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Women Living with HIV: Social Stigma and Reproductive Decisions

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by

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Yvette P. Cuca

Abstract

Since HIV was first diagnosed, the pandemic has changed substantially in terms of both life expectancy and quality of life. One of the most significant has been the substantial reduction in mother-to-child transmission of the disease. Evidence from around the world shows that many HIV-positive women continue do want children, but that they may experience stigmatization regarding their decision, ostensibly out of concern for the child. Much of the field's understanding of HIV-related stigma revolves around the idea that it is predominantly a disease of sexual promiscuity and drug use. However, many people living with the disease are also marginalized based on other factors, such as race, poverty, homelessness, and gender, thus making stigma a profoundly more complicated issue, and blurring our ability to specify the causes of stigmatization that a person may experience. Thus the overarching goal of this dissertation was to examine factors that may influence reproductive decisions for HIV-positive women. In particular, what is the role of social stigma for these women, and how do their social situations affect their decisions? In order to examine different aspects of these questions, three research studies were conducted: a secondary analysis of quantitative data from pregnant women in Kenya with unknown HIV status; a quantitative study of social capital and stigma in HIV-positive women in the San Francisco Bay Area; and a qualitative study of childbearing decision-making in HIV-positive women in the San Francisco Bay Area. The results of all three studies demonstrate how HIV-related stigmatization affects women's lives, and trace the ways that cultural meanings, power inequalities, and creation of difference lead to stigmatization. Women living with HIV continue to want to bear children for many reasons, but all are aware of negative public opinions about this. The provision of health care in specialized environments may be one way to mitigate the effects of stigmatization and provide social support. However, structural changes such as empowerment of women are needed to truly address the stigmatization that women experience related to their HIV.

Table of Contents

List of Tables

I. INTRODUCTION

Statement of the Problem

Since HIV was first identified in the early 1980s, the pandemic has changed substantially in terms of both life expectancy and quality of life. One of the most significant has been the reduction in mother-to-child transmission of the disease. Prior to the development of HIV medications, HIV-positive women had a 25% chance of transmitting the infection to their babies during pregnancy, childbirth or breastfeeding (Centers for Disease Control and Prevention 2009). Today, women living with HIV who receive medical treatment have less than a 2% chance of transmitting the disease to their baby (Centers for Disease Control and Prevention 2002). In San Francisco, no babies have been born with HIV since 2005 (San Francisco Department of Public Health 2012), though the situation differs greatly in many other countries with different epidemics and different resource constraints (UNAIDS 2010).

Despite the development of successful treatments for people living with HIV, many still face social stigmatization, a reality that exists in all parts of the world. Much of society's understanding of the phenomenon of HIV stigma revolves around the idea that it is predominantly a disease of sexual promiscuity and drug use. However, many people living with the disease are also marginalized based on other factors, such as race, poverty, homelessness, and gender, thus making stigma a profoundly more complicated issue, and blurring the ability to specify the causes of stigmatization that a person may experience.

Ample evidence shows that women around the world experience stigmatization that is related to their HIV-positive status (Lather and Smithies 1997; Sandelowski, Lambe and Barroso 2004; Simbayi et al. 2007), often being blamed for bringing the disease into intimate relationships. Research has also shown that HIV-related stigmatization, even the anticipation of such stigmatization, affects women's decisions about childbearing. For example, some women living with HIV have reported that their perceptions of negative public opinion about HIV-positive women putting their babies at risk for HIV influenced their decision about whether or not to bear a child (Nobrega et al. 2007; Sandelowski and Barroso 2003; Sanders 2008). On the other hand, most women still live in situations of pronatalist ideals, many of them in places where a woman's main social identity and worth is based on her ability to bear children (Hayford, Agadjanian and Luz 2012). Women's perceptions and experiences of public opinion and the cultural discourses of stratified reproduction (Colen 1995; Collins 1999) that some women "should" have children while others "should not" may thus have an impact on their decision-making process. Existing research has not shown, however, the interrelationship of other marginalities in those decisions.

The stigmatization that women living with HIV experience, whether associated with childbearing or not, may also be influenced by the level and intensity of their integration into broader social worlds and social networks. Interactions among individuals in these social worlds create the meanings – about HIV, about women, about reproduction – that can affect whether and to whom a woman discloses her HIV status, as well as the possibility for stigmatization. It has been suggested that social networks may provide support or may themselves be sources of stigmatization of people who are different from them, or both, and this may be a factor in the stigma that an HIV-positive women experiences (Pescosolido et al. 2008). However, the relationships among social networks, social capital, marginalization, and HIV social stigma have never explicitly been examined.

Thus, the overarching goal of this dissertation is to examine factors that may influence reproductive decisions for HIV-positive women. In particular, what is the role of social stigma for these women, and how do their social situations affect their decisions? Three research studies examine different aspects of these questions:

1. Factors Associated with Pregnant Women's Anticipations and Experiences of HIV-related Stigma in Rural Kenya;
2. The Association of Social Capital and HIV Stigma among Women Living with HIV/AIDS;
3. Social Stigma and Childbearing for Women Living with HIV/AIDS.

The lack of understanding of the ways in which HIV-positive women come to bear children or not limits the ability of health care workers to provide the support and care that HIV-positive women need. Such support could range from discussing and providing contraception, to providing abortion information and services, to providing assisted reproduction services, to discussing the impact of HIV status disclosure and related stigma in their decisions. In order to fully address the health and social-well being of women living HIV, we need a more nuanced understanding of the role of social stigma, as well as the broader context within which HIV-positive women are living on a daily basis.

Epidemiologic Situations

In the United States today, approximately one million people are living with HIV and/or AIDS; women currently account for one-quarter of those cases, and rates of HIV infection are increasing among both women and minorities (Centers for Disease Control and Prevention 2013). The U.S. Centers for Disease Control and Prevention (CDC) reports that in 2010, rates of HIV infection were 41.7 per 100,000 Black women, 9.2 per 100,000 Hispanic women, and only 2.1 per 100,000 White women, indicating significant disparities based on race (Centers for Disease Control and Prevention 2011). In San Francisco, women accounted for 11% of AIDS cases in the city in 2012, compared to just 3.7% in 2002; they also made up 6% of those living with HIV, but 10% of those newly diagnosed (San Francisco Department of Public Health 2012). In 2012, African Americans in San Francisco accounted for 16.2% of all cases, and Latinos accounted for 20.9%, up from 11.8% and 11.4% in 2002 (San Francisco Department of Public Health 2012). While the San Francisco HIV/AIDS epidemic still largely affects white men who have sex with men, the disease is expanding in female and racial/ethnic minority populations. And although HIV infections continue, San Francisco has seen no babies born with HIV since 2006 (San Francisco Department of Public Health 2012). The first two papers in this dissertation are drawn from data on this San Francisco population, with at least one woman known to have participated in both studies.

In Kenya in 2011, approximately 1.6 million people were living with HIV (6.2% of adults), and 59% of them were women (National AIDS Control Council and NASCOP National AIDS and STI Control Programme 2012). While overall HIV prevalence in Kenya is 6.2%, in Nyanza Province almost 14% of adults are infected with HIV. In addition, people of the Luo tribe have a higher prevalence of HIV (20%) compared to other Kenyan tribes. According to the National AIDS Control Council, “Adults in stable, seemingly low-risk heterosexual relationships make up the largest share of new HIV infections” (2012:2). Class differences in HIV do exist in Kenya, with the wealthiest people having the highest prevalence of HIV (7.2%), particularly as compared to those with the least wealth (4.6%). In contrast to San Francisco, perinatal HIV transmission continues to be a substantial problem, with the majority of the 12,894 newly infected people under the age of 15 having been infected perinatally or through breastfeeding. HIV/AIDS has had a substantial impact on fertility desires and actual fertility, as seen by the fact that HIV-positive women are having 40% fewer babies than other women (National AIDS Control Council and NASCOP National AIDS and STI Control Programme 2012). The third paper in this dissertation draws mainly from Luo people living in Nyanza province in Kenya, clearly one of the most affected tribes and regions in that country. Polygamous marriages are not uncommon in this area.

Theoretical Frameworks

Stigma

The overarching theoretical perspective in this dissertation is an examination of social stigma in the lives of women living with HIV, with a focus on contextual situations. One of the seminal works on social stigma was that of Erving Goffman almost half a century ago (1963). Goffman defined stigma as "an attribute that is deeply discrediting," but went on to explain that "it should be seen that a language of relationships, not attributes is really needed" (1963:3). In this, Goffman emphasized that stigma is not just an isolated attribute or characteristic, but rather that it becomes defined as discrediting only through social interactions.

Since Goffman (1963), theory about stigma has evolved to take into consideration the essential role of power differentials. Parker and Aggleton explain that:

> Stigma and stigmatization function, quite literally, at the point of intersection between *culture, power* and *difference* – and it is only by exploring the relationships between these different categories that it becomes possible to understand stigma and stigmatization not merely as an isolated phenomenon, or expressions of individual attitudes or of cultures values, but as central to the constitution of the social order (2003:17).

In explicitly pointing to dynamics of power and differentiation, Parker and Aggleton see power differentials – whether based on gender, race, class or other marginalizations – as a *cause* of stigma, and further argue that stigmatization serves as a tool to reproduce existing and unequal power structures within social systems. They additionally acknowledge the "intensifying interaction between multiple forms of inequality and exclusion" (Parker and Aggleton 2003:19), similar to the conceptualization of intersectionality (Collins 2000; Crenshaw 1991). Based on this framework, we can see the intersections of gender and other power relations with stigmatization in all three studies, and can examine the roles of culture, power and difference in stigma.

Parker and Aggleton's understanding of *culture* is based on work by Bourdieu, and relates to the notion that cultural practices and meanings function to reproduce social differences, and that power is central to legitimizing these differences. Cultural understandings about people living with HIV/AIDS in both the U.S. and Kenya revolve around the ideas of sexual promiscuity and drug use, and stereotypes regarding the "types" of people who become infected with the disease, often racial minorities in the U.S. These stereotypes become embedded in cultural understanding through, for example, portrayals of prostitutes or "unfaithful women" as fueling the AIDS epidemic in the media, which is largely controlled by men (Orchardson-Mazrui 2006). Women in these three studies have indicated an awareness of the cultural meanings of people living with HIV. In San Francisco, most of the women spoke about how "people" view women living with HIV, assuming that they acquired it through prostitution or drugs. In Kenya, participants reported negative attitudes within their communities about people living with HIV. Cultural attitudes and norms about gender and sex are also important as they emphasize women's roles as mothers and wives over other socially valued identities. In addition, cultural norms in some parts of Kenya support polygynous relationships, further differentiating men's roles from women's roles and solidifying men's power in marriages and communities. These meanings are social creations, and are strengthened and perpetuated through continued use and social interactions.

The second component of Parker and Aggleton's conceptualization of stigma, *power*, is clearly a factor of the lives of the participants in all three of the studies. Power differentials based on gender can put women at risk not only for contracting HIV, but also for poverty and dependence, making them vulnerable to those with greater power, for example, physicians or male partners. In both San Francisco studies, the majority of participants were women of color, many with little income. For these women, gender and race intersect to limit their options economically as well as socially. Power differentials within their intimate relationships put them at risk of HIV. Many had male partners who were HIV-positive but did not tell the women. In other cases, women stayed in violent relationships and one woman was forced into prostitution by her male partner. Being in a relationship may offer women a sense of security and "normality" in lives that are already so unstable. For women in Kenya, gender-based power differentials affected many aspects of their lives. A 2006 UNESCO reports stated that:

> Women in Kenya constitute a subordinate, disadvantaged and muted group who are routinely treated as inferior and who face coerced sex, harmful cultural practices, stigma and discrimination. Their inferior legal status in relation to marriage, inheritance, guardianship, property ownership, maintenance and other legal matters places them in a disadvantaged position economically and politically, which in turn compromises their ability to challenge their marginalization (Creighton and Yieke 2006).

Within this structure, women are valued mainly for their ability to bear children, and existing social structures serve to keep them in this role. The system of polygyny, whereby men can have more than one wife, further serves to commoditize women, and creates households in which women may need to vie for attention and resources from their husband (Bove and Valeggia 2009), rather than being able to turn to them for support. Severe restrictions on women owning property make them dependent on men, and thus vulnerable to poverty, homelessness, and illness, including HIV/AIDS. Because of their overall vulnerability due to structural factors, women may also lack power within their intimate relationships, making it difficult or impossible to refuse sex or insist on condom use, putting them at risk of HIV. If a woman does become infected with HIV, she is at risk of being blamed for bringing it into the household, and of being stigmatized with consequences such as loss of status among wives, divorce and subsequent loss of support, or physical abuse, for example.

Finally, Parker and Aggleton emphasize the importance of *difference* for stigmatization. Building in prior theoretical work on individual and group identity formation, Robert Crawford explains that the increasing focus on health in the United States in recent decades has significant moral undertones, and protecting one's health is seen as each person's individual responsibility and a way of demonstrating values such as self-control (1994). HIV/AIDS has always had moral meanings, in part because of its link to already stigmatized identities such as drug user or prostitute, but also because of the blame associated with not adequately protecting one's health and allowing oneself to become infected. As Crawford explains, by creating an unhealthy "other" who is to blame for becoming infected with HIV/AIDS, those who are uninfected established boundaries that distinguish "us" from "them" (Crawford 1994). In Kenya, HIV/AIDS has similar moral meanings (Nzioka 2000). Thus HIV is not just a health condition, it is a mark of difference that has been used to separate and categorize people.

In sum, the *cultural* meanings of HIV and their embeddedness in society, the *power* differentials that women living with HIV experience at the individual and structural levels, and the moral *difference* that HIV implies come together in a dialectical manner to create the stigmatization that many women living with HIV experience. People who are uninfected and who have greater social power use HIV as another way to differentiate themselves from people who are already considered lesser for other reasons such as their gender, race and/or class. The stereotypes of people with HIV as unhealthy and to blame for their own illness are perpetuated through cultural institutions such as the media, and become a form of truth that is used to justify unequal social relations and the consequences thereof.

Some women living with HIV may also experience stigmatization related to their decisions to bear children. Powerful figures in their lives – physicians, nurses, parents, and partners – may tell them that they should not continue these pregnancies and encouraged them to abort. This rationalization is very much in line with the idea of stratified reproduction, which suggests that there is differential value placed upon childbearing, depending on race, class and other hierarchies (Colen 1995; Collins 1999). Haraway also emphasizes the fact that reproduction is political because it generates future social worlds, including power structures (1999). Providers who encourage HIV-positive women not to have children – because they are poor, using drugs, of color – may engage in stigmatization and may be acting in such a way as to influence future social worlds. On the other hand, some women may feel that the only way to gain power and respect is to have children and to become mothers. These women may choose to proceed with their pregnancies and not to disclose their HIV status in order to emphasize their valued social identity of mother over their non-valued identity of HIV-positive women, similar to Goffman's idea of managing one's identity (Goffman 1995).

Building on this conceptualization of stigma, Pescosolido and colleagues proposed a "Framework Integrating Normative Influences on Stigma" or FINIS (2008). As they explain, FINIS is not a model of stigma, but rather a framework that can be tailored to different stigmatizing conditions to help identify areas that should be examined for their impact in a particular context. Explaining that "stigma lies at the interface of community and individual factors" (2008:433), Pescosolido and colleagues identify some of the micro-, meso-, and macro-level contextual issues that take place in communities and among individuals, and which make stigmatization more or less likely to occur. Among others, these factors include social characteristics (age, race/ethnicity, class), disease characteristics, the role of the media, and the national context of economic development, culture and social systems. Three issues are of particular interest in the context of women living with HIV. Each of these issues informs this dissertation proposal.

Social Marginalization

First is the issue of social marginalization, in particular as based on gender and race. R.W. Connell provides an important examination of gender relations, which she explains are social in their very essence (1987). She asserts that "personal life and collective social arrangements… are linked in a fundamental and constitutive way," suggesting that an individual's actions and decisions are not independent from the social world in which they live, but rather are directly influenced by that world and co-constitutive of it (Connell 1987:17). Gender relations pervade all aspects of social experiences, from the macro level (e.g., national laws against abortion), to the meso-level (e.g., gender-informed hiring practices in businesses), to the micro-level (e.g., intimate-partner violence). As individuals interact with each other and with institutions, gender relations are influenced and often reinforced. This is very much in line with the theoretical approach of symbolic interactionism, or the idea that meanings are created and modified through constant interaction and interpretation, and that it is through these processes that social worlds are created and maintained (Blumer 1969; Mead 1934). As Connell explains, although individuals act within gender systems and may influence them, they are also constrained in their actions by these same systems (1987). Through such systems, men and women are expected to behave in certain ways and take on certain social identities, and because of this are constrained from behaving in other ways.

Simone de Beauvoir (1953) was one of the first to point out that gender relations have inherent aspects of power, which Connell describes as “a balance of advantage or an inequality of resources…. [t]he ability to impose a definition of the situation, to set the terms in which events are understood and issues discussed, to formulate ideals and define morality, in short to assert hegemony” (1987:107). Connell further explains that the leaders of institutions from the government to corporations to many marriages are in most cases men, providing them with the power to define social organization and reproduce it to their own benefit with the tacit agreement of those who are most negatively affected by the system, a phenomenon defined by Gramsci as hegemony (1971). Through such institutional arrangements, women are marginalized from centers of power and thus disadvantaged compared to men in most spheres of political, economic and social life. These power differentials are also key to the disadvantage that many women face in terms of health, often resulting in increased risk of poor health compared to men (Bird and Rieker 1999; Connell 2012; Denton, Prus and Walters 2004; Doyal 2001; Moss 2002).

Jewkes and Morrell further explain that “[t]here is strong evidence that gender power inequity in relationships, which is a cause of intimate partner violence, places women at enhanced risk of HIV infection” (2010). Other researchers have also noted the impact of both individual- and structural-level gender-based power differentials on increased risk of HIV among women and girls (Gupta 2002; Hahm et al. 2012; Horton and Dworkin 2013; Teitelman et al. 2008; Tsai and Subramanian 2012). At an individual level, power differentials may give women less ability to negotiate condom use or other safe sex practices within intimate relationships for fear of violence, blame, or other forms of reprisals. On a broader level, the social systems within which women and men live may prescribe passive behavior on the part of women, and the need to please one’s male partner, thus muting women’s ability to advocate for themselves in socially acceptable ways. Interventions that consider gender relations at all levels may be needed to reduce the spread of HIV around the world (Dworkin and Ehrhardt 2007; Jewkes 2010; Lewis 2006).

Gender relations are also deeply implicated in childbearing decisions, which directly influence the production and reproduction of social worlds. In many parts of the world, women are valued largely for their ability to bear children. While this may be somewhat less true in parts of the United States than in places such as Kenya, the dominant discourse is that a woman’s identity is linked to her childbearing. Many women and men buy in to the idea that a woman is not a true woman or that she has not fulfilled her social "role" until she bears children. For women who have few or no other opportunities to gain and maintain other valued social identities, having children may not be experienced as a choice but rather as an imperative. Some women may face substantial consequences including stigmatization or divorce if they do remain childless, particularly in countries such as Kenya (Orchardson-Mazrui 2006).

In addition to and complicating gender relations, race is similarly an overarching social stratification system that affects all aspects of life and influences and constrains behavior. (Various other forms of marginalization exist based on, for example, class, sexuality, disability, drug addiction, and mental illness. These are beyond the scope of the projects reported here). This is especially true in the United States, where racial inequalities are so deeply embedded in social and political systems.

Omi and Winant describe racial formation as "the sociohistorical process by which racial categories are created, inhabited, transformed, and destroyed" (1994:55). In the U.S. racial inequalities are the outcome of myriad racial projects led by different groups of people, at different levels of social worlds, synthesized over time. Omi and Winant trace these historical processes, beginning with the arrival of Europeans in North America, where they encountered new and different people. The wealth that they also discovered became the motivation for distinguishing "Europeans, as children of God, full-fledged human being, etc, from 'Others'" (Omi and Winant 1994:63). In this way, the idea of the lesser "other", and resultant inequalities first became embedded into American society at large, and were built on and strengthened by other racial projects over time. Feagin further points to historical processes over time, emphasizing the country's founding economic basis in slavery and the racial inequalities written directly into the U.S. Constitution (Feagin 2000). Over the course of history, wealth and poverty are transmitted from one generation to the next, through institutional and both social and individual/familial means.

These historical processes embed inequalities into the very structure of society and state, much like gender relations. Omi and Winant also draw upon Gramsci's (1971) idea of hegemony to explain how, through the establishment and reproduction of ideologies in social institutions such as schools and the media, unequal systems and the rationales for them come to be seen as natural, and normative, as "common sense" ways of the world. As these are integrated into society's cultural values, they are no longer questioned, and become part of the system that maintains social order (Omi and Winant 1994). Along with prejudice and discrimination, this institutionalization of inequality is one structural basis of the racialized society within which we live. For people of color, these inequalities have, over the course of generations, led to a perpetual burden inherent in the lived experience of racism, ultimately reducing people's life chances (Feagin 2000) over generations. Thus racialized social worlds can put people of color at risk for negative life consequences such as poverty, homelessness, and poor health, including diseases such as HIV.

