



Institute for Policy Research
Northwestern University
Working Paper Series

WP-12-01

**‘Dying From’ to ‘Living With’:
Framing Institutions and the Coping Processes of African
American Women Living with HIV/AIDS**

Celeste Watkins-Hayes

Associate Professor of Sociology and African American Studies
Faculty Fellow, Institute for Policy Research
Northwestern University

LaShawnDa Pittman-Gay

Postdoctoral Fellow, National Poverty Center
University of Michigan

Jean Beaman

Postdoctoral Fellow, Institute for Policy Research
Northwestern University

Version: November 2011

DRAFT

Please do not quote or distribute without permission.

Abstract

How do HIV-positive individuals transition from believing and behaving as though they have a “death sentence” to interpreting and coping with HIV as a chronic but manageable illness? Using interview data collected from 30 HIV-positive African American women, this working paper reveals how and why interactions with nonprofit and government institutions help to explain variation between those who thrive and those who do not following an HIV diagnosis. The researchers argue that “framing institutions” shape the form and tenor of coping trajectories by offering *initial information* about one’s HIV status, a *conceptual framework* for understanding what it means to have HIV, *language* to talk about one’s condition, and *resources* to begin restructuring one’s life in the wake of a diagnosis. Ultimately, the researchers highlight how a diverse array of nonprofit and government institutions not only play a critical part in helping women cope with HIV, but also renegotiate their self-conceptions as black women in the wake of receiving another stigmatizing social marker. In short, organizational ties shape women’s movement from beliefs and behaviors that suggest that they are “dying from” this disease to attitudes and actions consistent with the notion that they can “live with” HIV.

‘Dying From’ to ‘Living With’: Framing Institutions and the Coping Processes of African American Women Living with HIV/AIDS

INTRODUCTION

A serious health diagnosis can drive a person’s identity into a state of flux. Individuals in such circumstances often undergo meaning-making and strategizing to achieve stability in the face of uncertainty (Pierret, 2003; Siegel & Krauss, 1991). Coping with a newly discovered health status is therefore a complex, multidimensional process that is presumably shaped by available resources and demands; the psychological and social dispositions of individuals; and the family, friends, and medical providers who constitute one’s support network (Bury, 1991; Charmaz, 2000; Parsons, 1951).

We suggest that a diverse array of non-profit and government institutions join medical providers in supporting the coping process for socially marginalized populations. Our study of African American women living with HIV/AIDS as they learn to accept their health status and adopt attitudes and behaviors meant to slow the progression of the disease reveals how individual relationships *with* and *within* institutions facilitate and frame the interaction between a newly acquired medical status and existing social statuses and identities. We argue that the role played by ‘framing institutions’ in these women’s lives is critical in explaining how and why members of socially marginalized groups adopt healthy behaviors to fight HIV. We begin by identifying two issues at the intersection of medical and organizational sociology literatures that deserve greater attention: (1) illness coping strategies that develop within diverse institutional environments and (2) the interaction between individuals’ social locations and institutional experiences in shaping the coping process. After providing background on HIV/AIDS among

black women and outlining how data for this study were collected, we examine the interactions that respondents characterize as instrumental in helping them come to grips with their HIV diagnosis and re-formulate their lives in its wake. We contrast the lives of these women before and after establishing such relationships and warn that, despite institutional involvement, personal and institutional barriers may continue to challenge their ability to manage their health consistently with prevalent prescriptions for healthy living with HIV. We conclude that the *framing institution* is a useful conceptualization for understanding how stigmatized populations manage chronic illness.

REVIEW OF RELEVANT LITERATURE

Following the work of Parsons (1951) and Strauss and Glaser (1975), several key findings about the coping processes of people living with chronic illness have been established. Unlike acute illnesses, chronic illnesses exhibit an “unfolding” or “emergent” quality in which sufferers must continuously negotiate how they understand their conditions and reconcile these beliefs with their health management behaviors (Bury, 1982, 1991; Charmaz, 2000). In the early stages of a serious health diagnosis, individuals generate preliminary illness-management strategies to achieve or maintain a sense of control and emotional equilibrium as they struggle with shock, anguish, anxiety, powerlessness, and fear of mortality (Pierret, 2003; Siegel & Krauss, 1991). Chronically ill individuals must interpret the meaning and significance of the illness; tolerate, adjust to, and reduce negativity; maintain a positive self-image; access resources; and maintain satisfying relationships with others (Pierret, 2003; Siegel & Krauss, 1991). Such ongoing adaptations have been shown to improve quality of life and slow disease progression (Siegel & Krauss, 1991).

