

Social Disparities in Health and Health Care
Series Editors: Ronald J. Angel · William R. Avison

Eric R. Wright
Neal Carnes *Editors*

Understanding the HIV/AIDS Epidemic in the United States

The Role of Syndemics in the Production
of Health Disparities

 Springer

Social Disparities in Health and Health Care

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Preface

The idea for this book grew out of a series of conversations with many colleagues grappling with the challenge of understanding and intervening in both the domestic and international HIV/AIDS epidemics. In the United States, 35 years, significant advances in clinical treatment, and the stabilization of the epidemic among some of the most marginalized populations in our country have taken away the sense of emergency that once permeated discussions of domestic HIV prevention and intervention. We appreciate and applaud the continued public attention and commitment to the global HIV/AIDS epidemic—most visible in the virtual explosion of global HIV-related research and in the President’s Emergency Plan for AIDS Relief (PEPFAR), initiated by President George W. Bush and continued by President Barack Obama. This research, PEPFAR and other public health initiatives have been critically important in broadening our understanding and contextualizing the U.S. experience with this disease. Midway through the fourth decade, however, we felt it was time to reflect on the state of the domestic epidemic, particularly among populations in this country that continue to be most heavily burdened by HIV/AIDS.

The theoretical lens of syndemics is proving to be a powerful tool for improving our understanding of the epidemiological dynamics of HIV/AIDS. Indeed, there has been an exponential increase in theory and research informed by or guided by this framework. This trend has been driven, in large part, by the persistent complex realities of the domestic epidemic, which increasingly have demanded that we look beyond traditional intellectual boundaries and integrate medical science, epidemiology, prevention, and social science. Because of the promise of syndemic theory, we asked each team of authors to consider the syndemic framework in their discussions of the interrelated issues that are shaping the HIV/AIDS experience in the populations they considered. In this regard, this volume represents a series of case studies that simultaneously update us on many of the important contours of the domestic HIV/AIDS epidemic and encourage readers to reflect on the potential, limits, and empirical challenges of syndemic theory.

Looking beyond narrowly defined biomedical disease processes to incorporate psychological, social, structural, and environmental forces into complex models of disease dynamics is no simple task. As the reader will learn, syndemic processes have been theorized, and sometimes operationalized, as being *multilevel* (i.e., linking individual, organizational, community, and societal forces); *multifocal* (i.e., clustering of multiple, intersecting and/or overlapping communities); and *multi-determinant* (i.e., involving virological, biological, physiological, psychological, and social causes or drivers). Only adding to this theoretical and empirical intricacy, the existing research literature signposts that these dynamics most likely also *evolve and shift over time*.

Each chapter in this volume offers an interesting and important overview of the syndemic processes at work within a particular subpopulation in the U.S., based on the available literature and/or the authors' own work. Individually, each chapter calls attention to a specific range of forces and/or dynamics that will help the reader understand and appreciate the potential value and challenges in applying syndemic theory. The reader will, however, likely be disappointed in that the chapters do not collectively suggest a single, clear, general road map to guide future research. This is clearly an inherent challenge in that the framework implies that scientists should and must focus more detailed attention on contextually specific or local forces operating within particular communities.

In the end, we believe that the collection of essays in this volume will paint a deeper understanding of the U.S. HIV/AIDS epidemic. We also hope that it will stimulate more theoretical speculation and empirical research on the syndemic processes in HIV/AIDS and other diseases. Future understanding and our ability to intervene effectively will depend on our collective ability to acknowledge and disrupt the syndemic forces that are shaping communities' risk behavior as well as their experiences living with HIV/AIDS.

Atlanta, GA, USA

Eric R. Wright
Neal Carnes

Acknowledgments

As with any major endeavor, many people contributed to the completion of this book. First and foremost, we must acknowledge the enduring impact of the many millions of people in the U.S. and around the world affected by HIV/AIDS. Both of us grew up and became medical sociologists “in the time of AIDS.” Not surprisingly, our scholarship and professional work is propelled by this history and the many courageous stories of people infected and affected directly and indirectly by this disease.

We also wish to thank our many colleagues who have been struggling with the concept of syndemics and the many practical realities associated with disentangling the many intricacies involved. We would like to extend a special thank you to the many contributors. In addition to reviewing the existing literature, each author or team of authors also has offered important insights and/or challenges for future research and public health practice. We are especially indebted to Ron Stall, Sam Friedman, Mackey Friedman, and Judith Auerbach for their thoughtful comments early in the development of this project. We also thank Bill Avison, Esther Otten, and Hendrikje Tuerlings for the opportunity and their support in contributing this book to Springer’s very important book series on “Social Disparities in Health and Health Care.”

We also would like to thank Indiana University-Purdue University Indianapolis (IUPUI) and Georgia State University for their institutional support of this project. We conceptualized and began work on the project while we were both affiliated with the Indiana University Richard M. Fairbanks School of Public Health at IUPUI and completed it in the Department of Sociology and School of Public Health at Georgia State University. Both institutions offer outstanding, rich, intellectual environments and support for scholars committed to translational work that bridge the academy and “the real world.”

Finally, we wish to thank our friends, family, and especially our partners, Tony Bayles and Steve Moore respectively, for putting up with us during the long process of pulling this book together. We could not have done it without their love and support.

Atlanta, GA, USA

Eric R. Wright
Neal Carnes

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Chapter 1

Understanding the HIV/AIDS Epidemic in the United States—The Role of Syndemics in Shaping the Public’s Health

Eric R. Wright, Neal Carnes and Matthew Colón-Díaz

1.1 Introduction

Thirty-five years ago, doctors identified a handful of cases of a suspicious new medical syndrome in the United States (U.S.), a series of events now widely recognized as the beginning of the epidemic of Human Immunodeficiency Virus or Acquired Immune Deficiency Syndrome (HIV/AIDS). From the very beginning, the story of the HIV/AIDS epidemic has been a chronicle of health disparities, exposing and worsening social inequality both in the U.S. and around the world. The concentration of HIV/AIDS among socially marginalized subgroups and communities remains a vexing scientific challenge for epidemiologists as well as social and public health scientists. The social patterning of the disease also has shaped the geographic, social, and political context within which community leaders, public health officials, and healthcare providers have struggled to respond to the needs of those directly and indirectly impacted and to contain and prevent the spread of the virus.

In this book, we take stock of the U.S. domestic experience of the HIV/AIDS epidemic midway through the fourth decade. Much has been written about the epidemiology of HIV/AIDS in the US. Our aim in this book is to focus in-depth attention on HIV/AIDS as a socially bound epidemic—perhaps more accurately

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designated now as an endemic—a disease deeply situated within particular marginalized subpopulations.

In this introductory chapter, we map out what is meant by a disparity and how HIV meets the definitional criteria. We briefly review the current HIV/AIDS landscape highlighting critical advances and problems defining the path before us. For example, there have been significant advances in pharmacology and concentrated pockets of behavior change that are shaping the epidemic; at the same time, there also appear to be many factors that mitigate these medical and social breakthroughs. Of particular relevance for this volume, comorbid diseases inherent in all syndromes,¹ including HIV, remain problematic, as do the particular social contexts that appear to perpetuate infection and disease progression rates. We then turn our attention to the explanatory frameworks attending to these on-going concerns, specifically medicine's notion of comorbidities and the social science's syndemic construct. The latter framework expands the prior by infusing social context as a central issue often overlooked in medical science and clinical practice. The syndemic framework argues that any intervention or study intending to address HIV must incorporate a sound understanding of the array of structural factors, such as poverty and marginalization, and how they work together to drive infection and disease progression.

With this in mind, we review the evolution of syndemic theory arguing that recent applications, and evidence from the empirical literature, are moving the framework away from its original, and most compelling roots, particularly when considered from a social science perspective. Indeed, the particular social context or collective location of specific subpopulations impacted by HIV is critical, even central, to understanding the importance, potential, and application of syndemic theory. After mapping out this emergent theoretical framework, we briefly review how it has been applied to provide the reader an operational understanding of the syndemic construct and how it has and is helping to improve scientific understanding of the extensive disparities in the HIV epidemic. We conclude with an overview of the chapters included in the volume. We believe this collection of papers make a compelling and theoretically informed case for understanding the myriad of health and social disparities manifesting in the subpopulations most affected by the HIV/AIDS epidemic in the US.

While our principal aims are to document the contemporary contours of the American HIV/AIDS epidemic and the utility of syndemic theory for understanding the epidemic, the people directly and indirectly impacted by HIV were and always are in the fore-front of our and the contributing authors' minds. Our perspective is that HIV/AIDS is not merely “extra-individual.” Rather, we believe it is a profoundly personal experience inextricably intertwined with the social structural conditions that shape the lives of people who are affected by and at risk for HIV

¹According to Medline Plus's online medical dictionary a syndrome is “a group of signs and symptoms that occur together and characterize a particular abnormality” (Source: <http://www.merriam-webster.com/medlineplus/syndrome>).

infection. Real people are behind the numbers and the scientific analyses presented throughout this book. Real people experience HIV, its respective social determinants and co-occurring conditions. We hope this text speaks to those affected about their experiences and stimulates a deeper understanding for public health research, policy, and practice.

1.2 What Is a Disparity and How HIV Meets the Definition?

The story of HIV is one of disparities, both with regard to health status and social conditions. According to Adler and Stewart (2010) a disparity emerges when a community's experiential rate with phenomena, such as HIV, exceeds their proportion of the population. As a result, a discrepancy in HIV cases produces an excess burden of disease in a particular subpopulation. Such has been the case for a number of communities who are also disproportionately experiencing social factors and illnesses contributing to an elevated HIV disease burden. For example, the federal government estimates that gay and bisexual men constitute approximately 2–6 % of the U.S. population, yet they make up over 50 % of HIV morbidity and mortality (Centers for Disease Control and Prevention [CDC] 2014a; Gates 2011; Purcell et al. 2012; Wolitski and Fenton 2011). It has been argued this disparity is in part explained by societal homophobia and the resulting social marginalization (Stall et al. 2008). Gay and bisexual men are not alone in their experience with HIV as other subpopulations have or are also experiencing a disproportionate burden. For instance, Smedley et al. (2009) discuss various discrepant disease rates, including HIV, experienced by African Americans (supported by CDC 2015a; Morris et al. 2009). Further examples extend to several other subpopulations such as incarcerated people (Binswanger et al. 2011), women (Gómez 2011) and African American gay and bisexual men (CDC 2015a; Millett et al. 2012). Indeed, the most troubling aspect of the contemporary landscape is the persistent fact that the subpopulations experiencing HIV are overwhelmingly members of marginalized groups—those regulated to an “unimportant or powerless position within society” (Adamshick 2010, p. 541). This pattern continues to beg the question: why?

Behaviorists assert disease transmission is determined by risk exposure. That is, if a person engages in particular behaviors, they are deemed to be “at risk.” For members of marginalized communities, exposure is far more likely given the concentration of cases within their community and the discrepancy in conditions fostering the respective risk behaviors. For instance, even though most people do not use condoms consistently (Reece et al. 2010), members of socially dominant or privileged communities are not coming into contact with HIV infected persons at the same rate as their marginalized counterparts. In fact, many people engaged in condom-less sex are not seroconverting and transmitting the disease. In support, gay and bisexual men are 60 times more likely to experience HIV in comparison to

men who do not have sex with other men (Woltiski and Fenton 2011). Further evidence supporting the concentration assertion exists among other subpopulations such as African Americans and transwomen. The CDC (2015a) reports the HIV infection rate among African Americans is seven times that of whites noting, for example, they constitute 44 % of HIV incidence in 2010, yet only comprise 12 % of the US population. Among transwomen the HIV infection rate is 50 times higher than that of the general adult population (CDC 2015b). These estimated disproportionate rates clearly indicate an HIV health disparity exists among marginalized groups.

To help explain why a health disparity exists in terms of HIV/AIDS, the CDC (2014b) summarized current knowledge stating, “Factors—such as stigma, discrimination, income, education, and geographic region—affect their risk for HIV.” This empirically established landscape offers critical insight into some of the social factors underpinning the complex and dynamic context within which HIV is transmitted. The social contexts in which risk-related behaviors take place are determining influences on HIV transmission and progression as well as on health disparities in general (Dean and Fenton 2010; Friedman et al. 2009). Therefore, to speak of HIV as a health disparity is also to speak of it in terms of social disparities. While HIV serves as a quintessential example of a health condition defined by social disparities, its story involves some extraordinary advances and numerous challenges. In the following, we briefly consider the advancements as well as concerns for they indicate why disproportionate cases of HIV remain contained to marginalized groups and to the areas needing attention to address the disparity.

1.3 The Promise of Historical Medical Advancements and Epidemiological Shifts

The HIV story has not been all doom and gloom. Recent advances in medicine as well as community level changes among particular risk groups offer hope. Medically speaking, HIV/AIDS has transitioned from a fatal to a chronic disease. This medical transition heralds an opportunity to reduce the excess burden of disease among highly impacted subpopulations. The transition is exemplified by a significant decline in mortality. In 1995, the U.S. government recorded the highest number of deaths—approximately 50,000—involving an HIV positive person (CDC 1997). As of 2010, this rate fell to just over 8,000 people (Murphy et al. 2012). This dramatic reduction reflects the development of anti-retroviral therapies (ART) in large part (Palella et al. 2006). ART effectively suppresses the virus (CDC 2013) as well as reduces transmission risk (Cohen et al. 2011). Furthermore, early medical intervention has shown to produce better outcomes over delayed treatment (Kitahata et al. 2009). Current scientific evidence further suggests administering a 28-day supply of Truvada[®] within 72 hours of an exposure provides protection for the uninfected, re: pre- and post-exposure prophylaxis (Curran and Crosby 2013;

Ware et al. 2012). This medical intervention has the potential to revolutionize HIV once again; yet, much work needs to be done regarding access and community acceptance (Crosby et al. 2014; Grant et al. 2010) as well as on the long-term effects and cost of using ART medications for prophylactic purpose, e.g. resistance (Baeten et al. 2012; Paltiel et al. 2009).

In addition to the medical transitioning of HIV, we also have seen community-level changes in associated risk behaviors, suggesting important shifts in local social ecologies. For example, we have seen a reduction in needle sharing along with HIV incidence among injection drug users, a community hit hard and early, because of increased education and targeted intervention efforts (Mehta et al. 2011; Prejean et al. 2011). We also have seen dramatic reductions in mother to child transmission, which predominately impacts racial and ethnic minorities, because of opt-out testing efforts, prenatal care, and administering ARTs during pregnancy as well as the birthing process (CDC 2015c). Lest we forget, there also was a brief but significant reduction in the incidence of HIV among gay and bisexual men in the late 1980s and early 90s (Epstein 1996) only to rebound around the time of the discovery antiretroviral therapy (Woltiski and Fenton 2011). While these patterns are critical for understanding the historical shifts in the epidemiology of HIV/AIDS in the U.S., they remind us that we must remain vigilant and continue to support community-level behavioral change to achieve consistent and/or longer-term results (Rotello 1998).

1.4 The Persistent Problem of Comorbidities in HIV

While the epidemiological shifts precipitated by advances in anti-retroviral medications, and social change in particular communities represent important positive shifts, the morbidity and mortality associated with co-occurring conditions in addition to the persistently high HIV incidence among certain marginalized populations remain significant problems and prominent features of the U.S. epidemic (Deeks and Phillips 2009; Gazzola et al. 2010; Prejean et al. 2011). Regarding comorbid conditions, any number are fatal or debilitating in their own right, or as a result of interacting with HIV (Guaraldi et al. 2011; Nasta et al. 2013; Rodriguez-Penney et al. 2013). Battegay and Elzi (2009) noted the increase in deaths among HIV infected individuals due to hepatitis-related liver disease as well as cardiovascular conditions and kidney failure. These deaths reflect the current landscape in which comorbid conditions are central challenges encountered by people infected with HIV, particularly problems associated with accessing appropriate care and managing complex medication regimens (Horberg et al. 2013; Kinsler et al. 2007; Wood et al. 2003). While medical science has done incredible work producing the knowledge needed to manage HIV effectively and treat a host of its co-morbid conditions, much remains to be done to effectively and strategically incorporate treatment technologies into the unique community environments of the most heavily HIV-impacted subpopulations.

Medicine has long recognized and addressed co-occurring disease states in HIV/AIDS care. Indeed, clinical medical science defines co-occurring diseases as comorbidities—the presence of more than one disease or condition in the same person at the same time (CDC 2015d). Comorbid conditions have been central to the medical model of HIV/AIDS from the very beginning (i.e., many co-occurring diseases were originally defined as “opportunistic infections”). The traditional biomedical approach to comorbidity emphasizes the interaction of co-occurring diseases and typically ignores the social influences driving the behaviors that produce, as well as propel, various disease states. The biomedical conceptualization of comorbidity has been particularly effective in helping to control or slow the progression of HIV disease. But this model has been less helpful in understanding features of the contemporary HIV epidemic in the U.S. For example, why are we seeing increased rates of HIV and TB, especially among marginalized communities (Long and Boffa 2010)? How can we combat interacting disease states in socio-ecological conditions that foster or encourage dual infections? Why does HIV appear to progress to AIDS more quickly in at-risk populations (World Health Organization 2010a)? The traditional biomedical approach conceptualizes HIV and its comorbid conditions virtually independent of their social context. Syndemic theory provides an opportunity to bridge traditional biomedical and social scientific knowledge regarding HIV transmission and treatment.

Since the earliest days, epidemiologists have observed that HIV/AIDS manifests disproportionately in communities living on the margins of society and that the disease takes advantage of social context. Furthermore, HIV/AIDS also takes advantage of a suppressed immune system resulting from the presence of other diseases, such as tuberculosis and viral hepatitis, and suppresses one’s immune system fostering these and other conditions. This dynamic interrelationship presents an on-going challenge to conceptualize effective strategies to prevent transmission and meet the clinical needs of those most affected. In fact, medical and public health efforts targeting HIV and its co-morbid landscape can be and have been thwarted by a lack of attention to the corresponding social environment. As a result, people treated for various co-occurring conditions often become re-infected or infected with new health concerns that are simply nurtured in social contexts that remain unchanged. The failure to address the social context as a critical and central determinant of HIV and comorbidities is not simply a problem for clinical medicine and public health, since social service providers involved in HIV services also often ignore the lived social experiences and community contexts of their client populations.

The syndemic framework has contributed to a better scientific understanding of the HIV epidemic as occurring in tandem with other medical and social concerns, including mental illness, drug use, poverty, and other factors. Over the past decade, the syndemic construct has been utilized by a growing number of public health and social scientific scholars. Unfortunately, despite the expanding theoretical interest, there is still no comprehensive understanding of, or consistent approach to, applying the concept in research or practice. The potential of syndemic theory, when integrated into a biosocial model, is that it can help to account for the

complex social and epidemiological context within which diseases like HIV occur. In the following section, we familiarize the reader with the syndemic framework through a brief review of its history, definitions, potential, and application.

1.5 *Syndemic Theory as a Biosocial and Biomedical Model Regarding Comorbidities*

The syndemic construct was conceived through an insightful reading of the biomedical and social factors contributing to disparities, particularly in regard to HIV. The model is rooted in the social factors faced by the disadvantaged that help explain the apparent synergy among related health disparities. By taking into account how social positional identifiers (e.g. race, gender, and sexuality) and the surrounding community contexts interact to impact overall health and risk behaviors, syndemic theory cuts across disciplines by exploring many elements of culture, identity, and biology. Syndemic theory considers multiple, interrelating processes, such as interactions with intimate partners, access to resources, and adequate nutrition to further a model of comorbid and compounding epidemics. Applying this perspective shifts the focus away from discrete biomedical processes or behaviors to understanding a subpopulation's lived experience in a more holistic and complex way.

Studying high rates of HIV alongside any number of other health concerns among economically disadvantaged, inner city residents, Singer (1994), a medical anthropologist, is often credited as the first to formally conceptualize and theorize about syndemic processes. Singer conceived syndemic as a way to improve understanding of HIV, and other health disparities, as “a set of synergistic or intertwined and mutual enhancing *health and social problems* (emphasis added),” (p. 933). This perspective views HIV as manifest in a communal petri dish which serves as a host and feeds interacting diseases, such as hepatitis, addiction, and mental illness, as well as social contexts defined primarily by poverty and marginalization. For instance, transwomen are more likely to use drugs and alcohol, experience poverty, as well as acquire HIV (Brennan et al. 2012; Sausa et al. 2007); and, HIV infected transwomen who consume drugs or alcohol progress to AIDS faster than if they do not use substances (Greub et al. 2000; Lucas et al. 2006; Poundstone et al. 2001). Thus, the social ecology in which transwomen live distinctly impacts the disparities that manifest and how they interact. Similar patterns are found in other marginalized groups susceptible to HIV infection.

Singer more developed his views regarding syndemic further in a paper focused on the relationship between substance abuse, violence, and HIV/AIDS among urban ethnic minority women (Singer 1996). In this paper, he argued inner city communities' poverty and marginalization place them at inflated risk for various health disparities that compound one another. Not only are they more likely to experience HIV, they also confront any number of health problems disproportionately. More

importantly, the specific array of health problems actually aggravates and compels one another. According to Singer's conceptualization, the compounding relationship between disease and social structural condition is how and why marginalized communities experience a disparity in HIV/AIDS. Marginalized communities, such as the poor and minorities, often lack the resources to address health concerns compared with their privileged counterparts. Given their disadvantaged social position, marginalized people experience a host of other diseases that facilitate higher rates of HIV infection and disease progression.

In 2003, Singer and Clair proposed an updated definition of syndemic: "two or more epidemics² interacting synergistically and contributing, as a result of their interaction, to excess burden of disease in a population" (p. 425). This definition shifts the original biosocial model ("mutual enhancing health and social problems") toward a more traditional biomedical model. The updated model focuses on disease interaction as much as the interaction between diseases and their social influences. This updated definition moves the social factors to a more nebulous place within the syndemic framework. In the new model, we are left to ponder the placement of "social problems" within the petri dish. Are social conditions exclusively the petri dish or stage on which various "epidemics" happen to interact or compound one another? Or, do social conditions actually shape the nature and course of synergistic disease processes? And, what impact do synergistic disease problems have on the social conditions that facilitated their emergence?

While the original definition appears to treat social conditions as integral to the synergistic interaction, the more recent conceptualization treats social factors merely as the domain in which synergism occurs. If social context and disease states are mutually causal and there is synergism among these states then logically there is synergism between the context and the diseases. For example, social marginalization is a significant determinant of alcohol and drug use as well as HIV; at the same time addiction and HIV can contribute to further marginalization (Fritz et al. 2010; Ibañez et al. 2005; Kreek 2011; Levi-Minzi and Surratt 2014; Room 2005; Semple et al. 2012; Ware et al. 2006). Theoretically, this view of syndemics suggests the presence of HIV and addiction progress the state of marginalization as much as marginalization progresses HIV and addiction. This reading of syndemics moves beyond a complex biological model toward a more interconnected and dynamic theoretical framework of multiple factors involved in communities' experiencing HIV disparities. In other words, the research question becomes what dynamic interplay exists among HIV, mental illness, substance abuse, victimization, poverty, and social conditions have on each other among the affected marginalized sub-populations. This is a very different and, we believe, a more important and challenging set of questions at this stage of the HIV epidemic than, what impact do HIV, mental illness, substance abuse, and Hepatitis C have on each other among impoverished and/or marginalized people. We know the presence of one disease

²An epidemic is as an increase in the rate of specific disease, e.g. HIV, in a population while endemic references persistent rates of disease in a population (Friis and Sellers 2009, p. 18).

complicates the other because of clinical medicine's understanding of comorbidities. Treating the social simply as a correlate or even intervening variable stops short of the framework's larger potential to expose the intricate relationship between health and social conditions. As the reader reviews the forthcoming chapters, we hope you will continue to reflect on how the factors discussed impact HIV as a disparity among each marginalized group and work together to shape their lived experience with this disease.

We raise these nuanced, definitional concerns to highlight the importance of syndemics' biosocial roots. Shifting syndemic theory in the direction of a medical model regulates the social context to a less central position within the explanatory framework. Unfortunately, the recent empirical literature appears to rely largely on the narrower, biomedically oriented conceptualization of syndemics and pays less attention to structural conductions, (see, for example, Kwan and Ernst 2011; Seth et al. 2014). In this regard, recent applications fall short of using the concept of syndemic to truly bridge the social and the medical. Rather, this work serves only to describe the social environments in which synergistic comorbidities are present. In the following section, we briefly consider how the framework has been applied as a biosocial model to highlight some of the central theoretical challenges facing those who have tried to apply the syndemics framework to understand HIV disparities.

1.6 Applications of Syndemic Theory in the HIV Literature

Syndemics theory has increasingly served as an analytic tool in HIV research where co-occurring conditions, such as TB, mental illness, other sexually transmitted infections (STI), hepatitis B and C, and factors such as race/ethnicity, gender, sexuality, socioeconomic status, and their particular social position are considered. The synergic relationship between HIV, other diseases, and these ecological factors helps illustrate the impact social structures have on health and a wide-range of health-related disparities. For example, studies focused on men who have sex with men (MSM) have adopted the syndemic model to further identify and comprehend the social factors that increase risk of HIV exposure and/or contribute to a more complicated case of HIV. Research such as Jie et al. (2012) focused on the psychosocial factors prevalent among MSM that contribute to increased risk of HIV through sexual risk taking as well as injection drug use. The psychosocial factors that increase risk for HIV infection among MSM have also been explored by other research, such as Halkitis et al. (2012, 2013, 2014), Klein (2011), and Mustanski et al. (2007, 2014). This research suggests that MSM engaged in bareback sex (aka condomless sex) and sex with multiple partners are at increased risk of HIV infection, depression, and represent a syndemic determined, in large part, by their social marginalization (supported by Stall et al. 2008). But these are not moderating effects nor are the relationships as linear as the findings suggest. MSM with HIV are

more likely to engage in sexual risk taking and experience mental illness while MSM with mental illness are more likely to engage in sexual risk taking and be at greater risk for HIV infection. These relationships have been identified and examined across settings and applied to other communities, e.g. alcoholics (Barta et al. 2010) and the incarcerated (Kelly et al. 2014).

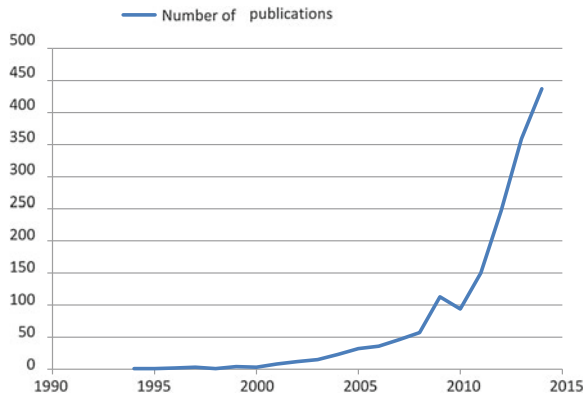
A growing number of studies have also applied syndemic to the context HIV infection occurs and progresses among women (German and Latkin 2012). For example, consideration of the role interpersonal or intimate partner violence (IPV) and mental illness has on HIV infection and STI rates have been explored (Meyer et al. 2011). The authors found that the presence of violence increases the likelihood of mental illness, that mental illness increases the likelihood of experiencing IPV, and both of these decrease autonomy in sexual health which in turn increases HIV infection rates. In addition, a syndemic analysis on HIV rates in transwomen shows that IPV and psychosocial factors (e.g. low self-esteem, verbal threats, harassment, and physical violence) also further rates of sexual risk taking and HIV infection (Brennan et al. 2012; Operario and Nemoto 2010).

In addition to marginalized groups defined by sexuality and gender other research has extended an application of syndemic to the context experienced by racial/ethnic minorities. For example, González-Guarda and her colleagues have been key figures in extending the model in their research focusing on Hispanic communities (2009, 2011, 2012, 2013). In a series of published papers, these authors identified social disparities such as lower socio-economic status, victimization, and interpersonal violence, poor employment rates, and gender ideology synergistically interact with poorer overall health outcomes, such as HIV infection. These works do not stand alone, as other studies aligned with Singer's concentration of racial/ethnic minorities frame the syndemic focus on health disparities among African-Americans (see, for example, Egan et al. 2011; Senn et al. 2010).

In terms of practice, knowledge regarding the treatment of co-occurring diseases benefits from the syndemic model. For example, the presence of tuberculosis in individuals infected with HIV has been long been a significant clinical concern (Litteton and Park 2009). The use of a syndemic model in studies of TB and HIV along with other illnesses, such as HPV and other STIs, have helped to further knowledge of disease interactions as well as the importance of treating these conditions in tandem (Kwan and Ernst 2011; Liao et al. 2014; Littleton and Park 2009). Kwan and Ernst (2011) provide a detailed analysis of the relationship between TB and HIV, finding that the presence of both has adverse effects on TB and HIV treatment individually. These authors argue that treatment of this dual infection should be implemented at the same time rather than isolated treatment for TB or HIV alone.

These are just a handful of examples of studies in which the syndemic framework has been used to understand key disparities in the HIV epidemic. Over the past decade, there has been a virtual explosion of research by social scientists and public health researchers that have utilized syndemic theory to explain health disparities, especially when HIV is present. Figure 1.1 presents the annual number of publications referencing syndemic in the title or text since 1994. To achieve this

Fig. 1.1 Number of scholarly publications referencing “syndemic” in the title or abstract, 1990–2015



point of reference we conducted a search on the term “syndemic” per annum in Google Scholar. At its peak in 2014, 437 publications noted syndemic in their work, more than any year since Singer introduced his framework. The steady increase in application demonstrates the growing influence the syndemic construct is having on our understanding of the social, behavioral, and disease profiles among those at greatest risk for social and health disparities, especially those related to HIV.

1.7 Chapter Overview

This edited volume considers HIV/AIDS as a disease disproportionately impacting marginalized communities resulting from and magnifying social and health disparities. The following chapter provides an overview of the history of HIV/AIDS in the United States from an epidemiological perspective and emphasizes the central challenge of addressing the myriad of inter-related health disparities prevalent in this epidemic.

The remaining chapters provide in-depth examination of specific populations with epidemiologically disproportionate HIV burden. Specifically, the experiences of self-identified gay men and men who have sex with men, bisexuals, racial and ethnic minority women, transwomen, injection drug users, people with serious mental illness, the homeless, sex workers, and currently as well as previously incarcerated men are examined. This section is organized to highlight groups of people living within particular social ecologies. Each author team was asked both to review the current literature and identify and critically examine, in as much depth as the current literature and/or their own research reasonably permits, one or more key syndemic dynamics prominent in these subpopulations.

This organization is a bit of a misnomer and theoretically problematic, however, given the lived experience often transcends the social boundaries of the chapters. That is, the subpopulations discussed are not mutually exclusive; any single person

could fall into multiple groups discussed. Consequently, it should not surprise the reader when you encounter the same background knowledge, patterns, or concepts in more than one chapter. Our choice to organize the chapters around subpopulations may seem reminiscent of formal policy and traditional epidemiological defined “risk groups” and at odds with the broad theoretical focus on syndemic processes. We could have, for example, organized the chapters based on particular syndemic dynamics and how they work across different subpopulations. Because of the complexity and socially bounded nature of the theoretical dynamics involved and the growing, but still limited literature, however, we felt it wise to encourage a more in-depth exploration of the social ecologies and experiences of people living in communities. There are, of course, significant limitations in this approach. Defining communities (and associated social ecologies) based on social characteristics, for example, may overlook important geographical variation within a social category or the special dynamics impacting individuals with multiple, intersecting identities. We discuss some of the crosscutting theoretical and methodological issues and highlight some directions for future work on syndemics in our brief concluding chapter. Nevertheless, we hope this text compels further research and interventions based on this powerful framework to better understand the complex medical and social processes driving the persistent disparities in the US HIV/AIDS epidemic.

Finally, as you read through the many rich chapters, think about the people you know who live their lives within the communities discussed. We bet you will be able to apply the experiences and insights discussed to people you know. For example, do you know an ethnic minority woman who has experienced serious mental illness and HIV or a gay man who has served time in jail as well as been a sex worker and has been diagnosed with AIDS? While the focus of these chapters is primarily on summarizing the extant literature and advance syndemic theory, we believe each chapter also can help the reader appreciate the complex challenges that people affected by HIV experience every day. To address disparities, health and social, we must begin to move beyond simplistic categorical boundaries and theoretical models if we are going to be effective in reducing the extensive disparities in, and ultimately eradicating, the HIV/AIDS epidemic in the U.S. and around the world in the years ahead.

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Chapter 2

A Historical Overview of the Epidemiology of HIV/AIDS in the United States

Jamal Jones and Laura Salazar

2.1 Introduction

What began as an unknown, debilitating disease with a certain death sentence, has evolved. HIV infection can be prevented, but if infection does occur, due to the effectiveness and availability of over 20 antiretroviral drugs HIV is now viewed as a manageable, chronic illness. Much information on HIV treatment and prevention is available and accessible on the web and through various texts and other resources; however, 30 years into the epidemic, how and when the disease first surfaced may have been forgotten or, its origin may not be known, especially to those generations born after 1980. What first began as an anomalous infection afflicting a small subpopulation within the United States has progressed to a disease that affects nearly 1.2 million Americans today (CDC 2014a). This chapter provides an historical overview of the epidemiology of HIV/AIDS in the United States so that its history won't be forgotten, and for those new to the study of HIV/AIDS, they will become familiar with how the epidemic unfolded and mutated much like the virus. Each of the following sections will discuss key developments related to the epidemic such as the emergence of HIV testing and antiretroviral therapy, and how HIV/AIDS evolved from a disease designated to the gay community to one in which multiple populations face heightened risk for HIV infection. There may be some overlap between sections, as many of the developments in HIV surveillance, treatment, and prevention occurred concurrently; however, each section is discussed separately and in the context of the epidemic during certain points in time. The goal

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of this chapter is to provide the reader with a comprehensive overview so they may understand the reasons behind certain actions taken during the epidemic and learn from the missteps and achievements that occurred during its early stages.

2.2 Origin of the HIV Epidemic in the United States

The June 5, 1981 edition of *Morbidity and Mortality Weekly Report* (MMWR), which is published by the Centers for Disease Control and Prevention (CDC), described five cases of *Pneumocystis carinii* pneumonia (PCP), a rare lung infection that causes inflammation and fluid buildup in the lungs (CDC 1981a). Although contracting PCP is rare, its etiological cause is a very common fungus called *Pneumocystis jiroveci* that is spread through the air. Most people are exposed to it by age 3 or 4 without issue. However, in 1981, the treatment for PCP was a drug called pentamidine isethionate, which was not licensed in the United States. Physicians had to request the drug from the Parasitic Disease Drug Service, housed within the Parasitic Diseases Division of CDC's Center for Infectious Diseases. CDC staff noticed a substantial increase in requests for the drug to treat patients with PCP with no known cause of immune deficiency (Curran and Jaffe 2011).

The five cases were described as, drug-using, sexually-active homosexual men living in Los Angeles, California (CDC 1981a). The men described in these cases were previously healthy, had not known each other, nor did they have any known common contacts. It was documented that the occurrence of PCP among five previously healthy individuals was unusual because the illness almost exclusively affected immunosuppressed individuals and there was no clinically apparent underlying immunodeficiency in these cases. By the time the report was published, two of the five men had died. An editorial note in the MMWR report suggested that some characteristic of "homosexuality" may have been involved in the occurrence of PCP among these individuals. Following the initial MMWR report, a second MMWR report released 1 month later on July 3, 1981 described the occurrence of other life-threatening opportunistic infections (OIs) and a rare malignancy, Kaposi's Sarcoma (KS), in 26 homosexual men who had been treated during the previous 30 months in New York and Los Angeles (CDC 1981b). KS is a rare and aggressive cancer that in the United States primarily affected older men. Following the CDC's announcement, *The New York Times* reported that 41 homosexual men had been diagnosed with KS, eight of them dying less than 24 months after receiving the diagnosis (Altman 1981). These first reports in 1981 marked the beginning of what would later be known as the HIV/AIDS epidemic in the United States.

To respond to the growing concern of documented cases of PCP and KS among previously healthy homosexual males, the same year, the CDC under the leadership of its Director, Dr. William Foege, formed a Task Force directed by Dr. James Curran (Fig. 2.1) and consisted of CDC Epidemic Intelligence Service (EIS) officers and staff to begin surveillance and conduct epidemiologic



Fig. 2.1 James W. Curran, M.D., M.P.H., formerly, the Centers for Disease Control's Director of the Acquired Immunodeficiency Syndrome (AIDS) Activity Task Force, in the Division of HIV/AIDS, National Center for Infectious Diseases

investigations. However, before surveillance and further investigation could begin, a case definition had to be established to guide EIS officers and health departments to know what to look for. A case definition is critical to an investigation of an outbreak and allows for standardization of the cases during a current outbreak and also over time and geographic areas between outbreaks. Case definitions typically specify the criteria for people, place, time, and clinical features related to the outbreak. EIS officers were aware that both PCP and KS typically occurred in patients with severe suppression of the cellular immune system, but with treatment, neither was typically life-threatening. The original CDC case definition included the following: (1) biopsy-proven KS among persons <60 years of age or biopsy- or culture-proven life-threatening or fatal OIs, and (2) no known underlying illness (e.g., cancer or immune deficiency disease) or history of immunosuppressive therapy. This definition was soon adopted in the United States and all fifty states required reporting of any cases (Curran and Jaffe 2011).

In 1981, the Task Force contacted state and local health departments to assist with identifying potential cases fitting the case definition (Levine 2009). Towards the end of 1981, 5–6 cases were being diagnosed weekly (*The New York Times* 1981) and the surveillance task force, by years end, had identified 270 reported cases among gay men where 121 had died (AIDS.gov 2014). During this time, scientists had yet to identify or isolate the infectious agent or disease that was

causing the immunosuppression and resulting in the OIs and KS. Although a heterosexual woman fitting the case definition had been reported to the CDC in August of 1981, and a New York investigation of eleven men included seven drug users, five of whom were heterosexual (Levine 2009, p. 207), because most cases documented were among homosexual men, the disease was deemed by scientists as Gay-Related Immunodeficiency or GRID. While in the media, it was pejoratively being called the “gay plague.”

Early in 1982, to explore possible causes that were being hypothesized and that could explain why gay men were being affected, the CDC conducted a national case-control study. A case-control study is a classic epidemiological study design in which people who have the disease or outcome (cases) are matched to similar people who don't have the disease or outcome (controls) on certain characteristics such as age, gender, and race/ethnicity. Then, interviews are conducted retrospectively with both cases and controls to determine potential exposures or risk factors that contribute to having the disease. Possible risk factors were infectious agents such as a new sexually transmitted disease or environmental exposures such as street drugs. Case patients were 50 gay men with PCP and/or KS, and the control subjects were 50 apparently, healthy gay men matched to the cases by age, race and city of residence. The results showed that the cases had more sexually transmitted infections and were more sexually active in terms of number of partners, thus supporting the sexually transmitted infectious agent hypothesis (Jaffe et al. 1983). But, because many gay men who were highly sexually active also used street drugs such as amyl nitrite, an inhalant sexual stimulant, combined with cocaine, the environmental exposure hypothesis was not entirely discarded.

Between June 1981 and May of 1982, 355 cases of KS and serious OIs, chief among these was PCP, had been reported to the CDC as fitting the case definition and were described in an updated report in CDC's MMWR (CDC 1982a, b). Most of these illnesses occurred in previously healthy individuals between the ages of 15 and 60 years. These reports were consistent with previous reports of PCP and KS occurring in healthy individuals who would not ordinarily be susceptible to these illnesses. Most of the cases reported in MMWR were still occurring among gay men and a sexually transmitted infectious agent was still being theorized, but the agent had yet to be discovered and competing hypotheses were still being considered. It was in the spring of 1982 that more evidence was gathered to support the sexually transmitted infectious agent theory. Dr. David Auerbach, an EIS officer in Los Angeles collaborated with Dr. William Darrow, a sociologist and member of the Task Force. They conducted in-depth investigations into 13 of the first 19 reported cases in LA and Orange County. The results were startling: of the 13 men, 9 reported sexual contact with another man who was a reported “GRID” case within 5 years of having any symptoms (Auerbach et al. 1984). Given these results, Auerbach and Darrow expanded their investigation nationwide to an additional 90 cases, 40 of whom could be linked sexually to other case patients. This clustering of 40 cases provided strong evidence that GRID was caused by a sexually transmitted infectious agent.

Unfortunately, this ground-breaking epidemiological work would have unintended consequences. Auerbach and Darrow's sexual network analysis also identified one non-Californian man, who had sexual contact with 4 men from LA and 4 men from NYC, and who was considered from an epidemiological perspective as the index case within this cluster. This index case was later identified in Randy Shilts' 1987 book, *And the Band Played on: Politics, People and the AIDS Epidemic*, as French-Canadian flight attendant Gaetan Dugas. Dugas was erroneously deemed "patient zero" implying that he was the first HIV case in the United States and all other infections stemmed from him. Dugas died due to complications from KS in 1984. He was subsequently vilified and infamously blamed for the start of the HIV epidemic in the United States (McKay 2014), although later retrospective research disproved this notion and showed that HIV was brought to the United States much earlier and could never be attributed to only one person (Faria et al. 2014).

As the case reports continued to pour in, what would eventually be called AIDS began affecting populations outside of the gay community as occurrences of KS and serious OIs were not limited to gay men, as stated in the June 1982 MMWR report. Although 79 % of the cases were among homosexual or bisexual men, these illnesses were also documented in heterosexual men (12 % of reported cases) and women (4 % of reported cases), as well as men whose sexual orientation was unknown (6 % of reported cases). In fact, the proportion of heterosexuals succumbing to KS and serious OIs increased from 1 to 16 % by June 1982. In addition, of importance, the PCP heterosexual cases were more likely than the homosexual PCP cases to be Black or Hispanic (CDC 1982a, b).

During this time, twenty states reported cases of KS and serious OIs, yet reported cases appeared to be concentrated in just a handful of states: California, Florida, New Jersey, New York, and Texas accounted for more than 85 % of the reported cases. For example, the State of New York accounted for just over half of the homosexual male cases, almost half of the heterosexual male cases and 46 % of the female cases (CDC 1982a, b). A defining characteristic for reported groups affected (i.e. women, heterosexual men, and gay men) was the age at onset of symptoms. Individuals displaying symptoms of KS and serious OI were fairly young, as the median age at symptom onset was 26–36 years.

During the beginning of the epidemic, reported case-fatality ratios (the number of fatalities from a specific illness divided by the number of reported cases for the illness) for PCP cases were high among gay men. During the early stages of the epidemic, gay men constituted a large proportion of patients succumbing to symptoms and ultimately dying compared to their heterosexual counterparts. Though gay men accounted for a large number of fatalities stemming from PCP infection, the number of PCP diagnoses increased among the heterosexual population. The ratio of gay men to heterosexual men with PCP slightly decreased from 5–1 in 1980 to 4–1 in 1982, so one can see that as more and more heterosexuals began to account for prevalent cases the illness began to impact different populations who were at risk for infection. As it became evident that the disease was not limited to the homosexual population, by September of 1982, the CDC abandoned

the term GRID and designated the condition as Acquired Immune Deficiency Syndrome or AIDS.

In September 1982, a MMWR report stated that 593 AIDS cases had been reported, and on average, 1–2 new cases were reported each day (CDC 1982c). Most AIDS cases were still occurring among gay men (75 % of reported cases), however it was documented that 12 % of the cases occurring among gay men involved intravenous drug use (CDC 1982c). Intravenous drug use was also described in the majority of the known heterosexual cases (both male and female). Another subgroup, hemophilia patients, was also described as a subpopulation affected by AIDS. Specifically, the CDC reported that of the 14 AIDS cases that involved males under 60 years of age (who did not use drugs, did not report homosexual activity and who were not of Haitian nationality), two (14 %) had hemophilia A.

Hemophilia is a rare bleeding disorder in which the blood does not clot properly. The main treatment for this disorder is replacement therapy. Concentrates of clotting factor VIII (for hemophilia A) or clotting factor IX (for hemophilia B) are given intravenously. These infusions help replace the clotting factor that is missing or low. Clotting factor concentrates are derived from human blood plasma. To produce this coagulant, blood from hundreds of individual donors is pooled; thus, a single donation of infected blood could contaminate a large batch of Factor VIII with the potential to infect thousands. Dr. Dale Lawrence of the Task Force investigated the two hemophilia A cases and was able to determine that both had unexplained immunosuppression, no history of homosexual contact, or injection drug use (CDC 1982c).

Further, the December 10, 1982 MMWR report described four additional cases of patients with hemophilia A, who were heterosexual, in which serious OIs developed as evidenced by a compromised immune system. Like previously described cases of hemophiliacs, there was no evidence to suggest that these patients could have been immune compromised as a result of homosexual contact, illicit drug use, or contact with Haitian immigrants (who were a suspected risk group during this time) (CDC 1982d; Jaffe et al. 1983). Another hemophilia case was identified as being “highly suspected” to have AIDS but did not meet the surveillance definition. A common characteristic among these cases was that each patient had received Factor VIII concentrates in addition to having compromised immune systems (CDC 1982d). Thus, there was evidence to suggest that what was causing AIDS could be an infectious agent transmitted by blood, through homosexual and heterosexual contact, as well as injection drug use practices.

Perhaps the most widely known reported hemophilia case was a young boy, Ryan White, who in 1984, at age 13, was diagnosed with AIDS. Over the next 6 years, Ryan became a national advocate fighting for the right to attend school, becoming a spokesperson who sought to educate the public about AIDS and reduce the stigma. In 1990, Ryan succumbed to a severe respiratory infection and died. Months later, Congress passed the AIDS bill that bears his name—the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act. The legislation has been reauthorized four times since—in 1996, 2000, 2006, and 2009—and is

now called the Ryan White HIV/AIDS Program—the largest federal program in the United States focused on HIV/AIDS care.

In addition to the hemophilia A cases, the September 1982 MMWR report also documented that Haitians residing in the United States represented a small proportion of all cases (only 6 %), however, this subgroup comprised half of the cases in which both homosexual activity and intravenous drug abuse were denied. Investigations into these cases showed that 34 were Haitian men, who had migrated to the United States and reported to be heterosexual with no known risk factors.

The CDC (1982c) broadened its scope to identify groups most at risk for AIDS, stating:

Reported AIDS cases may be separated into groups based on these risk factors: homosexual or bisexual males – 75 %, intravenous drug abusers with no history of male homosexual activity – 13 %, Haitians with neither a history of homosexuality nor a history of intravenous drug abuse – 6 %, persons with hemophilia A who were not Haitians, homosexuals, or intravenous drug abusers – 0.3 %, and persons in none of the other groups – 5 % (pp. 507–508).

The fact that being of Haitian nationality was classified as a risk factor for AIDS was met with serious backlash and protests as the stigma of AIDS seriously compounded life for Haitian migrants living in the United States. Many had fled Haiti to avoid severe poverty and political persecution, but were now being fired from their jobs or evicted from their homes (Farmer 1992).

2.3 Evolution of the AIDS Case Definition and the Discovery of the HIV-1 Virus

2.3.1 The 1982 Case Definition of AIDS

At the onset of the HIV Epidemic, the CDC Task Force and Department of Health and Human Services initiated surveillance activities to monitor cases fitting the case definition. Almost immediately the CDC received case reports directly from health care providers and State and local health departments documenting AIDS cases in which PCP and KS co-morbidity were present. The initial case definition was, “a disease, at least moderately predictive of a defect in cell-mediated immunity, occurring in a person with no known cause for diminished resistance to that disease” and required the diagnosis of one of eleven opportunistic infections or one of at least two cancers. The 1982 case definition for AIDS was intended for surveillance purposes with goals of monitoring trends in the number of AIDS cases as well as monitoring the scope of severe morbidity due to infection with the human immunodeficiency virus. Since 1982, the CDC’s case definition for AIDS has been revised multiple times: in 1985, 1987, 1993, 1999, 2008, and most recently in 2014. Each revision had an impact on how HIV was reported and how the populations most at risk were identified.

2.3.2 *The 1985 Case Definition of AIDS*

After the publication of the CDC's initial case definition for AIDS in 1982, two research teams independently identified a novel retrovirus present in individuals most at risk for AIDS. One research team, led by Luc Montagnier of the Pasteur Institute in Paris, termed the newly discovered virus as lymphadenopathy-associated virus (LAV) as it was isolated from a patient presenting with lymphadenopathy and asthenia (Barré-Sinoussi et al. 1983). The report published by Montagnier and his colleagues suggested LAV was immunologically different from other classes of human T-Lymphotropic viruses (HTLV). The other research team, led by Robert Gallo of the National Cancer Institute, termed the virus human T-cell lymphotropic virus-III (HTLV-III) due to its shape and similarity to previously isolated HTLVs (Popovic et al. 1984). However, both teams had discovered the same virus, which was deemed as the cause of AIDS. It was renamed the human immunodeficiency virus in 1986. Laboratory tests were then developed to detect the presence of HIV antibodies—proteins produced by the body's immune system to protect against foreign substances called antigens—and these tests were used as diagnostic indicators for HIV manifestation. Thus HIV testing and confirmed positive results for the presence of HIV antibodies were incorporated in the revised case definition for AIDS. The CDC (1985) changed its AIDS surveillance definition in 1985 to define it as:

In the absence of the opportunistic diseases required by the current[1982] case definition, any of the following diseases will be considered indicative of AIDS if the patient has a positive serologic or virologic test for HTLV-III/LAV [human T-cell lymphotropic virus, type III/lymphadenopathy-associated virus] (pp. 373–375).

The CDC's 1985 case definition specified that a positive test for HTLV-III/LAV, cases of disseminated histoplasmosis, isosporiasis causing chronic diarrhea, bronchial or pulmonary candidiasis, non-Hodgkin's lymphoma, and Kaposi's sarcoma in persons 60 years of age or over were to be included in the surveillance case definition of AIDS (CDC 1985). Following the expanded case definition, there were 16,458 reported AIDS cases in the United States between June 1981 and January 1986 with over half of the adult (51 %) and child populations (59 %) infected with HIV/AIDS dying from the disease during this time. A quarter (25 %) of the reported cases occurred among African Americans and 14 % occurred among Hispanics, although African Americans and Hispanics constituted only 12 and 6 % of the U.S. population respectively during that time (CDC 1986a). By the end of 1986, black/non-Hispanic and Hispanic women accounted for large proportions (52 and 20 %, respectively) of women living with AIDS, while black/non-Hispanic and Hispanic men accounted for 22 and 14 % respectively of men with living with AIDS (CDC 1986b). All 50 States in the Union, the District of Columbia, and four U.S. Territories had now reported at least one AIDS case to the CDC.

2.3.3 The 1987 Case Definition of AIDS

In August of 1987, the CDC revised the case definition of AIDS to reflect increases in the understanding of HIV infection (CDC 1987). The 1987 case definition for AIDS included 23 AIDS defining conditions including: bronchial, tracheal, or pulmonary candidiasis; esophageal candidiasis; HIV encephalopathy; HIV wasting syndrome; and a broader range of malignancies (CDC 1987). The CDC aimed (1) to simplify AIDS reporting; (2) to make the definition consistent with standards of medical care for HIV-infected persons during that time; and, (3) more accurately record the number of persons with severe HIV-related immunosuppression (CDC 1987). The 1987 definition allowed for a presumptive AIDS diagnosis based upon the presence of clinical signs and symptoms of opportunistic illnesses, such as PCP and KS, and other AIDS indicator diseases in the absence of a confirmed laboratory HIV-positive test. That is, clinicians could diagnose a person with AIDS if he/she presented with signs and symptoms of one of the indicator diseases (e.g. Kaposi's sarcoma, PCP), even if the person did not have a confirmed HIV-positive test. The case definition of AIDS was also accompanied or qualified according to laboratory evidence of HIV infection: unknown or inconclusive HIV test, positive HIV test, and negative HIV test. Twenty-nine percent of the 40,836 AIDS cases reported between September 1987 and December 1988 met the newly established criteria of the CDC's 1987 revised case definition and most likely involved people who were presumptively diagnosed with AIDS or presented with wasting syndrome or one of the other nonmalignant HIV-associated conditions (such as a neurologic manifestation). These cases would not have been reported as AIDS cases under earlier definitions.

As a result of the revised case definition, increased proportions of AIDS cases in women, injection drug users, and minorities were reported to the CDC. Among the cases meeting the criteria of the 1987 definition, 15 % were women, as compared with 9 % of cases meeting the pre-1987 definition. A sizeable percentage (35 %) of the cases were heterosexual injection drug users, as compared with 18 % meeting the pre-1987 definition. About 34 % of the cases meeting the 1987 definition were African American compared to 26 % based on the pre-1987 percentage of this population living with HIV/AIDS. Roughly 21 % of the cases were Hispanic compared to the pre-1987 percentages of 14 % for Hispanics (CDC 1989).

2.3.4 The 1993 Case Definition of AIDS

The CDC proposed a revision to the surveillance case definition and the disease classification system to differentiate asymptomatic HIV infection from symptomatic infection and the more severe AIDS illness (CDC 1991). By changing the definition, the CDC sought to simplify the classification of HIV infection to reflect standards of medical care for HIV-infected persons in the early 1990s, and

categorize HIV-related morbidity more accurately (CDC 1992a). It is important to note that at this point in time of the epidemic AIDS was the leading cause of death among persons 25–34 years of age and eighth among all causes of death.

Studies examining the natural history of HIV infection documented a gamut of disease manifestations, ranging from asymptomatic infection to life-threatening conditions characterized by severe immunodeficiency, serious opportunistic infections, and cancers (CDC 1992a). Studies began to show that lower than expected counts of CD4 or T lymphocyte (T-cell) cells, which are white blood cells that play a major role in fighting infection, predicted more advanced immunosuppression and severe illness. These measures were used to guide clinical and therapeutic management of people living with HIV (Fernandez-Cruz et al. 1990). Antimicrobial prophylaxis and antiretroviral therapies developed during the 1980s (to be discussed in later sections) were shown to be effective within certain levels of immune dysfunction (CDC 1992b; Easterbrook et al. 1991; Fischl et al. 1990; Lagakos et al. 1991; National Institutes of Health 1990; Volberding et al. 1990). The revised classification system for HIV emphasized the clinical importance of CD4 or T-cell count as it relates to HIV-related medical conditions for those infected as these cells were now included as a marker for HIV-related immunosuppression.

Under the revised classification system, the human immunodeficiency virus was designated as the retrovirus that causes AIDS. The CDC documented that the HIV virus targeted the CD4 (T-Cell) because of its affinity for the CD4 cell surface marker. It was also documented that CD4 cells coordinate numerous, important immune functions and that any compromise to these functions results in “progressive impairment of the immune response.” The 1993 revision to the AIDS case definition established mutually exclusive subgroups for which the spectrum of clinical conditions were included with the T-cell count. That is, diagnosis of HIV or the more severe disease of AIDS would now be categorized based upon separate groups related to the individual’s T-cell count and any opportunistic co-infection or HIV-related illness. Thus the 1993-revised case definition for HIV/AIDS was expanded to include all HIV-infected persons who have less than 200 CD4 or a CD4 percentage of total lymphocytes of less than 14. Any person meeting this condition would be considered to have AIDS. The CDC recommended that “antiretroviral therapy should be considered for all persons with CD4 T-lymphocyte counts of less than 500/ μ L, and prophylaxis against *Pneumocystis carinii* pneumonia (PCP), the most common serious opportunistic infection diagnosed in men and women with AIDS, is recommended for all persons with CD4 T-lymphocyte counts of less than 200/ μ and for persons who have had prior episodes of PCP” (CDC 1992a, para. 3). As a result of these recommendations, CD4 T-lymphocyte determinations became an integral part of medical management of HIV-infected persons in the United States.

The revised CDC classification system for HIV-infected adolescents and adults categorized persons on the basis of clinical conditions associated with HIV infection and CD4 T-lymphocyte counts. The system during this time was based on three

ranges of T-cell counts and three clinical categories and was represented by a matrix of nine mutually exclusive categories. This system replaced the classification system established in 1986, which included only clinical disease criteria and was developed before the widespread use of CD4 T-cell testing.

2.3.5 Impact of 1993 Case Definition on Women and Overall Epidemiology in the U.S.

Although it was 12 years into the epidemic and there had been many heterosexual or injection drug use female AIDS cases, the CDC claimed there was insufficient evidence to include gynecological conditions in previous versions of the case definition. There were few studies implemented that used large scale observational research designs to describe HIV at the onset of the epidemic and to accurately define all the populations most at risk for HIV acquisition. Because most of the early reports of HIV/AIDS involved cases in which homosexual activity among men was described, women were overlooked as a population at risk. However, as described in previous sections of this chapter, there were many documented reports of women infected with HIV as early as 1982. Prior to 1993, medical conditions specific to women had not been included in the formal case definition for HIV as it was still considered to be a primarily gay-related illness. The expansion included three clinical conditions: pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer—and it retained the 23 clinical conditions already used in the 1987 case definition of AIDS. This marked the first time a female-specific condition was included in the case definition for HIV and officially recognized women as a population at risk for HIV infection.

Upon expanding the HIV/AIDS case definition, the CDC predicted that the number of reported cases would increase by approximately 75 % (CDC 1992a). Officials determined that the early effects of the expanded surveillance would be greater than long-term effects because prevalent and incident cases of immunosuppression would be counted following implementation of the expanded surveillance case definition. In subsequent years, the effect on the number of reported cases was expected to be much smaller. It was believed that the immediate increase in the number of cases reported would be most attributable to the addition of severe immunosuppression to the definition. A smaller impact was expected from the addition of pulmonary TB, recurrent pneumonia, and invasive cervical cancer because many persons with these diseases would also have CD4 T-lymphocyte counts of less than 200 cells/ μ . Officials estimated that if the AIDS surveillance definition for case reporting was unchanged, only 50,000–60,000 reported AIDS cases would have been expected in 1993. The expanded case definition had a far greater impact than anticipated.

The expanded case definition had a dramatic effect on the number of reported HIV/AIDS cases as the number of cases within certain subpopulations were more than double the reported number of cases in the previous year. Following the expanded definition, in 1993, 103,500 AIDS cases were reported in the United States among the population aged at least 13 years (CDC 1994a). This was a 111 % increase over the 49,016 reported in 1992. Of the reported AIDS cases in 1993, 54 % were reported based on conditions added to the 1993 case definition with most of these cases having severe human immunodeficiency virus (HIV)-related immunosuppression only. Other conditions related to the 1993 expanded case definition criteria such as pulmonary tuberculosis (TB), recurrent pneumonia, and invasive cervical cancer made up substantially less proportions of reported AIDS cases. The increase in reported AIDS cases during this time was greater among females (6,571 in 1992 to 16,514 in 1993, or a 151 % increase) than among males (42,445 in 1992 to 86,986 in 1993 or a 105 % increase) and the largest increases occurred among adolescents and young adults (177 in 1992 to 555 in 1993 for persons aged 13–19 years, a 214 % increase and 1,600 in 1992 to 3,722 in 1993 for persons aged 20–24 years, a 133 % increase). Among adolescents and young adults reporting AIDS based on the expanded criteria, a greater proportion of cases were reported among women (35 and 29 %, respectively) and were attributed to heterosexual transmission (22 and 18 %, respectively). Though there was a 102 % increase in the reported number of white/non-Hispanics living with HIV/AIDS (47,003 in 1993 vs. 23,305 in 1992) attributed to the expanded case definition, racial/ethnic minorities also represented increases that were greater than the percent increase for white/non-Hispanics. The number of black/non-Hispanics accounting for reported AIDS cases in 1993 was 36,951 which was a 123 % increase from 16,582 cases reported in 1992. The number of reported Hispanics living with HIV/AIDS was 18,318 in 1993, up from 8,541 reported in 1992 (a 114 % increase). By the time 1996 arrived, this trajectory of increased reports among minority race/ethnicities reached a major turning point. For the first time, there were more reported AIDS cases among African Americans (41 %) than among whites (38 %). With the 1993 AIDS case definition, there was also a substantial increase in HIV/AIDS reported cases among injection drug users (28,687 in 1993 vs. 12,163 in 1992) as well as among hemophiliacs (1,041 in 1993 vs. 360 in 1992).

2.3.6 1999 and 2008 Case Definitions for HIV/AIDS

In 1999, the CDC published another revision to the case definition for AIDS to combine the reporting criteria for HIV and AIDS into a single case definition to reflect advances in laboratory techniques that were unavailable in 1993 (CDC 1999). The case definition also made specific provisions for children under the age of 13 for surveillance purposes. Under the revised system of reporting:

...children aged 18 months to <13 years, laboratory-confirmed evidence of HIV infection is now required to meet the surveillance case definition for HIV infection and AIDS. Diagnostic confirmation of an AIDS-defining condition alone, without laboratory-confirmed evidence of HIV infection, is no longer sufficient to classify a child as HIV infected for surveillance purposes. No changes have been made to the 24 AIDS-defining conditions or the HIV infection classification system for children aged <13 years (CDC 1999, p. 7).

By the end of the year 2000, there were approximately 337,731 people in the United States living with AIDS (CDC 2002). Of those living with AIDS, about 139,522 cases (41 %) were black, 127,838 cases (38 %) were white/non-Hispanic, and 65,991 cases (20 %) were Hispanic. The Southern region of the U.S. accounted for 129,333 (38 %) of AIDS cases, the most of any other region, followed by the Northeast which accounted for 99,482 cases (29 %), the West which accounted for 66,085 cases (20 %) and the Midwest, accounting for 32,909 cases (10 %). Other U.S. Territories accounted for 3 % of cases during this time. Not only were more risk groups added as a result of the changing case definition, but the geographic region in which cases were concentrated had also shifted to other parts of the United States. HIV/AIDS had become a major burden in the Deep South, such that HIV clusters developed in this region. The majority of male cases among the estimated 264,149 adult and adolescents (i.e., person aged >13 years) living with AIDS, were men who have sex with men (MSM), who accounted for approximately 151,325 cases (57 %). About 24 % (64,522) of adult and adolescent male cases were IDUs, and 20,528 cases (8 %) were MSM who reported IDU. Only 23,333 (9 %) of adult and adolescent male cases were exposed through heterosexual contact. Most of the 69,775 adult and adolescent women living with AIDS were exposed through heterosexual contact (40,051 cases or 57 %), and 27,475 (39 %) were IDUs. There were approximately 3,807 children aged <13 years living with AIDS, the majority of whom (90 %) were infected via perinatal (mother to child) transmission of HIV.

By 2008, all states had implemented confidential, name-based HIV infection reporting, and the case definition of HIV was revised extending the definition to apply to HIV-1 or HIV-2 and to AIDS-defining conditions for adults and children >13 years of age that require laboratory evidence of HIV (CDC 2008). The 2008 HIV infection case definition for adults and adolescents (aged >13 years) replaced previous HIV infection and AIDS case definitions as well as the HIV infection classification system from previous iterations. The definition applied to all HIV variants (e.g., HIV-1 or HIV-2) and excludes confirmation of HIV infection through diagnosis of AIDS-defining conditions alone. For surveillance purposes, the CDC categorized a reportable case of HIV infection among adults and adolescents aged >13 years by increasing severity as follows:

Stage 1 HIV Infection

No AIDS-defining condition and either T-cell count of >500 cells/ μ L or T-cell percentage of total lymphocytes of >29 or as stage unknown.

Stage 2 HIV Infection

No AIDS-defining condition and either T-cell count of 200–499 cells/ μ L or T-cell percentage of total lymphocytes of 14–28.

Stage 3 HIV Infection (AIDS)

A T-cell count of <200 cells/ μ L or T-cell percentage of total lymphocytes of <14 or documentation of an AIDS-defining condition. Documentation of an AIDS-defining condition supersedes a T-cell count of >200 cells/ μ L and a T-cell percentage of total lymphocytes of >14.

Stage Unknown HIV Infection

No information available on T-cell count or percentage and no information available on AIDS-defining conditions.

In 2011, there were 50,007 reported HIV diagnoses among adults and adolescents, following the revised case definition (CDC 2013a). Among those diagnosed with HIV/AIDS in 2011, most were among MSM who accounted for 61.8 % of diagnoses. Of the 30,896 cases attributed to MSM, 38.2 % were estimated among black/African Americans, 33.6 % were among whites, and 23.5 % were among Hispanic/Latinos. The greatest number of new HIV infections occurred in young black/African American MSM aged 13–24 years, who accounted for 45 % of new HIV infections among black MSM and 55 % of new HIV infections among young MSM overall. Women accounted for 21.6 % of new HIV infections in 2011, most of which occurred through heterosexual contact.

Racial and ethnic disparities in HIV/AIDS still persisted in 2011 and continue to persist where Blacks/African Americans accounted for 46 % of new HIV infections. More than 260,800 black/non-Hispanics living with AIDS have died since the epidemic began. Hispanics have also faced a burden of HIV infection. In 2011, the Hispanic population accounted for 22 % of new HIV infections and more than 96,200 Hispanics/Latinos with an AIDS diagnosis have died since the beginning of the epidemic. Figure 2.2 shows this disproportion burden African Americans and Hispanic/Latinos experience in terms of new HIV infections in 2011. As shown, for both males and females, African Americans and Hispanic/Latinos have the highest and second highest rates respectively of HIV infection in the United States.