People who are marginalized on more than one axis, for example women of color, are at a particular disadvantage, though we cannot assume that their disadvantage is simply additive. Instead, some theorists have suggested the conceptualization of intersectionality (Crenshaw 1991). Collins explains that, rather than "examining gender, sexuality, race, class, and nation as separate systems of oppression, the construct of intersectionality references how these systems mutually construct one another" (2000:47). Intersectionality is not about layered identities or experiences, but rather about synergies, and the ways that identities are co-constructed. For example, Collins explains that the poverty that black women in the U.S. experience is substantially different from that of black men, and is due less to wage differentials than to "gender hierarchies" that manifest in ways that limit black women's ability to earn and keep wealth (Collins 2000). Historical laws in the U.S. against miscegenation worked to protect the intergenerational transfer of wealth within white families, leaving black women and their black or interracial children with no inheritance of property or wealth despite genealogical blood ties. Like other women, black women have greater household and childcare responsibilities than men, and this further limits their ability to work outside the home for pay. The intersection of their race and gender influences their class and their ability to move up in the social hierarchy in different ways than it does for black men or white women. This experience of the "interlocking oppression," as Collins terms it, is one of the key features of intersectionality. As rates of HIV infection increase among women and among people of color, it is important to examine the constructs of gender and race, and how they intersect in the lives of people living with the disease.

Although these systems marginalize certain groups and individuals, the power upon which they exist is not unchecked. As Foucault has suggested, power is diffuse and relational, but where power exists, resistance is also present (Foucault 1978). Through the interactional process, small acts of resistance on the part of individuals can change meanings and thus change social worlds. Collins, who asserts that individual and group identities are often assigned rather than chosen, and that related stereotypes are used as a means of dominating others, also explains that embracing these stereotypes is one form of self-definition, and a means of "resisting the dehumanization essential to systems of domination" (Collins 1986:S18). Social worlds are constantly in flux, changing through interaction and resistance to systems of power.

Social Capital

A second issue that informs this dissertation, based on Pescosolido's FINIS framework and discussion of social networks, is the concept of social capital, and the ways that social networks may be supportive of or stigmatizing for women with HIV (2008). One of the first significant analyses of social capital was that of Pierre Bourdieu who defined it as "the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition" (1985:248). Bourdieu explains that social capital is created through interactions among individuals, and that it exists within a group. While Bourdieu emphasized the group, Alejandro Portes focused somewhat more on the social capital of individuals, defining it as "the ability of actors to secure benefits by virtue of membership in social networks or other social structures" (1998:6), and further describes it as an “accumulation of social chits” (1998:7). One may question whether the value of those “social chits” influences whether or not a person living with HIV experiences discrimination within her/his social network. Does someone who is “owed” more within her/his social network have a level of power that mitigates potential social stigmatization and discrimination and/or ensures greater social support? In the case of women living with HIV, does the social capital that one might gain from having a valued social identity lessen the stigma that she might experience because of her HIV status? Or does that person have “further to fall” when a potentially stigmatizing condition is disclosed?

Macinko and Starfield (2001) review a number of instruments designed to measure social capital, including questions included in the U.S. General Social Survey. Publishing more recently, and building on work of prior theorists , Onyx and Bullen developed a Social Capital measurement instrument, which included eight sub-factors: participation in the local community, social agency, feelings of trust and safety, neighborhood connections, family and friends connections, tolerance of diversity, value of life, and work connections (2000). A modified version of this instrument has been validated in people living with HIV (Webel et al. 2012).

Reproductive Politics

A final major issue that informs this dissertation, also based on the FINIS framework, is the idea of reproductive politics. Clarke explains that the “central argument of reproductive rights is that reproductive issues must be viewed in their specific social, historical and institutional context” (1984/1989:189). Here Clarke emphasizes the idea that reproductive decisions and actions are not individual, but inherently social, taking into account the situations in which women and men live. And while much of the discourse about reproduction in the United States is pronatal, a particular segment of it revolves around ideas of who “should” or “should not” reproduce, manifesting eugenic and populations concerns. The idea of “stratified reproduction” – differential value placed on childbearing depending on the woman’s race, class and other hierarchies – is particularly relevant for HIV-positive women, who live within various hierarchies and forms of marginalization (Colen 1995; Collins 1999; Maternowska 2006). Decisions to reproduce or not terminate a pregnancy occur within dense and complex webs of discourses and concerns.

The idea of reproductive “choice” also provides a useful framework in this discussion. The term “choice” is used by abortion rights activists to denote the idea that all women can and should be allowed to make their own decisions about having children, particularly in terms of the choice to have an abortion. But Donna Haraway problematizes the idea of “choice,” asking “What counts as choice, for whom, and at what cost?” (1999:66). For Haraway, choice extends well beyond abortion rights, to include control of women’s bodies, and the women’s ability not only to make decisions for themselves, but also to act upon those decisions and to be free from coercion in their decisions and actions. For women experiencing multiple intersecting vulnerabilities, such as many of those living with HIV, does “choice” truly exist?

In this dissertation, the overarching theoretical framework is that of social stigma. Based on the FINIS framework, the additional theoretical areas of gender and race, social capital, and reproductive politics have informed the three papers included here.

Methodological Approaches / Three Papers Overview

Much of the existing literature about reproduction in women living with HIV focuses on whether or not they desire children in the future, and their conscious decision-making about reproducing. What is substantially missing, however, is an in-depth examination of the situations within which reproduction actually occurs, and the extent to which actual reproduction is based on conscious decisions. Three research studies examine the factors that may influence reproduction decisions for HIV-positive women, particularly social stigma and social situations.

In the first study, I examined the stigma that pregnant women in Kenya anticipate and experience related to HIV. This was a quantitative study of pregnant women in Kenya who did not know their current HIV status, some of whom were also interviewed post-partum. While this study did not specifically address whether or not HIV-positive women want children, it examined the importance of stigma and lack of power in the lives of women in Kenya, and how this may intersect with childbearing. The cultural context and role of reproduction are important factors in the lives of these women. Polygyny, in which men may have more than one wife, may disempower women, forcing them to compete with other wives for attention, affection and/or resources. The role of gender in polygynous relationships is crucial for these women, and bearing children is one of their primary valued social identities. Thus, not bearing children may in fact result in greater stigmatization than bearing children as an HIV-positive woman. Within their constrained circumstances, women may “choose” to bear children in order to gain or maintain a socially-valued identity, but must weigh this against potential stigmatization if they are diagnosed with HIV.

In the second study, I hypothesized that social capital could serve as a form of power due to its nature as a resource. Because stigmatization is based on power differentials, women with greater social capital might be less likely to experience HIV-related stigmatization, in line with Pescosolido’s notion of the importance of social networks (Pescosolido et al. 2008). The study also examined possible confounding variables of the relationship, such as race and class (measured by proxies). In order to examine this potential relationship, I collected quantitative data from 135 HIV-positive women living with the San Francisco Bay Area. Although the findings were not statistically significant, there was a trend in the hypothesized direction. The results of this study suggest that social capital is to some extent negatively associated with stigma, and this could extend to the situation of childbearing. HIV-positive women with greater social capital in their social worlds may be less likely to experience stigmatization if they decide to have a child when compared to women with less social capital.

Finally, in the third study, I interviewed women living with HIV in the San Francisco Bay Area in order to examine how and why they made the decisions that they did regarding reproduction. The purpose was to understand not only the specific factors that influenced their decisions, but also the overall social situations within which this occurred, particularly the aspect of stigmatization. Most of the participants in this study were women of color, and most had long histories of reduced life chances and trauma in their lives. For these women, decisions regarding childbearing were made within chaotic and unstable situations that limited their options and made them highly vulnerable to stigmatization. Some were encouraged by providers to abort their pregnancies based on their HIV and their perceived inability to be good mothers. All of the women were aware of public opinion about women with HIV, particularly opinions about HIV-positive women having children. At the same time, many of the women found ways to resist the power behind the stigmatization, and most had established themselves in care with HIV specialists who provided not only health care, but also emotional and social support that the women may have lacked at other times in their lives.

Medical advances have made it possible for women living with HIV to have healthy children, but myriad other social and situational factors may play into whether or not a woman living with HIV bears children. Further, we lack an in-depth, theory-based understanding of the role of stigmatization in HIV-positive women's lives, particularly as related to their reproduction. This area of research is significant because it can help to inform interventions that may help women living with HIV fulfill their personal goals. Thus, the purpose of the three papers in this dissertation is to gain a greater understanding of the factors that may affect reproductive choices of women living with HIV, particularly in terms of stigmatization and social situations.

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Factors associated with pregnant women's anticipations and experiences of HIV-related stigma in rural Kenya

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Pregnant women who fear or experience HIV-related stigma may not get care for their own health or medications to reduce perinatal transmission of HIV. This study examined factors associated with anticipating and experiencing HIV-related stigma among 1777 pregnant women attending antenatal care clinics in rural Kenya. Women were interviewed at baseline, offered HIV testing and care, and a sub-set was re-interviewed at 4–8 weeks postpartum. Women who were older, had less education, whose husbands had other wives, and who perceived community discrimination against people with HIV had significantly greater adjusted odds of anticipating HIV stigma. Over half of the HIV-positive women interviewed postpartum reported having experienced stigma, much of which was self-stigma. Women experiencing minor depression, and those whose family knew of their HIV status had significantly greater adjusted odds of experiencing stigma. Lack of women's empowerment, as well as depression, may be important risk factors for HIV-related stigma and discrimination.

Keywords: HIV; stigma; pregnancy; Kenya; empowerment

Introduction

In Kenya, in 2009, approximately 1.3 million adults were living with HIV and 58% of them were women (UNAIDS & World Health Organization, 2010). The advent of antiretroviral medications has transformed HIV into a chronic illness for many people (Gifford & Groessl, 2002), allowing them to live longer and healthier lives after an HIV diagnosis, as well as reducing the risk of perinatal transmission (The International Perinatal HIV Group, 1999). Although the physical health outlook for people living with HIV has improved in recent years, the issue of stigma remains as an important factor adversely affecting health and quality of life.

Since HIV/AIDS was first identified, the disease has been surrounded by stigma and discrimination. People who are infected, or even suspected of having HIV, have experienced emotional, physical, and structural abuse (Dlamini et al., 2007; Kohi et al., 2006), and the fear of experiencing such stigma can become a substantial barrier for HIV testing and treatment (Pulerwitz, Michaelis, Weiss, Brown, & Mahendra, 2010). In many countries of Africa, women are disproportionately affected, not only by the disease itself, but also by the related stigma and discrimination (Bond, Chase, & Aggleton, 2002). Women who experience or fear stigma may be less likely to access health care services, and research has shown that pregnant women who anticipate HIV-related stigma are less likely to get tested for HIV (Turan, Miller, Bukusi, Sande, & Cohen, 2008). The result is that pregnant women may not be aware of their HIV-positive status, may not get the care that they need for their own health, may infect sexual partners, and may not receive medications to reduce the risk of perinatal transmission of HIV (Desgrees-du-Lou et al., 2009).

Having a greater understanding of the characteristics of women most likely to fear or experience HIV-related stigma may help health care workers identify women at risk and provide more appropriate advice and services. This may be particularly important for pregnant women, with whom there has been relatively little research on the issue of stigma. The purpose of this study was to identify factors associated with anticipating and experiencing stigma among pregnant women attending antenatal care (ANC) clinics in rural Kenya.

Methods

The data and analyses presented here are part of a larger longitudinal study conducted by the University of California, San Francisco (UCSF) and the Kenya Medical Research Institute (KEMRI), who jointly run the Family AIDS Care and Education Services (FACES) program in Kenya. The general objective of

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the larger study (the Maternity in Migori and AIDS Stigma [MAMAS] Study) was to examine the effects of HIV-related stigma on use of maternity and HIV services by pregnant women (Turan et al., 2011). The institutional review boards of KEMRI and UCSF reviewed and approved the study. After receiving an explanation about the study, those who chose to be in the study gave their consent to participate and to have their HIV test results abstracted from their medical records.

Sample

Women were recruited for the MAMAS study from nine health facilities in rural Nyanza Province, Kenya (Turan et al., 2011). They were eligible to participate if they were 18 years of age or older, in the first 7 months of pregnancy, appearing for their first ANC visit of their current pregnancy, and did not know their current HIV status (never tested or tested negative more than 3 months ago). Participants were interviewed by a trained interviewer in local languages (Dholuo, Swahili, and English) before their ANC visit. During the ANC visit, they were offered HIV testing and counseling as per Kenyan national guidelines.

Of the 1777 women with baseline data, 598 were selected for participation in subsequent follow-up interviews. All of the women who tested positive for HIV or who refused HIV testing after the baseline interview were automatically selected for follow-up. In addition, a random sample of those who tested HIV-negative was also selected, using a computer-based random number generator. Our analyses of experienced stigma focus only on the 411 women (69% of those selected for follow-up) who could be located and participated in the follow-up interview 4–8 weeks after the birth. Of these 411, 154 tested HIV-positive at baseline (68.1% of HIV-positive women selected for follow-up), 165 tested negative at baseline (72.7% of those selected), 52 refused HIV testing at baseline (61.2% of those selected), and 40 did not have HIV testing services available on the day they visited the ANC clinic at baseline (66.7% of those selected).

Independent variables

Socio-demographics

These included age, ethnicity, religion, education, reading ability, marital status, whether the husband had other wives, reproductive history, the woman's main contribution to support of the household (housework, selling things, farming/agriculture, and other), and household ownership of goods as a proxy of wealth (electricity, radio, television, landline telephone, cell phone, and refrigerator). Age was dichotomized into < 25 years and $25+$ due to the lack of normal distribution, and because peak fertility in Kenya occurs around age 25 (Kenya National Bureau of Statistics (KNBS) and ICF Macro, 2010). Since the vast majority of participants were Luo, ethnicity was not included as a variable in the multivariable analysis. Religion was excluded because of the very wide range of religions reported.

HIV knowledge

Two questions were assessed: "Do you think a healthy-looking person can be infected with HIV, the disease that causes AIDS?" and "Can the HIV virus be transmitted from mother to child during delivery?"

HIV status

If the woman agreed to HIV testing during her initial ANC visit, her HIV status was obtained from her medical record, per her consent. If she was not tested for HIV at the initial ANC visit, she was asked her status at the follow-up interviews, though she may have declined to state.

Disclosure

At the postpartum interview, women were asked whether they had disclosed the results of their HIV test and to whom. They were also asked who knew about their HIV status, in order to identify situations in which she did not disclose herself.

Perceived stigma (Genberg et al., 2008, 2009)

This is a 22-item instrument, rated on a Likert scale from 0 to 3. It assesses (1) the respondent's own negative attitudes toward people living with HIV/AIDS (PLHA), (2) the respondent's perception of discrimination that PLHA experience in the community, and (3) the respondent's opinions about equity that PLHA should have. The scale has been tested in Tanzania, Zimbabwe, and South Africa and Cronbach's alpha reliability scores of 0.86, 0.82, and 0.81 have been obtained for the sub-scales (Genberg et al., 2009). In the multivariable analysis, the equity sub-scale was excluded because of low reliability (Genberg et al., 2009). The negative attitudes sub-scale was excluded due to collinearity with the perceived discrimination sub-scale. We dichotomized the perceived discrimination sub-scale variable by whether or not the woman answered yes to any of the items.

Edinburgh Postpartum Depression Scale (EPDS) (Cox, Holden, & Sagovsky, 1987; Pop, Komproe, & van Son, 1992)

The 10-item EPDS was originally designed to screen women for postpartum depression. The items ask about the woman's experiences in the past 7 days, and responses are coded on a Likert scale from 0 to 3. When validated among pregnant women, the reliability scores by trimester were 0.82, 0.83, and 0.84 (Bergink et al., 2011). A cut-off of 13 is recommended for probable major depression and a cut-off of 10 is recommended for probable minor depression (Matthey, Henshaw, Elliott, & Barnett, 2006).

Outcome variables

Anticipated Stigma Scale (Wolfe et al., 2006)

This 9-item scale measures whether or not a person anticipates experiencing stigma or discrimination from various sources if one is found to be HIV-positive and one's HIV-positive status is disclosed to others. In this study, this construct was measured at baseline, when none of the women knew their current HIV status. The instrument was developed and tested in Botswana (Cronbach's $\alpha = 0.77$) (Wolfe et al., 2006). We dichotomized the scale into those who anticipated 0–2 forms of stigma, and those who anticipated more than two forms of stigma. In this way, we were able to identify those who anticipated a substantial burden of stigma.

HIV/AIDS Stigma Instrument-PLWA (HASI-P) (Holzemer et al., 2007)

This 33-item instrument measures experiences of stigma among people living with HIV, and consists of six subscales (Cronbach's $\alpha = 0.76$–0.91): verbal abuse, negative self-perception (self-stigma), health-care neglect, social isolation, fear of contagion, and workplace stigma. On a scale of 0–3, participants rate how often various stigmatizing events have happened to them in the past few months, because of their HIV status. The HASI-P was developed and tested in Lesotho, Malawi, South Africa, Swaziland, and Tanzania (Holzemer et al., 2007). Both total and subscale experienced stigma scores at postpartum were dichotomized because of low reports of experienced stigma, possibly due to low levels of disclosure by this point.

Analysis

Bivariate logistic and linear regression methods were used to examine factors that were *a priori* considered to be associated with the outcomes based on the literature. Variables that were associated with the outcomes ($p \leq 0.10$) were entered into multivariable regression models in order to identify significant predictors of anticipated and experienced stigma. We adjusted these analyses for clustering by clinic, using mixed models. All analyses were conducted using Stata 11 (StataCorp, 2009).

Results

At baseline, the mean age of the 1777 participants was 24 years (Table 1), and most had only primary education or less. Most were married and currently living with a male partner and, of these, 27% had husbands who had other wives. Among the women who were selected for follow-up, only radio ownership (as a proxy for wealth) and number of living children were significantly different between those who could be located and participated in a postpartum interview, and those who were lost to follow-up.

Anticipated HIV-related stigma

Anticipated stigma was measured at baseline, when none of the participants knew their current HIV status. Women 25 years or older had 1.4 (95% CI 1.0, 2.0) greater adjusted odds of anticipating substantial stigma than younger women ($p = 0.03$), after adjustment for other variables in the model (Table 2). Similarly, women who had primary education or less (Adjusted Odds Ratio (AOR) = 1.8; 95% CI 1.2, 2.8; $p = 0.004$), who could read only with difficulty (AOR = 1.60; 95% CI 1.2, 2.1; $p = 0.001$), and whose husbands had other wives (AOR = 1.5; 95% CI 1.2, 2.0; $p = 0.002$) had greater adjusted odds of anticipating substantial stigma. Women who perceived discrimination in the community against PLHA had 10.2 greater adjusted odds of anticipating substantial stigma for themselves if they were to become HIV-positive ($p < 0.0001$). Conversely, women who knew that HIV can be transmitted during delivery had lesser adjusted odds of anticipating substantial stigma (AOR = 0.5; 95% CI 0.3, 0.8; $p = 0.003$). Similar results were obtained in analyses using the different sources of the anticipated stigma as the outcomes (partner, family, community; data not shown).

Experienced HIV-related stigma

Experienced HIV-related stigma was measured only at follow-up, and only among women who had tested positive for HIV. At the postpartum visit, over half (55.8%) of the HIV-positive women reported

Table 1. Demographic, health and stigma characteristics of study participants at baseline ($n = 1777$).