While Bury (1991), Ball et al. (2002), Ingram and Hutchinson (1999) and others have suggested that the quest for meaning and the strategies that people deploy serve as components of the coping trajectory, we know little about the institutional environments in which these emerge and are sustained. Along with personal spirituality, social support networks comprised of friends, family members, and intimate partners are thought to help build and sustain coping trajectories (Bloom et al., 2001; Gielen et al., 2001; Owens, 2003; Serovich et al., 2001; Simoni et al., 2005). Medical providers and other health professionals offer specialized knowledge for naming and framing diagnoses and prescribing health management strategies (Brown, 1995; Davis, 1960; Fox, 1974; Friedson, 1970; Parsons, 1951; Perakyla, 1998; Stewart & Sullivan, 1982).

In cases in which an illness is highly stigmatizing and there are few coping resources available, affected individuals might search outside of their social, familial and medical support networks to help them integrate the illness into their everyday lives. In the case of HIV/AIDS, support groups, legal and housing services, and advocacy groups have been found to be critically important in this regard (Anderson, 1992; Berger, 2004; Doyal & Anderson, 2005; Epstein, 1996; Jennings et al., 1988; Kobasa, 1990). Yet, if we view medical providers and HIV-focused support groups and services as the most significant institutional actors assisting HIV-positive people, we underestimate the role played by other institutional ties (Crossely, 1998).

The social meanings that people assign to illness experiences and the strategies they deploy to address their health through their institutional ties must be explored in the context of stratified social environments. Social status based on race, class, gender, and sexuality shapes the micro-processes that affect coping by arming individuals with varying levels of power and access to institutional resources (Lutfey & Freese, 2005). To understand this we must do more

than observe how individuals cope with disparities in access to or the quality of medical care (Smedley et al., 2003) and learn how personal biographies and environments interacting with institutional experiences shape the *process* by which individuals understand and respond to a serious health diagnosis.

Black women living with HIV/AIDS face distinct challenges that shape the progression of HIV coping processes, necessitating an analysis focusing on their experiences (Farmer, et al., 1996; Gilbert & Wright, 2003; Goldstein and Manlowe, 1997; Marcenko & Samost, 1999; Owens, 2003). The Centers for Disease Control (CDC, 2009) reports that black women represent 14% of the female population yet currently account for two-thirds of new HIV infections among women. In 2007, HIV/AIDS was the third leading cause of death for black women ages 25–44.

Several factors cause such disproportionate HIV infection rates within black communities. Cohen's (1999) *Boundaries of Blackness* provides a comprehensive explanation. When cases were first reported in the 1980s, mainstream media, public discourse, public health interventions, and political activism focused on the experiences and needs of white gay men, whose hard-fought mobilization efforts are well documented (Epstein, 1996). The initial framing of HIV thereby largely ignored African American AIDS victims. Black political leaders and black media contributed to this collective silence as infection rates rose. Cohen (1999) argues that class divisions likely fueled this dynamic as community leaders who invested in a politics of racial respectability were reluctant to rally behind those most likely to be infected—gay men, intravenous drug users, low-income women, and sex workers. Moreover, tensions arose between black gay men who spearheaded the earliest HIV-related activism and human services professionals who entered the AIDS arena later.

Adding to these political setbacks, environmental factors also encouraged the rise in HIV infection rates among blacks. Media obsession with black men who have sex with women but do not disclose their sexual relationships with men, or “the Down Low” phenomenon, has led to blaming increased infection rates among black women on “DL men.” However, there is little scientific evidence to support this explanation, which de-emphasizes the more significant structural risk factors (Ford et al., 2007; Millett et al., 2005; Peterson et al., 1993). Compared with whites, blacks are more likely to live in segregated communities where poverty, homelessness, drug infestation, high crime rates, and mass incarceration facilitate the spread of HIV by destabilizing sexual relationships and lowering the quality of self-care (Adimora & Schoenbach, 2005; Fullilove et al., 1993; Grinstead et al., 2001; Johnson & Raphael, 2006; Kim et al., 2002; Mahon, 1996). Lacking affordable and accessible health care also discourages many blacks from seeking HIV testing, prevention, and treatment services (Gardner et al., 2007; Ickovics et al. 1996; Misener & Sowell, 1997). As a result, the CDC (2010) has suggested that 2.1% of heterosexuals living in high-poverty urban areas are infected with HIV, well above the 1% rate associated with a generalized epidemic.