2.3.7 2014 Case Definitions for HIV/AIDS

Beginning in 2013, the CDC began referring to AIDS as HIV infection, stage 3 (AIDS) in all HIV surveillance reports. There was a need to revise the case definition based upon changes in diagnostic criteria. There was also a need to change the definition based upon early recognition of HIV, distinguishing HIV-1 from HIV-2 infection, consolidate the staging systems for adults/adolescents and child cases, simplify the criteria for opportunistic infections indicative of AIDS, and revise the criteria for reporting HIV/AIDS diagnoses in the absence of laboratory evidence (CDC 2014b). The new surveillance case definition now includes a

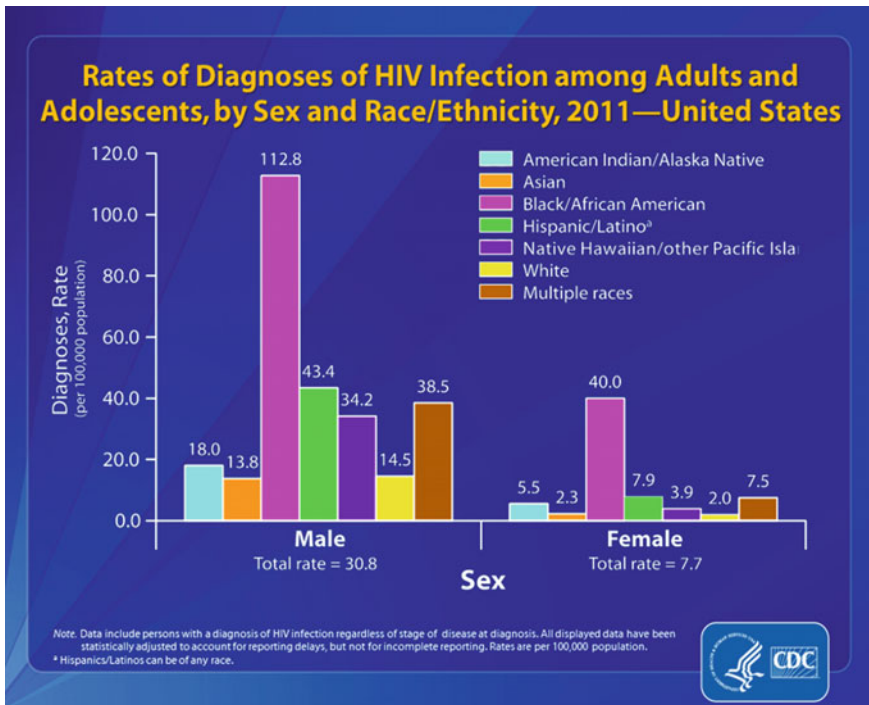


Fig. 2.2 2011 Incidence Rates of HIV among Adults and Adolescents by race and sex in the United States (Source Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, Sexual Transmitted Diseases and Tuberculosis Prevention, Centers for Disease Control and Prevention)

“stage 0” based upon a series of positive and negative tests that may indicate early HIV-infection. It takes advantage of new testing algorithms that are more sensitive to early HIV infection. The new case definition also does not distinguish between presumptive and definitive HIV infection to avoid complexity for surveillance purposes. Although 2011 represents the most recent surveillance data available, for specific details regarding the 2014 case definition for HIV/AIDS, the reader is encouraged to consult the CDC’s MMWR report which can be found at the following website: http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6303a1.htm?s_cid=rr6303a1_e. A summary of the changes can be found below:

- Specific criteria added for defining HIV-2 case, not included in the 2008 case definition. The new definition incorporates criteria for HIV-2 infection used in surveillance for HIV-2 infection.
- Eliminates the requirement to indicate if AIDS-defining conditions, indicative of stage 3 (AIDS), were diagnosed by “definitive” or “presumptive” methods.
- Classifies stages 1–3 of HIV infection on the basis of the CD4 count unless persons have had a stage-3–AIDS defining opportunistic illness. The CD4+

T-lymphocyte percentage is used only when the corresponding CD4 count is unknown.

- Removes the requirement that a “physician-documented” diagnosis must be based on laboratory evidence.
- Combines the adult and pediatric criteria for a confirmed case of HIV infection and specifies different criteria for staging HIV infection among three age groups (<1 year, 1–5 years, and ≥ 6 years).
- Eliminates the distinction between definitive and presumptive diagnoses of HIV infection in children aged <18 months.
- Removes lymphoid interstitial pneumonia (pulmonary lymphoid hyperplasia) from the list of opportunistic illnesses indicative of stage 3 in children. This illness is associated with moderate rather than severe immunodeficiency.
- Evidence of HIV infection in a child’s biologic mother is no longer needed to define a case of HIV infection in a child aged <18 months when laboratory testing of the child independently confirms HIV infection.
- Extends the use of CD4 counts and percentages for determining the stage of HIV infection to children as well as adults and adolescents. CD4 counts are now used to determine the stage in children aged 6–12 years the same way as in adults and adolescents (CDC 2014b, p. 2).

2.4 Overview of HIV Testing and the Fight Against AIDS

Isolation and identification of the HIV virus was pivotal in addressing AIDS early on in the epidemic. As discussed earlier in the chapter, the teams of Robert Gallo and Luc Montagnier independently isolated and identified the HIV virus in early 1983. In 1984, then Secretary of Health and Human Services, Margaret M. Heckler, announced the discovery that the HIV virus was the cause of AIDS and federal researchers revealed they had developed a test that could identify antibodies specific to HIV in the blood (Altman 1984). Upon that announcement, federal researchers applied for patents to develop commercial tests for HIV. In March of 1985, the Food and Drug Administration (FDA) granted the first commercial license for screening tests which could detect HIV antibodies in the blood that indicate viral infection via enzyme linked immunosorbant assay (ELISA); this was originally intended to screen blood products for treatment among hemophiliacs. This initial test was implemented in blood banks, plasma collection centers, health departments, and clinical-care settings to deter HIV acquisition in hemophiliacs receiving blood transfusions. Since the licensure of the first commercially available screening test, more than 40 different ELISA test kits have become available, but only about 10 are licensed by the FDA for use in the United States. Other HIV testing methods have been developed and are now regularly used to test for various aspects of the virus including: antibody screening tests (immunoassay), the most common form of the HIV testing that can be conducted in the lab or in one’s home (via rapid testing);

polymerase chain reaction (PCR) tests, which are used to test for the genetic material belonging to the virus; antigen tests, which tests for specific HIV viral proteins; and, RNA tests, which are used to detect the virus directly (instead of the antibodies to HIV) and can detect HIV approximately 10 days after one becomes infected. Advances in HIV rapid testing are highlighted in the next section.

2.4.1 Development of HIV Rapid Testing

Prior to the development of rapid HIV testing, testing for HIV involved ELISA, a long process which initially required blood to be drawn in order to detect HIV antibodies. This process involves using fluorescent enzyme probes linked with antigens that are used to detect antibodies present in the blood serum. The process usually requires a person to wait several weeks in order to receive test results. With the advent of quicker and cheaper tests, results could be provided during the clinical visit and infected patients could be counseled and placed on therapy before HIV progressed into the more severe manifestation of AIDS. Persons with a confirmed positive test could take the steps necessary to prevent the transmission of the illness to a sexual partner, a child, or another injection drug user. This dramatically changed the epidemiology of HIV as incident cases slowly decreased and more people could be tested than before.

In 1989, a rapid immunoassay, the Recombigen HIV-1 Latex Agglutination assay, was licensed to Cambridge Biotech Corp. Several years later, in 1992, a second rapid HIV assay, the SUDS HIV-1 Test, was licensed to Abbot Murex Diagnostics, Inc. (Poffenberger 2000). These tests were originally licensed as screening tests (including use in blood banks under restricted conditions) for the rapid detection of antibodies to HIV-1 in plasma or serum. The licensure of these tests offered a greater advantage for clinicians and researchers conducting screening and testing in resource poor settings as these tests provide a result that indicates the presence or absence of antibodies to HIV within 20 min (usually less than 10 min). Although the tests were designed to be rapidly performed and interpreted by a trained individual on-the-spot (at the site the sample is taken), the kits in which the tests were provided included all reagents, no need of specialized equipment, and in some cases no requirement of refrigeration (Poffenberger 2000). The result of the test is based on visual detection of an HIV specific spot or line (usually pink or blue in color). Unlike laboratory testing, individuals could receive results on the detection of HIV antibodies within minutes instead of waiting several weeks using laboratory-testing techniques. The Recombigen HIV-1 Latex Agglutination assay and SUDS HIV-1 Test were the only commercially available tests on the market in the U.S. during this time, in contrast to countries in Europe and nations in Africa where several rapid HIV assays were available in the market (Poffenberger 2000).

2.4.2 Reduction of Mother-to-Child Transmission

During the early stages of the epidemic, women were not treated as a risk group for HIV/AIDS. The CDC estimated that mother-to-child HIV transmissions peaked in 1991 when 1,650 cases were reported. However, more studies began to show that routine testing was a cost-effective and crucial method for identifying and treating people with HIV who were previously unaware of their status. During the early 1990s, testing policies of pregnant women were geared toward voluntary testing as a mechanism to increase education, prevention, and medical follow-up services for women with a confirmed positive test. It soon became clear that women who tested positive and received AZT therapy during the early stages of pregnancy were less likely to transmit the virus vertically to their unborn fetus (CDC 1994b). More health departments and professional medical societies began to move in favor of mandatory screening policies for pregnant women (Bozzette 2005; Paltiel et al. 2005; Sanders et al. 2005). With more hospitals requiring mandatory HIV screening for pregnant women, by 2005, the reported number of mother-to-child transmissions declined to a range of 100–200 transmissions (CDC 2007). Screening of pregnant women is seen as a success in the U.S. HIV epidemic because fewer children are born with HIV and it has helped to quell the incidence of the disease in the United States.

2.4.3 Ten-Year Trends in HIV Testing

With numerous developments made in HIV testing, testing for the virus is emphasized in the National HIV/AIDS Strategy (NHAS) and the Division of HIV/AIDS Prevention (DHAP) Strategic Plan and is seen as an important prevention measure against the spread of new infections. Ten-year HIV testing trends have shown significant increases in reported HIV testing among all adults (36.6 % in 2000 to 45.0 % in 2010) including: all race/ethnicity groups, adults aged 25–64 years, males and females, and adults who did and did not report a risk for HIV (based upon NHIS reporting) (CDC 2013b). However, NHANES reporting of HIV testing has not shown significant increases between 2000 (42.5 %) and 2010 (43.1 %) among adults who have reported ever receiving an HIV test (CDC 2013b). Increases in the percentage of adults who reported an HIV test in the past 12 months has also been observed, from 80.7 % in 2000 to 84.0 % in 2010 (CDC 2013b). Many adults have received HIV tests in a health care setting as HIV testing in this context has increased from 78.2 % in 2000 to 83 % among adults who had ever been tested for HIV (CDC 2013b). Gains in HIV testing have been met with some challenges. Significant increases in HIV testing among adolescents (11.6 % in 2005 and 13.2 % in 2011) and pregnant women (59.3 % in 2000 and 53.7 % in 2010) have not been observed, two groups vulnerable to HIV transmission (CDC 2013b).

2.4.4 FDA Approval of the First Over-the-Counter Home-Based Rapid HIV Test

On July 3, 2012 the U.S. Food and Drug Administration approved the OraQuick In-Home HIV Test, the first over-the-counter home-use rapid HIV test kit to detect the presence of antibodies to HIV types 1 and 2 (HIV-1 and HIV-2) (Food and Drug Administration 2014a; OraSure Technologies 2014). Prior to approving the home-based rapid HIV test, the FDA approved the Home Access HIV-1 Test System in 1996 (2014b). However, this over the counter HIV test requires a finger prick to collect a blood specimen, sending the specimen to a laboratory and then waiting for the laboratory to confirm the results. This HIV testing kit was not as successful commercially as the OraQuick In-Home HIV test. The OraQuick In-Home HIV test, an immunoassay manufactured by OraSure Technologies, is designed to allow individuals to collect an oral fluid sample (OraSure Technologies 2014). By swabbing the gums inside of their mouths, individuals can collect oral fluid and then place the sample swab into a developer vial, and obtain HIV antibody test results in about 40 min. This marked the first time people could purchase an HIV testing kit from their local pharmacy and test for HIV without sending a sample to a lab or verifying results in the presence of a trained professional.

Excitement surrounding the test was due to its potential to identify vast numbers of previously undiagnosed HIV infections, especially among those who were unlikely to use standard screening methods. Another important aspect of the OraQuick HIV rapid testing kit is its high degree of sensitivity and specificity. According to the manufacturer, clinical studies for self-testing have shown the test has a sensitivity of 92 %, the percentage of results that will be positive when HIV is present (one false negative result would be expected out of every 12 tests in HIV-infected individuals) and a specificity of 99.98 % (one false positive would be expected out of every 5,000 tests in uninfected individuals). Advancements in HIV testing, such as the development of HIV rapid tests, helped to influence the progress of surveillance and prevention strategies aimed at combating the epidemic.

2.5 Development and Impact of Antiretroviral Medication

One of the biggest developments in the fight against HIV/AIDS was the development of antiretroviral drugs. For the first time, infected individuals could take medication that would slow the replication of the AIDS virus. On March 19, 1987, the FDA approved the first antiretroviral drug, zidovudine (AZT) (AIDS.gov 2014). Although there were severe side effects associated with the drug, it was seen as a crucial step in limiting the spread of HIV. Congress approved \$30 million in emergency funding to states for AZT, which laid the groundwork for what would eventually become the AIDS Drug Assistance Program (ADAP), authorized by the Ryan White CARE Act in 1990. With the benefits of antiretroviral therapy unfolding, on August 18, 1987, the

FDA sanctioned the first human testing of a candidate vaccine against HIV. There was more drive than ever in the scientific community to find a cure for HIV/AIDS. Several years later, in October of 1990, the U.S. Food and Drug Administration (FDA) approved use of AZT for pediatric AIDS (AIDS.gov 2014). Following the success of AZT, new therapies were developed to fight HIV viral replication among infected individuals. The advent of highly active antiretroviral therapy (HAART), which involved a combination of three antiretroviral drugs, made it possible for people to live meaningful lives for those infected with HIV. In 1996, for the first time in the history of the epidemic, the number of new AIDS cases diagnosed in the U.S. declined (AIDS.gov 2014). AIDS was no longer leading cause of death for all Americans ages 25–44. However, HIV/AIDS remains a significant health disparity in the African American community and is a leading cause of death for African American men and women in this age group.

2.6 Summary

Since the beginning of the HIV/AIDS epidemic, numerous gains have been made in understanding the virus and modes of transmission as well as prevention of HIV/AIDS in vulnerable populations. The evolving case definition changed who was identified as being most at risk for HIV acquisition, which documented that what began as a white gay men's disease progressed dramatically over the years to one that affects Black/African Americans and Hispanic/Latinos disproportionately. Advances in HIV testing and screening have prevented transmission through blood transfusions, thus hemophiliacs no longer face fear of contracting HIV. Campaigns surrounding HIV testing have raised awareness about HIV and what people can do to prevent transmission. HAART therapy has made it possible for mothers infected with HIV to bear children who are free of infection and those living with HIV now live much longer lives. In addition, researchers have tested HAART therapy as a form of prevention (deemed pre-exposure prophylaxis or PrEP) among groups most at risk. Studies have shown that PrEP equates with promising rates of effectiveness. Biomedical approaches hold great potential, but because sexual contact is the most common mode of transmission, numerous behavioral interventions to reduce risk sexual behavior have been implemented and have been found to be effective. Yet, scale up of behavioral interventions is difficult unless we find a way to reach large numbers of persons most at risk.

The incidence of HIV has reduced dramatically since its peak in the 1990s due to testing, treatment, and prevention; however, even with the progress that has been made, incidence has been stable at approximately 50,000 annually. Although this suggests that prevention efforts may be working given the rising prevalence each year, clearly, there is still much work to do. Of concern are the high transmission rates among MSM as well as adolescents and young adults. HIV/AIDS remains a significant health disparity among blacks and Hispanics with new subgroups being identified. The transgender population is a subpopulation that was not initially

described in the early reports, however, this population faces a significant risk for HIV acquisition and more efforts in terms of research and policy are needed to reduce the burden of HIV in this hidden population.

To overcome the HIV/AIDS disparities facing subpopulations in the U.S., innovative efforts are needed that will involve a combination of experts in academia, public health practitioners, medical providers, community stakeholders, and policy makers at every level of government, to develop practical, cost-effective strategies and policies that affect social determinants, target risk factors that contribute to HIV transmission, and reduce stigma so that more people will get tested and treated. Specifically, much work needs to be done to address poverty and lack of access to affordable HIV medication. Practitioners and other persons in the field of HIV prevention must work with communities to reduce stigma associated with HIV and homosexuality, especially in communities of color. Education on correct and consistent condom use should target youth in various settings. The academic and scientific community must work with policy makers to enact laws that are not biased against the transgender community and do not criminalize behaviors associated with their survival. It will also take motivated individuals to educate themselves on HIV risk and practice health behaviors that minimize risk. Through collaborative efforts, HIV can be eradicated in the United States.

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Chapter 3

Gay Men and Men Who Have Sex with Men: Intersectionality and Syndemics

Neal Carnes

3.1 Introduction

Throughout the western world, gay men and men who have sex with men (MSM) manifest more HIV/AIDS cases than all other risk groups combined (Centers for Disease Control and Prevention [CDC] 2015a; World Health Organization [WHO] 2014). Globally, HIV/AIDS rates among gay men and MSM are increasing at alarming rates (UNAIDS 2014). According to WHO (2013), gay men and MSM are 19 times more likely to be HIV positive than the general population, and the situation is more dire among gay men and MSM of color. Bar none, gay men and MSM's experiences with HIV/AIDS constitute a pervasive health disparity—disproportionate in comparison to the group's population prevalence, at least from prevalence thresholds calculated thus far.¹ This excess burden of disease within a population defines a health disparity (Carter-Pokras and Baquet 2002).

While HIV/AIDS continues to take a toll on a number of communities, we cannot ignore the fact that gay men and MSM maintain a dominate presence in the HIV imagery (Halkitis 2010; Rowe and Dowsett 2008). Since diagnosing cases of pneumocystis pneumonia (PCP) in young, sexually active gay men heralded the oncoming epidemic, HIV/AIDS has been marked as a gay disease (Epstein 1996; Shilts 1987). Even as medical and social narratives attempt to untangle gay from HIV, reality is they remain synonymous. If societies, government agencies, public health professionals, and gay men/MSM do nothing different, particular networks of gay men and MSM will continue to experience infections at devastating rates. As

¹See Chap. 4 for a more detailed analysis of the prevalence literature.

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a result, their vastly disproportionate infections will continue to reify HIV/AIDS as a gay disease. Escaping this trajectory calls for prevention and treatment efforts theoretically grounded in the lived and diverse social contexts in which seroconversions occur.

HIV/AIDS is relational, thus social in nature, in that nearly all HIV infections result from unprotected sex or sharing needles with a person living with HIV (CDC 2015a). The social context in which these behaviors occur involves structural factors (e.g. stigma attached to sex between men and drug use), biomedical factors (e.g. comorbid diseases that weaken the immune system making a person more susceptible), and psychological factors (e.g. one's commitment to self-preservation and experiencing pleasure). These influences intermingle constructing the lived experience, and their interaction compels or mitigates risk as well as disease progression. To explain the complexity of transmission scenarios, overlapping frameworks assist in informing why disparities persist among networks of gay men and MSM. This chapter reviews the pervasive role of HIV/AIDS within these populations reflective of syndemic theory and intersectionality.

Public health narratives discussing disparities in HIV/AIDS speak in "risk group" terms, such as MSM. This narrative leaves the impression of risk groups as broadly conceived collectives. Such thinking overlooks the fact that not all gay men or MSM live with or are at risk for HIV/AIDS, even though their rates are quite disproportionate. As will be explored, distinct networks within the larger MSM collective are disproportionately infected and at-risk, even though all are affected. Indeed, gay men and MSM do not constitute a monolith. These are diverse networks of varying racial and ethnic backgrounds that experience a range of socio-economic statuses. Gay men and MSM hold varying degrees of education, live in a variety of geographical locations, and maintain interests that fracture as well as draw each other together. Gay men and MSM experience the world in convergent and divergent ways, with varied outcomes. Rowe and Dowsett (2008) state, "In order for HIV prevention to regain lost traction, the notion of a singular gay community must give way to the dynamism and creativity of gay men's sociality today" (p. 341). As such, it is a fallacy to conflate gay men as a single, uniform, and cohesive community, let alone to conflate gay men with MSM, as well as with bisexual men. The literature notes important distinctions between gay and bisexual men (Rust 2000; Weinberg et al. 1994, 2001; see Chap. 4 for additional analysis of these distinctions), between gay men and MSM (Goldbaum et al. 1998), and as will be explored, within the gay "community." In this chapter I reflect on gay men and MSM's divergent experiences (as the data/research allows), thus the social context in which gay men and MSM encounter problematic health outcomes, as well as the resilience that counters negative life situations.

The unique conditions in which particular networks exist are informed by varying social positions (as well as desires). These positions consist of privileges, oppressions, and resiliencies impacting health and well-being. While many, if not all gay men experience the burden of stigma (as do MSM), distinct networks face diverging degrees of stigma and handle the stigma in distinct ways. For example, African American gay men are stigmatized by larger society for being gay and

African American, by the African American community for being gay, and by white gay men—and other racial/ethnic minorities—for being African American (Crawford et al. 2002). Approaching gay men and MSM in the aggregate is problematic for it muddles the factors contributing to disproportionate rates of HIV. The distinctions of particular networks are defined by intersecting influences, some contributing to risks while others protect us from risks.

Empirical and anecdotal narratives on gay men and MSM's experiences with HIV/AIDS notes the factors related to transmission and disease progression differ according to embodied characteristics and social positions. For example, while all gay men are socially marginalized and stigmatized due to their sexuality, some are further marginalized due to mental illness and/or their struggle with substance abuse. In addition, subpopulations of gay men are impoverished and/or lack access to consistent healthcare; these men confront distinct factors their counterparts do not confront. Syndemic theory bridges social context with the respective health outcomes; in fact, the theory functions best as a socio-biomedical explanation for health disparities that include HIV/AIDS.

When we unpack syndemic theories' assertions in light of an intersectional framework, the social influences mediating and mitigating disease transmission and progression become more evident (Bowleg 2012; Community Based Research Centre 2011; Reisen et al. 2013; Watkins-Hayes 2014). Syndemic theory asserts social context produces various disease states, and that multiple co-existing diseases interact in a compound manner. Intersectionality informs the social context that produces as well as prevents a syndemic by linking social privileges and oppressions across demographic and behavioral characteristics, and from the macro structural level to the individual micro-level and their meso-level networks. Combined, these theories offer a more evolved means to understand how and why HIV/AIDS manifests disproportionately within networks of gay men and MSM.

3.2 The Syndemic Framework

Studying health concerns among the urban poor, Singer (1994) asserted this population is distinctly impacted by poverty and marginalization that results in a host of diseases. Singer noted a number of disparate health outcomes, e.g. cardiovascular disease, tuberculosis, and drug abuse are threaded into a synergistic helix. As a result of a social context that is more likely to include various disease states, impoverished, marginalized communities' also experience an excessive burden of HIV. In addition to inflated risk for transmission, their HIV burden evolves in distinct and compelling ways—their expansive disease landscape unfolds along a progressive trajectory. In essence, the whole is greater than the sum of its parts (supported by Greub et al. 2000). The picture Singer framed explains disparities as socially interactive and structural in nature, thus more involved than can be explained by individual behaviors as decontextualized events.

Singer suggests we must move forward knowing the prevention and treatment landscape involves complex factors driving causal behaviors. Causal behaviors emerge within and from complex ecological conditions: they do not spring forth simply from personal deficiencies or factors controlled by the individual or even their networks. By including structural forces such as poverty, marginalization, and victimization, we approach a more in vivo perspective regarding the challenges that impact HIV risk and disease progression. At the same time, we must acknowledge context varies according to unique social positions manifest from intersecting characteristics and contexts.

3.3 Intersectionality

HIV/AIDS reflects unique intersections of social and personal oppressions that compound risk and disease progression as well as social privileges and resiliencies that mitigate the potential outcomes. These social and personal forces are embedded in the distinct positions occupied by sexualities, races and ethnicities, age cohorts, geographies, and health statuses, to name a few. At the intersection of the various positions, we see distinct ecologies fostering discrepant and varying diseases. For example, socio-economically disadvantaged African American gay men encounter factors contributing to their HIV risk/disease progression middle-class, married African American men who have sex with men (MSM) do not encounter. Married MSM will experience unique outcomes reflective of their social position that their impoverished, homeless, gay counterparts do not experience. Intersectionality allows us to map the factors faced by particular groups, or what I am referring to as networks, based on the oppressions, privileges, and resiliencies embodied. As such, intersectionality helps conceive how networks are differently affected by HIV/AIDS, given the oppressions and privileges each network experiences.

Crenshaw (1991) introduced intersectionality, asserting African American women experience life as women *and* as African Americans. She argued we cannot parcel out lived experience into isolated characteristics; we must maintain the conjoined integrity of the various characteristics people live. Collins (1999) expanded Crenshaw's argument stating, "Race, class, gender, sexuality, nation, age, and ethnicity among others constitute major forms of oppression in the United States" (p. 6). These forms of oppression (and their counter privileges and resiliencies) shape the behaviors we engage, the context these behaviors unfold, and thus the diseases we experience. Indeed, intersectionality frames the landscape gay men and MSM navigate through a consideration of embodied structural, relational, and personal factors. The theory provides a means to assess HIV as a disparity contextualized by the social and personal conditions driving risk and disease progression; it maps the social ecology, thus the context that produces and reinforces a syndemic.

3.4 The Burden of HIV Among Gay Men and MSM

Of the roughly 1.2 million domestically diagnosed HIV/AIDS cases at the conclusion of 2012, men engaged in same-sex sexual encounters² and/or sharing needles accounted for over half (57.6 %: CDC 2015a). The CDC estimates just over 48,000 new infections occurred in 2013, with 67 % attributed to men engaged in sex with other men and/or injection drug use (CDC 2015a). These data clearly note gay men and MSM, whether through sexual behavior, injection drug use, or a combination of behaviors are the most impacted “risk group” in the U.S. This picture becomes more insidious given over half of the 683,076 deaths among HIV infected people are attributed to gay men and MSM (CDC 2015a).

Informing the disparity argument, population prevalence estimates suggest only 2–6 % of men identify as gay, and less than 10 % of men report having had a same-sex sexual encounter at least once in their lifetime (Binson et al. 1995; Purcell et al. 2012). When we intersect sexuality with, for example, race/ethnicity, age cohort, and geography we come to understand the HIV burden is more problematic among certain groups of gay men and MSM. As will be explored, the data indicate the social and personal factors within subpopulations of gay men and MSM are essential to understanding discrepancies in HIV infections.

At the intersection of race/ethnicity and sexuality, 38 % of newly diagnosed HIV cases in 2010 were attributed to white gay men, 36 % to African American gay men, and 22 % to Latino gay men (CDC 2015b). Regarding living, diagnosed cases (prevalence) as of the end of 2009, 48 % of MSM living with HIV were white, 30 % were African American, and 19 % were Hispanic/Latino (CDC 2012a). These rates indicate a considerable within group discrepancy given data from the U.S. Census Bureau (2015) reports whites comprise 77.7 % of the population, African Americans 13.2 %, and Latinos 17.1 %. Assuming an equitable distribution of race/ethnicity among gay men and MSM, the data indicate HIV is a problematic health disparity among African American gay men in particular, given they make up 13 % of the population yet 30 % of HIV prevalence and 36 % of incidence.

HIV rates at the intersection of age, sexuality, and race/ethnicity expose a cohort effect. African American gay males aged 13–24 comprise the single-most impacted group in terms of new infections (CDC 2015c). The CDC states,

Gay, bisexual, and other men who have sex with men account for most new infections in the age group 13 to 24; black/African American or Hispanic/Latinao gay and bisexual men are especially affected... In 2010, young gay and bisexual men accounted for an estimated 19 % (8,800) of all new HIV infections in the United States and 72 % of new HIV infections among youth. These young men were the only age group that showed a significant increase in estimated new infections—22 % from 2008 (7,200) through 2010 (8,800) (para. 1).

²The CDC conducts surveillance on HIV/AIDS based on causal behaviors not the identity of those engaged in these behaviors, thus we actually know very little about gay men compared to bisexual men compared to MSM’s prevalence and new diagnoses of HIV. Surveillance data aggregates all of these communities, as well as transgendered individuals under the umbrella of MSM.

When reviewing data over time, however, this trend does not translate among whites and Latinos given those 25–34 years of age were most impacted in terms of new diagnoses, and 2009 data indicates 40–49 year olds were most impacted among white gay men (CDC 2012a). In sum, the data suggests age, sexuality, and race/ethnicity-related factors contribute distinctly to disproportionate case rates among networks of gay men. Furthermore, the factors contributing to rate differentials shift temporally and spatially.

Variation exists geographically whereby the majority of HIV/AIDS cases live in urban settings, and in particular states, such as Florida and Georgia (CDC 2012b, 2015d; Reif et al. 2006). In fact, the southeastern region of the country stands out as significantly troubling; those living in the South experience the largest percent of new AIDS diagnoses as well as AIDS deaths (Adimora et al. 2014; CDC 2015d). For instance, Georgia was fifth in new HIV diagnoses (in 2011), sixth in AIDS cases, yet eighth in population in the nation (CDC 2013; Georgia Department of Public Health 2011; U.S. Census Bureau 2013). In support of the urban concentration and racial disparity assertions, Atlanta’s metropolitan area reports 70 % of Georgia’s HIV cases and African American’s, specifically African American gay men and MSM, make up the overwhelming majority of prevalence as well as new diagnoses (Georgia Department of Public Health 2011). The data illuminates an intersectional reality suggesting various communal characteristics make distinct ecological contributions to HIV risk. Underlying this assertion, regional variation often signifies distinctions in attitudes toward gay men. Social attitudes manifest degrees of stigma and marginalization that in turn foster variable health outcomes (Hatzenbuehler 2011, 2014; Hatzenbuehler et al. 2012). Understanding the variable social and disease conditions faced by different racial/ethnic groups as well as age cohorts across localities is providing for a more nuanced understanding of the ecology faced by networks of gay men and MSM (Huebner et al. 2004). The following reviews several diseases that occur in tandem and synergistically interact with HIV. According to empirical and surveillance data, these diseases disproportionately impact gay men and MSM, either measured generally or among particular networks.

3.5 Gay Men and MSM’s Epidemic- and Endemic-Level of Diseases

3.5.1 Sexually-Transmitted Infections

In addition to HIV, gay men experience disproportionate rates of syphilis, gonorrhea, and chlamydia (CDC 2014a; Klausner and Wong 2003; Wolitski and Fenton 2011). In fact, in 2012 and 2013 gay men and MSM comprised 75 % of diagnosed primary and secondary syphilis cases (CDC 2015e). Supporting syndemics’ assertion of disease synergism, Dr. Bolan of the CDC (2012) stated, “There is an

estimated two to fivefold increased risk of acquiring HIV if exposed to that infection when syphilis is present, and studies have also shown that syphilis will increase the viral load of someone who is already HIV infected” (para. 2). In addition, gay men comprise 10 % of Hepatitis A and 20 % of Hepatitis B incidence (CDC 2014b), and are at considerable and inflated risk for human papillomavirus (HPV) (CDC 2015e; Dunne et al. 2006). Like the relationship between syphilis and HIV, an HIV positive gay man is more likely to be living with HPV (Vajdic et al. 2009; Videla et al. 2013).

Additional infections transmitted during sex occur at inflated rates among gay men and MSM. For example, community-acquired Methicillin-resistant *Staphylococcus aureus* (MRSA)—a skin-to-skin or surface-to-skin disease—occurs more frequently among gay men than in the general population (Diep et al. 2008). The discrepancy is said to reflect sexual transmission, and from a syndemic lens, infection is more likely among gay men who use drugs in association with sex (Diep et al. 2008). Like HPV and syphilis, higher MRSA rates have been found in HIV positive compared to HIV negative gay men (Lee et al. 2005). In total, gay men, especially those living with HIV are significantly more likely to experience a number of sexually transmitted infections (STIs). The combined associations of sexually transmitted infections reflect social ecologies favoring multiple disease states as well as progressive disease interaction (Aynaud et al. 1998; Kent et al. 2005; Tumbarello et al. 2002).

In line with syndemic theory’s social contextualization, the CDC (2011) notes gay men’s discrepant STI, including HIV, rates reflect homophobia, homonegativity, stigma, and discrimination. This acknowledgement effectively situates transmission within a context driven, in part, by identification. The relationship between identifying as a gay man and STI infection has been found to be significant, especially when compared to heterosexuals, bisexuals, as well as MSM (Everett 2013). This finding suggests the environment in which gay men live (read: a homophobic, homonegative society that takes aim at gay men in particular) compounds their social and disease concerns. The stigma and marginalization surrounding a gay identity expands when stigmatized diseases are thrown into the mix. For instance, HIV positive gay men who acquire stigmatized diseases, such as syphilis, are marginalized for their sexuality as well as disease states (Brooks et al. 2005; Cadwell 1991; O’Byrne and Watts 2014; Overstreet et al. 2013). These findings support a nuanced consideration of networks over broadly conceived risk groups for not all MSM identify as gay and not all MSM confront multiple diseases.

3.5.2 *Mental Illness*

In addition to STIs, research demonstrates inflated rates of mental health concerns among gay men, which correlate with HIV risk as well as disease progression (Meyer et al. 1998; Stall et al. 2003; Yoshikawa et al. 2004). Irrespective of HIV, or rather as a precedent factor, being a gay man more often involves disproportionate

rates of mental health concerns (Cochran et al. 2003; Meyer 2003; Sandfort et al. 2001). For instance, King and colleagues (2008) conducted a meta-analysis looking at mental disorders, substance abuse, suicidal ideation, and self-harm. They found,

A two fold excess in suicide attempts in lesbian, gay and bisexual people [pooled risk ratio for lifetime risk 2.47 (CI 1.87, 3.28)]. The risk for depression and anxiety disorders (over a period of 12 months or a lifetime) on meta-analyses were at least 1.5 times higher in lesbian, gay and bisexual people (RR range 1.54–2.58) and alcohol and other substance dependence over 12 months was also 1.5 times higher (RR range 1.51–4.00) (p. 1 of 17).

Furthermore, gay men report higher rates of major depression as well as earlier onset major depression, and gay youth experience higher rates of anger, loneliness, and depression (Cochran and Mays 2009; Kosciw et al. 2012; Rivers and Noret 2008). Meyer's (1995) seminal work on mental health and minority stress found a simultaneous impact of "internalized homophobia, stigma, and prejudice events-significantly predict psychological distress outcomes (e.g. demoralization, guilt, and suicidal ideation)" (p. 45). So pervasive are the mental health concerns resulting from sexuality-based stigma, Meyer defined his conceptualization of minority stress on the experiences of gay men, lesbians, and bisexuals.

Regarding the relationship between mental illness and HIV transmission risk, a number of studies have correlated mental health concerns with sexual risk taking (Diaz and Ayala 2001; Gold and Skinner 1992; Parsons et al. 2012; Sabato 2009; Stall et al. 2000). In addition, research has demonstrated an association between disengagement coping (measured by condom fatigue, HIV treatment optimism, and anxiety) and unprotected sex (Yi et al. 2010). Among HIV uninfected gay men, unprotected sex is significantly associated with internalized homophobia, fatalistic ideology, a lack of HIV treatment optimism, anxiety levels as well as drug use (Yi et al. 2010). Indeed, gay men who struggle to effectively cope with mental health issues increase their chances of encountering HIV and STIs.

Mental health concerns also aggravate the situation HIV positive gay men and MSM navigate. For instance, Herek and colleagues (2013) reported a significant relationship between "felt-stigma and depression" among people living with HIV. Mood, as a mental state, has also been linked to HIV-positive MSM's sexual risk-taking, which effectively places them at risk for other STIs and their negative partners for HIV—a socially bound disease synergism (Wilson et al. 2014). Furthermore, we have linked HIV infected gay men's depressed sense of self-esteem to decreased rates of status disclosure with sexual partners, which again, can expose them to other STIs and their partners to HIV (Moskowitz and Seal 2011). In total, mental health status is a predictor for HIV risk as well as a mediator impacting disease progression.

3.5.3 *Substance Use*

As a standalone health concern, gay men report both one-time and lifetime use of marijuana, inhalants, cocaine, hallucinogens, amphetamines, opiates, tobacco,

poly-drug use (using more than one drug), as well as alcohol consumption in rates exceeding those reported by heterosexuals (Cochran et al. 2004; Dermody et al. 2014; Fredriksen-Goldsen et al. 2013; Ostrow and Stall 2008). Gay men are also significantly more likely than heterosexuals to use gamma hydroxybutrate (GHB) as well as methamphetamine (meth) (Degenhardt 2005; Parsons et al. 2009). Cochran and associates (2004) noted gay men are more likely to report daily drug use as well as reporting “at least one symptom indicating dysfunctional drug use across all drug classes” (p. 989). Inflated rates of substance use among gay men have been linked to experiences of discrimination (McCabe et al. 2010), increased numbers of sexual partners (Boyd et al. 2003; Degenhardt 2005) as well as high rates of sexual risk-taking (Beyrer et al. 2013; Goldstone et al. 2011; Valdiserri et al. 1988). This body of work imprints the reality that some gay men use and abuse drugs at discrepant rates and these rates are linked to HIV, STIs, as well as mental health concerns, such as addiction and psychosis.

Toward a synergistic understanding of drug use and HIV, meth serves a pointed example. Meth use negatively impacts adherence to HIV treatment regimens (Rajasingham et al. 2012; Reback et al. 2003) as well as serves a significant risk for HIV seroconversion (Reback and Grella 1999). Meth use impacts HIV positive gay men’s sexual risk-taking exposing them to other diseases and their partners to HIV (Schilder et al. 2005). Green and Halkitis (2006) conducted a qualitative study among 49 meth-using gay men. They reported the connection between sex and drug use occurs, in part, from the enhanced sense of “sexual pleasure and self-confidence” (p. 323). These desirable outcomes foster epidemic-level drug use while perpetuating inflated rates of a number of health conditions and concerns.

Gay men living with HIV and who inject meth report inflated rates of poly-drug use and high rates of needle sharing (Gorman et al. 1997), which opens them up to a host of other health concerns, e.g. hepatitis C (Gonzales et al. 2006; Hahn et al. 2001). One participant in Gorman et al.’s (1997) study stated he quit using meth for several years resulting in a sexually abstinent life. The result was a less desirable life, so he started injecting and having sex again. The authors note this man passed away from AIDS-related complications months after his initial interview. The ramifications of situations exemplified by this participant cannot be overstated; death remains a very real and tragic possibility.

Research details when gay men initiate drug use they do so for reasons that include sex alongside other factors, e.g. to mitigate mental health issues, to deal with abuse, to be social, and have a good time (Carnes 2012; Halkitis and Palamar 2008; Kurtz 2005; Reback 1997). If use continues, new motivations and environments linking drugs to sex and mental health concerns evolve in ecologically synergistic fashion. This linkage is partly driven by the hostility they experience from larger society—the homophobia, homonegativity, stigma, and discrimination discussed previously. Investigating the distinct social ecology of drug use initiation, Halkitis and Palamar (2008) discovered poly-drug use (four or more substances in the 4 months prior to baseline) was the norm, while those more likely to report using fewer drugs tended to be older, African-American, and bisexually-identified (the finding regarding African Americans is supported by Millett et al. 2007, 2012;

Newcomb et al. 2011, yet Newcomb et al.'s study contradicts the finding regarding older participants). This finding suggests young white gay men are more likely to experience substance use, which links to unprotected sex, as an intersectional aspect of their social networks (supported by Halkitis and Palamar 2008).

Disproportionate rates of HIV, STIs, mental illness, and substance use manifesting among gay men informs and reflects on intersectional positions. The literature also points to a number of other biomedical, behavioral, and social factors that influence health outcomes distinctly, specifically HIV disparities among gay men and MSM. The following summarizes literature describing additional factors contributing to gay men and MSM's risk and disease profile.

3.6 Social Ecology

3.6.1 *Childhood and Adulthood Victimization*

Gay men experience inflated rates of physical and mental abuse from childhood through adulthood (Balsam et al. 2005; Doll et al. 1992; Paul et al. 2001; Tomeo et al. 2001); further troubling is that gay men/MSM of color experience childhood physical and sex abuse at rates exceeding those of their white counterparts (Balsam et al. 2010). Those who report experiences of abuse also report higher rates of sexual risk-taking as well as higher rates of HIV infection (Brennan et al. 2007; Strathdee et al. 1998). As such, violence and victimization help define the social ecology impacting a number of gay men's excess burden of disease.

Gay men that report being sexually abused as a child are more likely to be living with HIV (Brennan et al. 2007). Arreola and colleagues (2008) found an association between mental health status, substance use, and sexual risk-taking among gay men who encountered forced sex under the age of 18 (supported by Rosario et al. 2006). Childhood abuse is linked to later intimate partner abuse suggesting the ecological factors defining early experiences remain defining into adulthood (Craft and Serovich 2005). Speaking to the synergistic relationship between victimization and mental health concerns, gay men reporting child and adult sexual abuse score higher on assessments of dissociation, trauma, and borderline personality disorder (Kalichman et al. 2001). Furthermore, when gay men report being victimized as children and as adults, they report significantly more drug-sex occurrences, more unprotected anal sex with two or more partners, more likely to have traded sex for drugs or money, and to have been treated for a sexually-transmitted infection (Balsam et al. 2005). These trends remain problematic when gay men report adulthood sex abuse. Gay men victimized as adults, especially when the abuser is their romantic partner, also experience increased rates of sexual risk-taking.

In a telling quote from Green and Halkitis' (2006) study regarding methamphetamine use among gay men, one participant linked adulthood experiences of victimization and drug use. He stated:

I have been beaten, knocked unconscious from the beating with sex... It's a kinda sick thing-kind-a-but what this drug does to me as sex goes and what I allow myself to do and be done to me is just, I just could not endure without it, without being on it [meth] (p. 326).

From this snapshot we see further evidence of how social context fosters synergistic interaction among social and disease states among gay men and MSM.

3.6.2 Poverty and Marginalization

Singer's analysis of the social contexts that produce syndemics focused on poverty and marginalization. Poverty is an important ecological factor defining some gay men and MSM's experiences with HIV (see, for example, Diaz 2013; Vaughan et al. 2014; and asserted by Halkitis et al. 2013b). As a result, we should include this social determinant in future investigations that intend to explain the burden of disease and how it/they manifest among networks of gay men and MSM. Unfortunately, poverty's influence on health disparities within gay men and MSM's networks remains woefully understudied. More research needs to be conducted as to socio-economic status as well as level of education's impact on the lives of gay men and MSM.

Unlike the under-developed attention poverty has been granted, considerable effort has gone into exposing how gay men are marginalized, and the relationship between marginalization and HIV. We know gay men are marginalized because of their sexuality (Bruce and Harper 2011; Herrick et al. 2011; Meyer 1995, 2003; Stall et al. 2008) as well as their HIV status (Parker et al. 2002; Ware et al. 2006). Synergistically, marginalization furthers gay men living with HIV's experience with depression, substance use as well as diminishes their adherence to HIV treatment (Courtenay-Quirk et al. 2006; Vanable et al. 2006). For gay men living with HIV, the marginalizing entity is not only larger society, but also HIV negative gay men (Courtenay-Quirk et al. 2006). Such within group discrimination provides additional support for an intersectional understanding critical to conceptualizing the synergistic forces driving multiple health disparities within communities, and how these disparities play out.

3.6.3 Intersectional Understanding of Social Ecologies

Intersectionality is more often conceived in terms of characteristics such as race/ethnicity, sexuality, age, and socio-economic status—major demographic forces defining oppression and privilege. Yet, the factors we socially oppress and privilege, and which impacts disease transmission and progression, extends beyond demographics to include behaviors, disease states, and relationship statuses. When a person becomes defined by such factors as being an injection drug user or

schizophrenic, even single, these additional identifications get overlaid with being black, white, Latin, gay, straight, bisexual, young, middle-aged, or old, poor, middle class or wealthy. The oppressions and privileges that impact disease transmission and progression apply, for example, to mental illness and drug abuse, as well as race and sexuality. Identities, disease states, and behaviors produce unique intersections that help define the contextualized risk landscape faced by networks of gay men and MSM.

MSM and gay men who inject drugs serves a pointed and developed example of how intersectionality is an appropriate consideration regarding gay men and MSM's experience with HIV. Anecdotally, it appears distinct networks have formed around particular drugs, e.g. methamphetamine and heroin, as well as means of drug administration, e.g. injection drug use. Regarding the latter mode of drug use administration and its association with condomless sex, HIV surveillance efforts attribute seroconversion to a conjoined cause. Therefore, we have come to understand injection drug using/sexually active gay men's ecology produces a unique and concerning disparity in HIV/AIDS, distinct from gay men who do not inject drugs. In support of an intersectional understanding of how syndemics work, injection drug using gay men report higher rates of unprotected sex than non-injection drug users and non-drug users (Ibañez et al. 2005). In addition, a significant minority of gay men who inject drugs report sharing needles, which compounds their risk for HIV as well as other blood-borne diseases (Gorman et al. 1997). Injection drug using gay men are also more likely to report being unemployed, have less education, and report an AIDS diagnosis (advanced HIV disease—stage III) (Gorman et al. 1997). These findings suggest when investigating and intervening, specific intersectional factors are relevant for research and interventions. Such variation also exists among age-based cohorts.

In a study comparing homeless adolescents' (13–24 years old) risk factors for psychological and physical outcomes, Cochran et al. (2002) found gay youth reported higher numbers of sexual partners, which has been linked to increased risk for HIV. Furthermore gay youth report considerably higher rates of mental health disturbances and sexual risk-taking. In an earlier study comparing age cohorts, Gold and Skinner (1992) noted, "In young gay men, a negative mood state is associated with unsafe sex, an opposite finding to that obtained with older gay men" (p. 1021). These studies suggest differing factors contribute to the disease profile among age-based networks of gay men (see Le 2013). This assertion is extended in research that compares gay men based on race/ethnicity.

A number of unique aspects manifest among racial and ethnic groups that impact their experiences with HIV. Research has delineated differences between African American, Latino, and white gay men in their levels of self-efficacy, disclosure of HIV status and unprotected sex, especially when they also have female sexual partners (Mutchler et al. 2008). Regarding disclosure and unprotected sex with male partners, gay identification among white participants is more significant than among their racial/ethnic counterparts. In a sample of predominately white gay men, Stall et al. (2003) noted a significant relationship between substance use, including poly-drug use, partner violence, childhood sexual abuse, depression, and

unprotected sex. “Notable...is the extent to which each of these psychosocial health conditions appears as an independent correlate of the others” (Stall et al. 2003, p. 940). The link between drugs and unprotected sex did not hold up among racial/ethnic minorities, especially African-American men, suggesting the importance of intersectionality when determining the factors driving disease rates. These conclusions support contextual dimensions to syndemics as measures of mental health status and drug use have been found to be significant in the latter group, yet not sexual risk-taking.

Investigating differences between racial/ethnic groups and the importance placed on identification as a sexual minority, degree of internalized homophobia, and unprotected sex, Flores et al. (2009) surveyed men living or working in the San Francisco Bay Area. With near equal sample distribution of African-American, Latino, and white men the study concluded whites (86 %) followed by Latinos (78 %) then African-Americans (69 %) were likely to identify as gay. Furthermore, white men were found to be more involved in the gay community and involvement in the gay community was found to influence increased rates of unprotected receptive anal intercourse. In addition, one’s internalized homophobia score, found to be higher among African-Americans, was not associated with unprotected sex. While some studies found African Americans report more sexual partners compared to white gay men, they are also less likely to know their sexual partner’s HIV status (Eaton et al. 2010). Yet, no study reviewed found African-American gay men engage in higher rates of unprotected sex. These findings suggest African-American men live a distinct context conflating their risk for HIV, disease progression as well as other synergistically interacting epidemics (supported by Friedman et al. 2015). In addition to demographic-based variations, gay men and MSM’s landscape also involves distinctions based on particular behaviors.

Men who purposefully engage in unprotected sex, aka “barebacking,” constitute a distinct subpopulation of gay men (Dean 2009). Working toward a characteristic and behavioral profile, Reisner and colleagues (2009) found barebackers report less education, more alcohol abuse, and lower scores on the HIV Optimism/Skepticism Scale, meaning they viewed HIV as less a threat and HIV infection to be a manageable disease. HIV positive barebackers are significantly more likely to report missing doses of their HIV treatment regimen fostering a medical situation conducive to other epidemics given the on-going suppression of one’s immune system (Halkitis et al. 2005). In addition, barebacking HIV infected men also reported higher rates of substance use, more likely to inject drugs, and more likely to use drugs during sexual encounters (Halkitis et al. 2005). Overall, HIV positive barebacking gay men were also more likely to report a range of unprotected sexual behaviors with HIV negative or status unknown partners.

A sub-set of the barebacking community, “bug chasers,” has also been given empirical attention (Gauthier and Forsyth 1999; Grov and Parsons 2006; Tewksbury 2006). This body of work further notes the heterogeneous nature of gay men and MSM’s networks. Bug chasing refers to one’s desire to become infected with HIV; thus the “bug” they chase is HIV. Bug chasers incorporate drug use into their sexual encounters even more so than barebackers, yet barebackers were more

willing to engage in unprotected sex (Moskowitz and Roloff 2007). While not definitive in distinguishing these groups, this study suggests a select group of gay men form social networks that involve unique factors that contribute to their health disparities.

When we view gay men as heterogeneous, intersecting networks we approach a more refined and nuanced understanding of the lived experiences informing disease burden and the social factors contributing to these burdens. Some gay men and MSM deal with chronic or acute mental illness, some do not. Some gay men and MSM suffer drug and/or alcohol addiction, some use drugs with varying degrees of use or abuse, and some do not use or drink at all. Some gay men and MSM have a history of physical, sexual, and/or emotional abuse. Some gay men and MSM are currently being abused and/or are abusing, and some have never encountered such experiences. These contexts help us understand what health conditions networks of gay men and MSM confront, and what diseases and social conditions may be synergistically compelling one another. A number of studies have considered gay men and MSM's social context and disease landscape utilizing a syndemic framework. The following reviews a select group of this growing body of work.

3.7 Post Hoc and Empirical Tests of Syndemic Theory Applied to Gay Men and MSM

Research has applied syndemic theory in a priori as well as post hoc analyses of gay men's excess burden of HIV. More often these studies analyzed the correlational impact of disease states and their psychosocial context applying the syndemic framework after-the-fact. These applications did not intend, nor could they measure the biological impact of one disease on another, let alone how social conditions mediate the effect. These applications, while earnest in their intent and attempt, should be considered preliminary and suggestive rather than conclusive. A few studies, however, have directly tested syndemic's assertions. As a preview, the take-away message is that the landscape in which HIV is unfolding is far more complex than framed by behavior, a risk group, or can be captured by a single framework.

Reviewing data from the Urban Men's Health Study, which assessed the relationship between poly-drug use (using three or more illicit drugs in the prior 6 months), depression, childhood sex abuse, partner violence, and "high risk sex" (anal intercourse minus a condom with a partner of unknown or discordant HIV serostatus) Stall and colleagues (2003) found "A syndemic—exist among urban MSM and that the interconnection of these problems functions to magnify the effects of the HIV epidemic in this population" (p. 941). The authors noted, in this post hoc analysis, as the number of psychosocial health problems increased so did the percentage of participants reporting high-risk sex and HIV infection. Regarding within group syndemic effect where HIV is present, poly-drug use as well as partner violence were significantly related.

In an updated analysis of the Urban Men's Health Study data, Stall et al. (2008) refined the argument stating only a minority of participants (18 %) had two or more co-occurring psychosocial disease conditions. The authors concluded, "The vast majority of the men in the Urban Men's Health Study *could not* be characterized as being caught up in a syndemic (emphasis added)" (p. 253). When positioned against syndemic as a disease model and given the available data, their conclusion appears valid. This assertion, however, excludes a number of unmeasured, yet potentially important health outcomes that may be involved in a syndemic. For example, research has linked social marginalization with suicide attempts (Garofalo et al. 1999) and a host of other health concerns not captured in the Urban Men's Health Study dataset (Brotman et al. 2003). We must measure marginalization (and poverty) as directly and indirectly related to health outcomes, and broaden our lens regarding possible synergistically interacting diseases, such as those that are stress-related. This assertion exposes a limitation of Stall et al.'s (2008) argument as well as syndemic theory. We cannot assume marginalization as a critical social factor, nor can we measure only prescribed disease outcomes, e.g. HIV, depression, and substance abuse. Gay men live in far more complex contexts with a broad range of unmeasured health concerns that potentially contribute to their overall health and well-being reflective of their social position (IOM 2011). This assertion finds support in O'Leary and associates (2014) review of the literature reflecting on syndemics among MSM that include various psychosocial conditions.

Herrick et al. (2013a) reported findings from the 2008–2009 Multicenter AIDS Cohort Study, which measured participants' feelings of marginalization and compared these data to a series of health concerns. Utilizing a syndemic framework, the authors noted marginalization was significantly associated with sexual compulsivity, stress, stimulant drug use, partner violence, and depression. They found a significant adjusted relative risk of 2.6 for a syndemic effect between marginalization and the psychosocial conditions measured. From a life course perspective, the authors argued syndemic as a viable theoretical framework to understand the on-going disparity of HIV among gay men.

Additional studies have also conceived gay men's HIV disparity from a syndemic perspective. Parsons et al. (2012) concluded that in the presence of three or more health concerns, HIV was more likely to be one of the conditions involved, and the person suffering three or more health concerns also reported "high-risk" sexual behavior. Interestingly this study assessed for income and found those with higher incomes (greater or equal to \$40,000 annually) were more likely to engage in poly-drug use, report sexual compulsivity as well as engage in more "high-risk" sexual behavior. At the same time, gay men with higher incomes were *less* likely to report depressive symptoms, childhood sexual abuse, and partner violence as well as report living with HIV. This finding supports Singer's conceptualization of syndemic contextualized socially by poverty and marginalization. Overall, the data asserts that the intersectional aspects of gay communities present opportunities for a syndemic, those that include HIV and those that do not.

In a direct test of syndemic theory, Halkitis et al. (2013a) studied young gay men in New York City. By employing structural equation modeling the authors addressed prior methodological shortcomings, such as those underpinning correlational analysis. They included measures of mental health, drug use, and unprotected sex as concerns informing an “all-encompassing health condition,” aka a single syndemic (p. 664). They reported,

...we have effectively developed a second-order model (drug use and mental health burden) using multiple indicators and associated it with a first-order model for unprotected sex, also indicated by numerous variables. Thus we provide robust statistical support to a theory of syndemics inasmuch as these more complex models overcome the potential spuriousness associated with findings of previous research (p. 671).

Their findings noted that mental health concerns and substance use “precede” unprotected sex, which places the person at risk for HIV. While mental health issues and drug use can and often do precede sexual risk-taking, this does not mean they end at the point in which the person engages in sexual risk just as poverty and marginalization do not end once a person acquires HIV. As noted, not all gay men and MSM are at risk for HIV, and not all who are at risk necessarily seroconvert. The lived experience involves resiliencies salient to our analyses of the context in which HIV and other health outcomes occur.

3.8 Resiliency, Love, Affection, and Pleasure

With all the adversity gay men and MSM face as well as live with, we often overlook what is good, how gay men and MSM survive, even thrive. Resiliency as well as privileges helps mediate the social and personal factors underlying health concerns and their causal context. Gay men and MSM socially connect and “fight the good fight” to not only survive, but also to thrive. A number of studies have called for more inquiry on resiliency as a mediating factor for health disparities among gay men (Herrick et al. 2013b; Kurtz et al. 2012; Parsons et al. 2012; Stall et al. 2008). The few studies that have embraced this call have found, for example, whether you are a gay man living with HIV (Harper et al. 2014; Rabkin et al. 1993), a gay man of color (Carballo-Diéguez et al. 2005; Meyer 2010; O’Leary et al. 2014), or an elderly gay person (Genke 2004), survival has occurred through manifest resilience. What has become cliché, the mantra of “I will survive,” has been lived in defiance of considerable stress and oppression (supported by Russell and Richards 2003).

Toward a syndemic conceptualization, resiliency has been operationalized in comparisons of HIV positive to HIV negative gay men who serosort—select their sexual partners based on a common HIV status (Kurtz et al. 2012). Measures of resiliency included self-efficacy, social engagement as well as negative and positive coping behaviors. Reflecting on the syndemic implications, Kurtz and associates (2012) noted,

Although the HIV-positive men in the study exhibited very high levels of syndemic symptoms, including severe mental distress and substance dependence, the data suggest that significant number of these men manage to enact HIV risk reduction in spite of these problems (p. 201).

This finding suggests that while many gay men are experiencing a convergence of various diseases reflective of their social ecology, they enact measures to help “a brother out,” thus engage in communal resiliency. Specific to black MSM, O’Leary and colleagues (2014) found the resilience afforded by optimism and education “buffered the syndemic effect on HIV prevalence” (p. 280). Moving forward, inquiry should consider how varying social ecologies impact gay men’s risk for as well as experience with disease reflective of what is also protective and supportive.

Inquiry into gay men and MSM’s resiliency must consider this survival/thriving factor as personal, relational, as well as communal. We should ask about the mediating influence relationships and networks have on health outcomes as much as the individual’s agency as well as capital—what tangible, psychological, and social resources a person and their networks have available to help them thrive. In addition, attention must be granted to gay men and MSM as seeking not only physical pleasure and coping mechanisms to mitigate negative life situations, but also the desire for love, affection, and intimacy (Bauermeister et al. 2012), which impacts their decision-making. For instance, Diaz and Ayala (1999) found Latino gay men’s unprotected sex encounters were, in part, driven by the belief that condoms oppose trust, intimacy, and love. This narrative helps us understand why condom use is not *modus operandi* among all gay men and MSM, and thus another factor contributing to health disparities.

Research is also unearthing the disproportionate context of HIV risk (as well as protection) within gay men’s romantic relationships, including when the romantically partnered gay men are in “open” relationships, meaning they have partner-negotiated sex with men other than their partners (Goodreau et al. 2012; Hoff et al. 2012; Mitchell and Horvath 2013; Stachowski and Stephenson 2015). Implied in these findings is an expansive dynamic pertaining to participation in various communities and relationships, thus involving more than micro-level influential factors that impact health outcomes—syndemics cannot nor should they be measured squarely at the person level. Ultimately, to understand disparities in HIV/AIDS and how this condition interacts with other diseases as matters of social context, we must shift our attention from the disease to the people at risk and living with the disease, and as socially and structurally situated. As stated previously, and bears repeating, we are greater than the sum of our parts.

Finally, we must recognize and embrace the critical role pleasure and a sense of social connectivity (as a micro, meso, and macro level phenomenon) play with regard to sex and drug use among gay men and MSM. Regulating disease transmission and progression as mediated outcomes of, for example, mental illness, drug use, or as a result of childhood or more recent emotional/physical/sexual abuse, overlooks how risk behaviors are also pleasurable, thus desirable. Gay men and MSM are not social dupes without conscious, rational choice. Approaching risk-taking as irrational seems a convenient framework to understand health

disparities, including HIV, but it is a truncated and decontextualized perspective. The reality is that for many, if not most gay men and MSM, sex and/or drug use is pleasurable, and as such, disease-causing behaviors come to make sense (Carnes forthcoming; Race 2008, 2009). Furthermore, in addition to pleasure, some gay men and MSM also develop a sense of belonging and social connectivity via sex and drug use encounters (Carnes forthcoming; Halkitis and Parsons 2003; Jerome and Halkitis 2009). Again, to understand health disparities as contextualized we must accept the richer tapestry underscoring the behaviors that produce the concerning outcomes, and that the tapestry looks different to different collectives of gay men and MSM.

3.9 Summary

This chapter presents data supporting syndemic theory's primary assertions: multiple disease states result from social and structural factors defining gay men's and MSM's lives; and, when multiple disease states are present, they interact in a progressive manner. I assert the progressive effect applies as much to the social ecology as the health conditions.³ When gay men and MSM face an oppressive social context as well as experience various diseases, this context compounds the overall lived effect. The intersectional experience across various forms of oppression, and as mitigated by privileges and resiliencies, is critical to understand when attempting to frame interventions that address health disparities. When applying syndemic to gay men and MSM, we must keep in mind the variability, thus intersectionality, underscoring the people in question. Men who have sex with men, whether they identify as gay or not, exist heterogeneously not homogeneously.

The significance in pursuing syndemic theory from an intersectional lens may help turn the tide on risk and disease progression. Such a vantage point should focus our attention on contextualized lived experiences that reflect macro, meso and micro-level factors. Perceiving and approaching gay men and MSM as a uniform "risk" community, and HIV/AIDS as a solitary disease, will surely perpetuate on-going health disparities. Syndemic theory in combination with intersectionality can frame public health interventions by focusing us on the convergence of demographic and social characteristics to prevent and treat health conditions. In addition, this convergence of frameworks can and should move future research beyond the confines of variable-driven, decontextualized perspectives and toward lived experiences and how people embody as well as manifest oppressions, privileges, and resiliencies. Anything short of a holistic perspective will truncate the potential in countering the formidable health disparities impacting networks of gay men and MSM.

³See the Introduction for more on this point.

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Chapter 4

The Role of Syndemic in Explaining Health Disparities Among Bisexual Men: A Blueprint for a Theoretically Informed Perspective

M. Reuel Friedman and Brian M. Dodge

4.1 Health Disparities Among MSM: Distinctions Between Gay and Bisexual Men

Compared with men who have sex with women (MSW), men who have sex with men (MSM) have been found to suffer profound health disparities. These health disparities include mental health problems, such as depression, illicit substance use, anxiety, and suicidality (Cochran and Mays 2009; Marshal et al. 2008; Mills et al. 2004; Wolitski et al. 2008); risky sexual behaviors, such as unprotected anal intercourse with multiple partners of serodiscordant or unknown HIV status, sex work, and concurrent stimulant use and sex (Baral et al. 2015; Ostrow et al. 2009); sexually transmitted infections (STIs), particularly syphilis and gonorrhea (Wolitski and Fenton 2011); and HIV infection (Purcell et al. 2012). Disparate rates of childhood and adult adversity among MSM, such as peer-based bullying, physical and sexual violence, and hate crimes (Friedman et al. 2011a; Purcell et al. 2007), may increase feelings of social marginalization and further contribute to future HIV risk behavior (Herrick et al. 2013).

Contemporary health behavior theories, for example Minority Stress Theory and Syndemic Theory, postulate that social marginalization and internalized homophobia contribute to these health disparities by compelling MSM into stress-induced, self-destructive behaviors such as substance abuse and risky sex (Meyer 1995; Stall and Purcell 2000). The scientific literature on MSM largely conflates two groups: men who have sex with men exclusively (MSM) and men

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who have sex with both men and women (MSMW). (For the purposes of readability, we will heretofore refer to MSMW as “bisexual” and MSM as “gay,” although we recognize that these identity labels are not always, or often, concordant with behavior.) While a great majority of research studies into MSM health disparities report findings on “gay and bisexual” men, a very limited number disaggregate gay men from bisexual men in their findings, ostensibly for statistical power reasons (Dodge et al. 2007). Public health literature demonstrates that both gay and bisexual men, in fact, suffer significant health disparities compared with men who have sex with women exclusively. However, when we consider relevant public health responses to these disparities, we should distinguish between gay and bisexual men for four important reasons. First, there are strong indications that bisexual men suffer significant HIV-related health disparities above and beyond those suffered by gay men. Second, bisexual men appear to face subtly different HIV-related health disparities than gay men, which may be influenced by subtly different stressors. Third, by having sex with both men and women, bisexual men are at risk for acquiring and transmitting HIV and other sexually transmitted infections (STI) across different sexual networks than those inhabited by exclusively gay men and exclusively heterosexual men. Fourth, just as bisexually-behaving men might not be effectively reached by messages targeting communities of exclusively heterosexually-behaving men, bisexual men may also be ineffectively reached by messages directed toward gay men; bisexual men may thus require unique techniques for recruitment into public health research and interventions. For these four reasons, public health responses to health disparities among MSM should not be assumed to work with equal effectiveness for both gay and bisexual men or heterosexual and bisexual men.

This review will contextualize previous findings of HIV-related health and risk disparities among bisexual men, using the Syndemic Theory framework to examine adverse childhood events (sexual violence, physical violence, and peer harassment/bullying); psychosocial conditions (depression, suicidality, loneliness, anxiety, and substance use); HIV risk behavior (concurrent substance use and sex, unprotected sex with male and female partners, transactional sex, and other factors such as disclosure of HIV positive status to partners); incidence and prevalence of HIV and other STIs; and, among those who are HIV positive, differences in adherence and viral load suppression. But first, we will examine more generally what is known about MSMW which, relative to other MSM, is relatively little.

4.2 Prevalence of Bisexual Behavior Among Men

Estimates vary on how common men’s bisexual behavior is in the United States, depending on the sample taken and the measure used. In the last 20 years, several studies have used representative samples to calculate sexual behavior by partner gender. Table 4.1 organizes these findings by the proximal measure used to assess

Table 4.1 Proportions of gay and bisexual men in representative samples, U.S. studies

Author(s)	Study site	Sampling strategy	Measure (timeframe)	Bisexual male prevalence (%)	Gay male prevalence (%)
Rogers and Turner (1991)	U.S. (General Social Survey, 1989 and 1990)	Household national probability sample, age 18+	Sexual partners, past year	0.3	0.9
Laumann et al. (1994)	U.S. (National Health and Social Life Survey)	Stratified cluster national probability sample, age 18–59	Sexual partners, past year	0.7	2.0
Smith (2006)	U.S. (General Social Survey, 1991–2004)	Household national probability sample, age 18+ (sexually active sub-sample)	Sexual partners, past year	0.3–1.2 (varying by GSS year)	1.1–3.8 (varying by GSS year)
Jeffries and Dodge (2007)	U.S. (National Survey of Family Growth 2002)	Household area probability sample, ages 15–44 (sexually active sub-sample)	Sexual partners, past year	1.6	3.8
Udry and Chantala (2002)	U.S. youth (National Adolescent Longitudinal Health Survey)	School-based national probability sample (sexually active sub-sample)	Romantic partners, past 18 months	1.4	0.9
Binson et al. (1995)	U.S. adults 18–49 (National AIDS Behavioral Survey)	Probability sample, 20 U.S. urban areas	Sexual partners, past 5 years	2.1	4.4
Laumann et al. (1994)	U.S. (National Health and Social Life Survey)	Stratified cluster national probability sample, age 18–59	Sexual partners, past 5 years	2.1	2.0
Smith (2006)	U.S. (General Social Survey, 1991–2004)	Household national probability sample, age 18+ (sexually active sub-sample)	Sexual partners, last 5 years	0.5–1.9 (varying by GSS year)	1.6–3.3 (varying by GSS year)
Billy et al. (1993)	U.S. (National Survey of Men)	Stratified cluster national probability sample, age 20–39	Sexual partners, past 10 years	1.2	1.1
Laumann et al. (1994)	U.S. (National Health and Social Life Survey)	Stratified cluster national probability sample, age 18–59	Sexual partners since age 18	4.0	0.9

(continued)

Table 4.1 (continued)

Author(s)	Study site	Sampling strategy	Measure (timeframe)	Bisexual male prevalence (%)	Gay male prevalence (%)
Laumann et al. (1994)	U.S. (National Health and Social Life Survey)	Stratified cluster national probability sample, age 18–59	Sexual partners since puberty	5.8	0.6
Rogers and Turner (1991)	U.S. (General Social Survey, 1989 and 1990)	Household national probability sample, age 18+	Sexual partners, lifetime	2.2	0.7
Eisenberg and Wechsler (2003)	U.S. colleges (College Alcohol Study 1999)	Nested random probability sample (sexually active sub-sample)	Sexual partners, lifetime	2.0	2.7
Levin et al. (2009)	Seattle, WA (2003 Seattle Sex Survey)	RDD area probability sample, ages 18–39 (sexually active sub-sample)	Sexual partners, lifetime	8.9	6.0
Pathela and Schillinger (2010)	New York City youth (Youth Risk Behavior Survey 2007)	School-based area probability sample (sexually active sub-sample)	Sexual partners, lifetime	3.7	3.2
Zellner et al. (2009)	San Diego County (Latino community)	Time-location sampling	Sexual partners, lifetime	6.0	5.4
Reece et al. (2010)	National Survey of Sexual Health and Behavior, NSSHB	Internet probability sampling	Sexual identity	1.5 (14–17 year olds)—2.6 (adults)	1.8 (14–17 year olds)—4.2 (adults)

bisexual men's behavior and adds, for context, a recent study assessing sexual identity.