Characteristic	Mean ± SD (or) #(%)
Age, years, mean ± SD, median	23.6 ± 5.4, 22.0 (range: 18–49)
Level of education completed	
Primary or less	1483 (83.2%)
Secondary or more	294 (16.5%)
Literacy	
Read easily	764 (43.0%)
Read with difficulty	728 (41.0%)
Do not read at all	285 (16.0%)
Ethnicity (Luo)	1641 (92.4%)
Religion	
Roman Catholic	331 (18.6%)
Seventh day adventist	583 (32.8%)
Other	863 (48.6%)
Marital status	
Single (never married)	150 (8.4%)
Married	1554 (87.5%)
Separated or divorced	19 (1.1%)
Widowed	53 (3.0%)
Currently living with male partner (yes)	1546 (87.1%)
Husband has other wives (yes) (valid $n = 1556$)	439 (28.4%)
Woman's contribution to support of the household	
Housework	402 (22.6%)
Selling things	355 (20.0%)
Farming/agriculture	742 (41.8%)
Other	274 (15.6%)
Ownership of household goods	
Electricity	64 (3.6%)
Radio	1330 (74.9%)
Television	187 (10.5%)
Landline telephone	23 (1.3%)
Mobile phone	839 (47.2%)
Refrigerator	17 (1.0%)
Number of pregnancies, including current pregnancy (mean ± SD, median)	3.2 ± 2.0, 3.0 (range: 1–16)
Number of live births (mean ± SD, median)	2.2 ± 2.0, 2.0 (range: 0–15)
Has living children (yes)	1328 (74.7%)
HIV Knowledge Index (mean percent correct)	87.9%
HIV status after first ANC visit	
HIV-positive	257 (14.5%)
HIV-negative	1204 (67.8%)
Refused HIV testing	99 (5.6%)
Testing service not available	203 (11.4%)
Missing result in records	14 (0.8%)
Anticipated any stigma (valid $n = 1687$)	1136 (67.3%)
From partner (yes) (valid $n = 1582$)	627 (39.6%)
From family (yes) (valid $n = 1686$)	621 (36.8%)
From community/others (yes) (valid $n = 1608$)	1051 (65.4%)
Perceived any stigma	
Negative attitudes (yes)	1065 (61.5%)
Perceived community discrimination (yes)	782 (45.2%)

experiencing any stigma in the past few months, due to their HIV status. This was largely driven by the 45.5% of the women who said they had experienced self-stigma, but women experienced a range of types of stigma: verbal abuse (6.1%), healthcare neglect (7.9%), social isolation (4.9%), fear of contagion (3.0%), and workplace stigma (11.5%). Women who anticipated more stigma at

Table 2. Predictors of anticipating more than two forms of HIV stigma at baseline ($n = 1687$).[a]

	OR (95% CI; p-value)	Adjusted OR[b] (95% CI; p-value)
Age		
< 25 years	(ref)	(ref)
≥ 25 Years	1.3 (1.1, 1.6; $p = 0.02$)	1.4 (1.0, 2.0; $p = 0.03$)
Number of pregnancies		
1–3	(ref)	(ref)
4 +	1.3 (1.0, 1.5; $p = 0.03$)	0.8 (0.6, 1.1; $p = 0.16$)
Education		
Primary or less	2.0 (1.5, 2.7; $p < 0.001$)	1.8 (1.2, 2.8; $p = 0.004$)
Secondary or more	(ref)	(ref)
Literacy		
Read easily	(ref)	(ref)
Read with difficulty	1.7 (1.3, 2.1; $p < 0.001$)	1.6 (1.2, 2.1; $p = 0.001$)
Not at all	1.8 (1.3, 2.4; $p < 0.001$)	1.2 (0.8, 1.8; $p = 0.30$)
Marital status		
Single/never married	(ref)	(ref)
Ever married	1.8 (1.2, 2.6; $p < 0.01$)	0.7 (0.2, 3.3; $p = 0.65$)
Husband has other wives	1.6 (1.3, 2.0; $p < 0.001$)	1.5 (1.2, 2.0, $p = 0.002$)
Lives with male partner	0.7 (0.5, 1.0; $p = 0.03$)	(excluded because of collinearity)
Woman's major contribution to support of the household is housework vs. other types of contribution	0.8 (0.6, 1.0; $p = 0.03$)	1.0 (0.7, 1.3; $p = 0.83$)
Ownership of household goods		
Electricity	0.9 (0.5, 1.5; $p = 0.64$)	
Radio	0.9 (0.7, 1.1; $p = 0.23$)	
Television	1.0 (0.7, 1.3; $p = 0.86$)	
Landline telephone	0.8 (0.3, 1.0; $p = 0.64$)	
Mobile phone	0.8 (0.7, 1.0; $p = 0.08$)	1.0 (0.8, 1.2; $p = 0.78$)
Refrigerator	1.0 (0.3, 2.7; $p = 0.95$)	
Know that healthy-looking people can have HIV	0.6 (0.4, 0.8; $p < 0.001$)	0.9 (0.6, 1.2; $p = 0.52$)
Know that HIV can be transmitted during delivery	0.6 (0.4, 0.8; $p = 0.01$)	0.5 (0.3, 0.8; $p = 0.003$)
Has partner been tested for HIV (woman's report)		
Yes	(ref)	
No	0.9 (0.7, 1.2; $p = 0.55$)	
Do not know	0.8 (0.6, 1.1; $p = 0.13$)	
Know partner's test result		
HIV-positive	(ref)	
HIV-negative	1.2 (0.5, 3.1; $p = 0.67$)	
Do not know	1.5 (0.5, 1.6; $p = 0.48$)	
Perceives any community stigma (yes)	5.1 (4.1, 6.3; $p < 0.0001$)	10.2 (7.1, 14.7; $p < 0.0001$)

[a] Sample size for adjusted odds ratios is 1440.
[b] Analyses for adjusted odds ratios take into account clustering by site (clinic) using random effects logistic regression (mixed model).

baseline were no more likely to actually experience stigma than other women, although levels of anticipated and experienced stigma were substantial.

Using an EPDS cut-off score of 13, women experiencing probable major depression at the postpartum visit tended to be more likely to have experienced any HIV-related stigma, as were women whose families knew their HIV status (data not shown). Using the lower EPDS cut-off score of 10, however, women experiencing probably minor depression and those whose family knew their HIV status had significantly greater adjusted odds of having experienced stigma in the past few months (Table 3). Other factors associated with experienced stigma in the bivariate analyses were not found to be significant in the multivariate analysis. Looking at just self-stigma, women who were experiencing probable minor depression at postpartum had 4.6 times greater adjusted odds (95% CI 1.7, 12.9; $p = 0.003$) of experiencing HIV-related self-stigma, compared to women without depression. No other factors were found to be independently associated with self-stigma.

Table 3. Final model for predictors of HIV-positive women experiencing any HIV-related stigma in the past few months ($n = 147$).

	OR (95% CI; *p*-value)	Adjusted OR[a] (95% CI; *p*-value)
Age (<25 vs. ≥ 25)	1.0 (0.5, 2.0; $p = 0.97$)	0.5 (0.2, 1.3; $p = 0.17$)
Woman's major contribution to support of the household is housework	4.0 (1.4, 11.0; $p = 0.01$)	1.6 (0.4, 6.2; $p = 0.5$)
Family knows HIV-positive status	4.0 (1.3, 12.3; $p = 0.02$)	4.4 (1.0, 19.7; $p = 0.05$)
Perceives any community stigma on full scale (yes)	0.5 (0.3, 1.0; $p = 0.04$)	0.6 (0.2, 1.5; $p = 0.23$)
Depression (EPDS score of 10 or more)	4.9 (2.2, 10.9; $p < 0.0001$)	4.6 (1.5, 14.0; $p = 0.01$)

[a] Analyses for adjusted odds ratios take into account clustering by site (clinic) using random effects logistic regression (mixed model).

Discussion

Women who were older, had less education, whose husbands had other wives, and who perceived community discrimination against people with HIV had significantly greater adjusted odds of anticipating HIV stigma for themselves if they were to test HIV-positive in the future. Pregnant women who were married to men who had other wives (in a polygynous relationship) were particularly likely to anticipate HIV/AIDS stigma at baseline. It may be that women in polygynous relationships lack power and stability, resulting in concern about the consequences of their HIV status being disclosed to others. Muldoon et al. (2011) report higher levels of sexual risk behaviors among men in polygynous relationships, and a trend toward men having greater control over decisions regarding sex in such a relationship. Bove and Valeggia (2009) describe polygyny as a situation of "co-operative conflict," where women benefit from cooperating with their co-wives, but also must compete with them for affection and resources of the husband. In such a situation, disclosure of HIV status may put a woman at a disadvantage in her relationships with both her husband and co-wives, making her less likely to disclose and get the care she needs.

Although lack of education and HIV knowledge may be associated with being in a polygynous relationship, both showed independent effects on the anticipation of stigma, and both may be related to an overall lack of empowerment. As Bond et al. explain, "HIV and AIDS-related stigma, being linked to power and domination in the community as a whole, plays into, and reinforces, extant social inequalities" (Bond et al., 2002, p. 348).

Women who perceived more HIV-related stigma in their communities also anticipated stigma for themselves if they tested positive for the disease and their status were disclosed. Both experiences of stigma and fears of stigma can have negative effects on health behavior and health outcomes. Stigma has been shown to be associated with psychological distress and with negative health outcomes (Quinn & Chaudoir, 2009), and has also been shown as a substantial barrier to uptake of HIV testing and other health services (Kalichman & Simbayi, 2003; Meiberg, Bos, Onya, & Schaalma, 2008; Turan et al., 2008, 2011; Yang et al., 2006).

Over half of the HIV-positive women interviewed at postpartum reported having experienced some HIV-related stigma, much of which was self-stigma. Women whose family knew about their HIV status had experienced somewhat more stigma in the past few months compared to other women. While not surprising, it is unclear why disclosure to other sources (friends, health care workers, etc.) showed less of an association with actual experiences of stigma. This may be because 33% of the women had not disclosed their HIV-positive status to anyone by the postpartum interview, or because expectations are worse than reality for these women.

Experienced stigma was also associated with depression at the postpartum interview. It may be that women are depressed because of the stigma they had experienced, or that because of their depression they were more likely to view people's actions negatively and assume that they were related to her HIV status. Prior research from South Africa and the US has shown significant associations between internalized stigma and depression among both women and men (Lee, Kochman, & Sikkema, 2002; Simbayi et al., 2007; Vyavaharkar et al., 2010), and research in Canada has demonstrated an association between stigma and psychological distress among women of reproductive age (Wagner et al., 2010). This association could also be related to the recent birth of a child, which may have increased depression as well as perceptions of stigma among the women. At the postpartum visit, women who were experiencing depression were also more likely to experience self-stigma, but as these were both measured at the same visit, it is not possible to identify whether one predicts the other.

This study had several limitations. First, participants were recruited using convenience sampling, and selection bias through differential refusal to participate may have affected the results. However, the refusal rate among eligible antenatal clients was only 3.3% (Turan et al., 2011). Second, we were not able to examine the role of religious affiliation because of the plethora of different religions reported. The emergence of polygynous relationships as an important predictor of anticipated stigma was unexpected, and a more in-depth understanding of wife rank/order, as well as other measures of women's empowerment, would be particularly useful in understanding stigma.

Finally, there was a 30% loss to follow-up for the postpartum interview, which although relatively low for a prospective study of pregnant women conducted in rural Africa, may have affected the validity of the results, and also left a fairly small sample of HIV-positive women for the analysis of experienced stigma. Those lost-to-follow up were very similar to those who were not lost-to-follow up, with the only significant socio-demographic differences being household ownership of a radio and number of children. Radio ownership is unlikely to have affected the results, but number of children may be an important factor. In Kenya, bearing children is expected, and having more children may bring more status and familial power for a woman. Thus, this difference may have had an impact on the results.

Conclusions

These results emphasize the complex nature of HIV-related stigma. Anticipated stigma was positively associated with the partner having other wives, low education, low HIV knowledge, and perceptions of discrimination in the community. For pregnant women with these characteristics, health care workers providing HIV counseling and testing services may consider additional counseling and interventions to reduce the impact of anticipated stigma on the women; to facilitate counseling, testing, and treatment; and to ensure that women get the care that they, their male partners, and their children need.

Experienced stigma was associated with both disclosure and depression. Counseling women about the risks and benefits of disclosure, and interventions focused on safe disclosure could help mitigate the impact of stigma on women's lives, and their decisions about accessing testing and care. Early screening of pregnant women for depression may also be warranted to reduce the effect of stigma.

When discussing stigma, most researchers simply refer to Erving Goffman's 1963 definition of "a deeply discrediting attribute." Goffman went on, however, to explain that stigma "requires a language of relationships," by which he meant that stigma is socially constructed. Recent theorists have built on this by emphasizing the essential role of differential power relationships in creating and perpetuating stigma. This research provides evidence to support these theories. The women who were most affected by stigma were those who were most disempowered within society. Though interventions may reduce the problem of stigma somewhat, larger social changes may be needed (Deacon, 2006; Link & Phelan, 2001; Parker & Aggleton, 2003).

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The Association of Social Capital and HIV Stigma among Women Living with HIV/AIDS

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Abstract

Since the beginning of the HIV/AIDS pandemic, people around the world have experienced HIV-related stigmatization. Social theory explains that stigmatization is based in power differentials, such as those due to race, class and gender. At the same time, individual or group social capital may be seen as a resource, or even as a source of power that could potentially mitigate stigmatization. Based in these theoretical approaches, this cross-sectional study examined the association between social capital and HIV-related stigma in 135 women living with HIV/AIDS in the San Francisco Bay Area. The mean age of study participants was 48.2 years; most were African American (60%) or non-Hispanic White (17%); 29% had less than a high school education; mean annual income was $14,619; and only 19.3% of participants were currently employed. In this sample, age was significantly associated with total perceived HIV stigma (p=.001), but total social capital, annual income, education, disclosure and years since HIV diagnosis were not. Total stigma scores for Asian/Pacific Islander women tended to be substantially higher than for White women (22.8 points, p=.07), but these results are difficult to interpret because of the small number of API participants. In further analysis, women with lower scores on the Value of Life factor of social capital had significantly higher total stigma scores (p=.010) and higher scores on the Negative Self-image factor of stigma (p=.001). In the models tested, education and annual income, as proxies for social class, did not contribute significantly to the explained variance in perceived stigma. These results together indicate that women who feel less valued in their social worlds, who are marginalized or lack a valued social identity, may be more likely to perceive HIV stigmatization, including internalized stigma, which could have negative health

consequences. This work also begins to elucidate the possible relationship between social capital and perceived HIV stigma.

Research Highlights

- Women who feel less valued in society are more likely to perceive HIV stigma.

- Older women are significantly less likely to perceive HIV-related stigma.

- More effective measures of social power, social capital and HIV stigma may be needed.

Keywords

HIV/AIDS, stigma, social capital, women, marginalization, power, United States

The Association of Social Capital and HIV Stigma among Women Living with HIV/AIDS

Introduction

Since the beginning of the HIV/AIDS pandemic over 30 years ago, people living with the disease have experienced stigmatization by an array of other people and by varied organizations. This has been, and continues to be the case around the world (Castro & Farmer, 2005; Greeff et al., 2008; Henkel, Brown, & Kalichman, 2008; Holzemer et al., 2009; Turan et al., 2011). HIV stigmatization has a range of consequences, from emotional (e.g. verbal abuse, shunning), to physical (e.g. beatings, forcing someone to leave their home), to financial (e.g. firing someone from a job) because of their HIV status. It can also have direct impacts on the health of people living with the disease, as it may act as a barrier to testing (Bokhour, Solomon, Knapp, Asch, & Gifford, 2009; Kalichman & Simbayi, 2003; Turan, Miller, Bukusi, Sande, & Cohen, 2008), to accessing care (Turan, et al., 2008), and to understanding and adhering to treatment regimens (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006).

Women, who currently account for approximately 27% of those living with HIV/AIDS in the United States (Centers for Disease Control and Prevention, 2011), may be particularly vulnerable to HIV-related stigmatization. Many of these are women of color living in poverty, already marginalized not only for their gender, but also for their race, social class, or behaviors vis-à-vis sex or drugs. The various social worlds in which they live may provide them with support as they deal with their illness or, conversely, may be sources of stigmatization. Because of the complexity of stigmatization processes, it is important to have a more nuanced understanding of the social situations in which it occurs in order to address it more effectively. An understanding of this relationship could inform strategies for addressing HIV-related stigmatization. The present study examines the association of HIV-related stigma and social capital in a sample of women living with HIV/AIDS in the San Francisco Bay Area. Social stigma and social capital serve as the theoretical frameworks for the research presented here.

Stigma

While stigma is a concept used in many domains over the years, it is often not clearly understood (Link & Phelan, 2001). In the early 1960s, Erving Goffman provided the pioneering social science definition of stigma as "an attribute that is deeply discrediting," but he went on to add that "it should be seen that a language of relationships, not attributes is really needed" (1963:3). Goffman emphasized that an attribute is deemed "deeply discrediting" only through interaction, and is thereby socially constructed by people, their social networks, and the larger social worlds in which they live. He also pointed out that an attribute can be given its discrediting meaning because of associated stereotypes. HIV/AIDS, for example, is often associated with stereotypes related to who gets the disease (e.g. drug users, homosexual men) and how (e.g. promiscuous sex). Because of this, people living with the disease may be stigmatized, even if they do not fit the stereotyped categories.

Building on Goffman (1963) and others (DeBeauvoir, 1953; Foucault, 1980), Robert Crawford examined the ‘othering’ of people living with HIV (1994). Crawford proposed that “the concept of health is absolutely central to modern identity…. [and that] the ‘healthy’ self is sustained in part through the creation of ‘unhealthy’ others, who are imagined as embodying all the properties falling outside this health-signified self” (1994:1348). The unhealthy other serves not only to delineate the boundaries of individual identity, but also reinforces existing social group differences. Because HIV/AIDS in the United States originally affected mainly men who had sex with men and intravenous drug users, groups already considered marginal and lacking in the self-discipline to be healthy, these groups were ripe for becoming the antithesis of the ‘healthy self’. They became the ‘other’ against which mainstream, straight, white, middle-class people could compare themselves. HIV/AIDS has moral meanings not only because of its link to already stigmatized identities, but also because of the blame associated with not adequately protecting one’s health and allowing oneself to become infected: “The healthy body is the property of a deserving owner” (Crawford, 1994:1356). By creating unhealthy and stigmatized ‘others’ who were to blame for becoming infected with HIV/AIDS, those who were uninfected established boundaries to distinguish ‘us’ from ‘them’.

More recently, Link and Phelan proposed a revised theory of stigma to address concerns about the lack of clarity or agreement about the definitions of stigma, and the overly individualized focus of prior work (2001). This theory is based on a set of interrelated components:

> [S]tigmatization is entirely contingent on access to social, economic, and political power that allows [1] the identification of differentness, [2] the construction of stereotypes, [3] the separation of labeled persons into distinct categories, and [4] the full execution of disapproval, rejection, exclusion, and discrimination (Link & Phelan, 2001:367).

Link and Phelan make two major theoretical contributions here. First is their discussion of structural discrimination, usually invisible, inscribed through naturalized social structures that ultimately reduce the opportunities of the stigmatized person or group. Second is their emphasis on the importance of power relationships in the enactment of stigma; Only those with power can effectively reduce the "life chances" (Goffman, 1963) of others and participate in the creation and maintenance of structural discrimination. The extent of stigmatization thus depends on the relative power between particular individuals or groups, which can be racially, ethnically, sexuality and/or (dis)ability based.

Parker and Aggleton (2003) see stigma as an ongoing dialectical process that serves to reproduce the power inequalities discussed by Link and Phelan (2001). In their explication of HIV stigmatization, Parker and Aggleton draw on Gramsci's idea of hegemony, "a complex interlocking of political, social and cultural forces which organize dominant meanings and values… in order to legitimize the structures of social inequality, even to those who are the objects of domination" (2003:18). They connect this to Bourdieu's notion of symbolic violence, the process through which every-day practices benefit already dominant groups and legitimate these power differentials through hegemony. And the authors engage Foucault, for whom difference is socially constructed "in the service of power" (2003:17), and who asserts that 'othering' of certain groups is based on relationships of difference. Based on these ideas, Parker and Aggleton propose that "Stigma and stigmatization function, quite literally, at the point of intersection between *culture, power* and *difference*" (Parker & Aggleton, 2003:17). In explicitly pointing to dynamics of power and differentiation, Parker and Aggleton see power differentials as a *cause* of stigma and as a way for dominant groups to legitimize their status, rather than just a necessary presence for stigma and discrimination to occur. And they specifically acknowledge the "intensifying interaction between multiple forms of inequality and exclusion" (Parker & Aggleton, 2003:19) such as race, ethnicity, and gender, as stigmatization builds on existing forms of difference and inequality.

Based on both older and more recent theoretical work in the area of stigma, Pescosolido and colleagues propose a tool for researching stigmatization, their "Framework Integrating Normative Influences on Stigma" or FINIS (2008). As they explain, FINIS is not a theory of stigma, but rather a framework that can be tailored for different health-related stigmatizing conditions to help identify areas that should be examined for their impact in a particular context. Explaining that "stigma lies at the interface of community and individual factors" (2008:433), Pescosolido and colleagues identify some of the micro-, meso-, and macro-level contextual issues that take place in communities and among individuals, and which make the stigma process more or less likely to occur. In particular, at the meso-level, Pescosolido and colleagues discuss the role of social networks, finding conflicting empirical evidence. In some cases, social networks may offer increased social support if a member needs help, while in other cases social networks may have lower tolerance for people who are or become different from them, making stigmatization of a group member more likely if s/he discloses something such as

HIV. Many theorists have built on the idea of social networks by examining the social capital that is created within them.

