

Social Stigma and Childbearing for Women Living With HIV/AIDS

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Abstract

As more women become infected with HIV, the issue of childbearing becomes increasingly salient. A more nuanced understanding of women's situations is needed to provide high-quality and relevant services and support. We examined reproductive decision making among 20 women living with HIV through in-depth interviews. These women made decisions within situations of chaos, instability, and trauma, which often limited their ability to make truly informed choices about their lives and childbearing. Despite their HIV, many of the women wanted children, but experienced stigmatization related both to their HIV and to their decisions to have children. This stigmatization came from multiple sources, including health care providers, some of whom encouraged their patients to abort pregnancies because of their HIV. Participants, however, demonstrated resistance to stigmatization, through building supportive communities and developing trusting relationships with HIV providers. These results support the need for specialized HIV care for women of childbearing age.

Keywords

HIV/AIDS, marginalized populations, pregnancy, reproduction, stigma, trauma, women's health, qualitative, interviews, USA

In the United States today, approximately 1,000,000 people are living with HIV and/or AIDS, and women account for one quarter of those cases (Centers for Disease Control and Prevention, 2015). 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 high-quality and relevant 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 situations. The purpose of this study was to examine reproductive decision making among women living with HIV.

Background

Before HIV medications were available, HIV-positive women had a 20% to 30% chance of transmitting the disease to their babies, either during pregnancy, delivery, or breastfeeding (Andiman et al., 1990). With the advent of highly active antiretroviral therapy (HAART) in the late 1990s, however, the rate of transmission has been reduced to less than 2% (Forbes et al., 2012; Townsend et al., 2008; Warszawski et al., 2008).

Over the course of the HIV/AIDS epidemic, extensive 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; De La Cruz, Davies, & Stewart, 2011; Ingram & Hutchinson, 2000; Kirshenbaum et al., 2004; Kline, Strickler, & Kempf, 1995; Myer, Morroni, & El-Sadr, 2005; Sanders, 2008; Sowell & Misener, 1997; Wesley et al., 2000). This research has also shown that, like women without the disease, many HIV-positive women have unintended pregnancies (Bedimo-Rung et al., 2005; Kline et al., 1995), and must make decisions regarding whether to carry the pregnancy to term or have an abortion (Craft, Delaney, Bautista, & Serovich, 2007; Sunderland, Minkoff, Handte, Moroso, & Landesman, 1992). As we know, approximately half of all pregnancies in the United States are unplanned and about 40% of those end in abortion (Finer & Zolna, 2014). Furthermore, many women are initially diagnosed with HIV during prenatal care, regardless of whether the pregnancy was planned or not. These situations, as well as a lack of knowledge among some providers, may make it difficult for women to get the HIV and pregnancy information that

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they need and to make active and informed decisions about their reproductive lives.

In prior research on reproduction in women living with HIV/AIDS (WLHA), much of the concern has focused on transmission of HIV to children (Kirshenbaum et al., 2004; Sanders, 2008; Wesley et al., 2000). In the early 1990s, Sunderland and colleagues (1992) 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. More recent 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) or about how their health may affect their ability to parent (Ingram & Hutchinson, 2000; Kirshenbaum et al., 2004; Stanwood, Cohn, Heiser, & Pugliese, 2007; Wesley et al., 2000).

Research conducted in the United States has shown that health care providers are quite influential in women's decisions. In work by Sowell and Misener (1997), HIV-positive women discussed their mistrust of the medical community and felt that doctors focused on medications and encouraged them not to have children. Similarly, health care providers may stigmatize women and question their decisions to carry pregnancies rather than terminate (Kirshenbaum et al., 2004). Ko and Muecke (2006) found that AIDS care professionals fell into three main groups: "pro-children," focused on 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 child care; and "pro-rights," focused on the rights of the couple and seeing HIV as just another life challenge. These authors discuss the inherent differences in 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. Some 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, for those struggling with addiction, as a reason to get off drugs, get their lives together, and get their own health in order (Sanders, 2008; Wesley et al., 2000). Prior studies have also 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; Kline et al., 1995; Sanders, 2008; Sowell & Misener, 1997). Other individuals may also influence women's decision making regarding childbearing, including male partners, mothers, and other women (De La Cruz et al., 2011; Kline et al., 1995; 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).

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 Misener (1997), women reported feeling that having a baby made their lives as women complete. Wesley and colleagues (2000) found that being a mother fulfilled an important role; one woman stated that "giving birth is the only way to be a real woman" (p. 297). Other studies have shown similar results (Chen et al., 2001; Harries et al., 2007; Ingram & Hutchinson, 2000; Sandelowski & Barroso, 2003; Sanders, 2008). Bedimo-Rung and colleagues (2005) 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" (p. 1409). Barnes and Murphy (2009) found that women who had other roles that gave them respect or social status were less likely to want (more) children. Among non-minority working class and poor women, Greene identified the importance of motherhood as a way to transition to adulthood and become "responsible" (Greene, 2006). Though this study was not among women living with HIV, it demonstrates the importance of social class in childbearing decision making. Many women living with HIV experience multiple intersecting social marginalizations based on race, class, and gender, and these women may see having children as a way to demonstrate their social worth.