Many HIV-positive black women confront what political scientist Berger (2004) terms “intersectional stigma”, marginalization based on HIV status as well as race, gender, socioeconomic status and sexuality. Black women are typically diagnosed at later stages of HIV/AIDS, experiencing more debilitating symptoms and dying sooner than do their white counterparts (CDC, 2009). One reason for this is that stress associated with institutional and interpersonal racism and economic hardships compounds the psychological distress common among people living with HIV/AIDS (Battle, 1997; Catz et al., 2002; Ciambrone, 2001; Feist-Price & Wright, 2003; Gilbert & Wright, 2003; Jones-DeWeever, 2005; Zierler & Krieger,

1997). Cohen (1999) posits that, within black communities, many of these women are viewed as undermining racial respectability, linked to drug addiction, sexual promiscuity, poverty, and welfare dependency. As the stigma of the disease, and the compounded effects of cultural norms that emphasize family connection to overcome difficulties, weakens the support they would normally find in their kinship networks, they suffer more acutely than others do (Misener & Sowell, 1998; Sobo, 1995; Stein et al., 2009).

Research suggests that women living with HIV/AIDS are also more likely to have histories of, and current experiences with, domestic and sexual violence (Ciambrone, 2001; Wyatt et al., 2002). Insofar as heterosexual transmission causes most HIV infections among women, their relative powerlessness in a patriarchal culture undermines their abilities to successfully negotiate safe sex practices and assimilate disease management protocols provided by medical and social institutions (CDC, 2009; Ciambrone, 2001; Sobo, 1995; Brander & Norton, 1993; Coward, 1994). Thus, black women coping with HIV/AIDS contend not only with health management obstacles but also with renegotiating their self conceptions as black women while facing yet another stigmatizing social marker.

More recently, formal organizing through conferences, community education, and targeted interventions have increased public acknowledgment and acceptance of HIV/AIDS in the black community, improving basic services for those in need. This suggests that we should conceptualize the experience of coping with HIV/AIDS more broadly, introducing dimensions that extend beyond women's immediate social networks to add greater complexity to the traditional understanding of the 'sick role' (Parsons, 1951). Women are more likely to adhere to treatment regimens when they have positive relationships with providers, confidence in the knowledge being provided, and an opportunity to demonstrate agency in their care (Gardner et

al., 2007; Ickovics et al. 1996; Misener & Sowell, 1997). This suggests that women's *institutional relationships* may help explain variation between women who thrive and those who do not following an HIV diagnosis. How do African American women living with HIV formulate attitudes and behaviors that strengthen and protect their health? What do institutions offer to help women move from believing that they are 'dying from' HIV to believing that they can 'live with' their infections? What does this reveal about the role of institutions in the lives of marginalized populations as they marshal the resources to grapple with pivotal life events and situations?

FRAMING INSTITUTIONS

Framing institutions generate language, adaptive skills, and practical knowledge that shape how individuals interpret a new life condition and whether they ultimately see it as a platform for growth. They operate as intermediaries between micro-level perceptions and actions and macro-structural forces and systems, positioned between one's personal response to a new circumstance and the larger set of privileges and disadvantages that she experiences due to her social location. Inspired by Goffman (1974), who defined frames as "schemata of interpretation" on which individuals understand and respond to events (21), we see institutions and individuals as active, agentic, dynamic, and at times contentious in the project of reality construction (Benford & Snow, 2000).

Framing institutions are not consequential only for people living with HIV, but the disease's unique medical and social implications demonstrate and inform how framing institutions operate within the coping trajectory. Coping with illness often means simultaneously managing physical demands and a stigmatized social status that obliges its carriers to face a kind

of social death—the potential loss of connections, existing resources, and social standing (Patterson, 1985). As society has historically assigned moral labels to the infected, those with HIV must learn how to reconcile feelings of “guilt” and “innocence” (Alonzo & Reynolds, 1995; Lather & Smithies, 1997; Marcenko & Samost, 1999; Remien et al., 2006; Scambler & Hopkins, 1986; Siegel & Krauss, 1991; Tewksbury, 1994; Weitz, 1990). These dynamics serve as filters through which individuals interpret and address their physical symptoms and the social significance of their diagnoses.