Social Capital

Pierre Bourdieu was one of the first social scientists to use the concept of 'capital' beyond the traditional view, explaining that capital is made up not only of economic capital, but also of cultural and social capital (1985:243). While cultural capital refers to a person's socialization throughout life, and is largely based on family, education, and social origin, social capital is based upon a person's social networks and membership in groups. More specifically, Bourdieu explains that social capital is "the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition" (1985:248). Thus, it is the resources that a person can potentially call upon, based on her/his interactions and relationships with other group members, which comprise social capital. These resources are created through investment by individuals in their social relationships. For example, a person may do a favor for another member of the group, and in this way transforms her/his own investment of time and effort into an obligation that can be called upon later. In essence, an exchange is made. A person who makes greater investments in the relationships of the group will accumulate more social capital, and this becomes a resource that can be used in the future. Further, Bourdieu suggests that individuals choose to interact and exchange with other group members, and this helps to define and reinforce the group. Exchange "reaffirms the limits of the group, i.e. the limits beyond which the constitutive exchange – trade, commensality, or marriage –

cannot take place. Each member of the group is thus instituted as a custodian of the limits of the group" (Bourdieu, 1985:250). Thus, membership in a social network includes both entitlements/resources as well as obligations and responsibilities to others. Members can call upon the resources of others when in need, but are also responsible for maintaining the integrity of the group, including by "expelling or excommunicating… [or] embarrassing individuals" (Bourdieu, 1985:251).

For Bourdieu, the forms of capital – economic, cultural, social – are convertible into one another, though not always easily: "The different types of capital can be derived from *economic capital*, but only at the cost of a more or less great effort of transformation, which is needed to produce the type of power effective in the field in question" (1985:252). For example, the freedom to invest time and effort in the relationships of the group in order to generate social capital is often based upon having existing economic capital. Because of this capacity of convertibility, Bourdieu's work suggests that economic, cultural, and social forms of capital are indicators of power, and that accumulated resources of social capital can be seen as a form of greater power of one individual or group over another.

For James Coleman, the characteristics of social capital begin with the idea of trust. Obligations that are incurred through exchanges or favors are like credit that can be called upon in the future, and he states that "the analogy to financial capital is direct" (Coleman, 1988:S102). In some very hierarchical groups, one individual (e.g. the godfather in the case of the mafia) may hold a large number of obligations owed to himself, giving him a certain degree of power within the group. This credit, however, is based largely on the notion that the person who did the favor *trusts* (or can coerce) the other person to repay her/him at some point in the future. Coleman further suggests that norms and the capacity for sanctions are important aspects of networks, and that they serve both positive and negative functions. For example, norms and sanctions against crime in a neighborhood make it safer for people to walk around outside. On the other hand, norms may also results in constraints against differentness and innovation.

Alejandro Portes' work is particularly useful in his clear description of three main functions of social capital: "(a) as a source of social control; (b) as a source of family support; (c) as a source of benefits through extrafamilial networks" (1998:9). These functions are useful for interrogating the potential relationship between social capital and HIV-related stigma. For example, social controls work to define acceptable and non-acceptable behaviors for group members. The threat of sanctions could limit behaviors that put women at risk of HIV, such as alcohol and drug use, but could also limit disclosure of HIV-positive status. For women with HIV, lower levels of social capital could lead to sanctions such as stigmatization and exclusion from their social networks. Social capital may also function as social support for women living with HIV, particularly in terms of support for their children and families. Social support may or may not outweigh social controls, depending on the social group. Finally, Portes explains that the relationships of social capital can provide benefits such as access to jobs and "individual mobility" (1998:12), which could help empower women living with HIV, reducing the likelihood of stigmatization.

More recently, authors have begun to examine the role of social capital and HIV-related stigma. In a study of 619 people in a South African community, Chiu and colleagues found that various factors of social capital predicted stigmatizing attitudes (2008). People with a greater sense of empowerment and more education were less likely to have stigmatizing attitudes toward people living with HIV. People with a greater sense of trust and safety in their neighborhoods were less likely to perceive stigmatizing attitudes in their communities. Sivaram and colleagues found that community members in India who perceived themselves as having greater social capital – through participation in groups, collective action, reciprocity among community members, and trust in providers – had less stigmatizing attitudes toward people living with HIV/AIDS (Sivaram et al., 2009).

To date, research on social capital and HIV stigma mainly examines the stigmatizing attitudes that non-infected people feel towards people living with HIV. The purpose of this paper, however, is to use the FINIS framework to begin exploration of the relationship between social capital and the stigma that people living with HIV have experienced due to their HIV-positive status. An understanding of this relationship could provide innovative strategies for addressing HIV-related stigmatization and its negative health and social consequences.

Methods

The data and analyses presented here are part of a larger longitudinal study to validate a self-management instrument for women living with HIV/AIDS (Webel et al., 2012). For the analysis presented here, data were collected in the San Francisco Bay Area in California, from October 2010 to February 2011.

Human Subject Protections

The institutional review board of the University of California, San Francisco reviewed and approved the study. Women who were interested in the study received an explanation of the purpose and activities of the study. Those who agreed to participate signed an informed consent form, and then completed a self-report questionnaire on paper. Investigators were present to answer any questions. Upon completion of the questionnaire, participants received a $25 gift card.

Sample

Women were recruited from three sites in the San Francisco Bay Area, including two women's HIV clinics and one women's AIDS services organization. At the two clinics, investigators were present in the waiting rooms during the clinic hours specified for HIV-positive women and invited all women to participate. At the AIDS services organization, flyers were posted in advance, and those who were interested went to the organization on a specified date to complete the questionnaire. Women were eligible to participate if they were HIV-positive, 21 years or older, self-identified as female, and fluent in English. The final sample included 135 women who completed the self-report survey instrument.

Independent Variables

Socio-demographics. This included information about age, race/ethnicity, marital status, parental status, employment status, education and annual income (as a proxies for class), and year of HIV diagnosis.

Social Capital. Social capital was assessed using the Social Capital Scale (Onyx & Bullen, 2000). This 36-item instrument seeks to measure an individual's perceptions of social capital in eight domains: participation in the local community (e.g. Do you help out a local group as a volunteer?); social agency (e.g. If you disagree with what everyone else agreed on, would you feel free to speak out?); feelings of trust and safety (e.g. Do you agree that most people can be trusted?); neighborhood connections (e.g. Can you get help from friends when you need it?); family and friends connections (e.g. How many people did you talk to yesterday?); tolerance of diversity (e.g. Do you think that diversity makes life in your area better?); value of life (e.g. Do you feel valued by society?); and work connections. In addition, one general factor measures overall social capital. Because we expected low levels of employment in this sample, the five items related to employment were not included in the instrument. This shorter 31-item instrument has previously been validated among people living with HIV (Webel, et al., 2012). Participants responded to each item on a 4-point Likert scale. Factor scores and the total social capital score are calculated by summing responses and dividing by the number of items. Cronbach's alpha reliability coefficient was 0.90 for the total score in this sample.

Disclosure. Women were asked whether they had disclosed their HIV-positive status to anyone and, if yes, to whom. This included husband/wife/partner, children, relatives, neighbors, friends, church community, work colleagues, and other members of the community. Because they were recruited from HIV service organizations / clinics, they were not asked about disclosure to medical providers.

Outcome Variables

Perceived Stigma. The Perceived Stigma Scale (Berger, Ferrans, & Lashley, 2001) is a 40-item instrument examining the experiences, feelings and opinions of people living with HIV. Participants respond to each item on a 4-point Likert scale (strongly disagree to strongly agree) and responses are summed to generate a total score, and four factor scores: personalized stigma (e.g. I have lost friends by telling them I have HIV); disclosure concerns (e.g. I work hard to keep my HIV a secret); negative self-image (e.g. Having HIV makes me feel that I'm a bad person); and concern with public attitudes (e.g. Most people believe that a person who has HIV is dirty). Cronbach's alpha reliability coefficient was 0.96 for the total score in this sample.

Analysis

Study data were entered into a Research Electronic Data Capture (REDCap) system (Harris et al., 2009), then exported into Stata 11 for cleaning, scoring and analysis (StataCorp, 2009). Multivariate linear regression analysis was used to examine the relationship between variables that were *a priori* considered to be relevant to HIV-related stigma based on the concepts of social capital (Total Social Capital), possible marginalization (age, race, and income and education as proxies for class), and potential confounders (disclosed to anyone, years since diagnosis). Subsequent analyses examined the relationships between specific social capital and marginalization factors and stigma factors.

Results

The mean age of the 135 study participants was 48.2 years ± 8.9 (Table 1). Most participants were African American/ Black (60%) and non-Hispanic White (17%), and most were single (66%) or currently married / partnered (12%). Almost a third of the participants (29%) had less than a high school education, while another third (30%) had two years of college or an associate/technical school degree. Mean annual income among participants was $14,619 (± $16,733), and only 19.3% of participants were currently employed. One-hundred participants had permanent housing (74%). Among the 135 women, most had been pregnant at some point in their lives; 29.6% had been pregnant when they were first diagnosed with HIV, but only 37% currently had children living with them. Mean perceived stigma overall among participants was 51.5 on the scale of 0-120. The mean social capital score was 2.58 ± .59 on a scale of 0-4. Of the study participants, 117 (88.6%) had told at least one person of their HIV status; 58.3% had told their husband/partner, 51.5% had told their children, 61.4% had told relatives, 60% had told friends, and fewer had told others.

In a multiple regression model for total perceived stigma (Table 2), age was significantly associated with stigma (F=1.85, p=.05, adjusted R^2=.11). Women who were older were significantly less likely to perceive experiences of stigma related to their HIV-positive status than were younger women (beta = -1.08, 95% Confidence Interval (CI) -1.73, -.45, p=.001). For each additional year of age, women's total stigma scores declined by just over one point, meaning that stigma experiences for women in their 20s, 30s, 40s and on could be significantly different. Total stigma scores for Asian/Pacific Islander women tended to be substantially higher than for White women (22.8 points, p=.07). While total stigma scores for African American, Hispanic, and Native American women were also higher than for white women, the differences were not significant, and when these categories were combined into one "other" category because of the small numbers, differences between White, African American and other minority races were not significant. In this model, total social capital, annual income, education, disclosure and years since HIV diagnosis were not significantly predictive of total stigma.

To further probe the relationship between social capital and stigma, we examined the effect of the Value of Life factor of the Social Capital Scale on total stigma, a model that provided greater explanation (F=2.50, p=.008, adjusted R^2=.17). Women who had lower scores on the Value of Life factor had significantly higher total stigma scores (p=.010), suggesting that women who do not feel valued by society are also more likely to perceive experiences of stigma related to their HIV-positive status. As in the first model, younger women and Asian/Pacific Islander women were more likely to perceive experiences of HIV stigma compared to older women and women of other races. We also examined the relationship between the Value of Life factor of social capital, and the Negative Self-Image factor of stigma. Again, there was a significant relationship between value of life and negative self-image, controlling for other variables (F=3.21, p=.002, adjusted R^2=.11). Women with lower scores on the Value of Life factor of the social capital scale perceived significantly greater internalized stigma (negative self-image) than did women with higher scores (p=.001) (data not shown).

Women who were pregnant when diagnosed with HIV had Total Stigma scores 14 points higher than women who were not pregnant when they were diagnosed (95% CI 1.8, 26.4, p=.03). Although this effect was confounded by the age of the participant, a non-significant trend was still present after age was controlled for (data not shown).

Discussion

In this analysis of women living with HIV in the San Francisco Bay Area, total social capital was not significantly associated with total perceived HIV stigma, although a trend was noted in the expected direction: those with less social capital perceived more social stigma. The lack of a significant association in this relationship may be due to differences in the concepts measured in the sub-factors of each of the two measurement scales. For this reason, the Value of Life factor of the Social Capital Scale was examined in greater detail, and a significant association was found with both total stigma and with the Negative Self-image factor of the stigma scale. These results indicate that women who feel less valued in their social worlds, who are marginalized or lack a valued social identity, may be more likely to perceive HIV stigmatization, including internalized stigma. Prior work has shown, for example, the importance of having a valued social identity such as mother for some HIV-positive women (Barnes & Murphy, 2009; Bedimo-Rung, Clark, Dumestre, Rice, & Kissinger, 2005), as well as the linkage between social identity and self-esteem (hooks, 1994). Women living with HIV are aware of public opinions and stereotypes about who gets HIV. For the women in this sample – who were largely poor, unemployed, and of color – not feeling valued by society could lead to internalization of some of these negative opinions into their own views of themselves. Research has also identified depression as a significant symptom of HIV, regardless of the stage of progression (Willard et al., 2009), and this could be a form of internalization of negative public opinions and stigmatization. Lee and colleagues found that, among 268 people living with HIV, most experienced internalized stigma, and this contributed significantly to depression (2002).

In the models that we tested, education and annual income, as proxies for social class, did not contribute significantly to the explained variance in perceived stigma. While being of Asian/Pacific Islander descent was associated with perceived HIV stigmatization in these models, this may have been an anomaly due to the small sample of such participants. When combined with other small sample groups (Hispanic/Latino and Native American Indian), the trend of Asian/Pacific Islanders and other minorities having higher perceived stigma remained, but was not significant. Prior research, however, has identified disclosure and stigmatization as substantial issues for people of Asian descent due to cultural norms (Kang, Rapkin, & DeAlmeida, 2006), and further exploration of this may be warranted.

In all of the models examined, age contributed significantly to the variance in stigma. Younger women were more likely to perceive social stigma, including negative self-image, than were older women. It may be that younger people, many of whom are still developing their identities, are more conscious of and concerned with other people's opinions of them. Other research, however, suggests that older people living with HIV may experience more stigma (Charles et al., 2012). In a study of 44 people aged 20-39 and 44 people aged 50+, Emlet found no difference in total HIV-related stigma between older and younger adults, but significant differences in terms of sub-factors (Emlet, 2006). Younger people with HIV were more concerned about losing their jobs, while older people disclosed their HIV status to fewer people. Differences in definitions of "older" and "younger" have made it difficult to compare results of prior studies, suggesting that further research in this area may be important.

There were several limitations to this study, including the use of a convenience sample. In addition, the lack of longitudinal data limits the results to associations, and does not allow us to determine possible causal effects of social capital on stigmatization. The adjusted r-square results for the models examined were relatively low, suggesting that the models did not fully explain the variance in stigma that the participants perceived. There were also limitations related to the data collection instruments used. Although we theoretically presupposed that social capital can serve as a form of power within networks, we did not have a true measure of social power. However, in our review of the literature, we did not find an operationalized measure of social power appropriate for a study of health.

The measure of social capital, though previously used and validated in populations of people living with HIV, has more of a focus on measuring social capital at a community level, rather than solely at the individual level. Further, this instrument does not take into consideration the fact that all people inhabit multiple social worlds and not only may have different degrees of social capital in each world, but also may or may not have "bridging capital" to be used outside of their own social worlds (Putnam, 2001). Women living with HIV may, for example, have social capital within their networks of other HIV-positive women, but less social capital in their neighborhoods, or even in the cities within which they live. Therefore, better instruments to measure the nuances of social capital are needed.

The Perceived Stigma Scale poses another issue. Although it has been used widely in research with people living with HIV (Bunn, Solomon, Miller, & Forehand, 2007; Charles, et al., 2012; Holzemer, et al., 2009; Ivanova, Hart, Wagner, Aljassem, & Loutfy, 2012; Ostrom, Serovich, Lim, & Mason, 2006), its use may in itself be a source of stigma for study participants. The scale, which includes items such as "Having HIV makes me feel unclean" and "I feel I am not as good a person as others because I have HIV," may suggest to participants that some women living with HIV feel this way. It may also suggest that this is the type of meaning that "woman living with HIV" has for other people. As symbolic interactionism explains, meanings are created and revised through interactions with other people, even indirect interactions (Blumer, 1969; Mead, 1934). Thus, through the interactive research process, a woman completing this scale may interpret these items as meaning that other people believe that she is herself "unclean" or "not as good a person as others" because of her HIV, and may begin to internalize this into her identity (Ashcroft, 2003). In this way, completing the stigma scale may in itself inscribe stigma. This may be particularly true when a power differential between researcher and participant is perceived. In this case, the researchers were mostly white, educated women as compared to the participants who were mostly less educated women of color.

Research itself can have significant effects on study participants, even when not intended (Ashcroft, 2003). This is perhaps most evident in work on the placebo effect. Although definitions of a placebo vary (Harrington, 2006), it is clear that medications or interventions that are considered not to be clinically active in any way can result in physiologic and psychological changes in patients who believe they may be getting active treatment. "We treat patients in a social and psychophysiological context that can either improve or, alas, worsen outcome. The meanings and expectations created by the interactions of doctors and patients matter physically, not just subjectively"(Spiegel & Harrington, 2008). The same may be true in research, where participants, like patients, are being acted upon by those who they perceive as having more power than they have themselves. If study participants feel that researchers have negative perceptions about them, they could internalize these beliefs. As Thomas and Thomas explained, "situations defined as real are real in their consequences" (1928/1970:154). While we hope that the research participants did not feel stigmatized by participation in this study, we must be aware of this potential. To address these issues, further research on HIV stigma may use different instruments; may include qualifying introductory statements such as "we know this is not true, but…"; or may use qualitative approaches that allow for more organic approaches to the issue, rather than suggesting it to study participants.

Conclusion

Although the overall hypothesis in this study was not supported, further analysis identified a significant association between the Value of Life factor of the Social Capital Scale, and both Total Stigma and Negative Self-image. Young women living with HIV who do not feel valued by society, and who may lack a valued social identity, may be more likely to perceive HIV-related stigmatization, which could lead to increased morbidity and mortality.

A woman's various social networks may be important sources of empowerment and support that can reduce HIV-stigmatization and its distal effects. Many women living with HIV experience social isolation either brought on by their own fears of stigmatization, negative self-image, or active exclusion by others (Emlet, 2006; Sandelowski, Lambe, & Barroso, 2004). However, women who are able to create new social networks for themselves or involve themselves in supportive social worlds (e.g., support groups, supportive communities, women's groups) may be better equipped to avoid or deal with HIV-related stigmatization, particularly internalized stigma. In addition, efforts to empower women may also help HIV-positive women deal with stigmatization. For example, employment programs help women financially and also provide a valued social identity – worker – and may be crucial in providing women with both economic and social capital, which may reduce the health and stigmatization effects of HIV.

Finally, health care providers are part of the social context of women's lives and therefore it can be useful for them to be aware of these factors for identifying women who may be more likely to experience HIV stigma. Health care providers may also be able to encourage women to become involved in their communities, and clinics can serve as networks of support for women living with HIV and can help organize support groups.