Overall, when assessed using past-year proximal measures, bisexual men have constituted between 0.3 and 1.6 % of men in the sampling frames and were somewhat less prevalent than gay men (0.9–3.8 %). When assessed using intermediate proximal measures (18 months to 10 years), bisexual men constituted 1.4–2.1 % of men in the sampling frame and overlapped prevalence of gay men (0.9–3.3 %). Over the lifespan, more men behaved bisexually (2.0–8.9 % across samples) than exclusively homosexually (0.6–6.0 %) in all but one study. These U.S.-based estimates also compare favorably with research on male sexual behavior in 10 countries in Europe, wherein 8.6 % of men overall reported lifetime bisexual behavior, 0.6 % did so within the past year (Sandfort 1998). In terms of self-identified bisexuality, Indiana University researchers Reece and colleagues collected a refined assessment of sexual behavior and identity in large probability

sample of adolescents and adults in the U.S. with the National Survey of Sexual Health & Behavior. They found that self-identified bisexuality among men was between 1.5–2.6 % (respectively among adolescents, ages 14–17, and adults) (Reece et al. 2010).

Within MSM populations, there is significant variation in bisexual behavior by race/ethnicity. Black and Latino MSM have consistently been found more likely than white MSM to be bisexually active (Binson et al. 1995; Heckman et al. 1999; Montgomery et al. 2003; O’Leary et al. 2007a; Torian et al. 2002). A critical literature review found that Black men “more likely than MSM of other races and ethnicities to identify themselves as bisexual and to be bisexually active” (Millett et al. 2005). Cultural differences are frequently cited for this discrepancy, generally relating to higher levels of homophobia in Black communities that may impel MSM to “pass” as heterosexual by continuing to have sex with female partners (Miller et al. 2005; Millett et al. 2005), and norms in the Latino community that minimize stigma inflecting same-gender sexual behavior as long as one takes an active (top) role in sex (Agronick et al. 2004; Davila 2000; Diaz 2013; Finlinson et al. 2006).

A recent meta-analysis estimated that 33.8 % of U.S.-based MSM were bisexually active within the last year (Friedman et al. 2014d); this estimate was coupled with CDC estimates of MSM population size (Purcell et al. 2012) and Census data to calculate that 1.2 million men in the U.S. are currently bisexually active. Despite important definitional and sampling differences, the rates of male bisexual behavior are stable across samples and cultures, with some significant and corroborated variation across ethnic groups (Sandfort and Dodge 2008). These background findings show that bisexual men constitute a population nearly as large, or even larger (depending on the timeframe and the subgroup of interest) than gay men.

4.3 Early Life Adversities in Bisexual Men

Substantial evidence exists that, compared with their peers, lesbian, gay, and bisexual (LGB) people face severe childhood adversities; these adverse conditions include bullying, harassment, and sexual and physical violence that are linked to mental health problems and HIV risk behaviors (Blake et al. 2001; Bontempo and d’Augelli 2002; Friedman et al. 2006; Garofalo et al. 1998). Recent research makes a very strong case that bisexual male youth may face the most adverse childhood conditions. A large-scale meta-analysis of population-based studies that also conducted retrospective data analysis from Youth Risk Behavior Surveillance (YRBS) surveys illustrates this disparity. Across 5 YRBS surveys from 1992–2007, distributed to high school youth, young bisexual men were significantly more likely to have been victims of forced sexual activity compared with young heterosexually exclusive men; the effect size ranged from 4.95 to 7.57 over this span, and was consistently higher than that for other men and women of all other gender-partner groups (Friedman et al. 2011a). These data are supported by findings from YRBS studies in Massachusetts, wherein young bisexual males had more than twice the

rate than young gay men of being forced to have sex against their will, and eight times the rate of young heterosexual men (Goodenow et al. 2002). (It should be noted that these studies were centered on youth aged 14–17, and questions did not specify when abuse occurred; for these reasons, it is difficult to assess whether and how coercive sex might have impacted later sexual expression.) At the network level, a respondent-driven sampling (RDS) study of high risk men in North Carolina reported that bisexual men were more likely to have had their first sexual encounter be forced (13.1 %) than heterosexual men (4.4 %); gay men (23.7 %), however, had the highest rate (Zule et al. 2009). Similarly, another RDS-recruited study of Black MSM in New York City and Philadelphia found that gay men were more likely than bisexual men to have been victims of forced sex—this was a lifetime measure, however, and could be describing current rather than childhood adversity (Wheeler et al. 2008).

Physical violence disparities have also been demonstrated among bisexual men. Minnesota YRBS data from 1992–2007 show that young bisexual men suffer significantly disparate rates of being physically abused by a parent or guardian, with odds ratios ranging from 2.1 to 2.8 compared with exclusively heterosexual male youth (Friedman et al. 2011a). Intimate partner violence was also reported by significantly higher proportions of young bisexual men compared with their gay and straight peers (34.8 % vs. 13.2 % vs. 6.0 %, respectively) in New York City YRBS surveillance (Pathela and Schillinger 2010).

Young MSMW also report disproportionate rates of suffering peer harassment. Data from three population-based Minnesota Student Surveys completed between 2001 and 2007 indicate that bisexual men had 143–204 % the odds of reporting being threatened or injured with a weapon or otherwise assaulted, compared to their exclusively heterosexual male peers; they were 24–57 % more likely to suffer this bullying than young gay men. In addition, bisexual men were consistently three times more likely than straight men, and more than twice as likely than gay men, to skip school because they felt scared (Friedman et al. 2011a). These results provide context to findings that bisexual men feel less school connectedness than their peers (Saewyc et al. 2009). Data from an YRBS survey conducted in Massachusetts confirm these reports: young bisexual men were significantly more likely than both gay and straight peers to skip school because they felt unsafe (Goodenow et al. 2002). Finally, data from a longitudinal adolescent health survey indicate that an adolescent bisexual male was more likely to have been in a physical fight in the last year compared to his straight or gay peers (Udry and Chantala 2002).

An analysis of Minnesota Student Surveys demonstrated that young bisexual men had significantly lower levels of family connectedness, liking school, and school connectedness than both young gay and straight men. These themes were corroborated in similar samples from British Columbia (Saewyc et al. 2009) and in 13 cities in the U.S., where young bisexual men rated their social support levels much lower than young gay men rated theirs (Flores et al. 2009). Since these background factors have been shown to help explain the relationship between sexual minority status and ensuing psychosocial disparities (Eisenberg and Wechsler 2003; Ueno 2005), they are important to account for when developing

interventions for bisexual men. These findings of disparate peer bullying suffered by bisexually behaving men may also explain why they often are shown as adults to have lower educational attainment than their exclusively heterosexual and homosexual peers (Jeffries and Dodge 2007; Maulsby et al. 2012; Wheeler et al. 2008).

These data paint a stark picture. A typical bisexual male in a U.S. high school will be, compared to his peers, more likely to be bullied and engaged in physical fights. He may be ostracized by both straight and gay peers for his sexuality, and coerced into sexual activities he does not desire. He will have comparatively few friends to turn to for support, and feel disconnected to his family, his peers, and his school system, which may feel so unsafe that he will begin skipping classes. If these are the experiences of a typical bisexual male in high school, is it any wonder that, by the time he is a young adult, he will face profound psychosocial health disparities, including depression and substance use?

4.4 Psychosocial Syndemics Among Bisexual Men

A growing body of evidence demonstrates that people who identify as lesbian, gay, bisexual, or transgender suffer severe psychosocial health disparities compared to the general population (Cochran and Mays 2009). These disparities, which include depression, anxiety, substance abuse, sexual compulsivity and suicidality have been theorized and demonstrated to contribute to HIV risk among gay and bisexual men (Wolitski et al. 2008). Minority Stress Theory argues that individuals whose identities (including sexual identities) and/or behaviors (including sexual behaviors) are outside the mainstream are bullied, ostracized, alienated, and marginalized by their larger communities, causing minorities significant stress and exacerbating self-harm behaviors (Meyer 2003). Bisexuals have reported experiencing social marginalization from both straight and gay/lesbian communities (a unique stigma that is termed “biphobia”), which may estrange them from potentially supportive socio-sexual environments (Dodge et al. 2007, 2012a; Friedman et al. 2014a; Rust 2000; Weinberg et al. 2001). In fact, researchers concluded that (self-identified) bisexual men were rated the most negatively of any other sexuality, race, religious, or ethnic group, by a nationally representative sample of heterosexuals (Herek 2002). Negative attitudes toward bisexuals may be driven by the general population’s fears that they are non-monogamous and/or promiscuous; that they are confused about their sexuality; that they are vectors of HIV/STI infection; and/or that they threaten the dominant cultural notion of sexuality as a binary (gay/straight) construct (Dodge et al. 2007, 2008b; Friedman et al. 2014a; Herek 2002; Ochs 1996; Rust 2000). The additional stigma that bisexuals face from the gay and lesbian community related to their identities and sexual behaviors has been hypothesized to increase homonegativity—negative feelings about same-sex relationships—within bisexual individuals. This increased homonegativity likely compels high levels of substance use, whether as a form of acting out or as self-medication.

We can conceive the experiences of bisexuals to be similar to those of other MSM, but with some important distinctions. First, bisexual men may have less access to minority strengths than men who have sex exclusively with men. Second, bisexual men may have less success resolving sexual identities because of the liminal status of bisexuality in a culture that emphasizes binary categories over continua. As a result, they may be more susceptible to using substances—for reasons of escape, belonging, sexual disinhibition, and self-destruction. On the other hand, sexual partnerships with women offer bisexual men the opportunity to “pass” as heterosexual, potentially mitigating some minority stress effects. Qualitative research has examined the experience of mental health issues among bisexuals: focus groups in the United States and Canada have reported frustrations with “invisible” identities and biphobic harassment from both gay/lesbian and straight communities and partners, which can substantially inflect mental health (Nakamura et al. 2011; Ross et al. 2010; Weinberg et al. 2001). Given this context, it is perhaps unsurprising that bisexual-identified and “mostly heterosexual”-identified adolescents have been shown to suffer significantly higher rates of substance use than their peers (Coker et al. 2010; Corliss et al. 2008; Marshal et al. 2008; Ziyadeh et al. 2007).

With this in mind, we will analyze domestic findings on psychosocial health disparities among bisexual men by first looking at substance use. Data from a national probability sample demonstrated that bisexual male adolescents drink alone more; have more problems caused by drinking; and use more illegal substances than either gay or straight male youth (Russell et al. 2002). Since young MSM have been found to have significant substance use disparities in nationally representative samples, the researchers surmised that these effects could be driven by bisexually behaving men. Similar disparities for cocaine use and marijuana use among bisexually behaving youth have also been found using YRBS data (Robin et al. 2002).

Smaller, more targeted samples make the case for additional male bisexual substance use disparities. Bisexual HIV-positive men have reported using injection drugs at higher rates than their gay peers (Chu et al. 1992; Ibañez et al. 2005; O’Leary et al. 2007b); among HIV-positive injection drug users (IDU), bisexual men were significantly more likely to report alcohol use and non-injection drug use than gay or straight men IDUs (Knight et al. 2007). A study of HIV-positive methamphetamine-using men discerned significantly higher crack use, IDU, alcohol, marijuana, crack, cocaine, hallucinogen, and heroin use among bisexual men compared with gay men (Nakamura et al. 2011). The Supplemental HIV and AIDS Surveillance Project further argued the case for disparities among HIV positive bisexual men, who used significantly more non-injection drugs than HIV positive gay or straight men (Spikes et al. 2009). Among poor, mostly Black MSM in Los Angeles, bisexual Black men were more likely than gay men to use cocaine and to have higher internalized homophobia scores (Shoptaw et al. 2009); a similar RDS study of Black MSM in New York and Philadelphia discerned significantly higher alcohol use and illicit drug use among MSMW compared to other MSM (Wheeler et al. 2008). Elevated rates of substance use among bisexual men appears to be

persistent: bisexual male participants of a longitudinal cohort study had significantly higher levels of poly-substance use (2 or more drugs, used at least monthly) than gay men over a period of 7 years (Friedman et al. 2014c).

The formative research on substance use rates of bisexually behaving men is remarkably consistent, steadily illustrating significantly elevated proportions of bisexual men using illicit drugs like marijuana, cocaine, crack, and meth, and limited evidence of differences in tobacco and alcohol use. Theories have been presented that argue that elevated substance use rates among bisexual men are indicators of severe marginalization from both straight and gay/lesbian communities, and that biphobia is a specific construct unique from homophobia (Rust 2000). Second generation research to develop and implement scales that can reliably measure phobia and stress specific to bisexuality is essential to test the theory that elevated substance use rates among bisexual men result from internal and external stressors particular to this population.

Outside the domain of substance use, relatively few studies have assessed other syndemic psychosocial health conditions among bisexual men. Several studies have found higher rates of depression and suicidality among people who identify as bisexual than those who identify as gay or as straight (Paul et al. 2002), with evidence that bisexual boys are at increasing risk of suicidality disparities, perhaps due to a reduction in homophobia without an equal reduction in biphobia in school settings in recent years (Saewyc et al. 2008). A study of Vermont and Massachusetts YRBS data noted substantial differences between bisexual youth compared to youth with same-sex partners in models controlling for gender: bisexually-behaving youth were much more likely to be depressed and attempt suicide (Robin et al. 2002). Similar findings were reported in a large-scale meta-analysis of sexual minority status and suicidality (Marshal et al. 2011). In more targeted samples, one study of HIV-positive methamphetamine-using MSM found that bisexual men had significantly more depressive symptoms than gay men (Nakamura et al. 2011); another sample of HIV-positive MSM demonstrated that bisexual men had higher levels of sexual compulsivity than gay men (O'Leary et al. 2007a). Findings from a 4-city, longitudinal cohort study demonstrate that bisexual men were more likely to report clinical depression symptoms compared with gay men, and that this persisted over a wide timeframe in adulthood (Friedman et al. 2014c). It should be noted that psychosocial disparities between gay and bisexual men are not universal: for instance, among Black MSM in New York and Philadelphia, gay and bisexual men shared similar levels of depression (Wheeler et al. 2008).

Other factors may serve to increase risk for, or protect against, psychosocial health disparities among bisexual men. Several studies have found that bisexual men are less likely than gay men to disclose their sexual behaviors and/or identities to family and friends, suggesting that they received less emotional support for their sexual expression (Kalichman et al. 1998; Myers et al. 2003; Solorio et al. 2003; Wheeler et al. 2008). Within a sample of bisexual men, black men have been found less likely to disclose their same-sex sexual behaviors to others, compared with white men (McKirnan et al. 1995). One study from Los Angeles linked higher

internalized homophobia among black bisexual men to lesser disclosure of their same-gender sexual activities to female partners (Shoptaw et al. 2009). Another study of behaviorally bisexual men in New York City found that these men are reluctant to disclose their bisexual behavior and/or identity to heterosexual female partners or to gay male partners for fear of negative reaction and even physical violence and emotional retaliation; however, many were enthusiastic at the opportunity to disclose their bisexuality to fellow bisexual male and female partners (Dodge et al. 2008a).

4.5 Sexual Risk Behavior Disparities Among Bisexual Men

In this section, we examine the following domains of risk behavior associated with HIV acquisition and transmission: transactional sex; concurrent substance use and sex; unprotected anal and vaginal intercourse; and disclosure of HIV positive status to partners. This section critically examines disparities in risk behavior between bisexual men and straight men, while also attending to subtly different risk behaviors between bisexual men and gay men. The latter might confer protective factors for bisexual men and/or uncover behavioral risk domains for bisexual men that could serve as promising intervention loci.

Studies of bisexual men have uncovered a substantial amount of transactional sex: trading sex for money or drugs, trading money or drugs for sex, or both. Transactional sex has been newly examined in light of Syndemic Theory and has been shown to be strongly associated with other syndemic variables such as substance use, depression, and condomless anal sex (Biello et al. 2014; Friedman et al. 2014b). In eight of nine studies reporting comparative rates of male sex work involvement, bisexually active men were significantly more likely to report having sold sex than gay men: in these studies, bisexual men were between 5 and 38.6 % more likely to engage in sex work. In the 7 studies that also provided sex work estimates for exclusively heterosexual men, bisexual men were between 8.3 and 45.4 % more likely to engage in sex work; in contrast, differences in sex work proportion within studies between gay and straight men varied from 0.9 to 17.7 % (see Table 4.2).

Not included in this table (because studies did not distinguish between buying sex and selling sex) are findings from North Carolina, Baltimore, and Los Angeles that demonstrate bisexual men were more likely to have transactional sex partners than their gay and/or straight peers (Hightow et al. 2006; Latkin et al. 2011; Udry and Chantala 2002; Wyatt et al. 1998).

In almost all studies that have assessed comparative rates of sex work, transactional sex rates among bisexual men have been significantly higher than those for gay and straight men. It is important to note that some of these findings may be definitional, artifacts of a generally accepted—though not fully corroborated—

Table 4.2 Sex work prevalence among bisexual, gay, and straight men in the U.S.

Author(s) (date)	Target population (site)	Bisexuality recall window	% sex work, bi	% sex work, gay	% sex work, straight	Measure
Knight et al. (2007)	HIV + IDU, 18+, sexually active (4 U. S. cities)	Sexual partners, past 3 months	81.4	42.8	36	Exchanged sex for money or drugs, past 3 months
Wheeler et al. (2008)	black MSM, 18 + (Philadelphia and New York City)	Sexual partners, past 3 months	61.1	38.9	—	Exchanged sex for money, food, or drug, past 3 months
Gorbach et al. (2009)	MSM and MSW substance users and partners, 18+ (Los Angeles)	Sexual partners, past 6 months	34.3	18.3	17.4	Received drugs or money for sex, past 6 months
Zule et al. (2009)	MSM and MSW substance users, 18 + (Raleigh-Durham)	Sexual partners, past 6 months	47.4	28.9	19.4	Received drugs, money, or other goods for sex, past 6 months
Spikes et al. (2009)	HIV + black men (23 U.S. health departments)	Sexual partners, past year	56	32.7	15	Received money or drugs in exchange for sexual intercourse, past year
Friedman et al. (2014b)	Substance-using MSM (Miami and Fort Lauderdale)	Sexual partners, past year	34.9	20.9	—	Trade sex for money, drugs, or gifts, past 3 months
Jeffries and Dodge (2007)	General (U.S., National Survey of Family Growth 2002)	Sexual partners, past year	19.3	8.5	1.3	Traded sex for money or drugs, past year
Diaz et al. (1993)	AIDS-diagnosed (U.S., 11 Health Departments)	Sexual partners, past 5 years	9	4	3	Received money for sex, past 5 years
Levin et al. (2009)	Sexually active, 18–39 (Seattle)	Sexual partners, lifetime	14	21	5.7	Exchanged sex for money, lifetime

premise that male sex work is fueled by demand from male, and not female, clients (Baral et al. 2015; Pedersen and Hegna 2003). Recent studies demonstrate that male transactional sex engagement is associated with significant childhood adversities, mental health disparities, and other HIV risk behavior; male sex work has also been shown to exacerbate future depression and substance use (Friedman et al. 2011b), and male sex workers with higher numbers of male paying partners are more likely

to be HIV-positive (Bacon et al. 2006). Male sex work involvement has been shown to mediate the relationship between bisexual behavior and unprotected anal intercourse with partners of serodiscordant/unknown status among MSM substance users in South Florida; this study also found that bisexual men were significantly more likely to sell sex (AOR = 1.8), buy sex (AOR = 2.4), and both sell and buy sex (AOR = 2.5) than gay men (Friedman et al. 2014b).

Among bisexual men, sex work has been associated with other HIV risk behaviors, including IDU and inconsistent condom use with casual female partners (Rietmeijer et al. 1998). During qualitative research with black bisexual men, it emerged that for many, sex work has served an introduction to same-gender sex, and that the sex work milieu could be seen as a closely intertwined, mixed-gender scene where substance use and sexual needs could be met: sex work served as motivator and enabler of concurrent sexual and substance use behaviors (Harawa et al. 2008; Jeffries et al. 2008; Rhodes et al. 1999; Wheeler 2006). These findings validate those from a qualitative study of Black male bisexuality in rural Alabama, which contextualized sex work as particularly enticing for poor youth and older, straight-identified crack cocaine smokers (Lichtenstein 2000). Previous research has suggested that bisexual men may use the exchange component of sex work to psychologically process their same-gender desires while still engaging in same-gender sexual behaviors (Boyer 1989).

Concurrent sexual and substance use behavior (i.e., having sex under the influence of drugs and alcohol), especially stimulant use, has been shown to be an important predictor of HIV seroconversion among MSM (Ostrow et al. 2009). Data from the 2002 National Survey of Family Growth demonstrates that, compared with straight and gay men, a significantly higher proportion of bisexual men reported being high during sex at least 50 % of the time (Jeffries and Dodge 2007). These findings are corroborated by the 2005–2007 New York City YRBS (Pathela and Schillinger 2010) and a national surveillance study of HIV-positive black men (Spikes et al. 2009), which demonstrate that a significantly higher proportion of bisexual men reported alcohol/drugs at last sexual intercourse compared with straight and gay men. Other probability samples have shown higher rates of concurrent substance use and sex among bisexual men compared with straight men, though not compared with gay men (Goodenow et al. 2002; Levin et al. 2009). In a convenience sample of young Latino MSM in New York City, bisexual men were significantly more likely than gay men to have been high on drugs or alcohol during their last male sexual contacts (Agronick et al. 2004). Among bisexual black men in Oakland, researchers found that concurrent substance use and sex was associated with 5 times the rate of unprotected sex with transgender partners and 10 times the rate of unprotected sex with men, though it was not associated with unprotected sex with women (Operario et al. 2011). Of the studies we found that assessed comparative rates of concurrent substance use and sex, consistently robust disparities for bisexual men were uncovered when compared with their straight peers; and there is substantial—though not in every instance corroborative—evidence that a higher proportion of bisexual men have concurrent substance use and sex than their gay peers. Within bisexual men, qualitative research has shown that substance use

before sex can serve important dissociative purposes, allowing sexual contact between men to happen while allowing participants to buffer their internalized stigma conferred by these activities (Wheeler 2006; Zea et al. 2003).

Despite the behavioral risk disparities we have noted among bisexual men in transactional sex engagement and in concurrent substance use and sex, few substantiated differences in condomless sex between bisexual and gay and straight men have been seen. A recent meta-analysis determined no significant differences between these populations in rates of condomless sex, with one exception: bisexual men were less likely than gay men to engage in condomless receptive anal sex, likely due to their relatively lower likelihood of engaging in receptive anal sex in general (Friedman et al. 2014d). Ultimately, there appears to be no preponderance of evidence that rates of condomless sex among bisexual men are, in general, disparate relative to those with exclusively gay or straight sexual behaviors. Additional background disparities that may play a role in increasing HIV risk among bisexual men include earlier sexual debut (Goodenow et al. 2002; Levin et al. 2009; Wyatt et al. 1998); higher proportions of multiple sexual partners in the time frame assessed (Goodenow et al. 2002; Knight et al. 2007; Latkin et al. 2011; Levin et al. 2009; Li et al. 2009; Spikes et al. 2009; Wyatt et al. 1998); and greater likelihood of having sex with transgender partners, which was highly associated with recent condomless sex (Bockting et al. 2007). Perhaps the best approach to examining HIV risk behavior disparities is one that is multifactorial, taking into account such varied behaviors as transactional sex, condomless anal and/or vaginal sex with single and multiple partners, and concurrent substance use and sex. Researchers who used this method with Black men in Los Angeles demonstrated that multifactorial sexual risk behavior was significantly predicted by bisexuality (Myers et al. 2003).

4.6 Disparities in Health Care Access/Utilization and Health Outcomes

Several studies propose that bisexual men are less likely than gay men to have received a recent HIV test (Flores et al. 2009; Hays et al. 1997; Jeffries 2010; Wheeler et al. 2008). This may be linked to both internal and external factors. Higher internalized homophobia has been shown to be associated with less uptake of HIV testing (Shoptaw et al. 2009), which may apply to bisexual men who struggle with their same-sex desires and behaviors.

External factors related to lower HIV testing among bisexual men have been associated with sexuality disclosure to health care providers. Researchers in New York City found that only 16.9 % of bisexual men had disclosed their same-sex attractions to their health care providers, compared to 70 % of gay men; in this study, bisexual behavior was the most significant independent predictor of same-sex attraction non-disclosure to health care providers, potentially limiting the chances of

bisexual men being offered HIV testing consistently (Bernstein et al. 2008). Because bisexual men may be less likely than gay men to avail themselves of HIV testing in gay-targeted community sites, and less likely to come out to health care providers, alternative testing procedures could benefit them. Researchers in San Francisco found that bisexual men comprised a significantly higher proportion of men receiving home-based HIV test kits (33.8 %) than men receiving HIV testing at publicly-funded sites (28.3 %) (McQuitty et al. 1999). A nationwide study found that bisexually behaving men made up significant proportions of those accessing home-based HIV testing (Branson 1998).

The National HIV/AIDS Surveillance System has neither historically collected nor reported data specific to bisexual men (all MSM have been sheltered under that umbrella term). However, many HIV prevalence studies have differentiated bisexual from gay men. A recent comprehensive review and meta-analysis examined 33 separate samples of HIV prevalence among bisexually-behaving men in the U.S., finding a weighted mean HIV prevalence of 17.9 % (95 % CI: 12.7 %, 24.6 %). These HIV prevalence estimates were significantly higher (OR = 5.7) compared with straight men, but significantly lower compared with gay men (OR = 0.41) (Friedman et al. 2014d). Within these studies, bisexual men in samples with greater than 90 % racial/ethnic minority populations hosted significantly higher HIV prevalence rates than bisexual men from non-minority based samples, mirroring surveillance results in the U.S. among MSM as a whole.

As we have noted when analyzing HIV prevalence data, there is little bisexual-specific information available for STI prevalence. Separate studies have noted that both gay and bisexual men have similarly elevated rates of syphilis (Hightow et al. 2006), HPV, and herpes (Zule et al. 2009), and gonorrhea (Levin et al. 2009) compared with straight men (Jeffries 2010), although differentiation of STI results among these populations are not always unequivocal (Zule et al. 2009). The 1999 Massachusetts Youth Risk Behavior Survey indicate that young bisexual men were significantly more likely to have ever been diagnosed with an STI than adolescent men who were exclusively heterosexual in behavior; in this study, adolescent men who had sex only with other men did not differ significantly in STI self-report than adolescent men who had only female partners (Goodenow et al. 2002). An analysis of the Baltimore subset of the Young Men's Survey determined that young MSM with a lifetime history of 3 or more female sexual partners suffered more than twice the odds (AOR = 2.3) of herpes simplex 2 infection, with no effect for greater numbers of male partners noted (Mark et al. 2005). Other studies of MSM have found that bisexual and gay men do not differ significantly in STI infection burden (Huhn et al. 2008; Lu et al. 2011; Wheeler et al. 2008), and a meta-analysis of STI prevalence within a sample of HIV prevalence studies found no significant differences in STI burden between gay, bisexual, and straight men (Friedman et al. 2014d). To our knowledge, no studies or surveillance reports have been published that examine HIV or STI incidence rates specific to the bisexual male population in the U.S. For this reason, it is not possible to estimate whether new HIV or STI infections in this population are increasing, decreasing, or holding steady over time. However, recent multi-method exploratory studies of sexual

health among behaviorally bisexual men have incorporated self-sampling for STI diagnostics; for example, Dodge and colleagues (2012b) found a rate of approximately 10 % chlamydia positivity in their sample of behaviorally bisexual men from the Indianapolis area. Studies such as these may offer opportunities for researchers to calculate STI incidence among bisexual men by following natural cohorts over time.

Compelling data has recently indicated that health care outcomes among HIV-positive bisexual men are comparatively worse than for HIV-positive gay men. Data from a longstanding, multicenter longitudinal cohort study demonstrate that, relative to HIV-positive gay men, HIV-positive bisexual men were less likely to have unsuppressed viral load and more likely to have higher mean viral load levels at a given observation over a period of 7 years (Friedman et al. 2014c). Buttressing these findings, a review of data from the National HIV/AIDS Surveillance System suggested that, among HIV-positive MSM, bisexual men experienced later HIV diagnosis and potentially more rapid disease progression than gay men (Singh et al. 2014).

4.7 HIV-Related Interventions for Bisexual Men

Beyond the media firestorm created by sensationalism over “down-low” men in the early 2000s, there have been few HIV prevention campaigns targeting bisexual men (Dodge et al. 2008a; Friedman et al. 2014a; Mimiaga et al. 2009). The CDC has compiled a list of evidence-based HIV prevention interventions as part of the Effective Interventions project (www.effectiveinterventions.org). Of the 41 interventions and strategies listed, none have been designed to target bisexual men. No external modules addressing bisexual behavior exist that can be inserted into existing material. In recent years, researchers have argued convincingly that existing HIV/AIDS prevention campaigns initiated by community based organizations for purportedly gay and bisexual men focus specifically on recruitment from gay-affiliated venues and do not effectively reach bisexual men, who may have hold weaker gay community connections (Dodge et al. 2012b; Operario et al. 2011; Rust 2000). Even as public health researchers have recruited substantial proportions of bisexual men into studies, bisexually behaving men report significantly less exposure to HIV prevention interventions than gay men (Flores et al. 2009). This does not appear to result from any lack of interest in enrolling: at least one study has shown that MSM with primary female partners were no more likely to be HIV intervention non-participants (Orellana et al. 2006). In addition, involvement specific to bisexual men in HIV-related interventions for MSM has not been typically presented in outcome evaluation data, to denote, for example, differential effects for a bisexual subgroup, or sexual risk outcomes with female partners (as an example, though substantial proportions of bisexual men were included in a “d-Up!” demonstration project, no findings specific to bisexual participants or heterosexual risk behavior outcomes were provided in published reports) (Jones

et al. 2008). A survey of bisexual men in Ontario, Canada, demonstrated that reported rates of unprotected intercourse with men were significantly lower in communities where HIV prevention programming existed; however, no effect on rates of unprotected intercourse with women were noted, perhaps because existing interventions did not address heterosexual risk behavior among bisexual men (Leaver et al. 2004). Thus, there is a tremendous missed opportunity that can be remediated by informed intervention design attending to needs particular to bisexual men.

Recently, two interventions have been designed and piloted taking into account specific populations of bisexual men. These two, *Hombres Sanos* and the *Bruthas Project*, are intended to reach Latino and black bisexual men, respectively. The *Bruthas Project*, an individual-level intervention, was designed after substantial qualitative research in Oakland, California. It consists of 4 risk reduction sessions, with HIV counseling and testing provided; it was initiated within a community-based participatory research (CBPR) framework, and its theoretical underpinnings include the AIDS Risk Reduction Model and the information-motivation-behavior skills model of HIV preventive behavior change (Operario et al. 2010). Evaluation was conducted using a pre-test/post-test (3-month follow-up) design. Preliminary risk behavior outcomes from 36 black bisexual men found significant reductions in condomless insertive anal sex with male partners; condomless receptive anal sex with male partners; number of male and female unprotected sex partners; and concurrent substance use and sex. Psychosocial health outcomes included significantly higher social support and self-esteem, and significantly reduced loneliness.

Hombres Sanos, a social marketing campaign to increase awareness of HIV risk and uptake of HIV prevention among Latino bisexual men in North San Diego County, was also developed as a result of formative research with community members (Martinez-Donate et al. 2010). This seven-month campaign distributed safer-sex and HIV testing-themed print materials (brochures and flyers) and condoms, with radio ads, sponsorships, and promotional event components. Although Latino bisexual men were the target audience, the campaign was disseminated across the larger Latino male heterosexual community, and advertised a free comprehensive male health exam at a local clinic friendly to the Latino community. Effectiveness was assessed through the distribution of repeated cross-sectional intercept surveys to men congregating at Latino community venues. A preliminary evaluation based on exposure to the campaign demonstrated that 6 % of male survey respondents had sex with men and women; the rest were exclusively heterosexual. Bisexual men were significantly more likely than their peers to have gotten tested for HIV and to have thought of ways to reduce HIV/AIDS risk as a result of exposure to the campaign (Martinez-Donate et al. 2009). Post-campaign evaluation indicated that bisexual men significantly reduced their rates of condomless anal sex with male partners within a 60-day period, and were marginally more likely to have taken an HIV test. Interestingly, exclusively heterosexual Latino men showed greater positive benefit from the campaign. This could be a result of a higher numbers of survey respondents, increasing statistical power for this subgroup; an artifact of current HIV prevention not reaching heterosexual

Latino men, so that they stood to benefit more from increased knowledge; or an effect of the campaign's messages for the broader Latino male community diluting its effects on a target population that seen markedly little dedicated attention from health providers.

In terms of implications for future interventions, Dodge and colleagues (2012a) conducted qualitative interviews with behaviorally bisexual men in which they asked about their preferences for how to be "reached" with health services, including sexual health interventions. Overall, the types of health services participants described as most relevant were influenced by issues of privacy and trust. Individual and one-on-one services were considered to be the most private and easiest ways to establish trust (Dodge et al. 2012a). Group services, while important to some participants, were the least favored because of potential threats to privacy and trust. Future researchers and practitioners providing services at the individual level may consider further developing relationships among health care providers and patients by setting up systems that facilitate an individual being seen by the same provider over time. Consistency of relationships was also central to the participants' discussion of trust.

4.8 Summary and Implications

This review yields important findings on social disparities and health outcomes specific to bisexual men. First, it is clear that bisexually-behaving men, though a relatively small segment of the general male population, may be as or more common at the population level as exclusively homosexual men, depending on the proximal measures used to demarcate sexual partnerships. Men who engage in sex with both men and women can fit any number of categories: married men; gay-identified men who occasionally have sex with women; sex workers who only have sex with men for money; young people who are exploring sexuality; and men who live openly bisexual lives, just to give a few examples. Second, this review has illustrated that, particularly when compared with their exclusively straight peers, bisexual men experience consistent and severe disparities across a broad spectrum of health and social conditions. These disparities include childhood adversity experiences, such as childhood sexual and physical abuse and peer bullying; psychosocial health conditions, such as substance use, depression, and suicidality; HIV risk behaviors, such as concurrent substance use and sex, high numbers of partners, early sexual debut, and transactional sex; and higher prevalence of HIV. Third, for many background conditions (for example, childhood adversity, substance use, transactional sex, and concurrent substance use and sex), bisexual men exhibit rates even above and beyond those found for exclusively gay men. Why does this happen, and what does it mean? In this section, we summarize our findings and explore directions for future research and implications for intervention design.

Syndemic Theory offers a valuable and empirically tested framework to explore underlying causes of syndemic production (Herrick et al. 2013). We can use this

framework to offer explanations for the differential rates of health and social disparities we have found among bisexual men. Though this theoretical model has been applied generally to gay men when used to theoretically explain psychosocial and health conditions among MSM, its focus on sexual minority-specific stressors, resilience, and outcomes provides areas of both broad overlap and of distinction between gay and bisexual men's experiences. What are the areas of overlap? Both gay and bisexual men experience stages of sexual minority identity development, during which they become aware of their minority sexual attractions; act upon these attractions; develop sexual minority identities; and disclose their attractions, identities, and behaviors to others. However, during (and even before) this process of marginalized identity development, both gay and bisexual men are inculcated with homophobic messages from communities-at-large, and may internalize negative messaging about homosexuality. This internalized homophobia can lead to devaluation of themselves and others; social isolation; the secreting of identities and behaviors from loved ones to minimize expected rejection; and dissociation, for example during sexual expression. This process is often marked by social developmental delays, as gay and bisexual men struggle to fit into social groups, and sets the stage for vulnerability to developing syndemic psychosocial health problems. When they begin to form social attachments to sexual minority communities, gay and bisexual men are privy to both the strengths and weaknesses that these communities confer. Strengths conferred by gay communities include social bonding; a sense of community; potential for establishing romantic and sexual partnerships; and gender and sexual identity constructs that may be more expansive and inclusive than those conferred by straight communities. Gay community weaknesses, however, include norms of sexual shaming; experiences of discrimination and resultant stress; disconnection from sexual majority communities (communities-at-large); and high background prevalence rates of HIV, STIs, substance use, mental health issues, behavioral risk-taking, and violence. The exposure of young gay and bisexual men to the social adversities they experience in childhood and adolescence, and the community-level weaknesses they encounter when forming minority community attachments, leave them highly vulnerable to negative health outcomes, and explain (both theoretically, and in some cases, empirically) many of the health disparities we have found in both gay and bisexual men.

There are, however, several areas of distinction within Syndemic Theory that are specific to bisexual men and may explain the extraordinary health disparities they experience. First and foremost, as bisexual boys become aware of their attractions, they may also begin to realize that there is very little cultural identification specific to bisexuality in U.S. society. Studies have reported bisexuals feeling "invisible," with identities that fit neither into dominant straight or minority gay/lesbian paradigms (Ross et al. 2010). Faced with a sense of de-legitimization, it is not hard to fathom why bisexual men may not come out to others: why tell people you are something that they do not see as a legitimate sexual orientation (Friedman et al. 2014a)? Unfortunately, as we have seen, non-disclosure has side effects, including weaker sexuality-related social support and reduced sexuality-specific medical care. The notion of exposure to biphobia, and resultant internalized biphobia, is also

relevant here largely as it is differentiated from homophobia and its internalization. Bisexual men are still subject to the effects of homophobia, but they face additional bisexual-related stigma, which includes dominant cultural constructs suggesting that bisexuality is transient (“just a phase”); that bisexual men are hypersexual (“anything that moves”); and that bisexuality, as practiced with female partners, is disrespectful and dangerous due to HIV risk (Friedman et al. 2016). In addition, gay and lesbian communities may further stigmatize bisexuals by not accepting that their sexual desires are honestly embodied. As we have seen in this literature review, as bisexual men try to attach to larger communities (whether their peers, their schools, or their families), they are much less successful than their gay peers (Saewyc et al. 2008, 2009), likely because of cultural notions that stigmatize bisexual people above and beyond gays and lesbians.

Another important distinction between bisexual and gay men in this model can be seen in bisexuals’ access to minority strengths and weaknesses. Our review has shown that, among the minority weaknesses addressed, bisexual men may be disproportionately affected: they show higher rates of social disconnection, identity non-disclosure (sexual silence), and abuse, while their socio-sexual partnerships with MSM confer the high background prevalence of HIV, STI, mental health problems, violence, and substance use. In addition to facing homophobia, they also face the pressures of being bisexual in a dichotomous, mono-sexual culture. At the same time, their access to minority strengths may be buffeted by a breezy disregard or, more severely, a lack of acceptance for bisexuals within gay communities coupled with the relative non-existence of bisexual communities to bond with. As bisexual men begin to have sex with male and female partners, they may dissociate even further during sex (especially with men), using situations that combine money, drugs, and sex to escape from the realities of their desires. Given these sociocultural conditions, it is not surprising to find that bisexual men show such profound syndemic health disparities in depression, substance use, violence, concurrent substance use and sex, and transactional sex engagement compared even to their gay male peers. The persistence of these psychosocial disparities, such as substance use and depression, over time appears also to have downstream effects over the life-course, such as weaker viral load suppression and faster HIV disease progression for those bisexual men who are HIV-positive.

How can we reduce these health inequities among bisexual men so that their lived experience is on even footing with their straight and gay peers? In order to develop targeted interventions that address the psychosocial, behavioral, and biomedical disparities among bisexually-behaving men, there is a clear need for further second-generation research into mediators and moderators and experiential contexts that are related to bisexual health disparities. Strength-based theories such as resilience (and such corollaries as positive deviance, asset-based youth development, and community mobilization) offer an intriguing framework for intervention design (Herrick et al. 2014). Centered on elevating health and promoting wellness by boosting social support, social capital, social acceptance, community attachment, civic engagement, and empowerment, resilience-based interventions may buffer the effects of endured stigma and discrimination: social support, for

instance, has been recently shown to buffer the relationship between syndemic and viral load suppression among MSM (Friedman et al. 2015).

We might start by considering ways to address background adversities: working to make our schools safe for young bisexuals by reducing violence and bullying. Social marginalization related to gays and lesbians continues to abate, but effects may not be trickling down commensurately to bisexuals. Social marketing campaigns, for example such programs as it “It Gets Better” and “Acceptance Journeys,” are positioned to help de-stigmatize bisexual men if an effort is made to reflect their unique experiences. The scientific literature has lately recommended network-level interventions to address HIV-related health risks among bisexual men. This is a sensible solution: community-level interventions are unlikely to work with this population, given the available evidence indicating a relatively feeble bisexual community and infrastructure in most U.S. cities. We can envision an intervention design approach that diffuses resiliencies through the social and sexual networks of bisexual men, perhaps focusing on helping these men reduce their levels of psychosocial health disparities (depression and substance use) most strongly associated with behaviors that facilitate risky sexual behavior in this population (transactional sex and concurrent substance use and sex). We respectfully suggest that interventions tailored to this population must contain components that empower men to celebrate bisexuality as a unique and valid sexuality and to increase self-acceptance, as well as promoting acceptance toward bisexuality among both gay and straight individuals and communities.

Much research needs to be conducted to fully understand the subtle differences both between bisexual men and other sexual minority groups and within groups of bisexual men. Qualitative research is necessary to contextualize our findings on higher viral loads, higher syndemic burden, higher levels of internalized homophobia, and lower levels of condomless receptive anal intercourse found among bisexual men compared to other MSM. Formative epidemiology cannot fully explain the pathways to these multiple and potentially synergistic conditions. Larger samples than have traditionally been achieved (perhaps through recruitment that sincerely targets behaviorally bisexual men) will offer researchers the power to conduct such subgroup analyses across biomedical, psychosocial, and behavioral domains that incorporate the unique adversities and disparities we have reported and pinpoint the most fruitful interstices for intervention delivery.

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Chapter 5

It's not just About Condoms and Sex: Using Syndemic Theory to Examine Social Risks of HIV Among Transgender Women

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5.1 Introduction

The term syndemic is used to describe the clustering of conditions or health disparities that occur within a particular group. Syndemics are mutually occurring, meaning that more than one epidemic is occurring at the same time, and are intertwining, meaning that one disease is related to the next. Syndemic theory is based on the premise that diseases occur as a result of complex interactions between an individual and their social environment (Singer et al. 2006). Interacting epidemics commonly occur within groups who are socially marginalized and suffer from health disparities.

In general, syndemics are fueled by social stigma and oppression, minority stress, lack of family support, poverty, and violence (Meyer 2003; Meyer and Dean 1998; Singer et al. 2006; Stall et al. 2003, 2008). More specific to causes of syndemics among transgender persons are stigma and discrimination, cultural marginalization, heteronormativity (the assumption and privileging of heterosexuality), and cisnormativity (the assumption and privileging of cis-, or non-transgender, gender experiences).

The application of syndemic theory to the study of HIV-related risk among transwomen is still in its infancy (Brennan et al. 2012), but is growing in popularity. This chapter discusses the various factors contributing to the HIV syndemic in transwomen. Throughout, case vignettes and quotes are used to contextualize the intersecting epidemics, illustrate their additive effect on HIV risks, and elucidate the

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inextricable links between various social and structural factors and HIV risk. Vignettes and quotes appearing in this chapter come from published studies that have examined the HIV epidemic among transwomen. Our goal is to illustrate intersecting epidemics and HIV risk factors affecting transgender women without pathologizing their non-conforming gender identities, and without assuming that diseases are the direct outcome of deviant or non-heteronormative behaviors.

The authors are from disciplines with unique understandings of the world—Dana from nursing and public health and Maura from sociology. We believe these interdisciplinary perspectives provide a more holistic portrait of this complex topic. We will begin with a brief overview on what is known about the transgender population. Then we will provide an overview of terminology commonly used to describe transwomen. Finally, we will review the existing literature and present a syndemic model that incorporates the multiple, intersecting factors driving the HIV epidemic among transwomen and that can be used as a framework for informing and tailoring interventions aimed at minimizing their HIV-related disparities.

5.2 The Transgender Population

The transgender population makes up an estimated 0.5–1 % (about 700,000) of the U.S. population (Gates 2011). Estimates vary, in part, because transgender persons often identify themselves by their internal sense of self (sometimes referred to as their psychological gender), rather than their assigned sex at birth, and because varying definitions of transgender are difficult to standardize for population-based surveys (Gates 2011; Lombardi 2001). Lack of conceptual clarity regarding transgenderism, the absence of direct survey questions about assigned sex at birth and preferred gender identity, and fear of discrimination associated with claiming a transgender identity are among the other major factors contributing to the variation in estimates (Gates 2011; Kenagy 2005; Lombardi and van Servellen 2000b).

5.3 Transgender Terminology

In its broadest sense, the term transgender is used to describe people whose gender identity, expression, or behavior, does not conform to the norms and expectations traditionally associated with their biological sex assigned at birth (Clements-Nolle et al. 2001; Gilbert 2000; Keatley and Bockting 2008; Lev 2006b; Lewis and Nin 2012; Lombardi 2001; Lombardi and van Servellen 2000b; Ogbuokiri and Davis 2010). The transgender category is not reflective of sexual or romantic practices or preferences and should not be confused with sexuality or romantic attraction (Clements-Nolle et al. 2001; Kenagy 2005; Lombardi and van Servellen 2000b; Nemoto et al. 2004b; Unger 2014). For example, sexual orientation among transwomen varies in that some may identify as lesbian, bisexual, heterosexual, simply

“sexual,” or in other diverse ways (Lombardi and van Servellen 2000b; Operario et al. 2008a; Wylie 2004). In short, all of the sexual diversity that applies to cisgender populations also applies to transgender populations. Making clear distinctions between gender, gender identity, sex, and sexual orientation is critical to comprehending the disconnect between the internal sense of self and the physical body experienced by transgender people, as well as the societal confusion that often arises in regards to trans-gender identities and sexual orientations (American Psychological Association [APA] 2012; Lombardi 2001).

Collectively, transgender people may also be referred to as gender variant or gender-nonconforming (Coleman et al. 2012; Lev 2006a). These classifications are not static, have diverse meanings and interpretations (Lewis and Nin 2012; Young and Meyer 2005), vary widely among racial and ethnic groups, cultures (Sevelius 2012), and among transgender people themselves. In addition, all people in the transgender community do not readily accept these classifications (Kenagy 2005; Lev 2004). The term “transgender” will be used throughout this chapter when referencing the population because it is considered broad enough to encompass the wide range of gender variant people or subgroups that fall within the larger classification of transgender (Lev 2006a; Stryker 2008). The term “transwoman” will be used when referring to an individual transgender woman. A brief description of each subgroup follows.

5.3.1 *Transgender Women (Transwomen)*

Transsexual (TS) women are individuals assigned male genders at birth, but who transition to or assume female/woman/feminine gender identities and expressions in order to be congruent with their subconscious sex. Generally transsexuals are most likely to desire sex reassignment surgery and other physical transitions (Coleman et al. 2012; Doorn et al. 1994; Lev 2004; Lewis and Nin 2012); however, not all transsexuals desire bodily changes. Many transsexuals may feel a great amount of discordance with their pre-transition bodies, and, as a result, experience a great amount of psychological and emotional distress because they cannot gain access to hormones or surgical interventions. This distress is often categorized as *Gender Dysphoria (GD)*, the discomfort with one's biological gender. GD, previously known as Gender Identity Disorder and Gender Incongruence in the DSM-V (Lewis and Nin 2012), is considered a pathological mental disorder among some helping and psychiatric professions (Coleman et al. 2012; Lev 2004).

It should be noted that these categories arise out of a Western medicalized philosophy that views gender as a dichotomous concept, male or female, and not transgender individuals themselves. In addition, the diagnostic categories used to describe transgender identities are informed by the biomedical framework, which operates through socially constructed ideas of a binary gender system and pathologizes those who are non-conforming (Spade 2006). With regards to categories and

labels, some transwomen may see their transsexualism as a medical problem that will be solved by accessing hormones and sex reassignment surgery. In a process known as going “stealth,” these women may stop identifying as transsexual, choosing instead to identify only as women after achieving the body they desire. However, other transsexual women, who have achieved the body they desire, may continue identifying as transgender as a political identity that recognizes how their gender history diverges from women who were assigned female at birth.

Cross-dressers, historically referred to as *transvestites* (Coleman et al. 2012) are individuals who are assigned male at birth, and primarily identify with the sole role of a man in everyday life. Cross-dressers dress in women’s clothing, shoes, make-up, and wig on a part-time basis, but usually identify as heterosexual (Doorn et al. 1994; Lev 2004, 2006a; Lewis and Nin 2012; Taylor and Rupp 2004; Wylie 2004). Cross-dressers often conceal their practice of wearing women’s clothing because of the stigma associated with the practice (Lewis and Nin 2012; Wylie 2004).

Drag queens are usually, but not always, gay men (Taylor and Rupp 2004), who “perform” drag or dress as caricatures of women (Gilbert 2000; Lewis and Nin 2012). Drag queens typically do not desire to have a woman’s body, however, some do undergo breast augmentation or acquire breasts through hormone therapy (Taylor and Rupp 2004). That is, typically drag queens display a feminine role as an artistic performance for an audience, but because of labor market’s discrimination against transwomen, some transwomen may perform as drag queens as a way of making a living. Even drag queens who identify as men, but perform as women, may be expressing a nuanced or dual gender identity (Rupp and Taylor 2003).

A final term to consider is *genderqueer*. Genderqueer refers to the deliberate mixing and matching of gender roles and gender-assumed clothing, in order to defy societal assumptions about gender (Lewis and Nin 2012). Genderqueer people may or may not refer to themselves as transgender or may consider themselves to be androgynous (Lewis and Nin 2012), but usually have no desire to undergo sex reassignment (Lev 2006a).

Here we have provided some terms to help illuminate the diversity among feminine-spectrum transgender individuals. However, it should be noted that it is impossible to distinctly categorize people into discreet and totalizing categories. As Cox (2015) has said:

A lot of people think that being trans is about surgery and bodies, and a lot of trans folks choose not to have surgery at all. Surgical costs are prohibitive and many trans people can’t afford it. Trans identity is about more than our bodies. It’s important to me that we dispel the misconception that we are not who we say we are because of our bodies.

The terminology specific to the transgender population is fluid, and can be unique to individuals. Therefore it is important that health professionals who work with transgender populations exercise sensitivity by asking the respective individual how they would prefer to be addressed (Singh et al. 2011).

5.4 HIV-Related Syndemics

Within the context of HIV, syndemic theory has historically and most commonly been applied to understanding intertwining social and health conditions that increase HIV risk among gay men. We felt it was important to acknowledge the previous contributions that these studies have made to the state of the science on syndemics and HIV among MSM and to illustrate the similarities between the HIV syndemic in MSM and transwomen. Most commonly noted syndemics are the substance abuse, violence, and AIDS (SAVA) syndemic (Singer 1996), the mental health and HIV/AIDS syndemic (Stall et al. 2003), and the psychological distress, substance abuse, and intimate partner violence among young, urban dwelling gay men (Mustanski et al. 2007). The co-occurring social conditions of stigma, social marginalization and discrimination have also been commonly reported among HIV-positive gay men, male adolescents and emerging adults (Bruce and Harper 2011).

Intersecting conditions are configured in ways that vary according to race, ethnicity, culture (González-Guarda et al. 2011), and in the case of the transgender population, gender. As a result, syndemic models should be tailored to each respective population. Unlike the biomedical framework, which excludes the social, psychological, and behavioral dimensions of illness (Engel 1977), syndemic models account for the social, behavioral, and structural causes of disease. Operario and colleagues (2014) described a syndemic of HIV-related health risks in transwomen that included unprotected receptive anal intercourse (URAI), alcohol intoxication, and drug use that worsened within the context of social stigma. Substance use also emerged as part of the HIV syndemic among young, transwomen in a study by Brennan and colleagues (2012). Brennan et al. (2012) observed a pattern of intersecting factors such as low self-esteem, polysubstance use, intimate partner violence, and transgender victimization that was further intensified by sex work and incarceration among transwomen in their study. Nemoto and colleagues (2005) described a syndemic of HIV, substance abuse, and mental health problems among transwomen. Lack of access to mental health and substance abuse treatment, transgender discrimination, unstable housing, and economic hardship have also been identified as factors contributing to syndemic impact in this population (Bowers et al. 2012).

Gonzalez-Guarda and colleagues (2011) presented a syndemic model of substance abuse, intimate partner violence, HIV (SAVA) infection, and mental health among Hispanics. Central to their model was SAVA and mental health as intertwining conditions and contributing factors to health disparities among Hispanics. Surrounding these core concepts were individual, cultural, relationship, and socio-environmental variables that function as interacting and linking factors, and that may serve as a risk or protective factor within the syndemic. Although the SAVA model and its risk and protective factors were configured from qualitative research conducted on Hispanics, it was used to organize the review of literature for this chapter and inform the factors that we included in our syndemic model for

transwomen. The relationships depicted at the core of our model and the risk and protective factors at each corner were modified to reflect the intertwining conditions that contribute to HIV-related disparities among transwomen.

5.4.1 Transgender Identity, Sex Work, Substance Abuse and Mental Health as Intersecting Factors

Two major factors that set transwomen apart from MSM in the HIV epidemic, and underscores the need to treat them as a separate population, is their need to resolve the disconnect between their sexual and gender identity, and their desires to achieve a feminine appearance and state of mind (Beyrer et al. 2012; Sevelius 2012). The most major and obvious distinction of transwomen from MSM is that in a social context, they are women. This resolution can manifest itself through high-risk sex acts, such as unprotected receptive anal intercourse, which validates and reinforces their feminine identity (Boles and Elifson 1994; Crosby and Pitts 2007; Edwards et al. 2007; Sevelius 2012). Engaging in unprotected receptive anal intercourse significantly increases HIV risk for anyone: MSM, transwomen, and heterosexual women. Transwomen, however, may be more susceptible to this practice because of the added stress associated and social oppression associated with being a gender minority (Burdge 2007).

Gender minority stress increases the psychological need for gender affirmation, the need to be loved by a male partner, and the willingness to engage in unsafe sexual practices in an effort to secure a sense of belonging and acceptance (Melendez and Pinto 2007; Sevelius 2012). Thus for transwomen, unsafe sexual practices may be used as a means for establishing social acceptance as a women, gaining emotional support and love from their male romantic partners, and attaining financial support (Boles and Elifson 1994; Crosby and Pitts 2007). The following quote from a 43-year-old, white transwoman illustrates the relationship between gender affirmation and certain sexual practices.

Having unprotected anal sex just proved to me that I was woman enough to do it. I proved to myself I was a real woman. It was just an ego boost to me (Reisner et al. 2009).

We should see these behaviors in social context whereby transwomen may participate in risky sexual behaviors because of their inferior social status. In other words, it is not an objective reality that a transgender woman would participate in these behaviors to “feel like a woman,” but that the culture devalues them as women, placing them in a position to “prove” themselves as women.

It is also true that sexual partners of transwomen may know that transwomen can be manipulated into unprotected sex because of self-esteem issues or financial need—both occurring because of transphobia and cisnormativity in the wider culture (Nemoto et al. 2004b). The following story illustrates the emotional complexities and HIV risk that occur within the context of romantic relationships for many transwomen.

We know how hard the life is so when you meet a guy it's like you go through all means to keep this man, because you really want to be with him, you know what I'm saying? So it's really hard. You just want to be loved, that's it. Being ridiculed so much, called this called that, being used...It's just like after a certain point in your life you just...you get needy, I guess...And a lot of people don't want to admit it, but a lot of people settle. A lot of us settle...I really think that it's so many of us that are getting this (HIV) because we want to be loved and you know...and a lot of times you meet somebody and you feel as though that this person's going to love you, so you...you risk a lot of things that...you know what I'm saying? To make this person happy, you know, you feel as though if you don't use it (condom) it's going to be closer, it's going to make him love you even more.

-A 22-year-old African American transwoman (Melendez and Pinto 2007).

Transwomen, especially those who are African American and/or Hispanic, who dress femininely full-time, and who disclose their transgender identity are at higher risk for HIV when compared to transwomen who continue dressing and performing in a male role in their daily lives (Nuttbrock et al. 2009). There are a couple of social factors attributing to this outcome. First, transwomen who dress and live their lives as women are more likely to be entrenched in social networks where HIV is prevalent and are more likely to encounter a sexual partner who is HIV-positive (Boles and Elifson 1994). Second, transwomen who dress full time as women tend to be more socially isolated, are more likely to be victimized, and are not able to secure and maintain employment that does not involve sex work (Boles and Elifson 1994; Nuttbrock et al. 2009).

5.4.2 Sex Work and HIV Risk

There are multiple social, individual, psychological, and relationship factors driving transwomen into survival sex work and increasing their risk for HIV. These include cultural discrimination in the labor market, transphobia, lack of family support, and the need for gender affirmation. Because of their unique gender identities, transwomen are less likely to occupy formal, paid labor positions that would allow them access to essential social services such as health insurance, stable housing, and transportation (Ryle 2011). On average, transwomen are more socioeconomically disadvantaged and earn one-third less than transgender men, and are subjected to job harassment, termination, and loss of authority (Clements-Nolle et al. 2001; Schilt and Wiswall 2008). As a result of these non-accommodating, misogynistic and heterosexist work environments, transwomen are often forced into commercial sex work for survival, face greater risk for physical exploitation, violence and incarceration, and suffer from adverse health outcomes such as illness, disability, and death (Clements-Nolle et al. 2001; Keatley and Bockting 2008; Nemoto et al. 2004a; Ryle 2011; Sausa et al. 2009; Sen et al. 2007).

HIV sero-positivity rates among transwomen commercial sex workers surpass those who do not exchange sex for survival needs (Reback et al. 2005). Compared to their non-transgender counterparts, transwomen aged 18–25 experience higher levels of discrimination and are more likely to engage in URAI (during sex work)

(Sugano et al. 2006). Most transwomen engaging in sex work are African American, under 30 years of age, and beginning their gender transition (Sausa et al. 2007). Sex work may function as a means to afford feminization surgeries and hormones (Nemoto et al. 2004b); and by young transwomen (Reback et al. 2005), as a means of establishing ties with other transwomen in the community, gaining social support (Sausa et al. 2007), and validating their gender identity (Nemoto et al. 2004b). For transwomen of color, who experience extreme marginalization because of the intersecting factors of transphobia and racism, sex work may be regarded as a kind of rite of passage (Nemoto et al. 2004b; Sevelius et al. 2009). A young, transwoman who began engaging in sex work at an early age, described how she learned about the trade through her social ties with other transwomen.

I started prostituting when I was about 14 years old, and when I first started off, I really didn't know too much about it. But I had other girls teach me and stuff. So they taught me the ropes (Sausa et al. 2007).

Another transwoman described a similar sex work trajectory that started when she was very young and was viewed as a standard way of survival in her social network.

I was 13 years old when I put my first dress on...the first thing that came to my mind was working the streets, cause the rest of the girls were out there working the streets, so I started working the streets (Sausa et al. 2007).

In other words, the limited opportunities for transwomen to be incorporated into aspects of social life—including fair labor market participation—has siloed them into a dangerous, exploited, and stigmatized line of work. Janet Mock, a transwoman of color activist, explains her own sex work history,

I perceived the sex trades as a rite of passage, something a trans girl had to do in order to make the money necessary to support herself. I had also learned (from media, our laws and pop culture) that sex work is shameful and degrading...So because I learned that sex work is shameful, and I correlated transwomanhood and sex work, I was taught that transwomanhood is shameful. This belief system served as the base of my understanding of self as a trans girl, and I couldn't separate it from my own body image issues, my sense of self, my internalized shame about being trans, brown, poor, young, woman (Mock 2015).

Transphobia seems to be uniquely problematic during childhood, a time of great psychological distress associated with discovering one's gender identity (self-discovery) and dealing with rejection from family and friends. Family support and acceptance may provide protection against transphobia; however, transgender youth often lack the support of their families (Garofalo et al. 2006). In many instances, these young women are kicked out of their homes and must resort to sex work for survival.

If the decision to take part in sex work feels like a coerced choice, a choice born from social isolation and financial hardship, it is also likely that public health prevention strategies, such as condom usage, may not be prioritized. Reports vary on consistency of condom use in this population. Yet studies have demonstrated

that condom use decreases during times of financial hardship, when transwomen earn more money for performing sex acts without protection, and with a steady partner (Crosby and Pitts 2007; Reback et al. 2005; Sausa et al. 2007; Nemoto et al. 2004b). One transwoman who earned her living through sex work shared,

I usually carry condoms on me, you know. It's just that when you're out there trying to turn tricks and you finally get a trick, if he's going to give you more money for not putting on a condom, it's almost as if you've got to do it (Reisner et al. 2009).

We want to be clear that sex work does not have a direct causal link with HIV. In fact, many HIV-positive transwomen report being infected by a primary, steady partner (Clements-Nolle et al. 2001; Nemoto et al. 2004a, b). Rather, the limited choices offered to marginalized women contribute to dangerous circumstances more common to the sex trade. An African American transgender woman who was incarcerated and who had worked in the sex trade for more than 20 years, said, "Look at me. That's the only line of business some of us can get. They aren't going to hire us at Target. Only real girls get hired at Target," (Sexton et al. 2010).

Furthermore, the stigma and criminalization associated with sex work only exacerbates the problem of riskier sexual exchanges. Janet Mock goes on to clarify her feelings about participating in sex work,

I do not believe using your body—often marginalized people's only asset, especially in poor, low-income, communities of color—to care after yourself is shameful. What I find shameful is a culture that exiles, stigmatizes and criminalizes those engaged in underground economies like sex work as a means to move past struggle to survival (Mock 2014).

Structural barriers such as lack of job training, educational training, and non-inclusive work environments potentiate transwomen's grave economic situation, further increases their dependency on sex work for survival, and magnifies their vulnerability to violence, physical assault, and rape (Sausa et al. 2007; Farley and Barkan 1998; Nemoto et al. 2004a). Prior history of incarceration, unstable housing, and minimal monthly income are other structural factors that reinforce their economic need to remain engaged in commercial sex work and other illegal activities (Clements-Nolle et al. 2001; Lombardi 2001; Meyer 2001; Nemoto et al. 2004a; Operario et al. 2008b).

5.4.3 Substance Abuse and HIV Risk

Substance abuse clusters within social networks and overlaps other high-risk behaviors, such as high-risk sex work, multiple sexual partners, and homelessness (Nemoto et al. 2004b). These behaviors often co-occur among transwomen, not because there is a direct relationship between transgender identities, drug use, and sex work, but because the psychosocial factors (e.g. gender minority stress, transphobia, depression, and discrimination) that more often link these conditions

together. Transwomen have higher rates of drug and alcohol abuse compared to their non-transgender counterparts; and those who use drugs are also more likely to engage in transactional sex work (CDC 2011, 2015a; Lombardi and van Servellen 2000a; Nemoto et al. 2004b). For example, transwomen engaging in transactional sex work may start using drugs in an attempt to cope with the psychological distress of being rejected by their families and surviving on the street (Garofalo et al. 2006; Reback et al. 2005; Sausa et al. 2007). One transwoman of color described how using drugs made it easier for her to have sex with customers. She said, “Eventually I didn’t like working [on] the streets, and I didn’t like to be touched in a sexual way, and it’s like the...uglier the trick was, the more dope I had to use,” (Nemoto et al. 2004b).

Research has also suggested that substance abuse among transwomen occurs in part because of the additive effects of disruptive and traumatic family relationships and transgender identity stigma and discrimination (Garofalo et al. 2006; Reback et al. 2005; Sausa et al. 2007). Disruptive or traumatic family relationships in and of themselves do not increase transwomen’s risk for HIV. Rather, the coping mechanisms (e.g. drug use) used to manage the emotional and psychological distress of being a gender minority, and the strategies employed to survive (e.g. transactional sex work), increase transgender women’s risk for HIV. One transwoman described how growing up in an abusive home pushed her to using drugs.

I grew up in a very, very, very abusive home...and it was like, it was like every day there was always a bunch of trauma going on, and once I turned 18 and I got out of the trauma, I still...had thoughts of all the stuff that transpired, and all the things I’d seen, and in order to get rid of that...I needed to get high in order to deal with it (Nemoto et al. 2004b).

Substance abuse is part of a viscous cycle of dependency and vulnerability for many transwomen. First, substance abuse increases HIV and other sexually transmitted infection risk by diminishing their ability to negotiate condom use during sex work (Sausa et al. 2007) and with casual sex partners. Second, it increases transwomen’s dependency on transactional sex to pay for drugs and other essentials of living; it also forces them to engage in sex acts that they normally would not entertain when sober (Reback et al. 2005; Sausa et al. 2007). One transwoman of color explained,

[If] a man comes up to me...and when the rent is due, or... You know it depends on your... your desperate level [whether you use a condom or not]. It’s just weird, how you know, people will pay extra. A male will pay you extra without the condom thing... (Nemoto et al. 2004b).

Finally, substance abuse increases their risk of being raped and victimized. One transwoman said, “No one’s going to kill a gay man if he finds a dick between his legs...But they will definitely put a knife through a tranny’s throat if they see breasts and dick,” (Nemoto et al. 2004b).

5.4.4 Mental Health and HIV Risk

Historically transgenderism was viewed as a mental illness requiring treatment through behavior modification (mainly punitive measures to discourage feminine behaviors) and psychotherapy (Bailey 2003). This history, coupled with the attitude of mental health professionals towards transgender identities as deviant, and the lack of formal and practical training and education on the mental health care of transgender patients (CDC 2011), has engendered among the trans population, a long-standing sense of skepticism and mistrust towards mental health professionals. In this way, the pathologizing and labeling of transgender identities as an “illness,” or as something that is perverse (Bailey 2003), contributes to the avoidance of mental help seeking, to the HIV syndemic, and to subpar care for their general health needs (Edwards et al. 2007; Lombardi 2001). As such, the effects of stigma and discrimination on multiply marginalized communities such as transwomen are physically and emotionally debilitating.