Inasmuch as those in an individual’s preexisting social network may understand HIV/AIDS poorly, framing institutions can provide alternative means of support. They differ from other organizations in that they facilitate or impede a “turning point” that represents a marked change in coping strategies. *Framing agents* are actors within these institutions who individually inform how illness is constructed and addressed, offering explicit and implicit directives for coping. Framing agents’ interventions can coincide or conflict with those of the broader framing institution, adding further complexity to individuals’ coping trajectories. People may utilize multiple framing institutions, each offering tools with which to accept and address a particular circumstance. Framing institutions lead people to adopt positive or negative behaviors and attitudes, depending on the *initial information* that they share about one’s HIV status, the *conceptual framework* they offer to understand having HIV, the *language* used to talk about one’s condition, and the *tangible resources* offered to begin restructuring one’s life. In short, they facilitate a set of social interactions that can prove pivotal in health-based decision-making.

DATA AND METHODS

Data are drawn from a qualitative study conducted by the first author from 2005 to 2008 on the social consequences of HIV/AIDS for African American women. This group was selected as a population of focus because of its disproportionate rates of HIV infection relative to white women and Latinas. The overall goal of the study was to explicate the effects of HIV on four social domains: social support, labor force participation, child bearing and rearing, and intimate relationships. Data were collected through two in-depth semi-structured interviews with thirty HIV-positive African American women, a group small enough to conduct an in-depth analysis but large enough to generate the analytical depth necessary to show clear patterns among respondents.ⁱ

Potential participants were alerted to the study through Chicago-area healthcare providers, HIV social service agencies, and word-of-mouth.ⁱⁱ Subjects were recruited so as to maximize the contrast between HIV-positive women who relied heavily on AIDS Service Providers (ASPs) and those who used non-ASPs or had fewer institutional ties. This helped to highlight the importance of framing institutions and to portray the range of relationships that women developed with organizations that helped them cope with their HIV status.

Women were eligible to participate in the study if they: (1) self-identified as black; (2) were born biologically female; (3) were English-speaking, native-born, and non-Hispanic; and if, as the time of recruitment, they: (4) self-identified and were officially documented as HIV-positive (or AIDS-diagnosed); (5) were living in Chicago; (6) were 18–45 years of age; (7) were not hospitalized, in hospice care, or incarcerated; and (8) had received their HIV diagnoses more than six months earlier.ⁱⁱⁱ

All 30 participants self-identified as U.S.-born black women with an average age of 36 years. Four respondents had been diagnosed with AIDS at recruitment, and the rest were HIV-

positive. Five of the women reported annual household incomes over \$50,000, and seven reported incomes in the \$20,000-49,999 range. Most respondents were, however, impoverished, reporting yearly household incomes of less than \$15,000.^{iv} The twelve that reported \$20,000+ annual household incomes were working at the time of recruitment. All respondents have children (two on average). Five women were married, three were divorced, and four were widows. The rest were single. HIV diagnoses were made between 1984 and 2004, with the average year of diagnosis being 1996. All participants, regardless of socioeconomic status, possess private or publicly subsidized health insurance and have access to HIV medical specialists and highly active antiretroviral therapy (HAART). Names of respondents and the institutions mentioned have been changed to protect confidentiality, per Human Subjects approval by the university Institutional Review Board.

Interviews were tape-recorded and transcribed. The interview transcripts were then coded in two stages using HyperResearch data analysis software. Transcripts were first coded following themes identified in the interview guide. We were intrigued by the women's accounts of their HIV coping trajectories, suggesting that the majority of respondents had experienced what we termed a 'dying from' to 'living with' process that rendered them able to constructively address their condition. We found ourselves building on extant theories of stress-related growth (Siegel & Schrimshaw, 2000), wanting not only to *describe* the process using the 'dying from' to 'living with' conceptualization but also to *explain* the catalysts for this process. We then noticed the strong link between institutions and women's coping processes in the data, and interview transcripts were recoded using a new set of emergent codes, thereby unpacking the role institutions played in shaping *how* participants adjusted to their HIV status.^v Through this data analysis, our concept of the framing institution emerged. This multi-staged coding process

therefore employed a grounded theory approach that allows categories to emerge from the data obtained, rather than imposing a theory upon data before research has begun, while maintaining connections with the extant literature to draw theoretical conclusions (Straus and Corbin, 1990).

