

A Right to Live: Understanding How Women with HIV Manage and Overcome Stigma

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Introduction

Four months before her death, Arthurene sat across from me and told me about her life with AIDS. She was only forty-seven years old, but she looked decades older. She spoke in a tiny voice that was difficult to hear over the oxygen tank she needed to breathe, but she was laughing when she told me, “Someone need to write a book on me. I’m gonna go ahead and call some talk show” (5). Arthurene was never the subject of a book and never did call a talk show, but it is long past time for her story to be heard.

As an African American single mother, Arthurene was not alone in her silent fight against HIV/AIDS. She represents a new demographic facing HIV/AIDS. Although AIDS was originally considered a “gay disease,” low income minority women now have the fastest growing rates of infection. AIDS was the number one killer of African American women in 2004; the next year the rate of AIDS diagnosis for African American women (49.9/100,000 women) was approximately twenty-four times the rate for white women (2.1/100,000 women). And while African American and Hispanic women together only represent twenty-four percent of all U.S. women, they accounted for eighty-two percent of the estimated total of AIDS diagnoses for women in 2005 (*HIV Infection in Women*).

After their positive diagnoses, women experience HIV/AIDS in a particularly gendered way (Bunting 1996; Buseh and Stevens 2006; Sandelowski, Lambe, and Barroso 2004). A poor understanding of

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their experiences has led to an inadequate response to their needs, which are all the more urgent when they are women with children. Research about life as a woman with HIV/AIDS is needed to increase understanding and aid in the development of supportive programs. Studies focusing on the way that these women experience HIV/AIDS-related stigma are particularly important, since the discrimination they experience as a result of their infections has a tremendous affect on their lives.

Although Treichler and Warren write that HIV has long been recognized as an “equal opportunity virus” (109), women were not included in the diagnostic guidelines for AIDS until 1993 (Bunting 65). Until recently, little was known about women’s unique experience with the disease. Researchers are now beginning to fill that gap by studying the social impact of the virus on women, particularly among minorities and those with low socioeconomic status. In a well-documented trend known as the “feminization of poverty,” more and more women live below the poverty line and head single parent households. To contribute to a newly emerging literature on women and HIV, this paper will focus on how low-income women with children manage the stigma of HIV/AIDS. For such women, the diagnosis of HIV/AIDS adds a layer of stigma to an already deeply stigmatized identity. In their interviews, the women revealed techniques they have developed in order to manage societal blame.

Method: Sample

A local AIDS agency was used as a resource to identify participants for this study. Lowcountry AIDS Services (LAS) is the only organization dedicated to serving the needs and improving the quality of life for those living with HIV/AIDS in Charleston, Berkeley, and Dorchester counties of South Carolina. An internship there opened the door to a sample of HIV-positive women. The agency generously allowed me to use their office to conduct my interviews, which lent credibility to my research and helped participants feel at-ease during the interview process.

Ten women who are currently clients of the agency were individually interviewed over a period of four months using a qualitative interview process to explore their experiences of HIV as

poor women. The sample was drawn using purposive sampling, a method “well-suited and scientifically appropriate” for qualitative research with a focus on sensitive issues like HIV/AIDS involving a population difficult to access (Buseh and Stevens 5). All of the women in the sample group were HIV-positive and at least one had AIDS. With one exception (a woman currently working at LAS as an AIDS educator, who now considers herself to be financially stable), all of them had low or no income. Seven of the ten women identified themselves as African American or black; the remaining three identified themselves as white.

In regard to their HIV/AIDS experiences, the women’s common experience of poverty seems to be more significant than their race. I would argue that race has a significant effect on the way women experience AIDS, because it may subject them to additional stigma. However, at this level it is more important to consider low-income women together regardless of their race; their poverty makes them more similar than different. Buseh and Stevens report that prominent HIV researchers have found HIV-positive African American women are a “unique population with distinct cultural experiences and histories of oppression, whose needs and strategies for coping in daily life may be different from those of other populations of HIV-infected individuals” (4). While African American women may face more problems accessing care, that aspect of the HIV experience falls outside the scope of this study. With the small sample size used, it was not possible to control for race or make comparisons about “white” versus “black” HIV experiences, and I would argue such differentiation is limited in its usefulness in helping HIV-positive women of any race, ethnicity, or color.