Another major consideration is social stigma. In one of the seminal works on the subject, Erving Goffman (1963) defined stigma as "an attribute that is deeply discrediting," but he emphasized that attributes are defined as discrediting only through social interactions (p. 3). Ingram and Hutchinson's (2000) work in the Southeastern United States shows the importance of the social aspect of stigma, finding 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" (p. 122). In a qualitative study of HIV-positive women, Barnes and Murphy (2009) similarly found that HIV-positive women faced a substantial dilemma about whether to become pregnant or not, in

light of the potential for stigmatization. Craft and colleagues (2007) found that HIV-positive women who were more influenced by societal factors were less likely to choose to become pregnant. Sanders (2008) also found that pregnant WLHA often did not disclose their HIV status to other friends who were pregnant for fear of being stigmatized. 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 WLHA, both quantitative and qualitative research shows that many WLHA continue to want children despite their HIV status. Furthermore, in the current era of HAART and prevention of vertical transmission, 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, particularly for marginalized groups. Nor does it specifically examine the situations within which women make these decisions, including the various actors, discourses, and social worlds. Therefore, 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. We argue that stigmatization and the social situations within which WLHA live their lives make it difficult for them to have true reproductive choice.

Method

Study Design

For this study, a qualitative research methodology was used, including in-depth interviews and participant observation. The study was based on grounded theory methodology, which utilizes constant comparisons, progressive coding and analysis, and memoing. This empirical methodology is used for developing theories inductively, based on “sensitizing concepts” that are observed in the data. In addition, it provides the flexibility to build on and follow early findings, rather than focusing on testing hypotheses. Situational analysis (Clarke, 2005) was also used as a supplement to grounded theory. The purpose of situational analysis is to examine not only the participants’ own experiences but also the “situations” in which their lives are lived, conceiving the broader situation as the unit of analysis. Mapping techniques are used to identify the major elements of the situation, including not only personal experiences but also the various actors, societal discourses, and overarching discourse and debates about the issue (Clarke, 2005; Strauss & Corbin, 1998).

Data Collection

Participants were recruited in the San Francisco Bay Area. Eligible participants had to have received an HIV

diagnosis at least 1 year prior to participation, be biologically female, at least 18 years of age, and English speaking. They needed 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 in order not to influence current decision-making processes. 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 service agencies around the Bay Area. Women interested in the study called the investigators and were screened for eligibility. If eligible, the participant and investigator set an appointment for the interview.

At the interview, participants completed the consent process and a brief demographic form, followed by the in-depth interview. Based on the grounded theory methodology, later interviews took into consideration issues and trends gleaned from coding earlier interviews. The interviews were audio recorded with permission and the investigator also took notes. Most interviews lasted 45 to 60 min. 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. 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 US\$25 in cash or as a gift card as a token of the investigators’ appreciation.

Sample

Twenty women living with HIV participated in in-depth interviews. Although the number of participants was limited in part by the time period of the study, saturation of the themes described here was achieved. Through the constant comparative analytic method, interviews were conducted and data were analyzed until there was consistent repetition of themes that had previously emerged from the data. The average age of participants was 46 years and the

Table 1. Sample Description ($n = 20$).

Characteristic	$M \pm SD$ or number (%)
Age, years, $M \pm SD$, 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 (M)	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 (M)	2.4 (range = 0–6)
Live births after HIV diagnosis (M)	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 (CPS)	4 (20%)
Left a child/child taken by CPS/child given to relative	8 (40%)
Mental health issues	7 (35%)
Incarceration	5 (25%)

Note. GED = general educational development; AA = associate of arts. Results

majority was African American (Table 1). Many were long-term survivors of HIV, 2 having been diagnosed in the late 1980s. Four participants had been diagnosed within the past 10 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 or less education. Of these 20 women, 8 were diagnosed with HIV when they were pregnant. Among those who became pregnant after their HIV diagnosis, only 1 had actively planned her pregnancy.

Data Analysis

The investigators coded the text using the open coding technique. As an element of grounded theory, open coding calls for line-by-line coding of the text, as a first step in the development of concepts (Strauss & Corbin, 1990). This technique allows for the text to be broken down to its key elements, and for these elements to be compared and related with other elements, using a constant comparison analytic approach. This approach calls for initiating coding while data are still being collected to identify important themes early, and thus to be able to delve into these issues in greater depth in later interviews and to compare examples of the theme throughout. Open coding is particularly useful for situational analysis, to identify relationships between actors, social worlds, and discourses. Ideas and themes were recorded, and codes with similarities were categorized into concepts or themes. As data were collected and coded, the investigators also reviewed participant observation notes and field notes, and wrote memos, which became 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.