FINDINGS

“I thought it was a death sentence”: The Role of Institutions in Naming and Framing HIV

We trace respondents’ coping trajectories from diagnosis to the active management of HIV/AIDS to demonstrate how framing institutions perform at each stage of the ‘dying from’ to ‘living with’ process. Framing institutions make their first contributions to women’s coping processes by providing the initial diagnosis. Shelia explains her reaction to the HIV diagnosis she received while hospitalized with pneumonia in 1994 at age 32:

I started crying before [the doctor] even got it out. And I was distraught. I was emotionally broken down . . . I thought it was a death sentence. I just knew I was going to die soon. Matter of fact, after I left the hospital, I used [drugs] more. I was in denial. I didn’t tell nobody for about two years.

The news triggered a downward spiral of denial and drug abuse as she, like the majority of our respondents, immediately associated HIV with physical, social, and emotional death. This is not surprising given that protease inhibitor-based HAART was not widely available until 1996, years after Sheila and approximately 55% of our sample were diagnosed.^{vi} Consistent with previous research, many women upon diagnosis failed to properly manage their health with medication, diet, rest, exercise, and regular doctors’ visits; ignored depressive symptoms; and returned to (or initiated) risky behaviors, including those that may have led to infection in the first place (Barnes, et al., 2000; Broman, 1996; Hackl et al., 1997).

Upon diagnosis, a conceptual framework begins to develop that structures how women address medical directives, take care of their bodies, and battle their own sense of internalized stigma. Women funnel multiple and often conflicting messages about HIV into a set of organizing principles, generating their initial approach to coping with the disease. Framing institutions inform this process, as the messages that doctors and nurses couple with the diagnosis immediately affects how women conceptualize their situation. For example, Jackie, who was diagnosed with HIV in 1991 after giving birth to her daughter, remembers exactly how she was told:

[The nurse] told me, “I want you to know that you’re HIV positive.” So I kind of sat there in shock, kind of like blank, because I don’t believe too much she said registered

And then there was another lady who . . . asked me, “Can you tell me how you think you got it or who would do this to you?” And she was like, “Who would do this to you?” . . .

That’s when my madness started. I went and had me a drink. And I wanted the strongest . . . [they had] And I didn’t tell anybody.

What Jackie remembers about the diagnosis encounter helped frame how she initially understood the implications and gravity of her condition. Although the question about “who would do this to [her]” presumably was asked to help trace the epidemiology of the illness, it reinforced the message that HIV represented some sort of violation, complete with nameable “culprits.” This framing experience, with the shock of the diagnosis, left Jackie feeling ashamed.

Traditional hospitals and clinics are not the only framing institutions providing initial information and conceptual frameworks that shape what HIV means for women. While Stevie was incarcerated for drug possession, prison offered her the first tools with which to understand and address her diagnosis. Although she took an HIV test voluntarily in 2002, Stevie was not

prepared for the shock of the results: “So when I took it and she told me that I had HIV, I passed out” Navigating prison with her newly discovered status would become a pressing concern. The advice given by the prison’s health advocate to presumably protect Stevie’s confidentiality solidified her belief that HIV required silence to avoid stigmatization:

I felt so bad because I couldn’t talk to nobody about it because [she told me], “Don’t let nothing like that get out Don’t tell anybody.” And then it hurt me so bad because . . . this other young lady was in [prison], and she was doing them [medication] cocktails [Someone] was like, “Oh, man, I don’t want to be by that bitch. That bitch got AIDS.” And then one time . . . the girl [who was HIV-positive] asked someone for a cigarette and [the one she asked] was like, “No, You crazy, you got that shit.” I felt sorry for her.

The health advocate’s advice, coupled with the public rejection of another known HIV-positive inmate, sent Stevie explicit and implicit messages. In trying to explain why she avoids medication against the advice of her doctors even outside the prison walls, Stevie maintains, “I am half a woman because I got something they can’t cure and I can’t shake.” Since her diagnosis was initially framed by the belief that she cannot ‘live with’ HIV, she effectively relies on what protected her in prison: silence. Stevie feels depressed and isolated from others, including her own family. Turning inward, she seems unable to accept, productively talk about, or positively address her health status, demonstrating the power of a negative framing institution.

Dani had a very different framing experience when she was diagnosed in 1993, three years before HAART’s wide availability. She too initially saw her diagnosis as a death sentence:

[T]he first words out of my mouth was, “God’s punishing me.” But then [my] doctor said, “God doesn’t punish us.” And I was like, is he really telling me this? And I stopped crying, because of course I was crying and all upset. And he said, “No, God loves you.”

And I'm thinking, how in the world does God love me? This is so dirty. That was my biggest problem . . . I couldn't get clean . . . eh, from the inside, and there is no way to clean that except God does that.

