many IPs had already had children through IVF clinics there, and it was relatively more affordable and involved contracts privileging IPs claim to the child over the surrogate mother's claim. Surrogacy was unregulated and available for a relatively small window of time⁴ to foreigners seeking commercial surrogacy arrangements. While I was conducting fieldwork in India, the contract was considered⁵ to be legally enforceable (Munjal-Shankar 2014).

The ban on commercial surrogacy in Australia (and its extension to overseas arrangements for NSW residents) was viewed by the Australian IPs I discuss here, as intimidating but not prohibitive. This view was reinforced during the process of obtaining a passport for children born via surrogacy in India. Despite the illegal status of commercial surrogacy for Australian residents, the Australian consulate in New Delhi was able to fast track the processing of passports for children born via surrogacy in India. In 2011, it took a record two weeks to produce these passports.⁶ The director of one of India's more popular surrogacy clinics stated in a conversation with me that the Australian consulate telephoned her every month to get the quota of Australian babies due the following month. The disjuncture between Australian states extending the ban on commercial surrogacy to overseas and the Australian consulate's efficient processing system suggests a double standard, but a kind, process that helped soothe the fears of Australian IPs not being able to take their children home.

Gamete Donor Selection

My approach in initial interviews with IPs was to simply ask for a narration of their surrogacy story. An interesting trend emerged in these narratives in which gay men mainly discussed selection of their egg donor and women discussed only selection or connection to their surrogate. I thought this was perhaps because women were using their own eggs. Yet, in follow-up conversations, I learned that some of the women had used an egg donor as well. Men in same-sex relationships had the additional moment of selection in making the decision as to which of them would provide the sperm. In the following section, I draw out the role of emotion and concepts of success in selecting the egg donor and sperm provider.

Fitting In

When Jonathon and David first came across surrogacy in India as an option, they were exhilarated. They had always hoped to have children of their own but did not think it would ever happen for them. Surrogacy in India presented an affordable path into parenthood that had worked for others:

Jonathan: The clinic just send you a big bunch of profiles, I think there were twenty five egg donor profiles. I hate the term but it's like a bit of a shopping catalogue, they have heights and weights and previous illnesses. We decided not to spend too much time choosing the egg donor because there is no way of really knowing them anyway. We didn't care about university education or anything like that, that is more a sign of class than intelligence. We went through and just went on feeling, we got it down to five that gave us a good feeling and then just chose the one that had produced the most eggs in the past. So, gut feeling then number of eggs, that's how we decided. There is no such thing as a perfect choice. We did the same with the surrogate but the doctors only gave us three to choose from, I think they chose actually, you think you have a choice but then you don't know what will actually happen.

Although Jonathan viewed the clinics' presentation of egg donors and surrogates as a form of shopping, he did not think of his and David's selections in this way. They chose not to take too much time over selection of their egg donor, it was a moment of selection they did not wish to overthink. This emotive approach to selecting an egg donor was common in same-sex male couples' narration of their surrogacy journey. Pete and Dave describe a similar experience of looking through donor profiles online. Pete explains that selecting an egg donor was an unusual and overwhelming experience;

Pete: One of the most difficult decisions we actually made.

Dave: You've got 20 women and you've got to look at 20 women and little tiny write ups about each woman and decide well, which one do I want to be [the] egg donor? And in the end it came down to which one looked most like females from the other person, the one who wasn't the biological father, who looked like the females from the other person's family.

They were seeking a connection but presented with very little information with which they could make this connection. Jonathan was not only seeking a match he had a good feeling about, he was also seeking a successful match; a donor that was also a 'good producer'. While Pete and Dave were equally vexed by the scant information and small photographs they were given to decide on an egg donor, they sought out someone who appeared to share the phenotypical features of the partner who had no genetic connection to their future children, by selecting a donor who looked like his sisters or aunts. This speaks not only of valuing the genetic connection but also of valuing the appearance of genetic belonging or fitting in. Pete and Dave's selective moment focused on identifying their Indian surrogates shared features. Others IP narratives describe seeking out egg donors based on shared skin colour:

Mark: We chose an egg donor with fairer skin, who was willing to donate in India, we saw a profile we really liked and we got to meet her which was wonderful. She wanted to know that we were good people too, so she wanted to meet us. It's a big commitment. William and I decided that I would be the genetic father, we thought about the health of our families, genetic history, we spoke about it a lot and then decided it would be me. If it didn't work with my sperm, he would try.