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Table 1. Demographic, Health and Stigma Characteristics of Study Participants at Baseline (n=135)

Characteristic	Mean ± SD (or) # (%)
Age, years, mean ± SD, median	48.2 ± 8.9 (range: 22 - 71)
Race / Ethnicity	
Asian / Pacific Islander	5 (3.9%)
African American / Black	78 (60.5%)
Hispanic / Latina	9 (7.0%)
Native American Indian	7 (5.4%)
White (non-Hispanic)	22 (17.1%)
Other	8 (6.2%)
Marital Status	
Single (never married)	85 (65.9%)
Married or Domestic Partnership	18 (14.0%)
Separated or Divorced	18 (14.0%)
Widowed	6 (4.7%)
Other	2 (1.6%)
Education	
11th grade or less	37 (29.1%)
High school or GED	52 (41.0%)
2-year college / AA degree / Tech school	28 (22.1%)
College or higher	10 (7.9%)

Works for pay (yes)	26 (19.3%)
Annual income	$14,620 ± $16,733
Currently on Antiretroviral Therapy (yes)	96 (73.9%)
Ever been pregnant (yes)	109 (80.7%)
Pregnant when diagnosed with HIV (yes)	32 (29.6%)
Have children (yes)	89 (82.4%)
Have children living with you (yes)	30 (37.0%)
Stigma	
Total stigma score (possible range 0-120)	51.46 ± 25.84
Personalize stigma (possible range 0-48)	20.29 ± 13.59
Disclosure concerns (possible range 0-30)	15.30 ± 7.16
Negative self-image (possible range 0-39)	15.35 ± 8.33
Concern with public attitudes (possible range 0-60)	25.70 ± 13.59
Social Capital (range 0-4)	
Total social capital	2.58 ± .59
Value of life	2.80 ± .96
Social agency	2.75 ± .72
Participation in the local community	2.22 ± .84
Feelings of trust and safety	2.36 ± .80
Neighborhood connections	2.54 ± .80
Family and friends connections	2.75 ± .85
Tolerance of diversity	2.97 ± .98

Table 2: Relationship between Total Social Capital, Marginalizations and Total Perceived Stigma

Model 1	***β***	**95% Confidence Interval**	**p-value**	**F (df)**	**Adjusted R^2**
Age	-1.08	-1.73, -.45	.001		
Race					
White	(ref)				
Asian / Pacific Islander	22.85	-1.89, 47.58	.070		
African American / Black	3.58	-10.96, 18.13	.625		
Hispanic / Latina	12.26	-15.73, 40.25	.386		
Native American Indian	3.82	-21.05, 28.69	.760		
Other	-8.15	-32.27, 15.96	.503		
Annual Income	-.00007	-.0004, .0002	.688		
Education					
11th grade or less	(ref)				
High school or GED	5.61	-7.99, 19.20	.414		
Any college or higher	6.31	-7.85, 20.47	.378		
Disclosed to anyone (yes)	-1.05	-19.02, 16.93	.908		
Years since HIV diagnosis	.45	-.30, 1.20	.234		
Perceived Social Capital	-4.11	-12.75, 4.54	.347		
Constant	99.46	59.44, 139.48	.000	1.85 (12,75)	.11

Table 3: Relationship between Value of Life, Marginalizations and Total Perceived Stigma

Model 2	***β***	**95% Confidence Interval**	**p-value**	**F (df)**	**Adjusted R^2**
Age	-1.12	-1.73, -.51	.001		
Race					
White	(ref)				
Asian / Pacific Islander	24.20	.51, 47.89	.045		
African American / Black	5.89	-8.20, 19.98	.407		
Hispanic / Latina	12.76	-14.10, 39.62	.347		
Native American Indian	5.41	-18.51, 29.33	.654		
Other	-5.13	-28.48, 18.21	.663		
Annual Income	-.00003	-.0003, .0003	.840		
Education					
11th grade or less	(ref)				
High school or GED	4.34	-8.77, 17.45	.512		
Any college or higher	5.48	-8.15, 19.11	.426		
Disclosed to anyone (yes)	.10	-17.16, 17.35	.991		
Years since HIV diagnosis	.50	-.22, 1.22	.167		
Value of Life	-6.95	-12.22, 1.69	.010		
Constant	106.55	70.33, 142.77	<.0001	2.50 (12,75)	.17

Social Stigma and Childbearing for Women Living with HIV/AIDS

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Bio

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Abstract

As more women become infected with HIV, the matter of childbearing becomes more salient. We need a nuanced understanding of their situations in order to provide quality services and support. The purpose of this study was to examine reproductive decision-making among 20 women living with HIV in the San Francisco Bay Area through in-depth interviews. These women made decisions within situations of chaos, instability and trauma, which to some extent limited true reproductive choice. Despite their HIV, many of the women chose to have children because of experiences of 'missed mothering.' Many experienced stigmatization related to their HIV and to their decisions to have children. This stigmatization came from multiple sources, including some health care providers who encouraged their patients to abortion pregnancies. Participants, however, found ways to resist this pressure. These results support the need for providers and care settings focused specifically on the needs of HIV-positive women.

Keywords

HIV/AIDS; marginalized populations; pregnancy; reproduction; stigma; women's health issues

In the United States today, approximately 1,000,000 people are living with HIV and/or AIDS, and women account for a quarter of those cases (Centers for Disease Control and Prevention, 2013). While women are increasingly affected by the disease, substantial within-group differences exist. In 2010, rates of HIV infection were 41.7 per 100,000 Black women, 9.2 per 100,000 Hispanic women, and only 2.1 per 100,000 white women, indicating significant disparities based on race (Centers for Disease Control and Prevention, 2011), and a similar situation exists in San Francisco (San Francisco Department of Public Health, 2012). While the San Francisco HIV/AIDS epidemic still affects largely white men who have sex with men, the disease is expanding in female and racial/ethnic minority populations.

As more women in the United States become infected with HIV, the matter of childbearing while HIV-positive becomes more salient, and issues related to health, transmission and social stigma arise. To provide services and support to HIV-positive women who are or will become pregnant, it is important to understand their situations, and how they decide what to do in those situation. The purpose of this study was to examine reproductive decision-making among women living with HIV. The term “decision-making” is used to describe the situations in which women get pregnant and the way those pregnancies are resolved. As we know, approximately half of pregnancies in the U.S. are unplanned, and about 40% of those end in abortion (Finer & Zolna, 2011). Although many HIV-positive women don’t “plan” their pregnancies, this may have little to do with their HIV, and is not greatly out of line with the U.S. general population. It is also important to note that even when a pregnancy is unplanned, it may still be very much wanted.

Background

Before HIV medications were available, HIV-positive women had a 20-30% chance of transmitting the disease to their babies, either during pregnancy, delivery, or breastfeeding (Andiman et al., 1990; Falloon, Eddy, Wiener, & Pizzo, 1989). In 1985, the U.S. Centers for Disease Control and Prevention (CDC) recommended that HIV-positive women delay or consider not having children (1985), and in 1987 the American College of Obstetrics and Gynecology (ACOG) made a similar recommendation (Kass, 1994). With the approval of zidovudine (AZT) by the U.S. Food and Drug Administration (FDA) in 1987, the rate of perinatal transmission could be reduced to as little as 8% (Connor et al., 1994), and with the advent of highly active antiretroviral therapy (HAART) in the late 1990s, the rate of transmission could be reduced to as little as 2% (International Perinatal HIV Group, 1999). Both ACOG and the CDC later changed their recommendations to focus on counseling HIV-positive women regarding their reproductive options (Al-Khan, Colon, Palta, & Bardeguez, 2003; Centers for Disease Control and Prevention, 2001).

Over the course of the HIV/AIDS epidemic, extensive quantitative and qualitative research has clearly demonstrated that many women and men living with HIV continue to want children (Barnes & Murphy, 2009; Bedimo-Rung, Clark, Dumestre, Rice, & Kissinger, 2005; Chen, Philips, Kanouse, Collins, & Miu, 2001; Cooper et al., 2007; da Silveira Rossi, Fonsechi-Carvasan, Makuch, Amaral, & Bahamondes, 2005; De La Cruz, Davies, & Stewart, 2010; Finocchario-Kessler et al., 2010; Ingram & Hutchinson, 2000; Kirshenbaum et al., 2004; Kisakye, Akena, & Kaye, 2010; Kline, Strickler, & Kempf, 1995; Myer, Morroni, & El-Sadr, 2005; Myer, Morroni, & Rebe, 2007; Nobrega et al., 2007; Sanders, 2008; Smith & Mbakwem, 2010; Sowell & Misener, 1997; Ujiji, Ekström, Ilako, Indalo, & Rubenson, 2010; Wesley et al., 2000; Worth, 1989). This research has also shown that, like women without the disease, many HIV-positive women have unintended pregnancies (Bedimo-Rung, et al., 2005; Cooper et al., 2009; Kline, et al., 1995), and must make decisions regarding whether to carry the pregnancy to term or have an abortion (Bedimo, Bessinger, & Kissinger, 1998; Craft, Delaney, Bautista, & Serovich, 2007; Sunderland, Minkoff, Handte, Moroso, & Landesman, 1992). Bedimo and colleagues noted that many women affected by HIV are also marginalized based on race, class, drug use, and/or commercial sexual activity (1998). Further, many women are initially diagnosed with HIV during prenatal care, regardless of whether the pregnancy was planned or not. These situations may make it difficult for women to make active and informed decisions about their reproductive lives.

In research on reproduction in women living with HIV/AIDS (WLHA), much of the concern focused on transmission of HIV to children (Kirshenbaum, et al., 2004; Sanders, 2008; Wesley, et al., 2000). In the early 1990s, Sunderland and colleagues found that pregnant women living with HIV were more likely to abort than HIV-negative women, largely due to fear of transmission to the child (1992). More recently, research has shown that women with greater fear of HIV transmission were less likely to choose to become pregnant (Craft, et al., 2007). Women may also be concerned about the effects of pregnancy on their own health (Craft, et al., 2007; Sanders, 2008; Sunderland, et al., 1992), or about how their health may affect their ability to parent (Ingram & Hutchinson, 2000; Kirshenbaum, et al., 2004; Kline, et al., 1995; Sowell, Murdaugh, Addy, Moneyham, & Tavokoli, 2002; Stanwood, Cohn, Heiser, & Pugliese, 2007; Wesley, et al., 2000).

Not surprisingly, health care providers are quite influential in women's decisions. In research by Sowell and colleagues, HIV-positive women discussed their mistrust of the medical community and felt that doctors focused on medications and encouraged them not to have children (1997). Similarly, health providers may stigmatize women and question their decisions to carry pregnancies rather than terminate (Kirshenbaum, et al., 2004). Ko and Muecke found that AIDS care professionals fell into three main groups (2006): "pro-children," which revolved around concern for the welfare of the child; "conditional pro-choice," supportive of women's rights to have children but only if they had carefully considered the risks and made plans for childcare; and "pro-rights," focused on the rights of the couple and seeing HIV as just another a life challenge. These authors discuss the inherent power and authority in patient-provider relations, suggesting that health care providers can have a significant impact on their patients and their reproductive decisions.

For many HIV-positive women, personal factors also affect their childbearing decisions. Research has shown that HIV-positive women see having a baby as something generally positive in their lives (Sowell & Misener, 1997), as a “joy” (Wesley, et al., 2000), as a purpose in their lives (Ingram & Hutchinson, 2000; Kirshenbaum, et al., 2004), and as a reason to get off drugs, get their lives together, and get their own health in order (Sandelowski & Barroso, 2003b; Sanders, 2008; Sunderland, et al., 1992; Wesley, et al., 2000). A number of prior studies have identified the notion of “missed mothering” as an important factor in the decisions of WLHA to have children (Barnes & Murphy, 2009; Sanders, 2008). Missed mothering may occur in women who feel they did not do a good job with prior children, who had prior miscarriages, abortions, or sterilization, who had children who died, and women whose children had been taken away by a child protective agency or who had given up their children (Barnes & Murphy, 2009; Kirshenbaum, et al., 2004; Kisakye, et al., 2010; Kline, et al., 1995; Sanders, 2008; Sowell & Misener, 1997; Stanwood, et al., 2007). Other individuals may also influence women’s decision-making regarding childbearing, including male partners, mothers and other women (De La Cruz, et al., 2010; Kline, et al., 1995; Nobrega, et al., 2007; Sowell & Misener, 1997). A woman’s relationship with God, or her personal spirituality has also been shown to be an important factor in childbearing (Kirshenbaum, et al., 2004; Sowell & Misener, 1997; Sunderland, et al., 1992).

Women living with HIV may see having children as an important way to fulfill their social roles as women, particularly when they do not have other socially-valued identities. In work by Sowell and colleagues, women reported feeling that having a baby made their lives as women complete (1997). Wesley and colleagues found that being a mother fulfilled an important role; one woman stated that “giving birth is the only way to be a real woman” (2000:297). Other studies have shown similar results (Chen, et al., 2001; Harries et al., 2007; Ingram & Hutchinson, 2000; Sandelowski & Barroso, 2003a; Sanders, 2008). Bedimo-Rung and colleagues explained that “within minority communities where poverty, lack of education and unemployment offer few alternatives to pregnancy, great value is placed on a woman’s fertility, and pregnancy is often seen as a source of self-esteem and social respect” (2005:1409). Barnes and Murphy found that women who had other roles that gave them respect or social status were less likely to want (more) children (2009).

Another major consideration is social stigma. In work in the Southeastern U.S., Ingram and Hutchinson found that “society expects women to be mothers, yet at the same time, it negatively judges HIV-positive women who choose to become pregnant or refuse to abort an existing pregnancy” (2000:122). In a qualitative study of HIV-positive women Barnes and Murphy similarly found that HIV-positive women faced a substantial dilemma (2009:481). Craft and colleagues found that HIV-positive women who were more influenced by societal factors were less likely to choose to become pregnant (2007). Sanders also found that pregnant WLHA often did not disclose their HIV status to other friends who were pregnant, for fear of being stigmatized (2008). Thus, actual and potential stigmatization may be important factors in the reproductive decisions that women living with HIV make.

In existing work on childbearing among women living with HIV/AIDS, both quantitative and qualitative research shows that many WLHA continue to want children despite their HIV status. Further, in the current era of HAART and prevention of mother-to-child transmission (PMTCT), it is very possible for them to have healthy children. Little of this research, however, purposefully integrates social theories that may help us understand the dynamics of decision-making. Nor does it specifically examine the individual situations within which women make these decisions. The purpose of this study was to examine how women living with HIV make decisions about childbearing, and to examine the role of social stigma in that process.

Methods

Study Design

For this study, a qualitative research methodology was used, including in-depth interviews and participant observation. The study was based in grounded theory methodology, which utilizes constant comparisons, progressive coding and analysis, and memoing, and which has the flexibility to build upon early findings. Situational analysis (Clarke, 2005) was also used to consider not only the participants' own experiences, but the "situations" in which their lives are lived. This includes not only personal experiences, but also the various actors, societal discourses, and overarching discourse and debates about the issue.

Data Collection

Participants were recruited in the San Francisco Bay Area. Eligible participants had to have received an HIV diagnosis at least one year prior to participation, be biologically female, at least 18 years of age, and English-speaking. They had to have been pregnant at least once since their HIV diagnosis, including if they were diagnosed with HIV while pregnant. Currently pregnant women were excluded. These criteria were self-reported by the women.

Recruitment efforts consisted mainly of posting flyers about the study in public areas in or near a variety of clinical and social services agencies around the Bay Area. These included San Francisco General Hospital’s HIV clinic and family health clinic; the University of California, San Francisco (UCSF) Women’s HIV Program; the Tenderloin Clinical Research Center; Oakland’s Women Organized to Respond to Life-threatening Diseases (WORLD); Glide Memorial Church; San Francisco Department of Public Health’s Tom Waddell Clinic and Southeast Health Center; and the San Francisco Women’s Building. In addition, flyers were sent to the San Francisco AIDS Foundation. Women interested in the study called the investigators, and were screened for eligibility. If eligible, the participant and investigator set an appointment. Most interviews were conducted in study rooms at the San Francisco Public Library or the UCSF library. One woman chose to be interviewed in a busy café. Two others were interviewed in their offices.

At the meeting, participants completed the consent process and a brief demographic form including date of diagnosis, childbearing history, and health status. After this, an in-depth interview was conducted. The interview guide included questions about history of HIV diagnosis, desire for children, a more in-depth discussion of history of pregnancy since diagnosis, and a discussion of how the decisions were made, including people who may have influenced those decisions. Based on the grounded theory methodology, later interviews took into consideration issues and trends gleaned from coding earlier interviews. This largely had to do with the overall situation of women's lives. The interviews were audio recorded with permission and the investigator also took notes. One woman changed her mind about being recorded so the investigator only took notes. Most interviews lasted 45-60 minutes. After each interview, the investigator recorded field notes. Data were collected between October 2009 and February 2010, and between October 2012 and February 2013.

Protection of Human Subjects

The study protocol was approved by the Committee on Human Research at the University of California, San Francisco. Participants received information about the purpose of the study and were informed that participation was completely voluntary and would not affect the health care services they received at any of the clinics. They were also told that some of the issues might be sensitive and that they could take a break or withdraw from the study at any time. While no women withdrew from the study, one asked to change the subject as the conversation veered toward domestic violence in her life. Participants were also assured of confidentiality. Participants signed an informed consent form and at the conclusion of the interview received $25 in cash or as a gift card as a token of the investigators' appreciation.

Sample

Thirty-six women called the information phone number to inquire about study participation. Eight were not eligible; six were unreachable upon call-back; and two did not show up at scheduled interviews and were unable to reschedule. Twenty women living with HIV participated in in-depth interviews. Their average age was 46 years and the most were African American (Table 1). Many were long-term survivors of HIV, two having been diagnosed in the late 1980s. Four participants had been diagnosed within the past ten years. Almost two-thirds of the participants had ever been told that they had progressed to AIDS, and most of these were currently taking HIV medications. One participant had a Master's degree and another had graduated from college, but most others had only a high-school or 11th grade education. Of these 20 women, eight were diagnosed with HIV when they were pregnant. Among those who became pregnant after their HIV diagnosis, only one had actively planned her pregnancy.

INSERT TABLE 1 ABOUT HERE

Data Analysis

The investigators coded the text using the open coding technique. Ideas and themes were recorded, and codes with similarities were categorized into concepts or themes, as the basis for the construction of a conceptual framework for the study. This enabled the investigators to begin theorizing about the factors and situational elements that influence an HIV-positive woman's decision about childbearing.

RESULTS

Chaos, Instability and Trauma

One of the overarching themes in these data was the chaotic, unstable, and often traumatic situations within which these women were coping with HIV and dealing with pregnancies. All of the women had experienced one or more of the following: homelessness, poverty/hunger, drug abuse, mental illness, incarceration, domestic violence, sexual violence, involvement of child protective services, and/or involvement in a transactional sexual relationship (e.g., for money, food, shelter, drugs). In some cases, these situations were directly related to their HIV infection, and for some, their pregnancies as well. Barbara[1] described the situation that led to an unplanned pregnancy:

> During last year [I] was homeless, living in my car. I did have a boyfriend who was… there, but not in terms of anything that you would want to be a boyfriend…. And I got pregnant. So when I went to the doctor I thought it was just because I was stressed, really stressed out because I was I was homeless. I was living in a car….And I have mental health [issues], so I had some bipolar hospitalizations and some manias that really just took over my life.

For this woman, her homelessness and mental health issues were substantially more salient than the HIV or the possibility of pregnancy. It was unclear whether she made a conscious decision to have unprotected sex, whether she did not have enough money for contraception, or whether it just did not occur to her that she might get pregnant given her life at the time. She did then decide to continue with the pregnancy, but it was not the situation she had hoped for in terms of having a baby: "I was like, 'This is not the person I would choose to ever raise a

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[1] All names are pseudonyms.

child with, but if I'm pregnant… I'm gonna have the baby.'" The instability in this woman's life made it difficult for her to plan for what she actually wanted in life, or to protect her own health.

Over half of the women in this study had a history of drug and/or alcohol addiction, which also contributed to and/or was a manifestation of the instability in their lives:

> This guy… goes out and buys me some crack for my birthday, and that was the end of my… everything. I fell apart again…. And I got pregnant. And we had no money… we were using…. And I remember calling several places because I did want to get checked…. I sat in the payphone and I remember trying to call and I couldn't get the right information. I had no medical coverage. I couldn't get any help. It wasn't as easy as I thought it was going to be…. I never got any kind of care…. And we hardly had anything to eat…. We used to beg people for food. I remember going in trash cans looking for food….

For Caroline, dealing with both the unplanned pregnancy and her HIV ultimately took a backseat to her daily survival efforts. She did attempt to get help but, perhaps because of cognitive lapses due to her drug use or lack of easily accessible services for pregnant women with HIV, was unable to follow through. While this is an extreme situation, it shows what some women face while pregnant. The multitude of issues in Caroline's life – HIV, drug use, lack of food, lack of health care for herself or the baby – certainly contributed to the unplanned pregnancy, and likely contributed to the baby ultimately dying before birth.

Other participants in the study also experienced varying degrees of instability and trauma in their lives. For example, one woman's two young children were killed by her own mother; two women ran away from home at young ages and ended up involved in drugs and prostitution; two women had been sexually abused or raped; another four had experienced violence from their intimate partners. For some of the women, the HIV diagnosis itself seems to have contributed to this chaos while for others, HIV was just one more issue to deal with and often less urgent than others.

Although all of the women had chaotic or traumatic experiences in their past, a number of them appeared to have found ways to move on. Karen, a 43-year old African American woman, explained a long history of domestic violence, homelessness, incarceration, and drug rehab programs. Finally, having a stable housing situation had enabled her to take control of her life and make significant changes. At the time of the interview, Karen was living with her mother, partner and children, and continuing to participate in drug rehab. For most of the women in this study, finding any source of stability amidst chaos in their lives seemed to help them be able to take more control of their lives.

Missed Mothering

The experience of "missed mothering" (Barnes & Murphy, 2009; Sanders, 2008) may lead a woman to decide to have a child in circumstances when she otherwise might not. Many of the women in the current study had the experience of missed mothering caused by a variety of situations.

Caroline described her second pregnancy when she was HIV-positive: “The way I calculated was, when I had the baby I was 8 months pregnant…. I thought everything was fine…. [T]hen when they came back, they couldn’t find the heart beat. So I had to deliver the baby dead.” Caroline also left her first baby, who was HIV-positive, in the hospital and does not know what happened to him. Interviewed at age 50, when she can no longer have children, she feels shame for leaving the first child, sadness about the death of her second child, and a deep sense of regret and loss for never having had a child later, once her life had settled down somewhat.

Many of the participants in this study had lost prior children through Child Protective Services (CPS) or to family members who raised them when they were unable to. Tanya explained how this influenced her when she became pregnant after her HIV diagnosis:

> My other three kids, I didn’t actually raise. They were raised by family members because I’m also an ex-drug addict and alcoholic…. And I really wanted this baby…. Because I never had a chance to raise my other ones. And I did want to be a mom.

For Tanya, having missed out on the chance to raise her previous children made her want to continue a pregnancy that was unplanned, similar to many other women in the study. For Irene, however, missed mothering had the opposite effect: “[S]o I was just like, ‘Why do I keep… having kids to put them in the system,’ you know?.... It was enough kids and then it was like I’m not raising any of them, so…” While Tanya had reached a more stable point in her life that made her feel capable of raising a child herself, Irene knew that she still would not be able to raise the child, and so she decided very consciously not to continue with the pregnancy.