What makes Dani's story different from Jackie and Stevie's is that her framing agent actively contested her immediate shame and offered a counter-narrative for interpreting her status. At a time when public discourse within both black communities and the larger society explicitly linked HIV with immoral behavior and religious reckoning, this example suggests that the conceptual frameworks that framing agents offer can revise women's personal frameworks and directly challenge the societal narratives within which they initially frame the diagnosis.

The experience of being diagnosed, and the institutional interlocutors in this interaction, shaped how women began to conceptualize what it means to have HIV. Particularly for those who were asymptomatic at diagnosis, the *social* meaning of HIV often took on greater significance than any *physical* signs of infection. Because many of our respondents were diagnosed prior to the advent to HAART, framing institution messages competed with waves of AIDS-related deaths and the public's understanding of AIDS as a terminal illness with few possible interventions. The examples presented also highlight the diversity of frameworks that women co-create with their framing agents, depending upon the individual, her circumstances, and the framing institution with which she interacts.

Respondents' experiences demonstrate that framing institutions do not merely deposit information or dictate behaviors to passive recipients. HIV-positive individuals exercise agency when interpreting information and engaging conceptual frameworks. In the next section we see that the women themselves ultimately decide how they respond to their diagnoses, often interacting again with framing institutions.

Framing Institutions: Acquiring the Language and Resources to ‘Live With’ HIV

Following initial diagnosis and the formation of an early conceptual framework for coping, framing agencies continue to shape the coping trajectory. Institutions often help individuals integrate their health status into their everyday lives through both *language* and *resources*. As respondents confront additional stigmatization, the most effective framing institutions and agents devise methods for addressing the potential influence of black women’s intersectional marginality on disease management. In order to help black women advance from ‘dying from’ to ‘living with’ HIV, these framing institutions consider the many social circumstances that accompany respondents’ seropositive status. In this sense, the HIV coping trajectory becomes not only internal but external, as respondents realign their sense of themselves as black women living with HIV.

Many respondents, after undergoing an unproductive post-diagnosis period, were drawn by a later physical or emotional crisis to another framing institution that could offer messages that they might not have heard or accepted from their first framing institution. Following her diagnosis Jackie was mired in drug and alcohol abuse: “I would have to say that [the diagnosis] played a major part [in my addiction], because I felt like I was dying anyway. And I just didn’t care.” In the absence of other tools, drug and alcohol abuse became her primary coping mechanism. She began accepting her health status only after a police officer was called to settle a fight between her and her brother-in-law.

Then [the cop] says, “Now, back to you. What’s bugging you?” I said, “I’m HIV positive and I drink a whole lot.” She said, “All right. You want some help about your drinking?” I said, “Yes.” At that point, I started crying. She said, “You really want some help?”

Because if you really want it, I'm going to help you." I said, "I think I really need that help."

Jackie's time in a drug and alcohol rehabilitation program facilitated her acceptance of being HIV-positive. She began to construct a new conceptual framework to help her manage both HIV and alcohol abuse (Tangenberg, 2001). Substance abuse programs with a 12-step framework served as important framing institutions for 17 of our 30 respondents. As these programs emphasize individual responsibility rather than structural intervention, coping with social disadvantage and its health implications is constructed as a personal pursuit supported by framing agents and institutions. Through regular support groups, information sessions, and frequent contact with others who have drug addictions *and* may be HIV positive, these institutional ties helped Jackie and other respondents name, frame, and address these significant events in their lives. The tools of substance abuse treatment merge with HIV management strategies and practices. Respondents often discuss balancing a sense of personal agency with spiritual surrender, acknowledging past mistakes, and learning to live a healthier life, describing HIV and drug addiction interchangeably. Moreover, respondents describe needing to avoid "people, places, and things" that threaten their progress, applying the language of drug and alcohol rehab to the management of HIV and their post-diagnosis lives.

Respondents who did not require drug and alcohol treatment access a diverse array of institutions that help them accept their HIV status. Although churches have often been criticized for their failure to provide support to those living with HIV/AIDS (Cohen, 1999), Monet's pastor was a positive framing agent. She finds in the church both a spiritual framework through which to understand her condition and specific health management tools because her pastor is a

physician. Although she had reservations about sharing her status with other parishioners, her pastor created a safe space for her:

He said, “You don’t have AIDS, you have H-I-V. You just have to be a little more conscious about how you deal with your health You just have to be on that. [Your] lifestyle is changing. That’s it” . . . He was like “Monet, when you think of viral load, this is what you have to think about, and your T-cell counts always have to be here. The best way to minimize your viral load is to . . . keep up with your health, come up with a workout regimen. You can’t let anything stress you out. Everything deals with your viral load. Your body reacts to everything.”