Mark was not the only IP to choose an egg donor with fairer⁷ skin. While the majority of the IPs I spoke with did not speak about skin colour as a feature of fitting in, Mark was keen for his child to not stand out in any way from other members of his family. Mark felt that his child was likely to suffer some discrimination during his childhood because he would have two dads, and he wanted to limit this discrimination in any way possible and felt that his child 'fitting in' to his family in terms of shared skin colour would help reduce stigma and discrimination. Another same-sex male couple chose a South African egg donor with fair skin and offered similar explanations. A third IP, Dan, chose an egg donor from Ukraine because his family also descended from Eastern Europe, and he wanted his child to look like part of his family. This example illustrates an imagined connection between genetics, kinship and nationality, while highlighting a desire for some sort of connection between himself, his family, his child and egg donor. He also wanted his child to have the option to meet his egg donor later in life. Whereas egg donation in India is anonymous, it is not anonymous in Ukraine.

Like Mark, Dan projected an imagined future for his child and hoped to mitigate emotional suffering as much as possible. He explained that he had read a lot about donor-conceived children and felt his child would have a greater chance of emotional adjustment in a known donor relationship. While Dan was unusual among my informants, his decision was not unusual in the context of domestic gamete donation in Australia. Jenni Millbank's (2014) research into donor conception in Australia describes parents of donor-conceived children as anticipating the future needs of their children and establishing connections with their sperm donor as a means of ensuring their child will have access to their genetic lineage.

The selection of EDs and surrogates is an emotive process in IPs navigation of this novel territory while attempting to build their families. Though selection of specific characteristics such as skin colour and shared phenotypical features comprises part of the process, the prevailing feature of IPs selective moments is that they follow their 'gut feeling' and select egg donors based on their perception of a connection. In addition to this, they make choices based on projected futures—a future that may involve discrimination or the child's desire to know about their genetic lineage—and make selective decisions with the aim of curbing emotional turmoil

in these imagined futures. In contrast, some IPs experienced failure after failure in their surrogacy attempts. In such cases, the selection process becomes increasingly less important.

Ravelingien et al.'s (2015) qualitative study of lesbian couples in Belgium and their views of anonymous sperm donation identified family cohesion and health as the primary concerns when considering why they might want some choice in the donor selection process. Similarly, Whyte and Torgler's study of women's preferences in buying donor sperm online identifies behavioural traits rather than physical appearance as central to the selection process (Whyte and Torgler 2015), indicating that social cohesion was more important than appearance. There is a clear distinction here; whereas the women in the latter studies did not indicate that physical appearance would influence donor selection,⁸ some of my gay male participants did indicate that they ideally would like their child to *look* as though they were part of their family. Couples were not seeking 'designer babies' at all but were imagining their children as members of their family that they hoped would be healthy and would fit in.

Selecting the Sperm Provider and Thoughts on Genetic Connection

Unlike heterosexual couples, same-sex male couples' selection is not limited to the egg donor and surrogate; they must also select which of them will be the genetic father, as is clear in Mark's description of his and William's choice of the genetic parent. Same-sex male couples speak of the genetic tie as the primary, or perhaps primal, tie; it is more important in their selection process than the 'blood tie' their child will have with the surrogate. Greenfield and Seli's (2011) assessment of gay men seeking ARTs at a university clinic in the USA describes that male couples must decide which partner will provide the sperm in surrogacy arrangements; however, as Norton et al. (2013) highlight in their summary of research into gay men's pursuit of surrogacy, the authors do not offer qualitative analysis of the decision-making process. I offer a small contribution to this developing area of knowledge here.