The impact of stigma and discrimination on transwomen's health extend well beyond those related to their HIV status. For instance, in an effort to avoid discrimination, transwomen are likely to conceal pertinent health information from health care and social service providers and to avoid situations and environments where they are not accepted (Burns et al. 2012; Mahajan et al. 2008; Poteat et al. 2013). This lack of disclosure limits their access to appropriate health screenings for HIV and related illnesses (Williams and Freeman 2007). Fear of harassment and discrimination also force transwomen to use emergency rooms for their urgent and primary health care needs, thereby decreasing their chances of receiving optimal mental health and HIV care (Lombardi 2001; Williams and Freeman 2007).

Given that transwomen are typically estranged from their families, often at a young age, they are often left to grapple with the social effects (social isolation, shaming, bullying, and discrimination) of their gender non-conformity alone. Because of this, and other intersecting factors already discussed, rates of depression, anxiety, low self-esteem, and psychological distress are disproportionately higher among transwomen when compared to the general population (Bockting et al. 1998; Burns et al. 2012; Garofalo et al. 2006; Grant et al. 2010; Hoffman 2014; Kelleher 2009a; Lombardi 2001; Mustanski et al. 2007; Rotondi et al. 2011; Williams and Freeman 2007).

Risk for intimate partner violence, victimization, sexual assault, and suicidal ideation are also higher among transwomen (Bailey 2003). In a study conducted by Clements-Nolle and colleagues (2001) on transgender people in San Francisco, experiences of depression and suicidal ideation were common. When compared to prevalence rates in U.S. household probability samples and a population-based sample, the suicide prevalence rates among transgender people were much higher (Clements-Nolle et al. 2001). A diagnosis of HIV can trigger the onset of depression and suicidal ideation, or worsen existing mental health conditions. Discrimination and victimization often co-occur with depression, substance abuse

and sexual violence (which increase the risk for HIV infection), and further diminishes mental health and increases the risk of attempted suicide (Clements-Nolle et al. 2006).

Potential Links: Risk and Protective Factors

5.5.1 *Individual Factors*

Far too often, the transgender population is depicted as a disparaging group of individuals plagued by mental illness, identity crises, HIV, discrimination, stigma, and social isolation. Less commonly, their resilience, courage, and strength in the face of chronic social adversity and rejection is represented (Singh et al. 2011). The biomedical paradigm undergirds many of the public health interventions that target HIV prevention and treatment and focuses on the “problems” of a specific population. In order to fully and more appropriately address the HIV prevention and treatment needs of the transgender population, their strengths and resiliencies must also be considered (Kwon 2013). Resilience as a protective factor among the transgender population is an emerging area of research (Hendricks and Testa 2012; Kwon 2013); further insight into the transwomen’s resiliencies can be used to inform the development of wellness models. In what follows, we highlight individual factors that can function as potential sources of resilience (or risk) in the HIV syndemic among transwomen.

Collective Self-Esteem (CSE) is a term used to describe the self-esteem or social identity that is generated from membership in a particular group. Because transwomen are likely to experience greater psychological distress and loss of significant relationships due to their non-conforming gender identities, those who feel more positively about being transgender experience less psychological distress (Sánchez and Vilain 2009; Singh et al. 2011). Psychological distress and lack of meaningful relationships are often associated with low levels of self-esteem, self-efficacy, and can lead to avoidant coping (Sánchez and Vilain 2009). These factors are consistent with previous studies that have found that high self-worth protects individuals in ambiguous situations associated with the threat of HIV (Anderson 1995).

Studies have shown that CSE may also moderate one’s attempt to protect or enhance their social identity when it is threatened (Arnold and Bailey 2009; Berger 2004; Crocker and Luhtanen 1990; Dean 2009). In their study on resilience strategies of transgender individuals, Singh and colleagues (2011) reported five common traits that were consistent with resiliency among their trans participants: (1) a self-generated definition of self, (2) embracing self-worth, (3) awareness of oppression, (4) connection with a supportive community, and (5) cultivating hope for the future. Trans individuals who established ownership over their gender identity and generated their own sense of self, were able to reject negative words used to describe their non-conformity. A participant in their study described this in the following,

Being trans or “other” means being in a state that is highly scrutinized and polarized. For me it’s just very complicated and because it comes up a lot, where people ask me what transgender means—and my definition changes depending on where I am and how I feel. I don’t fall into “M” or “F.” I don’t identify with social labels placed upon me from birth...I define myself, and that keeps me resilient (Singh et al. 2011).

Within other marginalized groups, the concept of self-generated definition of self has been presented as reevaluation or identity reconstruction. Reevaluation, or identity reconstruction is a process through which individuals from socially marginalized groups such as people living with HIV, HIV-positive African American women, barebackers (men who intentionally have condomless sex with other men), and transgender women in the Ballroom community, attempt to turn negative group attributes into positive ones (Arnold and Bailey 2009; Berger 2004; Dean 2009). This process has also been used to build social capital, and mobilize to develop resources in marginal communities (Berger 2004; Pinto et al. 2008).

Among trans individuals, self-worth is critical for establishing a positive self-image and group identity (Singh et al. 2011). Crocker and Luhtanen (1990) noted that individuals, who have a negative group identity, may attempt to restore their threatened identity by leaving the group, thereby decreasing their chances of being connected to a supportive community, and increasing their vulnerabilities to social oppression (supported by Singh et al. 2011). A transwoman explained it in the following way,

I tend to surround myself with people who are a little more like me in that they don’t judge people for who they are. I don’t let people get close to me who aren’t supportive and ‘get it’ [being trans-positive]. Having a community of people like me [transgender] has saved me after growing up in a world that denies I exist. I came to realize that I like consistency and structure in my relationships, and understanding, and that is who is in my community (Singh et al. 2011).

Insight into the development of CSE, identity reconstruction, and the inner workings of trans-positive communities, may assist public health practitioners and researchers in understanding the community structure, and socialization and behavioral patterns. Such knowledge may be useful in establishing relationships with communities of transwomen and engaging them in strategies to curtail the HIV syndemic (Berger 2004; Heckathorn 1997; Pinto et al. 2008).

5.5.2 Relationship Factors

Although we have detailed individual factors above, these factors are intimately tied to relationship factors and social influences. For example, problems with self-esteem or substance abuse can be linked to interactions with others in the social world, and the ways in which trans-negativity influences individual factors. In a more specific example of the connections between individual and relationship factors, Brennan and colleagues (2012) point out that while self-esteem is an individual factor, collective self-esteem, positive feelings about one’s social group,

is something to consider for marginalized people. In their study, negative collective self-esteem about the transgender community and negative feelings about transgender status in society were positively related to psychological distress. What is more, the fear of how being transgender could negatively impact their lives was the best predictor of extreme psychological distress.

Alongside considering a broader social relational context, more direct relational factors like intimate partnerships should be discussed as well. In general, women who experience violence may be more likely to take part in risky sexual behaviors (with their romantic/sexual partners). One transwoman described her relationship with her intimate partner in the following way,

Sometimes they make you do things when you love them that you would not normally do... There are times they want you to top them, and this is a very, very bad issue for a girl. But sometimes we love them, we will do sick shit like that just to prove [yourself], keep them, or do something you would not normally do (Nemoto et al. 2004b).

Cohen and colleagues (2000) have found that women who experience childhood sexual abuse experience a “continuum of risk,” where early abuse leads to later domestic violence, which increases risky behaviors associated with HIV. In regard to transwomen specifically, Brennan and colleagues (2012) found that polysubstance use and intimate partner violence were significantly and positively related to self-reported HIV infection and sexual risk behavior. In addition, transgender victimization and intimate partner violence were significantly and positively related to each other (Brennan et al. 2012). While Cohen and colleagues suggest that experiencing violence may lead women to risky behaviors, Heintz and Melendez (2006) ask us to remember that risky behaviors can happen in the violent partnership itself, through forced unprotected sex or indirectly through the abused partner’s inability to negotiate safer sex. Pondering the intersection of social discrimination and intimate partner violence may also matter. Brennan and colleagues (2012) found that participants who experienced transgender victimization (verbal threats and insults, damage to property, stalking, and physical violence) and intimate partner violence (controlling behavior, verbal abuse, threats to safety, sexual and/or physical violence) experienced an additive association with sexual risks and HIV infection.

While anyone can experience intimate partner violence (IPV), and while the experience of IPV may increase the likelihood of HIV, there are unique factors for transwomen. As far as the experience itself, Heintz and Melendez (2006) point out that LGBT individuals in abusive relationships experience decreased perception of control over sex, fear of violence, and unequal power distributions within the relationship, but in addition, they also experience this abuse within a context of homophobia and/or transphobia, compounding the effects of abuse. Crenshaw (1991) famously argued that marginalized women are more likely to be abused by their partners because their partners know they lack institutional legal recourse and, often, economic resources to effectively hold them accountable or to leave the relationship. In addition, the pervasive cultural ideology that transwomen are

inadequate partners, particularly for heterosexual men, may be internalized by the transwoman and their partners, which could exacerbate violence in the relationship.

We do not mean to suggest that transgender people do not and cannot have positive and affirming relationships. In fact, the idea that transgender people cannot have fulfilling intimate relationships is part of the narrative that needs to be rewritten. Trans people are capable of having healthy, fulfilling relationships that become the foundation of their resilience and connectedness. As Tiq Milan says in the NBC News video documentary, *Trans Love in the Black Community: Living Color*,

[It's a common idea] that trans people aren't going to be loved or are going to receive love, and that our lives are just full of detachment and lots of isolation. And that is true. There is a lot of isolation among the transgender community. There are a lot of trans folks who are not receiving any love from their families and it's hard for them to create partnerships. So when this [finding love] does happen it is a revolutionary act. It's countering this dominant narrative that there is a pathology with transgender people. It's showing that we are happy and healthy and deserving of love.

Part of countering the dominant narrative that trans lives are pathologic is restructuring our definitions of what "normal" looks like within the context of relationships and family and using those relationships to build and sustain resilience. As Kim Katrin Milan, Tiq Milan's wife, says,

I don't really have a connection to my biological family. A lot of queer people can lose access to our family because of bigotry, because of all sorts of different kinds of violence. So I think it can feel really hard when you're making a family new and people have all these specific ideas of what a family is supposed to look like. So what is always important to me is wanting to communicate to people that you can start over. And I think that it is in falling in love with yourself and learning to value and respect the person that you are, you can also start to find people who are on a similar journey and start to create a family that actually honors you for the person you are (NBC News 2015).

5.5.3 Community Factors

Lesbian, gay, bisexual and feminist communities have strategically disassociated themselves from transgender people, particularly transwomen (Spade 2011). Mainstream gay politics stands to politically benefit from this disassociation by disconnecting sexual orientation and gender non-conformity. Discussing how transwomen initiated the modern fight for gay rights and then watched as transgender protections have been written out of gay civil rights platforms, Rivera says,

...if it wasn't for us, they would not be where they're at today. They wouldn't have anything, none of them, from one corner of the world to the other. Because it was our community, the street kids, the street queens of that era, who fought for what they have today. And they still turn around and give us their backs (Bassichis 2007).

Feminists too have a long history of excluding transwomen from their platforms. Serano (2007) argues that this is due to cis feminist essentialist logic—the refusal to accept transwomen as women. It is also related to mainstream feminist disassociation from the most marginalized women. Not unlike mainstream gay politics, feminists in positions of power—those who are cis, heterosexual, white, and class privileged—have a vested interest in political campaigns that will increase their power, and a vested interest against challenging the institutional privileges that benefit them. This political isolation may certainly be a negative factor in risky behavior and HIV contraction.

Speaking back to the opening idea in this section, if negative collective self-esteem impacts psychological stress, which can lead to risky behaviors, conceivably, then, having positive feelings about belonging to the transgender community may be helpful in detouring risky practices. Consider Sylvia Rivera's friendship with Marsha P. Johnson during the Stonewall era. They built S.T.A.R (Street Transvestite/Transgender Action Revolutionaries), a political organization that sought to help homeless transgender sex workers through projects like the Transy House Collective, a transitional house for young transwomen (Bassichis 2007). More recently, Janet Mock's memoir tells a beautiful story of how street-based trans sex workers looked out for one another, protected each other from dangerous "johns," and taught each other how to safely negotiate the use of condoms (Mock 2014). As marginalized people, transwomen have built chosen family networks with one another that can be hugely effective. Although transgender victimization in society cannot be overstated, we also want to highlight the moments of resistance that are possible in this social context.

5.5.4 *Cultural Factors*

Gonzalez and colleagues suggest that cultural factors play a critical role in the intersecting factors that create syndemics (González-Guarda et al. 2011). In their model, cultural factors were defined as acculturation, Hispanic stress, traditional gender norms, and religion. For our model, gender minority stress, traditional gender norms, and religion were selected as the corresponding cultural factors. For this portion of the model, we focus on factors such as the social construction of gender and sexuality, transmisogyny, and religion as factors that influence the HIV syndemic among transwomen.

Social Construction of Gender and Sexuality. In Western cultures, the lay public associates transgenderism with homosexuality and social deviance (Bockting et al. 1998; Grossman and D'Augelli 2006; Lev 2006b; Lewis and Nin 2012). This is due, in part, to the socially constructed gender binary categories of male and female (also referred to a biological sex), the conflation of gender with sexuality, and the dichotomous social expectations regarding gender roles (Gilbert 2000; Grossman and D'Augelli 2006; Hwahng and Nuttbrock 2007; Lev 2006a). The social construction of sexuality refers to how the society in which we live and culture of

which we are a part, shape our emotions, desires, sexual relationships, and sexual identities (Baumeister 2001).

Interpersonal relationships and social interactions within our social networks play an integral role in how we define our sexuality, express our sexual behaviors, and dictate with whom and how we engage in sexual encounters (Baumeister 2001; Simon and Gagnon 2003). In addition, social norms, power relations, and geographical location of one's social network determine how we define and normalize sexual meanings (Brickell 2009). It is through the social network that an individual learns the social and sexual expectations of their ascribed gender role (Simon and Gagnon 1986) and comes to accept (often without interrogation) the definitions of normal sexual behaviors and expressions established by social institutions of power such as religion, medicine, and the state (Baumeister 2001; Brickell 2009; Diamond 2003; Simon and Gagnon 2003).

Transmisogyny. In addition to the culturally pervasive issue of transphobia and transgender discrimination—experienced by both transgender men and women—transwomen experience a uniquely gendered form of transphobia, referred to as transmisogyny (Serano 2007). The intersection of cultural disapproval of gender non-conformity and cultural disrespect for femininity places transwomen in an especially vulnerable position. To maintain patriarchal control, sexism has two intertwining facets—*OPPOSITIONAL sexism*, the belief that male and female are rigid, mutually exclusive categories and *traditional sexism*, the belief that maleness and masculinity are superior to femaleness and femininity. Oppositional sexism affects all transgender individuals, but transwomen also experience traditional sexism. That is, while transwomen experience some parallels of transgender discrimination with transgender men, unlike these men they also experience persecution for resigning from a position of male privilege and joining the category of women, already marked as an inferior group. This is why the majority of jokes in media at the expense of trans people center on “men wearing dresses” or “men who want their penises cut off” and this is why the majority of violence against trans people is experienced by transwomen. In short, becoming a man in patriarchal culture makes some amount of sense to most cis people, but the decision to become a woman will be seen as a reviled choice. Even before economic or violent consequences, transmisogyny is why it's permissible for women to wear ‘men’s’ clothing, but men who wear ‘women’s’ clothing will be diagnosed with “transvestic fetishism” (Serano 2007).

Religion. For some transwomen, belonging to a religious community is associated with decreased sexual risk behavior, which may function as a protective factor against HIV (Bockting et al. 1998; Dowshen et al. 2011). Religious behaviors and beliefs are also thought to function as buffers against life stressors and have been associated with higher levels of self-esteem and lower levels of depression as well as HIV risk (Bockting et al. 1998). In a study conducted by Dowshen and colleagues (2011), formal religious practices such as attending church service, and reading and studying scripture, may deter sexual risk behaviors among young, transwomen. In this same study, social support, connectedness, and forgiveness, emerged as potential mediators that explained the relationship between religion and

positive health behaviors (Dowshen et al. 2011). While research on the role of religiosity in decreasing HIV risk among transwomen is still in its early stage, the study by Dowshen and colleagues (2011) suggests that it should be explored as an innovative approach to HIV prevention in this population.

5.5.5 *Socio-environmental Factors*

In Gonzalez-Guarda and colleagues model (2011), social-environmental factors were defined as: access to culturally sensitive services, discrimination, laws regarding legal status, poverty, and structural unemployment and underemployment. In what follows, we summarize evidence that illustrates the most fundamental socio-environmental issues that affect all women in a male dominant culture, but for transwomen have consequences that are more dire because of their gender non-conforming status. Inequalities in accessing work, in equal pay, and in symbolic power and representation in the culture negatively affect the life chances of all women. However, at each turn we suggest that these overall structural inequalities are especially challenging for transwomen because of the structural barriers associated with their transgender status (Spade 2011).

Heterosexist Gender Classification and Gender Denial. Factors such as age, race/ethnicity, gender, employment status and socioeconomic status form the basis for the identification and labeling of human differences, negative stereotyping, and categorization. Collectively, these factors result in a process known as internal stigmatization, which occurs when members of a non-conforming group assume a spoiled identity, and leads to health disparities (Clements-Nolle et al. 2001; Edwards et al. 2007; Goffman 1963; Kenagy 2002; Lombardi 2001; Sayles et al. 2009). The effects of socially constructed classifications create barriers to accessing care and results in further erasure of transwomen across individual, interpersonal/relational, and institutional levels.

Educational and Employment Factors. Completing financial priorities, low educational attainment, and unemployment have been cited as barriers to health care access among transgender individuals (Turmen 2003). Few studies, however, have explored the social factors contributing to the existing and growing financial, health and educational disparities among transwomen (Grant et al. 2010; Lombardi 2001; Pinto et al. 2008; Schilt and Wiswall 2008). Of those studies that have made these factors explicit, institutional policies and administrative practices are regarded as structural barriers that prevent transwomen from obtaining the legal, mandatory documents necessary for securing substantial employment and validating their membership in society (Namaste 2000). As a result, the unemployment rate among the transgender population is twice that of the general population (Grant et al. 2010). For transwomen who are able to successfully secure the legal documents that would provide them entry into the workforce, they still encounter problems with social integration, described in the literature as the legal sex and social gender gap (Namaste 2000). This gap restricts transwomen's employment and educational

opportunities and contributes to the gender wage gap. These conditions create an additive affect that leads to ongoing psychological stress, anxiety, and poverty; all of which increase their vulnerability to exploitation (Namaste 2000).

Incarceration. Approximately 17 % of individuals living with HIV/AIDS pass through the correctional system each year (Edney 2004). Transgender communities face disproportionate rates of incarceration compared to their cis-gendered counterparts (Sexton et al. 2010). Due to various social and structural circumstances, transgender people are more likely to be working in an illegal economy, to be homeless, to be victims of violent crimes, and to experience more interaction with police simply for being transgender (Bassichis 2007). For example, police officers often harass transwomen for being visibly transgender and in public (Bassichis 2007). One study found that 54 % of transgender people have had a negative interaction with police, 46 % of transgender people do not feel comfortable seeking police help, and 22 % of those who have interacted with police reported harassment due to anti-trans bias. In addition, 6 % of transgender people who have reported interactions with police report also being physically assaulted by police officers. Among African American transwomen, 15 % were physically assaulted by police and overall, 2 % of transwomen (7 % of African American transwomen) were sexually assaulted by police (Forge-Forward n.d.).

Overall, almost 1 in 6 transgender people (16 %) have been incarcerated at some point in their lives. If we just look at rates among transwomen that number becomes more than 1 in 5, or 21 %. At the intersection of transgender discrimination and racism, almost half (47 %) of African American transwomen have been incarcerated (Forge-Forward n.d.). These numbers are staggering rates due to disproportionate poverty caused by discrimination, the participation in street economies, disproportionate homelessness caused by a lack of familial and social support, and law enforcement bias (Grant et al. 2010).

A transgender advocate described the patterns and pathways of incarceration among the transgender population,

In my experience working with the trans community, I have seen many transgender people become entangled in the criminal justice system through activities they engage into raise money for and access safe, adequate, and nondiscriminatory medical treatment related to their transition. It is easy to see the direct connection between discrimination in trans healthcare and the over-incarceration of transgender people (Bassichis 2007).

Within correctional facilities, transwomen are susceptible to violent acts such as rape and other acts of sexual violence, intimidation, and discrimination (Edney 2004; Sexton et al. 2010). An African American male, who lived for decades as a transgender woman in prison, but later stopped identifying as transgender, described his early experiences with being incarcerated (Sexton et al. 2010),

Transgenders have a very big problem in the prison system. When I came in, they were automatically ostracized. They were not treated well by anyone — not the inmates, not the guards, not the people who were supposed to help them....I'm a people person. I like everybody, but everybody does not like me [as a transgender person] (Bassichis 2007).

Transwomen also receive inadequate or inconsistent hormonal therapy and HIV care during their period of incarceration; and are often lost to care upon release (Edney 2004). When asked to describe what she wanted others to know about her experiences in prison, a middle-aged, White, HIV-positive transgender inmate with a history of drug abuse, said,

I would like staff in here to be more familiar and not be prejudice towards us. I'd like to see some sensitivity training. I wish they knew that being transgender is hard. Going from prison to the community is hard. We need drug treatment that is HIV- and transgender-friendly (Sexton et al. 2010).

Explaining the institutional nature of the problem, The National Center for Transgender Equality (NCTE) said, "These abuses occur within the context of a broken, overcrowded, and increasingly privatized prison system. Addressing both the causes of over-incarceration and the intolerable conditions of prisons, jails, and detention facilities are urgent issues for trans people and our communities," (Grant et al. 2010).

Non-Inclusive Data Collection. Prior to release of the Institute of Medicine's 2011 report, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, sexual orientation and transgender identity data were excluded (or inaccurately categorized) from HIV surveillance reports and most federal, state, and local data health-related surveys (Sanchez and Vilain 2009; Dowshen et al. 2011; Bockting et al. 1998; Sayles et al. 2009; Allen 2007). For example, transwomen were historically categorized as MSM in HIV surveillance data, even though they do not identify as being men (Clements-Noelle et al. 2001; Bockting et al. 1998; Allen 2007). As a result, HIV prevention and treatment needs specific to the transgender population have been neglected, and funding to support transgender-specific research has been scarce (Gates 2011; Bockting et al. 1998; Burns et al. 2012).

Accurate data collection is essential for dissemination of reliable and factual public information, and is critical for the development of meaningful education and prevention programs as well as HIV care services (Sayles et al. 2009; Burns et al. 2012). The lack of inclusive and comprehensive data on the transgender population has potentiated health disparities among transwomen, contributed to their erasure (disappearance from public view); and, created further marginalization, self-denial, shame and internal stigmatization (Crenshaw 1991; Kelleher 2009). Since the release of the 2011 IOM report, funding for transgender health research has flourished and transgender health has become a leading health priority (Williams and Freeman 2007; Grant et al. 2010; Burns et al. 2012; Kelleher 2009; Mahajan et al. 2008). Major cities and the District of Columbia have responded by modifying health surveys to include questions that will capture transgender identity data (Poteat et al. 2013; DiClemente et al. 2009). Additionally, national agencies have intensified their efforts to improve the quality of HIV data collected on transgender communities (Williams and Freeman 2007). For example, the CDC now uses a two-step data collection method that includes asking sex assigned at birth and current gender identity (CDC 2015a). While this modification will improve our data

Table 5.1 Evidence-based interventions that included transgender women

Evidence-based intervention	Target population	Description	Percentage of original sample reported as Transgender
Retention through enhanced personal contacts*	HIV clinic patients who missed visits or were new clinic patients	<p>The group-level intervention uses trained interventionist to facilitated retention in care through personal relationship building and consistent interpersonal contact. Face-to-face meetings during HIV care visits and phone calls in between visits are used to maintain contact. Reminder calls are provided for appointments and missed visits. Patients receive assistance with personal organization and problem solving skills, and identifying personal strengths to achieve goals</p> <p>Intervention guided by the Information-Motivation Behavioral (IMB) Skills Model</p>	<p>N = 1,838 1 % (n = 15) were transgender, not specified as men or women (Gardner et al. 2014)</p>
Healthy relationships*	People living with HIV	<p>Small-group skills based intervention that focuses on reducing HIV risk through self-efficacy and positive expectations about new behaviors. Sessions include skills on enhanced decision making, disclosing HIV status to sexual partners, maintaining safer sexual practices, and developing a personalized plan for risk reduction practices</p> <p>Interventions based on Social Cognitive Theory</p>	<p>N = 328 1 % (n = 4) were transgender, not specified as men or women (Kalichman et al. 2001)</p>

(continued)

Table 5.1 (continued)

Evidence-based intervention	Target population	Description	Percentage of original sample reported as Transgender
In the mix- <i>best practice</i> *	HIV-Positive Persons	A seven-session individual or group-level intervention that focuses on reducing HIV risk behaviors and improving medication adherence Interventions based on the Conflict Theory of Decision Making	N = 436 7 % (n = 30) were transgender men (Kalichman et al. 2011)
Drug users intervention trial (DUIT)**	Young HIV-negative and hepatitis C virus (HCV)-negative injection drug users (IDUs)	Drug Users Intervention Trial (DUIT) is a small group, cognitive behavioral, peer education intervention designed that focuses on reducing injection and sexual risk behaviors for HIV and HCV infection in young injection drug users Interventions based on the following theories or models: Information, Motivation, and Behavioral (IMB) skills model, Peer education framework, and Social Learning Theory (SLT)	N = 854 1 % (n = 6) were male to female transgender (Garfein et al. 2007)

*Best practice interventions are HIV behavioral interventions that have been rigorously evaluated and have been shown to have significant and positive evidence of efficacy

**Good evidence interventions are HIV behavioral interventions that have been sufficiently evaluated and have been shown to have significant and positive evidence of efficacy

quality, greater efforts to develop prevention strategies specific to transwomen are warranted.

Lack of Transgender-Specific HIV Prevention Strategies. Transgender communities, particularly transwomen, are among the groups at highest risk for HIV infection, are less likely to be on antiretroviral therapy, and are less likely to be engaged in HIV care, yet there are no evidence-based or evidence-informed strategies that target HIV risk reduction, entry and retention in care, and medication adherence in this population (CDC 2015b). A review of the CDC's Compendium of Evidence-Based Practices for HIV Prevention revealed that of the 127 evidence-based or informed interventions, only four (4) of the studies that informed these interventions included transgender persons (Table 5.1). Not only are transwomen notably absent from the studies that inform HIV prevention strategies, but the existing evidence-based prevention strategies do not target the individual,

Table 5.2 Recommendations for Research and Policy*General recommendations*

- When possible, interventions should be delivered by transwomen in settings that are trans-friendly
- Recruitment for intervention studies should be expanded to include settings such as pre-release programs in jails or prisons, homeless shelters, substance abuse treatment, and detention (criminal justice) centers
- Gender affirmation, syndemic, feminist, and queer theories, and the minority stress model should be used to inform interventions for HIV prevention, linkage, and retention in care
- Interventions that target individual, relationship, and cultural risk factors should include a component that focuses on gender affirmation through social interactions (Sevelius 2012)

Recommendations for interventions that target sex work and HIV

- Life skills coaching that focus on building self-efficacy and self-esteem* (Operario and Nemoto 2010)
- Job training programs that facilitate entry into non-sex trade labor markets*
Since sex work and substance abuse often occur concomitantly, offer comprehensive programs that provide assistance with transitioning away from sex work and recovering from substance abuse/addictions
- Adopt workplace policies that support diversity and inclusion and equal employment opportunities for transwomen*
- Transphobia and discrimination causes chronic psychological distress and trauma and increases transwomen's risk for entering the sex trade. Media campaigns that educate and promote and awareness about the social, health, economic, and relational needs of the transgender population can help minimize these stressors
- Because some women resort to sex work in order to pay for feminization hormones and surgery, adopting standards that will require insurance companies to cover hormone therapy and feminization procedure will minimize these structural risk factors
- Many transwomen experience homelessness at a young age because they are rejected by their families. In order to survive, many enter the sex trade market. Therefore, interventions that target the families of young transgender women are warranted
- Structural interventions such as condom distribution programs are considered part of the CDC's high-impact prevention approach (CDC 2015a). For transwomen, however, the accessibility, availability, and acceptability of condom use in their social networks may not be enough to motivate condom use, especially in dire financial situations. Therefore, condom distribution programs should be paired with programs that can support life and job skills training
- Explore the efficacy as rectal microbicides to prevention transmission during casual and transactional sex encounters
- Stop the criminalization and incarceration of sex workers*

*Also applies to recommendations for socio-economic interventions and policy changes

Recommendations for interventions that target substance abuse and HIV

- Provide substance abuse counseling and referral services in conjunction with social supportive services such as housing assistance and mental health services
- Eliminate barriers to substance abuse counseling by bundling or packing with complementary services such as housing and food assistance, mental health services, and HIV medical care
- Residential substance abuse treatment programs that are inclusive, trans-friendly, and gender affirming

(continued)

Table 5.2 (continued)

Recommendations for interventions that target mental health and HIV

- Focus on strategies that build self-esteem, that promote empowerment, and that support life-skills training (Operario and Nemoto 2010)
- Offering transgender-specific support group (Sánchez and Vilain 2009)
- Provide assistance with mental health counseling and referrals to trans-friendly and trans-competent mental health professionals (Sánchez and Vilain 2009)
- Enlist the use of transgender peer models to support utilization of mental health services and care

Recommendations for addressing individual factors

- Young transgender women are especially at risk for homelessness, substance abuse, sex work, and HIV. Therefore, programs that target the developmental and social needs of young transwomen and that promote their self-acceptance, self-esteem, and self-efficacy are greatly needed (Operario and Nemoto 2010; Singh et al. 2011)
- Gender affirmation is an interactive process through which an individual receives social recognition and support for their gender identity and expression, using gender affirmation (e.g. correct name and pronouns) can facilitate positive self and group identities, bolster self-esteem, and increase resiliency (Sevelius 2012)

Recommendations for addressing relationship factors

- Transwomen often benefit from the collective/cumulative knowledge of “girls” in similar situations, therefore, targeting the social networks of transwomen may be more effective in addressing relationship factors that increase HIV risk (Bailey 2003)
- Trans people may have non-traditional families (e.g. chosen kin/families, or fictive kin), therefore including supportive members of these family structures in efforts to reduce HIV risk may be beneficial

Recommendations that address cultural factors

- To address HIV-related stigma and raise awareness about, the CDC has released campaigns such as, *Act against AIDS* and *Let's Stop HIV Together*. Similar media campaigns are needed to raise awareness and understanding about transgender people and to promote acceptance and inclusion (Singh et al. 2011)
- There is a small, but growing body of evidence that suggests religiosity as a protective factor against HIV, more studies are needed to describe how religion and formal religious practices (attending church) reduce HIV risk. Engaging inclusive faith-based entities may be instrumental in these efforts

Recommendations that address socio-economic factors

- Adopt federal laws to protect the employment rights of transgender individuals (Singh et al. 2011)
 - Include questions that directly assess assigned sex at birth and preferred gender identity on major health and population surveys (e.g. U.S. Census) to improve the quality of data available on the transgender population
 - Remove structural barriers (e.g. medical documentation and evidence of sexual reassignment surgery) to changing gender markers on legal documents
 - Develop and implement interventions that are informed by evidence that is specific to the transgender population, which also means conducting larger, randomized controlled trials to identify and inform effective prevention strategies for transgender people
-

relationship, cultural, socioeconomic, psychosocial, and structural factors that increase transwomen's risk for HIV.

Summary

Our syndemic model advances an understanding of the unique factors that increase this population of women's risk for HIV, and can help advance our efforts to prevent HIV, support entry into HIV care, and create greater health parity. However, interventions targeting the substance abuse, mental health sex work, and HIV syndemic affecting transwomen are desperately needed. Behavioral interventions that have been developed for use in other high-risk groups with similar risk behaviors have been adapted for use with transwomen, however their efficacy in reducing HIV in this population is unknown (CDC 2015a). We do not believe that merely adapting existing prevention programs by simply adding new language will address the complex social and behavioral risk factors that increase their risks for HIV (Sevelius 2012; Sevelius et al. 2009). Therefore, we conclude this chapter by offering recommendations on factors that should be considered when developing interventions and policies that target the intersecting factors of the HIV syndemic among transwomen (Table 5.2 and Fig. 5.1).

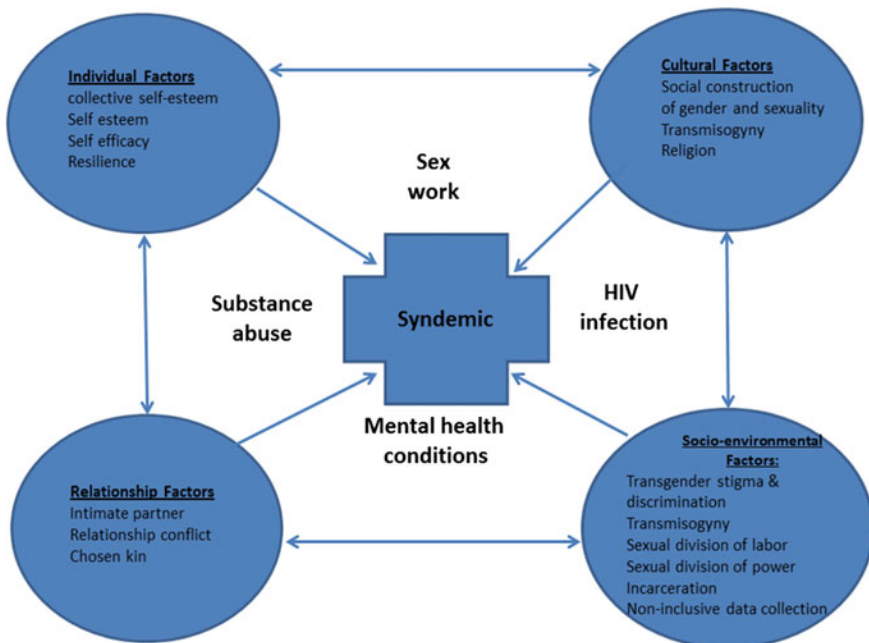


Fig. 5.1 A syndemic model of sex work, substance abuse, mental health, and HIV infection in transwomen

The configuration of this model illustrates the intersecting factors unique to, and that are driving the HIV syndemic among transwomen. Central, or core relationships, and the risk as well as protective factors included in this model were informed by empirical evidence. Although this model expands our understanding of the intersecting factors that attribute to health disparities among transwomen, it must be interpreted with limitations. First, the model was informed primarily by qualitative studies that were conducted on relatively small groups of transwomen. Second, because the model was informed primarily by qualitative studies, it makes no assumptions about the direction of the relationship between the core factors, or the risk and protective factors. Further research to determine causality between the factors in the model is warranted.

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Chapter 6

The Social, Structural, and Clinical Context of HIV Prevention and Care for Black/African American and Hispanic Women/Latinas in the United States

Tiffany M. Aholou, Ashley Murray and Madeline Y. Sutton

6.1 Epidemiology of HIV Among Women

In 1981, when the Centers for Disease Control and Prevention (CDC) published the first Morbidity and Mortality Weekly Report (MMWR) on cases of pneumocystis pneumonia and Kaposi sarcoma (Gottlieb et al. 1981), as part of what has now become known as acquired immune deficiency syndrome (AIDS); heterosexual women were not highlighted as a risk group (Koop 1987). In 1987, AIDS became the eighth leading cause of death among women of childbearing age (15–44 years) (Ellerbrock et al. 1991), and several reports began to describe the disproportionate spread of HIV among black/African American (black) and Hispanic women/Latinas (Chu et al. 1990; Karon et al. 2001; Wortley and Fleming 1997). By 1993, research efforts also began to increasingly engage women (Hader et al. 2001). As we learned more about human immunodeficiency virus (HIV), and the degree to which HIV affected women, the 1987 case definition of AIDS was expanded in 1993 to include an AIDS-defining illness specific to women (cervical cancer) (CDC 1987; Wyatt et al. 2013). Since the 1990s, black/African American and Hispanic women/Latinas have been, and continue to be, disproportionately affected at all stages of HIV infection compared with women of other races/ethnicities, as described further below.

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6.2 Women and HIV Infection

Although female adults and adolescents (aged ≥ 13 years) accounted for 7 % of reported persons living with AIDS in 1985, new diagnoses among women have steadily increased since that time. In 2011, women accounted for 21 %, or 10,257 of the estimated 49,273 newly reported diagnoses of HIV infection in the United States (CDC 2013b); the racial/ethnic distribution is shown in Table 6.1. For the same period of time, women also accounted for 25 % of the estimated 891,857 people living with HIV (CDC 2013b). Figure 6.1 shows the rates of diagnoses HIV

Table 6.1 Diagnoses of HIV infections among adult and adolescent females, by race/ethnicity 2011—United States

Race/Ethnicity	Number	Rate per 100,000 women
American Indian/Alaska Native	51	5.5
Asian	153	2.3
Black/African American	6,595	40.0
Hispanic/Latino	1,530	7.9
Native Hawaiian/Other Pacific Islander	8	3.9
White	1,776	2.0
Multiple Races	144	7.5
TOTAL	10,257	7.7

Source CDC (2013b)

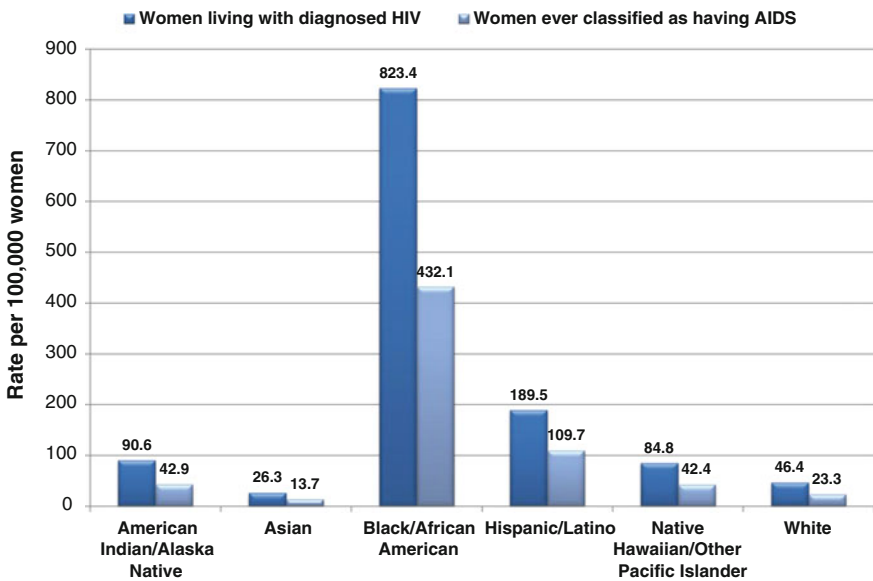


Fig. 6.1 Women living with HIV (prevalence) and women living with HIV ever Classified as having AIDS, by Race/Ethnicity, Year-end 2010—United States (Source CDC 2013b)

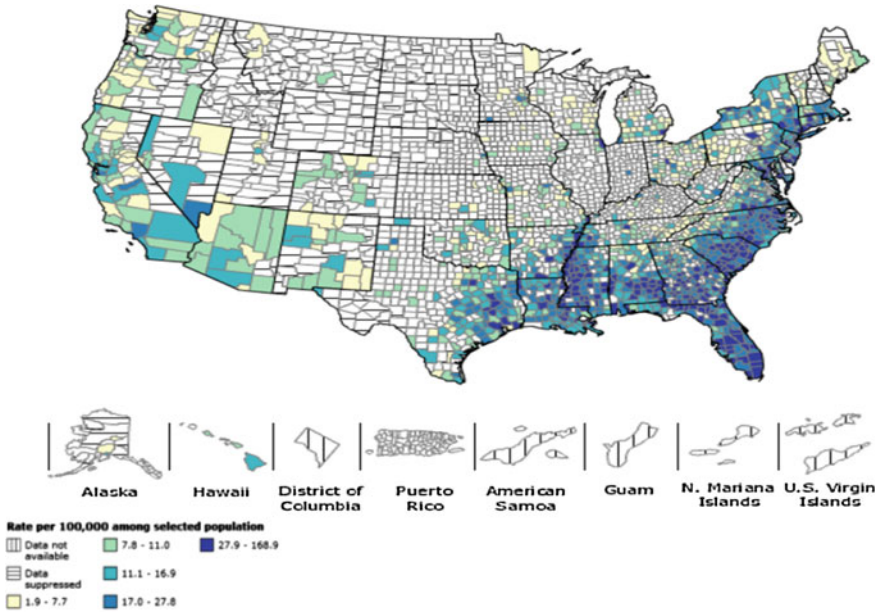


Fig. 6.2 Female adults and adolescents living with diagnosed HIV, by county, United States and Territories, 2010 (Source Centers for Disease Control and Prevention [CDC]. NCHHSTP Atlas. <http://gis.cdc.gov/GRASP/NCHHSTPAtlas/main.html>)

and AIDS among women, by race and ethnicity (2010 data), and also highlights the alarming racial/ethnic disparities in these rates. Also, women are affected by HIV across their reproductive life span, including high school youth, as highlighted in recent HIV surveillance report (CDC 2013b). In 2013, 47 % of all females in the United States, in grades 9–12, reported ever having had sexual intercourse (Kann et al. 2014). By race/ethnicity, black female youth and Hispanic women/Latina youth reported higher rates of sexual intercourse and suboptimal condom use compared with their white female peers (Kann et al. 2014); these factors contribute to the context of HIV exposure risks for young women of color.

When geography is considered, rates of HIV infection among women are the highest in the South and Northeast regions¹ of the United States (Prejean et al. 2013) (Fig. 6.2). In 2010, the South had a higher percentage of the estimated

¹There are four U.S. regions: Northeast (Connecticut, Maine, New Hampshire, New Jersey, New York, Pennsylvania, and Rhode Island); Midwest (Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin); South (Alabama, Arkansas, Delaware, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia); and West (Alaska, Arizona, California, Colorado, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming).

diagnoses among women as compared with other regions of the United States (23.8 % of diagnoses in the South were among women vs. 18.7 % of diagnoses outside of the South) (Prejean et al. 2013).

6.3 Black Women and HIV

In the United States, black women accounted for 12 % of the female population in 2011, and 64 % of the diagnoses of HIV infection among women for the same time period (CDC 2013b). At some point in their lives, an estimated 1 in 32 black women will be diagnosed with HIV (Hall et al. 2008a). In 2011, the estimated annual HIV diagnosis rate (per 100,000) for black women was 20 times as high as the rate for white women (40.0 vs. 2.0 respectively), and the majority of black women acquired HIV as a result of heterosexual contact (89 %) (CDC 2013b). Of the remaining women, 11 % had HIV infection attributed to injection drug use (IDU), and <1 %, to “other” or unidentified risk factors (CDC 2013b). At the end of 2010, an estimated 134,171 black women were living with HIV, which represented 61.8 % of all women living with HIV (CDC 2013b). Also, black women had the highest HIV prevalence rate, at 823.4 per 100,000 (CDC 2013b); this rate was 17.7 times as high as the prevalence rate for white women (46.4 per 100,000) and 4.3 times as high as the prevalence rate for Hispanic women/Latinas (189.5 per 100,000) (CDC 2013b).

6.4 Hispanic Women/Latinas and HIV

In 2011, Hispanic women/Latinas accounted for 15 % of the female population and 15 % of the diagnoses of HIV infection among women (CDC 2013b). At some point in their lives, an estimated 1 in 106 Hispanic women/Latinas will be diagnosed with HIV (Hall et al. 2013). In 2011, the estimated annual HIV diagnosis rate (per 100,000) for Hispanic women/Latinas was four times as high as the rate for white women (7.9 vs. 2.0 respectively). Similar to black women, the majority of Hispanic women/Latinas acquired HIV as a result of heterosexual contact (86 %) (CDC 2013b). Of the remaining diagnoses, 14 % were attributed to IDU and, <1 % was attributed to “other” or unidentified risk factors (CDC 2013b). At the end of 2010, an estimated 35,585 Hispanic women/Latinas were living with HIV, which represented 16.4 % of all women living with HIV (CDC 2013b). Also, Hispanic women/Latinas had the second highest HIV prevalence rate among women, with

189.5 per 100,000 living with HIV. This rate was 4.1 times as high as the prevalence rate for white women (46.4 per 100,000) (CDC 2013b).

6.5 Limitations of HIV Surveillance Data

There are several limitations of national HIV surveillance data. First, estimated HIV diagnoses among women may be underestimates because only women who have been tested for HIV and were reported to the health departments during the period of analyses were included (Forbes et al. 2011; Gómez 2011). Second, the reported data are subject to statistical adjustments to account for reporting delays and for cases reported with no identified risk factor, for which statistical imputations² are done (CDC 2013b). In 2009, CDC reported that no risk factor was identified for 29.5 % of adult and adolescent women with HIV diagnoses (CDC 2012a); this was particularly true for women who were unaware of any high-risk exposures (McNair and Prather 2004; Wyatt et al. 2013). For women, high-risk heterosexual exposure is often a default category for HIV surveillance (Cohen 2011); yet women's risks may also include simultaneous IDU exposure and sex with a man, a dual-risk for women not presently captured in CDC surveillance reports (McNair and Prather 2004; Wyatt et al. 2013).

Even with limitations in mind, national surveillance estimates have consistently shown that the United States has a significant HIV epidemic among women of color. In 2010, HIV was the 7th leading cause of death for black women ages 25–44 years, but did not rank among the top 10 leading causes of death for white women in that same age group (CDC 2013a). In 2010, the HIV death rate per 100,000 women, ages 25–44, was 10.3 for black women, higher than the rate for other women in this age group, and second only to the rate among black men (National Center for Health Statistics 2013). These findings underscore that even with surveillance data limitations, women of color are disproportionately affected by HIV infection, and a public health response for this subgroup is a priority. In this chapter, we explore the factors associated with high burden of HIV infection among women of color, taking a syndemic approach, by discussing some of the underlying social, cultural, and economic factors that contribute to HIV risk and prevalence for women (CDC 2013b; Selik et al. 1993).

²Multiple imputation is a statistical approach in which each missing risk factor is replaced with a set of plausible values that represent the uncertainty about the true, but missing, value (McDavid Harrison K, Kajese T, Hall HI, Song R. Risk factor redistribution of the national HIV/AIDS surveillance data: an alternative approach. Public Health Rep). <http://www.publichealthreports.org/archives/issuecontents.cfm?Volume=123&Issue=5>.

6.6 Structural, Social, and Individual Contexts of HIV Prevention for Women

6.6.1 *HIV-Related Syndemics Among Racial/Ethnic Minority Women*

A report published by The National Commission on AIDS (1992) encouraged researchers and public health professionals to focus on the underlying social, cultural, and economic factors that put communities of color at risk for acquiring HIV. Recent studies have shown that HIV acquisition often occurs in the context of multiple, simultaneous health problems and social disparities or syndemics (Gonzalez-Guarda 2013; Gonzalez-Guarda et al. 2011; Meyer et al. 2011; Singer and Weeks 1996; Singer et al. 2006); these syndemics may include sexually transmitted infections (STIs), substance abuse, mental illnesses, and violence and may, by acting synergistically, significantly increase a woman's risk of acquiring or being exposed to HIV.

Historically, research and discussions about HIV have often used race and gender as proxies for individual risk factors instead of broader social and structural risk factor contexts (Wyatt et al. 2013); however, emphasis on individual risk behaviors alone do not sufficiently explain the vast racial/ethnic disparities that exist (Dean and Fenton 2010; Doherty et al. 2007; Wyatt et al. 2013). In considering the multi-layered context of potential HIV exposure, prevention and infection for women of color, we developed a framework (Fig. 6.3), which considers structural, social, and individual factors and their effect on HIV exposure and prevalence among women. In this section, we expound on these multiple drivers and other syndemic factors that interplay to either facilitate risk or protect against HIV for women of color.

Regarding STIs, black women and Hispanic women/Latinas have the highest reported rates of chlamydia, gonorrhea, and infectious syphilis when compared with women of other races and ethnicities (CDC 2013c). In 2012, the chlamydia rate for black women was 1613.6 per 100,000 and for Hispanic women/Latinas was 574.7 per 100,000, compared with 260.5 per 100,000 for white women. The rate of gonorrhea among black women was 456.3 per 100,000 and 58.5 per 100,000 among Hispanic women/Latinas, compared with white women, whose rate was 33.1 per 100,000. The infectious syphilis rate for black women was 4.9 per 100,000 and 0.8 for Hispanic women/Latinas, compared with 0.3 per 100,000 for white women. In 2012, the congenital syphilis rate was highest among blacks at 29.6 per 100,000 live births. Black women are also disproportionately affected by trichomoniasis (Sutton et al. 2007) and herpes infections (Fanfair et al. 2013). Research shows individuals who are infected with STIs are two to five times as likely to acquire HIV infection if exposed through sex (Fleming and Wasserheit 1999), which exacerbates the syndemics, based on high prevalence of STIs in some communities of color.

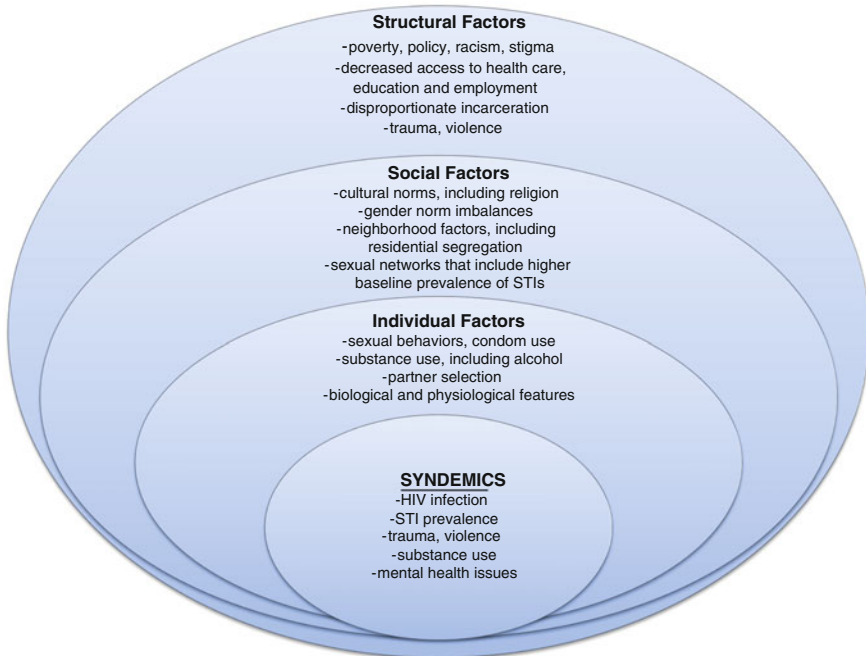


Fig. 6.3 The structural, social and individual-level contexts of human immunodeficiency virus (HIV) risks and syndemics for women of color in the United States

Regarding drug use, IDU as a route of HIV transmission among women has decreased over the past decade, but IDU remains the second leading cause of new HIV cases among women (Hall et al. 2008b; Magnus et al. 2013). In 2011, black women had the highest estimated number of HIV diagnoses attributed to IDU (715) compared with white and Hispanic women (445 and 210 respectively) (CDC 2013b). In 2012, the prevalence of illicit drug use among blacks was 11.3 % and 8.3 % among Hispanic/Latinos, compared with 9.2 % among whites (Substance Abuse and Mental Health Services Administration 2013). Substance use, which includes IDU, alcohol, crack use, methamphetamine, etc., may have the additional effect of increasing women's risk of experiencing physical or sexual violence and higher risk sexual activities (Meyer et al. 2011), thus, further putting substance-using women at increased HIV risk in the context of overlapping syndemics.

Intimate partner violence (IPV) includes physical violence, sexual violence, stalking, and psychological aggression by a current or former intimate partner (Breiding et al. 2014; Saltzman et al. 2002). Approximately 43.7 % of black women and 37.1 % of Hispanic women/Latinas have been a victim of rape, physical violence, or stalking by an intimate partner in their lifetime (Breiding et al. 2014). Women exposed to IPV are less likely to make healthy choices to reduce

their sexual risk (Cohen et al. 2011; Maman et al. 2000) and more likely to be forced to engage in sex with an HIV-infected partner (Maman et al. 2000; Spikes et al. 2010). Johnson and colleagues (2003) measured concurrent IPV, depression, and active substance abuse among black women, and concluded that all three factors were correlated with increased sexual risks for women.

Mental illness also plays an important role in HIV/STI risk for women. Women in the United States have a higher prevalence of any mental illness³ (AMI) compared with men (22.0 % vs. 14.9 %, respectively) (SAMHSA 2013). Of adults 18 years and older in the United States in 2012, prevalence of AMI among black, Hispanic/Latino, and white persons was 18.6, 16.3, and 19.3 %, respectively (SAMHSA 2013). A national U.S. study of young adults found that recent or chronic depression in adulthood was most prevalent among black women compared with other groups and was associated with multiple sex partners but not associated with condom use (Khan et al. 2009b). For HIV-infected persons, depression remains a common comorbidity; the excess burden of depression among HIV-infected persons receiving care is about three-times that among the general population (Do et al. 2014). Women living with HIV infection, especially black and Hispanic women/Latinas are also affected by depressive symptoms (Do et al. 2014; Lubana 1999; Vyavaharkar et al. 2011), but are less likely to receive depression treatment compared with their non-Hispanic white peers (Cook et al. 2014; Schraufnagel et al. 2006). Depressive symptoms, lack of coping mechanisms, and poor mental health are associated with decreased antiretroviral therapy (ART) medication adherence for women (Cook et al. 2002; Pence et al. 2012; Vyavaharkar et al. 2007). These additional factors contribute to the syndemics that increase HIV risk and challenges to care for women (Johnson et al. 2003). Strengthening mental health quality of life for women may positively contribute to HIV prevention, care, and treatment efforts.

6.7 Structural Factors: Poverty, Gender Norms, Policy and Race

6.7.1 Socioeconomics, Poverty and Women's Sexual Risk

Poverty in the United States disproportionately affects communities of color. Based on data reported in 2014, four out of five people living in areas of concentrated poverty were either black or Hispanic/Latino (Meade 2014). As depicted in

³The National Survey on Drug Use and Health (NSDUH) defines any mental illness as: a mental, behavioral, or emotional disorder (excluding developmental and substance use disorders); diagnosable currently or within the past year; and, of sufficient duration to meet diagnostic criteria specified within the 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).

Fig. 6.4a–c, blacks and Hispanics/Latinos, especially along the southeastern corridor, had poverty rates that exceeded the national average (Macartney et al. 2013).

Socioeconomic variables, namely poverty, low educational attainment and unemployment, are at the center of many unfavorable social and health conditions. In 2012, 20 % of women in the United States lived below the poverty line (The Henry J. Kaiser Family Foundation 2013). Black women and Hispanic women/Latinas accounted for nearly three-fourths of families with female heads of household (45 and 25 %, respectively) compared with 16 % percent for their white counterparts (U.S. Department of Labor 2013). Higher levels of education correlate with a greater likelihood for employment (U.S. Department of Labor 2013). However, from 2007–2012, black women consistently had higher rates of unemployment and for longer periods than their other racial/ethnic female counterparts (U.S. Department of Labor 2013), regardless of whether they had a high school or college degree.

Poverty is associated with a myriad of social, economic and health conditions, including HIV infection. The maps (Figs. 6.2 and 6.4a, b) portray a stark parallel between states with higher poverty and the disproportionate rates of HIV in states with high numbers of black and Hispanic/Latino residents (Prejean et al. 2013). As an example of this phenomenon, Reif and colleagues (2006) found that the Deep South,⁴ a region largely populated by blacks, had higher rates of poverty for individuals and families, more uninsured residents and higher levels of STIs compared with other United States regions and attributed the disproportionate rates of STI and HIV in the Deep South to both poverty and the inadequate access to healthcare. In another study that examined 23 urban poverty areas, findings revealed that HIV in the United States is more concentrated among households with low annual income, low education, and unemployment, with particularly high prevalence rates for blacks in impoverished areas (Denning et al. 2011).

The implications of low socioeconomic status are amplified for black women and Hispanic women/Latinas in the United States, many of whom are also female heads of households and may have economic hardships that cause them to defer their basic needs (U.S. Department of Labor 2013), or to consider exchanging sex for money, housing or other necessities (U.S. Department of Labor 2013; Zierler and Krieger 1997). Impoverished women are predisposed to homelessness (U.S. Department of Labor 2013; Jenness et al. 2011), high levels of stress (Belle Doucet 2003; U.S. Department of Labor 2013; Gilbert 2003), and risk taking behaviors that increase women's susceptibility to STI and HIV exposure. In a recent New York study regarding patterns of heterosexual sex exchange (N = 850), researchers found that 40 % of the 438 women in the sample, largely made up of black and Hispanic women/Latinas, reported trading sex for material goods like money, drugs or shelter within the last year (Jenness et al. 2011). A national study examined factors

⁴The Deep South includes states: Alabama, Georgia, Louisiana, Mississippi, North Carolina, and South Carolina. The Deep South is historically defined as those Southern states that actively promoted slavery and whose agricultural and economic base was in cotton. This region is disproportionately affected by the HIV/AIDS epidemic (Reif et al. 2006).

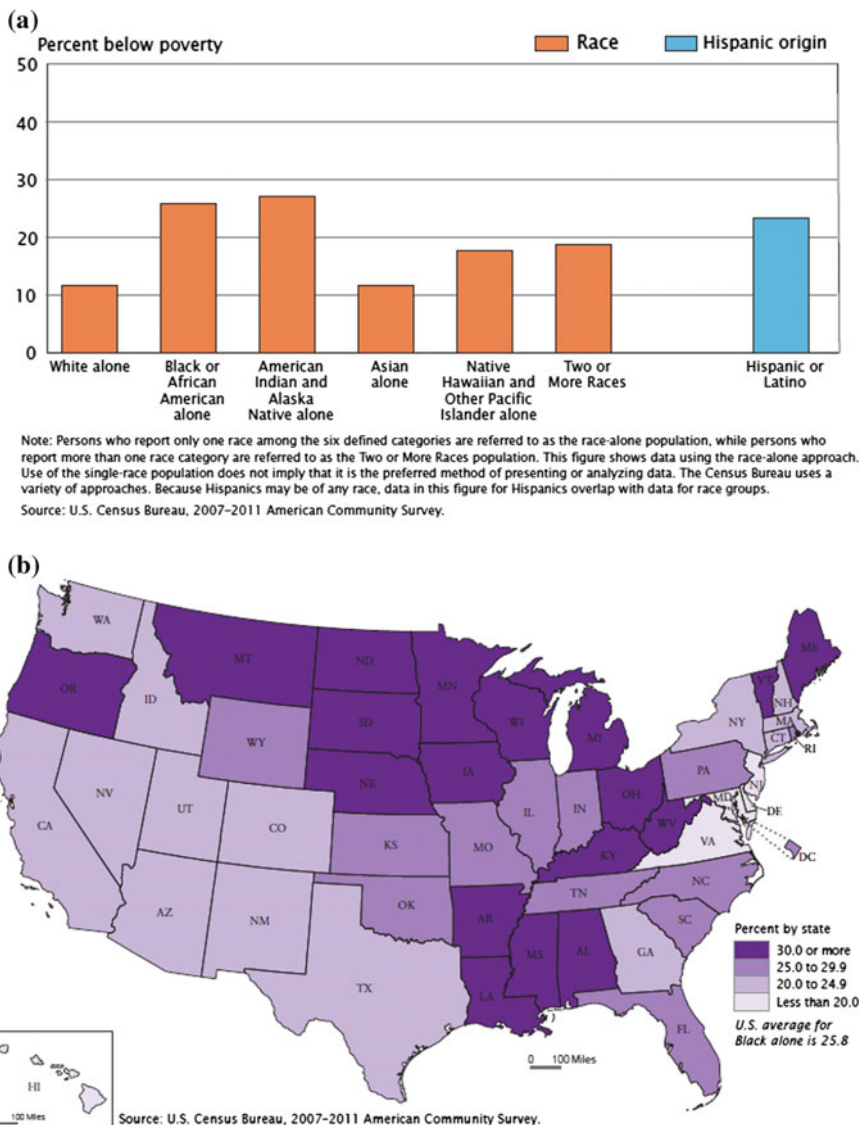


Fig. 6.4a U.S. poverty rates by race and hispanic or latino origin, United States, 2007–2011 (Source <http://www.census.gov/prod/2013pubs/acsbr11-17.pdf>). **b** Percentage of the Black/African American (non-Hispanic) population in poverty, United States, 2007–2011 (Source <http://www.census.gov/prod/2013pubs/acsbr11-17.pdf>). **c** Percentage of the Hispanic/Latin population living in poverty, United States, 2007–2011 (Source <http://www.census.gov/prod/2013pubs/acsbr11-17.pdf>)

associated with transactional sex and found that 33 % of all women were economically motivated to remain in relationships longer than desired (Dunkle et al. 2010). However, black women were twice as likely as white women to start a relationship and four times as likely to engage in transactional sex with a casual partner to have their economic needs met as compared with their white counterparts (Dunkle et al. 2010). In addition, data suggest that some Hispanic women/Latinas, particularly undocumented female immigrants, with perceptions of little hope and opportunity, sometimes sell their bodies to supply basic needs for themselves and their families (Adimora and Schoenbach 2013; Marín 2003). The competing priorities that poor women face adversely affect sexual decision making and risk outcomes (Aziz and Smith 2011). Moreover, the financial dependence on male partners often weakens the female's ability to safely negotiate condom use and other HIV prevention strategies during sexual encounters (Kline et al. 1992).

6.8 Gender Norms and Power Imbalances

According to the National Office on Women's Health, gender is a key social determinant of health that contributes to the heightened risk of HIV (National Native American AIDS Prevention Center 2013). Across all cultures, men and women are socialized according to different gender roles (Gómez 2011; Gupta 2000). These gender roles influence how men and women interact with their sex partners (Amaro 1995), whereas gender norms express the social expectations regarding appropriate attitudes and behaviors for women and men (National Native American AIDS Prevention Center 2013), particularly within the social and sexual context (Nguyen et al. 2010). Women are typically socialized at an early age, to be feminine/"good girls," which is characterized in the literature as passive, naïve, and silent about sex, nurturing, and subordinate to their mate (Amaro 1995; Fasula et al. 2014; Gupta 2000; National Native American AIDS Prevention Center 2013). Conversely, men are expected to be strong, protective, and to "prove their masculinity" (Marín 2003).

Culture's influence on gender roles and sexuality tends to create a conflict around HIV prevention between women and men in heterosexual relationships (Bowleg et al. 2000; Gupta 2000; Moreno 2007). This is often seen in the lives of Hispanic women/Latinas and black women. Within the Hispanic/Latino community, there is sometimes a tension between gender-related cultural values that are protective versus risk factors for HIV (Gonzalez-Guarda et al. 2011; Moreno 2007; Ortiz-Torres et al. 2000). For example, the *machismo* tradition allows for male dominance, expects men to know about sex, and makes it culturally acceptable for men to have multiple partners (Gonzalez-Guarda et al. 2011; Marín 2003; Moreno 2007), whereas the *marianista* tradition prohibits women from knowing about sex, negotiating sex and expects women to remain virgins until marriage (Moreno 2007). Therefore, men and women who ascribe to traditional gender roles and expectations may perpetuate gender inequalities in heterosexual relationships with

women as the disadvantaged partner (Amaro 1995; Amaro and Raj 2000; Gupta 2000).

For undocumented female immigrants, the power differentials in relationships are further exacerbated by Hispanic Stress, which Gonzalez-Guarda et al. (2012) defines as “common stressful events related to being members of an ethnic minority group in the United States.” Studies conducted among Hispanic women/Latinas have found Hispanic Stress related to their immigration status and the threat of deportation to correlate with depression and other maladaptive behaviors, including substance abuse, risky sexual behaviors and remaining in abusive relationships (Amaro 1995; Gonzalez-Guarda et al. 2012; Moreno 2007). Because Hispanic/Latinos are heterogeneous populations, there is some variability in the strict adherence to prescribed gender norms across the different ethnic subgroups, often based on several factors, including levels of acculturation (Fernandez 1995; Wyatt et al. 2013).

For black women, the traditional masculine and feminine descriptors of gender do not adequately reflect their modern-day, complex contexts (Nguyen et al. 2010). Studies have shown that black women tend to be socialized in a manner that embraces both masculine and feminine traits such as being independent and assertive (Bowleg et al. 2000; Nguyen et al. 2010) as well as nurturing and exhibiting strength (Nguyen et al. 2010). Because of their position in society often as single heads of households within some families, some black women take on the role of provider and protector, yet are also expected to be caring and sensitive to the needs of others, particularly within the context of their relationships with men (Bowleg et al. 2000). For example, despite the inclination to be assertive in other contexts, studies have shown that black women may actually hold back their assertiveness around safer sex negotiation to allow their black men partners to maintain their masculinity (in a society that sometimes undermines the manhood of black men) (Nguyen et al. 2010). This underscores the added burden and complexities that black women have to grapple with to accommodate perceived societal expectations (Davis and Tucker-Brown 2013; Fasula et al. 2014; Goldman and Stryker 1991; Gómez 2011).

Traditional gender roles and sexual norms pose challenges for women regarding sexual health (Amaro 1995; Amaro and Raj 2000; Campbell 1995; Marín 2003; Wyatt et al. 2013). In the context of heterosexual HIV/STI transmission, prevention efforts have largely focused on women negotiating condoms with males without adequate consideration to gender roles and power dynamics (Campbell 1995; Wyatt et al. 2013). For example, as the caretaker in the relationship, a woman is often concerned about her health, the health of her family and her sexual partner (Campbell 1995). This places the responsibility on women to manage risk (Campbell 1995), yet some women tend to lack adequate interpersonal power in the relationship to control decision making (Amaro 1995; Campbell 1995; Wingood and DiClemente 2000). For black women and Hispanic women/Latinas, their unequal status in society and in heterosexual relationships may contribute to their lack of interpersonal power (Amaro 1995). Gender inequalities and the propensity for violence against women, may stifle women’s ability to broach discussions about

sex, negotiate condoms or refuse other risky behaviors (Campbell et al. 2008; Maman et al. 2000; McNair and Prather 2004; Spikes et al. 2010; Zierler and Krieger 1997). Among women living with HIV, the threat of physical violence by partners and HIV stigma often decrease the likelihood of disclosing their HIV status (Maman et al. 2000; McNair and Prather 2004).