The sample is diverse within its demographic. Participants varied in the number of children they have, their caretaking responsibilities, their health condition, time lapsed since their diagnosis, how they were infected, and their marital status. One woman had no children while another had nine living children; the mean number was 3.4. Most of the women’s children were no longer legal dependents, but five of the nine women with children still have kids who live with them. While several of the women were not experiencing symptoms when we spoke, others were ill at the time of our interview. One, Athurene, has since

died from AIDS. There was significant difference in the duration of time since the women were diagnosed with HIV, ranging from Maya, who was diagnosed six months before our interview, to Granny Kitty, who was diagnosed in 1984, or twenty-three years before we met. Eight of the ten women were infected through heterosexual sex; the other two reported they did not know how they contracted the virus. In terms of marital status, the study includes one widow, one woman who was engaged, and one woman in a troubled marriage; the other seven women were all single. They ranged in age from 40 to 78, with a median age of 48.5.

Data Collection

The study design was based on the naturalistic perspective (Lincoln and Guba 1985). The naturalistic perspective, and especially the grounded theory approach, are well-suited for studies that focus on personal narratives (Rohleder and Gibson 2006: 30). In the case of women with HIV/AIDS, stories are powerful in the fight against the HIV-related stigma they suffer. As W. M. Diggelmann wrote, "Stories are weapons against disease" (qtd. in Mohammed and Thombre 2005: 347). It is, therefore, paramount that this topic be studied in a manner that allows for the expression and analysis of narratives.

Interviews were semi-structured and conducted in a "field setting" at Lowcountry AIDS Services (Esterberg 2002: 89). An interview guide (see Appendix) was used to ensure that every topic of interest was covered with each interviewee. Subject areas were determined in advance but specific questions varied among interviewees. This structure allowed for a balance between providing the client with enough freedom to share her stories and enabling the researcher to cover all major topic areas. After verbal informed consent was given, interviews lasted between one and two hours. They were tape-recorded for accuracy, then transcribed verbatim.

Interviews were analyzed using open and closed coding techniques that are widely accepted in the field of exploratory qualitative social science research. During open coding, researchers study their transcribed interviews, noting recurring themes or points of interest in the margins. Closed coding takes place after open coding has identified the main themes, and involves a second reading of the

transcripts. Each time a word or theme appears in the interviews, the researcher marks it using a code system, creating an index of recurring themes or ideas. This index, called a coding tree, helps researchers analyze the content of their interviews. In this study, the coding tree effectively revealed patterns of common experiences among the study participants.

Analysis

The project began broadly with interviews aimed at discovering the lived experiences of women with HIV. Early on it became clear that the stigma associated with HIV/AIDS is central to the struggle of an HIV-positive woman. Stigma is the one common experience of all women with HIV/AIDS, defined by Buseh and Stevens as “prejudice, discounting, discrediting, or discrimination directed toward HIV-infected persons and those with whom they associate” (3). The women in their study, like the women in mine, experience stigma in complex ways because for them, HIV-related stigma is layered with racist, classist, and sexist discrimination.

Katie Mosack calls this “multiplicative stigmatization,” a term she defines as “moral reproach across multiple personal attributes and conditions” (2005: 588). The women in this study faced reproach for their race, their social class, their children, and their gender. But unlike these other sources of social stigma, their HIV status came on them suddenly and was not something that they could necessarily share with their families and friends. In order to gain access to the support services and human interaction, these women have developed emotional resources and strategies that came out in their interviews. They each had stories to tell of the experiences that have forced them to learn to manage their “multiplicative stigmatization.”

Sex-Related Stigma

The literature explains that stigma experienced by women leaves them vulnerable at every step of the disease process, from infection to death. In *Labeling Women Deviant* (1984), E. M. Shur connects women’s susceptibility to stigma with their lower status and lack of power. In fact, gender-related stigma is one of the reasons that women are at such great risk of acquiring and transmitting HIV (Bunting 64).

Janet Maia Wojcicki, who studied socioeconomic status as a risk factor among women in regions of Africa, found that being poor and female led to sexual powerlessness that contributed to HIV infection risk. “The degree to which [women] are able to express their own will is often limited,” she argues; “This lack of choice – or lack of power – leads some women to engage in high-risk behaviors, which increases their chance of contracting the HIV virus” (2004: 4).

Gender roles can make it difficult for women to initiate conversations about sex, because open discussions about sexuality can leave women victims of stigma related to traditional ideas of femininity, namely that women who talk about sex must be promiscuous. However, having HIV forces women to have these conversations. The women interviewed for this study spoke frankly about condoms. Sheila, a 63-year-old white woman and mother of three, explained that in her experience, “American men don’t wanna use condoms. I mean, they don’t care... And I don’t know what’s wrong with their thinking, but that’s the way they are” (62). This poses obvious problems for women with HIV/AIDS who do not want to infect their sexual partners. Sheila had an arrangement with her last boyfriend that negated the risk of transmission: “I would just take care of him. And I just refused for him to do anything with me. He was a mild-tempered person, so it worked out perfect. I didn’t have to tell him anything at all, so we got along great” (72). Although her tone was optimistic, Sheila felt that she had suffered a loss in terms of her sexuality as a result of her diagnosis. She said, “The only thing you give up [because of HIV] is sex. At the time it was a big loss. I was younger, and it’s just a natural drive that you have when you’re younger. Now it doesn’t bother me, but I’m older. Yeah, that was a loss” (62). Another woman expressed the similar feeling that “being intimate, that’s the only thing I miss. But then, I don’t let it bother me. I don’t let it bother me” (Mickey 154).