I met Ben and Dean about a year into my fieldwork. They were unusual in some respects. Every other IP I met had tried, or considered trying, alternative paths into parenthood before seeking surrogacy in India, and Ben and Dean had not considered any other option. They also contrasted with other IPs I had met because they sat at the lower end of the socio-economic strata. They earned a modest annual income with Ben as the sole earner working in a factory. Ben unexpectedly received an inheritance, and they decided to use some of the money to put a deposit on a house and the remaining money to enter into a surrogacy arrangement in India. Like Mark and William, their description of choosing an egg donor included choosing which of them would provide sperm:

Ben: The one [whose sperm sample] came back with the more positive results would be the lucky winner.

Ben and Dean decided which of them would provide sperm based on which of them had the best sperm quality and best chances of success in terms of forming a healthy embryo.

Whereas Ben and Dean thought of success in terms of sperm quality, Mark and William made their selection based on family histories of mental health. William had a history of depression and they therefore chose Mark to be the genetic father. Unlike egg donor selection, selection of sperm provider between same-sex male couples was less based on gut feeling, yet like egg donor selection, the examples described here draw out ideas of selection for success: Which of us can provide sperm that will be more likely to ensure pregnancy? Which of us can provide sperm that is more likely to result in the kind of healthy child we want to raise? Similarly, egg donors were chosen on proven success, high production of eggs, a 'gut feeling' and shared phenotypical features with female relatives. Selective decisions were centred on achieving pregnancy as well as fitting in with their family.

The primacy of the genetic tie is dramatically illustrated in Ben's description of his children's egg donor.

Ben: When we went back to the clinic with the babies after they were born, there was the egg donor! She was working for the clinic, we have no idea if

she knew that she was looking at her own genetic children. That was a real moment, it gave us chills.

In a later discussion, Ben and his partner Dean ponder whether or not their egg donor recognised the children as her own somehow, did she know? But it's anonymous, how could she know? She must have known. Like the 'gut feeling' IPs follow in selecting their child's egg donor, we see an expectation that the genetic link is something that can somehow be sensed. This speaks of an understanding of genetic relatedness and kinship that is beyond biomedicine, the idea that we connect with our genetic kin instinctively. In de Castro's words, kinship is more than a 'weird biology', kinship is magic (de Castro 2012). De Castro describes modern kinship as a combination of choice and magic: we construct kinship groups choosing both non-genetic and genetic relations while also choosing not to create kinship with genetic relations (e.g., anonymous gamete donors). Reproductive technology, as another form of construction, is 'our own particular brand of magic', expanding our options in the construction and negotiation of kinship (de Castro 2012).

Alfred Gell's (1988) theory of technology is an interesting tool to think through the selective moments IPs describe. Gell (1988) explains that technology is entwined with techniques of the body, drawing on Marcel Mauss's theory of exploring how we learn to use our bodies in specific ways. Technology, according to Gell, is not just about the tool or the creation of the tool but our bodily ability to master the use of that tool however simple or complicated it may be. He identifies three forms of technology. The first is the technology of production, our ability to gather the things we need to survive such as food and shelter. The second is the technology of reproduction and this encompasses our systems of kinship. And the third is the technology of enchantment. Among these technologies, enchantment is the most sophisticated. Gell includes all forms of art, gifting and rhetoric as just a few of the technologies of enchantment. Attracting other people (and animals), according to Gell, is the most sophisticated human technology. So, the gut feeling in selecting an egg donor could be understood as IPs' description of selecting the most subjectively enchanting genetic traits

for their children, rather than the most phenotypically ideal or normative traits.⁹ One of the fascinating features of ARTs and SRTs is that in the separation of reproduction from intercourse and the inclusion of third and fourth parties, we have a means of understanding something of the values associated with family and its formation. Although Gell does not describe the categories of technologies as overlapping or working together, I suggest that third-party reproduction is a useful example illustrating technologies of enchantment and technologies of reproduction as technologies that work together. In order to reproduce, we must exercise our sophisticated technologies of enchantment to attract another or perceive connection to another.