A subset of participants had had prior abortions or miscarriages, which also affected their decisions about whether to plan or continue pregnancies after their HIV diagnoses. Anne, who had a prior abortion at age 14, explained:

> I chose to terminate the pregnancy. And it's just a decision that's hard to me…. I always knew that at some point I wanted to have a child…. But when I was diagnosed it was just really a feeling like, 'No one's ever gonna want to have a baby with me.'

Anne, who also had two miscarriages as an adult, was very much aware of the effect that her HIV-positive status might have on her ability to have children later in life. At the time of the interview, 11 years after her diagnosis, she was actively working with her partner and doctor to get pregnant because she consciously wanted a child. For Laura, who had experienced multiple miscarriages, giving up on having a baby after her diagnosis was not quite so difficult as she already had two children: "I was really trying to have that one, and I lost it, so then I said, 'This wasn't meant to be so let's not do this right now.'" Having already had the opportunity to raise children made it somewhat easier for her to move on with her life after two miscarriages post-HIV diagnosis, even though both unplanned pregnancies were wanted.

Among this group of women, being a mother was an important part of their lives. Those who had children described themselves as "blessed" and said that having children was “a joy”. Even the few women who had not mothered their own children expressed a sense of pride in at least having borne children. For the one woman who had never had a child, however, missed motherhood was a source of pain, and she actively strove to have a child despite her concern about possible HIV transmission to the child and her partner. Jamie described her HIV-positive friend’s situation:

> I can kind of see why she’d want to have children. See I already have a child… so like for me, that desire has been fulfilled. So I can see how women who, let’s say they never had a child, they get the diagnosis, it’s like, ‘Oh does that, that mean they shouldn’t be allowed to have life?’ That’s not right.

While she was adamant that she would never choose to become pregnant knowing that she had HIV, and even expressed some concern about other women doing it, Jamie believed that women should have a choice, and seemed to see motherhood as trumping other concerns.

For women who had never had the opportunity to raise children, carrying a pregnancy to term while HIV-positive helped fulfill a perceived gap in their lives, and was truly important for them. In addition, motherhood is a valued identity in most social worlds and for these women, many of whom had chaotic and traumatic pasts, this valued identity may have been particularly important to them. Almost all of these women were aware of medications that significantly reduce the chance of transmission to the baby, and were willing to take those medications, even if they went off of them after the child was born: “When I got pregnant, you know, I wanted to make sure I had a healthy child, so I took medicine. But after that, that was it." Once they had decided to continue with the pregnancy, they were committed to making sure the baby did not get HIV.

Stigma

In the context of their chaotic lives, many of the women in this study had experienced overt stigmatization due to their HIV status, or related to being pregnant while HIV-positive. In some cases these were clear examples of stigmatization with power differentials obviously in play. In other cases, women lost friends or had other negative experiences that affected them deeply.

Rachel's HIV status was disclosed publicly without her consent, and she explained the impact that it had on her:

> I would have went to my grave and never told anyone…. It's horrifying, it's ridiculed. Everywhere I went all the people were like 'You're the lady with AIDS.'… I was newly diagnosed. I stayed in my house for maybe six months. I had to be under psychiatric treatment. It was really bad…. It kinda destroyed my life for a long time.

She further explained that people immediately applied negative stereotypes to her, assuming that she became infected through drug use or commercial sex work, without actually knowing her history. "You know, only dope fiends get AIDS, hookers. I wasn't neither. I was a wife all my life." Rachel's experience of stigmatization extended to her own family, who forced her to eat off of paper plates at Thanksgiving dinner, and who disinfected the bathroom after each time that she used it. And while she says that she no longer cares what people think about her, she had recently felt humiliated and chose not to disclose her HIV status to someone who spoke negatively about people with AIDS.

Other women had similar experiences:

> It was my best friend's mother. She had made a comment about, you know 'these people with AIDS deserve it,' you know 'they've done something that they shouldn't have been doing, and now they've got AIDS'… And she was a Christian woman… so that kind of hurt. It was like, OK, but if you only knew…. So that made me then retreat more, 'cause if somebody whose, who professes to love God, and then supposedly this person is all accepting, and will tell you like that…

Barbara had not disclosed her HIV status to her friend's mother, and has not forgotten the pain of this comment even many years later. In contrast, Laura tried to see the benefit of the responses that she got from people upon her disclosure: "I don't care, great, because… you know, think people are your friends or whatever and they're not really, so, that's good…. I was glad I learned it now instead of later." Laura eventually disclosed to her church: "And so I made it very clear to them at my church, you know, if me being positive affects the way you look at me and treat me, then I don't need you or want you in my life." The stigmatizing reactions, though hurtful, helped both of these women distinguish between who would support them and who would not, and allowed them to distance themselves from people with negative attitudes.

Even before disclosing their HIV-positive status, many women anticipated stigmatization, leading them to decide not to disclose. Jamie, diagnosed in 2009, explained how this affected her life:

> I know a lot of people, so like when I shop at like Project Open Hand[2] I use alias names…. I try not to let a lot of people know, yeah. I live in a world where I rip the labels off the food so that people don't see the symbol and get suspicious. None of my family knows.

She had such great concern about potential stigmatization from other people that she chose to live in what she describes as a "silent hell" rather than disclose her status and open herself up to potential negative attitudes and stigmatization from others.

Mary explained her moral dilemma regarding disclosure. Upon diagnosis:

> I was like, 'How am I going to tell my people? My friends? Or someone else I get involved with?' I like to be honest with a person…. And it's like, it's hard you know, because the rejection that you get when people find out you're HIV…. They look at you a lot different.

Other participants expressed similar sentiments. One woman even explained that she knew she would be stigmatized because she had had similar feelings toward HIV-positive people before being diagnosed herself.

Some women also had stigmatizing experiences related to having children. One woman described that when she was pregnant:

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[2] Project Open Hand is a non-profit organization in San Francisco that was founded to provide healthy meals to people living with AIDS. It now also serves the elderly and people with critical illnesses.

> One of [the nurse practitioners] told me ‘Well, you know, if God was here, he’d probably strike you to hell already’…. And it devastated me. After I went home I sat, I sat down and all I could do was just cry. I cried, I cried, I cried, I cried, I cried, I cried, I cried.

Although she continued with her pregnancy, the response of just one health care provider made a lasting impression on her. The fact that the stigmatizer was someone of respect in a position of power may have made the effect more profound.

Caroline described the reactions that she got when she discussed wanting to get pregnant as a woman living with HIV:

> My doctor thought I was crazy. So did the gynecologist. So did anyone else I spoke to. They all told me I was crazy…. My mom told me to erase it out of my head…. And it was always the same thing: I was selfish. ‘Cause, what if something happened to me?

Although some of this stigma may have been due to the other issues in her life, she believed that it was largely because of her HIV status, and related concerns about possible transmission to the baby, her own life expectancy, and her history of homelessness and drug use.

Olivia described the role of health care providers in her subsequent abortion:

> The people had pretty much brainwashed me… they just reared into me, telling me… ‘Right now it’s not a good time…, you ain’t got a place to live, you ain’t got no food, you ain’t got no job, you ain’t got this, you ain’t got that.’ So I took a look at all that and just decided to have an abortion…. [I]t

> hurt, you know, because I wanted to keep it but I had to take a look at the situation and say, oh okay, that, that was right, yeah, okay. That's true, though, but let me make that decision, you know, it was just like a rushed thing and… and I said okay, I'll have an abortion, I can't do anything else.

She felt that she had not had the opportunity to thoroughly consider her options and that, in the end, the decision had not really been her own. As a result, Olivia felt "hateful, mad, disgusted, emotionally disturbed" about essentially having been coerced into aborting a child that she wanted to keep. Although she may ultimately have decided on her own to have an abortion, she felt resentful about how the "decision" had come about. Of the three women in the study who experienced abortion coercion that was perceived as due to HIV, only Olivia actually had an abortion. On the other hand, one woman who did want an abortion was turned down for one, she believes due to her HIV status.

Jamie believed that stigma and stereotypes led directly to an adverse outcome during her daughter's birth after nurses saw HIV listed in her medical chart:

> When I got to the hospital I noticed the way I was being treated by the nurses when they were triaging me, it was a form of prejudice because I know the experience of when I went with my son [before she had HIV]…. They looked at my, my chart and they saw what my situation is and I know that they treated me differently because I can tell…. [S]o when I was in there in the triage I kept saying 'Look I'm in labor, I need to be admitted,' and they wouldn't…. Next thing you know they bum rushed the door open,

> they pushed me on a gurney, ripped my nightgown off me and spray iodine over my stomach, choked me out, put me to sleep, and I wake up, and they say my daughter lost oxygen…. My daughter now has cerebral palsy…. I believe the way they treated me in the triage aspect, they took too long and they weren't taking me serious…. Because the stereotype is…. HIV, oh this f*****g girl is probably a junkie, she's probably hooking, a ho, she don't know what she's talking about, she's not in labor, she don't know nothing.'…. I remember the way that lady talked to me… She wasn't taking me seriously, she was having her own biased opinion.

Although it is impossible to know exactly what happened, Jamie firmly believed that her HIV and the associated stereotypes led the health care providers to ignore her and her knowledge about her own body and pregnancy. In this situation, stigmatization of the mother may have led directly to 'reduced life chances' (Goffman, 1963) for her child. Similarly, a woman who was incarcerated believed that stigma related to her HIV made it difficult to get surgery that she required for ovarian cysts.

The negative attitudes and stigmatization experienced as a result of their HIV status or being pregnant and HIV-positive had substantial negative consequences for some of the participants. In addition to seriously compromised health care discussed above, a number of women reported self-isolation as one consequence. Sarah described her perceptions of public opinion about HIV-positive women and the effect on her:

> That we have the cooties. And we just got germs. That, that we're just some nasty, dirty people or something…. That's why I just keep to myself…. I have trust issues because of this happening to me. So I hold my guard up with people.

Internalized stigma, or believing the negative stereotypes about themselves, is another consequence of stigma. Jamie described her initial reaction upon diagnosis with HIV: "[W]ho's ever going to want to be with me anyways? I'm gross, I'm contaminated, I'm poison, I'm a ticking time bomb." As in the case described earlier, her reaction may have been due to her own ideas about people living with HIV before she was herself diagnosed. For these women, isolation and internalization of stigma can hinder disclosure, keep women from accessing services and support networks, and could lead to negative health consequences.

Resistance Against Stigma

Although most of the women had experienced some form of negativity or stigmatization since their HIV diagnosis, many of them resisted in a variety of ways. Among those who had negative experiences with health care providers, Gabrielle explained that "I had to tell a few of them, you know, 'I don't give a f*** what you think about what I'm doing. This is my body, this is my baby, and this is what I'm doing!'" Gabrielle reported the nurse to her supervisor: "I made a big deal about it because it needed to be done, because she couldn't, you can't do that…. That's not job-like. Let along humanly like…. But yeah, she um, she didn't last there too long after that." Other women who had had similar experiences at the same clinic chose to get their prenatal care at other sites. Similarly, one woman discussed a physician who encouraged her to abort her pregnancy because of her HIV, and the patient chose to switch providers. These women resisted the stigmatization and poor treatment from health care providers despite their own marginalization.

Many of the participants also sought out or created more positive social worlds for themselves. Some of them gave up friendships with people who were not supportive of their decisions. Others attended support groups for HIV-positive women, seeking to surround themselves with people who would understand their situation and not engage in negativity. Gabrielle described her support group: "It's nothing but women, just beautiful beautiful women…. And I mean, that's our hang out. That's where we can dump…. It makes it easier because you got somewhere and you have some people to talk to." And Anne chose to work for a community organization focusing on HIV-positive women:

> This is the first time I've worked with all women, most of them living positive, you know, so it is a *different* environment and it's an *empowering* environment…. Whatever I come in with, whatever my issues are, there's somebody in here that's gonna relate to that and be supportive to that.

In choosing to work with this organization long-term, she has surrounded herself with a supportive network of people. Olivia discussed the fact that, in her drug rehab program for people living with HIV, she is able to relate to others in the group, and they are supportive of whatever she is dealing with at a particular time: "Surrounding myself around people that's HIV…. It helps me a lot, it chills me down." These women have found ways to resist stigmatization and the negativity that often surrounds living with HIV, through what Rabinow (1992) calls biosociality – choosing to spend time with others because of embodied commonalities.

Providers

As described above, a number of women had negative, even stigmatizing experiences with health care providers, either based on their HIV-positive status, or as related to pregnancy. Patient-provider interactions are fraught with power differentials, as providers are presumed to know more than patients and because they act as gatekeepers to care. Some participants who had negative experiences exerted their own power by changing providers, or by reporting the provider to a supervisor. In most cases, the negative experiences either occurred with providers who were not HIV specialists (e.g., emergency room personnel), occurred early in the epidemic at a time when less was known about the disease and when there were many fewer HIV specialists, or occurred with interns who may not have intended to go into HIV specialty care and thus may have had their own biases about women living with HIV.

Most participants in this study were currently receiving their health care services from HIV specialty providers and were generally very pleased with the care: “I have a team of people that are really there for me…. I mean, no matter if I call day, night, my doctors and the social workers, the nurses, um, the case managers, they’re just ‘Bam! What can we do? We’re here for you.’” For many of the women, some of whom were in denial after their diagnosis, pregnancy was a reason to seek specialized HIV care. Anne explained the difference:

> I’ve heard people whose doctors have told them, ‘Why would you bring a child here’ and ‘You’re gonna be sick’ or ‘You know that you’re dying.’ I’ve heard that before…. I haven’t personally had that experience because I had a very good relationship with my doctors… They’re like, ‘No matter what… we’re gonna keep you healthy. Your baby’s gonna be healthy.’

For Anne, and others, the fact that the providers focused on *her* health and on her as a *person*, rather than solely on the fetus, was essential for providing quality care. This also enabled the establishment of a strong patient-provider relationship, and an important sense of trust.

Many of the participants suggested that any HIV-positive woman who becomes pregnant should go to specialized HIV services for women: “Get in with someone that specializes in women with HIV…. Because [program name] helped me through it all. Because they could answer any questions I had about HIV and the transmission and, um, what to look for.” Another simply said: “I would not have been able to do it if it wasn’t for [list of staff at women’s HIV clinic].” Sarah and others felt that these health care providers went the extra step to help them in areas of their lives beyond just health:

> That's the only doctor I trust. That's the only doctor I love. I really love her. And she knows everything about me…. Because we talk about everything. Even my lifestyle. She helped me. I used to do drugs. I used to do crack. She helped me with that. She put me in a 21-day detox and it helped. It worked…. So I stopped you know, I changed my life a lot…. I wanted to commit suicide, to tell you the truth…. That’s how hard I couldn’t deal with

> it at first. And then, until I got hooked up with [nurse practitioner's name], my doctor. I got hooked up with their women's program and I've been hooked up with them ever since and they've been helping me deal with it, physically and mentally.

Another woman described an experience in which her nurse wrote a letter to a housing unit to help get her a room, so that she could be off the streets. For a woman who has been stigmatized and or treated differently because of her HIV and possibly for other reasons as well, having a health care provider who supports her and goes out of her/his way can make a significant difference in her life trajectory.

> All of them they're great…. They've stuck with me no matter what…. [Social worker] went to bat for me…. They done see me go through so many changes, my addictions, then seeing me and then them not seeing me. Having a baby and they being there. Me catching pneumonia, they come in to visit me. You know, they make sure I'm alright…

Danielle explained how her doctor reacted after she had a baby: He "congratulated me so, he said 'I am so proud of you for what you've come through.' Because he knew when I came to his, his office I was loaded, I was loaded on crack." She first went to this particular doctor when she was pregnant and using drugs, but with his help and encouragement, she was able to get off of the drugs and have a healthy baby. The simple fact of telling her that he was proud of her was very significant for this woman. Other women described the relationships more simply: "These people, they are like my family." "If I saw her on the street today I would run up and hug her." "See they don't want me to die, and um, and that's kinda cool to know that people do love me." For these HIV-positive women, providers who demonstrated that they cared and valued them as individuals really mattered. A few reported switching clinics to stay with particular providers, demonstrating the importance of their relationships.

Choice

Reproductive rights discourses in the United States focus on a woman's right to make decisions about her reproduction, though most often the discussion centers around the right to have an abortion, rather than the right to choose to have a child. For HIV-positive women, however, particularly those experiencing chaos and instability, rights and choice may take on different meanings. Most of the women had at least one unplanned pregnancy since their HIV diagnoses. Although some made the decision to have unprotected sex, others had less choice in the matter. They may have been raped, involved in commercial sex work, or involved in a relationship for food, shelter and/or protection. In addition, a number of them had partners who lied about their own HIV status, denying the woman an informed choice about whether or not to have unprotected sex. Once these women found themselves pregnant, their situations may have made it difficult for them to have a real choice about what to do.

Barbara, who had planned her pregnancy but found out at seven months that she was HIV-positive explained her situation. "One of two things could've happened. I couldn't have an abortion, I was too far along. I wasn't gonna give my child up for adoption, so that meant having the child." Although this woman talked about her “options”, when she explained them it became clear that they were not really options for her in that situation. She went on to discuss her choice to have a tubal ligation:

> When I went back to my doctor for a follow-up appointment, I told her my husband and I had discussed it and I told her I wanted to have my tubes tied… because…I didn’t wanna have another child that was positive…. And so that, really, for a lack of a better…that was my ‘informed decision’ that I made…. Now I know I can have a child who’s negative, and so I regret it, I do regret, you know, making that decision.

She continued:

> But I can say, I honestly thought I would’ve had an abortion…. But I would have regretted it…. I would’ve just had my one [son from before her HIV diagnosis]. And she’s brought so much to my life. So I’m thankful that I was so far along that I couldn’t have an abortion. And that I have her in my life.

Barbara was diagnosed in 1993, before antiretroviral medications that substantially reduce risk of transmission. She was offered AZT, but opted only to take it during delivery rather than the rest of her pregnancy because her doctor could not explain the potential side effects on her or her baby. The shock of both her and her new daughter both being diagnosed with HIV may have resulted in what she ironically called “an informed decision.” She had to make a series of “choices” under stress and lacking information and options.

For others, abortion was not an option because of religious or other personal beliefs. Gabrielle explained that:

> I had had my fill of abortions when I was younger, and I'm I'm older now, and that that's just not an option. The only option that I did have was after I have this baby I'm gonna get my tubes tied, and that'll be the end of that. And that's what I did. Yeah, so, that's a lot to carry.

In contrast to Barbara, Gabrielle did not end up regretting the tubal ligation, but had a great deal of difficulty making the decision and carrying the baby to term.

As described above, a few women felt that providers tried to coerce them to have an abortion: "They blackmailed me there, they tried to tell me, well they influenced me to have an abortion…. They was telling me I'm in no condition, my health was bad." Olivia felt that she had little choice in the decision.

Other participants similarly lacked real choices in their childbearing. Some knew they were HIV-positive, but did not recognize the signs of pregnancy until it was too late to have an abortion, according to their own definition of "too late". Two women specifically mentioned the anti-abortion discourse, but did not directly relate it to their decisions to continue with their pregnancies. Even if a woman had considered abortion as an option, getting an abortion requires a conscious choice followed by actively seeking out specialized services. For some of the women, the lack of stability in their lives may have led them to the more passive "choice" of continuing with the pregnancy.

One woman was actively planning to get pregnant. She was educated about HIV and about the efficacy of ARVs in reducing mother-to-child transmission, and was in discussion with her HIV-negative partner and her physician about the safest way to get pregnant. This woman was making an informed choice to get pregnant as a woman living with HIV. Although she was the only participant in this particular situation, among almost all of the participants there was a clear relationship between the level of stability in a woman's life, and her ability to make a real choice about her reproductive health.

DISCUSSION

The 20 women who participated in this study had a wide range of experiences, not only related to their reproductive decisions, but also to the situations in which they lived. However, a number of themes stood out.

Most of the women in this study had lived unstable lives from a young age, including running away from home, growing up in households with violence and/or drugs, and engaging in early sexual activity. Undoubtedly, the instability derived from these factors and social marginalization formed a social context that put women more at risk of acquiring HIV, and also put them at risk of unplanned and possibly unwanted pregnancies. To a large extent, this instability continued into their adult years, and may have been related to a lack of power at both the individual and structural level.

In most parts of the world, women lack the degree of social, economic, and political power that men have, and this puts them at risk for HIV and other negative life consequences, in part because it leads to a lack of control over their sexuality (Gupta, 2002). Research has shown the effect of power differentials in intimate relationships on safer sex practices (Pulerwitz, Amaro, De Jong, Gortmaker, & Rudd, 2002). Further, women may be at greater risk for experiencing intimate partner violence in their relationships. The lack of economic power, often due to lack of education or larger structural factors, can make them dependent on their partners, and unable to leave violent relationships. Women who lack power in their social worlds are more likely to engage in transactional sex, which also puts them at risk for drug use. They may also use drugs to numb themselves to unwanted sex (Yahne, Miller, Irvin-Vitela, & Tonigan, 2002).