Because of the difficulties of disclosure and navigating safe sex conversations, all but one of the women who had been sexually active stopped engaging in intercourse after their HIV diagnoses. For these women with HIV, it was easier to just be “asexual, like a roach” (101), as Granny Kitty described it, than to deal with the stigma issues that come with a sexual relationship for people with HIV. Even Mickey,

the only married woman in the study, had stopped having sex with her husband after her diagnosis. (The fact that he had infected her perhaps contributed to her decision.) She confided, “My sex life is not like it should be. Things started happening in my sex life that I didn’t wanna be intimate. I guess the age, or the hormones, you know. Doesn’t even phase me. I’m not a very loving person... to my husband... And I guess it shouldn’t be that way – like I said, he’s in one room, I’m in one room – but that’s the way I want it” (154-5).

At the time of her interview, Pat, a forty-year-old African American, was engaged to be married and the only woman in the study still sexually active. She explained the difficulty of having a relationship after HIV. In the beginning, she said, “I didn’t date nobody, ‘cause I knew I was sick” (201). She avoided men because she wanted to keep her status to herself. She explained that her fear of disclosing her status came partly from a visit paid to her by the Health Department. “Somebody had came to my house and told me in order to have a relationship with somebody ‘round here, you have to tell them from the beginning that you’re HIV-positive; they made me sign a paper, so that made me even scarer to deal with people” (203). Eventually, she was introduced to a man by a family member. Although she was not at all interested at first, after seeing how he cared for her son, she began to change her mind. She explained:

He was showin’ interest so I... I lied. He knew I was goin’ back and forth to the hospital in Charleston, so I told him I was goin’ up there ‘cause I’m getting tested for HIV ‘cause I think I have contracted the disease. And he had wanted to get involved and I was like, ‘I don’t want to get involved in no relationship, I need to know.’ So once I seen that he knew that much and he still showed interest in me, he had already shown interest in my child, so he went with me to an appointment and that’s when I came out and told him. (205)

Pat is now engaged to this man, whom she has found to be a supportive caretaker for herself and her children. They have a healthy and safe sexual relationship using female condoms (206).

Women’s experience of HIV-related stigma is exceptionally brutal

if they have children. They may be associated with “dirty sex” and “moral contagion” in heterosexual communities (Lichtenstein, Laska, and Clair 2002: 27). Their right to bear children and raise them is challenged when society thinks HIV makes them unfit. Unmarried mothers (of whom there were eight in the study) face the additional stigma of single parenthood, a stigma they hardly deserve or need when already they find themselves struggling with the emotional and physical burden of raising children alone. This struggle was a common theme throughout the interviews. The women’s stories tell about surviving the feminization of poverty. Raising children alone, they have little chance to improve their circumstances. Adding insult to injury, society blames women who find themselves with the burden of children and without the support of family or husbands.

Martha Ward, an American anthropologist, describes the urban folklore that describes mothers with AIDS: “Those women have food stamps. They buy alcohol or luxury items. They have infected their innocent babies. They should use birth control, get abortions, get a job, finish school, use condoms, and say no to drugs” (qtd. in Farmer 1996: 28). This quote addresses the poverty and sex-related stigma that was expressed by the women I interviewed, and it clarifies the devastating effect of stigma on women’s experience of HIV.

Sarah, a 49-year-old white woman, tries to escape stigma by hiding her HIV. She described what it would be like for her kids if her neighbors discovered her HIV status. “It’s gonna happen like, ‘their mother has what?’ ... So they’ll start, they’ll call your mama nasty and think things ridiculous like oh, she been out there havin’ sex with everybody, or havin’ drugs. They get to, ‘you mom has AIDS, maybe your daddy ain’t your daddy’” (40).