Surrogate Selection and Emotional Connection

As stated earlier, whereas same-sex male couples would describe ‘falling in love’ with their selected egg donor, intending mothers more often expressed this emotional connection with their surrogate. In part, this is because heterosexual couples tended to use the intending mothers’ ova in their first few surrogacy attempts. However, even after using an egg donor, intending mothers would more often refer to their surrogate than their egg donors. Sheena and her husband Matt, for example, sought out surrogacy in India after years of failed IVF. They had almost given up hope of becoming parents when they came across this new path and their hopes were reignited:

Sheena: Our surrogate is very calm, very beautiful, we got to meet with her and she is happy with us too. It’s a two way process, we chose her and she chose us. It just makes me feel really emotional. We Skyped throughout the pregnancy, but not as much as we could have. We get on really well, the day before the baby was born we met and she was just amazing, it is such a miracle, I never thought I’d be a mother. It’s just incredibly emotional. It just happened that we were there in the clinic on the day that our surrogate was there saying she wanted to be a surrogate, she’d donated her eggs previously and now she wanted to be a surrogate. She phoned me on my birthday to say I was pregnant! It was just amazing. I think I spent a month

crying, I was so happy. When the children are older I will bring them here to meet their surrogate. I have to arrange it through the clinic though because there is a confidentiality agreement. Her family and children don't know she is doing this so it would be her decision.

Like many intending mothers, Sheena refers to the surrogate mother's pregnancy as her own. This idea of the body as a shared space is common to ethnographic work on surrogacy where surrogate mothers describe the pregnancy as the intending mother's pregnancy rather than their own and vice versa. However, the surrogacy arrangements Teman (2010a) and Ragoné (1996, 1994) describe in Israel and the USA, respectively, also explain an intimacy between the surrogate mother and intending mother that is not possible in the transnational arrangements I describe. Sheena felt she and her surrogate had bonded and 'get on well' yet she also described the limitations of the relationship. While she described the emotional side of her relationship with her surrogate, she understood that this was not an ordinary relationship—the clinic mediated their relationship and would go on doing so. Sheena's surrogate was happy to carry a pregnancy and earn money for her family through this labour; however, she did not want her own children to know about her work or her relationship with Sheena's family.¹⁰

Carmel had a very difficult pregnancy and birth with her first son. She and her husband Lachlan were eager to have a sibling for their first son but Carmel suffered multiple miscarriages over several years and eventually decided she could not cope with another miscarriage. They attempted to adopt a younger child and were accepted on the waiting list of an adoption agency in their state. After five years of waiting with no success, they decided to give up on the idea of having another child. Years later, they came across surrogacy in India and chose to pursue this avenue. After three unsuccessful attempts, Carmel was ready to give up. In their final attempt, their IVF specialist recommended they try using an egg donor. Like Sheena, she felt a strong emotional connection with her surrogate. Carmel contrasts her understanding of the surrogate-IP relationship with that of same-sex male IPs:

Carmel: I think that is why he [another IP Carmel met on her first trip to India for surrogacy] said ‘don’t meet the surrogates! They’re not in it for anything else, they are in it for the money’ and I said to Lachlan later on ‘did he [other IP] not know that?’ That’s quite a male point of view too because it was pretty obvious to us.

Carmel has publically acknowledged her surrogate on her Facebook page every mother’s day since her child was born but has not acknowledged her child’s egg donor in the same way and did not share the fact that she had used an egg donor with me until her child was around a year old. During the pregnancy, Carmel showed me an ultrasound of her child at around four month’s gestation. She was excited yet afraid to feel too hopeful after so much loss and spoke of her beautiful surrogate but did not talk about having used an egg donor at all. Although Carmel felt sure that her surrogate carried out her labour for the money, she did not see this as a negative in the same way some of the same-sex male IP couples she describes.