Framing institutions bring respondents into contact with framing agents that either reinforce or revise the messages of the initial framing institution. While we cannot assign causality, we note a relationship between those who initially or eventually found a more “positive” framing institution and those who progressed along their coping trajectories, responding to a productive set of strategies and aided considerably by the increased access to life-extending HAART in the late 1990s. Framing institutions (1) help women address health crises by providing medical information and care or drug and alcohol treatment; (2) encourage women to finally accept being HIV-positive by providing a language, shared knowledge, and a support structure in a de-stigmatizing setting; and (3) connect women with resources that support the long-term coping process. Such institutions provide information about and introductions to other agencies, further strengthening their vital role as resource brokers (Small, 2006). While these women are ultimately responsible for navigating their own coping processes, positive framing institutions offer a structured, safe environment enabling them to replace beliefs and

behaviors suggesting that physical, social, and emotional death are imminent toward beliefs and behaviors conducive to living with HIV.

Not Just Surviving, but Thriving

Given that HIV/AIDS can be a life-threatening disease, it might be surprising to learn that three-fourths of the study's respondents describe not just surviving but thriving despite being HIV positive. Physical challenges abide, largely due to side effects associated with HAART, and the women still grapple with stigma and other negative consequences of HIV. However, the majority of respondents describe HIV as a chronic but manageable condition rather than as a debilitating 'death sentence.' More than any other source in their lives, they credit framing institutions for motivating them to visit their doctors regularly, manage their diets, take prescribed medications, reduce and manage stress, avoid drugs and alcohol, and learn about symptoms and medications.

The distinct social meanings related to HIV—how observers assign guilt or innocence to those infected based on attitudes towards risky behaviors—makes coping an ongoing process. For these women, feelings of internal shame and external stigma threaten to throw them “off course” at any time. Yet, as Monet's description shows, her spirituality and her therapist help her overcome such obstacles:

I've accepted . . . that I have HIV. This is a part of my life. I can't change it. It is my belief and I have faith that I can be healed from it, and if I'm not it's still okay I'm working with my position, I'm keeping myself healthy, I'm lowering my stress. It's okay Therapy [is what got me there] Going to some consistent therapy, my belief in God, but also I would have to say really looking at all the difficult stuff [in my life] and

really going back and saying, “Okay, you played into some of this because, you know, nobody’s perfect. But it’s okay. You know, this is how your life is, this is what happens; take it and move on.” If I hadn’t gone to therapy . . .

Learning to live with HIV is not only about managing the emotional turmoil and physical symptoms of the disease, it is also about examining and coming to terms with prior experiences of pain and marginalization that may have led to exposure to HIV. Not surprisingly, difficult experiences associated with extreme poverty, racial exclusion, and limited economic mobility persist after the women are diagnosed. Those who do not experience such extreme economic marginalization because of their class status still grapple with intersectional stigma on the basis of their racial, gender, and HIV statuses. ‘Living with’ HIV therefore includes learning how to avoid unhealthy coping strategies. Joyce, who lives in a housing complex designed for recovering addicts living with HIV/AIDS, captures this struggle:

If the issues are getting too strong for me, that’s why I have a therapist. And a sponsor. And, you know, people in the fellowship that I can . . . just vent to without no feedback. And if I want some feedback, that’s when I just let them know that . . . “Hey, this is what’s going on with me. I need some help. Can you help me out and tell me what kind of solution we can come to?” And, you know, I get feedback.

Framing institutions can therefore help respondents view themselves and their situations positively, regardless of their personal and environmental struggles, reinforcing perseverance through adversity. By giving women leadership roles among their peers, they challenge dominant narratives that construct black women as powerless, socially dysfunctional, irresponsible and unable to contribute. In short, the support network offered by these institutions helps women

navigate social and economic deprivation. All of these elements within the most effective framing institutions affirm women's power to address their health and shape their destinies.

Once many of their needs were being met with the help of framing institutions, respondents moved even further along the coping trajectory by leveraging their experiences for a greater purpose. While Joyce pursued a GED, Jackie set her sights on becoming a framing agent herself by working with people who are HIV positive. "It's our responsibility to help other women going through this . . . [that] don't know that you can still have a life," she explained. Framing institutions had helped these women re-interpret the implications of their HIV status, and they can now participate in activities that *bolster* rather than undermine their social status and offer them a greater sense of control (Berger, 2004).