In this study, one of the main themes to emerge—trauma—was not anticipated during the development of the interview guide. Although the theme was identified early on as an important issue, the investigators did not specifically ask about trauma in later interviews in order not to trigger participants. Despite this, all of the women brought up traumatic experiences without being asked. When this occurred, the investigators probed with questions such as “Can you tell me more about that experience?” “How do you think that might have affected your desire for children?” Some women discussed these experiences extensively, whereas others limited their responses.

Chaos, Instability, and Trauma

Although the purpose of this study was to explore the role of social stigma in women's reproductive decision making, one of the overarching themes to come from the data was the chaotic, unstable, and often traumatic situations within which these women were coping with HIV and dealing with pregnancies. The participants were not specifically asked about trauma, but all reported having 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, such as for the women who believed that they became infected through injection drug use or

commercial sex work. And for a number of the women, these situations were also related to their pregnancies. Barbara¹ 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. Once pregnant, she decided 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 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.

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

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 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 HIV and an unplanned pregnancy 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, lack of easily accessible services for pregnant women with HIV, or fear of what reception she might get at a clinic because of her drug use, she 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—certainly contributed to the unplanned pregnancy, and likely contributed to the baby's death just before birth.

Other participants in the study also experienced varying degrees of instability and trauma in their lives: 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 transactional sex, two women had been sexually abused or raped, and another four had experienced violence from their intimate partners. For some of the women, HIV was the result of the trauma and chaos in their lives. For others, the HIV diagnosis contributed to the chaos, and for some others, HIV was just one more issue to deal with, and was 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, described a long history of domestic violence, homelessness, incarceration, and drug rehab programs. Finally, entering 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 amid chaos in their lives seemed to help them be able to take more control of their lives.

Stigma

In the context of their chaotic lives, many of the women in this study had experienced overt stigmatization due to their HIV status. As Goffman explained, stigmatization is a social process with social consequences that can result in reduced opportunities in life (Goffman, 1963). Parker and Aggleton emphasized the essential role of power differentials for stigmatization to occur, and this was clearly demonstrated in the lives of a number of women in this study (Parker & Aggleton, 2003). In other cases, women lost friends or had other negative experiences that affected them deeply. Some women also had stigmatizing experiences related to having children. One woman described going for care when she was pregnant:

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.

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.

Another woman 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 abortion experience:

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.

Olivia felt that she had not had the opportunity to consider her options thoroughly and that, in the end, the decision had not really been her own. The power difference between her and her provider created a situation in which she was stigmatized, and thus coerced to do something that reduced her life opportunities, her ability to have a child that she had wanted. As a result, she felt "hateful, mad, disgusted, emotionally disturbed" about essentially having been pushed into aborting a child that she had 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:

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 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.

Although she told the nurses in the hospital that she was in labor and needed help, they only admitted her when the situation had become an emergency:

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.

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.

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 the seriously compromised health care discussed above, a number of women reported self-isolation as another 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, believing the negative stereotypes about themselves, is another consequence of social stigma. Jamie described her initial reaction on 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." She explained that 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

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. Gabrielle, for example, 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 one 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 alone 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 and communities 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 . . . That's where we can dump . . . It makes it easier because you got somewhere and you have some people to talk to." And Amanda 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 biosociality—choosing to spend time with others because of embodied commonalities (Rabinow, 1992).

In addition to surrounding themselves with supportive peers, many women also resisted stigmatization by carefully choosing providers who would support them, and leaving providers who would not. 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 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 been interested in HIV care. Providers who lack knowledge about HIV may fall back on existing social stereotypes about people who get HIV, resulting in the stigmatization that many of these women experienced.

The majority of participants in this study were currently receiving their health care services from HIV specialty providers and were generally very pleased with the care. By selecting HIV specialty clinics and providers who were supportive, women were able to create health-related social worlds for themselves that countered the stigma and trauma of their daily lives:

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. Amanda 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 Amanda, 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.

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 or 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 drugs and have a healthy baby. The simple fact of telling her that he was proud of her was empowering for this woman who had worked so hard to get off drugs. 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 women living with HIV, providers who demonstrated that they cared and valued them as individuals really mattered. A few reported switching clinics to stay with particular providers who moved, demonstrating the importance of their relationships.

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. A number of themes, however, stood out.

Most of the women in this study had lived unstable and traumatic 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 in some of their lives led directly to them becoming infected with 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. The trauma and instability that these women experienced supports existing research on the extent of trauma among women living with HIV (Machtiger, Wilson, Haberer, & Weiss, 2012).