Sarah’s story shows how damaging HIV can be to a woman’s sexual identity. Although she was not “havin’ sex with everybody,” revealing her HIV status would risk Sarah’s reputation as a mother and respectable woman. Her concern is for her children and their social and emotional well-being. She claimed, “I would talk about it even on TV ‘cept for the children” (31). On one hand, concern for her children keeps her safe from stigma she might suffer, since it forces her to keep her status secret. On the other hand, hiding her HIV prevents her from seeking much-needed social support. Because she fears that she

cannot safely spend time with women who also face her struggles, she is socially isolated. Asked who she spends time with, she admitted, “I don’t socialize much. Just with my babies, in my house” (35). When social interaction is necessary, however, women who are HIV-positive must somehow deal with the stigma they face.

Stigma Management

According to Howard Becker (1963), those labeled as social deviants have three options: (1) to accept the label and its accompanying stigma as a “master status,” or the main aspect of their identity; (2) to fight the label by denying or hiding it; or (3) to face the label and use it to educate others. Women in this study made all of the three choices. Some changed their responses over time, or even made different choices at the same time.

Stigma management techniques vary greatly according to circumstance. For example, Maya, whose story follows, could have shared her HIV status with her family, but the circumstances of her case include her lack of emotional preparation to take such a step. Pamela, a 42-year-old African American who now works in outreach at LAS (and is the negative case study for this paper in terms of motherhood and poverty) explains why disclosure is not always appropriate and why alternative stigma management techniques are necessary. She asked, “Do I think that everyone should disclose their status? No, I don’t.” She went on to explain, “Some people can’t handle rejection. Some people are still dealing with the emotional part of HIV and AIDS themselves” (178).

Stigma management allows women to handle disclosure in the most personally appropriate way, according to need (for example, to receive care or support services) and relative risk. There is low risk sharing with an HIV case manager or outreach worker like Pamela, but higher risk sharing with family or coworkers.

Accepting Stigma as a Master Status

Of all the women in the study, Maya had taken the fewest disclosure risks. She had been diagnosed more recently than the other women in the study, and her case manager at LAS was the only one she had told about her HIV status. Research has shown that infected

individuals suffer especially from emotional distress shortly after their diagnoses (Siegal and Lekas 2002: S70), and Maya was in obvious distress. Her HIV status had become her “master status,” to use Becker’s term, in a way that was noticeable from her physical posture. During her interview she sat hunched over in her chair, hardly made eye contact, and cried – normal behavior for a victim of a fatal illness, but not for a respectable, middle-aged woman and successful mother of three children. Maya had “internalized” the stigma, or had fully accepted society’s negative view of her infection (Lee, Kochman, and Sikkema 2002: 313). Because of this she was still unable to question the shame she felt. Instead, she made efforts to hide the diagnosis from others, even her own children, explaining that “they not gonna understand. They just gonna think of it negatively, just like I would, I would too” (82).

By accepting HIV as a master status, Maya had lost sight of other aspects of her identity. She was not able to imagine that her children might be able to look past it and see her as their mother, continuing to love and support her in spite of her status. Fear of stigma crippled her from disclosure of any kind. She insisted she doesn’t know how she was infected, and she cried, refusing eye contact when she explained, “When you say HIV, I feel like I have to go through the process of tellin’ people the fact that I wasn’t sexually active and I wasn’t a drug abuser. I have to let people know that” (89). This shows Maya’s shame. She manages the stigma she fears by denying association with stigmatized activities (here, promiscuous sex and drug use).

Denying and Hiding

Even when women are able to shed the “master status,” they still may choose to deny their diagnosis for practical reasons. In contrast to Maya, women in the study who had had some time to adjust to their HIV status showed they saw stigma more as ignorance on the part of others than as a reflection of their actual self-worth. Sheila, who reported receiving “a couple death threats,” observed that “people are ignorant, they don’t study things, you know. I don’t care what it is, any new disease out. People go nuts” (60). Diagnosed twenty-three years ago, she believes that stigma is not her fault, but the fault of people who stigmatize her. She showed more self-confidence and less

fear, which, according to research, is typical as people with HIV/AIDS experience the virus as a “chronic illness” and overcome their initial fear of it as the cause of their death (Tewksbury and McGaughey 1998; Siegel and Lekas 2002). Becker’s model explains her greater confidence in that she does not see herself as primarily a victim of HIV. She holds onto other important identities, outside of the diseased one: she is still a mother, a friend, and an artist. In order to separate such safe identities from the stigma of HIV, the women interviewed sometimes hide their status.

Buseh and Stevens found that women begin to assert their rights about disclosure when they feel confident facing HIV and have experienced support from even just a few in their social networks (11). Betsy, a 48-year-old African American mother of four, had exercised her right not to disclose just minutes before our meeting. She told how she had arrived at the interview, which was at the LAS office:

The cab driver that brought me here, I was tellin’ him, “Would you drop me at this address?” And he said, “What’s the name of the place?” I didn’t even want to tell him the name of the place. But I come out and tell him and he said, “Do a lot of people go there?” I said, “Hell, yeah.” And he asked me if I’m sick. I said, “I don’t know, I got to wait til tomorrow to find out.” (223)

In a situation in which she didn’t feel safe, she chose not to reveal her status, while in situations that she perceived as less risky, such as with certain close family members, she had chosen to be open about her HIV.