Connections and Disconnections: Selecting and Outsourcing Selection

While some same-sex male couples and single intending fathers met their surrogate and had some say in the selection process, others chose anonymous arrangements and avoided selection of the surrogate altogether:

Ben: We let the doctor decide on the surrogate because she knows—you know there is no genetic link there so that was not as important to us. The doctor chose a surrogate whose cycle was linked up to the egg donor. The first attempt didn’t work. The second attempt would be our last attempt, we were clear about that with the doctor, we couldn’t afford any more than that. The doctor chose a different surrogate, we signed new contracts and then a couple of weeks later we had the email saying that we had twins. We spoke about meeting [the surrogate], but we heard from others that they wished they hadn’t, and we haven’t really decided yet.

Some of those who decided not to meet their surrogate felt that money as a central incentive to carry out this intimate labour signified a business relationship; they felt this was incompatible with more altruistic motivations and therefore did not warrant a more familial relationship and did not require even a moment of selection or connection. The inference that the exchange of money devalues this form of intimate labour (Anleu 1992) is a common trope in academic and popular debate of surrogacy. Arguments over paid and unpaid surrogacy, commercialisation and objectification are the foundation of the difficulty in regulating paid surrogacy (Markens 2007). The perception of the surrogate as somehow not connected with the child she gestates is also a familiar one.

It is common, in academic accounts of surrogacy, for surrogates to refer to themselves as ‘an oven’ baking ‘buns’, a vessel or sorts gestating someone else’s child (Berkhout 2008; Teman 2010b), while others emphasise the ‘blood tie’, as Pande’s (2009) surrogates in Gujarat explain that ‘it may be her eggs, but it is my blood’. This account, of the blood tie, corresponds with the biomedical concept of epigenetics. Epigenetics is the study of ‘molecular modifications that influence gene activity and chromosome structure’ (Novakovic and Saffery 2012: 959); in lay terminology, epigenetics is the study of the effect of environmental factors on genes. Studies of epigenetics and maternal/foetal gestation demonstrate that epigenetics can influence pregnancy outcomes and ‘foetal programming’ for adult disease (Pinborg et al. 2016). The surrogate is much more than just an ‘oven’, vessel or incubator; her body interacts with the foetus’ body, nourishing and affecting the foetus significantly at a genetic level (Novakovic and Saffery 2012).

While intending mothers experience a stronger bond with surrogate mothers, gay men place more emphasis on the genetic tie and their gut feeling about their egg donors. This is indicative of IPs extending their own reproductive bodies and perception of their reproductive roles onto the bodies of third and fourth parties. For women, pregnancy and birth are, normatively speaking, unique to the experience of becoming a mother, and in their bonding with, and relating to, their surrogate mothers, they are extending their bodily boundaries to the pregnant body of their surrogate. At a very basic, bodily level, men are limited to the selection of their conception partner—they may have a child and never

know about it. Women's preference for bonding with their surrogate rather than their egg donor could also be understood as employing technologies of enchantment, following their gut feeling in selecting a surrogate and then bonding with the surrogate to ensure the agreement ends with the surrogate's relinquishment of the child.

Conclusion

Australian regulation of surrogacy recognises certain kinds of families in recognising only certain methods of family formation. IPs seeking surrogacy overseas circumvent Australian laws to form a family with the help of friendlier regulations (Whittaker 2015) or more often unregulated 'pop up' fertility destinations. SRTs, including prenatal testing, oocyte and embryo selection, form part of the experience of seeking surrogacy. Selective reproductive moments also arise in the selection of egg donors and surrogates, just as some same-sex male couples consider family medical histories when deciding whose sperm to use. I highlight that IPs do not emphasise selection as motivating these journeys. However, in IP descriptions of selection, we learn that they are, at least initially, seeking a certain kind of child. They imagine a child that will look like them, is healthy and will fit in with their family.