6.9 Policy Challenges

Federal, state and local laws and policies may affect the ability of some women to navigate HIV prevention efforts. As of 2011, 33 states had 67 different laws that criminalized potential HIV exposure, including laws that require persons who are aware of being HIV infected disclose their status to their sex partners or needle-sharing partners (Lehman et al. 2014). While data do not suggest that criminal laws have reduced HIV transmission (Lehman et al. 2014), some women who have been exposed to HIV by a male partner who did not disclose his known status, do find some comfort in being able to pursue criminal prosecution (Druckerman and Welsh 2009). However, some state laws have negative effects by possibly increasing the likelihood of criminal prosecution for HIV-infected women who may unintentionally expose a child during pregnancy or breastfeeding, or women who may have increased risks of HIV-related violence or abuse after disclosure (Kehler et al. 2009). To date, no evidence supports HIV criminalization as an effective HIV prevention tool (Burriss and Cameron 2008), especially amongst disenfranchised women and men of color who may be dealing with multiple components of HIV-related syndemics.

Other policies also affect HIV prevention efforts with women. Anti-prostitution enforcement criminalizes possession of condoms, which compromises HIV prevention efforts (Forbes et al. 2014; McLemore and Human Rights Watch 2012, 2013). Human Rights Watch reported that sex workers, mostly women and transgender women, in major cities in the United States were the target of such practices that resulted in sex workers carrying condoms less or having unprotected sex out of fear of police harassment (McLemore and Human Rights Watch 2012, 2013). Scholars have argued that such practices are discriminatory, jeopardize women's sexual health, and may undermine longstanding public health messages and evidence-based programs that seek to empower women at greatest risk for HIV (Forbes et al. 2014; McLemore and Human Rights Watch 2012, 2013). Solutions to these policy challenges may require that legislative and public health officials consider approaches that also examine current HIV science and a social justice ethical framework as part of the dialogue, rather than a prosecutorial and often judgmental legal framework (Finitis et al. 2014).

Drug policies have also played a role in HIV prevention efforts. At the federal level, policies declared in 1986 led to harsh enforcement for illicit drug use and drug trafficking; both of which resulted in disproportionately high incarceration rates for blacks and Hispanic/Latinos (Doherty et al. 2007; Iguchi et al. 2002;

Poundstone et al. 2004). The associated laws and penalties regarding drug convictions often have long-term effects for offenders (Mauer and McCalmont 2013; Poundstone et al. 2004), including eviction from public housing (Crane et al. 2002; Iguchi et al. 2002; Poundstone et al. 2004), no access to healthcare (Iguchi et al. 2002), being barred from welfare benefits, including food stamps and Temporary Assistance for Needy Families [TANF] (Iguchi et al. 2002; Mauer and McCalmont 2013), being disqualified for student loans and some employment opportunities (Iguchi et al. 2002), being ineligible to vote (Adimora et al. 2014b; Iguchi et al. 2002), and, for immigrants, the risk of deportation (Iguchi et al. 2002). These policies further marginalize blacks and Hispanic/Latinos, who are disproportionately incarcerated (Poundstone et al. 2004). For black and Hispanic women/Latinas, the decreased access to fundamental resources perpetuates risk for HIV/STI in the context of syndemics, because it creates a potential pathway to homelessness, substance abuse, and the added risk of recidivism.

6.10 Incarceration: Race and Gender

The incarcerated population under the United States' criminal justice system is disproportionately comprised of blacks (CDC 2012b; Iguchi et al. 2002; Motivans 2013) followed by Hispanics/Latinos (Motivans 2013). According to Bureau of Justice data, at the midyear of 2009, black males were incarcerated at rates nearly seven times as high (4,749 vs. 708 per 100,000) as white males, whereas Hispanic/Latino males were incarcerated at rates nearly three times as high (1,822 vs. 708 per 100,000) as white males (West 2010). Likewise, black females were incarcerated at rates nearly four times as high (333 vs. 91 per 100,000) followed by Hispanic female/Latina at rates nearly twice as high (142 vs. 91 per 100,000) as their white female counterparts (West 2010). Although there are more male inmates, women are being incarcerated at alarming rates (Bonczar 2003; Gilbert 2003; Kramer and Comfort 2011).

There is inherent public health risks associated with incarceration, including HIV exposure and/or transmission. Annually, an estimated 1 in 7 persons living with HIV have cycled through the criminal justice system, mostly through jails (CDC 2012b). Of the 2.2 million people in the criminal justice system (Lovinger and Gay Men's Health Crisis 2012), at year end 2010, a total of 20,093 state and federal prisoners were estimated to be living with HIV (Maruschak 2012). Despite there being more males in prison, HIV rates are higher among female than male inmates (CDC 2012b; Lovinger and Gay Men's Health Crisis 2012). When compared with non-incarcerated populations, the probability of exposure to HIV increases for inmates with a history of drug use, commercial sex work, untreated mental illness, and poverty (Adimora and Schoenbach 2013; CDC 2012b). The likelihood may be amplified for black women and Hispanic women/Latinas whose male partners have often been disproportionately incarcerated (Alleyne and Gaston 2010).

The risk for acquisition and transmission of HIV in correctional facilities is amplified by some risk behaviors that transpire behind bars (Gilbert 2003; Lovinger and Gay Men's Health Crisis 2012; Mays et al. 2012), such as sharing unclean needles for injection drug use, tattooing, or body piercing (Campbell 1995; Khan et al. 2009a; Mays et al. 2012), and unprotected consensual and non-consensual sex between same and/or opposite sex inmates (Campbell 1995; Kramer and Comfort 2011), and between inmates and correctional personnel (Gilbert 2003; Kramer and Comfort 2011). The structural barriers of limited condom availability and/or clean needle exchange in correctional facilities limit the extent to which HIV transmission can be adequately prevented (Lovinger and Gay Men's Health Crisis 2012).

The cycle of risk continues as ex-offenders contend with added stress of reintegrating back into society with limited opportunities for employment, unstable housing, lack of education, and little to no access to healthcare (Green et al. 2012; Iguchi et al. 2002; Lovinger and Gay Men's Health Crisis 2012) and often tenuous social supports (Gilbert 2003). This increases the opportunities for ex-offenders to re-connect with former social and sexual networks and return to at-risk neighborhoods (Adimora and Schoenbach 2005; Freudenberg 2002; Green et al. 2012), thus increasing the likelihood of recidivism, risk exposure, and ongoing HIV transmission (Iguchi et al. 2002; van Olphen et al. 2009).

Another broader consequence of incarceration is the gender imbalance of men to women, particularly in black and Hispanic/Latino communities. The disproportionate removal of men from neighborhoods due to incarceration contributes to the low male-to-female sex ratio (Adimora and Schoenbach 2013; Alleyne and Gaston 2010) and to a decline in marriage (Adimora et al. 2009; Sharpe et al. 2012). Research has shown that low sex ratio is associated with power dynamics in relationships (Adimora and Schoenbach 2013; Alleyne and Gaston 2010) whereby the gender in demand may be viewed as a commodity (Adimora and Schoenbach 2013). With less relational power in the relationship, women are less likely to demand or negotiate safer sex options (Alleyne and Gaston 2010; Wingood and DiClemente 2000). In an effort to minimize conflict and remain sensitive to the added stressors their newly released male partner may encounter, some women may avoid or find it difficult to address important sexual health conversations regarding condoms or HIV testing (Kramer and Comfort 2011).

6.11 Social Factors: Religion, Stigma, and Neighborhood Sexual Networks

6.11.1 Religious Norms

Religion plays a significant role in the lives of black and Hispanic women/Latinas (Koenig 2000; Musgrave et al. 2002), and religious norms may have a major role to play in HIV education and prevention efforts. For women of color, the ability of

churches to become partners for HIV prevention can have a profound effect on the ability of women to navigate prevention and care efforts in a supported way. Research suggests that black women and Hispanic women/Latinas are more inclined to rely on their religious involvement and spirituality to help them cope with various adverse life and health conditions, such as an HIV diagnosis (Dalmida et al. 2011; Musgrave et al. 2002), substance use, trauma and mental illness (Collins et al. 2008b; Staton-Tindall et al. 2013). In many cases, the harmful effects of some religious and dogmatic teachings can foster silence and stigma surrounding various syndemic issues that affect women's lives (Koenig 2000). Lichtenstein (2005), for example, expressed concerns about STI control in the Deep South due to low treatment uptake coupled with stigmatizing attitudes held by many churchgoers. In the context of HIV, religious beliefs may result in shame, delayed medical care, depressive symptoms and increased risk for social isolation (Hickman et al. 2013; Koenig 2000; Lichtenstein 2005; Muturi and An 2010; Sutton and Parks 2013). However, there are an increasing number of examples in which the benefits of religion, faith, and spirituality for persons living with or affected by HIV infection are vital for and can facilitate successful HIV prevention efforts (Aholou et al. 2009; Sutton and Parks 2013).

The Black Church is a mainstay of the black community and plays a significant role in the lives of its members (Lincoln and Mamiya 1990; McMickle 2008). A majority of Black Churches have congregations that are ~60 % black women (Pew Forum on Religion and Public Life 2008). Most Black Churches (60 %) are located in the southern region of the United States (Pew Forum on Religion and Public Life 2008). As an institution, the Black Church has historically been instrumental in addressing many of the social issues and health disparities that disproportionately affect blacks (Aholou et al. 2011; Eke et al. 2010; McMickle 2008); even more support from the Black Church, and other churches attended by black women, is needed to support black women who are affected by the HIV epidemic.

Data suggest that Latinos tend to adhere to religious organizations in greater numbers than the rest of the population (Ramirez-Johnson et al. 2013), and therefore, may be susceptible to their religion's political stances. Many Latino religious leaders have instilled in their churches a conservative Christian/Catholic conceptualization as part of their theological repertoire (e.g., prohibition against condom use to limit conception, prohibition of same-sex relationships), which has historically been a challenge for HIV prevention efforts (Ramirez-Johnson et al. 2013). However, recent data show that the historic Catholic majority among Hispanics has been declining, with now 24 % of Hispanics/Latinos being former Catholics and increased numbers being Protestant or unaffiliated with any religion (Pew Research Center 2014). These shifts have resulted in increased numbers of Hispanics/Latinos with more liberal social and political views (Pew Research Center 2014), which include support of same-sex marriages and likely more supportive HIV prevention agendas. This shift can be vital for increased, visible support for many Hispanic women/Latinas disproportionately affected by HIV.

Many churches are increasingly involved in HIV prevention efforts in a manner that is incongruent with their theology, yet responsive to the needs of the community (Alder et al. 2007; Derose et al. 2011; Roman Isler et al. 2014). Some faith leaders offer voluntary HIV counseling and testing services and disseminate information about HIV in their place of worship (Berkley-Patton et al. 2010; Lightfoot et al. 2001), or provide care and support through pastoral counseling and support groups (Alder et al. 2007). Another way in which churches have demonstrated commitment to HIV prevention is through their support and partnership with external agencies such as universities (Wingood et al. 2011) and community-based organizations (Collins et al. 2007). Efforts by the Balm in Gilead through the National Week of Prayer for the Healing of AIDS with a wide range of faith denominations (Balm in Gilead 2013), and more recently with the National Association for the Advancement of Colored People's (NAACP) Social Justice Imperative (Brock 2014; NAACP 2013) and Day of Unity (<http://www.theblackchurchandhiv.org/pages/day-of-unity>) underscore that progress is being made with helping faith leaders and congregations take action against HIV in communities of color.

6.11.2 HIV and Stigma

Stigma remains a barrier for HIV prevention and treatments efforts (Foster 2007; Mahajan et al. 2008). Although HIV stigma is not limited to the southern United States, the social conservatism of the South (Foster 2007; Lichtenstein 2005), and dogmatic religious beliefs that AIDS is a punishment from God for sexual immorality (Lichtenstein 2005; Muturi and An 2010; Ramírez-Johnson et al. 2013) have contributed to silence and secrecy about HIV that is often disproportionate in the southern United States (Foster 2007; Lichtenstein 2005; Sutton and Parks 2013). HIV burden is also heaviest in the South (Prejean et al. 2013), especially for blacks and Hispanics/Latinos (Morales-Aleman and Sutton 2014). HIV stigma has contributed to fears that have created barriers to HIV education, prevention, and treatment (Lichtenstein 2003; Lichtenstein, 2005; Link and Phelan 2006; Mahajan et al. 2008). Despite the benefits of early detection of HIV (Branson et al. 2006) and the advancements in HIV testing technologies (Centers for Disease Control and Prevention and Association of Public Health Laboratories 2014), the negative undertones created by HIV-related stigma contribute to low uptake of HIV testing for some groups. Even with improvements in antiretroviral medications, there are still some who perceive HIV as a death sentence and have fear about HIV (Foster 2007).

Among women living with HIV, research suggests fear of stigma and discrimination in health care settings often results in delayed linkage to care (Aziz and Smith 2011). Also, fear of disclosing HIV status may be affected by perceived negative consequences, such as rejection, discrimination, and threat of abuse (Gielen et al. 1997, 2000). Fear of their illness being exposed if seen taking

medications (Sayles et al. 2006) as well as a history of trauma may result in low adherence to medical regimens (Whetten et al. 2008). Even with reductions in perinatal mother-to-child transmission [PMTCT], the fear of being criminalized for transmitting HIV to an unborn baby or having a baby taken away after birth has created challenges for PMTCT efforts (Mays et al. 2012).

Regionally, the rural/small town context gives rise to fears about breaches in confidentiality for those affected by HIV. Aholou et al. (2009) found that PLWHA in a Deep South state preferred to travel outside of their home county for HIV care in order to preserve their privacy, yet the remote distances to access services raised concerns about retention in care. The adverse effects of stigma are exacerbated psychosocially as guilt, shame, embarrassment, isolation, fear and denial of diagnosis (Collins et al. 2008a; Lichtenstein 2003) that are often encountered among women dealing with one or more of the syndemics. For example, women with mental illness may express feeling of rejection that makes them more susceptible to sexual risk behaviors (Collins et al. 2008a); women with a history of IPV may remain silent rather than seek help due to fear of negative consequences (Campbell et al. 2008); and women with a history of drug use and incarceration may experience feelings of shame and guilt upon their release yet have limited opportunities to obtain needed social supports (van Olphen et al. 2009).

6.11.3 Neighborhoods and Sexual Networks

“...Health begins at home, and is influenced by where we live, the jobs we hold, our knowledge of risk, and our support systems...” (CDC 2010, p.5); the environment in which one lives plays a significant role in one’s health and well-being. This statement illuminates the stark realities of black women and Hispanic women/Latinas at greatest risk for being exposed to or living with HIV based on their neighborhoods. Scholars have indicated that the most overt expression of racial discrimination in the United States today is racial/ethnic residential segregation (Adimora and Schoenbach 2013). Racially segregated neighborhoods are often characterized by high prevalence of poverty, suboptimal living conditions, scarce health and community resources, unemployment, and a lack of social capital (Adimora and Schoenbach 2013; Cene et al. 2011; Farley 2006; Poundstone et al. 2004). These factors work synergistically to contribute to poor social, economic and health outcomes and result in segregated and neighborhood sexual networks with higher prevalence of STIs (Farley 2006) and significantly higher rates of HIV; black women and Hispanic women/Latinas are disproportionately affected within these neighborhoods and networks (Adimora and Schoenbach 2013).

Residents living in racially segregated communities may also have limited sex partner selection choices, which may cultivate an environment for high risk sexual behaviors (Cene et al. 2011). Research shows that women, particularly black women, tend to select partners within their own race (Adimora et al. 2006) and from the communities in which they live (Adimora and Schoenbach 2013; Sharpe et al.

2012), which increases women's vulnerability for STI and HIV exposure in several ways. First, selecting partners within racially segregated neighborhoods with high STI prevalence and illicit drug use increases the probability that STI and HIV will spread within the racial group (Poundstone et al. 2004). Second, given the instability of some relationships, both women and men are likely to engage in concurrent sexual partnerships, thereby creating a dense sexual network where STI may proliferate within the community (Farley 2006). Last, research shows even if women only engage in low risk behaviors, their risk for STI and HIV is heightened by the increased likelihood of selecting partners who engage in high risk sex behaviors, otherwise known as disassortative mixing (sex between partners of unequal risk status) (Adimora and Schoenbach 2013).

Sexual networks help explain: (1) how individual sex partnerships may gradually evolve into groups of persons who are connected to one another sexually, and (2) why persons may have the same individual risk behaviors and yet one may have a much greater risk of contracting or transmitting HIV or other STIs (Doherty et al. 2005). Sexually active persons who are only sexually active with each other (mutual monogamy), who are not part of a sexual network, have the lowest risk of HIV exposure. Concurrent partnerships, sexual partnerships that overlap in time, can accelerate the spread of HIV/STIs if anyone in the partnership is infected. Sexual partnership concurrency has been identified as an independent risk factor for HIV infection among black men and women with heterosexually transmitted HIV infection (Adimora and Schoenbach 2005). More recent data suggest that women at high risk for HIV infection who were part of concurrent partnerships with non-monogamous partners and lacked of awareness regarding the HIV status of their male partners, had significantly increased opportunities for HIV exposure (Adimora et al. 2014a). The presence of sexual networks enriched in persons with HIV/STIs and the other adverse social and structural contexts create a perfect storm for women that can facilitate HIV exposure acquisition and transmission.

6.12 Individual Factors: Biology, Behaviors, and Condom Use

For women, the highest risk for HIV acquisition occurs during: (1) mother-to-child transmission (2,260 per 10,000 exposures), (2) anal sex without a condom (138 per 10,000 exposures), and (3) penile-vaginal sex without a condom (8 per 10,000 exposures) (Patel et al. 2014). The mucosal surfaces of the vagina and anus, when inflamed through infection, microscopic abrasions, douching, or decreased lubrication, can increase women's susceptibility to HIV infection (Adimora et al. 2013). Additionally, the presence of other STIs, including gonorrhea, chlamydia, herpes, and syphilis, can increase a women's HIV acquisition risk if she is exposed to an HIV-infected sex partner (Fleming and Wasserheit 1999). Research continues to

examine the role of hormonal contraception and other factors on potentially affecting HIV acquisition risk (Adimora et al. 2013).

As most women are exposed to HIV through heterosexual encounters, HIV surveillance data showing that ~50 % of women in some areas are unable to identify a risk exposure for HIV (Cohen 2011) is of concern and underscores that many women have a poor perception of their vulnerability to HIV. For example, some women perceive that anal sex is less risky than vaginal sex, and therefore do not use condoms as often during anal sex (McBride and Fortenberry 2010). Also, because of some community dynamics that may support concurrent sex partnerships and older male partners with younger women, women's risk of acquiring HIV may be increased (Adimora et al. 2013).

Even in the setting of these individual-level factors, correct and consistent condom use can still provide protection from HIV/STI transmission; condoms remain a very powerful tool for HIV prevention both for uninfected persons and for persons who are living with HIV who are trying to decrease risk for an uninfected sex partner (Davis and Weller 1999). It is estimated that latex condoms decrease the per-contact probability of male-to-female HIV transmission by 80–95 % (Pinkerton and Abramson 1997; Patel et al. 2014). For women living with or at risk for HIV infection, condoms may also serve a dual use as a contraceptive barrier for women who are trying to prevent an unintended pregnancy (Higgins and Cooper 2012; Wilson et al. 2003). Although the male condom is more widely used, the female condom, which also provides protection against HIV/STIs and unplanned pregnancies, has been available to women in the United States since 1993. The female condom has the benefits of providing more complete coverage of the vagina and vulva compared with a male condom, the ability to be placed by women, and the ability to be inserted into the vagina several hours before sex (Gollub 2000). However, uptake of the female condom has been suboptimal due to low user acceptability, high costs, and some reports of discomfort by users (Gollub 2008). There is room for improvement in any condom use among women, with only 18.4 % of women reporting condom use during recent vaginal sex acts and 13.2 % of women reporting condom use during recent anal sex acts (Reece et al. 2010).

6.13 Preventions, Solutions, and Clinical Contexts for Women at Risk for or Living with HIV Infection

In 2010, the development of the first-ever United States National HIV/AIDS Strategy (NHAS) signaled an increased visibility and commitment from United States federal agencies to work toward NHAS goals to reduce HIV incidence, increase access to care for those who are HIV-positive, and decrease HIV-related health disparities (Office of National AIDS Policy 2010). Efforts remain underway to ensure that the HIV prevention and care goals of NHAS strengthen efforts for

subpopulations most vulnerable for HIV, including women (Adimora et al. 2014b; Iguchi et al. 2002; Poundstone et al. 2004).

6.13.1 Prevention Strategies for Women

As women account for an estimated 21 % of new HIV diagnoses in the United States (CDC 2013b), enhancing current efforts with additional tools and novel interventions is vital for decreasing HIV rates among women. Yet, 30-plus years into the HIV epidemic, there are very few interventions that have addressed the underlying social, cultural, and economic factors that put women at risk for HIV (www.effectiveinterventions.org). HIV prevention for women of color requires multiple approaches that are as diverse as the factors that place them at risk, and optimally should include policy-, community-, and individual-level strategies across the lifespan. Efforts to date have included universal HIV screening approaches for women in prenatal care and as part of routine healthcare services for non-pregnant women, educational interventions, media campaigns, and peer-led, community-based strategies (Diallo et al. 2010). While there have been significant decreases in perinatal transmission (Lampe et al. 2010), and some prevention programs which focus on addressing risk behaviors (www.effectiveinterventions.org), more comprehensive and effective strategies are needed as part of a diverse toolkit for women. In this section, we discuss the many non-clinical and clinical opportunities to strengthen HIV-related prevention and treatment services for women at risk for or living with HIV infection.

6.13.2 Early Intervention/Prevention Opportunities

Strategies that empower women to get the HIV services they need at both community and individual levels have been highlighted as vital components of HIV prevention (Beeker et al. 1998; Kates et al. 2013) and underscore the importance of self-awareness and honest, open dialogue with sex partners about HIV status, concurrent sexual relationships, and the importance of mutual HIV testing. Ensuring non-violent contexts may also be an important part of these discussions for some women.

Early opportunities to educate about sexual health and how to have healthy dialogues exist for girls/women from parents and other family members (Miller et al. 2011; Murray et al. 2014; Sutton et al. 2014a), schools (Barr et al. 2014a, b), community-based groups, including churches and other faith communities (Ott n.d.). Data indicate that young adults are eager to get accurate, values-based sexual health information from their parents in a way that is comfortable, non-judgmental, and supportive (Whitaker and Miller 2000). Additional educational opportunities exist as girls get older and begin regular, annual visits in

clinical settings, where women often see providers for services that range from preventive well-woman checks, to contraception visits, to Pap screenings for cervical cancer (The American College of Obstetricians and Gynecologists 2014). Clinical visits are important opportunities to provide culturally and linguistically appropriate education about female and male anatomy, sexuality, abstinence, and contraception for young women and their parents, especially for those who do not receive this information in school venues (Guilamo-Ramos et al. 2011).

Part of HIV prevention requires accurate information for women about HIV risk and transmission, including the importance of sexual networks and risks when engaging in sex without a condom. Women in geographic areas with higher rates of HIV and STIs, have a higher risk of being exposed to an HIV-infected sex partner. The neighborhood context underscores the importance for women of knowing their own HIV status and the HIV status of their sex partners before having sexual intercourse. Clinical and community HIV testing efforts have increased in recent years (Hutchinson et al. 2012) to facilitate access to early HIV testing and, if necessary, early linkage to HIV care and treatment for persons who test positive. Streamlined clinical care facilities (where clients can receive services from multiple providers at one location and/or during one visit), including family planning sites, provide an important entry point for reaching women at risk for and living with HIV (Frost et al. 2012); a majority of women of reproductive age (60 %) report that a family planning site is their usual source of reproductive and general health care services; 41 % say it is their only source of care (Frost et al. 2012). Helping women navigate the complex multiple layers of HIV prevention services increasingly involves many clinical service providers, especially physicians, nurses, and social workers. Physicians might be trained to better understand and appreciate how intersectional identities and contexts (Fig. 6.3) shape the perceptions, experiences, and prevention needs, especially for women of color. Education may help providers understand how structural and historical social influences can lead some patients to feel mistrust (Dovidio et al. 2008) and, thus, help providers develop more effective, culturally specific, compassionate strategies for engaging patients positively and ultimately decreasing stigma related to HIV care and treatment.

6.13.3 Social Support and Mentoring for Young Women

Research shows that youth, especially youth of color, want to receive more information about sexual health, including HIV (The Henry J. Kaiser Family Foundation 2012). In addition, youth report that they consider their parents and other trusted adults as key persons for this type of information (Dittus et al. 2004). One area that may benefit from additional research is the effect of expanded parenting and mentoring programs for female youth, especially minority female youth (DuBois et al. 2011). DuBois and colleagues (2011) completed a meta-analysis of 73 independent evaluations of mentoring programs directed toward children and adolescents published from 1999–2010 and concluded that mentoring is an effective

mode of intervention for young people, although additional research is needed in this area. Nonetheless, women serving as mentors to other women, of all ages, may be a beneficial tool in increasing dialogue about sexual health (and other syndemic risk issues) among minority females (Satcher 2009).

6.13.4 *Microfinance as a Contextualized Prevention Solution for Women of Color*

The United Nations developed Millennium Development Goals, which include the eradication of extreme poverty and combating the spread of HIV by 2015 (<http://www.un.org/millenniumgoals/>). In response, global community stakeholders developed several microfinancing campaigns. Microfinance is defined as financial intermediation through the distribution of small loans, small savings, and provision of other financial products and services for people in economic vulnerability (Remenyi and Quinones 2000). A recent review of microfinance-based interventions shows that most had beneficial effects for HIV prevention (Arrivillaga and Salcedo 2014). One United States-based intervention (JEWEL-Jewelry and Education for Women Empowering their Lives) targeted drug-using, female prostitutes with the goal of HIV prevention education and teaching, making, and selling of beaded jewelry (Sherman et al. 2006); participants reported reduced number of sex-trade partners and daily injection drug use, at three-months following the completion of the intervention (Sherman et al. 2006). Several international studies have had promising results with both women at risk for acquiring HIV and PLWHA (Arrivillaga and Salcedo 2014). Further research is needed to determine the sustainability and cost-effectiveness of these programs in the United States (Arrivillaga and Salcedo 2014; Bateman 2010; Bateman and Chang 2012).

6.13.5 *National Marketing Campaigns and Evidence-Based Interventions*

National HIV prevention campaigns are believed to help reduce HIV stigma by normalizing conversations and decreasing complacency about HIV among audiences. HIV campaigns that specifically target women include *Take Charge, Take the Test* (TCTT) and *Empowered*. TCTT is a campaign developed by the CDC for black women aged 18–34 years. The goal of TCTT is to promote information seeking and HIV testing (Fraze et al. 2009). (<http://hivtest.cdc.gov/takecharge/>). Another national marketing campaign is the *Empowered* campaign. Developed by the Black AIDS Institute and led by philanthropist entertainer Alicia Keys, *Empowered* seeks to encourage women to change the course of HIV epidemic by every day actions, such as changing their thinking about HIV, and discussing HIV

within their social networks (<http://greaterthan.org/campaign/empowered/>). In addition to national marketing campaigns, the CDC created a compendium of evidence-based interventions. Interventions for women include those that are biomedical, behavioral, and structural, as well as public health and social marketing strategies and resources. A listing of HIV prevention interventions and best practices for women are listed at the following link: <http://www.cdc.gov/hiv/prevention/research/compendium/rr/characteristics.html>.

6.13.6 The HIV Continuum of Care for Women, Including Reproductive Health Planning

The HIV continuum of care is a conceptual tool that allows for assessment of how well people affected by HIV are covered along each of five stages of HIV-related care and treatment: HIV diagnosis, linkage to care, retention in care, antiretroviral therapy receipt, and plasma viral suppression. Achieving high coverage in each stage of the continuum is an essential component of effective prevention, because with adequate medical care and HIV viral suppression, HIV-infected persons are less likely to transmit HIV to uninfected partners (Cohen et al. 2012). National data indicate that a larger percentage of women (85 %) than men (81 %) with HIV had received a diagnosis, and among those with a diagnosis, a larger percentage of women (49 %) than men (43 %) were retained in care (Hall et al. 2013). However, among those retained in care a smaller percentage of women (86 %) than men (90 %) were prescribed ART. Among those prescribed ART, a smaller percentage of female (73 %) than male (80 %) persons had a suppressed viral load. Looking at each step of the continuum independently, blacks had lower percentages than whites at each step of the continuum (Hall et al. 2013).

Linkage and retention in care with ART use and viral suppression are crucial components in the fight against HIV, as persons who successfully achieve these stages of continuum experience reduced morbidity and mortality (Palella et al. 1998), decrease their risk of HIV transmission to others (Donnell et al. 2010), and reduce their medical expenditures (Fleishman et al. 2010). The CDC recommends that persons who test positive for HIV be linked to medical care with an appointment within 90 days of their initial HIV diagnosis (Keller et al. 2013).⁵ The National HIV/AIDS Strategy set a goal to increase the proportion of newly diagnosed patients linked to clinical care within 3 months of HIV diagnosis from 65 to 85 % by year 2015 (Office of National AIDS Policy 2010). Delays in medical care after HIV diagnosis have been documented (Althoff et al. 2010) and are especially relevant as barriers for the optimal care of women living with HIV infection. Among women, especially black women and Hispanic women/Latinas, some of the

⁵Editor's Note: the NHAS (2020) sets the standard for newly diagnosed individuals to be linked to medical care within 30 days of their diagnosis.

factors that have been associated with not entering into medical care include lack of medical insurance (Lillie-Blanton et al. 2010), lack of access to transportation, domestic violence, homelessness, and poverty (Aziz and Smith 2011).

Engagement in clinical care can also affect family planning options and potential mother-to-child HIV transmission. The majority of women living with HIV infection are diagnosed during their reproductive years (ages 15–45 years) (Craft et al. 2007), which is the window for potential planned and unplanned pregnancies (Sutton et al. 2014b). Yet HIV-infected women report that gender-specific discussions with their health care providers, including discussions of possible pregnancy intentions, contraception, and optimizing medical management for possible pregnancy are lacking (Squires et al. 2011). Since the early 1990s, routine HIV screening and advances in HIV care and treatment have prolonged survival and contributed to a 90 % reduction in perinatal, mother-to-child transmission of HIV infection in the U.S. (Rogers et al. 2010); elimination of perinatal HIV transmission may be a feasible goal. Challenges to further reduction of perinatal HIV transmission are largely due to inadequate or late access to effective pregnancy prevention methods, late HIV testing, and insufficient or lack of antiretroviral treatment during the perinatal and postpartum periods. Racial/ethnic disparities remain a huge challenge in perinatal HIV transmission with blacks (69 %) and Hispanics/Latinos (16 %) accounting for 85 % of all HIV diagnosed children in the United States in recent years (Lampe et al. 2010). Antenatal services and family planning care have to be prioritized for women of color who are at risk and living in communities where HIV and other syndemic diseases and social challenges are prevalent.

6.13.7 The Patient Protection and Affordable Care Act and Women

By the end of 2010, only 42 % of HIV-positive women who were diagnosed with HIV at the end of 2009 achieved viral suppression (CDC 2013d), and <25 % received the recommended routine annual Pap test screening for cervical cancer (Oster et al. 2009). The Patient Protection and Affordable Care Act of 2010 (ACA) was designed to ensure access to healthcare for all U.S. citizens, particularly the millions who have been uninsured or underinsured (Adimora et al. 2014b; Keith and Lucia 2014), including those living with HIV. Under the ACA, women with pre-existing conditions, like HIV, will still be able to obtain health insurance and cannot be charged higher health premiums. Preventive care services, like Pap tests, mammograms, IPV prevention and counseling, HIV screening (for uninfected women) and STI counseling (Fields and Forbes 2012), and most forms of contraception, will be available to women without co-pays and co-deductibles. Another provision of the ACA is the expansion of Medicaid, health insurance coverage for non-elderly, uninsured individuals (Keith and Lucia 2014), whereby states are allowed to opt out (Adimora et al. 2014a, b; Keith and Lucia 2014). Although it has

been documented that the expansion of Medicaid can significantly improve morbidity and mortality rates by increasing access to HIV care (Adimora et al. 2014b), several southern states have declined to participate in this provision (The Henry J. Kaiser Family Foundation 2014). These mostly southern states are the same ones that have high rates of HIV infection among women and the lowest numbers of doctors with HIV expertise (Hiers and Valdiserri 2012).

Women living with HIV infection, who may experience multiple competing responsibilities (e.g., as heads of households, caregivers, working parents) are often challenged to be fully compliant with multiple clinical visits. Integration of services, such that women may visit one location and engage multiple providers, would be ideal for streamlined service delivery and improved health outcomes (Forbes et al. 2014); data suggest that this is especially important for routine Pap tests for cervical cancer screening (Oster et al. 2009). Cross-training of health care providers and telemedicine facilitation for providers in remote locations are also important strategies to ensure a broad approach for providing services for persons living with HIV infection (Ohl et al. 2013).

6.13.8 Biomedical Interventions for Women at Increased Risk of HIV

With the recognition that heterosexual transmission is the main risk factor for HIV exposure for women in the U.S., and that negotiating use of condoms may not always be feasible for some women before or in the midst of an active sexual encounter, researchers have sought to develop topical and vaginal-ring microbicide products for the prevention of HIV, for use with or without condoms and controlled by the female sex partner (Guffey et al. 2014). Several new HIV prevention technologies that could be beneficial for women at risk of HIV exposure, such as cervical barriers and microbicides, are being investigated. Vaginal microbicides are a form of antiretroviral medicine that can be applied directly onto the surface of the vagina before sexual intercourse (Shattock and Rosenberg 2012). Microbicides can be gels, capsules, films, intravaginal rings, and creams. These strategies can be used by women with or without the knowledge of their partners, which maybe particularly important or women at risk of IPV.

Pre-exposure prophylaxis (PrEP), which has been shown to be efficacious for prevention of HIV acquisition in both heterosexual and same-sex couples, is increasingly researched for safe use by women (Baeten et al. 2012; Karim et al. 2011). PrEP was approved by the Food and Drug Administration in 2012 for adult use (U.S. Food and Drug Administration 2012). Although initial research focused on decreasing HIV transmission during sexual activity (regardless of pregnancy intentions), questions regarding PrEP use during pre-conception (Whetham et al. 2014) and pregnancy (Mugo et al. 2014) for women are increasingly being addressed as part of decreasing perinatal transmission risk and expanding options for women who may have HIV-positive sex partners.

6.13.9 Resilience Among HIV-Infected Women of Color in the United States

One of the understudied areas for many HIV-infected women of color involves their ability to often survive and thrive in the face of adversity and illness; this is often due to resilience. Resilience includes the ability to function competently following stressors, and/or achieve positive work, relational, cognitive and behavioral outcomes, and healthy psychological and physical functioning despite adverse experiences and environments (Bonanno et al. 2007; Dale et al. 2014). Women who are living with HIV are disproportionately affected by adversities, including limited income and employment opportunities, challenges of managing their HIV and the often-associated stigma, simultaneously prioritizing family needs as a primary caregiver, and for many women of color in the United States, the frequent experiences of racism (Kelso et al. 2014).

Despite the multi-layered context of challenges for women of color, the resilience of women to manage and thrive after an HIV diagnosis may be understood based on “framing institutions.” “Framing institutions generate language, adaptive skills, and practical knowledge that shape how individuals interpret a new life condition and whether they ultimately see it as a platform for growth,” (Watkins-Hayes et al. 2012, p. 2030). Black HIV-positive women often describe their personal spirituality, social support networks (friends, family and intimate partners), medical providers, support groups, and social service providers as vitally important to their “framing institutions” and their ability to build and sustain coping trajectories (Watkins-Hayes et al. 2012). Other research has identified culturally relevant resilience strategies used by people with intersecting identities (including women of color), including building supportive HIV-positive networks among women living with HIV (Logie et al. 2011); these networks help women maintain strategies and commitments to medication adherence and clinical care. As noted earlier, religion and spirituality may also increase resilience against HIV stigma for many women of color. Chaudoir et al. (2011) found that spiritual peace (a sense of peace and meaning) helps buffer people living with HIV from the negative effect of HIV stigma and depression.

6.14 Summary and Next Steps

Finding effective solutions to stem the spread and reduce the burden of HIV infection that disproportionately affects women of color in the United States requires a social justice paradigm that considers the multiple overlapping syndemics that contribute to risk for women of color. HIV prevention interventions for women need to consider strategies that include learning about self-defense, self-sufficiency, activism, self-efficacy, empowerment and influencing policy makers (Gómez 2011). However, as Gomez so eloquently states: “the dismantling of structural barriers, the

perseverance of racial discrimination, and the underprivileged social status of women remain our greatest challenges for HIV prevention with women” (Gómez 2011, p. S292).

The perspectives of women living with HIV should also be a part of considering next steps. Recent qualitative research and interviews with women living with HIV infection suggest that future research steps should prioritize: (1) integrating HIV prevention and care services with screening and interventions for sexual and reproductive health services, trauma, and violence; (2) interventions to remove structural barriers that place women at risk; and, (3) meaningful involvement and leadership of women living with HIV in setting the research and implementation agenda as biomedical tools are developed and introduced (Forbes et al. 2014). Including black women and Hispanic women/Latinas as part of the dialogue will also be a vital component of future research agendas for women at risk for and living with HIV in the United States.

In addition to the areas above, intervention research could test interventions that encourage adaptive strategies to help build resilience among women (Earnshaw et al. 2013). If syndemic conditions work together to increase vulnerability to HIV, then mitigating one or more of these conditions and increasing resilience, should work to decrease HIV vulnerability. Health care providers, including physicians, nurses, psychologists and social workers, can be trained to identify and promote resilience resources for patients, such as discussing with patients ways in which they could obtain social support through resources and persons who are less likely to stigmatize.

An NHAS-focused meeting sponsored by the federal Office on Women’s Health and held in 2010, engaged health care providers, United States policy makers, and governmental and nongovernmental organizations to promote increased leadership in gender-specific HIV prevention programming for women and girls in the United States (Forbes 2011). The final recommendations were aligned with NHAS goals and provide a good starting road map for how federal agencies and other public health practitioners and advocates could direct resources and efforts in line with the overall goal of making HIV prevention programs more responsive to the needs of women and girls in the United States. Selected recommendations for HIV prevention that may be particularly helpful for women of color and that consider a syndemics approach have been summarized in Table 6.2. Public/private partnerships and collaborations, at each level of the syndemics framework, will be an important component if we are to successfully reach these HIV prevention goals.

Finally, as we look toward the future years of HIV prevention with women of color, it is imperative that we remain open-minded to a range of strategies that engage women wherever they are in the spectrum of HIV risk, health care, and within the syndemics framework. By considering the complexities of women’s lives and developing innovative, dynamic approaches that remove structural and social barriers to HIV risk reduction, treatment and care, we can increase the capacity of women, their communities and their providers and work toward improved outcomes for black and Hispanic women/Latinas in the United States.

Table 6.2 Selected recommendations for implementing HIV/AIDS prevention for women and girls of color in the United States using a syndemic theory approach, 2014

National HIV/AIDS Strategy (NHAS) Goal	Direction/Action (Public/private partnerships will be important strategies to reach goals)	Recommendation(s)	Syndemic theory approach (focuses attention on multiple linkages and pathways between disease and society)
1. Reducing new HIV infections	NHAS commits to “testing and growing our portfolio of interventions that incorporate such issues as sexual networks, income insecurity, gender-based violence and other social factors that place some women at greater risk for HIV infection than others”	Explore how states and local jurisdictions currently record data on structural determinants such as income insecurity, food insecurity, employment, education and homelessness so that they can be factored into calculations of the need for public services. Use this information to develop standardized reporting mechanisms that states and localities can use to collect and record social and structural determinants data† for use in assessing HIV services needs and gauging the appropriateness of available interventions for their populations	Consider research and interventions that focus on reducing the poverty and violence that disproportionately affect women, especially black and Hispanic women/Latinas. Also, consider research that increases educational and employment opportunities for disproportionately affected women of color
	NHAS states that “CDC, HRSA, SAMHSA will collaborate with States and localities on pilot initiatives for expanding the most promising models for integrating HIV testing, outreach,	Continue funding streams that encourage cross-agency engagement and collaboration between CDC, NIH, HRSA, HUD, DOE, SAMHSA and Bureau of Prisons for HIV	Consider structural approaches that engage multiple, collaborative agencies that focus on public health, research, housing, education, drug use, mental health, and incarceration to

(continued)

Table 6.2 (continued)

National HIV/AIDS Strategy (NHAS) Goal	Direction/Action (Public/private partnerships will be important strategies to reach goals)	Recommendation(s)	Syndemic theory approach (focuses attention on multiple linkages and pathways between disease and society)
	linkage and retention in care in high risk communities”	prevention strategies. Demonstrable ability to retain the participation of women and girls in HIV and sexual and reproductive health (SRH) programs should be considered as a positive factor in funding decisions	design and evaluate innovative prevention strategies and combination approaches for preventing HIV in high risk communities
2. Increasing access to care and improving health outcomes for people living with HIV	NHAS commits to strengthening the current provider workforce to improve the quality of HIV care and health outcomes for people living with HIV	Increase the number of HIV and primary care clinical providers who are engaged in innovative approaches to health care delivery, including telehealth, home health visits, peer navigators, etc. Also, expand training for HIV clinicians and provider organizations to address provider-associated factors (e.g., appointment scheduling, cultural competency, provider continuity) and strengthen collaborations that may affect treatment adherence	Consider capacity-building strategies that diversify staff members and encourage community-level engagement for social support and buy-in. Also, consider streamlined treatment and care facilities, such that women can receive primary care, reproductive health care and social services at one location by a team of providers and also benefit from community-based outreach and education. The ACA language may support integrated screening and treatment services and provide incentives for this integration at the local level

(continued)

Table 6.2 (continued)

National HIV/AIDS Strategy (NHAS) Goal	Direction/Action (Public/private partnerships will be important strategies to reach goals)	Recommendation(s)	Syndemic theory approach (focuses attention on multiple linkages and pathways between disease and society)
	<p>NHAS states that “CDC, HRSA and SAMHSA and other relevant HHS agencies will work with States, tribal governments, localities and CBOs to promote co-location of providers of HIV screening and care services as a means of facilitating linkages to HIV care and treatment, and to enhance current referral systems within CBOs”</p>	<p>Expand the range of HIV service provision sites (including prevention, voluntary counseling and testing, and treatment) to include integration of these services (by direct provision or referral) at: Federally Qualified Health Centers, Other Federally-Funded Community Health Centers, Indian Health Service centers, Gender-based violence (GBV) service provider sites, mental health care provider sites, SRH provider sites</p>	<p>Consider funding community-based programs and ongoing peer-to-peer support services that empower, educate and assist women and girls living with HIV in communicating fully with their health care providers. This approach will also require simultaneous community education within homes, schools and churches that encourages dialogue about HIV and decreases the silence which contributes to the HIV stigma that hampers engagement and treatment adherence</p>
<p>3. Reducing HIV-related health disparities</p>	<p>NHAS states that DHHS agencies will collaborate “to engage in policy research and evaluation activities to identify effective prevention approaches to reduce disease burden in high prevalence communities”</p>	<p>Support community-based participatory research (CBPR) to identify barriers to HIV testing and treatment in areas of high HIV prevalence and incidence in the United States. CBPR should also be funded to develop effective tools for SRH promotion and HIV prevention programming, as well as optimal methods of program integration</p>	<p>Consider establishing implementation research programs that utilize collaborative, community models for multi-level HIV prevention approaches that also inquire about educational and employment needs, provide case management services if needed, and screen and treat for substance use, IPV, and mental health diagnoses, if present</p>

(continued)

Table 6.2 (continued)

National HIV/AIDS Strategy (NHAS) Goal	Direction/Action (Public/private partnerships will be important strategies to reach goals)	Recommendation(s)	Syndemic theory approach (focuses attention on multiple linkages and pathways between disease and society)
	NHAS directs “relevant HHS agencies to consider ways to enhance the effectiveness of prevention and care services provided for high risk communities, including services provided through the Minority AIDS Initiative”	Create a funded Congressional Initiative on Women and HIV that is directly analogous to the Minority AIDS Initiative	Consider targeted funding for public health collaborations (government, academic, private and community-based) that examine and implement best practices for HIV prevention for women and girls. Optimal collaborations would include prevention opportunities that target syndemics-focused social and structural needs in addition to individual and clinical needs

Notes: *ACA* Patient Protection and Affordable Care Act; *CBO* community-based organization; *CBPR* community-based participatory research; *CDC* Centers for Disease Control and Prevention; *DHHS* Department of Health and Human Services; *DOE* Department of Education; *GBV* gender-based violence; *HRSA* Health Resources and Services Administration; *HUD* United States Department of Housing and Urban Development; *NHAS* National HIV/AIDS Strategy; *NIH* National Institutes of Health; *SAMHSA* Substance Abuse and Mental Health Services Administration; *SRH* sexual and reproductive health

†Centers for Disease Control and Prevention. (2013). Social determinants of health among adults with diagnosed HIV infection in 18 areas, 2005–2009. HIV Surveillance Supplemental Report. <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/#supplemental>. Published April 2013. Accessed September 22, 2014

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Chapter 7

Sex Work

Paul Draus and Juliette Roddy

7.1 Introduction

We should state upfront that neither of us is, strictly speaking, an expert in either sex work or HIV/AIDS. One of us (Draus) a sociologist and the other (Roddy) is an economist, and our primary shared area of research has been substance use and misuse. Draus has a background in applied public health; he worked in tuberculosis (TB) control throughout the 1990s, at a time when the concept of syndemic was first developed to describe the collaboration of factors contributing to the TB resurgence as well as associated epidemics of HIV/AIDS and substance use. Roddy has used microeconomic analysis to examine the decision-making processes of substance users with a focus on public policy. We came to work together because we were both gathering data on the same set of active heroin users in Detroit.

Since that time, we have conducted extensive research on the interrelationship between sex work, substance use, and neighborhood context in the city of Detroit, which we approached from the standpoint of women's health. Nevertheless, as academic researchers our main focus was on substance use and the process of recovery, and we viewed both health risk and sex work as correlates of this central issue. However, our research has expanded in scope to include the neighborhood settings that surround both drug use and street sex work, and which also form the context for recovery processes.

Investigating a court-supervised substance abuse treatment program specifically directed at street sex workers, we found that while the legalistic-therapeutic model

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had success in diverting many women from street sex work and active substance use, it did not attempt to address the structural factors that contributed to those behavior patterns. Likewise, we also found that compromised health status, including HIV seropositivity in some cases, but also a variety of other physical and mental health problems, was a common experience for the women that we interviewed—an enduring and starkly individualized reminder of the costs incurred by sex work and life on the street.

7.2 Sex Workers and HIV/AIDS

Because sex work is illegal in most of the United States, it is of course impossible to know with great precision how many sex workers there are, much less their rates of HIV infection. A meta-analysis published in *The Lancet* in 2012 found that the risk of becoming infected with HIV was almost 14 times higher for sex workers than for the general population, though this varied significantly from country to country (Baral et al. 2012). Commenting on the study, Shannon and Montaner (2012) wrote,

The results stand as an important marker of the sheer scale of the HIV epidemic among female sex workers worldwide, and a call to action, both for investment in science and scale-up of evidence-based HIV-prevention interventions (p. 501).

However, the necessary interventions include not only biomedical and public health measures such as access to HIV testing, antiretroviral treatments, education and provision of condoms, but also policies that make sex work safer and less stigmatized (Overs and Loff 2012).

These policies also make HIV rates difficult to estimate. In the United States, the Centers for Disease Control (2013) openly acknowledge a lack of data concerning HIV prevalence among sex workers, stating “There are few population-based studies of sex workers in the United States or globally because sex work is a stigmatized occupation and is illegal throughout most of the United States and the world.” Data about U.S. sex workers has often been gathered through localized studies focused on street sex work or substance use. For example, a five-city sample of sex workers (Paone et al. 1999) who utilized syringe exchange programs found that greater HIV risk in women attending those programs who did not engage in sex work. Inciardi and colleagues (2006) found HIV infection rates above 20 % among a sample of 586 street sex workers in Miami. However, the women also had high rates of homelessness and drug use, factors which also may contribute significantly to the risk of HIV. In fact, it is this very collaboration of behavioral, environmental, and structural factors in shaping HIV risk that gave rise to the original concept of the HIV syndemic.

7.3 Defining Syndemic

Syndemic theory, according to Singer (2009), restores holism to the epidemiology of infectious disease, which has been dominated by a biomedical reductionism since the emergence of germ theory in the late 19th century. Prior to that time, a belief in miasma or environmental conditions as the preeminent causes of disease held sway in Western medicine. This approach was overturned by the evidence in support of germ theory, which also brought great improvements in medical efficacy. However, at the same time, something was also lost when this transition occurred.

Reflective of this atomistic approach to knowledge, biomedicine separates the person with an illness from his or her immediate social context and community, diseased organ systems from the whole body, and one disease from another (Singer 2009, p. 10).

Using the lichen as an analogy, Singer describes the symbiotic relationships that exist between organisms and environments in both states of health and in conditions of disease (2009, pp. 18–19). By focusing on species (specific diseases caused by specific agents within discrete organisms) and not on connections (inter-relationships between agents, organisms, and environments), biomedicine limited its own capacity to understand and respond to diseases characterized by complex causation.

In contrast to biomedical reductionism, syndemic is a multidimensional concept that seeks to capture the array of factors that not only contribute to contemporary epidemics, but which also interact in a dynamic fashion to reinforce the damage done by single afflictions. In a study of HIV, tuberculosis (TB), and homicide in New York City, Freudenberg et al. (2006) defined a syndemic as “2 or more epidemics, with biological determinants and social conditions interacting synergistically, that contribute to an excess burden of disease in a population” (p. 424).

While biological factors are listed first in this definition, the authors maintain that disease outcomes (specifically HIV and TB) occurred as a *downstream* result of structural factors that increased the vulnerability of populations to multiple types of bodily harm. In the case of New York City, they present evidence that the fiscal crisis of the 1970s was followed by severe cuts in social and health services directed at poor populations. “In summary, a variety of policy decisions made in the fiscal crisis and thereafter contributed to the TB, HIV and homicide syndemic that peaked in the mid-1990s” (Freudenberg et al. 2006, p. 429). They also argue that behavioral factors, such as drug use, sexual behaviors, and criminal involvement, are results of, or responses to, environmental conditions that were impacted by the overall fiscal crisis and specific policy choices.

Likewise, Talman et al. (2013) focus on the degradation of the natural environment due to global climate change as the primary factor driving changes in social and sexual behavior that facilitate the spread of HIV/AIDS in Sub Saharan Africa. In each case, the syndemic framework invites an exploration of the dynamic interaction of factors at multiple levels. As put by Ostrach and Singer (2012), “poverty, sexually transmitted infections, sexual violence, and structural inequalities, as well as other factors, contribute to synergistic pathways of interaction that

increase women's biopolitical risks for HIV" (p. 266). Sex work, particularly street sex work, fits into this picture because it is primarily an economic activity with bodily consequences.

As applied researchers investigating street sex work, we are drawn to syndemic theory because it reflects the complex interrelationship between multiple sets of factors that are so often evident in the lives of people that we have encountered. Street sex work is often, if not always, characterized by extreme social marginality. In our view, sex work itself is as much a response to this marginality as a source of it. Programs that are not equipped to address the sources of such marginality—which most are not—tend to engage instead in teaching individuals to cope with its effects. Hopefully, some will overcome them, but for most the deficits are long-term and in some sense, insurmountable. To put it in other terms, social and human capital takes a long time to build. While social marginality, by definition, equates to decreased or devalued social and human capital, it also imposes penalties of its own. Socially marginalized individuals cannot easily gain the social capital that they are missing. To make matters worse, while poverty and substance abuse may contribute to the likelihood of exposure to HIV, infection with HIV may in turn drive patterns of substance abuse, both of which contribute to increased stigma, social exclusion and marginality—in other words, the further magnification of bio-political risk that is mostly structural in origin.

This is the sense in which the concept and theory of syndemic is employed by Singer, who has been one of its most vocal proponents. However, the syndemic concept can also be employed in a more limited fashion, focusing on the dynamics of local contexts or environments and/or the intertwined and mutually reinforcing nature of psychosocial factors and biological risk at the individual level. We discuss each of these approaches in the sections below.

7.4 Sex Work, Structural Violence, and SAVA

While some use the terms “sex work” and “prostitution” interchangeably, we opt for “sex work” because it is less morally loaded and pejorative and because it emphasizes that this is first and foremost a form of labor and economic activity. In our work, we were often told it was one of the only consistent ways for women to make money. Drug dealing is another accessible means of obtaining income in poor urban neighborhoods with high unemployment. However, it tends to be dominated by males.

While sex work may be defined in very strict and narrow terms as the exchange of sexual services for money or other things of value, in practice sex work is not one clearly defined set of practices, but a broad continuum, with both “sexual services” and “things of value” being quite variously defined. As such, sex work may not be considered as an issue apart from the overall political economy of sex (Rubin 1975). In this view, everything from traditional marriage to erotic dancing might (and should) be defined as a form of sex work, given that all involve a tight

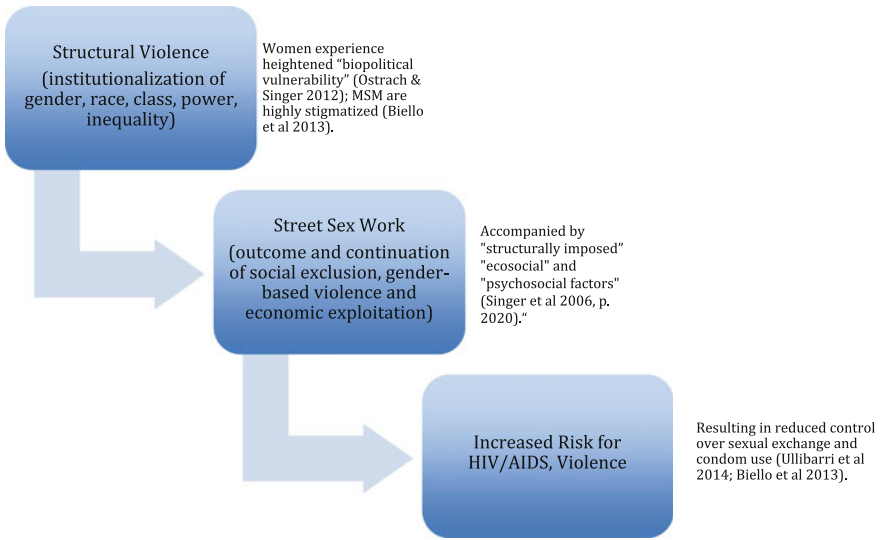


Fig. 7.1 Simplified schematic of relationship between structural factors, sex work and HIV/AIDS risk

connection between conceptions of sexuality, gender roles, value, and material exchange.

In the dominant cultural discourse, sex work is seen either as a matter of individual choice, in which case it is both criminalized and morally condemned, or as a matter of victimization (often called human trafficking) in which case it is also criminalized and morally condemned, but for different reasons. In the first instance, those who participate in sex work may be stigmatized multiple times over: seen as criminals, drug addicts, sexual deviants, and spreaders of disease. In the second instance, it is the traffickers who are identified as the source of the problem. (Interestingly enough, in both cases the customers, johns, or tricks, or often neglected as a cause of the behavior—it is assumed that men, in particular, will always find a way to pay for sexual services).

In the theoretical discourse of social science, on the other hand, sex work is often positioned as an outcome of structural determinants that place specific groups at heightened risk, largely as a result of factors outside of their control (see Fig. 7.1 for an intentionally oversimplified representation of this causal relationship). A passage from Singer’s *Introduction to Syndemics* (2009) posits this causal relationship:

Structural violence and interpersonal violence often go hand in hand, as victims of structural violence generate physical violence from their suffering. Being taught by their day-to-day experience that their options are few and the future unwelcoming, that their marginalized lives hold little value in the larger society, and that they are dispensable as people is the ultimate source of the trivialization of life and the explosive anger expressed through domestic violence of all sorts. It is within this type of noxious social context that the intersection of domestic violence, substance abuse, and AIDS risk is disproportionately

common. *Structural violence, in short, begets much interpersonal domestic violence...and also generates the accompanying facilitators and consequences of violence writ large and small, including drug use and AIDS risk behavior and infection* (emphasis added) (p. 33).

In this conceptualization, structural factors are seen as higher-order phenomena that exert an influence downward on community environments and individual lives, effectively channeling some populations towards risk exposure and risk behavior. Link and Phelan (2005) have argued that these structural or fundamental causes are those that place whole groups of people at “risk of risk.” Another central concept here is that of structural violence. Farmer et al. (2006) defines structural violence as:

One way of describing social arrangements that put individuals and populations in harm’s way... The arrangements are structural because they are embedded in the political and economic organization of our social world; they are violent because they cause injury to people – neither culture nor pure individual will is at fault; rather, historically given (and often economically driven) processes and forces conspire to constrain individual agency.

By focusing only on individual choice and risk, they argue, epidemiologists miss the larger-scale factors that are constraining those choices in advance. “This risk,” according to Singer et al. (2006), “is not random or meaningless; it is conditioned by socioeconomic factors that press participants to focus on short-term pleasure and emotional and material gains rather than on long-term planning and monogamous partnerships” (p. 2019). This particular variety of syndemic is sometimes described by the acronym SAVA, which stands for Substance Abuse, Violence, and AIDS, because these issues are interrelated and mutually reinforcing when structural factors remain unchanged. Street sex work, which is described by Singer (2009) as a form of *gender violence* as well as a *vector of disease* (p. 48), is seen as both an *outcome* of structural violence on the one hand and a major *risk factor* in its own right, a link on the syndemic chain.

7.5 Addiction, Sex-for-Drug Exchanges and HIV Risk

The SAVA concept was influenced by the specific history of HIV/AIDS in the United States, especially the interrelationship of sexual behaviors with drug use and conditions of poverty and disadvantage. The crack cocaine epidemic of the 1980s and 1990s introduced the widespread practice of women exchanging sexual services directly for the drug itself. In the eyes of many at the time, this undermined the traditional street “pimp” system and also introduced a new level of risk, as these women were observed engaging in multiple sexual acts within a short period of time, presumably without using condoms. An Institute of Medicine report, *AIDS and Behavior* (1994) summarized much of the research,

Users typically smoke for as long as they have crack or the means to purchase it – money, personal belongings, sexual services, stolen goods, or other drugs. It is rare that smokers have only a single “hit” of crack. More likely they spend \$50 to \$500 during a three- or four-day binge, smoking almost constantly. During these cyclical binges, crack users

neglect food, sleep, and basic hygiene, severely compromising their physical health. In addition, mouth ulcerations and burned lips and tongues from the hot stems of the pipes are not uncommon, and many smokers have reported and have been observed to have untreated STDs.

This idea of an extreme form of compulsive addiction clearly undermines the very idea of rational judgment or agency. It also forces a reconsideration of sex work itself. Is sex (or the promise of sex) exchanged for a share of an already purchased drug to be considered a form of sex work? And if this is done under the driving influence of an addiction, is it a matter of choice?

In a paper published in 2009, Draus and Carlson quoted women who had participated in such crack-for-sex exchanges, and they found that there was indeed agency involved in these negotiations, although this varied depending on who was involved. One 21-year old woman specifically rejected the idea of crack for sex as a form of prostitution,

I wasn't a prostitute, I mean go out on the street, and do stuff like that, but there was a couple dope boys, ya know that I did things with, to get crack. I don't know if that's considered a prostitute or not but I don't consider it that.

The limiting factor on a woman's agency in these circumstances was not necessarily that of addiction, but that of the lack of power in the relationship. Crack cocaine dealers, referred to above as "dope boys", could (and would) demand sexual services because they controlled the resource that people wanted, and most of them were not users of the drug themselves. In other cases, women would use the idea of sexual exchange to motivate men to purchase crack cocaine, and then try to delay the sexual act until after enough drug was consumed that the man would no longer want (or be able) to engage in sex. In either case, the idea of crack cocaine as a drug that obliterated free will through its pure addictive power was at best overly simplistic. At worst, it reinforced a victimization narrative that neglected the nuances of context and negated the assertions of agency that women made, in spite of the stark power differentials that they encountered in street settings defined by hierarchies and enforced by violence. Looking at context in this way invites thinking about the mid-range, or the environmental realm, as the main locus for the generation, and the disruption, of syndemics.

7.6 Syndemics and Risk Environments

As mentioned above, not everyone who applies the concept of syndemic to sex work and HIV adopts the strong structuralist perspective of Singer. For example, a recent article in *AIDS and Behavior* (Biello et al. 2014) focuses on the clustering of psychosocial problems such as depression, substance use, childhood sexual abuse among Vietnamese men who have sex with men (MSM), which may "combine and interact to increase HIV risk among MSM—a phenomena known as syndemics" (p. 1264). Appealing to Stall et al.'s (2008) theory of syndemic production, the

authors position the syndemic itself as occurring at the micro-level where psychosocial conditions emerge and “interact synergistically to increase HIV-related sexual risk behavior” (p. 265).

Likewise, numerous other studies examining sex work and HIV risk focus primarily on localized factors that increase or magnify risk for sex workers within specific contexts. Goldenberg et al. (2011a) for example, utilize Rhodes’ concept of “risk environment” in examining how the risks of female sex workers (FSW) and their clients in Tijuana, Mexico are shaped by the specific characteristics of the red-light district, or Zona Roja, where economic and sexual transactions take place, as well as structural factors such as migration and deportation. Positioned between affluent San Diego on the north, on the U.S. side of the border, and the surrounding city of Tijuana, the Zona Rosa is identified by both sides as a “risky place” where the normal rules of society don’t apply. In particular, they found that clients’ sense of social isolation and need for intimacy within the “madness” of the Zona Rosa contributed to lax use of condoms, thereby enhancing the risk of HIV spread. “Ironically, the efforts by clients and FSWs to cope with the chaotic and isolating environment of the Zona Rosa may pose the greatest source of HIV risk through the increased probability of unprotected sex within established relationships” (Goldenberg 2011b, p. 1189).

It is significant that in this view the syndemic itself is seen as composed primarily of conditions and factors that reinforce each other within the locus of daily interactions. This is in contrast to Singer’s view of syndemics, which positions structural factors front and center and sees psychosocial conditions as reflections or outgrowths of these larger forces. While the distinction is a subtle one, it has some implications in terms of proposed interventions. The risk environment approach sees potential for targeting at local contexts with programs that disrupt the cycle of reinforcement of risk behaviors. As defined by Rhodes (2009), a risk environment is “the space—whether social or physical—in which a variety of factors interact to increase the chances of harm occurring” (p. 193).

From a structural violence perspective, such efforts are clearly insufficient. Infectious diseases such as HIV/AIDS, tuberculosis, or hepatitis C simply exploit the biological vulnerabilities produced by social inequalities. Fundamental imbalances in power will continue to generate syndemic conditions, even if specific mechanisms of disease are disrupted. Rhodes (2009) refers to this perspective when he writes,

Structuralist and political-economic explanations give primacy to ‘social determinants,’ but sometimes insufficient attention to how these are incorporated into different local contexts, and often underplay agency in this process (p. 198).

Whether the actual syndemic consists in the original layering of structural disadvantage, or in the vicious reinforcing cycles of risk and vulnerability that result, may be more a matter of emphasis than of outright disagreement. In practice, these researchers tend to recommend the same types of interventions, those designed to reduce risk in the local context, such as needle exchange, condom distribution, or

sex worker empowerment programs, while simultaneously highlighting the importance of fundamental causes. Nonetheless, agency remains problematic in discussions of sex work.

7.7 Sex Work, Feminism, and the Problem of Agency

The problem of agency, as described by Archer (2004), is that it always exists in relation to a self, which is also constrained by social structure. The emergence of our “social selves” is something which occurs at the interface of “structure and agency.” It is therefore necessarily relational, and for it to be properly so, then independent properties and powers have to be granted to both “structures” and to “agents.”

To provide a concrete example, a woman who spent a decade on the street, using crack cocaine on a regular basis and engaging in street sex work as a means of subsistence, may in fact decide that she wishes to pursue an education and move into mainstream society. Aside from the fact that she is starting from a point of having little or no capital, which requires time to accumulate, she finds herself in a situation where that is more difficult to do: she is older, she has growing children, she has relationship conflicts, she does not have a stable place to live or a source of income, and she may wear the marks of her past status on her body, in the form of scars, dental problems, or simply age.

In spite of all these obstacles, there are individuals who persist, and succeed, often with the help of support networks and programs that compensate for some of the deficits listed above. However, those individuals who escape the marginality of the street, by successfully building bridges to mainstream society, may simply be replaced on the street by others who have not had the benefits of such programs (or have failed to comply with their strict rules). Nonetheless, one cannot discount such programs, because engaging with individuals’ sense of agency is a crucial component of addressing risk and improving health and quality of life. It is because of our interest in the complex interaction of multiple factors in producing both social marginality and high-risk behavior that we are drawn to syndemic theory, which might also be seen as the application of complexity theory to issues of health risk.

The issue of agency is directly relevant to discussions of the role of sex work in the HIV syndemic. If the agency of sex workers is discounted, because they are poor, oppressed, addicted, or in some other way the objects of forces beyond their control, then the primary focus of policy becomes that of addressing the factors that lead to sex work—if possible, addressing economic, racial, and gender inequality. If, on the other hand, sex work is viewed as an adaptive strategy that always entails some degree of creative agency, even when entangled with extreme economic need, structural disadvantage, and addiction, it then becomes possible to think about expanding that agency in ways that are protective, without necessarily ending sex work (as though this were possible) or the structural factors that underlie it.

In either case, women and men engaged in sex work may be identified as high-risk populations for HIV, and resources are devoted to educating them, screening them for disease, treating the disease, and preventing infection of others through use of condoms, sero-selection or other strategies. In some cases, however, the identification of sex work as a vector of HIV disease may contribute to repressive state policies on the one hand and paternalistic programs of therapeutic governance (Pupavac 2001; McKim 2008) on the other.