Not all of the women felt comfortable sharing their status with the family they live with, however. Some constructed more complicated stories to cover for their symptoms, doctor’s visits, lifestyle changes, and medications. Cancer was a common story used by the women in this study. Sheila says, “I just tell them I have cancer, which I do too. You know, a type of cancer that has to be removed every year” (62). Betsy has adopted a similar strategy. “Only thing I can say is, I’m in denial, and I’m tellin’ my kids I got cancer,” she reports (221). Cancer is not stigmatized the way HIV is. With sexually transmitted infections,

society automatically blames the infected individual's lifestyle (Heffernan 2002: 170), but people are not generally blamed for cancer. In addition, the cancer story can be used to explain fluctuations in weight, medication, and frequent trips to the doctor or hospital. Such an effective cover allows women with HIV/AIDS to receive the kind of encouragement and even physical help they might need, because cancer evokes sympathy rather than fear or disgust.

Even those women who weren't covering their HIV story with one about cancer had a comparison to make between the two illnesses. Betsy explained why she prefers to think of herself as a cancer victim when she said, "For me, [HIV]'s a form of cancer. 'Cause you gonna die from it eventually, if you don't take your medicine... I feel people shouldn't judge people" (221, 229). For Granny Kitty, thinking of her sickness as cancer helps her manage fear. "You know, I just try to deal with it as it's an illness. It's not a death sentence, it's an illness, just like cancer, just like leukemia" (112), she said. To many, cancer is less fearsome, partly because it lacks stigma and partly because of its more numerous treatment options. Sarah had found this to be true. She explained, "I just compare [HIV] to other things, like alcoholic or drug addict, cancer patient, whatever, it's all the same boat" (22).

These comparisons help these women frame their illness as something less stigmatizing in order to construct a safe illness identity. There is less to fear or feel ashamed of in a case of cancer, so a cancer story is one that women can tell themselves as well as others to evoke sympathy. This strategy was particularly important for those women who still had children at home to care for, since they must reconcile their sickness with their identities as mothers and caretakers on a daily basis. Telling *sometimes*, (when it is safe, such as telling a social service provider who could help with housing or drug co-payments but is professionally bound to confidentiality) allows these women to access the services they need but also shelter their families from HIV-related stigma.

The women with children at home were especially inclined to selectively disclose their status in order to avoid HIV-related stigma. Pat, who cares for two of her sons and a grandchild, explained that, "You gotta know how to wear a hat. Certain people you say certain things in front of, certain things you do in front of certain people. It's

like puttin' it on and takin' it off. You gotta know when to do that" (212). Granny Kitty learned about the benefits of selective disclosure the hard way. When she revealed her status to her supervisor, she was fired. Asked what she had learned from HIV, she responded, "One of the biggest lessons I've learned [this past eleven years] is how not to tell somebody" (108).

Granny Kitty had experienced severe HIV-related symptoms, including chronic diarrhea, loss of bladder control, and severe weight loss, all of which made it impossible for her to retain another job. Women with HIV/AIDS have no control over the physical havoc the virus wreaks on their bodies, but if they are able to manage its stigma, they can be strengthened emotionally. Becker spoke of social deviants using their labels to educate others, but I think his third category can and should be broader in the case of those with HIV/AIDS. Fear of stigma may prevent people with HIV/AIDS from using their label to educate others, but they may find other ways to benefit from their status. Nine of the women I spoke with showed amazing emotional resourcefulness in the way they had come to manage their HIV status.

Benefiting from Stigma

Among the women most recently diagnosed, I saw only the first two of Becker's choices demonstrated; the women who had benefited from their label had been diagnosed longer. For example, when Sheila was first diagnosed in the 1980's, she told no one. "If you told anybody back then, it was too dangerous. They might kill you" (62), she explained. Just after her diagnosis, she received death threats that could only have come from the clinic where she had gone. Since that time, there has been a change in climate, and HIV-related stigma has lessened (Poindexter 2005: 64). Sheila herself has made tremendous emotional progress. When interviewed for this study twenty-three years later, she was willing to use her real name. She was also able to identify positive changes in herself since her diagnosis. She told me that having HIV helped her learn to take care of herself (68).