Such struggles were characteristic of many of the women in this study. One described being dropped off on a street corner in New York City with no money and no place to go. As she explained, a man "took me under his wing." This man ended up being a pimp, forced her to engage in commercial sex work, physically abused her, and got her addicted to injection drugs. Through this relationship she was infected with HIV and became pregnant with a baby who also had HIV. Once the baby was born, the man deserted her. Later, when she was unable to get into a drug rehab program, she had to threaten to commit suicide to get help. While this is an extreme example, it clearly demonstrates how lack of power in intimate relationships and structural forces can put women at risk for negative health consequences. Similar situations of instability and trauma have been identified among other groups of women with HIV, either leading to infection or as a result of the disease itself (Lather & Smithies, 1997).

Power differentials may also put women at risk of stigmatization, and can be closely intertwined with ideas of stratified reproduction, or who should and should not reproduce, who can be a good mother, etc. (Colen, 1995; Collins, 1999; Haraway, 1999). Building on earlier sociological theory, Parker and Aggleton advanced stigma theory vis-à-vis power, explaining that:

> Stigma and stigmatization function, quite literally, at the point of intersection between *culture, power* and *difference* – and it is only by exploring the relationships between these different categories that it becomes possible to understand stigma and stigmatization not merely as an isolated phenomenon, or expressions of individual attitudes or of cultures values, but as central to the constitution of the social order (2003:17).

Parker and Aggleton thus see power differentials as a *cause* of stigma, and further argue that stigmatization serves as a tool to reproduce existing and unequal power structures within social systems. They additionally acknowledge the "intensifying interaction between multiple forms of inequality and exclusion" (Parker & Aggleton, 2003:19). This conceptualization of stigma is particularly relevant to participants in this study, and we can trace the culture, power and difference.

Cultural understandings in the U.S. about women living with HIV/AIDS revolve around the ideas of sexual promiscuity and drugs, and stereotypes regarding the "types" of people who become infected with the disease, such as racial minorities. These stereotypes become embedded in cultural understanding through, for example, media portrayals of prostitutes as fueling the AIDS epidemic or through abstinence-only sex education in schools. Numerous participants discussed what “people” think about women living with HIV – that they got it through sex or drugs; that they are dirty or contaminated; that they deserved it for behaving in a certain way. In some cases, participants were aware of these cultural meanings because they were opinions that they had themselves held prior to diagnosis. These social creations are strengthened and perpetuated through continued use in interactions.

Power, is clearly a major factor in the lives of these participants. Power differentials based on gender, as discussed previously, put them at risk of contracting HIV, but also made them vulnerable to those with other forms of power, for example, physicians, nurses, parents, or others. Most of the women experienced additional power differentials related to both race and class, as most were women of color and many had experienced poverty and/or homelessness at various points in their lives.

Finally, *difference* is an essential component of stigmatization. Robert Crawford explained that the increasing focus on health in the United States in recent decades has significant moral undertones, and protecting one’s health is seen as each person’s individual responsibility and a way of demonstrating valued traits such as self-control. HIV/AIDS has always had moral meanings, in part because of its link to already stigmatized identities such as drug user or prostitute, but also because of the blame associated with not adequately protecting one’s health and allowing oneself to become infected. By creating an unhealthy “other” who is to blame for becoming infected with HIV/AIDS, those who are uninfected can establish boundaries that distinguish “us” from “them”.

Thus HIV is not just a health condition, it is a mark of difference that has been used to separate and categorize people.

The *cultural* meanings of HIV and their embeddedness in society, the *power* differentials that poor women of color living with HIV experience at both the individual and structural levels, and the moral *difference* that HIV implies come together in a dialectically synthetic manner to create the stigmatization that many of the women in this study experienced. Those who are uninfected, with greater social power may use HIV as another way to differentiate themselves from people who are already deemed lesser for other reasons such as race and class. Stereotypes of people with HIV as unhealthy and to blame for their own illness are perpetuated through cultural institutions and become a form of truth used to justify unequal social relations and their consequences.

Some of the women in this study experienced stigmatization specifically related to their pregnancies post-HIV diagnosis, as has been found in prior research (Barnes & Murphy, 2009; Craft, et al., 2007; Kirshenbaum, et al., 2004). Powerful figures in their lives – physicians, nurses, parents – told them that they should not continue these pregnancies and encouraged them to abort. And while some of this many have been related to concern over the woman's HIV status and possible transmission to the baby, at least two women were told by providers that they should not have babies because they were poor and homeless. Rather than trying to help the women overcome these barriers in their lives, these providers encouraged them not to have children at all. This rationalization is very much in line with the idea of stratified reproduction, which suggests that differential value is placed upon childbearing, depending on race, class and other hierarchies (Colen, 1995; Collins, 1999). As Haraway discusses, reproduction is political because it generates future social worlds (1999). By discouraging these HIV-positive women from having children, in part because they were poor, providers were stigmatizing the women and actively working to influence future social worlds.

The stigmatization that these women experienced can also become internalized, as described by the woman who was coerced into having an abortion. Being told over and over by her provider that she should not have a baby because she was poor led her to believe that this was actually true. She gave up her choice to have a baby that she wanted because she internalized the idea that she was not good enough, either to make the decision herself or to have the baby.

Conversely, most of the participants were currently getting care from specialized HIV clinics and providers, which in fact provided an important source of support. For these women who were in care, HIV served as a resource in terms of access not only to basic health care services, but also to case management, to social workers, and to support groups for women living with HIV. In addition, this specialized care served as the gateway to drug rehab programs and housing for some of the study participants. And while none had been happy about their original HIV diagnoses, some had come to see it as an asset in their lives. As Danielle explained, “I think the HIV is causing me to stay more stable than had I not had HIV. My life is depending on it.” Similar results have been found in prior research, particularly in work by Lather and Smithies (1997). In their study, Rita explains that "I'd probably be dead if it wasn't for HIV, as crazy as that sounds" (Lather & Smithies, 1997:135). For some women living with the disease, HIV can be a wake-up call that gets them to change some behaviors and focus more on their health. For others, it gives them access to services. Clearly, though, this is not the case for all women with HIV. It does, however, indicates the importance of engaging women in care as well as the unique and effective role of specialized HIV care services.

Conclusion

Among these 20 women, reproductive "decisions" were made in situations of chaos, instability, and stigmatization. Not having had a chance to mother their own children in the past was one of the most important factors in their decisions about childbearing. At the same time, stigmatization played a role. For some of the women, providers were sources of stigmatization, but for many others providers became part of the social support network that women created or moved into after their HIV diagnoses, and the contrast is stark. Women who had trusting, established relationships with their providers, usually in specialized HIV care settings, were more able to take control of their lives, get off drugs, and have wanted pregnancies and healthy children who they mothered. It is clear that health care providers, as part of women's social worlds, are important influences on patients' reproductive decisions, and should continue to work to support their patient's choices.

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Table 1: Sample Description (n=20)

Characteristic		Mean ± SD (or) # (%)
Age, years, mean ± SD, median		46 (range: 35-60)
Race / Ethnicity		
	Asian / Pacific Islander	1 (5%)
	African American / Black	12 (60%)
	Hispanic / Latina	0 (0%)
	Native American Indian	1 (5%)
	White (non-Hispanic)	4 (20%)
	More than one	2 (10%)
Education		
	11th grade or less	6 (32%)
	High school or GED	8 (42%)
	2-year college / AA degree / Tech school	3 (16%)
	College or higher	2 (11%)
Year diagnosed with HIV (mean)		1996 (range: 1986-2009)
Ever told had AIDS (yes)		10 (50%)
Antiretroviral Therapy Status		
	Never taken HIV medications	3 (17%)
	Started and stopped taking HIV medications	3 (17%)
	Currently taking HIV medications	12 (67%)
Has had children (yes)		19 (95%)
Pregnant when diagnosed with HIV (yes)		8 (40%)
Live Births (mean)		2.4 (range 0-6)

Live Births after HIV diagnosis (mean)	1 (range 0-3)
Children born HIV-positive (yes)	2 (13%)
Chaotic / Traumatic Experiences (yes)	
Homelessness	8 (40%)
Poverty / Hunger	4 (20%)
Drugs	12 (60%)
Trading Sex	7 (35%)
Physical Abuse	4 (20%)
Sexual Abuse	2 (10%)
Involvement of Child Protective Services	4 (20%)
Left a Child / Child Taken by CPS / Child Given to Relative	8 (40%)
Mental Health Issues	7 (35%)
Incarceration	5 (25%)

V. Conclusion / Implications

Although HIV/AIDS has been diagnosed for over 30 years and people from all strata of society have been affected, stigmatization related to the disease still exists, both in the United States and abroad. Such stigmatization has been shown to be a barrier to testing and treatment (Pulerwitz et al. 2010), which may ultimately increase both morbidity and mortality. Some women living with HIV have additionally faced stigmatization when choosing to bear children, based in part on fear of transmission to the baby. While some earlier research has identified reasons why women with HIV choose to bear children, there has been little work that examines the situations within which they make these decisions, or that focuses specifically on the role of stigma in those decisions.

The shared purpose of the three papers that constitute this dissertation is to examine factors that may influence reproductive decisions among HIV-positive women. In particular, what is the role of social stigma for them, and how do their social situations affect their decisions? Although the three papers vary in terms of both context and methodology, they bring together overarching analytics for understanding the situations of women living with HIV/AIDS: gender relations, race relations and social stigma. As this work shows, gender and race are central to the stigmatization that women living with HIV may experience, including that related to childbearing decisions.

Summary of the Research

The purpose of the research in this dissertation was to examine HIV-related stigmatization in the lives of women living with HIV, with a particular focus on its effects on reproduction. In each of the three studies, we see how stigma matters in women's lives.

Factors Associated with Pregnant Women's Anticipations and Experiences of HIV-related Stigma in Rural Kenya

In the first study, I conducted a secondary analysis of data from pregnant women in Kenya who did not know their HIV status. At baseline, women were interviewed regarding perceptions of stigma in the community toward people living with HIV, as well as the stigmatization that they would anticipate if they were diagnosed with HIV and their status were disclosed. Women who were older, had less education, whose husbands had other wives, and who perceived local community discrimination against people with HIV, had significantly greater adjusted odds of anticipating HIV stigma. Among the HIV-positive women who were also interviewed post-partum, one-third had not disclosed their HIV status to anyone, and over half reported experiencing some HIV-related stigma, particularly self-stigma. In addition, experiencing stigma was associated with depression at the post-partum interview, though it is unclear whether there is a cause-effect relationship and, if so, in what direction.

These results suggest that gender relations in this region of Kenya disempower women and make them highly susceptible to HIV-related stigma. Systems of polygyny, of valuing women mainly for their ability to bear children, and of denial of female inheritance and property ownership make women more dependent on men, reducing their ability to resist stigmatization. In particular, the system of polygyny may reduce women's ability to create supportive social networks among women if they are competing for husbands and for their own husband's attention and resources. Such situations make disclosure difficult, which can have a direct impact on an HIV-positive woman's health, as well as that of any children she may have.

As in the qualitative study, the results of this study suggest that women may anticipate more HIV-related stigma than they actually experience once they disclose their status. It may be that in some circumstances, being open about one's HIV can be a source of empowerment for women that helps them resist stigmatization. This is not to suggest, however, that women should be held responsible for resisting stigmatization, but rather that larger scale social change may be necessary to truly address this issue.

Although this study provided important insight into the HIV-related stigma that women anticipate and experience in Kenya, the study had limitations, including both convenience sampling and substantial loss to follow-up, which may have introduced a degree of selection bias into the results. From a sociological perspective, however, two non-statistical limitations may have been more important. First was the inability to analyze data related to religion, which may be a substantial cultural factor in this region. A number of different religions were reported in open-ended questions in the survey, and the research team did not have the ability to deal with all of them. Additional analysis of this data could be useful in potentially understanding the various religions' stances on issues such as gender relations, support for people living with HIV, and efforts to strengthen women's positions in the community. This information could be very useful in determining whether religion plays a cultural role in the dialectic of stigmatization in this region of Kenya. Another important limitation was the lack of detailed information on polygynous relationships. Over one-quarter of participants had husbands who had other wives, but the data do not include information about wife order, which could be extremely important for understanding both power within relationships as well as social networks and the idea of social capital among wives of the same husband. As we know from Parker and Aggleton, stigmatization occurs at the crossroads of power, culture and differences. In order to fully understand HIV-related stigma in a particular context, it would be useful to have a greater understanding of two cultural institutions – religion and polygynous marriage – that are potentially very relevant to HIV and support or stigmatization of people living with the disease.

The Association of Social Capital and HIV Stigma among Women Living with HIV/AIDS

In the second study, I examined the relationship between social capital and HIV stigma. Based on the idea that social capital is a form of power, and power differentials are an essential element of stigmatization, I hypothesized that women with more social capital would experience less stigmatization due to their relative power in their social worlds. Although the relationship was found to be statistically non-significant, the trend was in the hypothesized direction, controlling for race, education, and proxies for class (education and annual income). In addition, women who scored lower on the Value of Life factor of the social capital scale perceived significantly more HIV-related stigmatization overall, and also scored higher on the Negative Self-Image factor of the stigmatization scale.

Together these results suggest that women who are not valued or do not feel valued in their social worlds may be more likely to perceive stigmatization, and have negative perceptions about themselves, potentially internalizing the stigma with negative consequences. Neither race nor the proxies for class were found to be significantly associated with stigma in the models, which is somewhat surprising since they are significant axes of power differentials in people’s lives. This result may have occurred, however, because of a lack of variability in race and class among the participants, most of who were African American and had low incomes.

This study too had limitations. First, as discussed in the paper itself, the Perceived Stigma Survey may in itself inscribe stigma on the women participating in the study. Being asked, even in a self-administered survey, whether having HIV made them feel dirty or guilty suggests that some people feel that way about people living with HIV. This could result in participants feeling stigmatized and/or internalizing some of these ideas.

A second limitation of the study is that fact that all of the statistical models examined, even when significant, had relatively low adjusted r-square values. This suggests that much of the variation in perceived stigma was not accounted for by the factors included in the models. So although social capital and particularly the Value of Life sub-factor may be involved in perceptions of stigma, there is much that still needs to be explored to understand the predictors of perceptions of stigma.

Finally, future research in this area should attempt to distinguish the social capital that women perceive in their various social worlds, as it may well differ from one to another. For example, many of the women who participated in the first study spoke highly of their HIV providers/clinics, social worlds quite separate from those of, for example, their families and friends. Women in this second study who considered their HIV clinics and/or support groups as part of their social networks may have reported higher social capital and Value of Life and less stigma compared to those who did not. Unfortunately, the existing data does not allow for making this distinction.

Social Stigma and Childbearing for Women Living with HIV/AIDS

In the last study, drawn from a similar population (with at least one woman participating in both studies), I interviewed HIV-positive women in the San Francisco Bay Area to understand their decisions about childbearing, with a particular focus on social stigma and on their situations. For these women, most of whom were women of color, decisions regarding childbearing were commonly made within chaotic and unstable situations that limited their options and made them vulnerable to stigmatization. Some of the women were encouraged by providers to abort their pregnancies based on their HIV and their perceived inability to be good mothers due to factors such as poverty, drug use, and possibly race. These were examples of both stigmatization and the concept of stratified reproduction (Colen 1995; Collins 1999). For many other women, stigmatization was less overt, but all of the women were aware of what “people” think about women with HIV, particularly what they think of HIV-positive women who choose to have children. At the same time, the women found ways to resist the power behind the stigmatization in order to care for themselves and meet their own needs. And for most of the women, HIV specialists provided not only health care, but also emotional and social support that the women may have lacked in other spheres of their lives.

Although not the focus of this study, the idea of social networks was important. Women who had disclosed their HIV status, particularly those who had become involved in HIV-related social networks, seemed better able to resist stigmatization than women who had not disclosed, and who ultimately seemed substantially more worried about potential stigmatization. That is, the ability to be open about one’s situation and to share it with others was a source of empowerment for many of the women in the study. Telling their stories in a variety of forums – schools, churches, rehab – gave many of them a sense of respect and possibly a degree of social capital among their peers, often validating their decisions to disclose. Even within the study interview, some of the women expressed happiness, gratitude, and almost a sense of relief at being able to talk to someone about difficult issues that they may never have discussed or possibly even consciously thought about before.

Although some women appreciated the chance to talk about their lives, and may have felt valued because of it, the study had several limitations that are important to examine. First, I personally interviewed all of the study participants, and the situation of a white, well-educated, not-poor woman interviewing mainly poor women of color was likely a substantial issue for some of the participants. I did not specifically ask the women about race, and only a few mentioned racial issues at all, though mostly just in passing.

Participants may also have identified or made assumptions about my class, based on how I presented myself and on the fact that I am a doctoral student. These cross-race and cross-class differences could well have affected the results of the study, leading participants to keep certain ideas hidden or, conversely, to tell me what they thought I wanted to hear. Further, because stigmatization is based on existing power differentials, such as those of race and class, participants may have chosen not to mention or discuss those issues in order to avoid potentially stigmatizing or even just uncomfortable situations. And, because of the nature of the discussion, and these obvious racial and class differences, it is possible that some of the women felt stigmatized as a result of the research process itself. Although this did not visibly seem to be the case, it is impossible to know for sure what they felt at the time of the interview, or afterwards.

Also in relation to racial differences was the fact that none of the study participants were Hispanic. This may have been due to the English-language requirement of the study (although I speak Spanish, I do not speak it well enough to conduct or interpret an interview), or to the fact that flyers were posted in clinics that mainly serve African American and white women living with HIV. Additional flyers were posted in the San Francisco Women's Building located in the Mission District and were sent to the Southeast Clinic in an effort to recruit Hispanic women, but none called the study information line. As Hispanic women are increasingly becoming infected with HIV, not having any women from this racial/ethnic group in the study is a substantial limitation. One Asian / Pacific Islander participated, which is also a limitation, though their low infection rate makes this somewhat less of an issue than the lack of Hispanic women.

Finally, all of the participants in the study were currently under medical care for their HIV, which potentially makes them very different from other HIV-positive women. Women under care are likely to be somewhat healthier overall just by the fact that someone is tracking their health issues, even if the woman has chosen not to take ARVs. In addition, being under care provides a variety of other resources for women, including linkages to drug rehab programs, prenatal care, HIV support groups, and other social services. And, as some of the women in the study pointed out, their health care providers can also be a substantial source of emotional support. Women who are not in care may be less likely to have access to these resources, and thus may have very different experiences and views on the issues of stigmatization and childbearing.

In addition, having HIV may itself become a resource for many women because it can provide new resources and can be an impetus for them to modify their behaviors in order to continue living. In qualitative research by Lather and Smithies, this was an important theme, with one woman stating “I’d probably be dead now if I didn’t have HIV” (1997:135). For this woman, as with women in the current study, HIV gave them a reason to change their lives, and got them under medical and related care, which provided further resources. In particular, women who were diagnosed with HIV when they were pregnant seemed to access care more immediately than other women, who did not have the added factor of a child’s health or an abortion to deal with. Barnes and Murphy similarly found that being pregnant provided HIV-positive women with a reason to live and to change potentially risky behaviors (2009).

Contributions to Extant Literature

In all three studies, we see how Parker and Aggleton's conceptualization of stigma as constituted by culture, power, and difference, manifests in and has consequences for women's lives (2003). Cultural meanings in both the U.S. and Kenya associate HIV with sexual promiscuity and drug use, and at the same time emphasize the importance of specific social roles for women. Hegemonic cultural institutions such as families, schools, governments and even marriages marginalize women, particularly poor women of color, from power, making them vulnerable to both HIV and the stigmatization that can accompany it. The creation of the unhealthy "other" who is different from "us" creates and emphasizes boundaries along which stigmatization can occur. The merging of culture, power and difference make stigmatization a possible tool for reinforcing existing power differentials. Although many studies cite Parker and Aggleton's conceptualization of stigma, few apply the specific elements to their research.

The effects of stigmatization on women's lives are particularly evident in the study of childbearing decision-making. While many of the women experienced stigmatization they perceived as related to their HIV, three were specifically urged by healthcare providers to abort their pregnancies. This idea that women living with HIV should not have children has previously been seen in the literature (Barnes and Murphy 2009; Kirshenbaum et al. 2004). In the current study, however, providers deemed these women to be unfit not only to be mothers, but even to make decisions for themselves, much like Rapp's findings in her work on amniocentesis (1999). Theorists such as Colen (1995) and Collins (1999) have discussed this stratified reproduction, the idea that only certain women should reproduce thus reinforcing existing social hierarchies. Individuals and groups with disproportionate power in these hierarchies hope to create future social worlds that continue such inequalities, and limiting reproduction among certain women serves this cause (Haraway 1999). However, in contrast to some work (Kirshenbaum et al. 2004), the rationale revealed here is not based solely on the woman's HIV status, but also on other discrediting aspects of her identity. Women in Kenya may face an even more difficult situation because of the greater emphasis on childbearing, lack of any other valued social roles for women, and the cultural system of polygyny. Like women in the U.S., women in Kenya may choose not to get tested for HIV for fear of stigmatization, which may ultimately impede them from receiving needed health care for themselves and their children.