According to Overall (1992), feminism is split in its views on sex work, “between an emphasis on sexual freedom and pleasure that views women exclusively as agents, on the one hand, and an emphasis on sexual degradation that sees women exclusively as victims on the other” (p. 707). Taking the former position, Ditmore (2007) argues that sex work is a form of affective labor, which involves not only bodily acts and money but also the establishment of emotions and sentiments. “For example,” Ditmore writes, “sex workers use intellectual skills to make and maintain personal connections...The creation of bonds between a sex worker and the client can be based on shared interests (sometimes feigned) or conversational skills” (Ditmore 2007, p. 172). From this perspective, Ditmore contends that “abuse within the sex industry should not...lead to equating all sex work with abuse; rather, it should highlight the need for the application of labor regulations to the sex industry” (p. 173).

Jeffrey and MacDonald (2006) contend that the dominant discourse “judges sex workers, reinforces their pathological stigmatization and, even in attempts to portray the sex worker as ‘victim,’ infantilizes her, denies her of agency and is contextual in explanation” (p. 314). In their research on sex work in the Canadian Maritimes, they found that sex workers “made choices based on income, the conditions of work, and the independence granted to them in determining these conditions and outcomes” (p. 323). Rather than alleviating risk, they argue that

The policy and program discourse that positions sex workers as ‘victims of poverty’ engages in, and supports, the same discursive power move that positions many women and youth as ‘cheap labour.’ That is, they are positioned as objects of management and control, rather than as political and social agents (p. 325).

However, as Dewey and Heineman (2013) have noted, “The limited amounts of funding available to organizations or individuals involved in advocating for sex workers’ rights contrasts rather starkly with the well-funded and highly organized abolitionist or anti-trafficking groups that position sex work as a simplistic problem of violence against women” (p. 63). For the same reason, much of the focus on sex work in regards to HIV/AIDS has been placed on limiting risk, often viewing women as victims and therefore opposing all forms of sex work as forms of oppression and exploitation as well as potential vectors of disease (Magar 2012). In some ways, these scholars argue, this has put traditional feminism in league with the victimization framework of the human trafficking discourse. The syndemic approach, if it is weighted too heavily towards structural determinants, may also reinforce this approach to sex work.

7.8 Beyond Structure and Agency: Syndemics, Complexity and Assemblage

7.8.1 Theory

We contend that the concept of syndemic, grounded in an understanding of complex systems, may encompass both of these perspectives—that which emphasizes structural determinants and that focus on creative human agency. Complex systems are defined by both emergence and irreducibility (Byrne and Callaghan 2013), meaning that patterns of regularity emerge out of dynamic interactions between different elements in the system, but that these patterns are not themselves traceable to any one of these elements.

As discussed above, the collaboration of addictive and sexual behaviors is a common occurrence that complicates the notion of agency in sex work, and introduces additional complexity into our understandings of HIV/AIDS. Because HIV is primarily transmitted through behaviors that are, at least on some levels, voluntary, simplistic models of structural determinism can run into problems. A further point of confusion lies in the fact that actors can vary in the interpretation of their own situations. While currently employed in sex work, she may interpret her actions as actively taking control of her life. However, often, once a sex worker has decided to exit that role, she may interpret her own role as that of victim. This evolving interpretation emphasizes the role of environment and circumstance in shaping behavior, perception, and translation. This is similar to the findings of other sex work researchers, who emphasize the simultaneous importance of individual agency and the durable constraints of structure, environment, and context (Sanchez 1997; Dewey and Kelly 2011; Izugbara 2011).

Clearly, in many places, the co-occurrence of poverty, sex work, and infectious disease follows similar patterns. However, to extrapolate from one setting to another without adjusting analysis to fit local contexts is problematic. There are many places where sex work is prevalent, for example, and TB or HIV risk is not high. People also adjust their behaviors over time, based on the diffusion of knowledge relative to HIV risk and other factors. In other words, the history of syndemics, like history more generally, is complex and contingent. There is no one model that represents risk everywhere; and in every case agency is entangled with social or structural determinants in dynamic ways that make prediction (and prevention) of risk difficult.

If we think about the SAVA formulation, for example, it might well be the case that the convergence of violence, substance abuse and AIDS has often been observed, and that this nexus is also a reflection of structural factors such as poverty and social inequality, but it does not necessarily follow that this pattern will manifest the same way everywhere. We can well imagine situations where substance abuse and HIV/AIDS might be strongly associated, without the presence of endemic interpersonal violence. In the early years of the AIDS epidemic, for example, the spread of the disease was associated with very different patterns in

different groups. Among gay men in the United States, sexual behavior and substance use were to some extent interrelated and contributed to HIV transmission in those populations, but violence was not a key component, unless one lumps all form of structural and interpersonal violence together, in which case analytical precision may be sacrificed in order to maintain the conceptual formulation.

Some of the other major risk groups identified in that phase of the epidemic included intravenous drug users, hemophiliacs and immigrants from high-prevalence countries. This led to the profiling of the “Four Hs”—homosexuals, heroin users, hemophiliacs, and Haitians (Gallo 2006). While it may have been accurate to see these groups as defined by statistically higher levels of risk for HIV, the error was in defining that risk as being somehow a logical outgrowth of group membership itself, thereby emblazoning them with what Gilman (1987) called “AIDS iconography.”

In fact, there is nothing inherent in any of these groups (or their behaviors) that makes them “high risk,” except when brought into association with the HIV pathogen through networks and technologies that enable it to leap from one location or population to another. In some places, such as Western European cities like Antwerp or Amsterdam, participation in sex work may be highly regulated and largely safe from risk of injury or infection (Weitzer 2013). In other contexts, such as sub-Saharan Africa, heterosexual masculinity and marriage norms, in conjunction with sex work, have been key factors in the transmission of HIV, while in Thailand police crackdowns on bars and nightclubs contributed to increased transmission in riskier street-based sexual encounters (Piot et al. 2008). Likewise, in Goa, India, the destruction of an established red-light district disrupted HIV prevention efforts and increased risk of HIV for sex workers, as a “concentrated and homogenous sex trade rapidly evolved into a clandestine, heterogenous and dispersed form” (Shahmanesh et al. 2009, p. 610).

Globally, sex workers are often viewed as a “core group” that may harbor HIV and allow it spread into the general population (Morison 2001). They have become the focus of HIV epidemiology and prevention efforts not merely because of their own behaviors, but because of their social position as mediators between different population groups. Whether that role is a source of risk is entirely dependent on the behaviors and characteristics of those seeking sexual services. In India, research showed HIV transmission and geographic spread as resulting from the sexual behaviors of long distance truck drivers who sought out sex workers in rural areas along their delivery routes (Singh and Malavia 1994). What is the source of the risk in that situation: sex work, poverty, masculinity, or highways? Clearly, all of these are involved, but the ways in which they come together are highly variable, even if there are common patterns.

A potentially complementary concept to syndemic is that of the *assemblage*. Originating with the work of Deleuze and Guattari (1987), and later elaborated by DeLanda (2006). Assemblage theory looks at how local factors converge in unique but patterned ways. While every assemblage is unique and contingent, elements of that assemblage may be present in other settings, with dynamics that are similar but once again unique. In a sense, any actual epidemic is always an assemblage, not an

entity. The epidemic assemblage itself is not transferable, though components of it (infectious agents, vectors, behaviors, and so on) may be. The main points of assemblage theory are outlined by Little (2012):

1. Social entities are composed of components and lesser systems.
2. The components of a social entity are heterogeneous.
3. The components include both material factors and meaningful expressions.
4. The components have their own characteristics and dynamics.
5. The components may have very different temporal and spatial scales.
6. The effects and interactions among components may be indeterminate because of complexity effects and probabilistic causal mechanisms.
7. The behavior of the whole is difficult or impossible to calculate even given extensive knowledge of the dynamics of the components.

According to Little (2012), “This reformulation suggests that large social entities are ‘messy’ but still amenable to analysis and study; and this is what sociology requires” (para. 10).

7.9 Summary

In our own research in Detroit (Draus et al. 2014, 2015), we found that women (and transgender men) entered into street sex work through their engagement with specific environments, though their trajectories were also shaped by their economic and educational backgrounds, their experiential histories, their psychosocial characteristics, and their behavioral choices or adaptations. To isolate any one of these as the primary cause of sex work, or the primary risk factor, would be to neglect the interaction of factors that occurs within specific settings, kicking dynamics into play that make certain sets of outcomes more likely. Likewise, their pathways out of sex work were influenced not only by physical surroundings and material resources, but also by social networks and belief systems that were engaged through the assemblage of substance abuse treatment programming.

If we consider what has been summarized above concerning syndemics, HIV and sex work, we can see how these points relate directly to the syndemic approach. No disease occurs in isolation from other factors—diseases do not have essential natures, nor are “risk factors” always the same everywhere. Instead, they are realized in social space through the convergence of other elements, both human and non-human. Likewise, the role of sex work and sex workers is highly contingent upon other factors, at the “macro”, “meso” and “micro” levels. One implication of assemblage theory is that these distinctions are themselves somewhat arbitrary, and this means that the debate over structural versus environmental or behavioral factors as primary causal agents in HIV syndemics becomes largely superfluous.

Instead, what is important is recognizing the interaction of elements, allowing for a wide range of possible outcomes, but a somewhat smaller range of *likely* outcomes. These represent the possible directions of a particular system, given its

internal dynamics, which are themselves always somewhat unpredictable due to the number of interactions and (in the case of human systems) the role of reflexive agency. Employing other terms associated with Deleuze and Guattari (1987), syndemics are rhizomatic; they branch off and spring forth in different directions (or not at all) depending on the characteristics of the soil, obstacles in the way, nutrients available, and so on. Using the example of the orchid fertilized by a wasp, Deleuze and Guattari (1987) maintain that causality in the real world does not flow in one direction, but always involves a multiplicity of pathways and potentials.

How could movements of deterritorialization and processes of reterritorialization not be relative, always connected, caught up in one another? The orchid deterritorializes by forming an image, a tracing of a wasp; but the wasp reterritorializes on that image. The wasp is nevertheless deterritorialized, becoming a piece in the orchid's reproductive apparatus. But it reterritorializes the orchid by transporting its pollen. Wasp and orchid, as heterogeneous elements, form a rhizome (p. 10).

Referring back to Singer's lichen analogy, it may be the case that lichen are all characterized by symbiotic relationships between organisms, but each lichen community will be in some ways distinctive. So it is with syndemics. HIV itself is a retrovirus, territorialized in the bloodstream and eventually manifested as AIDS if left untreated and allowed to run its course. However, an HIV/AIDS epidemic involves a multiplicity of connections and a manifestation at the population level. For this to occur, HIV must be de- and re-territorialized many times over: sex work practices, physical environments, psychosocial states, gender norms, violence, prevention education (or lack thereof), state policy, and so on, would all be elements of that rhizomatic emergence which we may also call a syndemic. Rather than a diagram showing a simple downward flow from structural causes to psychosocial and biobehavioral outcomes, a rhizomatic depiction of a syndemic might look more like this (Fig. 7.2).

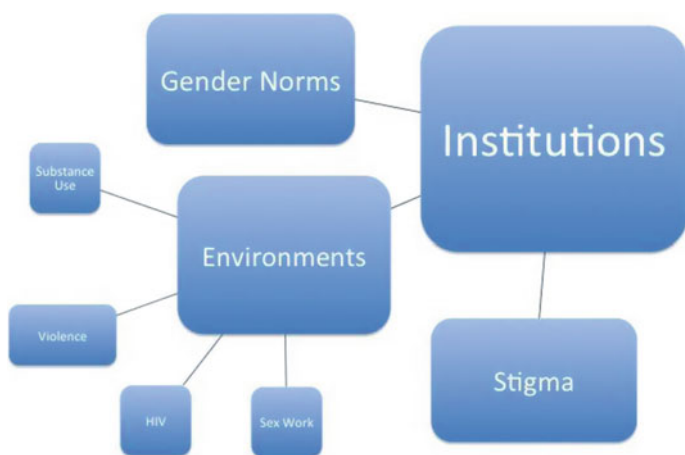


Fig. 7.2 Simplified schematic of rhizomatic relationship between structural factors, sex work and HIV/AIDS risk work

While the factors elsewhere described as structural are here depicted as larger units, reflecting the fact that they encompass the status of groups, as opposed to just the behaviors of individuals, the diagram is flat, rather than hierarchical. The lines are not directional arrows. The clustering of factors, such those involved in the SAVA syndemic (substance abuse, violence, AIDS), do not indicate a necessary causal ordering, but one that is rooted in a concrete description of a particular situation, such as that described by Simic and Rhodes (2009) among street sex workers in Serbia. One could imagine (and document) situations where the factors would be ordered or arranged differently. For example, if sex workers were able to access better information and services than women in society more generally, sex work would not be clustered so closely with HIV, substance use and violence. While this is an oversimplified depiction, it invites a somewhat different approach than that implied by either a biomedical reductionist model or a structural determinist approach.

Adam (2011) has criticized the idea that “treatment as prevention,” arguing that it privileges the role of biomedical technology while ignoring approaches that could be employed immediately. He maintains that,

...impeding the epidemic is work that needs tools available in the social sciences. These include examining how HIV moves (or is slowed) according to the ways that people are socially organized and networked; the popular strategies and folk wisdoms developed in the face of HIV risk; socio-historical movement of sexual and drug cultures; the dynamics of popular mobilization to advance health; the institutional sources of HIV discourses; and popular understandings of HIV technologies and messages (p. 6).

In line with complex systems approaches, syndemic theory maintains that these phenomena are not reducible to component parts. It is not simply a matter of targeting one risk factor or pathway. On the other hand, this multiplicity of HIV collaborators also provides a multitude of potential avenues for disruption of transmission (Shannon et al. 2008). As the work of Krusi et al. (2012) demonstrates, engaging with sex workers at the local level can inform environmental approaches that enhance agency and lower the risks of sex work, including risk for HIV, but also risks of violence and trauma.

The syndemic approach leads us away from the idea that environment and context are mere complicating factors which make diseases harder to isolate. Rather, it suggests that these elements are themselves constitutive of the emergent disease, manifested in social and bodily space, and must be engaged rhizomatically—through networks and associations composed of active agents. A recent issue of *The Lancet* (2014) focused on the role of sex workers in the global response to HIV. After discussing the need for research not only *on* but *with* sex workers; more attention to issues of social, racial, and gender inequality; and the need for structural reforms, Das and Horton (2014) conclude,

Sex work is part of the human story. Accepting and embracing sex work – supporting those engaged in sex work to protect their health and bodily integrity and autonomy – should be our humane, as well as our pragmatic, approach to the reality of our human lives. And to our common efforts to defeat AIDS (para. 6).

This represents a welcome shift from simplistic narratives of risk and victimization as well as narrowly biomedical approaches to treatment and prevention, and reflects the influence of syndemic theory. In a sense, this is merely recognition of a truth long known in epidemiology—diseases are only the same in the abstract, and all epidemics are unique, reflecting the particularities of population, environment, and context that usher them into existence.

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Chapter 8

A Syndemic Approach to Understanding HIV/AIDS Among People Who Inject Drugs in the U.S.

Enrique R. Pouget and Alexander S. Bennett

8.1 Introduction

People who inject drugs (PWID) have experienced the second highest number of HIV infections and HIV-related deaths of all risk groups in the U.S. second only to men who have sex with men (MSM; Centers for Disease Control and Prevention [CDC] 2015b). While incidence has been greatly reduced since the 1990s, there were still over 4,000 new HIV infections among PWID in 2012 (CDC 2015b). Moreover, PWID in the U.S. are also disproportionately impacted by Hepatitis B (HBV) and C (HCV), and are vulnerable to sexually-transmitted infections (STIs) and fatal drug overdose. Syndemic theory can help us better understand the etiology and epidemiology of HIV among PWID, and help inform improved prevention and treatment programs among PWID generally, and among high-risk subgroups, like African American and Latino PWID, and PWID who are also MSM. Ultimately, the true promise of syndemic theory lies in changing social structures to prevent multiple syndemic conditions, particularly among socially marginalized populations.

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8.2 Social Determinants of Drug User Policy

The harmful effects of drugs includes the harms of the drugs themselves, and the harms caused by efforts to control drugs (Burris and Burrows 2009). Policies around the use or injection of illicit drugs developed over time to address perceived social problems, and to respond to changing political interests, more often based on how drug users were perceived than on the effects of the drugs themselves. Punitive drug use policies compete with medical and public health approaches to problem drug use, and drug problems among disenfranchised groups have been more likely to be treated punitively.

The development of the hypodermic syringe in the 1850s and the practice of injecting drugs into a muscle or vein intensified the effects of opiates and other drugs, increasing the level of euphoria that could be achieved, but also increasing withdrawal symptoms (Acker 2002). As a result of the availability of syringes and doctors' practices of prescribing injectable drugs for a wide variety of ailments, injectable opiates became more readily available, and problems associated with dependency climbed beginning in the late nineteenth century (Spillane 2001). This early wave of drug use centered primarily on urban communities in larger cities on the East and West Coasts, and included a broad variety of users, including middle class white men and women (Schneider 2008). By the 1930s, however, problematic drug use began to be conflated in popular culture with the African American and Latino communities (Courtwright 2001; Peele and Brodsky 1997). For example, Federal Bureau of Narcotics Commissioner Harry J. Anslinger campaigned against marijuana, heroin, and other drugs which he associated with African Americans, Mexicans, and counterculture dissidents, as part of a moral crusade in which he prominently had singer Billie Holiday arrested multiple times for drug possession (Hari 2015). By the early 1950s, as historian David Courtwright has argued, the "model addict profile was that of a young black man (four out of five users were male) in his twenties" (Courtwright 2001).

While drug use negatively impacted a range of racially and ethnically diverse users and their communities, postwar demographic changes of cities had significant policy implications. Between 1950 and 1970, cities at the center of the postwar heroin injecting wave, such as New York, Chicago, Detroit, Philadelphia and Washington, D.C., saw dramatic rises in the proportion of city residents who were African American and Latino emigrating from Southern States and Puerto Rico, while the white populations declined or remained stable (Schneider 2008). Simultaneously, the unskilled urban labor market shrank (Wilson 2012). Poverty and unemployment in these cities became intertwined with problematic drug use and crime. Redlining led to disinvestment and urban renewal, and highway projects often had destructive effects on minority neighborhoods (Fullilove 2004; Wallace 1988). In 1971, President Nixon rhetorically declared a "War on Drugs," describing drugs in a press conference as "public enemy number one in the United States" (Nixon 1971).

Increasing severity of corrections policies for drug-related (and non-drug-related) offenses have impacted the African American and Latino communities more severely than white communities (Neal and Rick 2014). Up until the 1970s “Relatively few middle-class whites, insulated by increasing residential distance, had anything to do with the drug [heroin]” (Courtwright 2001). White suburban voters, perceiving that punitive law enforcement kept hard drugs out of their own neighborhoods, could be assured that the penal consequences of such policies would be borne, not by their own children, but by those of inner city residents (Csikszentmihalyi et al. 1999). By the mid-1980s to 1989, smoking crack became more prevalent than snorting powdered cocaine. While crack use proliferated among the poor, powdered cocaine users were more often affluent and white. Following the Anti-Drug Abuse Acts of 1986 and 1988 sentencing guidelines reflected this dualism: a user caught with one gram of crack received the same sentence as a user caught with one hundred grams of powdered cocaine (Reinarman and Levine 1997).

Rising crime rates related to the increasing population of young men in the post-war baby boom, and the fact that a disproportionate share of the burden of integration was borne by working-class whites led to white racial resentment and facilitated implementation of policies purported to get “tough on crime” (Alexander 2010). As Michelle Alexander showed in her book “The New Jim Crow,” racial discrimination arises in criminal justice mainly in two ways: first in the police discretion regarding whom to stop and arrest, and then in the high legal bar to prove racial bias in the criminal justice system (Alexander 2010). This is especially important in the War on Drugs, since drug offenses account for two-thirds of the increase in the federal prison population and over half of state prisons between 1985 and 2000 (Mauer and King 2007). Notably, arrest rates for drug offenses in the 1990s were found to be unrelated to the later prevalence of injecting drugs (Friedman et al. 2011). The high rate of incarceration, was borne most heavily among African American and Latino men, synergistically interacted with HIV/AIDS epidemic, further reducing resources in African American and Latino communities (Blankenship et al. 2005a, b; Drucker 2011; Iguchi et al. 2005).

8.3 HIV Transmission Through Shared Drug Injection Equipment

To understand how syndemics can increase risks for HIV transmission (and other blood-borne infections like HBV and HCV) among PWID, it is useful to describe the process by which HIV can be transmitted through shared drug injection equipment. HIV is transmitted through sharing syringes or drug preparation equipment, or by using syringes to share prepared drugs in a nonsterile manner. Removing a needle after injecting creates a vacuum that can cause a trace amount of blood to be taken up into the needle. If the person who is injecting is HIV-infected,

HIV is present in their blood. If an uninfected person subsequently uses the syringe, the HIV-infected blood pulled into the syringe is mixed with the drugs drawn into the syringe and injected into the body of the uninfected person, exposing them to HIV (Des Jarlais and Friedman 1987). Similarly, uninfected PWID can also become infected by sharing water used to rinse syringes; materials such as cotton balls, used to filter drug impurities, or containers, such as spoons, used to heat drugs into a solution, can cause infection because a trace amount of HIV-infected blood can remain on these materials, even after cleaning (Abdala et al. 1999; Jose et al. 1993; Pouget et al. 2012).

Thus, the risk of becoming infected with HIV as a result of injecting drugs is conditional on the prevalence of HIV in injecting partners and risk networks, and is related to the frequency of shared injecting. This risk also reflects social determinants of drug use and the economic decisions to inject rather than use other means to ingest drugs, such as snorting. Injecting produces a stronger effect for the same amount of drug, and the effects are felt more rapidly. Before the HIV virus was known, PWID frequently injected in groups, sometimes in “shooting galleries” (private rooms where drugs could be purchased and used) with both acquaintances and strangers (Des Jarlais and Friedman 1987). The common practice of shared injecting made transmission of HIV, HBV and HCV efficient among PWID in the years before the viruses were identified. PWID who injected cocaine or crack were more likely to have used shooting galleries, and to have been African American or Latino in the early part of the U.S. epidemic (Novick et al. 1989).

8.4 Substance Abuse, Violence, and Infectious Diseases

The term “syndemic” has facilitated a focus on complex social systems that produce health and illness at the population level. Syndemic is defined as 2 or more diseases or other health conditions that act synergistically as a result of social inequality (Singer 2009). Focusing on multiple interacting health conditions helps to reveal the causal role of social structural factors on multiple outcomes. The synergy of the HIV/AIDS epidemic with other health conditions, and their shared social determinants in inner cities was apparent in the early 1990s (Friedman et al. 1992; National Commission on Acquired Immune Deficiency Syndrome 1991; Wallace 1988). The HIV/AIDS epidemic disproportionately impacted poor people, people of color, drug users and gay men (Stoller 1998).

8.4.1 *The SAVA Syndemic*

Singer identified the SAVA (substance use, violence and AIDS; see Fig. 8.1) syndemic based on his work with the Hispanic Health Council in Hartford, Connecticut (Singer 1994, 2009). In Fig. 8.1, social structural determinants such as

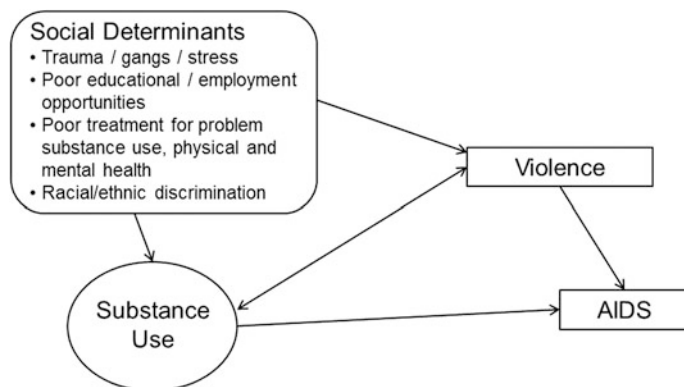


Fig. 8.1 Syndemic model of SAVA (substance use, violence, AIDS)

poor educational and occupational opportunities lead to substance use and violence. Life history interviews often reveal horrific episodes of violence among substance users. Alcohol, and other substance use is prevalent among perpetrators of violent acts (Shorey et al. 2014; Whiteside et al. 2013). Rape and coerced sex work likely exposed individuals to HIV in this era, although the extent is difficult to estimate (Singer 1994). The popularity of crack use in the 1980s, and the risks associated with obtaining enough drugs to alleviate symptoms of dependence was an important part of the SAVA syndemic. Description of the SAVA syndemic helps to contextualize individual substance use as part of a social system that marginalizes inner city problems, and blames individuals for bad outcomes even though the structural determinants (e.g., concentrated poverty and gang violence) are largely outside of the control of individuals.

One mechanism linking social conditions to HIV/AIDS is neighborhood disadvantage (Latkin et al. 2013). Social environmental conditions in disadvantaged neighborhoods such as poor housing, poor schools, low employment and high levels of violence are associated with higher levels of injection drug use, as well as with AIDS mortality (Friedman et al. 2013a, b; Galea et al. 2005; Roberts et al. 2010).

Social conditions can make decisions about injecting safely more difficult. PWID who become aware of being HIV-infected tend to reduce their risk behaviors to avoid transmitting HIV to others (Mateu-Gelabert et al. 2008). However, many PWID are unaware of their HIV-status, and some are uninformed about the risks of HIV transmission (CDC 2012b). Police crackdowns can increase the likelihood of unsafe infection, as PWID need to inject as quickly as possible, even when this means sharing equipment (Werb et al. 2008). Unstable housing and a lack of privacy makes it difficult for PWID to plan for future drug use or store drugs or syringes.

The limited ability of some PWID to plan for future drug use makes withdrawal symptoms more likely (Mateu-Gelabert et al. 2007). Withdrawal is a state resulting

from the non-use of drugs in which a person is dependent producing physical and psychological symptoms that move the person to use drugs again. The experience of withdrawal can alter behavioral norms that would otherwise support using only sterile syringes and drug preparation equipment (Wagner et al. 2010). For instance, people who inject cocaine may inject more frequently than those who inject heroin because the duration of the cocaine effect is shorter (Des Jarlais and Friedman 1988), leading to more frequent withdrawal symptoms. The use of methadone and other Medication-Assisted Treatment (MAT), such as methadone maintenance, effectively prevents withdrawal symptoms in people who are opioid-dependent. However, instability related to homelessness, incarceration, and natural disasters can interrupt MAT and lead to increased withdrawal symptoms (Dickson-Gomez et al. 2009; Maxwell et al. 2009; Mitchell et al. 2009; Pouget et al. 2015).

8.4.2 The Tuberculosis, HIV, and Homicide Syndemic

Links between social policy and syndemic are illustrated by circumstances surrounding the tuberculosis epidemic in New York from the late 1970s through the early 1990s. Tuberculosis (TB), a bacterial infection which most commonly affects the lungs, is widespread in the developing world and among immigrants in the U.S. (CDC 2015c; Kwan and Ernst 2011). In a historical impact assessment of New York City after the fiscal crisis of 1975, Freudenberg and colleagues concluded that the epidemic of TB, and epidemics of homicide and HIV constituted a syndemic because they appear to have shared underlying social determinants related to large cutbacks in public health, public safety and social services, including reduced funding for methadone treatment (Freudenberg 1995; Freudenberg et al. 2006). PWID were especially ill-served by hospital TB services due to a perceived lack of respectful care, fear of detention, and lack of adequate care to relieve the symptoms of withdrawal (Curtis et al. 1994). Importantly, the Freudenberg study suggests that the savings produced by the cutbacks were dwarfed by later costs incurred to control the syndemic. International research shows that these kinds of cutbacks, and failures to invest in public health can have substantial negative effects on subsequent population health (Stuckler and Basu 2013).

8.4.3 Injection Drug Use, HIV/AIDS and Hepatitis C (HCV)

Approximately 3.2 million Americans are living with chronic HCV infection, mostly acquired through injecting drugs (CDC 2014). HCV is the leading cause of liver cirrhosis and is the most common reason for liver transplantation. HCV is transmitted through injection risk networks more efficiently than HIV, and can be transmitted sexually among MSM, particularly those who are HIV-positive (van de Laar et al. 2010). HCV can also be transmitted through unsterile tattooing, from

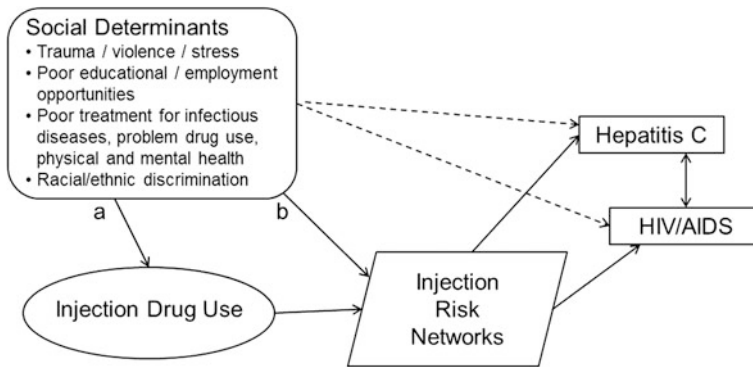


Fig. 8.2 Syndemic model of injection drug use, HIV/AIDS and Hepatitis C

having had a blood transfusion before 1992, and possibly through shared crack pipes (Tortu et al. 2004). Figure 8.2 below shows the syndemic of injection drug use, HIV/AIDS and HCV. Injection risk networks are displayed as serving to determine which PWID are exposed to and are subsequently infected with HIV or HCV. Although most arrows in the figure are unidirectional for clarity. There may also be some reverse causation with drug use and HIV or HCV causing increased stress, violence or discrimination (Link and Phelan 1995). Social conditions can increase the likelihood of injection drug use (arrow a), increase infection prevalence in risk networks (arrow b), and hasten progression to AIDS (for HIV-infected persons) and liver disease (for HCV-infected persons) through mechanisms related to poor healthcare, late detection and poor adherence to treatment (dashed arrows; Simoni et al. 2012). People with HIV are more vulnerable to HCV infection, and may have faster progression of liver disease (Hernandez and Sherman 2011). HBV is another liver infection that can be transmitted through sex or shared injecting equipment, however prevalence has declined steeply since the dissemination of an effective vaccine in the 1990s (CDC 2015d). HBV and HCV are both associated with worse HIV treatment outcomes (van Griensven et al. 2014).

The pattern of distribution of HCV prevalence among racial/ethnic groups is distinct from that of HIV. American Indians/Alaska Natives have the highest prevalence of any racial/ethnic group, and whites have higher prevalence than African Americans or Latinos (CDC 2014). The causes and epidemiology of the multiple syndemics affecting PWID are not necessarily the same for all PWID subgroups. Differences between the distributions of HIV and HCV in the U.S. highlight the need to understand potential syndemic vulnerabilities of all groups.

8.5 Networks, Social Contexts, and HIV/AIDS Disparities

While poor social conditions can lead to higher levels of drug use and less drug treatment, national data show similar patterns of drug use by race/ethnicity (Windsor and Negi 2009). In fact, African American and Latino PWID engage in fewer injection risk behaviors than white PWID (Kottiri et al. 2002; Williams et al. 2013), perhaps because they are aware of their greater vulnerability to infection due to higher HIV prevalence in their injection risk networks or because HIV-positive PWID avoid behaviors that can transmit HIV to others (CDC 2009). Research suggests that risk networks are important drivers of HIV prevalence differences (Kottiri et al. 2002), and social conditions can drive network composition (Hogben and Leichter 2008).

A social network represents the link between and among people who interact socially: one's friends and acquaintances and *their* friends and acquaintances. Research suggests that people have relatively little control over their position in a social network. Rather, networks arise from geographic, cultural and familial contexts (Valente 2010). Social networks tend to be homophilous (i.e., assortative, homogenous, populated by people with similar characteristics or interests). Similarly, sexual and injecting risk networks have been found to be homophilous for race/ethnicity (Doherty et al. 2009; Kottiri et al. 2002).

8.6 High Incarceration Rates and Imbalanced Sex Ratios

The high rate of incarceration among African Americans has been hypothesized to be related to HIV/STI transmission (Blankenship et al. 2005a, b). For people in committed sexual partnerships, incarceration can lead to the dissolution of those partnerships (Khan et al. 2011). Having a partner who was incarcerated has been found to be associated with having multiple, concurrent, and transactional sex partners, and having had a recent HIV/STI diagnosis (Adimora et al. 2003; Raj et al. 2008). High incarceration rates (and high mortality rates among young males) reduce the number of men, thus the male-female sex ratio in the non-incarcerated African American population. Since most sexual relationships are racially/ethnically assortative (of the same race/ethnicity), severe imbalance in the population sex ratio can affect heterosexual relationships. As men are removed from the population, more female partners become available for the men who are not removed. Men who have had more partners may be more likely to be infected with an STI, and may thus increase the likelihood of infection for their future female partners (Anderson 1991; Brunham 1997). Qualitative data suggest that some African American men and women perceive that the male shortage increases heterosexual risk behavior (Adimora et al. 2003; Senn et al. 2008). The limited number of potential male partners may diminish the relative power of women to insist on monogamy. In historical examples, women in communities with a shortage of men have tended to have less satisfying relationships with men than women in

communities with a greater gender balance (Guttentag and Secord 1983). Several quantitative studies have shown living in an area with a low sex ratio to be related to higher numbers of partners for men, or higher HIV/STI rates among African Americans, but results have been somewhat inconsistent (Adimora et al. 2013; Fichtenberg et al. 2010; Green et al. 2012b; Pouget et al. 2010).

Racial segregation increases the likelihood of risk networks that are homogeneous with regard to race/ethnicity, but heterogeneous with regard to HIV status or level of sexual risk behaviors (Laumann and Youm 1999). In a seminal work, Lauman and Youm found that African American people who were at the periphery of a sexual network (having only 1 partner) were 5 times more likely to have a partner at the core of the network (having 5 or more partners) than whites who were at the periphery (Laumann and Youm 1999). They concluded that this pattern of risk networks and mixing accounts for excess HIV transmission among African Americans because more low-risk African American partners are exposed to HIV through sex with high-risk partners. Though their work focused on sexual risk networks, injection risk networks may work similarly. Data from the HIV Prevention Trials Network (HPTN) 037 showed that uninfected African American drug users were more likely to have HIV-infected members in their risk networks, and less likely to have access to drug treatment and syringe exchange programs (Williams et al. 2013). Evidence suggests that African Americans live in highly segregated neighborhoods in part due to active discrimination in housing, employment and lending (Massey and Denton 1993). Thus, segregation may be responsible in part for excess HIV/AIDS cases among African American PWID and other risk groups.

Figure 8.3 shows the syndemic of problematic (injection and non-injection) drug and alcohol use, HIV/AIDS, other sexually transmitted infections (STIs) and HCV.

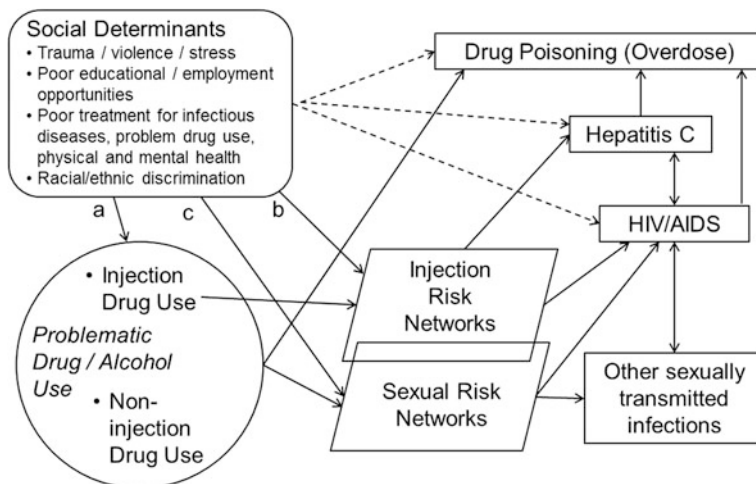


Fig. 8.3 Syndemic model of problematic drug and alcohol use, HIV/AIDS, other sexually transmitted infections, Hepatitis C and drug poisoning

For clarity we omit a dashed arrow connecting social determinants such as poor STI treatment to other STIs. Sexual and injection risk networks often overlap, especially for PWID who are also MSM or women-who-have-sex-with-women (WSW; Friedman et al. 2003; Kral et al. 2001; Strathdee and Sherman 2003). Substance use may serve as an indicator for being in a relatively high HIV or STI prevalence sexual network (Sionean et al. 2014). Synergistic interaction has been identified between HIV and a number of other STIs, including herpes simplex type 2 (HSV-2), gonorrhea, syphilis and chlamydia (Craib et al. 1995; Freeman et al. 2006; Ling et al. 2015; Otten et al. 1994). Chlamydia (*C. trachomatis*) is by far the most commonly reported notifiable disease in the U.S. with over a million new infections yearly (CDC 2013). In 2012 over 300,000 new gonorrhea cases and over 17,000 new syphilis cases were reported. While case reporting data are not collected for HSV-2, national data show higher rates for African Americans than for non-Hispanic whites (Fanfair et al. 2013).

8.7 Fundamental Causes

Link and Phelan developed “Fundamental Cause” theory to explain how vast improvements in mortality rates over the last century caused by improvements in sanitation and medical technology have fallen on a socioeconomic gradient, i.e., wealthier people live longer healthier lives than less wealthy people (Link and Phelan 1995). Rubin and colleagues extended these findings to racial/ethnic disparities in HIV/AIDS mortality (Rubin et al. 2010). From a fundamental cause perspective, racial/ethnic disparities in HIV/AIDS incidence and prevalence reflect underlying differences in social conditions and access to resources, including HIV prevention and treatment resources. These differences include proximal factors, such as access to harm-reduction programs and high-quality health care, and distal factors, such as a high risk of incarceration, and living in neighborhoods with high HIV prevalence (Hogben and Leichter 2008). Some social determinants can lead to later HIV diagnosis, less effective HIV treatment and faster progression to AIDS (Rubin et al. 2010). The social conditions that link race/ethnicity to HIV/AIDS risk act through multiple mechanisms, so that attempts to reduce disparities by eliminating one mechanism may fail because other mechanisms remain. Some of the mechanisms act outside of the direct control of individuals. For example, living in an area where HIV treatment is unavailable or is of poor quality can impact everyone in the area who is HIV-positive and is difficult to contend with individually, short of moving to an area with better treatment options. This is consistent with syndemic theory in the sense that without changing the disparate social contexts, racial/ethnic incidence disparities could remain the same or worsen, even as overall incidence falls. Indeed, racial/ethnic disparities in AIDS diagnoses among PWID show little change since the dissemination of effective HIV treatment in the

1990s (Pouget et al. 2014). However, having more rapid and broad access to developing medical technology can lead whites to experience harmful side-effects more rapidly, as we saw in the initial development of the syringe.

8.8 Prescription Opioids (POs) and the Drug Overdose Epidemic

More Americans now die from drug poisoning than from automobile accidents (National Center for Health Statistics 2015). Drug poisoning includes intentional and accidental use of legal and illegal drugs. From 1999 to 2013 the drug poisoning death rate more than doubled from 6.1 to 13.8 people per 100,000, and the rate of drug poisoning deaths involving POs nearly quadrupled from 1.4 to 5.1 people per 100,000 (Chen et al. 2015). Increasing prescription rates for pain medication such as OxyContin, Vicodin, Percocet, and methadone increased demand for these drugs, and when restrictions and drug monitoring programs were implemented, many PO users transitioned to heroin and/or transitioned to injecting drugs (Harocopos et al. 2009; Lankenau et al. 2012; Sherman et al. 2002). Current protocols for identifying and preventing accidental opioid overdose are now well established and indicate that the likelihood of an overdose is increased by: misuse of POs (e.g., medically unsupervised dose escalations); chemical coping practices (i.e., using opioids to treat symptoms other than physical pain), concurrent use of multiple substances including alcohol; changes in tolerance due to illness, a recent period of opioid abstinence or other physiological factors; and failure to get medical attention for fear of police. Overdose fatalities involving cocaine and benzodiazepines have also increased since the 2000s (National Institute on Drug Abuse 2015). The syndemic interactions of drug overdose with HCV, HIV/AIDS and other STIs are depicted in Fig. 8.3. Liver disease, including HCV, and other chronic diseases increase the risk of fatal overdose (Darke et al. 2006). People who are HIV-positive are more vulnerable to overdose; a recent meta-analysis concluded that having HIV infection makes fatal overdose about 75 % more likely (Green et al. 2012a). Socio-structural factors including poverty, lack of access to overdose prevention and response training, homelessness, and periods of abstinence from opioids due to incarceration, hospitalization or in-patient drug treatment can increase risk for overdose (Beletsky et al. 2015; Galea et al. 2003; Hembree et al. 2005). However, the overdose epidemic differs strongly from most of the other epidemics in one aspect: it has affected whites more than African Americans or Latinos, presumably because POs were disseminated more broadly among whites (Case and Deaton 2015; Cicero et al. 2014). For example, between 1999 and 2013 fatal overdose rates for middle-aged African American and Latino men increased by about 4 per 100,000, but those of non-Latino white men increased by about 22 per 100,000 (Case and Deaton 2015); these differences were more pronounced among less educated men.

Research is needed to better understand the relative resilience of African Americans and Latinos to overdose, and whether less-educated middle-aged white men have a somewhat unique syndemic vulnerability. Young white men may have had more injuries during the housing and construction boom of the 2000s, leading to more pain and disability in middle age, and have had greatly diminished economic prospects since the 2008 financial crisis (Case and Deaton 2015). Whites also showed increases in intentional self-harm and chronic liver cirrhosis in that study, signifying a pattern of harmful drinking and drug use, and potential mood disorders. Although determining the causes of this pattern is speculative without further research, less-educated middle-aged white men have had particular difficulty coping with their recent diminished economic expectations. This may be partly reflected in declining overall marriage and birth rates (Fry 2012; Hamilton and Sutton 2013). While incomes and wealth of African Americans and Latinos have not improved compared to whites (DeNavas-Walt and Proctor 2014), economic expectations of members of minority groups may be more measured, based on past experiences, potentially constituting a protective buffer against hard times.

8.9 Barriers to Intervening with Syndemics, and Mechanisms of Resilience

The epidemiology of the HIV/AIDS epidemic led to the recognition that disease-specific approaches miss opportunities for more broad improvements (Steiner et al. 2013). A syndemics approach, with a holistic focus on health and an emphasis on social determinants, holds the promise of radically transforming public health and health disparities. The Centers for Disease Control and Prevention (CDC) has led efforts in using syndemic concepts in public health programs. For example, the grouping of related illnesses in the CDC's National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP) reflects the recognition that greater improvements in health can be achieved through a holistic approach (CDC 2010).

However, important social, fiscal and political barriers prevent the full implementation of syndemic theory. Stigma and judgmental attitudes towards drug users prevents sufficient funding for drug treatment, prevents robust studies of violence prevention and harm reduction approaches to drug use problems, and prevents basing drug use policies on established evidence. For example, well-run syringe exchange programs have been shown to reduce harms related to injection drug use while not increasing drug use, but political considerations to express disapproval of drug use have prevented reform of federal laws prohibiting the use of federal funds to support syringe exchanges (Des Jarlais 2008). Controversy within the substance use treatment community about harm reduction versus abstinence is also a barrier to studying optimal strategies for preventing and treating drug use problems. In a

similar fashion federal law has effectively prohibited the CDC from studying gun violence since 1996 (Jamieson 2013).

Nevertheless, there may be an increased understanding that people who use drugs (PWUD), including PWID, are no less moral than other people, rather, they often have more stressful and traumatic experiences, untreated psychological or psychiatric disorders, and poorer educational and employment prospects (Compton et al. 2014; Khoury et al. 2010). PWID have been active in community mobilization activities, from ACT-UP to harm reduction and drug treatment activist groups, such as achieving policy goals like legalizing syringe exchange programs in some areas (Friedman et al. 1992). Relatedly, there is increasing domestic and international evidence that marijuana and other drug legalization or decriminalization can reduce the overall harms related to drug use (Goncalves et al. 2015). Further, a growing movement to reform criminal justice and the Black Lives Matter movement have brought increased attention to criminal justice disparities, including drug-related policing and criminal sentencing (Alexander 2010; Bassett 2015). Drug courts offer an alternative to incarceration for criminal defendants with drug dependence issues (Brown 2010). Criminal justice and sentencing reforms have recently been implemented at the federal level and in New York, New Jersey and California; and the federal government reduced the sentencing disparities for crack and powdered cocaine and eliminated mandatory minimum sentences (Office of National Drug Control Policy 2014).

The prevalence of injecting drugs shrank by approximately an estimated 40 % between 1992 and 2007 in the African American and Latino populations, and 6 % among non-Latino whites (Tempalski et al. 2013). This trend may reflect the aging of the overall population, but may also reflect young people actively avoiding negative outcomes associated with drug use, perhaps similar to generational changes that led to reduced use of crack cocaine in the 1990s (Broz and Ouellet 2008; Dunlap et al. 2006). Unfortunately, however, there is more recent evidence of an increase in the prevalence of injecting drugs among young people (Chatterjee et al. 2011), and of PO users transitioning to injecting.

A recent HIV outbreak among mostly white PWID in Indiana led to the temporary authorization of a syringe exchange program in the affected county, which led to testing and treating hundreds of PWID for HIV and HCV and spurred the expansion of syringe exchange in other locations (CDC 2015a; Harper 2015; Vanderhoff 2015). Nevertheless, this outbreak reflects an ongoing syndemic vulnerability, both among suburban and rural PWID mostly injecting POs, and among PWID who are young or who recently initiated injecting, who may be less knowledgeable about avoiding HIV and HCV infection, as well as overdose (Hagan et al. 2010; Havens et al. 2011; Heimer et al. 2014).

This outbreak, and the broad distribution of the current epidemic of fatal overdoses represent an opportunity to reach a political consensus for less reliance on punishment and greater acceptance of medical and public health approaches to problem drug use. For example, naloxone is an antidote for opioid overdose that can be administered by injection or nasal spray that was previously available by prescription only. Recent efforts to provide emergency response personnel with

naloxone to resuscitate people who have overdosed on opioids have led to thousands of overdose reversals and saved many opioid users' lives (CDC 2012a; Walley et al. 2013). Current syndemics of overdose and infectious diseases for PWUD and PWID represent an opportunity for whites to reach more meaningful alliances with people from racial/ethnic groups who have been most affected by HIV to advocate for more effective strategies to reduce the harms of drug use.

A syndemic approach is a call to move upstream in the prevention process. There has been a substantial amount of recent public health research using syndemic theory, but much of this research focuses on individual factors (Tsai and Burns 2015). Syndemic theory suggests the utility of structural intervention approaches to change social contextual determinants. Such research is complex and not amenable to randomized controlled trials; however, may still be testable using observational data. For example, the effects of increased healthcare access or of criminal sentencing reforms on HIV or STI transmission could be tested by comparing HIV or STI incidence in states that expanded Medicaid under the Patient Protection and Affordable Care Act or that implemented sentencing reforms to those that did not. Individual interventions, including efforts to seek, test, and treat HIV-infected persons may reduce community viral load and incidence, but do not address syndemic root causes, thus leaving populations at risk for other syndemic conditions. Further, events such as wars and transitions, and intensifying climate change are likely to increase vulnerability to future epidemics and syndemics (Friedman et al. 2013a, b).

8.10 Summary

Syndemic theory is a theory of social justice relying on a basic assumption that human beings are more or less the same, and equally deserving of social and economic opportunities.

Thus, structural determinants are the ultimate causes of syndemics, not individual behaviors. Public health practitioners are challenged to understand how syndemics are produced, and confront institutions not only to support treatment of illnesses once they occur, but to prevent unfair syndemic burdens on marginalized groups.

A structural syndemic approach can improve prevention by focusing on the mutual underlying determinants of the syndemically interacting afflictions. A syndemically oriented prevention approach would focus on social inequalities that expose individuals to multiple synergistic health problems, and would reduce vulnerability to future unknown syndemics. The HIV epidemic was entirely unexpected. Better social conditions and healthcare for PWID at the outset could have prevented a substantial number of infections and deaths in the U.S. Until we reduce social inequality and marginalization, we, especially those of us in disenfranchised groups, will remain unnecessarily vulnerable to future epidemics and syndemics.

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Chapter 9

Understanding the Syndemic Connections Between HIV and Incarceration Among African American Men, Especially African American Men Who Have Sex with Men

Erin McCarthy, Janet J. Myers, Keith Reeves and Barry Zack

9.1 Introduction

Prisons, jails and other detention settings of incarceration are facilities in which a number of social conditions come together to disproportionately affect the lives of African American men. Because of systematic and long standing structural inequalities in our society, including housing segregation, laws (and their selective enforcement) about the use and sale of illicit drugs that affect some communities over others and limited access to sustainable and living wage economic opportunities, African American men are incarcerated at much higher rates of other populations in the United States (U.S.). African American men are also more likely to be infected with HIV and diagnosed late in the course of infection, partly because of lack of access to quality health care and because the stigmatization of HIV and of behaviors that risks its infection limits an effective preventive response in the African American community. For these reasons, African American men and individuals living with HIV are disproportionately represented in prisons, jails and other detention settings, which serve as “syndemic nodes.”

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The term “syndemic” refers to two or more epidemics (defined as notable increases in the rate of specific diseases in a population), “interacting synergistically and contributing, as a result of their interaction, to excess burden of disease in a population” (Singer and Clair 2003; Frumkin 2002; Homer and Milstein 2002). In the case of prisons and jails, individuals who are incarcerated or have a history of incarceration are much more likely to be co-infected with HIV and with hepatitis C (HCV) than individuals who are not affected by incarceration (Burton et al. 2010). The syndemic of HIV/HCV co-infection disproportionately affects African Americans, and particularly black men. Substance use and mental health disorders are also highly prevalent and play a key role in the overlap of infectious diseases and incarceration (Wilper et al. 2009; Colfax et al. 2005; Strathdee and Stockman 2010; Sabol et al. 2010).

Racism, poverty, and segregation contribute to the syndemic nature of these co-occurring diseases. These forces are most visible in prisons, jails, and other detention settings where, compared to their white counterparts, African Americans with lower socio-economic status are more likely to be housed (Rourke et al. 2011).

Living conditions and the policies that shape them inside these facilities influence the impact that HIV has on people living in them—sometimes policies and procedures limit behaviors that risk transmission and contribute to better health for individuals who are infected (better health care, procedures that effectively limit sexual assault and or consensual sex inside). In other cases, individuals with HIV experience worse health outcomes because of substandard health care and lack of access to medications inside many prisons and jails, or because of the health effects associated with multiple re-incarcerations, which create chaotic, unstable access to housing, healthcare and social support systems after release from custody.

In this chapter, we will describe the disproportionate impact of the twin epidemics of imprisonment and HIV infection on African American men. We will then describe how conditions inside prisons, jails and other settings of detention support or limit an effective response to HIV inside and how these systems influence the life course of individuals affected by them once they are released.

The U.S. incarcerates more individuals than any other country in the world; African Americans are vastly overrepresented in correctional population.

The U.S. has the largest incarcerated population in the world.¹ Approximately 2.3 million Americans are incarcerated in the U.S. at any point in time, including 1,574,741 in state and federal prisons and 731,203 in municipal and county jails.²

¹Incarcerated population is the population of inmates confined in a prison or a jail. This may also include halfway-houses, boot camps, weekend programs, and other facilities in which individuals are incarcerated overnight.

²It is important to distinguish the different types of U.S. incarceration institutions. With few exceptions, jails are locally-operated, short term facilities that hold inmates awaiting trial or sentencing or both, and inmates sentenced to a term of less than 1 year, typically misdemeanors. Prisons are long term facilities run by the state or the federal government and typically hold felons and inmates with sentences of more than 1 year. Connecticut, Rhode Island, Vermont, Delaware, Alaska, Maryland and Hawaii operate integrated systems, which combine prisons and jails.

Men, particularly black men, are disproportionately impacted by incarceration in the U.S. correctional system compared to women and other races/ethnicities. In 2013, men accounted for 93 % of the prison population and approximately 86 % of the jail population (Carson 2014; Minton and Golinelli 2014). Black men represent 12 % of the U.S. male population, but 37 % of the male prison population and 36 % of the jail population (U.S. Census Bureau 2014; Carson 2014; Minton and Golinelli 2014). It is estimated that almost 3 % of all black men in the U.S. were imprisoned at year end 2013, compared to 0.5 % of white males (Carson 2014). Black men are imprisoned at rates six times greater than white men (Carson 2014).

A culture of racism and racial segregation facilitates differential rates of incarceration. When many African Americans migrated out of Southeastern states to escape slavery and to secure jobs, communities became concentrated in the inner cities of large urban areas. This residential segregation enabled institutional segregation because schools and hospitals, for example, were localized to these areas. When inner cities became blighted during times of economic downturn, institutional segregation facilitated the continued ghettoization of African Americans and the substandard education of African American children (Poole 2006; Massey and Denton 1993; Wilson 1987). Without access to quality education and without thriving areas of commerce, African Americans face pressures on their ability to earn a living wage. This deprivation in turn affects access to economic opportunity and drives up crime rates, and thus incarceration. In this way, the spatial concentration of an ethnic minority group, which plays out as residential and institutional segregation, has created a set of structural circumstances that reinforce the effects of social and economic deprivation.

African Americans are clearly limited by the residentially segregated environments in which many live. In her seminal book, “The New Jim Crow,” Michelle Alexander (2010) notes that it is not just that many African Americans lack opportunity, attend poor schools or are plagued by poverty, they are barred *by law* from “moving up.”

The current system of control permanently locks a huge percentage of the African American community out of the mainstream society and economy. The system operates through our criminal justice institutions, but it functions more like a caste system than a system of crime control. Viewed from this perspective, the so-called underclass is better understood as an *undercaste*—a lower caste of individuals who are permanently barred by law and custom from mainstream society. Although this new system of racialized social control purports to be colorblind, it creates and maintains racial hierarchy much as earlier systems of control did. Like Jim Crow (and slavery), mass incarceration operates as a tightly networked system of laws, policies, customs, and institutions that operate collectively to ensure the subordinate status of a group defined largely by race (Alexander 2010, p. 13).

9.2 African American Men Are Disproportionately Infected and Affected by HIV

Of all racial and ethnic groups in the U.S., African Americans—particularly men—account for a higher proportion of new HIV infections, those living with HIV, and those ever diagnosed with HIV/AIDS (Prejean et al. 2011; CDC 2014a). In 2010, black adults and adolescents accounted for 44 % of new HIV infections despite representing only 12 % of the U.S. population (CDC 2014a). Among this same group, black men accounted for 70 % (14,700) of the estimated 20,900 new HIV infections, representing an HIV incidence rate (103.6/100,000) that was seven times that of white men, twice that of Hispanic men, and almost 3 times that of African American women (CDC 2014a). Similarly, African Americans accounted for almost half of new AIDS diagnoses (49 %) in 2011 (CDC 2014a). HIV was the fifth leading cause of death for black men and the seventh for black women, ages 25–44, in 2010, ranking higher than for all other racial/ethnic groups.

Furthermore, the rate of new HIV diagnoses among younger populations is increasing. During 2006–2009, the only population with a change in HIV incidence over the entire 4-year period was among 13–29 year olds, and was primarily attributable to high rates of new HIV cases among young black men who have sex with men (BMSM). Young BMSM accounted for almost half (48 % total or 12.2 % annually) of the increase in new infections over the 4 year period and represented the only statistically significant increase in new HIV infections from 2006–2009 for all MSM subgroups (Prejean et al. 2011).

In a 2012 meta-analysis of the literature comparing the disparities and risks of HIV infection in black and other men who have sex with men in Canada, the UK and the U.S., Millett and colleagues (2012) found that there were specific and distinct effects of social factors on why black MSM are more frequently infected with HIV than other men. Social network and partnering dynamics play a role; black men typically partner with other black men and with older partners suggesting their partners are more likely to be infected with HIV. Social structural factors also influence the amount of virus an HIV-infected man is likely to have including low income, low education, lifetime incarceration and unemployment (and concomitant limitations to health insurance coverage), lack of health care access and underutilization of HIV-treatment medication (Millett et al. 2012). These social forces play out in the way that African American men are affected by HIV. They are much more likely to get infected, to be infected and to live with untreated virus than are their white counterparts. This is particularly true for young African American men who have sex with men, currently the group most likely to be newly infected with HIV.

9.3 African American Men Who Have Sex with Men and Incarceration

As noted above, young black men in particular are also most likely to be incarcerated. The syndemic relationship between race, HIV and incarceration is most pronounced among young BMSM. Longitudinal analysis of National HIV Behavioral Surveillance data from 15 cities and among 1,278 BMSM enrolled in a federally funded prevention research trial (HPTN Network 061) found that 305 (24 %) reported a new incarceration within one year of entering the study (Brewer et al. 2014). In an analysis of data from MSM participants, a 31 % history of arrest was documented among BMSM which was higher compared to other racial groups (Lim et al. 2011). A history of arrest among MSM, was also associated with sex that put men at high risk of HIV transmission (Lim et al. 2011). In addition, Kegeles and colleagues have been conducting yearly surveys in Dallas and Houston, Texas between 2009 and 2013 of young BMSM, ages 18 to 29, most of whom identify as gay. Of the 3,005 surveyed, 30.4 % reported having ever been in juvenile, jail, or prison (personal communication, November, 2014).

Although the reasons why young BMSM are disproportionately incarcerated are not well studied, these men are no less likely than their straight black male counterparts to face limitations of their “environment” or “activity space.” Many of these men reside in socially isolated neighborhoods characterized by crumbling infrastructure and frayed institutions (schools, churches, and health care facilities), (e.g. Anderson 1999; Gersti-Pepin 2002; Wilson 1987). These kinds of neighborhoods expose MSM to risks and/or resources, including increased risk of incarceration. Being “gay” often exacerbates these problems because homophobia keeps BMSM “in the closet” with their friends, family members and in important community institutions like church and school. Both gay stigma and stigma towards people living with HIV influence the degree to which BMSM are able to access support and resources in their communities and thus turn to underground activities to survive including sex work or exchanging sex for food or a place to live (MacKellar et al. 2005).

9.4 Structural Factors and Rates of Infection Among Young MSM

Structural-level factors have contributed to the substantial disproportionate rates of HIV among BMSM in the U.S. A recent review of the literature on structural barriers to HIV testing and prevention services among BMSM across four domains (healthcare, stigma and discrimination, incarceration, and poverty) found that BMSM experience inadequate access to culturally competent services, stigma and discrimination that impede access to services, a deficiency of health care services in

correctional institutions, and limited services in areas where BMSM live (Millett et al. 2012).

Stigma can be related to HIV/AIDS, homosexuality, gender conformity and/or race and may be the greatest driving force behind HIV infection among African-Americans. Many black communities continue to be reticent to accept and support community members living with HIV/AIDS, despite the prevalence of the disease in these communities. Michael K. Evanson, senior policy analyst in the Division of Science and Policy at the Health Resources and Services Administration (HRSA n.d.), HIV/AIDS Bureau (HAB), has said:

Unfortunately we are still dealing with stigma particularly in the South where the epidemic is still growing at a more alarming pace than in other areas of the country. You hear stories that people are still very much ashamed to have HIV due to religious beliefs and cultural stigma. People view the disease with a lot of disdain and blame those who are living with it. There are certainly huge barriers that still exist [to testing and care].

Erving Goffman defines stigma as ‘an attribute that links a person to an undesirable stereotype, leading other people to reduce the bearer from a whole and usual person to a tainted, discounted one’ (Goffman 1963). Stigma refers to the social devaluation of people who are different, whether due to conditions that do not affect the majority of a population (e.g., homosexuality, HIV/AIDS, mental illness), or more ordinary conditions that affect many or all in a population (e.g., demographic features tied to age, race/ethnicity, gender (Breyer et al. 2012)). Stigma can be understood as a process whereby individuals or groups are devalued based on the way society views a particular attribute or characteristic. Individuals who are stigmatized have higher levels of stress due to both the anticipation of negative treatment by non-marginalized/non-stigmatized individuals, and the internalization of stigma. This stress has direct and indirect impacts on the health of stigmatized individuals.

Stigma serves to both produce and reproduce relationships of power and control. It causes some groups to be devalued and others to feel that they are superior in some way. Ultimately, therefore, stigma is linked to the workings of social inequality and to properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce social exclusion in different settings (Parker and Aggleton 2003).

Previous understandings of stigma were limited to thinking of stigma in terms of individual-level and inter-group processes. The recent shift takes a more systemic approach that incorporates social, economic, political and cultural forces tied to power and privilege. Stigma impacts health and health seeking through prejudicial beliefs, stereotypes, and discriminatory actions of individuals and groups; moreover, the inherent stigmatizing practices and procedures carried out by systems of power and social processes also serve to legitimize and reinforce social hierarchies and inequities. These inequities are a driving factor in explaining incarceration and

HIV disparities affecting black and Latino gay men/MSM (Jones 2000; Wilson and Moore 2009).

Stigma exacerbates the syndemic of HIV and the comorbid conditions that accompany it by limiting health care seeking by affected individual and also by conditioning the way that health care providers and systems receive individuals who are infected. Particularly in settings that have historically be characterized by conservative values and beliefs, such as correctional settings. The ways that HIV services are conceived and delivered are likely to be particularly impacted by stigmatizing forces. In addition, African American men with HIV may be challenged by their own internalized stigmatization of their infections, their race or, if they are gay, of the way that their communities feel about men who have sex with men.

9.5 Settings of Incarceration and Syndemic Processes

It is true that black men and women at risk for incarceration are more likely to be at higher risk for HIV, with infection rates 3–5 times higher than the national average. It is estimated that one in seven persons infected with HIV move through the criminal justice system annually, with black men in prison and jail disproportionately represented. In 2006, for example, around one in four HIV-infected black men in the U.S. spent time in jail or prison (Spaulding et al. 2009). In addition, increased rates of STIs, prior sexual abuse, mental illness and substance use disorders (SUD)—all related to HIV—have been well documented among the incarcerated population. Although studies have documented that intra-prison transmission is low (Krebs and Simmons 2002; Arriola 2006; Hammett 2006; CDC 2006), incarcerated populations have more risk factors that are associated with acquiring and transmitting HIV, including injection and non-injection drug use, commercial sex work, untreated mental illness, and lower socioeconomic status (CDC 2012a).

TV shows and movies often portray correctional settings as lawless places controlled by gangs where correctional officers take bribes to ensure a steady supply of drugs and facilitate a dynamic of prisoner power and control. These same portrayals tend to support ideas that consensual sex and sexual assault are rampant and common. Although these ideas make for titillating media portrayals, and while some level of contraband and illicit sexual contact occurs, the reality is that prisons, jails, and other settings of detention are set up first around rules and regulations that control the behavior of individuals who are detained in them (Hammett 2006). These rules and regulations often serve to increase the stabilization of life routines and limit access to alcohol and drugs (so that they become clean and sober), and provide regular access to health care and other services that they may not be able to access on the outside.

Policies limiting behavior that risks HIV transmission include *The Prison Rape Elimination Act (PREA)*. PREA is a federal law enacted in 2003 that was created to eliminate sexual abuse during incarceration. In 2011–2012, an estimated 4 % of

individuals incarcerated in state and federal prisons and 3.2 % of individuals detained in jail reported experiencing one or more incidents of sexual victimization by another inmate or facility staff in the preceding 12 months or since admission to the facility (Beck and Johnson 2012). It is the first federal civil statute focused specifically on addressing sexual violence in juvenile and adult facilities, jails, prisons, lockups, and other facilities. Nearly 10 years after the legislation was passed, on May 17, 2012, the Department of Justice (DOJ) issued a final rule adopting national standards to prevent, detect and respond to prison rape, pursuant to PREA (PREA 2012) and began conducting audits of detention settings subject to these standards (U.S. Department of Justice 2012b; White House OPS 2012). The standards provide detailed guidance to federal, state, and local officials on how to prevent, detect, and respond to sexual abuse in their detention facilities. For example PREA addresses segregation in the case of sexual abuse against lesbian, gay, bisexual or transgender (LGBT) persons. PREA states, “the agency shall not place lesbian, gay, bisexual, transgender, or intersex inmates in dedicated facilities, units, or wings solely on the basis of such identification or status, unless such placement is in a dedicated facility, unit, or wing established in connection with a consent decree, legal settlement, or legal judgment for the purpose of protecting such inmates (U.S. Department of Justice 2012). While PREA does not mandate that U.S. states adopt the DOJ standards, states that do not will lose some of their federal prison funding. As of June 29 2015, eleven states certified compliance with the PREA standards and 51 of 56 states and jurisdictions were either compliant or had formally submitted assurances of compliance (PREA 2015).

9.6 Racial and LGBT Segregation

Segregation of incarcerated individuals in jails and prisons because of demographic factors is problematic. In general, civil rights law and common decency preclude segregation. However, in practice, settings of incarceration have used segregation— notably by race or ethnicity or by sexual identity—to supposedly “protect” individuals from retribution or harm by other incarcerated people. In the case of race and ethnicity, corrections officers and administrations have chosen to segregate particularly black and Latino individuals because of possible gang affiliation. Because of the overrepresentation of people of color in jail and prison, this often results in segregation of the majority of a population in a given institution. In the case of individuals who identify as gay or transgender, in particular, prison and jail officials segregate because of perceived vulnerability of “out” sexual minorities. In the recent past, it was even common practice to segregate individuals who were “gay” because they were assumed to be HIV infected. For whatever reason, segregation is problematic because it reifies the social processes that underlie syndemics and in this case, the syndemic nodes that are jails and prisons.

9.6.1 Racial Segregation

Prisons were one of the last institutions in the U.S. to be officially desegregated in the U.S. However, racial desegregation practices within prisons are not fully realized (Trulson et al. 2008). Although it is difficult to collect official policies of correctional facilities related to racial segregation, court cases documenting systematic racial segregation in prisons (i.e. California) and empirical evidence have brought the issue to the forefront. A 2000 national survey of U.S. prison wardens revealed that 45 % of represented Departments of Corrections did *not* have an official policy of racially integrating inmates within cells (Henderson et al. 2000). In addition, approximately 3 % of wardens reported that people were *not* housed in racially integrated cellblocks, and another 37 % of wardens indicated that cellblock integration was discretionary. Moreover, nearly 60 % of prison wardens revealed that people within their institutions may request an exemption from being integrated with someone of a different race, subject to the discretion of the prison warden (Henderson et al. 2000). Researchers estimated that among people sharing a cell in U.S. prisons, only 30 % of these cells were integrated by race (Henderson et al. 2000).