Granny Kitty also demonstrated how a woman might benefit from HIV-related stigma. Stigma has cost her friendships, her job, and her income. When she told her best friend she was positive, the friend "told everybody that she saw" (102). Later she was fired from her job

of sixteen years when she revealed to her supervisor that she had HIV, and she spent five years fighting the government for her disability benefits once she found herself unable to work (103-4). In spite of these obstacles, she was the only participant (aside from the negative case study) who had done any HIV-related advocacy work. When asked how she got to a place where she was willing to get in front of others to talk about her HIV experience, she said, "I think it's ... knowin' the stigma that it caused, and there's still people out there that treat you like a pariah, even though you're not. You're just a human being tryin' to make it though this world with an illness" (113). Granny Kitty was able to take her own experiences of HIV-related stigma and turn them into motivation to help others avoid similar trauma.

Helping others seems to have advantages for women with HIV. In their 2004 study on women's experiences of stigma, Sandelowski, Lambe, and Barroso found that many of their subjects went on to do advocacy work. That was not the case in this study. While the women expressed an interest in such work, material constraints prevented them from becoming involved. Several of the participants in the study said that they would like to begin volunteer or advocacy work, but they lacked the resources (or health status) necessary to do so. Sarah admitted, "I always wanted to be a advocate, to talk to other people about [HIV], but then I always sick and not well...so I stay here" (2).

The opportunity to engage in advocacy work could be empowering for women with HIV like Pat, who reported feeling a real need to do more with the life they have left. Of the three women who pointed out the ways that HIV had helped them to grow, Pat's was the most amazing story. She has not had an easy journey since receiving her HIV diagnosis while pregnant with her fifth child. "At the beginning," she recalled, "I couldn't keep it real. I couldn't talk to [my kids]; I fell into drugs; I didn't care. I just knew that I was gonna die ... but when I found out my baby was negative, I regrouped" (201). "Regrouping" meant going back to school to provide a positive example for her adolescent son who had recently dropped out. She reported that she has been taking classes in order to pass her GED high school equivalency test. She mentioned several times how precious her youngest child was to her – more so even than her other kids. This

makes sense in the light of Sandelowksi, Lambe, and Barroso's finding that "women wanted to be seen as women and mothers, but also as better women and mothers because they were HIV-positive" (125). For Pat, this chance to raise another child was another chance at life. Her prayer to be able to care for her child had become a prayer "to be able to share [her] story with somebody and try to make a difference in somebody else's life" (201). She has become the outreach director for her local community center, and instead of doing drugs, she works to help teenagers stay off of them. She said,

My story about HIV would be that the difference it made in my life was to make me better. Accepting I have HIV turned me out to be a better person, 'cause I probably wouldn't never have thought about goin' back to school. I never would have wanted to volunteer. I never would have wanted to help people. I was totally different from the way I am now. (213)

How Women Overcome

Time and social support both help women manage HIV stigma, but to effectively challenge a stigmatized identity in a constructive way, women need material resources. With the exception of the negative case study, the women participants largely lacked these resources and needed to consider their personal reputations in addition to the well-being of their children.

Pamela, the negative case study, had a broad social support network that the other women lacked, and she also had no children. With the financial and emotional support of her family, she survived PCP pneumonia and has since joined the staff of Lowcountry AIDS Services as an outreach worker and gone back to work part-time. Because of her higher level of education, stable financial situation, extensive support network, and the resources of the non-profit agency at her disposal, Pamela has been able to successfully do advocacy work and resist stigma in a public arena. Of the ten women interviewed, she was the only one who was open about her status with everyone she knows.

Middle-class whites and men can more easily take to the streets, make posters, and reclaim words like "queer." Low-income minority

women caring for their children do not have access to the same opportunities and resources as they work to reverse stigma. When we spoke about people with HIV/AIDS and their need for a voice, Pamela asked, “Are we gonna be bound by other people? Will we allow them to keep us captive, and do we want them to put us on an island and say ‘oh, these are all the HIV-positive people,’ or do we wanna say, ‘you know what? We have a voice, and we have a right to live, just as you live as well’” (183). However, realizing they have a voice may not be enough for people with HIV/AIDS who are disenfranchised in other ways (as are the poor, single mothers in this study). Even if they do speak, their message may not be heard by a society that mutes stigmatized voices. As Farmer writes, “The majority of women with AIDS [have] been robbed of their voices long before HIV appeared to further complicate their lives. In settings of entrenched elitism, they have been poor. In settings of entrenched racism, they have been women of color. In settings of entrenched sexism, they have been, of course, women” (6).