IVF clinics in India, and elsewhere (Levine 2010), present egg donor and surrogate mother-selection as a shopping experience. In the examples discussed in this chapter, IPs experience of selecting donors and surrogates is driven by gut feeling together with perceptions of success and is not as frivolous as the term shopping would imply. Although there are distinct aspects of seeking a certain kind of child, this is not very different from the kind of child most parents seek in their bid at family formation: a normative, healthy child who will fit in with the family. Perhaps then, just as ARTs and SRTs can be viewed as an extension of the self (Franklin 2013), selection and family formation via these technologies extend on normative decisions around reproduction.

The portrayal of IPs as shopping for 'designer babies' implies a level of choice and control that is extraordinary in comparison to so many other routes into parenthood; in fact, there is perhaps less control, perhaps

more worry and no more design than in normative choices of reproductive partner. As is the case in normative family formation, some seek specific phenotypical characteristics yet most describe seeking similarity and the ‘best fit’. IPs draw on their intuition and gut feelings about the look of a donor or surrogate in seeking out connection with their third- and fourth-party reproductive partners, while at the same time trusting that clinics or brokers have screened egg donors appropriately. Technologies of reproduction and technologies of enchantment work together. IPs draw on technologies of enchantment in feeling their way through technologies of reproduction, third-party selection and successful family formation. In the examples offered in this chapter, technologies of enchantment inform and assist the selective moments that are intertwined in such technologies of reproduction as surrogacy-aided family formation.

Notes

1. Sex selection is viewed to be a risk due to the historic preference for male children and female infanticide. Marcia Inhorn’s recent findings in Egypt demonstrate that although female infanticide is forbidden in religious doctrine, the availability of PGD has led to female ‘embryocide’ (Inhorn and Tremayne 2016).
2. The Kirkman sisters is the first known case, but it is assumed that this case was preceded by earlier traditional surrogacy arrangements in Australia; see, for example, Rowland, R. 1992. *Living Laboratories: Women and Reproductive Technologies*. Sydney: Spinifex Press.
3. This tension tugs at either end of kinship claims, that of the birth mother and that of the genetic kin. Prior to the availability of donor insemination (DI) and IVF, blood and marriage ties formed the basis of western concepts of kinship. Williams-Jones, B. 2002. Commercial Surrogacy and the Redefinition of Motherhood. *The Journal of Philosophy, Science and Law* 2. Gestational surrogacy (in which the surrogate is not genetically related to the child) challenges these notions.
4. India was the first of what I refer to as ‘pop up’ reproductive destinations—destinations for reproductive travel that are available for only a

brief period while surrogacy was unregulated. Other places include Thailand, Nepal and currently Cambodia and Laos.

5. The ARTs bill had not been passed during my fieldwork, and ARTs clinics were relying on contract law, however, this had not been tested in court. For a detailed discussion of the enforceability of surrogacy contracts in India, see Munjal-Shankar (2014).
6. This is in contrast to the UK, for example, where production of passports for children born via surrogacy would take at least three months.
7. IPs generally used the term 'fair skin' to mean ethnically Caucasian.
8. Although I am in no way universalising this distinction, see, for example, Bellware, K. 2014. White Woman Who Sued Sperm Bank Over Black Baby Says It's Not About Race. *The Huffington Post*, October 3.
9. In the sense that concepts of 'normal' overlap with concepts of 'perfection'. McDougall, L. 2014. *The Biomagical Vulva: A 'Clean Slit'*. PhD, Macquarie University.
10. This was possible because of the socio-economic strata of many surrogates in India. In this lower middle-class or working-class strata, women are commonly involved in informal economy (Hill, E. 2010. *Worker Identity, Agency and Economic Development: Womens Empowerment in the Indian Informal Economy*. London and New York: Routledge) and surrogates I spoke to described travelling to another city for work, such as domestic services which are a common feature of their working lives. It was therefore easy enough to hide surrogacy, telling family that they were contracted as domestic servants in another city.

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