There have been important legal cases in recent years changing the legal framework on racial segregation administrative tactics used in prisons. In the 2005 U.S. Supreme Court case of *Johnson v. California*, the court determined that prison administrators could not racially segregate people unless under extraordinary circumstances to maintain the security of inmates, staff, and institutions (Trulson et al. 2008). In October 2014, California correctional authorities agreed to overturn its policy related to racial segregation used during lockdowns, a policy that was allegedly aimed at helping to reduce racially-related gang violence. The 2014 ruling held that the California Department of Corrections and Rehabilitation unwritten policy of racially segregating people in double cells in reception centers for up to 60 days every time they enter a new correctional facility could only be justified if it satisfied the requirements of “strict scrutiny,” i.e., served a compelling governmental interest and was “narrowly tailored” towards doing so.

9.6.2 Segregation of LGBT Individuals

LGBT people in prison are sometimes placed in what is called “administrative segregation” or “protective custody” which separates them from the general population (Edney 2004). The stated intention of this action is to keep LGBT people safe from assault that can occur because of the discrimination they face. Although homosexuality is typically considered as a factor supporting an incarcerated person’s claim to protective custody, in practice, it can be hard to secure by gay inmates facing harassment and sexual assault. In these cases, stereotyping and misperceptions by prison officials and guards about homosexual sex

preclude protective custody (Mariner 2001).

Another problem for incarcerated LGBT³ individuals in seeking protective custody is that the housing units used for protective custody are often the same as those used for disciplinary custody. The restrictive nature of these units often prevents anyone housed in them from participating in drug treatment, education and job-training programs, from having contact with other incarcerated individuals or outside visitors, or from enjoying privileges such as the right to watch television, listen to the radio, or even to leave their cells (Transgender Law Center 2008). Not participating in job and educational programs can have the collateral effect of not allowing an incarcerated individual to get “time off” for “good behavior.” In essence, they end up trading safety for more time incarcerated. The degree of safety that protective custody provides depends on the facilities. Protective custody can provide a secure environment that is free from violence by other prisoners or it can isolate prisoners, and position them with a higher risk of violence by a correctional officer. Although the protective custody can offer some level of protection, the harmful physical and psychological impacts of isolation show that it is too often, an unwanted alternative to assignment in the general population (Fig. 9.1).

9.7 Health Care in Detention Settings

One additional moderating factor that can either mitigate or exacerbate syndemic processes during incarceration is the health care delivered, particularly for individuals with HIV. However, the quality and type of services and care available is largely due to the type of facility. There are three main types of detention settings in the U.S. In general, jails are usually run by sheriffs and are designed to hold individuals awaiting disposition of their case, waiting for transport to a state prison system following conviction, or serving time after a misdemeanor. State prisons are operated by the state Department of Corrections (DOC) or through state contracts with for-profit corporations where the person was convicted of a more serious crime (often a “felony”). Federal prisons are operated by the Federal Bureau of Prisons (BOP) and are designed to hold individuals convicted of federal crimes, such as tax evasion, bank robbery, kidnapping, and interstate crimes, among others.

In state prisons, delivery of health care services may be provided by the DOC itself or through contract with external (private-for-profit) providers. Probably for that reason, the quality of care varies considerably across states. In some states, the care has been so substandard that advocates and incarcerated individuals have resorted to litigation to improve conditions, which has been a very successful

³The experience for transwomen inside may be different than for gay men or men who have sex with men. Investigators have noted that some transwomen feel a great deal of gender affirmation when they are in the company of the general population, sometimes greater levels of gender affirmation inside than out (Jeness and Fenstermaker 2013).

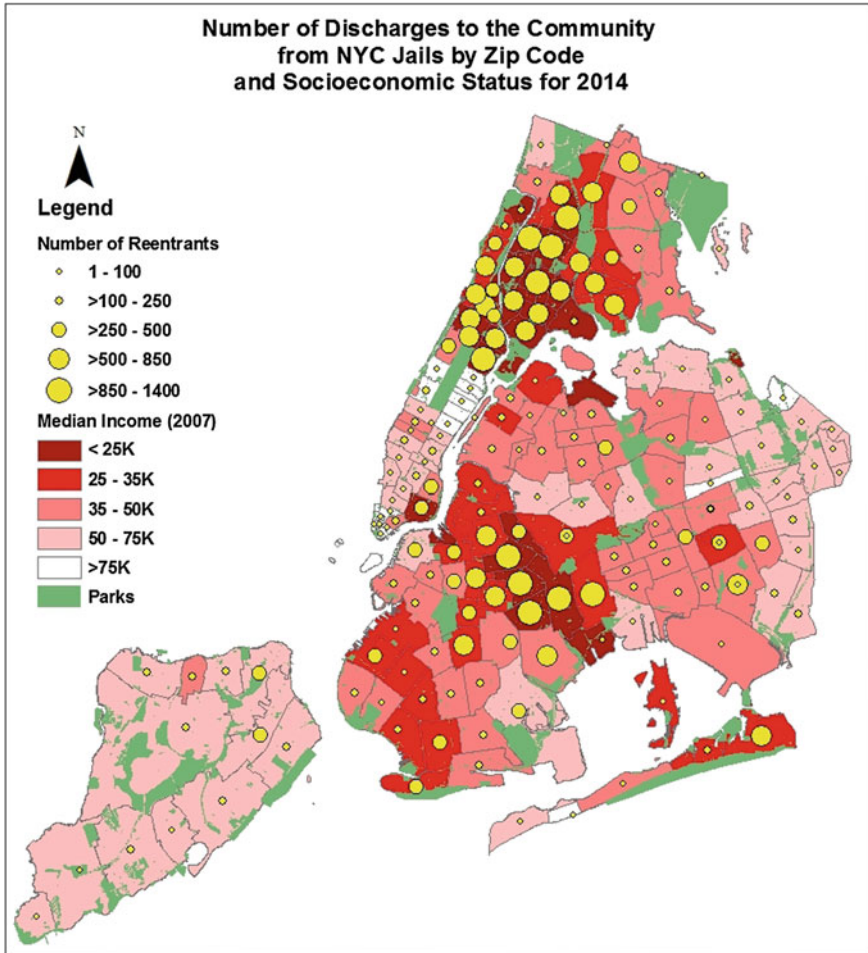


Fig. 9.1 Using New York City in 2014 as an example, the link between poverty, incarceration and HIV is clear: over 70 % of people released to the community after incarceration return to the areas of greatest socioeconomic and health disparities (*Source* New York Department of Public Health)

strategy (Rappaport 2010). Federal detention facilities, in contrast, have national protocols and procedures that are operationalized across the country, though these too, have come under court oversight (see www.prisonlegalnews.org/legal-action-map). Due to the “incarceration epidemic” there has been a rise in private prisons which work on contract with states to delivery privatized imprisonment. These settings have faced criticism for cutting costs rather than prioritizing humane conditions or care (Godard 2015). For example, the State of Hawaii has been criticized for sending its prisoners to private facilities in Arizona, where families

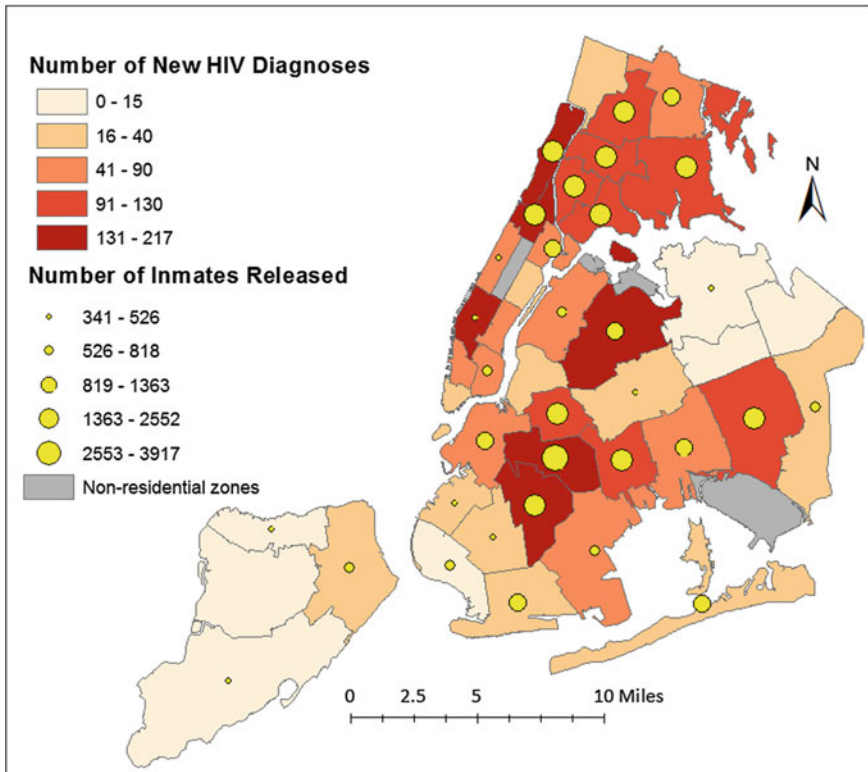


Fig. 9.1 (continued)

cannot visit and where incarcerated individuals are separated from their culture and families (Merce 2012).

While prison officials are obligated under the Eighth Amendment to provide prisoners with adequate medical care,⁴ there are no standards for delivery of it. There is more of a patchwork of care at the state and local levels. “Correctional care” systems are not equipped with the mission or resources to address the challenges posed by this fragmented system. The epidemic of incarceration, the burden of disease in those involved in the criminal justice system, and the sub-populations in need of increased prevention, testing, care and treatment, including the syndemic connection between young black gay males with HIV in jail and prison.

⁴*Estelle v. Gamble*, 429 U.S. 97, 103 (1976); *Brown v. Plata*, 131 S.Ct. 1910, 1928 (2011) (“Prisoners retain the essence of human dignity inherent in all persons. Respect for that dignity animates the Eighth Amendment prohibition against cruel and unusual punishment... A prison that deprives prisoners basic sustenance, including adequate medical care, is incompatible with the concept of human dignity and has no place in civilized society.”).

9.8 Released but not Free: Parole and Probation

In addition to the type of jail, prison or detention setting, most people leaving detention settings are not released as free individuals, but are instead released to community supervision (parole in the case of prison release or probation in the case of jail release, with some individuals needing to serve both). When this occurs, individuals are not “free” in the community and are typically required to confirm to a set of conditions, such as where one can live, and can include requirements for treatment for substance use disorders, mental illness or medical conditions such as HIV. In this way, parole or probation may provide some support to individuals who struggle to move from settings of detention back into the community. Case management provided by many publicly-funded social support providers also aims to improve the continuity of care and is often available to people living with HIV because of special federal funding (ref. Health Resources and Services Administration, *About the Ryan White Program*).

Since the deinstitutionalization movement in the 1950s and 1960s, when many large state mental health hospitals were closed because of increasing criticism of them as cruel and inhumane, many individuals with severe and persistent mental health issues have faced inadequate community care. As a result, local jails have borne a disproportionate burden of caring for these individuals as they cycle in and out of jail because of petty drug crime or for merely loitering due to homelessness or because temporary housing facilities (such as shelters or single room occupancy hotels) often require people staying there to vacate the premises during the day. This is true both of inner cities and also in rural areas; jails provide social support and care for the poor and mentally ill. Medical care in jails can be operated by the local jurisdiction (the Sheriff or the Health Department), or it can be contracted out to private companies who specialize in jail care. However, in some large cities such as San Francisco, care is delivered by the Department of Public Health (DPH). In systems where the department of public health is providing the medical care, people with HIV, who often need intensive, comprehensive, long-term care, experience more coordinated care because the health care provider sees the same patient in settings inside and outside jail.

9.9 HIV Prevention, Testing, Care and Treatment Policies in U.S. Prisons and Jails

During the early years of the HIV epidemic (primarily before the availability of highly effective antiretroviral therapy, or ART, in 1995), mandatory testing and HIV housing segregation policies and practices were common. Although these policies were intended to prevent HIV transmission, they resulted in discrimination, stigma and mistreatment of people with HIV. Between 1985 and 1994, the number of prison systems with segregated housing policies for people with HIV/AIDS

rapidly dropped from 46 of 51 in federal or state systems (Hammett et al. 1995; ACLU & Human Rights Watch 2010). In 2010, South Carolina, Mississippi, and Alabama were the last states to maintain these policies. The Mississippi policy was phased out that same year. In December 2012 a federal court indicated that Alabama's HIV segregation policy violated Americans with Disabilities Act, and in 2013 South Carolina was the last state to reverse this segregation policy (ACLU 2013). Currently every state prison with HIV housing segregation policies has reversed them.

Although there are still gaps in providing quality HIV care and treatment programs (i.e. routine testing and diagnostic programs that are linked with high-quality treatment, primary disease prevention, substance use treatment and discharge planning and other programs), correctional health systems in the U.S. have improved their response to HIV and other infectious diseases over time. These strategies fall into three broad categories: prevention, HIV testing and continuity of care for people living with HIV.

9.9.1 Prevention Strategies

There is a misperception that incarcerated men are responsible for increasing rates of HIV and sexually transmitted infections (STIs). Imprisonment does affect HIV/STI rates in the community, but not from men being infected on the inside and then bringing the virus out to their sexual partners once they are released. Instead, incarceration decreases the number of men in the community, which disrupts stable partnerships, changes the male-to-female ratio and promotes higher-risk concurrent, or overlapping, partnerships. Nevertheless, strategies for preventing HIV transmission in incarceration settings have been addressed in a variety of ways.

9.9.2 Condom Use in Prisons and Jails

Condoms are critical for HIV prevention and recommended by the CDC and the World Health Organization to be provided in prison and jail (CDC 2012a; WHO 1999). However, there is little to no access to condoms in most correctional settings in the U.S. (Hammett et al. 2007; Sylla et al. 2010). Although many European countries have distributed condoms at scale in prisons and jails, the U.S. has been slow to follow-suit. Condom provision in prisons and jails in the U.S. is controversial because many state laws prohibit sex between inmates (i.e. California classifies sexual intercourse in prison as a felony) with limited exceptions under some circumstances in some states such as conjugal visits for people that are married (i.e. Mississippi). In a 2005 national survey of 47 state and federal prisons and 33 large city and county jails, only seven correctional facilities reported *any* condom availability (Hammett et al. 2007).

In the U.S., jails in five cities—San Francisco, Los Angeles (in the MSM/transgender housing unit only), Philadelphia, Washington, DC and New York—have condom distribution programs. Currently three states—California (2014), Vermont (since 1992), and Mississippi (for conjugal visits only)—now have state-wide legislation to provide condoms throughout their correctional facility system. The 2014, a California state law was approved, in part based on successes of condom machines in large urban county jails in San Francisco and LA and pilot programs in state prisons (Lucas et al. 2014). The first condoms distributed in a jail setting were in San Francisco. They were first distributed by counselors and eventually made more accessible through a dispensing machine (Sylla et al. 2010). In a pilot study of what happened once the first machine was installed, evaluators studying the impact of it noted: (1) installation of the condom machine was associated with increases in awareness and utilization of condoms; (2) prisoners who were gay, female, transgender or previously diagnosed with HIV were more likely to obtain condoms than prisoners who were heterosexual, male, or HIV-negative; (3) sexual activity did not increase following installation of the condom machine; and, (4) installation of the condom machine did not impact jail custody activities. Similarly jail staff acceptance of condom access improved (Sylla et al. 2010). Another study in the Los Angeles county jail system found that condom distribution in the MSM unit can reduce transmission of HIV and societal costs of HIV treatment. (Leibowitz et al. 2013). Lucas and colleagues found that the use of condom dispensing machines, if placed in discreet locations, are a feasible and acceptable option for inmates and staff to prevent transmission of HIV and STDs and may provide medical cost-savings both during incarceration and in the community (Lucas et al. 2014).

9.9.3 *Syringe Exchange*

Syringe exchange programs (SEPs) are a vital public health intervention to prevent the spread of HIV, hepatitis and other blood-borne illness by supplying sterile syringes and injection equipment. In the U.S., **no** needle-exchange programs are offered in U.S. prisons or jails making it extremely difficult to obtain clean injecting equipment within correctional facilities. In fact, possessing a needle is often a punishable offense. As a result, many people share equipment that has not been sterilized between uses. In Europe and other countries, needle-exchange programs have proven effective at reducing HIV risk behaviors in a wide range of prison environments without resulting in negative consequences for the health of prison staff or prisoners (Jurgens et al. 2011).

9.9.4 HIV Testing

Testing is the first step in the HIV continuum of care and is critical for ensuring people with HIV receive appropriate care and treatment. More than 1.2 million people in the U.S. are infected with HIV, and almost 1 in 8 (12.8 %) are unaware of their infection (CDC 2012b). Given this statistic and that 1 in 7 people with HIV pass through prisons and jails, correctional facilities are important settings for key HIV interventions, including HIV testing. In 1999, the WHO published its international guidelines for *HIV Infection in Prisons and Jails* (WHO 1999). The guidelines state that all prisoners have the right to receive health care, including preventive measures. The guidelines indicated that compulsory testing of prisoners for HIV is unethical and ineffective and should be prohibited. In addition, preventive measures for HIV/AIDS in prison should be complementary and compatible with those in the community (WHO 1999). Since 2004 and 2006, the WHO and CDC have recommended HIV testing for adults in all clinical settings including correctional facilities as part of routine care although there are differences in the way the two suggest securing consent for testing (WHO 1999; CDC 2012a). In correctional settings, CDC recommends that HIV testing be provided upon entry into prison and before release, and that *voluntary* HIV testing be offered periodically during incarceration (CDC 2012a). In 2009, CDC published its HIV testing implementation guidance for correctional facilities, which support out-out routine testing. However, given the wide variety of institutions and state-specific legislation, CDC has not provided a specific framework for HIV testing in correctional settings, and numerous testing strategies are in use by prisons and jails (CDC 2009).

Currently, HIV testing in U.S. prisons and jails is mostly provided through voluntary programs (both opt-in and opt-out) where testing is provided on intake. In few cases, testing is mandated by state policy (for specific conviction/orders such as in the case of a sexual assault or under court orders). Voluntary testing can be opt-in (where one is offered the test and the individual must actively agree) or opt-out (where the test is given unless the person says no). Individual U.S. states and jurisdictions determine the HIV testing policies for correctional facilities and not all prisons and jails offer HIV testing (Hammett et al. 2007). In 2009, BJS published HIV testing data for state and federal prisons. All state prisons indicated that they tested people if they had clinical indication of HIV infection or if they requested an HIV test. During 2008, 24 U.S. states tested everyone for HIV upon admission or at some point during incarceration. Of these 24 states, Missouri and Nevada tested everyone upon admission, while in custody and upon release from prison (Maruschak 2009). Forty-two states and federal prison systems tested individuals if they were involved in an incident in which a person was exposed to a possible HIV transmission, 18 states and the federal system tested people who belonged to specific “high-risk” groups. In a 2005 survey of 47 federal and state prisons and 33 city and county jails, no mandatory HIV testing was reported by responding city and county jails, and 15 % indicated that they had no specific HIV testing policy (Hammett et al. 2007). In contrast, 32 % of state and federal prisons reported that

they conducted mandatory testing (Hammett et al. 2007) and is in line with HIV testing guidance provided by the Bureau of Prisons (Federal Bureau of Prisons 2013).

Scale-up of routine HIV testing in correctional setting is constrained by logistical and financial support (CDC 2012a; Spaulding et al. 2013). With the higher prevalence of HIV in this setting, identifying new cases would require following treatment guidelines that would have a serious budgetary impact; many systems prefer “not to know.” In jails, which are characterized by rapid turnover, implementing a screening program imposes logistical challenges on testing if not using rapid HIV tests. There are also ethical issues of testing upon entry into a jail system, as this time one may not be in a state-of-mind to give consent. In addition, some correctional facilities may also be reluctant to provide testing based on laboratory, medical and staffing costs. Nevertheless, there are programs that have been successful by demonstrating broad acceptance for and uptake of voluntary HIV testing programs in correctional facilities (Spaulding et al. 2013).

9.9.5 HIV Care and Treatment

Access to antiretroviral treatment (ART) is a critical intervention for maintaining the health of HIV-infected individuals by reducing HIV-related morbidity, mortality, and perinatal and sexual transmission. Antiretroviral treatment can also prevent transmission of HIV among sero-discordant partners by reducing the amount of virus a person has in their blood, thereby reducing exposure among sex and injection drug using partners. The Department of Health and Human Services (DHHS) has provided guidelines for initiating patients on ART in correctional health settings. State, county and city jurisdictions, including the Federal Bureau of Prisons have updated specific guidelines for correctional health systems in line with the most recent national recommended ART initiation and clinical management standards. In addition, the CDC recommends that newly diagnosed inmates with HIV infection should be provided with HIV prevention, referral for mental health support, medical evaluation, referral to a specialized HIV provider, and expedited care in the case of acute HIV infection, HIV infection with an acute opportunistic infection, and HIV infection during pregnancy. Given that HIV-infected African Americans are least likely to be in continuous HIV care and treatment, compared with other races and ethnicities, and have the lowest rate of viral suppression across all groups, correctional health systems provide access to HIV care and treatment.

Studies indicate that correctional facilities are providing antiretroviral treatment to HIV-infected inmates in some capacity and have the potential to improve health outcomes. Findings from a 2005 survey indicated that 100 % of responding sites provided antiretroviral treatment to at least some incarcerated inmates for HIV (Hammett et al. 2007). HIV-infected incarcerated populations achieve similar clinical outcomes compared with populations in the community when ART is available (Springer and Altice 2005) and recent studies have demonstrated positive

outcomes related to viral suppression (Meyer et al. 2014). In a sample of 882 HIV-infected prisoners receiving ART in Connecticut, significant increases in CD4 lymphocyte count and reductions in viral load were associated with treatment outcomes during incarceration; 70 % of individuals achieved viral suppression, much higher than in the U.S. general population (Meyer et al. 2014). While this is a recent success, earlier studies have identified limited provision of ART within prisons and jails. In 2007, Zaller et al. (2007) estimated that approximately one-third of HIV-infected inmates are being treated for HIV in prison and that there is unmet need related to HIV treatment of incarcerated populations.

A core issue faced by people with HIV in jail and/or prison is access to care and treatment after they have been released from a correctional facility. In most states, if someone is known to be HIV positive and has been treated by the correctional facility, the facility will provide the inmate with a transition supply of medications (from 7 to 30 days) and a referral to appropriate medical services. Linkage to and retention in HIV care following release from jail and prison are critical for optimizing health benefits. Nevertheless, while HIV medical care and treatment services are important, they may be less prioritized by releases than other basic needs such as housing, drug treatment and mental health counseling (Springer et al. 2011; Reznick et al. 2013).

9.9.6 Evidence-Based Interventions for Incarcerated Populations

Given the high rate of HIV prevalence among persons in prisons and jails in the U.S., correctional facilities are an important setting for public health interventions. Scientifically proven interventions do exist that can increase good outcomes for populations affected by HIV, substance use problems and incarceration. In particular, *Project START* (PS) is an evidence-based intervention designed specifically for people leaving correctional settings and returning to the community that is proven effective at decreasing HIV/STI/hepatitis risk after release (Wolitski et al. 2006; Grinstead et al. 2008). PS is the only corrections-based reentry intervention to be listed in the Centers for Disease Control and Prevention's (CDC's) *Compendium of HIV Prevention Interventions with Evidence of Effectiveness*. The intervention begins with sessions conducted in the correctional setting prior to participants' release and continues in the community during the three months immediately after they are released. PS incorporates a theoretical framework based on harm reduction that includes features of prevention case management, motivational enhancement, decision-making, problem solving, and goal setting (Grinstead et al. 2008). An adapted PS-based intervention—*Project START+(PS+)*—for people living with HIV has recently been shown to improve HIV medication usage and adherence, decrease both re-incarceration and sexual risk behavior (Reznick et al. 2013) in both

prisons and jails and conforms to the new U.S. HIV prevention guidelines for individuals infected with HIV (CDC et al. 2014b).

Given the rapid turnover of detainees in jails, many interventions have focused on jail settings given the unique opportunity and rapid window to test and link to care to ensure continuity of services. The *EnhanceLink* initiative was a demonstration project in 10 communities at 20 separate jails across the U.S., in which grantees implemented and evaluated innovative models of HIV testing and linkage of HIV-infected individuals to community services post release. Data from the initiative indicated that jails are important settings for testing at risk adults for HIV, reengaging those previously diagnosed back into care, and connecting HIV-infected persons with community-based services (Spaulding et al. 2013). All sites were able to link HIV-infected clients to treatment for HIV with HAART while in jail (Spaulding et al. 2013). *EnhanceLink* was also used to enroll people with HIV into transitional case management services while in jail to facilitate linkage to primary care in the immediate post-discharge period (Spaulding et al. 2013). Ultimately, the *EnhanceLink* initiative demonstrated the feasibility of HIV testing in jail settings and the continuity of linkage services to strengthen continuity of HIV care and treatment post release (Spaulding et al. 2013).

9.9.7 Intensive Case Management/Patient Navigation

Patient navigation has also been used as a strategy to enhance case management and strengthen linkages, retention and engagement of HIV-infected men and women released from the criminal justice system to HIV care and treatment services. Koester et al. (2014) conducted an ethnographic study to explore the complex strategies, roles and responsibilities of the patient navigator in supporting long-term engagement of HIV-infected persons released from jail with health and social services. As part of a 5-year randomized controlled trial focused on HIV-infected individuals leaving the San Francisco county jail, patient navigators were used to enhance case management, the standard of care typically provided to HIV-infected detainees in prison and jail and upon release (Koester et al. 2014). The patient navigators were matched based on similar characteristics (they were HIV-infected and shared similar backgrounds including a past history of incarceration and drug misuse) and had demonstrated consistent engagement with social and medical services and possessed good organizational and communications skills. Navigators worked directly with the case manager to monitor adherence to care and provide clinical supervision, while also providing coaching and mentoring support in all aspects of the patient's life. Qualitative findings illustrated that peer navigators were well positioned to facilitate a successful transition to care and social services engagement among HIV-infected individuals released from jail. By leveraging the experiences of successful people that were once incarcerated, interactions between the navigator and the patient were documented as very meaningful and

demonstrated potential to respond to recidivism and improve social and health outcomes related to engagement in care and services (Koester et al. 2014).

9.10 Summary

With unprecedented and disproportionate numbers of young African American men behind bars and who were also more likely to be infected with HIV, jail and prison settings across this country constitute “syndemic nodes” of increasing interest to scholars and public health practitioners of the U.S. criminal justice system. In addition to individual-level effects—particularly when a person is released from custody, a burgeoning literature highlights the often under-appreciated “collateral consequences” for families living in disadvantaged urban neighborhoods. In this chapter, we have suggested a number of structural and community factors that lead to disproportionate rates of incarceration and HIV-infection among young BMSM as well as a few data-proven prevention strategies.

Understanding why young gay black men with HIV are disproportionately represented in U.S. prisons and jails can help to address key factors related to high rates of new HIV diagnoses among incarcerated young black MSM and to design solutions to ensure linkage and continuity of HIV care and treatment programs. Given the low intra-prison transmission of HIV, it is critical that future research ascertain in richer empirical detail the syndemic processes (i.e., economic inequality, residential segregation, substance use, stigma, violence and abuse) that impact the disproportionate rates of HIV-infection among young BMSM. Failure to explore this link will only reproduce disadvantage and inequality by increasing the likelihood of ongoing risk behavior and stigma as well as distrust of HIV care and treatment.

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Chapter 10

People with Serious Mental Illness

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10.1 Introduction

People with serious mental illness (SMI) are disproportionately affected by HIV/AIDS. The term SMI describes a heterogeneous group of psychiatric conditions, most commonly including schizophrenia, schizoaffective disorder, bipolar disorder, and major depression with psychotic features (Lagios and Deane 2007),

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characterized by persistent duration, functional disability, hospitalization, and/or maintenance medication (McKinnon and Rosner 2000). SMI and HIV are linked health problems, interacting synergistically. The reasons people with SMI have greater rates of HIV infection than the general population are highly complex and not fully elucidated (Cournos and McKinnon 1997; Donenberg et al. 2002; Rosenberg et al. 2001b). Members of this marginalized population are frequently found within other groups described in this book. They have multiple medical comorbidities besides HIV infection, and shortened lifespans in comparison to the general population. The evidence that SMI is syndemic with HIV is striking, though a critical lack of data from many regions of the U.S. leaves policy makers and practitioners with scant basis for planning programs to reduce the dramatic health effects of these co-occurring conditions (Cournos and McKinnon 1997; de Hert et al. 2009; Jackson-Malik et al. 2011; Rothbard et al. 2009).

This chapter focuses on the U.S.' HIV/SMI syndemic: the prevalence of HIV among adolescents and adults with SMI and associated risk factors; patterns of sexual and drug-use risk behavior, other factors that increase the likelihood of exposure to HIV, available interventions and services. We draw conclusions and offer recommendations about the syndemic dynamics of HIV and SMI to guide future efforts to improve outcomes.

10.2 Prevalence of HIV Among Adolescents and Adults with SMI

The peer-reviewed literature contains 31 U.S. studies that ascertained HIV prevalence through blood or saliva testing of patients with mental illness (see Table 10.1) or chart documentation. Findings from HIV antibody testing studies are more reliable than those that rely on patient knowledge of their HIV status or medical records because HIV testing rates are low in psychiatric settings (Senn and Carey 2009). No studies of HIV prevalence among adolescents with MI have been published. The prevalence of HIV among individuals with SMI age 18 and older is as high as 29 % (Pirl et al. 2005; Senn and Carey 2009), compared to a general population rate of 0.5 % (McQuillan et al. 2009).

These studies provide evidence of variably increased HIV infection rates among those with SMI based on geographic location, subpopulation characteristics, and risk behaviors—factors potentially contributing to the syndemic of HIV and SMI.

Table 10.1 U.S. peer-reviewed studies reporting HIV prevalence of patients with MI

Study	Testing method	U.S. Region	Sample	N	Rate of HIV infection (%)
Clair et al. (1989)	Blood	South Carolina	Psychiatric facility inpatients	1228	0.3
Hatem et al. (1990)	Blood	Massachusetts	Psychiatric facility inpatients	163	1.8
Courmos et al. (1991)	Blood	NYC	Acute-care inpatient	451	5.5
Volavka et al. (1991)	Blood	NYC	Psychiatric hospital inpatients	515	8.9
Lee et al. (1992)	Blood	NYC	Psychiatric inpatient unit of hospital	135	16.3
Sacks et al. (1992)	Blood	NYC	Inpatient	350	7.1
Empfield et al. (1993)	Blood	NYC	Inpatients homeless psychiatric unit	203	6.4
Meyer et al. (1993)	Blood	NYC	Long-stay psychiatric inpatient unit	199	4.0
Meyer et al. (1995)	Blood	NYC	Inpatients homeless psychiatric unit	87	5.8
Susser et al. (1993)	Blood	NYC	Homeless men's shelter psychiatric program	62	19.4
Courmos et al. (1994)	Blood	NYC	Psychiatric facility inpatients	971	5.2
Silberstein et al. (1994)	Blood	NYC	Municipal hospital dual-diagnosis inpatients	118	22.9
Stewart et al. (1994)	Blood	Baltimore, Maryland	Psychiatric hospital inpatient/outpatient new admissions	533	5.8
Schwartz-Watts et al. (1995)	Chart	Columbia, South Carolina	Forensic inpatient unit for pre-trial detainees	220	5.5
Doyle and Labbate (1997)	Chart	National	Military hospital new-onset psychosis	246	0
Susser et al. (1997)	Chart	Suffolk County, New York	First-admission psychiatric inpatients referred from 12 hospitals	320	3.8
Krakow et al. (1998)	Blood	NYC	Municipal hospital dual-diagnosis unit inpatients	113	19.0
Rosenberg et al. (2001a)	Blood	Connecticut, Maryland, New Hampshire, North Carolina	Inpatient/outpatient treatment recipients in public mental health systems or VA	931 CT = 158 MD = 133 NH = 288 NC (VA) = 185	3.1
Blank et al. (2002)	Chart	Philadelphia, Pennsylvania	Medicaid and welfare recipients with schizophrenia spectrum disorder or major affective disorder	391,454	1.8

(continued)

Table 10.1 (continued)

Study	Testing method	U.S. Region	Sample	N	Rate of HIV infection (%)
Klinkenberg et al. (2003)	Blood	St. Louis, Missouri	Homeless outpatient with SMI + SUD	172	6.2
Beyer et al. (2005)	chart	Durham, North Carolina	Outpatient psychiatric clinic patients with bipolar disorder	1379	2.8
Pirl et al. (2005)	Chart	Boston, Massachusetts	Psychiatric hospital inpatients	62	29.0
Beyer et al. (2007)	Chart	Durham, North Carolina	General hospital psychiatric outpatients	11,284	1.2
Himelhoch et al. (2007)	Chart	National	Inpatient/outpatient veterans with versus without SMI	SMI: 191,625 No SMI: 67,965	SMI: 1.0 No SMI: 0.5
Rothbard et al. (2009)	Chart and blood	Philadelphia, Pennsylvania	Inpatient psychiatric units	588	10.0
Walkup et al. (2010)	Chart	California, Florida, Georgia, Illinois, New Jersey, New York, Ohio, Texas	Medicaid and Medicare claims from recipients with schizophrenia	1,000,000+	1.8
Himelhoch et al. (2011)	Blood	Baltimore metro area, Maryland	Outpatients in public mental health treatment settings with SMI + SUD	153	6.1
Jackson-Malik et al. (2011)	Saliva	Philadelphia, Pennsylvania	Veterans with a history of mental health and substance abuse diagnoses, residing in assisted living facilities	64	3.1
Walkup et al. (2011)	Chart	California, Florida, Georgia, Illinois, New Jersey, New York, Ohio, Texas	Medicaid beneficiaries with schizophrenia treated for HIV	NOT REPORTED	1.6
Prince et al. (2012)	Chart	California, Florida, Georgia, Illinois, New Jersey, New York, Ohio, Texas	Medicaid beneficiaries who were without HIV in 2001 but diagnosed with HIV 2002–2004	6,417,676 SMI: 443,994 SMI + SUD: 72,752 MDD: 130,788 BIPD: 55,582 SCH: 184,872	SMI: 0.7 SMI + SUD: 2.0 MDD: 0.6 BIPD: 0.6 SCH: 0.5
Blank et al. (2014)	Saliva	Philadelphia, Pennsylvania and Baltimore, Maryland	University-based inpatient psychiatric units (287), intensive case-management programs (273), community mental health centers (501)	1061	4.8 Inpatient = 5.9 ICM = 5.1 CMHC = 4.0 Baltimore = 5.9 Philadelphia = 3.9

10.2.1 Geographic Location

Studies comparing HIV infection rates among those with SMI in urban versus other locations found rates vary from 1.7 % in rural areas to 5 % in metropolitan areas (Brunette et al. 1999; Rosenberg et al. 2001a). Environmental factors associated with a greater prevalence of HIV/AIDS risk behaviors and infection, including poverty, unstable housing, and injection drug use, are more common in urban areas than elsewhere (Carey et al. 1997a; McKinnon et al. 2002; McKinnon and Rosner 2000). HIV infection rates among patients with schizophrenia who rely on Medicaid vary considerably from one location to another (Walkup et al. 2011).

10.2.2 Treatment Setting

Psychiatric inpatients are infected at higher rates than psychiatric outpatients in intensive case-management programs or community mental health centers (Blank et al. 2014).

10.2.3 Homelessness

A study of homeless people with concurrent SMI and substance use disorders found a 6.2 % HIV rate (Klinkenberg et al. 2003). Even among homeless patients not dually diagnosed, rates of HIV range from 5.8 to 19.4 % (Empfield et al. 1993; Meyer et al. 1993; Susser et al. 1993).

10.2.4 Veterans

HIV prevalence among American veterans with SMI is 1 % (veterans without SMI have an infection rate of 0.5 %) (Himelhoch et al. 2007). Veterans with a history of mental health and substance abuse diagnoses residing in assisted living facilities were found to have an HIV infection rate of 3.1 % (Jackson-Malik et al. 2011).

10.2.5 Men Who Have Sex with Men

Approximately one in four men with SMI and with a history of sex with other men is HIV-positive (Cournos and McKinnon 1997).

10.2.6 Dual Diagnosis

Generally, the highest rates of infection have been found among those dually-diagnosed with SMI and substance use disorder (SUD), with rates ranging from 6.1 to 22.9 % (Himelhoch et al. 2011; Krakow et al. 1998; Prince et al. 2012; Silberstein et al. 1994).

10.2.7 First Episode/New Onset Psychosis

Two studies examined rates of HIV infection among people having their first psychotic episode or psychiatric hospitalization, with rates up to 3.8 % (Doyle and Labbate 1997; Susser et al. 1997).

10.2.8 Conclusions About HIV Prevalence Among People with SMI

HIV prevalence studies have focused on narrow samples of people with SMI and have not included adolescents under age 18. Published studies derive from non-representative samples, some quite small, in few geographic locations, and have used highly variable criteria for recruitment and eligibility criteria beyond SMI (i.e. dementia, homelessness, veteran status, and use of illicit or injection drugs). Despite their limitations, including pre-dating DSM-5, these studies have provided insight into risk behaviors and infection rates among people with SMI and make a compelling case that SMI and HIV infection are syndemic across sub-populations and settings.

10.3 Patterns of Sexual and Drug-Use Risk Behavior Among People with SMI

Adults and adolescents with SMI demonstrate higher rates of HIV risk behaviors compared to their counterparts who do not have SMI. Adolescents with SMI are at particular risk for contracting HIV/AIDS (Brown et al. 1997a; Smith 2001); risk taking, thrill seeking, and a sense of immortality typical among adolescents can be exacerbated by symptoms of mental illness (MI) (Deas-Nesmith et al. 1999).

Meade and Sikkema (2005a) performed the most comprehensive review of HIV-related risk behaviors among adults with SMI and found high rates of risk behaviors. Adolescent studies have not sampled SMI participants exclusively; in these, mental illness (MI) is defined by serious emotional disorders or psychiatric

symptoms (Carey et al. 1997b; Donenberg et al. 2001, 2002; Otto-Salaj et al. 2002). What is known about risk among all these samples is summarized here for sex and drug use behaviors separately, then for overlapping sex and drug use.

10.3.1 Sex Risk Behaviors

Most studies show that the majority of adults with SMI are sexually active, and that those who are engage in high rates of sexual risk behavior (Senn and Carey 2009). Between 22 and 74 % of adults with SMI report being sexually active within the previous 12 months (Meade and Sikkema 2005a; Tucker et al. 2003; Wright and Gayman 2005) and between 32–65 % in the previous 3 months (Carey et al. 1997a; Devieux et al. 2007; Meade 2006; Meade and Sikkema 2005a, 2007). Between 2 and 14 % of individuals with SMI report having anal sex in the previous 3–12 months (Brunette et al. 1999; Coverdale and Turbott 2000; Weinhardt et al. 2001; Wright and Gayman 2005). Prevalence of anal sex during the previous 10 years or longer (i.e. lifetime) among adults with SMI is 13–84 % (Carey et al. 1997a; Cournos et al. 1994; Kalichman et al. 1994; Levounis et al. 2002; McKinnon et al. 1996; Menon et al. 1994; Rahav et al. 1998; Susser et al. 1995; Tucker et al. 2003).

Among adolescents ages 12–20 with MI, 39–75 % report ever having vaginal, anal and/or oral sex (Brown et al. 1997b, c; Donenberg et al. 2001, 2002, 2003; Valois et al. 1997) and between 39 and 45 % report being sexually active within the past 6 months (Brown et al. 1997d; Donenberg et al. 2001). Rates of lifetime sexual activity are higher among adolescents with MI compared to those in the general population (43–49 %) (Centers for Disease Control and Prevention 2002a). Early sexual debut is more common in this group: 42 % had sex before age 13 (Valois et al. 1997), compared to 5 % in the general population (Leigh et al. 1994). Earlier debut is in turn associated with more partners and less condom use compared to adolescents without MI (Baker and Mossman 1991). Adolescents in the general population are recognized as a high-risk group and those with MI have still greater risk.

Sexually active adults with SMI use condoms inconsistently. Lifetime unprotected sexual encounters are reported by 86 % of adults with SMI; between 12 and 68 % report inconsistent condom use in the previous 12 months (Brunette et al. 1999; Carey et al. 1997a; Dausey and Desai 2003; Levounis et al. 2002; Meade and Sikkema 2005a, 2007; Tucker et al. 2003); 28 % report having an unprotected sexual encounter in the last 6 months (Himelhoch et al. 2011); and 43–78 % report unprotected sex in the previous 3 months (Devioux et al. 2007; Meade and Sikkema 2005a). Among those reporting having unprotected sex in the last 6 months, 53 % report five or more unprotected sexual encounters (Himelhoch et al. 2011). Inversely, between 8 and 63 % report consistent condom use in the previous 12 months (Meade and Sikkema 2005a; Tucker et al. 2003), with the highest rate found in a sample of HIV-positive persons with SMI (Tucker et al. 2003). Rates of

unprotected sex are much higher for adults with SMI who engage in anal sex or have partners who are HIV-positive (Otto-Salaj et al. 1998; Weinhardt et al. 2001).

Rates of condom use are low among adolescents with MI. For those who report being sexually active in the past 12 months, between 44 and 67 % never or rarely use a condom (Brown et al. 1997d; Donenberg et al. 2001, 2002, 2003), and between 21–68 % report never or rarely using a condom during their lifetime (Deas-Nesmith et al. 1999; Dudley et al. 2002). Gender differences are present, with adolescent girls with MI almost two and a half times as likely as adolescent boys with MI to have unprotected sex (Donenberg et al. 2002). One study found 92–95 % of sexually active female adolescents with MI failed to use condoms at the last sexual act (Valois et al. 1997), much higher than condom use failure rates during the last sexual act among the general population (51–65 %) (Centers for Disease Control and Prevention 2002b).

Having multiple partners increases the potential for HIV transmission. Between 7 and 69 % of people in psychiatric samples report having two or more partners in the previous 12 months (Meade and Sikkema 2005a, 2007; Tucker et al. 2003), and 13–46 % report multiple partners in the previous 3 months (Devieux et al. 2007; Meade and Sikkema 2005a). Having multiple partners is common among adolescents with MI. One study of adolescent psychiatric inpatients found 27 % had five or more partners within the past 12 months (Brown et al. 1997d). Among sexually active girls with MI, between 10 and 24 % have a lifetime history of sex with four or more partners, and early sexual debut is significantly related to greater prevalence of multiple partners (Valois et al. 1997). More than a quarter of adolescents with MI had sex with at least five or more partners in the past year; rates of four or more partners among adolescents in the general population are lower (11–17 %) (Centers for Disease Control and Prevention 2002b; Kann et al. 2000).

High-risk partners include those who are known or thought to be HIV-positive, inject drugs, share needles with other partners, be sexually active with other partners, have unprotected sex with other partners, be men who have sex with men, or engage in sex trade with other partners. Among adults with SMI, between 2–58 % report having sex with a high-risk partner in the previous 3–12 months (Carey et al. 1997a; Coverdale et al. 1997; Tucker et al. 2003; Weinhardt et al. 1998a; Wright and Gayman 2005), 3–18 % report sexual intercourse with an injection drug user (Carey et al. 1997a; Coverdale et al. 1997; Kalichman et al. 1994; Otto-Salaj et al. 1998; Wright and Gayman 2005), 9–58 % report sex with a non-monogamous partner (Carey et al. 1997a; Otto-Salaj et al. 1998), and 20 % of men report ever having sex with a man (Himelhoch et al. 2011; Meyer et al. 1995). Between 1 and 14 % report ever having sex with someone they know is HIV-positive (Kalichman et al. 1994; Wright and Gayman 2005).

Among those sexually active, approximately 42 % of adolescents with MI report high risk partners within the past 3 months (Donenberg et al. 2001, 2002, 2003). Between 20 and 48 % of adolescents with MI have ever had sex with a stranger, and between 6 and 30 % have had sex with a prostitute or non-monogamous partner

(Brown et al. 1997d; Deas-Nesmith et al. 1999). Adolescents with comorbid MI and SUD have significantly higher rates of high risk partners compared to adolescents with only a mental illness (Deas-Nesmith et al. 1999). Rates of risky sex partners among adolescents in the general population are not available for comparison. Nonetheless, sex with high-risk partners is a distinct risk factor for HIV/AIDS among adolescents with MI with as many as half reporting this behavior at some point in their lifetimes.

Sexual services can be a means of obtaining food, shelter, money, and/or drugs. Trading sex is highly correlated with other HIV/AIDS risk behaviors: drug use, sex with high-risk partners, decreased condom use, and higher rates of IDU and needle sharing (Meade and Sikkema 2005a). Having sex for food, a place to stay, or money is reported by 28 % of adults with SMI lifetime (Himelhoch et al. 2011); between 2 and 42 % during the previous 12 months (Meade and Sikkema 2005a, 2007; Tucker et al. 2003); and between 5 and 38 % during the previous 3 months (Devieux et al. 2007; Weinhardt et al. 1998a; Wright and Gayman 2005). No studies examining adolescents with MI report rates of sex trading.

10.3.2 Drug-Use Risk Behaviors

Among adults with SMI, studies demonstrate an average rate of ever injecting drugs of about one-quarter and a past-year rate of 4 % (Himelhoch et al. 2011; Meade and Sikkema 2005a), with 61–92 % lifetime rates and 50 % past-year rates among those with injection histories. Despite prior findings documenting higher rates of IDU and needle sharing among adolescents with MI compared to adolescents in the general population (Aruffo et al. 1994; DiClemente and Ponton 1993; DiClemente et al. 1989), only one study examined prevalence of IDU in this population and found only one of 86 adolescent outpatients reported this behavior (Donenberg et al. 2001). Similarly, only one study reported needle sharing, with a rate 3.5 % of adolescents with MI (Brown et al. 2000). These rates are drastically higher compared to rates among adolescents in the general population (0.13 %) (U.S. Department of Health and Human Services 2003).

Substance use may lead to increased sexual behavior risk (e.g., Carey et al. 2004; Meade and Weiss 2007; Weinhardt et al. 2002). SMI inpatients with a history alcohol and other drug use have higher risk of HIV infection, even if they have no history of IDU (McKinnon and Cournos 1998). Substance use is highly correlated with HIV/AIDS risk behaviors (Logan et al. 2002; McKinnon et al. 1996). Among adults with SMI, HIV infection varies by type of substance use, with rates of 34 % among injectors, 15 % among non-injectors using illicit drugs, 11 % among alcohol users, and 3 % among those who did not meet criteria for current abuse or dependence diagnoses (McKinnon and Cournos 1998).

10.4 Overlapping Sex and Drug-Use Risk

Substance use may be a common part of the sexual experience of persons with SMI (Carey et al. 1997a; McKinnon et al. 1996) so it is important to examine the HIV sexual risk behaviors associated with the effects of using substances. Between 5 and 45 % of adults with SMI report using drugs or alcohol either prior to or during a sexual experience in the previous 12 months (Carey et al. 1997a; Coverdale et al. 1997; Katz et al. 1994; Weinhardt et al. 2001). Sexual intercourse under the influence of alcohol or other drugs is often unplanned, and is associated with having risky partners, lower condom use, and decreased ability to negotiate safe sex practices (McKinnon et al. 1996; Weinhardt et al. 2001). Risks differ between men and women with SMI. Among men, inconsistent condom use and sex with a high-risk partner is significantly associated with the use of crack or alcohol before sex; having sex with a high-risk partner is significantly associated with cocaine use. Among women, alcohol use before sex is associated with receptive anal sex (Menon and Pomerantz 1997). Adults with SMI who expect alcohol to increase the likelihood of engaging in risky sex are more likely to engage in sexual risk behaviors (Weinhardt et al. 2002). People with comorbid SMI and SUD are particularly vulnerable to HIV infection (Cournos et al. 1991; Kelly et al. 1992; Rosenberg et al. 2001a; Sacks et al. 1990; Volavka et al. 1991).

Among adolescents with MI, few studies report sexual risk behaviors related to alcohol or drug use. Donenberg and colleagues (2001) found that among those who were sexually active, approximately 49 % had sex while drunk or high within the past 3 months. Any alcohol use (not just prior to sex) is significantly associated with HIV/AIDS risk behavior among adolescents with SMI (Otto-Salaj et al. 2002), including early sexual debut (before age 13) (Valois et al. 1997). Only two studies have examined effects of comorbid MI and SUD: adolescents with both disorders are more likely to have engaged in unprotected sexual intercourse, have multiple or high risk partners, have sex before age 16, and have a history of STDs compared to adolescents with no disorder (Deas-Nesmith et al. 1999; Ramrakha et al. 2000). Comorbid SMI and SUD among adolescents is also associated with the presence of more HIV/AIDS risk behaviors compared to those with only mental disorders (Otto-Salaj et al. 2002; Valois et al. 1997), and in some cases higher than among adolescents with no disorder (Deas-Nesmith et al. 1999; Ramrakha et al. 2000).

10.5 Factors that Increase the Likelihood of Exposure to HIV Among People with SMI

Factors prominent in the lives of people with SMI appear to increase the likelihood of exposure to HIV when engaging in sex and/or substance use activities. We describe these factors by proximal to distal levels of influence, beginning with factors at the level of the individual, moving to interpersonal-level factors, then

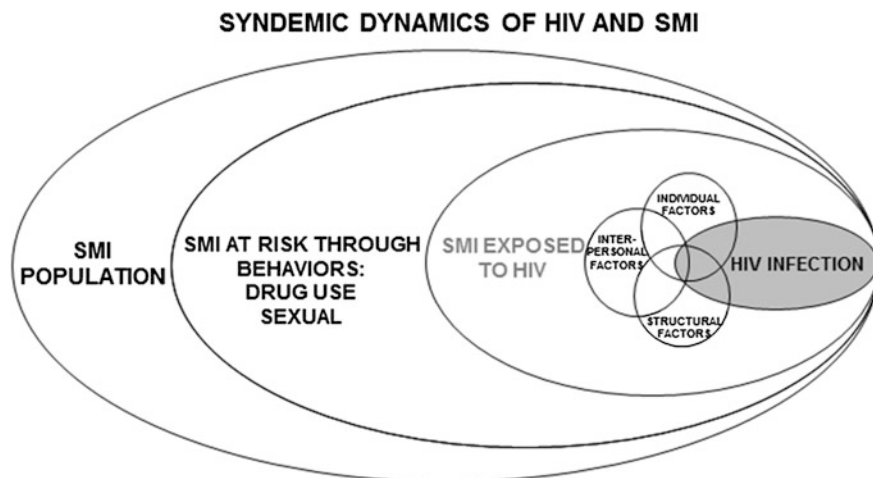


Fig. 10.1 Proximal to distal levels of influence on the likelihood of HIV infection when engaging in sexual and/or substance use activities

addressing structural/environmental factors (Fig. 10.1). Some factors have more extensive evidence than others, and some of the evidence requires new investigations; only those factors that have been directly investigated are presented.

10.5.1 Individual-Level Factors

Studies are inconsistent with regard to whether women or men with SMI are at higher risk of HIV infection (Carey et al. 2004; Cournos et al. 1991; Empfield et al. 1993; Essock et al. 2003; Himelhoch et al. 2007), and not all studies of people with SMI analyzed gender differences. Similarly, some studies have identified an increased risk of HIV among younger patients with SMI (Brunette et al. 1999; Carey et al. 2001, 1999; Empfield et al. 1993; Hellerstein and Prager 1992), though others have reported increased risk among older patients (Himelhoch et al. 2007).

Few studies report effects of age on risk behavior. Among studies of adults, being younger predicted higher HIV risk behavior (Carey et al. 1999, 2001) and infection (Brunette et al. 1999). Among adolescents with MI, studies show that the oldest age group is more likely to engage in HIV/AIDS risk behavior (Donenberg et al. 2002; Otto-Salaj et al. 2002; Rohde et al. 2001), suggesting that transition into young adulthood represents a high-risk phase of development (Rindfuss 1991; Roberts et al. 2001).

Other sociodemographic factors that have been associated with increased risk of HIV infection are being divorced, widowed, or never married (Carey et al. 2001; Himelhoch et al. 2007) and ethnicity (Hispanic or African-American) (Cournos et al. 1991; Hellerstein and Prager 1992; Himelhoch et al. 2007).

The high rates of HIV in individuals with SMI are in part driven by high rates of comorbid alcohol and/or other substance use disorders (SUD) (Angold and Costello 2002; Costello et al. 1999; Cournos et al. 1991; Davidson et al. 2001; Himelhoch et al. 2007; Hoff et al. 1997; Kelly et al. 1992; Parry et al. 2007; RachBeisel et al. 1999; Rosenberg et al. 2001a; Sacks et al. 1990; Senn and Carey 2009; Volavka et al. 1991). A primary non-addictive mental disorder often precedes and is a robust risk factor for the later onset of SUD (Swendsen et al. 2010) which is itself associated with higher rates of HIV *infection* compared to non-SUD mental health disorders (Deas-Nesmith et al. 1999; McKinnon and Cournos 1998; Prince et al. 2012). Patients with schizophrenia, bipolar disorder, depression, anxiety, antisocial personality disorder, among others, have rates of SUD that vary from 25 to 65 % (Meade and Sikkema 2005a, 2007). In one study the presence of a dual diagnosis increased the risk of HIV infection approximately 4–5 times that of psychiatric patients without substance abuse problems (Beyer et al. 2007). Adolescents with comorbid MI and SUD have significantly higher rates of inconsistent condom use compared to those with only MI (68 vs. 21 %) (Deas-Nesmith et al. 1999).

It is not clear whether or how sexuality or sexual risk-taking among those with SMI is affected by psychiatric illness and it cannot be assumed that all aspects of the sexual lives of psychiatric patients are only expressions of their mental disorders. No data on normative sexuality in this population has been published.

Personality disorders, multiple psychiatric diagnoses, positive symptoms of psychosis, and greater illness severity or distress appear to increase behavioral risk of HIV infection among people with SMI (Blank et al. 2014; Cournos et al. 1994; Kalichman et al. 1994; McKinnon et al. 1996; Otto-Salaj and Stevenson 2001; Sacks et al. 1990; Wu et al. 2011). While the literature shows that patients diagnosed with a schizophrenia-spectrum disorder are less sexually active than patients with many other categories of psychiatric diagnoses (Carey et al. 2001, 2004; McKinnon et al. 1996), trading sex is more than three times as likely among patients with schizophrenia than among those with others diagnoses (McKinnon et al. 1996).

However, psychiatric diagnosis has been inconsistently related to condom use (Kelly et al. 1995; Kim et al. 1992; Levounis et al. 2002; McDermott et al. 1994; McKinnon et al. 1996; Rahav et al. 1998; Susser et al. 1995), multiple sexual partners (McKinnon et al. 2002; Menon and Pomerants 1994; Otto-Salaj and Stevenson 2001; Susser et al. 1995), or risk of HIV infection (Brunette et al. 1999; Carey et al. 2001; Hanson et al. 1992; Hellerstein and Prager 1992; Knox et al. 1994; Sacks et al. 1990, 1992; Steiner et al. 1992). Until new studies are completed to address knowledge gaps and inconsistencies in the literature, targeting HIV-related services on the basis of behaviors rather than psychiatric diagnosis or symptoms is recommended.

Studies evaluating HIV/AIDS knowledge in psychiatric populations have shown accuracy scores ranging from 63 to 80 %, comparable to general population scores (McKinnon et al. 1996, 2002; Otto-Salaj et al. 1998). However, specific knowledge deficits also have been found (Bear et al. 1988; Carey et al. 1997a, 2004; Katz et al. 1994). Kelly and colleagues (1992) reported that 43 % of psychiatric outpatients

believe that heterosexual women could not get AIDS, and Strauss and colleagues (2006) reported high rates of inaccurate HIV knowledge among American veterans with SMI, with 40 % of patients demonstrating some inaccuracies.

There is little evidence that HIV/AIDS knowledge deficits are associated with risk behavior or risk reduction. Zafrani and McLaughlin (1990) found an association between lower HIV/AIDS knowledge and greater risk behavior, although other authors have not corroborated this finding (Hanson et al. 1992; Steiner et al. 1992). McKinnon and colleagues (1996) found that knowledge alone did not predict any risk behavior. A more recent study shows that psychiatric patients with a history of any STI have a higher level of HIV/AIDS knowledge than those without a prior STI (Vanable et al. 2007). Nonetheless, risk behavior often occurs in the context of misinformation about HIV/AIDS (Kalichman et al. 1994).

Other associations with lower knowledge about HIV/AIDS among psychiatric patients have been described, including schizophrenia-spectrum disorders (Knox et al. 1994; McDermott et al. 1994), diminished cognitive function (McKinnon et al. 1996), and negative symptoms of psychosis (Koen et al. 2007; McKinnon et al. 1996). Although McKinnon and colleagues (1996) found no association between knowledge and socioeconomic variables, another study with American veterans reported that psychiatric patients with less than 12 years of education, older age, unmarried, or with no history of homelessness in the previous six months show lower HIV/AIDS knowledge (Strauss et al. 2006). Among factors with inconsistent or no evidence regarding their effect on sexual behavior are having limited capacity for planning, assessing one's own risk, and being motivated to engage in safer sexual behaviors (e.g., Gordon et al. 1999; Otto-Salaj et al. 1998).

Lack of safer sex skills has been found in SMI samples (e.g., Kalichman et al. 2005; Meade and Sikkema 2005a), arguing for interventions that reinforce the behavioral skills needed to protect oneself and others from HIV transmission. Adults with SMI who are less assertive have more partners and are less likely to use condoms (Kelly et al. 1995; Somlai et al. 1998; Weinhardt et al. 1998a).

10.5.2 Interpersonal Factors

Having SMI can make social interaction a daunting and difficult task. Periods of hospitalization may interfere with forming long-term sexual relationships and acquiring condoms while hospitalized (Cournos et al. 2001; Gordon et al. 1999; McKinnon et al. 2002). Individuals with SMI commonly have short-term and unfamiliar partners (Cournos et al. 2001; Coverdale and Turbott 2000; Gordon et al. 1999; Sullivan et al. 1999). Marginalized by society, individuals with SMI tend to interact with members of other marginalized social groups, including others with mental illness, who are at high risk for HIV/AIDS (Carey et al. 2001; Gordon et al. 1999). This is particularly true for adolescents with MI (Brown et al. 1997a; Donenberg et al. 2001; Elkington et al. 2012; McFarlane et al. 1995) for whom

risky peer networks are associated with greater rates of HIV risk behavior (Doljanac and Zimmerman 1998; Elkington et al. 2013; Walter et al. 1992).

Although research has documented the negative effects of MI stigma in the social lives of those with SMI (Wright et al. 2000), few studies have examined the role of MI stigma in their sexual lives. Qualitative studies show a bifurcation of effects: on the one hand, sexual intimacy and relationship stability are difficult to achieve in the face of social isolation and stigma (Gordon et al. 1999), which might suggest the possibility of increased risk; on the other hand, experiences of stigma are prominent reasons for sexual inactivity (Perry and Wright 2006), suggesting a possible “protective” effect. For example, Wright and colleagues (2007) reported that 67 % of adults with SMI who had not been sexually active in the past three months gave feeling undesirable as a partner and avoidance of discrimination as a reason for not having a recent sexual relationship. The only peer-reviewed U.S. study to quantitatively measure mental illness stigma or link experiences of stigma to specific HIV sexual risk behaviors demonstrated that women with SMI who believe that having a mental illness limits partner choice and devalues their position in a relationship are more likely to engage in sexual risk behavior compared to those who do not report such beliefs (Collins et al. 2008). Similarly, youth with MI engage in HIV/STI risk behaviors as a method to manage a stigmatized identity, which suggests that MI stigma and sexual risk may be linked in this group (Elkington et al. 2013).

A history of childhood sexual abuse is common among people with SMI (Brown et al. 1997c; Smith 2001). Sexual abuse has been linked with early sexual debut, multiple partners, lower rates of condom use, and higher rates of alcohol use among school-aged adolescents (Brown et al. 2000; Lodico and DiClemente 1994), and is also associated with sexual risk and sexual assault in adulthood (Goodman and Falloot 1998). A history of sexual abuse is associated with low self-efficacy and less intention to change sex risk behaviors in adolescents with MI (Brown et al. 1997c, d). Involvement in abusive interpersonal relationships is associated with exploitation and sexual victimization (Jacobson and Richardson 1987; Silver 2002) in which there is little opportunity to enforce safer sex practices.

Lack of social support is associated with sexual risk behavior among people with SMI (e.g., Randolph et al. 2007). Residing in families with impoverished or chaotic functioning is a particular risk factor for adolescents who still require and receive care from primary caregivers (Brown et al. 1997a). High rates of sexual activity, multiple sexual partners and other sex risk behaviors are associated with parents who are less supportive, less available, and less involved (Biglan et al. 1990; Fleuridas et al. 1997; Rodgers 1999; Rosenthal et al. 1996). Symptoms of MI may alienate parents and other family members and make attachment difficult (Brook et al. 1998; Hamilton et al. 1999). Lacking familial involvement and closeness, youth may engage in risky sexual activities, often at earlier ages (Donenberg et al. 2003), as opposed to turning to family and the community for care and support (Bachanas et al. 2002).

Similarly, disruption in familial bonds may place adults with SMI at risk. In the face of overwhelming caregiver burden, family members may disengage as a

coping method from their sibling or adult offspring with SMI (Perlick et al. 2001). Stigma associated with having a family member with MI may translate into avoiding or blaming the ill family member (U.S. Department of Health and Human Services 1999). As adults, individuals with SMI may find themselves without family contact or support.

10.5.3 Structural Factors

Consumers and client advocates often report that treatment providers are reticent about discussing sexuality-related issues (Wright et al. 2007), including HIV transmission (Deegan 1999), and that sexuality is an “unmentionable” topic in most mental health programs (Coverdale and Aruffo 1992; Herman et al. 1994; Rowe and Savage 1987; Ryan 1990; Schell 1994). Social and economic consequences of mental illness (e.g., poverty, homelessness) may also lead to barriers to safer sexual practices. For example, insufficient money to purchase condoms and lack of privacy may interfere with safer sex negotiation for those whose sexual encounters occur in shelters, outdoors, or other public places (Carey et al. 1997a; McKinnon et al. 2002).

10.6 HIV Interventions for Adolescents and Adults with SMI

Despite comparable AIDS knowledge among people with SMI relative to the general population (Deas-Nesmith et al. 1999; Sullivan et al. 1999), risk behaviors and rates of infection are higher among those with SMI, so improving knowledge alone is not sufficient to reduce risk (Kelly 1997). Intervention programs targeted for adults deliver cognitive-behavioral risk reduction skills training strategies to increase knowledge, attitudes, motivations and cognition (Cournos et al. 2001; McKinnon and Rosner 2000; Weinhardt et al. 1998a) and to build the skills necessary to increase sexual assertiveness and improve negotiation and problem-solving approaches to sexual risk (Brown et al. 2014; Carey et al. 2004; Kalichman et al. 1995; Kaplan and Herman 1996; Otto-Salaj et al. 1996, 2001; Susser et al. 1998). In these studies, small groups of people with SMI are provided basic information about HIV, its transmission, and risk behaviors over a series of group and/or individual sessions and are given the opportunity to develop specific skills to implement risk reduction strategies.

These interventions, primarily using the Information, Motivation, Behavioral Skills (IMB) model (Fisher and Fisher 1992), have shown that while risk behaviors decrease over the short-term, they return over months to pre-study levels. For example, a study of adults receiving outpatient psychiatric treatment initially found

a large decrease in risk behavior from baseline to 3, 6 and 9 month follow-ups, but saw a decline in risk reduction after one year (Otto-Salaj et al. 2001). “Booster sessions” help (Sullivan et al. 1999; Weinhardt et al. 1998b) and should be a consistent part of risk reduction interventions.

For adolescents, IMB-based interventions have shown low to moderate utility in explaining sexual risk taking (Donenberg et al. 2005); some argue that models for risk reduction interventions that rely heavily on cognitive processing (such as judgment, reality-testing, problem-solving), require a level of intellectual maturity and stability not yet attained by this age (Donenberg et al. 2002). Theories that take into account the broader context and multiple interacting systems present in the lives of adolescents (Donenberg et al. 2002, 2003; Perrino et al. 2000; Schwartz et al. 2007) may provide a more effective basis for interventions. For example, Eco-developmental Theory understands sexual activity and psychosocial adjustment in the context of family, peers, schools and community in which adolescent risk-taking is part of a normal developmental process influenced by the social context; risk is the result of the reinforcement contingencies of multiple interacting systems. For adolescents with SMI, the interplay among these factors either heightens or diminishes risk of psychopathology and risk taking over time. In response to these interacting systems of risk, HIV prevention in adolescents has begun to include the family. A multi-family HIV/STI prevention intervention developed for youth in psychiatric treatment successfully reduced unprotected sexual behavior, increased condom use and HIV knowledge, and produced significant improvements in parent-teen sexual communication, parental monitoring, and parental permissiveness (Brown et al. 2014).

10.7 HIV-Related Services for Adolescents and Adults with SMI

Many care settings offer some HIV-related services to mental health clients. However, most people with SMI do not receive HIV-related services from their mental health clinicians (Coverdale and Aruffo 1992; McKinnon et al. 1999; Walkup et al. 1998). Mental health professionals are not consistently assessing or intervening with clients’ HIV-related needs (Coverdale and Aruffo 1992; Hellerstein and Prager 1992; Herman et al. 1994; Mitchell et al. 1996; Ryan 1990; Walkup et al. 1998). Mental health administrators have reported significant barriers to providing HIV services (Herman et al. 1994; Knox 1998; McKinnon et al. 1999). Advocates and consumers have noted that clinicians neglect their clients’ sexual needs (Deegan 1999; Lukoff et al. 1986), including their hopes and desires for developing romantic partnerships (Davidson and Stayner 1997; Ginsberg 1977; Wasow 1980), and their concerns about the sexual side-effects of psychotropic medication (Buffum 1982; Holbrook 1989; Kockott and Pfeiffer 1996), all of which may affect HIV risk.

Once infected, obtaining integrated medical and mental health treatment may be difficult for those with SMI (Sullivan et al. 1999), and providers in either sector may be reluctant to assume ultimate responsibility for the patient (Lieberman and Coburn 1986). The proportion of HIV-infected adults in treatment with viral suppression is about 25 %, and among adolescents the proportion is only 6 %.

10.7.1 HIV Risk Assessment and Counseling

General hospital psychiatric staff members often fail to identify clients with significant HIV risk or histories of serious sexual abuse (Hellerstein and Prager 1992; Mitchell et al. 1996; Walkup et al. 1998). By contrast, Walkup and colleagues (1998) found that of 53 psychiatric units in New York State, only 9 % reported that they did nothing to educate or counsel clients about HIV. Community mental health professionals surveyed reported nearly unanimously that clients should be counseled about HIV/AIDS and family planning but only 20–25 % of their patients actually received such information (Coverdale and Aruffo 1992).