The Trouble with Traditional Solutions

The question remains: What can we do to help this majority of HIV/AIDS-infected women overcome the trauma of stigma? The traditional solution has been to provide support groups where they can connect with each other. Of all the women interviewed, Maya was most in need of support. She stood out from the other women in the sample because she was diagnosed so recently and had revealed her status to no one but her case manager at Lowcountry AIDS Services. However, the support group solution is no solution at all for her. She is unable to attend group meetings. As she reports, “I don’t have a way to get there. My son works, so you know when I leave here I have to go home to give him the car. So then I’m home, by myself... I’m by myself a lot” (84).

If she were able to find transportation and overcome her fear of talking about HIV, Maya might benefit from meeting others with HIV, because she does suffer from isolation. Solidarity among HIV-positive women is liberating; there is no HIV stigma in situations where everyone has it. Pat was first treated at a hospital where everyone had HIV. She explained, “It was a shame, seein’ somebody you know. That was

kinda uncomfortable. But ... if they sick too, who they gonna tell?" (211). In such a group, secrets are safe. However, the support group framework does not seem to be the most uplifting or empowering way to connect these women with their peers.

Maya had yet to share her HIV status with her own children, a reluctance the other participants shared. Walker's study of "Women with AIDS and their Children" validates this finding, reporting that sixty-six percent of the mothers in her study did not report their status to their children "due to anxiety and fear related to the stigma and resulting isolation associated with HIV and AIDS upon disclosure" (1998: 28). It is no wonder that these women found themselves socially isolated and have difficulty committing to support groups where their HIV status is the focus of discussion. Maya and women like her have too many obstacles to overcome to be able to effectively use support groups to meet their urgent needs.

Other women interviewed were past that stage of their illness, having disclosed their status to at least one trusted family member. Granny Kitty actually attends a mental health support group, but she expressed mixed feelings about it. Twelve years after her diagnosis, she is relatively open about her status. She reports, "I just choose to tell certain people that I don't think it would bother, especially [my son's] friends" (108). Her youngest son knows about her HIV status and lives at home, so she constantly preaches safe sex to him and his friends. Going to a support group is of limited use to her in terms of dealing with her HIV, since she has moved on to a place where she can continue to move forward and to foster the growth of others (for example, through her participation in an AIDS panel at a local medical university). Rather than encouraging and "supporting" her, she had found the group depressing.

Similarly, Sarah described the support group she had attended as a room full of people experiencing situational depression with nothing they can do to improve each other's circumstances. She was ambivalent, saying, "I might be down, because of my life... So sometime you want to go back [to the group] sometimes you don't" (33). She no longer attended a group, explaining that the one she attended "went wrong" (27). When asked about her experience, she said, "I didn't say much. I never said much at all. A lot of talking one

way, then we switch to something else. I was like, ‘okay, whatever’” (35). It became clear that the support group had failed to help her in key ways when she commented that her own children would be better off getting an HIV education from a doctor or “professional person” (23). If women with HIV are taught anything, it should be the power of their narratives. Although Sarah had accepted her HIV status and wanted to do her own HIV/AIDS-related advocacy work, she had not realized the significance of her own story to impact the lives of her children.

However, even a woman with knowledge that her story holds power cannot resist stigma if she still lacks the resources to overcome it. For example, Sarah is reluctant to admit to her HIV status because she lives in an area where she feels it would be dangerous to “come out” as HIV-positive. She lacks the means to live anywhere else (or the basic resource of physical safety), so she is unable to begin the advocacy work she envisions.

Effective Relief

A program to connect women (like Sarah) with volunteer opportunities would give them the chance they are looking for to give back. Crucially, such a program would have to consider their needs for childcare, transportation, and confidentiality. These same considerations are necessary for viable support groups, so a volunteer program would not require more resources and could even be more valuable to participants than the current support group programs.

While these interviews demonstrate that women are taking small steps as they are able to fight the spread and stigma of HIV/AIDS, there is a real need for programs that will empower them by providing them with material resources. According to Paul Farmer, a noted doctor and anthropologist,

Endeavors focused on AIDS, though crucial, must be linked to efforts to empower poor women. The much-abused term “empower” is not here meant vaguely; it is not a matter of self-esteem or even parliamentary representation. Those choosing to make common cause with poor women must seek to give them control over their own lives. (36)

Farmer emphasizes that these women must gain control of property, production, and formal political structures in which their voices are not heard (36). His point is that women require real, material resources in order to improve their life chances, rather than the *talk* of help that is all women currently have.