These studies also bring attention to the social situations of HIV-positive women's lives, particularly the role of social networks and systems of support. Earlier in the epidemic, Lather and Smithies worked with a women's HIV support groups to document the experience of being HIV-positive in the United States at a time before highly effective treatments were available (Lather and Smithies 1997). Participants in these support groups describe the importance of social support to their well-being: "I don't have many friends outside of this group that I talk to" (Lather and Smithies 1997:182); "I don't have anybody. These people are more family than anybody I have" (Lather and Smithies 1997:187); and "I couldn't have gone public without having all this support. I knew that if people rejected me, I still had so much support and I'd be OK" (Lather and Smithies 1997:188). Many of these women had not disclosed their HIV status in other domains of their lives for fear of stigma. For the women in these support groups, having a place to talk and be with other people living through similar experiences helped them overcome some of the emotional impact and internalization of stigma. This can also be seen in the research presented here. Women who were able to be more open about their HIV, to tell their stories, and who participated in support groups seemed less affected and concerned about both overt and more subtle stigmatization because they knew that there were people who accepted them for who they were. Those women who felt they had more social capital within their existing social worlds also tended to perceive somewhat less stigmatization. While the importance of social support for mitigating the stigmatization that women living with HIV perceive is clear, the links between social capital and stigmatization are a newer conceptualization, and remain less understood.

Remaining Questions / Further Research

While these three studies contribute to the field's understanding of the stigma that women living with HIV may experience, particularly as related to pregnancy and childbearing, a number of questions remain.

The research presented here showed that pregnant women in Kenya anticipate and experience HIV-related stigma, and that this is more severe for women living in polygynous marriages. It remains unclear, however, how wife order may affect the stigmatization. It may be that a first wife has greater respect, status and social capital within the social world of her marriage and her community than a younger wife. However, results of the study presented here also show that older women anticipated greater HIV-related stigma than did younger women, which may mean that older first wives may anticipate greater stigma. Qualitative methodologies would be particularly useful for understanding the dynamics of stigmatization and systems of social capital and social support within polygynous marriages, especially grasping traditional expectations and possibly changing patterns.

Another important question that remains is how various axes of stigmatization interact with each other. Prior research has attempted to examine "layered stigma," but has not successfully developed a methodology for doing so (Henkel, Brown and Kalichman 2008; Reidpath and Chan 2005). In particular, what is the interaction between the stigma due to HIV and the stigma due to having had an abortion? New measurements for abortion stigma have been developed, but have not yet been used to examine interactions with other stigmas (Cockrill et al. forthcoming). If one's social worlds are opposed to women living with HIV bearing children, are women then more stigmatized for going through with an unplanned pregnancy or for aborting one? Does having HIV make a woman more or less "different" than "us," and thus at greater risk for experiencing multiple or layered stigma?

Although many other research questions remain, one that is particularly related to the research presented here deals with the question of measuring stigma. Is it possible to develop a quantitative measure of HIV-related stigma that does not itself inscribe stigma? Or should future research on this issue focus on qualitative methodologies that may be able to increase understanding of the issue without potentially stigmatizing research participants?

Policy Implications

The lack of understanding of the ways in which HIV-positive women come to bear children or not may make it difficult for health care workers to provide the support and care that HIV-positive women need. Such support could include discussing and providing contraception, abortion information and services, and assisted reproduction services, to discussing the impact of HIV status disclosure and related stigma in their decisions. In order to fully address the health and social-wellbeing of women living HIV, we need a more nuanced understanding of the role of social stigma, as well as the broader situations within which HIV-positive women are living on a daily basis.

The three studies presented here provide greater insight into the lives of women living with HIV, particularly as regards childbearing. For many of these women, marginalization within their social worlds, particularly based on gender relations, makes it difficult for them to have control over their lives in general and more specifically over their reproduction. Those who are able to access specialized HIV health care clinics and providers may have greater resources for dealing with stigmatization through supportive care and social networks. They may also be less exposed to stigmatization from providers who lack knowledge about and sensitivity towards people living with HIV. This is true not only in the United States but also in Kenya, where HIV clinics work to provide holistic care to families affected by the disease. And though the provision of specialized, team-based HIV care does not solve the problem of stigmatization, it provides additional resources and support for living with HIV. In order to truly address the problem of HIV-related stigmatization, structural changes that address gender and other inequalities will be needed, both in the U.S. and around the world.

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V. Conclusion / Implications

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The purpose of the research in this dissertation was to examine HIV-related stigmatization in the lives of women living with HIV, with a particular focus on its effects on reproduction. In each of the three studies, we see how stigma matters in women's lives.

Factors Associated with Pregnant Women's Anticipations and Experiences of HIV-related Stigma in Rural Kenya

In the first study, I conducted a secondary analysis of data from pregnant women in Kenya who did not know their HIV status. At baseline, women were interviewed regarding perceptions of stigma in the community toward people living with HIV, as well as the stigmatization that they would anticipate if they were diagnosed with HIV and their status were disclosed. Women who were older, had less education, whose husbands had other wives, and who perceived local community discrimination against people with HIV, had significantly greater adjusted odds of anticipating HIV stigma. Among the HIV-positive women who were also interviewed post-partum, one-third had not disclosed their HIV status to anyone, and over half reported experiencing some HIV-related stigma, particularly self-stigma. In addition, experiencing stigma was associated with depression at the post-partum interview, though it is unclear whether there is a cause-effect relationship and, if so, in what direction.

These results suggest that gender relations in this region of Kenya disempower women and make them highly susceptible to HIV-related stigma. Systems of polygyny, of valuing women mainly for their ability to bear children, and of denial of female inheritance and property ownership make women more dependent on men, reducing their ability to resist stigmatization. In particular, the system of polygyny may reduce women's ability to create supportive social networks among women if they are competing for husbands and for their own husband's attention and resources. Such situations make disclosure difficult, which can have a direct impact on an HIV-positive woman's health, as well as that of any children she may have.

As in the qualitative study, the results of this study suggest that women may anticipate more HIV-related stigma than they actually experience once they disclose their status. It may be that in some circumstances, being open about one's HIV can be a source of empowerment for women that helps them resist stigmatization. This is not to suggest, however, that women should be held responsible for resisting stigmatization, but rather that larger scale social change may be necessary to truly address this issue.

Although this study provided important insight into the HIV-related stigma that women anticipate and experience in Kenya, the study had limitations, including both convenience sampling and substantial loss to follow-up, which may have introduced a degree of selection bias into the results. From a sociological perspective, however, two non-statistical limitations may have been more important. First was the inability to analyze data related to religion, which may be a substantial cultural factor in this region. A number of different religions were reported in open-ended questions in the survey, and the research team did not have the ability to deal with all of them. Additional analysis of this data could be useful in potentially understanding the various religions' stances on issues such as gender relations, support for people living with HIV, and efforts to strengthen women's positions in the community. This information could be very useful in determining whether religion plays a cultural role in the dialectic of stigmatization in this region of Kenya. Another important limitation was the lack of detailed information on polygynous relationships. Over one-quarter of participants had husbands who had other wives, but the data do not include information about wife order, which could be extremely important for understanding both power within relationships as well as social networks and the idea of social capital among wives of the same husband. As we know from Parker and Aggleton, stigmatization occurs at the crossroads of power, culture and differences. In order to fully understand HIV-related stigma in a particular context, it would be useful to have a greater understanding of two cultural institutions – religion and polygynous marriage – that are potentially very relevant to HIV and support or stigmatization of people living with the disease.

The Association of Social Capital and HIV Stigma among Women Living with HIV/AIDS

In the second study, I examined the relationship between social capital and HIV stigma. Based on the idea that social capital is a form of power, and power differentials are an essential element of stigmatization, I hypothesized that women with more social capital would experience less stigmatization due to their relative power in their social worlds. Although the relationship was found to be statistically non-significant, the trend was in the hypothesized direction, controlling for race, education, and proxies for class (education and annual income). In addition, women who scored lower on the Value of Life factor of the social capital scale perceived significantly more HIV-related stigmatization overall, and also scored higher on the Negative Self-Image factor of the stigmatization scale.

Together these results suggest that women who are not valued or do not feel valued in their social worlds may be more likely to perceive stigmatization, and have negative perceptions about themselves, potentially internalizing the stigma with negative consequences. Neither race nor the proxies for class were found to be significantly associated with stigma in the models, which is somewhat surprising since they are significant axes of power differentials in people's lives. This result may have occurred, however, because of a lack of variability in race and class among the participants, most of who were African American and had low incomes.

This study too had limitations. First, as discussed in the paper itself, the Perceived Stigma Survey may in itself inscribe stigma on the women participating in the study. Being asked, even in a self-administered survey, whether having HIV made them feel dirty or guilty suggests that some people feel that way about people living with HIV. This could result in participants feeling stigmatized and/or internalizing some of these ideas.

A second limitation of the study is that fact that all of the statistical models examined, even when significant, had relatively low adjusted r-square values. This suggests that much of the variation in perceived stigma was not accounted for by the factors included in the models. So although social capital and particularly the Value of Life sub-factor may be involved in perceptions of stigma, there is much that still needs to be explored to understand the predictors of perceptions of stigma.

Finally, future research in this area should attempt to distinguish the social capital that women perceive in their various social worlds, as it may well differ from one to another. For example, many of the women who participated in the first study spoke highly of their HIV providers/clinics, social worlds quite separate from those of, for example, their families and friends. Women in this second study who considered their HIV clinics and/or support groups as part of their social networks may have reported higher social capital and Value of Life and less stigma compared to those who did not. Unfortunately, the existing data does not allow for making this distinction.

Social Stigma and Childbearing for Women Living with HIV/AIDS

In the last study, drawn from a similar population (with at least one woman participating in both studies), I interviewed HIV-positive women in the San Francisco Bay Area to understand their decisions about childbearing, with a particular focus on social stigma and on their situations. For these women, most of whom were women of color, decisions regarding childbearing were commonly made within chaotic and unstable situations that limited their options and made them vulnerable to stigmatization. Some of the women were encouraged by providers to abort their pregnancies based on their HIV and their perceived inability to be good mothers due to factors such as poverty, drug use, and possibly race. These were examples of both stigmatization and the concept of stratified reproduction (Colen 1995; Collins 1999). For many other women, stigmatization was less overt, but all of the women were aware of what “people” think about women with HIV, particularly what they think of HIV-positive women who choose to have children. At the same time, the women found ways to resist the power behind the stigmatization in order to care for themselves and meet their own needs. And for most of the women, HIV specialists provided not only health care, but also emotional and social support that the women may have lacked in other spheres of their lives.

Although not the focus of this study, the idea of social networks was important. Women who had disclosed their HIV status, particularly those who had become involved in HIV-related social networks, seemed better able to resist stigmatization than women who had not disclosed, and who ultimately seemed substantially more worried about potential stigmatization. That is, the ability to be open about one's situation and to share it with others was a source of empowerment for many of the women in the study. Telling their stories in a variety of forums – schools, churches, rehab – gave many of them a sense of respect and possibly a degree of social capital among their peers, often validating their decisions to disclose. Even within the study interview, some of the women expressed happiness, gratitude, and almost a sense of relief at being able to talk to someone about difficult issues that they may never have discussed or possibly even consciously thought about before.

Although some women appreciated the chance to talk about their lives, and may have felt valued because of it, the study had several limitations that are important to examine. First, I personally interviewed all of the study participants, and the situation of a white, well-educated, not-poor woman interviewing mainly poor women of color was likely a substantial issue for some of the participants. I did not specifically ask the women about race, and only a few mentioned racial issues at all, though mostly just in passing.

Participants may also have identified or made assumptions about my class, based on how I presented myself and on the fact that I am a doctoral student. These cross-race and cross-class differences could well have affected the results of the study, leading participants to keep certain ideas hidden or, conversely, to tell me what they thought I wanted to hear. Further, because stigmatization is based on existing power differentials, such as those of race and class, participants may have chosen not to mention or discuss those issues in order to avoid potentially stigmatizing or even just uncomfortable situations. And, because of the nature of the discussion, and these obvious racial and class differences, it is possible that some of the women felt stigmatized as a result of the research process itself. Although this did not visibly seem to be the case, it is impossible to know for sure what they felt at the time of the interview, or afterwards.

Also in relation to racial differences was the fact that none of the study participants were Hispanic. This may have been due to the English-language requirement of the study (although I speak Spanish, I do not speak it well enough to conduct or interpret an interview), or to the fact that flyers were posted in clinics that mainly serve African American and white women living with HIV. Additional flyers were posted in the San Francisco Women’s Building located in the Mission District and were sent to the Southeast Clinic in an effort to recruit Hispanic women, but none called the study information line. As Hispanic women are increasingly becoming infected with HIV, not having any women from this racial/ethnic group in the study is a substantial limitation. One Asian / Pacific Islander participated, which is also a limitation, though their low infection rate makes this somewhat less of an issue than the lack of Hispanic women.

Finally, all of the participants in the study were currently under medical care for their HIV, which potentially makes them very different from other HIV-positive women. Women under care are likely to be somewhat healthier overall just by the fact that someone is tracking their health issues, even if the woman has chosen not to take ARVs. In addition, being under care provides a variety of other resources for women, including linkages to drug rehab programs, prenatal care, HIV support groups, and other social services. And, as some of the women in the study pointed out, their health care providers can also be a substantial source of emotional support. Women who are not in care may be less likely to have access to these resources, and thus may have very different experiences and views on the issues of stigmatization and childbearing.

In addition, having HIV may itself become a resource for many women because it can provide new resources and can be an impetus for them to modify their behaviors in order to continue living. In qualitative research by Lather and Smithies, this was an important theme, with one woman stating "I'd probably be dead now if I didn't have HIV" (1997:135). For this woman, as with women in the current study, HIV gave them a reason to change their lives, and got them under medical and related care, which provided further resources. In particular, women who were diagnosed with HIV when they were pregnant seemed to access care more immediately than other women, who did not have the added factor of a child's health or an abortion to deal with. Barnes and Murphy similarly found that being pregnant provided HIV-positive women with a reason to live and to change potentially risky behaviors (2009).

Contributions to Extant Literature

In all three studies, we see how Parker and Aggleton's conceptualization of stigma as constituted by culture, power, and difference, manifests in and has consequences for women's lives (2003). Cultural meanings in both the U.S. and Kenya associate HIV with sexual promiscuity and drug use, and at the same time emphasize the importance of specific social roles for women. Hegemonic cultural institutions such as families, schools, governments and even marriages marginalize women, particularly poor women of color, from power, making them vulnerable to both HIV and the stigmatization that can accompany it. The creation of the unhealthy "other" who is different from "us" creates and emphasizes boundaries along which stigmatization can occur. The merging of culture, power and difference make stigmatization a possible tool for reinforcing existing power differentials. Although many studies cite Parker and Aggleton's conceptualization of stigma, few apply the specific elements to their research.

The effects of stigmatization on women's lives are particularly evident in the study of childbearing decision-making. While many of the women experienced stigmatization they perceived as related to their HIV, three were specifically urged by healthcare providers to abort their pregnancies. This idea that women living with HIV should not have children has previously been seen in the literature (Barnes and Murphy 2009; Kirshenbaum et al. 2004). In the current study, however, providers deemed these women to be unfit not only to be mothers, but even to make decisions for themselves, much like Rapp's findings in her work on amniocentesis (1999). Theorists such as Colen (1995) and Collins (1999) have discussed this stratified reproduction, the idea that only certain women should reproduce thus reinforcing existing social hierarchies. Individuals and groups with disproportionate power in these hierarchies hope to create future social worlds that continue such inequalities, and limiting reproduction among certain women serves this cause (Haraway 1999). However, in contrast to some work (Kirshenbaum et al. 2004), the rationale revealed here is not based solely on the woman's HIV status, but also on other discrediting aspects of her identity. Women in Kenya may face an even more difficult situation because of the greater emphasis on childbearing, lack of any other valued social roles for women, and the cultural system of polygyny. Like women in the U.S., women in Kenya may choose not to get tested for HIV for fear of stigmatization, which may ultimately impede them from receiving needed health care for themselves and their children.

These studies also bring attention to the social situations of HIV-positive women's lives, particularly the role of social networks and systems of support. Earlier in the epidemic, Lather and Smithies worked with a women's HIV support groups to document the experience of being HIV-positive in the United States at a time before highly effective treatments were available (Lather and Smithies 1997). Participants in these support groups describe the importance of social support to their well-being: "I don't have many friends outside of this group that I talk to" (Lather and Smithies 1997:182); "I don't have anybody. These people are more family than anybody I have" (Lather and Smithies 1997:187); and "I couldn't have gone public without having all this support. I knew that if people rejected me, I still had so much support and I'd be OK" (Lather and Smithies 1997:188). Many of these women had not disclosed their HIV status in other domains of their lives for fear of stigma. For the women in these support groups, having a place to talk and be with other people living through similar experiences helped them overcome some of the emotional impact and internalization of stigma. This can also be seen in the research presented here. Women who were able to be more open about their HIV, to tell their stories, and who participated in support groups seemed less affected and concerned about both overt and more subtle stigmatization because they knew that there were people who accepted them for who they were. Those women who felt they had more social capital within their existing social worlds also tended to perceive somewhat less stigmatization. While the importance of social support for mitigating the stigmatization that women living with HIV perceive is clear, the links between social capital and stigmatization are a newer conceptualization, and remain less understood.

Remaining Questions / Further Research

While these three studies contribute to the field's understanding of the stigma that women living with HIV may experience, particularly as related to pregnancy and childbearing, a number of questions remain.

The research presented here showed that pregnant women in Kenya anticipate and experience HIV-related stigma, and that this is more severe for women living in polygynous marriages. It remains unclear, however, how wife order may affect the stigmatization. It may be that a first wife has greater respect, status and social capital within the social world of her marriage and her community than a younger wife. However, results of the study presented here also show that older women anticipated greater HIV-related stigma than did younger women, which may mean that older first wives may anticipate greater stigma. Qualitative methodologies would be particularly useful for understanding the dynamics of stigmatization and systems of social capital and social support within polygynous marriages, especially grasping traditional expectations and possibly changing patterns.

Another important question that remains is how various axes of stigmatization interact with each other. Prior research has attempted to examine "layered stigma," but has not successfully developed a methodology for doing so (Henkel, Brown and Kalichman 2008; Reidpath and Chan 2005). In particular, what is the interaction between the stigma due to HIV and the stigma due to having had an abortion? New measurements for abortion stigma have been developed, but have not yet been used to examine interactions with other stigmas (Cockrill et al. forthcoming). If one's social worlds are opposed to women living with HIV bearing children, are women then more stigmatized for going through with an unplanned pregnancy or for aborting one? Does having HIV make a woman more or less "different" than "us," and thus at greater risk for experiencing multiple or layered stigma?

Although many other research questions remain, one that is particularly related to the research presented here deals with the question of measuring stigma. Is it possible to develop a quantitative measure of HIV-related stigma that does not itself inscribe stigma? Or should future research on this issue focus on qualitative methodologies that may be able to increase understanding of the issue without potentially stigmatizing research participants?

Policy Implications

The lack of understanding of the ways in which HIV-positive women come to bear children or not may make it difficult for health care workers to provide the support and care that HIV-positive women need. Such support could include discussing and providing contraception, abortion information and services, and assisted reproduction services, to discussing the impact of HIV status disclosure and related stigma in their decisions. In order to fully address the health and social-wellbeing of women living HIV, we need a more nuanced understanding of the role of social stigma, as well as the broader situations within which HIV-positive women are living on a daily basis.

The three studies presented here provide greater insight into the lives of women living with HIV, particularly as regards childbearing. For many of these women, marginalization within their social worlds, particularly based on gender relations, makes it difficult for them to have control over their lives in general and more specifically over their reproduction. Those who are able to access specialized HIV health care clinics and providers may have greater resources for dealing with stigmatization through supportive care and social networks. They may also be less exposed to stigmatization from providers who lack knowledge about and sensitivity towards people living with HIV. This is true not only in the United States but also in Kenya, where HIV clinics work to provide holistic care to families affected by the disease. And though the provision of specialized, team-based HIV care does not solve the problem of stigmatization, it provides additional resources and support for living with HIV. In order to truly address the problem of HIV-related stigmatization, structural changes that address gender and other inequalities will be needed, both in the U.S. and around the world.

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