10.7.2 HIV Testing

Only 10 % of patients in a state psychiatric hospital were tested for HIV during a single hospitalization, and among outpatient mental health centers in New York State, only 22 % provided pre- and post-test counseling, only 16 % offered testing on-site, and 13 % did not have a procedure to refer patients to other sites for testing (Satriano et al. 2007). In a survey of psychiatric units in hospitals, 53 % reported that they encouraged only a few patients to get tested, and 17 % reported encouraging almost no patients to get tested (Walkup et al. 1998). The percentage of individuals with SMI who report having been tested in the past year ranges from 17 to 47 %; lifetime prevalence of testing ranges from 11 to 89 % (Pirl et al. 2005).

In one study, adults with major depression, bipolar disorder, or schizoaffective disorder were more likely than individuals without a mental health disorder to have been ever tested for HIV (46 vs. 31 %), to have been tested in the past 12 months (18 vs. 10 %), and to expect to be tested in the next 12 months (14 vs. 7 %) (Blumberg and Dickey 2003). However, in another study, women with schizophrenia or schizoaffective disorders were less likely than women without a SMI to ever be tested for HIV (11 vs. 67 %; Miller and Finnerty 1996). Most adults with a SMI who report ever being tested for HIV were tested more than once, with 30 % reporting two lifetime tests, 21 % reporting three tests, and 35 % reporting ≥four HIV tests (Meade and Sikkema 2005b). Receiving services at an urban (vs. suburban) mental health center (Goldberg et al. 2005), using a greater number of treatment services (Meade and Sikkema 2005b), and recently using health services (Desai and Rosenheck 2004) were associated with being tested. Among the general

population, test return rates are poor, whereas 89–96 % of people with a SMI return for their results (Desai and Rosenheck 2004, Desai et al. 2007).

The national shift toward voluntary, routine HIV testing in all health care facilities, recommended by the Centers for Disease Control and Prevention (CDC) in 2006 (Branson et al. 2006), is not yet a standard practice in most mental health settings. Yet psychiatric settings are an opportune venue for HIV testing: patients are already there, reducing the need for additional transportation or appointments; mental health clinicians can provide support that is tailored for individuals with SMI (Satriano et al. 2007); and therapists can encourage HIV testing, address barriers to testing, and allay concerns about testing, confidentiality, and stigma. In one study a stronger therapeutic alliance was associated with a greater likelihood of HIV testing (Desai et al. 2007), suggesting therapists could be a valuable resource to encourage such testing.

10.7.3 HIV Prevention Approaches Used in Treatment Settings

Four general groups of HIV prevention interventions used by mental health professionals with adult clients with SMI have been described (Carmen and Brady 1990; Courmos et al. 1989; Knox 1989; Wright et al. 2007). First, early in the epidemic many institutions and some community-based programs emphasized *restrictions* to manage clients' disruptive sexual behavior, such as use of seclusion rooms, physical restraints, and/or one-on-one staff supervision (Ginsberg 1977; Holbrook 1989; Wasow 1980). These interventions may include less tangible forms of restrictiveness, such as no-sex policies on inpatient units (Bachrach 1980; Carpenter 1978; Garritson 1987; Munertz and Geller 1993).

Second, mental health professionals may offer clients basic *HIV prevention education*, often utilizing specialized curricula to address potential cognitive difficulties associated with SMI (Cates et al. 1994; Goisman et al. 1991; Lauer-Listhaus and Watterson 1988; Lewis and Scott 1997; Lukoff et al. 1992; Schindler and Ferguson 1995; Sladyk 1990). Prevention education may involve providing clients with brochures about the “facts” of HIV or safer sex (usually when clients ask about HIV or AIDS) or inviting clients to participate in voluntary sexuality or HIV discussion or education groups.

Third, mental health providers may *integrate HIV-related issues into standard psychotherapy and case management*. Several therapeutic assessment and intervention models targeting various risk behaviors have been proposed (Friedrich and Grannan 1998; Knox 1989, 1998). Counseling is a particularly effective forum for dealing with clients' sexual dysfunction, the sexual side-effects of medications, working through difficulties in maintaining sexual and/or romantic relationships, and addressing “co-factors” that reinforce high risk behavior, including substance use and self-esteem problems (Buffum 1982; Kockott and Pfeiffer 1996; Savin-Williams and Lenhart 1990; Vincke et al. 1993).

Fourth, *HIV prevention skills training*, the most intensive class of services, is the type of care least likely to be provided to the clients surveyed.

With the evolution of approaches to HIV infection, the use of therapeutic restrictions to manage high-risk behavior has become infrequent. Clients report receiving HIV prevention education and HIV-related therapy or counseling most frequently. HIV-related skills training is offered less often even though these methods reflect the only class of interventions for which there is demonstrated efficacy in reducing clients' HIV risk behavior, at least in the short term (Carey et al. 2004; Kalichman et al. 1995; Otto-Salaj et al. 2001; Susser et al. 1998).

HIV prevention-related services are provided most frequently to a small sub-set of clients. Those clients known to be HIV positive, currently sexually active, and more acutely mentally ill (i.e., hospitalized) were most likely to report receiving more of all four types of care. It's likely that these individual-level characteristics are influencing staff perceptions of need and/or clinical decision-making. It also may be that clients with easily identified risk are more likely to raise these issues with staff and request support and services.

Most clients who are not identified to be currently at risk are significantly less likely to receive HIV prevention-related mental health services. Clinicians may assume that clients are generally not at risk and/or rely on clients to bring up these concerns. Women reported receiving significantly fewer instances of HIV-related prevention education or HIV-related skills training than men, even after controlling for current sexual activity (Wright et al. 2007), which may reflect broader societal beliefs and assumptions regarding women's sexuality.

10.8 Treatment Setting Readiness to Provide HIV-Related Services for SMI

Treatment settings vary in their readiness to care for both HIV and mental health conditions. Appropriate services often are lacking due to reluctance of mental health systems to tackle issues relating to HIV (Lyketsos et al. 1993; Satriano et al. 1999), and/or lack of appropriate training and knowledge on the part of providers (Brunette et al. 2000; Satriano et al. 1999). One study found that the majority of mental health clinics in New York state reported unmet training need for their providers (McKinnon et al. 1999).

Although providers usually agree that HIV-related services are important (Satriano et al. 2007), barriers to providing such services include lack of training, discomfort with the topic, and competing priorities (Solomon et al. 2007). Community mental health centers are an important gateway to services needed by people with SMI to reduce HIV/AIDS risk and to increase their overall quality of life (McKinnon et al. 2002; Sullivan et al. 1999). However, clinicians may be uncomfortable delivering risk reduction counseling or obtaining consent for or administering HIV tests, patients may be uncomfortable talking about HIV, and

HIV testing and counseling might take time away from the provision of essential mental health services.

The vast majority of providers who receive training on HIV and mental health work in medical settings rather than mental health settings despite outreach to both types of settings, and medical providers are more likely than mental health care providers to deliver integrated services (Kim et al. 2014). Although providers working with HIV/AIDS patients show clear indication of the need for training to address mental health and substance use issues among their patients, with these issues being the top training need identified in 2013–2014 by 99 clinical sites, only 27 % of such sites actually obtained this training during the same time period (McKinnon 2014). Because providers are working hard to keep up with all the aspects of care they are responsible for, they may not have time to do anything else even where training resources are available. Most regions of the country do not have dedicated HIV behavioral health training programs that are accessible free of charge and it takes considerable practice to feel comfortable delivering behavioral health services to people with HIV/AIDS. Nonetheless, research demonstrates that capacity building through training increases clinical knowledge and service provision among individual providers (Cook et al. 2006; Linsk et al. 2002; Wright and Martin 2003) in community-based organizations, hospitals, and community mental health settings.

Increased training for service providers is critical for improving patients' risk reduction skills and increasing provider therapeutic skills around managing issues related to testing and HIV positive diagnoses (Brunette et al. 2000; Cournos et al. 2001; Satriano et al. 1999; Sullivan et al. 1999) and working to integrate psychiatric and medical care. The Ryan White Care Act and The Affordable Care Act create incentives to coordinate primary care, mental health care, and addiction services at the systems level. Fully coordinated or integrated care is not yet treatment as usual, with patterns of service integration varying by type of health-care setting, service setting location, and HIV caseload (Kim et al. 2014). HIV care training has been shown to improve agency-level service delivery, streamline care to reduce patient burden, and move healthcare practitioners along a continuum of service implementation (Bashook et al. 2010; Huba et al. 2000).

10.9 The Syndemic Dynamics of HIV and SMI: What We Need to Know

Available evidence about the extent to which HIV and SMI are syndemic and the factors contributing to the convergence and negative health interactions of the two conditions is scarce but suggestive. Syndemics occur when health-related problems cluster by person, place, or time, whereby preventing one illness is contingent upon controlling the other and the forces that tie those afflictions together. The available evidence, though incomplete, suggests that the sexual health and well-being of

psychiatric patients require greater attention. It is time to effectively include this population in our public health endeavors (Campos et al. 2008).

Given the clear vulnerability for HIV/AIDS infection that adults and adolescents with SMI possess, the available data must be scrutinized to ascertain what information is lacking, and to better inform treatment, intervention protocols, and public policy decisions for this population. Future research is suggested in five areas: epidemiology; psychiatric symptoms and disorders; trajectories of risk behaviors; drug use risk behaviors; environmental risk factors.

10.9.1 Epidemiology

More epidemiological research of HIV/AIDS risk behaviors using community matched control samples is needed (Smith 2001), especially in the adolescent population with mental illness where relatively few such studies have been conducted. We need to establish accurate rates of risk behaviors drawn from a variety of samples—in treatment, dual diagnosis, community, homeless/runaway, and jailed/detained—before we can adequately address, intervene and prevent HIV/AIDS risk behaviors. We need to better understand the differences in prevalence and patterns of risk behaviors among various demographic subgroups among both adults and adolescents so that we can develop more targeted approaches to reducing risk in specific groups.

10.9.2 Specific Symptoms and Disorders

Studies examining links between specific psychiatric disorders and HIV/AIDS risk have yielded inconclusive information (Otto-Salaj and Stevenson 2001) and further examination using standardized measures of mental disorder may help create a clearer picture and identify which patients are most at risk. Dual diagnosis populations warrant particular attention as comorbid substance use disorder and SMI is common and increases risk (Deas-Nesmith et al. 1999; Elkington et al. 2008; Levounis et al. 2002; Rahav et al. 1998; Ramrakha et al. 2000). While some studies measured drug risk behaviors, few controlled for or examined the presence of SUD when reporting these behaviors (Elkington et al. 2008). Future studies must parse out the effects of substance use disorders and other psychiatric diagnoses, as well as the combination of these conditions, so we accurately tailor our interventions to those most at risk.

10.9.3 Trajectories of Sex and Drug-Use Risk Behaviors

Longitudinal studies are needed to understand how diagnosis, symptom severity, and associated functional impairments affect the development and sequence of sexual and drug use risk behaviors over time (Donenberg et al. 2002; Guo et al. 2002; Hoff et al. 1997; Ramrakha et al. 2000). For example, such research can help elucidate which factors influence the trajectory of these behaviors as adolescents with mental illness transition into young adulthood and beyond. Which risk behaviors cease with mature development, and which get worse when mental disorders are chronic? These studies are crucial to optimize the timing of interventions.

10.9.4 HIV/AIDS Drug-Use Risk Behaviors

Many studies of HIV/AIDS risk among SMI populations provide limited information on drug use risk behaviors. More information is especially needed about the nature and extent of drug injection and associated behaviors (e.g. needle sharing, needle hygiene) (McKinnon et al. 1996), particularly among vulnerable adolescent populations, such as homeless or runaway youth, for whom psychiatric and substance use disorders frequently co-occur but data are sparse. Furthermore, few studies have examined the role of specific substances on sexual risk behavior among individuals with SMI (Menon and Pomerantz 1997). Studies of the general population have found that use of crack and alcohol confers increased risk of trading sex for drugs/money to buy drugs (Logan et al. 2002). This information will help identify specific groups of individuals with mental illness who may be at greatest risk.

10.9.5 Environmental Risk Factors

We need studies that assess if risk is illness-specific or related to the social and economic consequences of SMI (Carey et al. 1997a). For example, living in poor neighborhoods where there are high rates of HIV and STDs pre-selects the type of people with whom individuals with SMI come into contact. We also need to know more about the “competing contingencies” in the lives of those with SMI (Carey et al. 1997a). Sex for money with numerous partners enables some individuals with SMI to eat and obtain shelter, yet this behavior clearly places them at elevated risk for HIV/AIDS. Future research can help us identify important contextual or environmental factors to target and modify through intervention and treatment programs.

10.10 Curbing This Syndemic: Recommendations for Prevention of HIV Among People with SMI

10.10.1 Address Specific Subpopulations

Although HIV/AIDS prevention interventions modified for individuals with SMI have made gains in reducing risk behaviors, more needs to be done to enhance their success. Many intervention programs for individuals with SMI are “generic” in nature (Kelly 1997; Weinhardt 1998a, b) and need to be tailored to the needs of specific subpopulations such as girls and women, adolescents, and victims of sexual abuse for whom some—though not enough—evidence of need exists.

A variety of factors make women and girls more vulnerable than men to HIV infection, including a greater likelihood of being economically dependent, experiencing a need for intimacy or a fear of rejection, experiencing cultural stereotypes discouraging them from openly discussing sex, and being subject to male control of safer sex practices such as the use of condoms (Kelly 1997; Otto-Salaj et al. 2001, 2002; Weinhardt et al. 1998b). Interventions for females need to focus on sexual assertiveness, negotiation and communication skills. The manner in which interventions are delivered should be tailored for females. For example, Johnson-Masotti and colleagues (2000) compared the cost-effectiveness of three interventions among males and females and found only the one-to-one, single session, risk reduction program was efficacious among females whereas all three interventions worked for males. Similarly, women have shown reluctance to enter into mixed-gender prevention intervention groups (Carmen and Brady 1990), suggesting that women may require single sex groups or individual sessions to obtain maximum benefit from HIV/AIDS prevention programs.

The studies of risk behaviors among adolescents with MI suggest that prevention interventions must begin early (Bachanas et al. 2002), must emphasize the development of impulse control (Deas-Nesmith et al. 1999), and must work to increase their awareness of the risk of infection. Adolescents frequently associate infection with being gay or addicted to drugs (Brown et al. 1997a; Dudley et al. 2002) and not their own age cohort. Family and peer influences must also be addressed. Donenberg and colleagues (2002) suggest that “family is the ideal entry point for adolescent risk prevention and intervention,” creating a sense of cohesiveness and reducing the likelihood that these youth will rely on a deviant peer group for support. Helping adolescents associate with positive peers and navigate successful interaction with negative peer groups is also critical (Donenberg et al. 2001).

Adolescents with a history of sexual abuse respond poorly to HIV/AIDS interventions (Deas-Nesmith et al. 1999) and may require specialized interventions that develop assertiveness, self-esteem and self-efficacy regarding sexual behaviors.

10.10.2 Address and Modify Environmental Risk Factors

Interventions need to address environmental or mediating factors known to increase the risk of HIV/AIDS, including homelessness, financial instability, living in poor urban neighborhoods, lack of social relationships or support, and substance abuse. Case management (Brunette et al. 2000) and use of psychosocial rehabilitation strategies (Otto-Salaj et al. 2001) such as vocational counseling, dual diagnosis groups, stress management, assistance with securing funding (e.g. SSI, SSDI), and stable housing could be integrated into HIV prevention interventions to address these factors.

In addition to accommodating the distinctive needs of people with SMI, it's also important to search for ways in which they are similar to others. For example, multiple studies have found that contrary to early expectations, people with SMI often achieve levels of antiretroviral therapy adherence at least as good if not better than others with HIV (e.g., Walkup et al. 2001). It also may be that community-level changes relevant to HIV prevention will have a significant impact on those with SMI. For example harm-reduction and other approaches that address the spread of HIV among drug users, including those who inject drugs, may not only affect those people with SMI who use drugs, but also be effective in limiting new infections among people with SMI (Walkup et al. 2011). The risk of HIV infection for people with SMI needs to be viewed in the context of local patterns of infection, as very different patterns of risk may exist in different communities. A focus on this geographical variation can be a powerful analytic approach for future efforts.

Counseling and behavior change technologies adapted for people with SMI are valuable but labor intensive, and so may have their greatest impact if they are targeted to geographical areas where risks are higher, rather than being spread thinly across the whole population. A range of methods, including seroprevalence studies, ethnographic studies, surveys, and tracking of administrative datasets, should be used to identify locally specific transmission links between drug-using and SMI communities (e.g., co-location of these communities in downtown single-room-occupancy hotels with few services and active drug use) to inform intervention.

10.10.3 Provide Interventions for Those Already Diagnosed with HIV

Interventions that address the needs of those who are *already* HIV-positive (Kelly 1997) are also important. These “secondary prevention interventions” can help coordinate access to medical treatment, reduce symptoms of distress through illness education and provision of support, and promote the practice of non-risky sexual behaviors and drug use practices to reduce the risk of transmission to others (Kelly 1997).

10.11 Curbing This Syndemic: Recommendations for HIV Mental Health Service Delivery

It is well past time to build a workforce capable of addressing the complex needs of people living with or at risk for HIV/AIDS and SMI. Integrating HIV and mental health requires a mechanism for funding the services (e.g. a favorable state Medicaid program, Ryan White funding, etc.); an institutional commitment to integrated care (such as that in the VA system); and availability of mental health care providers working in the same setting as medical care providers (e.g. more likely in urban locations, hospital-based settings, etc.). There is no single approach to integrating mental health and HIV care; models for successful integration require team approaches using available resources and establishing and following clearly defined patient outcomes; teamwork (primary care clinicians cannot do it on their own without support and consultation); and training to build the capacities of team members.

Three recommendations that would facilitate better care for those caught in the syndemic dynamics of HIV and SMI are: (1) Stabilize funding for individual and systems-level capacity-building; (2) Generate evidence of best-practices to use as the basis of planning; (3) Generate evidence about “active ingredients” in moving providers and treatment organizations along a continuum of readiness to implement best practices as they emerge.

10.12 Summary

Only by addressing the complex interplay of individual, interpersonal, and structural levels that create a hospitable environment for the syndemic of HIV and SMI will we be able to end the confluence of these devastating epidemics.

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Chapter 11

HIV Housing Helps End Homelessness and HIV/AIDS in the United States

Julie Hilvers, Christine C. George and Arturo V. Bendixen

11.1 Introduction

HIV/AIDS is a health epidemic worldwide and in the United States, with the Centers for Disease Control and Prevention estimating that over 1.2 million persons in the U.S. are infected with HIV (Hall et al. 2015). In addition, homelessness is a significant public health problem in the U.S. (Wolitski et al. 2007, 2010). There is a strong relationship between HIV/AIDS and homelessness (Aidala et al. 2007; Milloy et al. 2012; Schwarcz et al. 2009; Wolitski et al. 2007, 2010). In examining the manifestation of HIV/AIDS in the U.S., the inter-relationship between economics and the illness is important to take fully into account (Fee and Krieger 1993; Singer 1994). Singer (1994) characterizes this relationship as syndemics, “the set of synergistic or intertwined and mutual enhancing health and social problems facing the urban poor” (p. 933). Arguing that social factors and social class play a strong role in exposure to HIV, Singer (1994) posits “...*AIDS itself emerges as an opportunistic disease*, a disease of compromised health and social conditions, a disease of poverty” (p. 937—emphasis in original). Citing Novick and colleagues’

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(1989) study of New York City's Lower East Side neighborhood, Singer asserts, "Note that the areas of the city with the highest levels of infection are poor inner city neighborhoods, where low income ethnic minorities constitute a substantial portion of the population" (p. 944). Whether or not HIV/AIDS is an "opportunistic" disease, it is clear that homelessness or housing status has a strong impact on the health and well-being of people with chronic illnesses such as HIV/AIDS.

This chapter focuses on homelessness/marginal housing as a syndemic issue for those living with HIV/AIDS. We focus broadly on the United States, and conclude with a case study from the city of Chicago. First, we provide background information regarding the interrelationship and prevalence of homelessness or housing instability and HIV/AIDS. We next discuss the policies and strategies in the U.S. to address the HIV/AIDS epidemic, and their relationship to housing status and poverty. Next, we review findings from recent housing program outcome data and studies about the impact of housing on health outcomes. We then describe the experiences of formerly homeless individuals living with HIV/AIDS and on Medicaid who are enrolled in a supportive housing program in Chicago. Through this case study, we explore the impact of the supportive housing program on these individuals' health behavior and status.

11.2 Background

11.2.1 Inter-relationship Between HIV-AIDS and Economic and Social Factors

As mentioned above, economic factors including housing status and HIV/AIDS status are intertwined in the U.S. Factors including high costs of medications and healthcare (National Alliance to End Homelessness 2006; National Coalition for the Homeless 2007), inadequate levels of affordable housing (National Alliance to End Homelessness 2006; National Coalition for the Homeless 2007), and insufficient income supports (Pelletiere et al. 2006) and employment insecurity due to discrimination and missed work days (Braveman et al. 2006; Maticka-Tyndale et al. 2002; National Coalition for the Homeless 2007; Timmons et al. 2004) are all factors which contribute to income and housing insecurity among people with HIV or AIDS.

Conversely, the risk of HIV infection is great among individuals who are homeless or lack stable housing. Precariously housed individuals are at high risk of contracting and transmitting HIV while stable housing can have a protective effect against acquiring HIV (Wenzel et al. 2007). Many studies have demonstrated a relationship between housing precariousness and engagement in sexual behaviors associated with risk of HIV infection including inconsistent condom use or unprotected sex (Kidder et al. 2008; Marshall et al. 2009), multiple sex partners (Kidder et al. 2008; Marshall et al. 2009; Wenzel et al. 2007) and high risk drug behaviors including injection drug use (Kidder et al. 2008) and inconsistent adherence to HIV treatment medications among those using drugs (Friedman et al. 2009; Palepu et al.

2011). Weir et al. (2007) analyzed the longitudinal relationship between housing and HIV risk behaviors among a sample of 493 women involved with the criminal justice system and engaged in HIV high risk behavior. The authors assessed multiple housing indicators (objective and subjective housing stability, residing in supportive housing, number of residences in prior 6 months, and housing assistance needs) and multiple HIV risk behaviors (sex exchange, unprotected sex, needle sharing, and hard drug use). Weir et al. (2007) found significant relationships between the various housing indicators and HIV risk behaviors. Not residing versus residing in supportive housing was associated with an increase in the odds of hard drug use, needle sharing, sex exchange, and unprotected sex. Viewing one's housing situation as unstable (subjective housing stability) rather than stable was associated with an increased odds of hard drug use and needle sharing. Likewise, needing but not receiving housing assistance compared to not needing services was associated with increased odds of sex exchange and hard drug use. Finally, residing in three or more locations in the previous 6 months was associated with a higher odds of sex exchange and of unprotected sex (Weir et al. 2007).

Homeless youth are also at risk of contracting HIV through high risk sexual behavior. Through a study of 192 youth aged 14–21 participating in a HIV prevention program and receiving services from a youth homeless agency in Los Angeles, Tevendale et al. (2009) report that over just under 70 % of the young people reported having unprotected sex in the prior 3 months. Over 18 % (18.2 %) reported trading sex for money or drugs, and 7.3 % reported trading sex for a place to stay.

11.2.2 Prevalence of Homelessness Among Those Living with HIV or AIDS

Homelessness, or housing precariousness, is extremely prevalent among individuals living with HIV or AIDS. The National Alliance to End Homelessness (2006) reports that HIV/AIDS is more prevalent among those who are homeless compared to the general U.S. population. An estimated 3.4 % of people who are homeless are living with HIV (National Alliance to End Homelessness 2006), relative to approximately 0.4 % of the U.S. population age 13 and older who are HIV positive, as reported by the Centers for Disease Control and Prevention (Hall et al. 2015). A number of studies demonstrate the prevalence of HIV infection and AIDS among individuals experiencing homelessness. In New York City, for example, among single adult users of the city's Department of Homeless Services shelters between the years 2001 and 2003, the rate of HIV infection was 16 times the rate of the overall city adult population (Kerker et al. 2005). Further, through a meta-analysis of 22 studies of homeless adults conducted in the U.S., France, Sweden, Iran, Brazil, India and Ireland, HIV prevalence ranged from 0.3 to 21 % (Beijer et al. 2012). Thirteen of these 22 studies were from the U.S.; HIV prevalence was higher in the U.S. studies than studies conducted in the other countries, the authors report.

In the city of Chicago, similar to the U.S., HIV/AIDS is prevalent among the city's homeless population. Various studies point to the prevalence of HIV/AIDS among the homeless in Chicago. Results from Chicago's 2014 Point in Time Count—a census of individuals sheltered (residing in emergency and transitional shelters) and unsheltered (on street and other locations not meant for habitation) on one night in January of 2014—show that among sheltered individuals, 4 % are HIV positive or have AIDS and 3 % of unsheltered individuals reported HIV/AIDS (City of Chicago Department of Family and Supportive Services and University of Illinois at Chicago Nathalie Voorhees Center for Neighborhood and Community Improvement 2014). Data gathered through the city's Homeless Management Information System (HMIS) indicate among all adults housed or receiving services through Chicago's homeless system, 3.8 % have HIV/AIDS. Many of these individuals living with HIV/AIDS in Chicago's homeless system are housed through its various permanent supportive housing programs, resulting in nearly one-tenth (8.8%) of adults housed through a permanent housing program through Chicago's homeless system are living with HIV/AIDS. Individuals living with HIV/AIDS represent a smaller proportion of adults temporarily housed or receiving homelessness prevention services (1.9 %).

11.2.3 U.S. HIV/AIDS Policies and Strategies

Beginning in the 1990s, the U.S. federal government enacted several policies and strategies to curb the HIV/AIDS epidemic in this country and, in particular, to support under-resourced individuals with living with HIV or AIDS.

The first of these national policies, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act recently celebrated its 25th anniversary. The Ryan White CARE Act is managed through the U.S. Department of Health and Human Services (DHHS), which allocates resources to states, local municipalities, and non-profit organizations to fund services for those living with HIV or AIDS, including housing, transportation, case management and other support services. The majority of recipients are impoverished, with 67 % of recipients having household incomes at or below the U.S. federal poverty level (U.S. Department of Health and Human Services 2014). While the Ryan White CARE Act does include some funding for housing, it does not fund long-term or permanent housing, which is a significant limitation of the Act (Aidala et al. 2007; Schwarcz et al. 2000).

To address the need for additional housing support for individuals living with HIV/AIDS, the Housing Opportunities for People with AIDS (HOPWA) was enacted by Congress in 1992. Managed by the U.S. Department of Housing and Urban Development (HUD), federal HOPWA funding provides housing and other support services for low-income individuals with HIV/AIDS. At the 2012 International AIDS Conference in Washington D.C., Nancy Bernstine, executive director of the National AIDS Housing Coalition asserted, "Housing remains the most critical need of people with HIV-AIDS living in the United States" (National

Alliance to End Homelessness 2012). As reported by Bernstine, HOPWA provides housing assistance to approximately 60,000 annually, yet 145,000 households in need of housing assistance are not served due to limited financial resources. HOPWA has two types of housing assistance: The Short-Term Rent, Mortgage, and Utilities (STRMU) and the Long-Term Rental Assistance (LTRA) programs. STRMU is limited to no more than 21 weeks of assistance, while the LTRA has no time limits and can continue indefinitely as long as the recipient remains eligible.

In 2010, the Obama Administration released the National HIV/AIDS Strategy for the United States (NHAS) and released an updated Strategy in 2015. The NHAS outlines the country's four primary goals to minimize the HIV/AIDS epidemic: (1) Reducing the number of new HIV infections, (2) Increasing access to HIV treatment and improving health outcomes for those individuals with HIV, (3) Lowering HIV-associated health inequalities, and (4) Greater coordination in the response and efforts to curb the HIV/AIDS crisis (White House Office of National AIDS Policy 2015).

Housing stability is highlighted as critical to achieving the goals of the National HIV/AIDS Strategy. In relation to Goal 1, the NHAS outlines the importance of access to housing, as well as education, transportation, employment, childcare and other critical structural resources to prevent HIV infection and transmission in the U.S. With regard to Goal 2, the NHAS cites a number of studies, which point to the relationship between stable housing and continued access to HIV treatment among those living with HIV. The NHAS asserts, "Access to housing is an important precursor to getting many people into a stable treatment regimen. Individuals living with HIV who lack stable housing are more likely to delay HIV care, have poorer access to regular care, are less likely to receive optimal antiretroviral therapy, and are less likely to adhere to therapy" (White House Office of National AIDS Policy 2015, p. 35). With regard to Goal 3, the NHAS promotes strategies to address social determinants of health including housing, food security, employment, and education in an effort to reduce HIV disparities in communities. In addition, the National HIV/AIDS Strategy advocates for housing supports for PLWHA with low incomes and specifically, an increase in the number of Ryan White HIV/AIDS recipients receiving permanent supportive housing.

Goal 4 of the National HIV/AIDS Strategy—increased coordination to curb the spread of HIV/AIDS—is attempted through the HIV Care Continuum Initiative. In 2013, through an Executive Order, President Obama Administration released the HIV Care Continuum Initiative (The White House 2013). Overseen by the Office of National AIDS Policy, several federal agencies including HUD, National Institutes of Health, Centers for Disease Control and Prevention, Department of Justice, and the Department of Labor have coordinated their strategies to achieve the Continuum's goals of reducing the HIV/AIDS epidemic in the U.S. The primary objective or stage in the Continuum is antiretroviral treatment (ARV) for those diagnosed with HIV. The HIV Care Continuum (also called HIV Treatment Cascade) consists of five stages: Step (1) HIV testing and diagnosis, Step (2) Linking

to care or treatment, Step (3) Engagement and retention in care, Step (4) Adherence to antiviral therapy, and Step (5) Viral suppression through antiviral medications.

11.3 Review of Studies Examining the Impact of Housing Status on Health Status and Behavior

An extensive body of research demonstrates that housing and other supports are critical for individuals with HIV or AIDS to maintain their health.

11.3.1 Impact of Housing Status on Receipt of HIV Medical Care

Through analysis of longitudinal data collected with a large probability sample of individuals diagnosed with HIV through the New York City Community Health Advisory & Information Network (CHAIN) study, Aidala et al. (2007) found an impact of housing status on medical care. Those who are homeless or with unstable housing were less likely to be engaged in HIV medical care. Likewise, those with unstable housing histories who received housing assistance were more likely to receive HIV medical care and retention in medical care. Further, case management and other social support were also associated with receipt of and retention in HIV medical care among those who lacked stable housing.

Through a study analyzing data from the Centers for Disease Control and Prevention's Supplement to HIV/AIDS Surveillance project, Kidder et al. (2007) compared health outcomes between the subset of respondents who were housed and the subset of respondents without homes (N = 304, 4 %). The authors found significant differences between the sample subsets. Homeless respondents were more likely to have received HIV care in the emergency room and been admitted to the hospital in the previous year, while those with housing received their care from a primary care physician.

11.3.2 Homeless Less Likely to Adhere to Treatment

Results from the aforementioned analysis of data from Centers for Disease Control and Prevention's Supplement to HIV/AIDS Surveillance projects show that those unstably housed are less likely to adhere to treatment. Kidder et al. (2007) compared health outcomes among the subset of housed respondents and the homeless respondents (N = 304.4 %), the authors report that homeless respondents were less likely to report adherence to HIV treatment in the previous 48 h. Similarly, Palepu

and colleagues (2011) report findings from a longitudinal study of individuals who are injection drug users (IDU) and are living with HIV. Results show that homelessness was positively associated with frequent heroin use and negatively associated with adherence to ART therapy.

11.3.3 Improvement in Health Outcomes

New York City has measured achievement for each of the five steps of the HIV Care Continuum (referenced above) among those infected with HIV. In 2011, researchers compared outcomes among three groups: (1) New York City's HOPWA housing program participants, (2) individuals with HIV/AIDS in New York City overall, (3) and people with HIV/AIDS in the U.S. overall. Results show better health outcomes among individuals in the New York City HOPWA group. In particular, a greater proportion of individuals in the HOPWA group—62 % of people—achieved a suppressed viral load; this compares to 44 % of New York City overall, and only 30 % of the U.S. overall (McAllister-Hollod and Rojas 2013). Data for the year 2013 showed better results compared to 2011 for New York City overall and for HOPWA,¹ as a greater proportion of those diagnosed with HIV achieved suppressed viral loads (Wiewel 2015). Wiewel explained that this increase in viral load suppression among the HOPWA group can be attributed to the high rates of retention in HIV care and treatment (Email correspondence with author, November 13, 2015). Viral suppression outcomes have improved greatly among the New York City HOPWA group over time. Between 2008 and 2013, viral suppression among HOPWA clients increased from 57 to 77%, a statistically significant increase (Wiewel and Rojas 2015). When examining viral suppression trends by HOPWA housing assistance characteristics (supportive housing, rental housing, and housing placement assistance), the largest increase in viral suppression between 2008 and 2013 was among those in supportive housing (Wiewel and Rojas 2015).

Buchanan et al. (2009) analyzed results for the one-third of participants from the Chicago Housing for Health Partnership (CHHP) study living with HIV/AIDS. CHHP was a randomized control study with individuals who were homeless and hospitalized for a chronic health condition. At discharge, individuals in the intervention group were housed in permanent supportive housing and case management and the control group received the usual care at discharge. Buchanan et al. (2009) report significant improvements in health outcomes among the intervention group compared to the control group. Among the stably housed intervention group, 55 % had “intact immunity (CD4 \geq 200 and viral load $<$ 100,000 at the time of their laboratory assessment)” after 12 months of follow-up; this compares to 34 % of the usual care control group. Further, 36 % of the intervention group had undetectable

¹2013 U.S. data not included.

viral loads, compared to 19 % of the usual care group. Similarly, Hawk and Davis (2012) report through a study of The Open Door, a Housing First, Harm Reduction permanent supportive program in Pittsburgh for formerly homeless individuals living with HIV or AIDS, that 69 % of housing residents achieved undetectable viral loads. Through Kidder et al.'s (2007) study to HIV/AIDS Surveillance project data collected by the Center for Disease Control and Prevention, the authors found respondents without homes self-reported worse medical, mental, and overall health, relative to the housed subset. Further, those without homes were less likely to report a CD4 count of 200 or above and an undetectable viral load (Kidder et al. 2007).

Wolitski et al. (2010) report results from the Housing and Health Study, a randomized control study examining the impact of receipt of HOPWA housing assistance among homeless and unstably housed individuals with HIV/AIDS. Those who experienced homelessness were more likely to have a detectable viral load (79 %), relative to those who did experience homelessness (61 %). Experiences of homelessness were also associated with increased stress and mental health conditions and visits to the emergency room. Also analyzing data from the Housing and Health Study, Friedman et al. (2009) found inconsistent adherence to HIV treatment medications among those individuals using drugs. These authors also found that those using substances were also likely to be engaged in high-risk sex behavior.

11.3.4 Disproportionate Death Rate Among Homeless

Studies also point to worse mortality rates among those individuals with HIV/AIDS who lack stable housing. Kerker et al. (2005) found through their study of single adult users of New York City's Department of Homeless Services homeless shelters a death rate much greater for those with HIV who used this shelter system relative to the general city population. Among those who used the adult shelters between 2001 and 2003, HIV/AIDS accounted for 13.8 % of deaths; among adults in New York City, HIV/AIDS was the cause of death for 2.9 % of deaths in those years.

Similarly, analyzing data from the San Francisco AIDS Registry of individuals diagnosed with AIDS between 1996 and 2006 (N = 6,558), the authors found significant differences in health outcomes between homeless (9.8 % of cases) and non-homeless (Schwarcz et al. 2009). Results show greater 5 year survival rates among housed individuals (81 %) compared to individuals who were homeless (67 %). There was a significant decrease in mortality (80 %) among those homeless who obtained permanent supportive housing.

11.3.5 Stable Housing Associated with Decreased Healthcare Spending

As demonstrated above, stable housing is associated with better health outcomes for individuals living with HIV or AIDS. Studies also show permanent housing is associated with decreased medical costs among those with chronic health conditions, including HIV or AIDS. Sadowksi and colleagues (2009) found through their study of the Chicago Housing for Health Partnership that among individuals who were homeless, were discharged from a hospital, and had chronic health conditions, some of which were HIV/AIDS, placement into a permanent housing program with supportive services was associated with reduced medical costs. Placement into stable housing with case management, on average, was associated with fewer hospitalizations, emergency room or nursing home visits, relative to those individuals who received the standard assistance at hospital discharge (Sadowski et al. 2009). In addition, to the CHHP program, many studies demonstrate how stably housing individuals with chronic health conditions is cost-effective for public systems (Gulcur et al. 2003; Larimer et al. 2009; Martinez and Burt 2006; Rosenheck et al. 2003).

11.3.6 Medicaid and Other Health Funding to Finance Permanent Housing

As studies demonstrated that supportive housing improved health outcomes and saved money for public systems, attention has focused on leveraging resources, including Medicaid, to fund integrated healthcare and supportive housing for individuals who are homeless and have chronic health conditions (Nardone et al. 2012).

For more than a decade, federal inter-departmental discussions and collaborations, involving entities including HUD, HHS, and Medicaid, have occurred to address the potential role of Medicaid funding to finance permanent supportive housing for individuals with chronic health conditions (George et al. 2014). According to a program administrator from the Medicaid Supportive Housing Program in Chicago, these conversations continued with the election of Barack Obama, “One of the things that...the Obama Administration has done is really pushed the silo entities of the federal government—HHS, HUD, the VA—to try to collaborate a lot more. So the first Obama budget had money for 4,000 HUD subsidies to be used for people on Medicaid with additional SAMHSA [Substance Abuse Mental Health Services Administration] dollars to help pay for services that Medicaid would not pay,” (George et al. 2014).

In 2011, New York State established the Medicaid Redesign Team (MRT) through an executive order from Governor Cuomo. The MRT, a collaborative comprised of healthcare experts and stakeholders, developed a multi-year

plan to restructure the state's Medicaid program. In line with the vision of the Centers for Medicare and Medicaid Services, part of the Department of Health and Human Services, the New York MRT outlined their "Triple Aims" of improving health outcomes and quality of healthcare for recipients and reduce healthcare spending (New York State Department of Health 2011). The Affordable Housing Work Group was developed to establish plans to provide housing support for individuals with chronic health conditions who are also high users of healthcare services (Shah et al. 2013). A primary strategy is allocating Medicaid funding to finance supportive housing for Medicaid high users. Since 2011, the State has allocated over \$400 million in cost saving to Medicaid to fund supportive housing, including capital investment, rental subsidies, and support services for low-income individuals who receive Medicaid (Corporation for Supportive Housing 2015). Seven pilot projects were developed as part of the MRT's 2013–2014 Supportive Housing Initiative. Among these seven models, one program, the Health Home HIV Rental Assistance Pilot, is specifically geared to support individuals with HIV/AIDS who are homeless or precariously housed. Other pilots assist low income individuals with HIV/AIDS, including the Senior Supportive Housing Pilot.

In addition to New York State, Housing for Health is a division of the Los Angeles County Department of Health Services. In Los Angeles, with the largest homeless population in the U.S. (Bendixen and Butzen 2015), the Housing for Health (HFH) program aims to stably house individuals that are homeless, have chronic health or mental health conditions including HIV/AIDS and are high users of the County Health Department (Los Angeles County Department of Health Services n.d.). Through placement in stable housing with intensive case management, HFH aims to both reduce costs to public systems and taxpayers and improve the health outcomes of those housed. In 2014, HFH released plans to fund 10,000 permanent supportive housing units in a 10-year period. These units are to be financed through a mix of private and public funding sources including LA County Health Department funds, HUD, MediCal (California State Medicaid), and the Housing Authority of Los Angeles (Bendixen and Butzen 2015).

11.4 Case Study: How Supportive Housing Program Affects Health Outcomes and Well-Being

Results from the studies discussed above demonstrate that stable housing is critical for individuals living with HIV or AIDS to maintain their health. The following section presents select findings from a process evaluation of a program in Chicago, the Medicaid Supportive Housing Program. These findings document *how* permanent housing with intensive case management supports assist formerly homeless individuals living with HIV or AIDS to maintain their health.

The Medicaid Supportive Housing Program (MSHP) is a permanent supportive housing program developed in Chicago, in 2012. Aiming to improve health

outcomes for formerly homeless program participants and to reduce Medicaid spending, the MSHP uses Harm Reduction and Housing First approaches to house individuals with at least two chronic health conditions and are high users of Medicaid.² Carried out through a partnership between the AIDS Foundation of Chicago and its Center for Housing and Health, Heartland Human Care Services, and Heartland Health Outreach, the MSHP consists of intensive case management and involves health-housing care coordination.

Researchers from the Loyola University Chicago Center for Urban Research and Learning partnered with the AIDS Foundation of Chicago and its Center for Housing and Health to conduct a process evaluation of the Medicaid Supportive Housing Program (MSHP). The Loyola University Chicago research team utilized a mixed methods approach to carry out this process evaluation of the MSHP pilot project. Select results obtained through interviews and focus groups with multiple informants (i.e., program participants, case managers, and program administrators) and a review of a sample of case manager case notes are reported below.³ Among the MSHP population, approximately half (45.3 %) reported they were HIV positive at their intake interview⁴; as part of the evaluation, the research team conducted 13 in depth interviews with individuals enrolled in the MSHP. Of them, 7 were living with HIV, others with other chronic illnesses.

11.4.1 Maintaining Stable Housing Is a Consistent Struggle

Many participants were chronically homeless prior to enrolling in the MSHP and a principal benefit of the program is becoming stably housed. As one individual related, “The best part is having shelter—my housing. When you have an apartment, everything else falls in line from there.”

Becoming stably housed and maintaining their housing was an ongoing struggle for many of the participants. The participants of the program were challenged on a number of fronts in seeking and maintaining housing. After enrolling in the MSHP, case managers helped participants locate and move into an apartment. Case managers reported that it was often difficult to find an apartment due to the limited affordable housing in neighborhoods that participants wanted to move into due to its proximity to their health care providers and their concerns about safety. Beyond finding housing, the program and case managers also assisted participants obtain furniture and household items.

²In the top sixth decile of Medicaid Expense Charts.

³See full evaluation technical report entitled “Evaluation of the Medicaid Supportive Housing Program” developed by researchers at Loyola University Chicago Center for Urban Research and Learning at <http://static1.squarespace.com/static/51e86261e4b00dfa7317c09b/t/54945da6e4b0b-89b6fa3fd55/1419009446197/FINAL+MSHP+Technical+Report.pdf>.

⁴This represents data entered into the AIDS Foundation of Chicago program Client Track Database as of July of 2013.

Overall, housing issues were a consistent issue that needed the assistance of case managers to one degree or another. As mentioned above, many participants were chronically homeless and one individual related that his apartment through MSHP was his first home in which he lived independently. Participants value their case manager's support in assisting with housing-related issues and challenges with their landlords. In reviewing case manager case notes, assistance with housing issues are a prevalent and ongoing area of support. Describing the challenges encountered with supporting participants as they transition into stable housing, one case manager explained,

We are housing people who have never lived independently before, who have never been a lease holder, and all the sudden it's, "Here's a lease, pay your rent, meet with me twice a month, have at it!" with really no skill building to be a good neighbor, pay your rent on time, contact the landlord when there is a problem. Everything becomes a crisis...So what I find a lot of kind of what the job entails is starting to then develop those skills in someone who may be in their late 40s early 50s and for the first time in their life is having to really be a good neighbor or be a lease holder. And then facing the consequences of the landlord when it doesn't go well.

While most of the participants had fairly stable housing circumstances, although not without some problems, about one third had major, ongoing problems with housing stability. In reviewing the selection of the case managers' notes on those cases, we can get an understanding of the varied issues that these participants experienced. Focusing on those individuals who had the most housing stability problems, we see a varying combination of issues:

- Re-hospitalization, death of a family member, falling behind in rent, beginning to hear voices again.
- Hospitalized after mugging when phone and wallet stolen, late on rent, case manager can't contact client, phone disconnected, front door does not lock properly, heat is not working so participant using oven.
- Participant informed landlord would be late with rent, therapist report participant *not doing well*, outstanding electric bill and electric shut off, damaged public transportation card, participant suspected of using substances, participant has not paid rent in 4 months, participant is hospitalized.
- Participant's phone not working and need to schedule housing inspection, participant has relapsed and is in hospital, participant reports housing has bed bugs and roaches and threw out furniture (calls health department); public transportation pass stolen, participant intoxicated, participant phone is disconnected again, participant goes to AA; recurring problem with bedbugs, participant intoxicated again.
- Working on housing location, housing resources education, participant has not moved in new apartment, case manager trying to locate participant, participant moved out of apartment without notifying landlord or case manager, hospitalized for mental illness, participants' refrigerator and stove stolen, food stamps have stopped, abusing substances.

11.4.2 Health Status and Behavior

As the main objectives of the MSHP are to improve health outcomes for program participants and to reduce Medicaid billing, case managers help participants to navigate and negotiate the healthcare system. In the case notes review, we find that 50 % of the issues case managers noted were health-related.

Over one-fourth of the health-related issues pertained to appointment and medication adherence. Case managers accompany them to appointments, go to a pharmacy to help them get prescription refills, and advocate for the individual if they are not getting the refills they need. In some cases, the case manager will help to negotiate the relationship between the participant and the physician or health program, as according to one stakeholder, “they know their client the best, a lot of times, out of anybody.”

Participants described several ways their health had changed since they became housed through the MSHP. Some participants self-reported having lower blood pressure and increased T-cells. Some reported not drinking anymore, which was problematic for them. Further, since becoming housed, some described being more organized, having more energy and being able to carry out basic self-care tasks including getting enough sleep and cooking for themselves.

Quite noticeably, most participants described improved mental well-being since becoming stably housed. They described decreased stress, increased “peace of mind” and being happier. One participant, happy to now invite her family to visit her apartment, expressed that “keeps joy in life” and “lifts spirits” as she formerly “felt isolated.”

A MSHP case manager provides insight into the challenges and setbacks participants’ experience which prevent adherence to HIV medication and treatment. It also elucidates the continuity and persistent support necessary for some vulnerable individuals to adhere to HIV medication and treatment.

I have a participant and she self-disclosed that whenever ... [she is] actively using, she just doesn't take any of her HIV medications and she's been actively using since like January of 2011. ... I had tried a combination of 'before you pick up the drugs can you just take your medication?' And that wasn't working, and ... she disclosed, 'Every time I have to take this medication, I'm reminded of the asshole who gave me HIV.' ... Then little by little we got her to go to the doctor. We were gonna go back in 2 weeks to get the results and she didn't show up ... then we get the Medicaid spending breakdown again and she ... she hasn't been taking her medication ... having that information I was then able to go back and have this conversation with her like, 'here's what we're trying to do, you're doing it, but in this case that's not what we want...' and still trying to just figure out a way that's gonna make her want to go and take the medication....

So I had another participant. She got mugged and hit over the head with a tire iron, and that just set her into such a bad depression that she stopped taking her medication, but she's really adherent to her medical appointments. She had gone and got her blood work done, and in just the 3 weeks she had stopped taking her medication. We saw her CD4 level drop

by 200, and so she was able to like have that tangible proof in front of her that like, ‘better get on this again,’ now that pulls her out of her depression and like, ‘I need to get back on track to improve my health.’ She has a number of other conditions that could worsen quickly if she were to stop taking her medication. It varies from person to person and so, I think those are the most concrete examples of how wildly medication adherence will vary among the population we’re working with.

11.4.3 The Key Role of “Supportive” in Supportive Housing

Most of the individuals with HIV/AIDS, unlike the other participants, already had stable medical providers, due to the Ryan White Care Act and other policies in place. Thus, for individuals living with HIV/AIDS, unlike the other participants in the study, the greatest impact was not in being connected to a “medical home.” For those with HIV/AIDS, the greatest impact was changes in health behavior, adherence, maintaining stable housing, and improved overall well-being.

The participants with HIV/AIDS, as with the other participants with other chronic illnesses, describe the impact of having case managers who provided a great deal of support and assistance with their health management. Case managers assisted with scheduling appointments; assistance managing medications; locating appropriate doctors, dentists and mental health professionals; assistance to obtain Medicare, to quit smoking and other forms of health assistance; visiting in the hospital and communicating with family; and regular check-ins to ask about health.

Participants describe extremely positive relationships with their case managers in the MSHP. Program administrators and participants alike, view the intensive case management and case managers as “vital” to the program. Many participants, with limited or strained family or friend relationships, value the support and friendship from their case manager. In addition to providing support with housing and maintaining health, participants described a broad range of assistance case managers provide. Participants are thankful case managers share information about a great deal of resources. Case managers help participants to meet their basic needs by recommending resources to obtain food and clothing. Case managers have also helped participants with transportation; including reduced fare public transit passes, as well as employment and educational assistance. For example, case managers assisted one participant to obtain their GED and another participant to obtain employment training and a CDL driver’s license.

An MSHP administrator described the barriers many participants experience to maintaining care, such as financial issues, family issues, substance use and addiction, mental health issues, organizational barriers, and negative relationships with

providers. Many of participants who are consistently engaged in care “have a very supportive, caring, and almost family-like relationship with their provider.” This MSHP administrator explained,

...their [participants’] engagement depends on a supportive relationship and someone they feel listens to them, cares for them, and has their best interest at heart. They describe their providers as like family members to me, ‘I love this person; they have cared for me when I was homeless.’ It is a very intimate close relationship, and that is where I see people going to their appointments, taking their medication, listening to what their doctor tells them to do because...they have that supportive relationship.

The MSHP adheres to the Harm Reduction model of programming, which does not require behavior change (such as abstinence from drugs or alcohol) before providing housing and services. Case managers utilize motivational interviewing and other harm reduction techniques to help participants work toward their goals. As one case manager described, they are charged to “help the participants help themselves.”

Participants described the benefits of the approach. They value that their housing is not dependent on abstaining from drugs and alcohol. One participant explained, “If I mess up, I can go home and be peaceful and recover. I want better. Stability.” Participants are safer if they are stably housed, this participant continued, “People are better off even if they are on drugs if they’re in the program. They aren’t homeless at least. They aren’t out there putting themselves at risk.” Further, participants feel empowered through the program, feeling more “in control” and describing a “sense of freedom as opposed to feeling like you’re on probation.” They also appreciate that case managers will support them and offer suggestions with how to address their substance use or addiction problems.

As described above, some respondents related how their overall well-being and health—both physical and mental—had improved through their experience with their permanent supportive housing program. One woman who provides safe sex education programming for teenagers and is active with HIV advocacy work described the positive impact of the housing program and other resources in managing her health,

It [harm reduction] deals with your health. I have a drink every now and then, or on special occasions... I don’t drink every day like it’s a habit. Drugs. None of that... I used to do drugs and drink alcohol for years and I see how it did my health as of today. It was very negative. I used to do all kinds of crazy shit to get drugs... I was in denial when I first found out in 2003 I had HIV. I was really in denial. I really didn’t want to talk to nobody about none of this. I was talking about killing myself. I was really in deep denial. As far as harm reduction, talking about my health is good. Now, I’m used to it now; I’m handling it [HIV positive status] much better than I was in 2003, now in 2013. I’ve come a long way in handling things. I think I’ve done pretty good, from support groups and counselors and my friends. I think I did pretty good. In 2003 I was a wreck. From 2003 to 2005 I was a messed up young lady. I got support from friends, support groups, counselors, and case managers. I have really gotten myself together through the support of them.

11.5 Summary

Through this chapter, we report the interrelationship between HIV/AIDS and housing stability and instability. In this final section, we summarize key findings from this chapter and propose policy recommendations to support individuals living with HIV/AIDS with limited economic resources.

11.5.1 Key Findings

- Homelessness and HIV/AIDS are interrelated. People with HIV/AIDS are vulnerable to becoming homeless. Conversely, people who are homeless or have precarious housing situations are at-risk of contracting or transmitting HIV.
- HIV/AIDS epidemic is more prevalent among those who are homeless in the U.S. than the general population.
- Stable housing is associated with a number of health outcomes including participation in and retention of HIV medical care, adherence to ART therapy, and suppressed viral loads.
- Unstable housing is associated with high-risk sex and drug behaviors, and higher mortality rates.
- Permanent supportive housing for homeless individuals with chronic health conditions reduces costs for medical care and other public systems.
- Intensive case management for individuals with chronic health conditions including HIV/AIDS and enrolled in permanent supportive housing programs is essential to help them maintain their health. Likewise, becoming housed and staying housed requires ongoing and consistent assistance from case managers.
- Permanent supportive housing helps to bring “joy”, “peace of mind”, and overall improved quality of life to formerly homeless individuals with HIV/AIDS and other chronic health conditions.

With these findings in mind, it is clear that providing permanent supportive housing is an important strategy in addressing the HIV/AIDS epidemic. It addresses the interrelated factors of economics and health. First, permanent supportive housing can increase the well-being and health of people with HIV/AIDS. Second, it is also a prevention strategy, as studies demonstrate an increasing number of individuals with HIV/AIDS who obtain a suppressed viral load. These studies also demonstrate how the interconnectivity of the economic, psychological and medical factors play out in the lives of people struggling HIV/AIDS and homelessness. Further, these studies point to the important health implications of programs that provide housing and supportive services for the homeless and unstably housed.

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Chapter 12

Conclusion

Neal Carnes and Eric R. Wright

Since we understood a new syndrome of illnesses was growing into an epidemic, we have also understood HIV/AIDS essentially impacts societies most marginalized people. Yet, now three and a half decades later, our responses remain perplexed by the social dynamics of the disease. To eradicate HIV/AIDS, we must contend with the complex social contexts in which causal behaviors are decided and take place. The vast majority of people engage in condomless sex; however, only a select few, concentrated in marginalized communities, are being infected. Altering the causal behaviors and sustaining this evolution is key, but such changes require mediating one or more structural and/or relational factors, such as poverty, victimization, and second-class citizenship that induce behavioral risk. In the face of loneliness or the drive to feel a sense of belonging, it is one thing to ask a person to protect themselves for an evening, quite another to do so over the course of their life, especially when forgoing condoms is perceived as a barrier to belonging and/or a foundation for rejection. Such sustained change, however, remains elusive.

As discussed in the Introduction, syndemic theory asserts interventions intending to reduce and/or eliminate HIV must address the social environment in which the causal behaviors unfold, especially given these behaviors and their context foster a host of detrimental and interrelated health outcomes. Individually, and as a collection, the chapters of this text demonstrate we can no longer afford to attend narrowly to the bio-medical nature of disease and neglect the milieu in which the agent and host connect. Behaviors do not occur spontaneously; they reflect

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a person's past, present, and even future. Where we have been, where we are, and where we hope to be all collide in shaping what we do and what results. Syndemic theory draws our attention to context when explaining health disparities, such as HIV, and how these diseases make matters worse in a comorbid landscape. Syndemic theory also provides us an empirically evolving, yet imperfect, framework to address HIV and its comorbid landscape among society's most vulnerable populations. The following reviews each chapter and the implications they suggest.

Chapter 2 paints the historical evolution of HIV providing a foundation for the assertion HIV primarily affects those who suffer a marginalized social standing as well as a number of disparate negative health outcomes. Throughout its domestic history, HIV manifests primarily among gay, bisexual and other men who have sex with men, women of color, substance users—especially people who inject drugs—the mentally ill, the homeless, the poor, and men of color, especially those who experience incarceration. As Jones and Salazar describe, Auerbach, Darrow and the other members of the CDC's Task Force (on what would eventually be known as AIDS) initial groundbreaking analysis asserted, the disease spreads within "risk" networks—networks shaped by and existing within particular social contexts. In addition, as Jones and Salazar's work also describes, shifts in the HIV case definition have exposed the broad comorbid "petri dish" HIV exists (and fosters), thus the potential to synergistically interact with a host of other disease states (the definitional base for a syndemic). As biomedical screening tools and pharmaceutical interventions have advanced, so too has the disparity in HIV morbidity and mortality—toward those who face intersecting marginal social positions.

The social context of the networks most likely to experience risk for infection and disease progression is one of intersecting marginalizing social factors. Chapter 3 asks us to shift our attention away from broadly conceived "risk groups"—that have thus far defined the HIV epidemic—to networks within these subpopulation-level groups. Gay men and men who have sex with men (MSM) face inflated risk when they engage in condomless sex with a partner who is living with HIV or of an unknown HIV status, but not all gay men engage in condomless sex with men living with HIV, known or not known. Gay men who suffer mental illness, experience or have experienced physical, emotional, or spiritual degradation, use illicit drugs, or have sex within concentrated networks more likely to include men living with HIV, known or not known, such as men of color, confront a scenario most likely to result in HIV. Framing this argument using intersectionality, Carnes points us toward the linkages that compound risk for infection and disease progression, e.g. stigma, while also raising factors that mediate risk, e.g. resiliency. This chapter helps expose the real-life messiness between social context and health outcomes, and calls for a more holistic and nuanced picture when considering why HIV and its common comorbidities remain a health disparity among the socially marginalized, especially gay men and MSM.

In Chap. 4, Friedman and Dodge further refine a lens to understand HIV disparities within a defined "risk group" when they review the social, behavioral, and disease context of bisexual men and men who have sex with men and women. Friedman and Dodge reflect on many of the same phenomena shaping gay men and

MSM's disproportionate experiences with problematic outcomes, yet note that in a number of instances the rates among bisexual men are more inflated, thus concerning. As this chapter suggests, it is unfortunate the mechanisms to identify and measure infection and disease progression risk remain defined by decontextualized behaviors rather than an earnest attempt to understand the social context in which these behaviors occur. This assertion asks us to move beyond binaries, such as gay and straight, whereby bisexual gets conflated with gay given a singular event between two men makes the person a gay man/MSM. Indeed, the authors suggest disparities persist in part, from the "melting pot" approach to prevention (whether primary, secondary, or tertiary). When we conflate groups, such as gay, bisexual, and MSM under "MSM," we do a disservice to all three populations—we render groups invisible and as a result perpetuate the problems that lead to disease causing behaviors, especially sex and illicit drug use, which can serve as means of coping with stigma and/or invisibility.

Like their gay and bisexual counterparts, transwomen face a society that marginalizes their non-conformity to hegemonic ideas of what is "normal," or expected. Yet, unlike gay and bisexual cis-gender men who benefit from male privilege, transwomen experience a double whammy. As described by Hines and Ryan, transwomen get subjugated by society's sexism as well as a particular disdain for those who claim a transgender identity, known as transphobia. In addition, transwomen also confront a world that inappropriately lumps them in with gays, bisexuals, and lesbians regardless of their sexuality. As a result of their double whammy, transwomen also struggle with disproportionately high rates of mental illness, substance use/abuse, and some turn to sex work when abandoned by family due to their non-conforming gender identities. This situation fosters social factors more likely to result in HIV, sexually transmitted diseases, and other related health outcomes.

From the onset of sex, women of color demonstrate higher rates of intercourse as well as lower rates of condom use. This scenario results in another within "risk group" disparity whereby African American women are twenty times, Latinas are four times, and American Indian women are nearly three times as likely to be HIV infected as their white counterparts. Aholou, Murray, and Sutton explore the social and disease factors contributing to these disparities across structural influences, e.g. poverty, social influences, e.g. "sexual networks that include higher baseline prevalence of STI's (sexually transmitted infections)," and individual influences, e.g. partner selection. They note that African American and Latinas are twice as likely to live in poverty, which limits access to healthcare as well as the tools to prevent infection, e.g. condoms and pre-exposure prophylaxis (PrEP), which costs in excess of \$1000 per month minus insurance coverage. Furthermore, as also discussed in Chap. 9, the criminal justice system jails Latino and African American men at alarming numbers, which impacts partner choice as well as relationship power dynamics, often to the detriment of condom usage. Interestingly, once diagnosed with HIV, women engage the healthcare system at higher rates than their male counterparts, thus their social context has distinct resiliencies (like seen among gay men, MSM, bisexual men, and transwomen).

In Chap. 7, Draus and Roddy consider sex work as “an apparently contradictory but self-sustaining paradox: a structural feature of patriarchal societies *and* a rational adaptation of intelligent actors who actively seek to limit risk and maximize opportunity (authors’ emphasis).” It is the maximization of opportunity (and the lack of other, viable employment avenues) that draw many to sex work as well as fosters the very risk they wish to avoid. In keeping with syndemic theories designation of marginalization as a key social factor explaining HIV disparities, Draus and Roddy argue marginalization minimizes available resources to escape second-class citizenship. When customers pay more for condomless sex or ask for unprotected sexual favors in exchange for drugs or services, the sex worker faces a precarious position—take a risk for a more expeditious exit to their marginalized standing or delay economic advancement to protect their health—sometimes they have no choice, the decision is made by force. This conundrum speaks to the social context in which HIV takes advantage. Ultimately the authors call for a focus on structural determinants, such as poverty, in addition to agency, such as one’s survival instinct, over isolated approaches that favor, typically the latter over the prior.

In Chap. 8, Pouget and Bennett map the evolution of illicit drug use as a modern dilemma contrasted by our society’s puritanical background and steeped in our racist fabric. To deal with concerns stemming from non-therapeutic use of drugs, social narratives marginalize users by painting an image of the dangerous man of color who is either out of control due to his illicit drug use or his willingness to do anything to sell the drugs to innocent children. From this image, policies have been enacted that punish illicit drug users regardless of the nature of their use, and inflate these punishments for people of color, especially men. As discussed in Chap. 5 through 9, incarceration serves as a social factor conducive to HIV risk and progression. In addition to fostering more distal factors that influence HIV risk, injection drug use is the second most common behavioral risk for HIV infection. Given many people who inject drugs (PWID) also engage in sex, their smorgasbord of disproportionate diseases is expansive, e.g. viral hepatitis, STIs, and tuberculosis. As described, these co-morbid conditions aggravate and are aggravated by HIV. Unfortunately, the reduction in HIV infections among PWID may be countered by our surmounting problems with prescription drug abuse, particularly pain killers, and their relationship with heroin, as is exemplified by the recent HIV outbreak in southern Indiana.

Chapter 9 introduces us to the concept of “syndemic nodes.” Institutions of incarceration are centralizing spaces for HIV in that they serve as “facilities in which a number of social conditions come together to disproportionately affect the lives of African Americans men (in particular).” In terms of HIV risk, imprisonment more often becomes relevant upon release in that only a select group acquire HIV while incarcerated, rather their environment is shaped by social marginalization as applied to the criminally “guilty.” Ex-convicts are plagued by housing and employment discrimination, thus poverty, as well as restrictions to voting, thus limits on their socio-political engagement as well as voice in policy-making. For the HIV infected, “an estimated 1 in 7...cycled through the criminal justice system,” which can seriously impact disease progression. Like their uninfected counterparts,

HIV positive ex-convicts face a limited social position and constrained opportunities upon release. This situation results in concerns that may be more immediate than healthcare, such as housing, food security, and/or personal safety. All of which helps shape incarceration as a problematic “node” that fosters a syndemic more likely to involve HIV.

People with serious mental illness (SMI) have been found to experience HIV co-infection at an alarming rate. In several studies noted by McKinnon and colleagues in Chap. 10, upwards of a third of people with SMI are also living with HIV—a rate comparable to the most impacted risk groups. As noted in prior chapters, this is not surprising given the rate of mental illness, including serious mental illness, is inflated among these groups, thus we see a picture of synergism emerging between social context and various diseases. In addition, geography plays a distinct role in rate variations suggesting the social factors contributing to syndemic vary, a pattern observed in many other chapters as well. Generally speaking, those who suffer SMI, like ex-convicts, are more likely to also experience homelessness, substance abuse concerns including injection drug use, as well as early onset sexual debut (like women of color), multiple sexual partners, and decreased rates of condom use. Furthermore, we know institutionalization of the SMI (similar to its criminal justice counterpart) creates a high-risk network. Finally, when multiple psychiatric conditions are present, the chances of HIV infection also increase. Fostering some of the concerns among people with SMI and HIV regards mental health providers’ unwillingness (or lack of training) to discuss or intervene in sexual matters.

Someone experiencing homelessness or unstable housing as well as HIV is at a pinnacle of risk for multiple health concerns as well as disease progression, including death. Like incarceration, homelessness serves as a node (minus a set boundary) in which various disconcerting factors collide resulting in concerns such as synergistic tuberculosis and HIV. Homelessness serves a pointed indicator for economic depression, which in turn hinders consistent care as well as presents unique challenges to medication adherence. Minus stable housing a person faces food insecurity, which mitigates one’s ability to take advantage of certain treatment regimens that require food prior to taking, as well as prevents the capacity for proper storage, including refrigeration, which is necessary for other treatment regimens. Improper or inconsistent treatment complicates comorbid conditions, which are common among the homeless, producing a perfect storm for disease interaction. As quoted by Hilvers, George, and Bendixen, “housing remains the most critical need of people with HIV-AIDS...” Stable housing also helps to prevent infection. Lacking a home does not result in a life void of sex or illicit drug use. In fact, homelessness or precarious housing can foster these causal behaviors as some homeless or unstably housed people may pursue sex and/or drugs as a way to find a place to sleep. At the same time, homelessness and unstable housing more often prevents a space to store condoms as well as other preventative measures, such as PrEP, while also mitigating one’s ability to negotiate safe sex options.

As we consider the narrative threads and arguments of this text as well as the broader conversation happening around HIV/AIDS, we must discuss the issues and

struggle for understanding contextualized by those who are affected. We must be careful to not dehumanize HIV, its syndemic landscape, or the social factors that foster disparities in HIV/AIDS. Lest we forget, there are 1.2 million people in the United States and nearly 37 million people globally that are living with HIV/AIDS, and significantly more who are affected either by being at risk for or loving someone who is living with HIV. Behind these numbers are people with dreams, aspirations, and hopes. While most of these people live a socially marginalized existence that does not mean we should or must pity them, let alone overlook them in favor of the issues underscoring HIV/AIDS. People affected by HIV/AIDS deserve our attention as much as the phenomena of HIV itself. This is the most important point we make for our reader—remember the people.

Erratum to: HIV Housing Helps End Homelessness and HIV/AIDS in the United States

Julie Hilvers, Christine C. George and Arturo V. Bendixen

Erratum to:
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The book was inadvertently published with an incorrect city and country name for the author Christine C. George in Chap. 11. It should be the ‘Center for Urban Research and Learning, Loyola University, Chicago, IL, USA’ instead of Chennai, India. The erratum chapter and the book has been updated with the change.

The updated original online version for this chapter can be found at
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