Women with HIV/AIDS have only had support groups as forums to exercise their voices. Quantitative literature supports the usefulness of these groups to women with HIV/AIDS in preventing the internalization of stigma (Lee, Kochman, and Sikkema 313), but this study suggests that women who participate in these groups have important needs that are left unmet by their participation. Further research is needed to investigate the value of support groups to women with HIV/AIDS and to consider more effective, more empowering options. A qualitative study of HIV-positive women who volunteer could be useful to determine if enabling women to participate in volunteer work would be of greater benefit than support groups. Future studies should ask women with HIV/AIDS directly what practical support they need, as well as examine current programs and policies to propose revisions that would place material resources in the hands of women so they could do advocacy and relief work in their own ways. Social service providers should consider what they can do to help women with HIV/AIDS build social networks in empowering ways, perhaps by providing them with group volunteer opportunities or establishing other innovative forums for the women to share their stories.

When women are thus empowered, they find hope they can share with their children and other women. Because I provided a platform for them to speak, safe from stigma, the ten women I interviewed entrusted me with their stories, which were rich, valuable, and valid. Pamela told me, “when you see someone close to you pass away from this disease, it causes you to have more compassion for other people” (176). If told, these women’s stories could inspire compassion so we would not have to wait for deaths like Arthurene’s in order for people to care. Their stories could inspire other HIV stories like Pat’s, summarized in her words: “I haven’t finished growin’ yet; I got a long ways to go to reach where I’m trying to reach” (207). For those researching women with HIV and for the women themselves, as Pat said, “It’s really just the beginning” (207).

Appendix: Interview Guide

Qualitative sociological literature shows that an effective way to gain access to narratives is through the use of semi-structured naturalistic interviews. These interviews put participants at ease and allow them the freedom to tell their stories as they were lived, rather than having to fit them into a pre-determined structure of questions. Exploratory and descriptive in nature, this type of research lays the groundwork for more in-depth and extensive study.

Mine is a narrative analysis study, so my interviews took a conversational form. If the questions seem open-ended, this was a deliberate choice on my part. It was essential to my research questions that I avoid “putting words” into the mouths of my participants so that they could tell their stories in their own words.

SUBJECT AREA: Initial experience with the Diagnosis

Lead Question: Can you tell me about the day you received your diagnosis?

- 1) How did you find out your positive status?
 - a) After you heard the diagnosis, what did you do?
- 2) Did you tell anyone about the diagnosis right away?
 - a) Was there anyone that you didn't want to tell?

SUBJECT AREA: Experience with HIV

Lead Question: Has your life changed much since your diagnosis?

- 1) Can you walk me through your daily routine?
 - a) How does this compare to your life before the diagnosis?
 - b) When you were diagnosed, were there things (such as friendships or a job) you were afraid of losing?
 - c) What do you miss most about your life before the HIV diagnosis?
 - d) Have your habits and routines changed since the diagnosis?
- 2) What is the most important thing that you have learned from your HIV experience?
- 3) What do you feel is the most difficult part of being HIV positive? How do you cope with those difficulties?
- 4) Do you find that you often feel angry, anxious, or depressed about your diagnosis? How do your feelings now compare to your feelings when you first found out?

- 5) What do you most enjoy doing in your life?
- 6) If there were one thing that you could improve in your life, what would it be?

SUBJECT AREA: Social Networks, Social Status, and Role Sets

Lead Question: Have any of your close relationships changed significantly since your diagnosis? If yes, how so?

- 1) Do you have friends with HIV? (Did you lose any friends after revealing your status?)
- 2) Is there anyone that you turn to for support? Can you tell me about your relationship with that person?
- 3) How often do you socialize with others?
- 4) Do others rely on you? If yes, how so?
- 5) Do you have children? If yes, does your diagnosis put any strain on your ability to care for your children?
- 6) Are you employed? If no, has HIV kept you from being employed? If yes, do you feel that that your illness impacts your performance at work? Do others at work know that you are HIV positive?

SUBJECT AREA: Perceptions

Lead Question: What does it mean to you to be HIV-positive?

- 1) When you think about your diagnosis, is there one word or one image that seems to really sum up the experience?
- 2) Do you view people with HIV differently now that you are HIV-positive? (Is it easier to have HIV-positive friends than friends who are negative?)
- 3) Do you tell people your status? If yes, how do you tell them? If not, why?
- 4) Do you feel people treat you differently now that you have HIV? If yes, what makes you feel this way?
- 5) Do you ever feel that others judge you? If yes, can you tell me about one of those experiences?

SUBJECT AREA: Demographic Questions

Much of this information will be provided in response to questions in other areas. I include this section in case one of these is not addressed elsewhere in the interview.

- 1) Race
- 2) Education level
- 3) Employment status
- 4) Year of diagnosis
- 5) Age

SUBJECT AREA: Sum Up

Lead Question: Is there anything you would like to add to what we've talked about today?

- 1) What would you most like others to know about HIV?

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