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 (Centers for Disease Control and Prevention, 2015). Research has shown the effect of power differentials in intimate relationships on safer sex practices (Pulerwitz, Amaro, De Jong, Gortmaker, & Rudd, 2002). Furthermore, 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 using drugs, possibly 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).

Such power differentials may also put women at risk of stigmatization. Building on earlier theoretical work, Parker and Aggleton (2003) explained stigma vis-à-vis power: "Stigma and stigmatization function, quite literally, at the point of intersection between *culture*, *power* and *difference*" (p. 17). Seeing power differentials as a *cause* of stigma, Parker and Aggleton further argue that stigmatization serves as a tool to reproduce existing and unequal power structures within social systems, structures that marginalize individuals and groups based on factors such as race, class, gender, disability, and behaviors that are considered deviant. Stigmas are ascribed to individuals who are already marginalized in some way, and Parker and Aggleton (2003) further acknowledged that there is an "intensifying interaction between multiple forms of inequality and exclusion" (p. 19). For example, the intersection of race and gender puts women of color at greater disadvantage, and therefore greater likelihood of experiencing stigmatization. This conceptualization of stigma is particularly relevant to participants in this study, many of whom were marginalized for multiple intersecting factors. In their experiences, we can trace the culture, power, and difference that Parker and Aggleton described.

Cultural understandings in the United States about WLHA revolve around what some consider to be deviant behaviors such as drug use and commercial sex work, as well as around stereotypes regarding the "types" of people who become infected with the disease. 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. This may be particularly true for individuals at the intersection of multiple marginalizations. 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 there were

opinions that they had themselves held prior to diagnosis, which may even have led to an internalization of the stigma among some of the women. These social creations are strengthened and perpetuated through continued use in social interactions.

Power is clearly a major factor in the lives of these participants. Power differentials based on gender, as discussed previously, not only 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. The intersection of multiple power differentials put many of these women at greater risk of experiencing stigmatization.

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 synergistic manner. Each on its own may create negative attitudes toward women living with HIV, but together, power, culture, and difference create the active stigmatization that many of the women in this study experienced.

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 may 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, providers encouraged them not to have children at all. This rationalization is very much in line with the concept of stratified reproduction, which suggests that differential value is placed on childbearing, depending on race, class, and other hierarchies (Colen, 1995; Collins, 1999). As Haraway (1999) discussed, reproduction is political because it generates future social worlds. Children born to poor women of color are likely to be poor themselves, thereby creating another generation of individuals living in poverty. People in positions of power may seek future social worlds with fewer people of color and fewer people living in poverty. Thus, by discouraging these HIV-positive women from having children, providers were stigmatizing the women for multiple reasons 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 convinced her that it was the right decision. She gave up her choice to have a baby that she wanted because she internalized the idea that she was not good enough to have a baby, or even to make the decision herself.

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, 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. Some of the women had even come to see HIV 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, p. 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.

The results of this study have practical implications for the care of women living with HIV. First, specialized HIV care remains an important and effective model of service provision for individuals living with HIV. It provides a safe space to bring people into care, and to address the range of their primary care needs in a non-stigmatizing and supportive environment. Second, additional work is needed to address ignorance, attitudes, and behaviors among non-HIV specialized clinicians. If women living

with HIV are concerned about negative attitudes that they might encounter from providers based on past experiences, they are less likely to seek out the health care that they need, leading to unnecessary morbidity, mortality, and general suffering. This is particularly important in the context of childbearing. Third, reproductive health should be prioritized as part of HIV care, both within and outside of specialized HIV settings. Such efforts are already underway in global health, but have been slower in the United States in part because of the multiple intersecting stigmas including race, class, drug use, and so forth. With so many women being diagnosed with HIV during pregnancy, it is important that reproductive care and HIV be linked more closely. Finally, both specialized and non-specialized HIV care settings need to adopt a more trauma-informed approach to care (Machtinger, Cuca, Khanna, Dawson Rose, & Kimberg, 2015). Sensitizing clinic staff and providers about the linkages between trauma and health, and training them to respond to such situations, has the potential to improve the care that women living with HIV receive.

Conclusion

For these 20 women, reproductive choices were made in situations of chaos, instability, and stigmatization. Although reproductive rights discourses in the United States focus on a woman's right to make decisions about her reproduction, rights and choice may take on different meanings for HIV-positive women. 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, having been raped or involved in transactional sex for survival, or having partners who lied about their own HIV status. Once these women found themselves pregnant, their situations may have made it difficult for them to have a real choice about what to do.

For some of the women, providers were sources of stigmatization, but for many others providers became part of the social support networks and communities 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, improve their own health, and have wanted pregnancies and healthy children. 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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Note

1. All names are pseudonyms.

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