Barely Making It: Inertia and Vacillation in the Continuing Struggle to Live with HIV

Perhaps it is unsurprising that many of the women in this study appear to be thriving and taking care of their physical and mental health. After all, in the U.S., where HAART is more readily available than it is in many other countries and people living with HIV are more visible and, by many accounts, quite healthy, it is possible to approach HIV/AIDS as a chronic but manageable illness. Yet 6 of the 30 respondents have never quite moved beyond the state of believing and behaving as though they are 'dying.' We saw the most troubling instances of risky or destructive attitudes and behaviors among women who rarely draw on institutional relationships or minimize their institutional interactions because of poor staff quality or concerns about confidentiality.

Low-income women who did not use institutions as a significant source of support were disadvantaged, as their combined economic and social support needs were so great. They

frequently relied on family members, but this support often came with constraints. Family resources were limited, and family members often knew too little about HIV to provide the language and conceptual frameworks that institutions provide. For example, Christine reports no ongoing institutional involvement and relies solely on her sister's help. Although her sister moved to town to help her maintain a proper diet and take her medications, Christine's depression and drug use continue. Low on energy and financial resources, unable to stay clean for more than a few days, uninterested in purchasing healthy foods or attending support group meetings offered by local Aids Service Providers, Christine experiences a healthy regimen only briefly, punctuating repeated health crises. Emergency room staff admonishes Christine repeatedly to take care of herself, but they are ultimately able to address only her short-term needs, unable to offer the more transformative frames that might encourage her to make significant changes. Unfortunately, her HIV diagnosis in 1988 topped a list of traumatic experiences, and Christine has not yet marshaled the resources she needs to address them effectively.

Ongoing traumas can also render institutional connections ineffective at helping women frame HIV/AIDS as a manageable illness. For example, Roslyn has struggled unsuccessfully to piece together her fragmented life since her diagnosis in 2002. Her HIV status joins a lengthy list of traumatic life events, and she has yet to experience the breakthroughs that so many of the other women describe. Poverty, a family life riddled with sexual and other forms of abuse, a recently incarcerated son, and an inability to manage her bipolar disorder diminish her capacity to address her HIV-status through organizational ties.

Unaddressed histories of trauma, untreated co-occurring illnesses, and stymied personal motivation can all interfere with effectively leveraging framing institutions. And *ineffective*

organizations make it difficult for women to believe and behave as though they can ‘live with’ HIV. Poor institutional staffing and meager funding render Roslynn’s relationship with her HIV housing complex fragile and unproductive. Her building’s high turnover among case managers means that temporary social work students who are unfamiliar with her case are assigned the task of delivering critical information. In addition, the clientele do not trust most staff members to create a healthy environment and prioritize confidentiality or service quality, so they do not take full advantage of the services offered. Roslynn and her co-residents have determined that the building functions as a negative framing institution, signaling to them that their status as HIV-positive women prevents them from receiving high-quality treatment from others:

[The executive director] know all of us. She know our ups and downs ’cause she interact with us. So she’s caring. But the rest of these people, no. They shouldn’t be in and out [of our case files] because all they do is gossip back and forth . . . I hear them . . . they have no respect for our [support] groups. They walk in and out It’s no respect here.

Other women experience temporary success in managing their health but soon find themselves back in a destructive state. For example, Dani has needed ongoing conversations with therapists and a constant internal reconciliation of her own guilt for engaging in sexual activity that violated her conservative religious belief system. However, when she took a break from therapy and moved out of her HIV-centered apartment building to assist her ailing father, the disconnection from institutions that seemed to help her manifested in poor HIV medication adherence:

I went off the meds totally for a long time I didn’t care . . . feeling unfulfilled.

Looking for, where is the purpose in all this? What is the meaning? Why is this? Why did it happen? What am I here for?

The coping trajectory is rarely linear or smooth. While framing institutions prove to be effective for many women, they are not panaceas. Some respondents continue to struggle with inertia and even vacillate between healthy and unhealthy behaviors as they balance other stressors with HIV. Factors that reduce the likelihood of ‘living with’ HIV predominate, and some women’s relationships with framing institutions threaten to crumble under the weight of their life histories or agency missteps. When HIV/AIDS and other stressors such as violence, poverty, mental illness, and drug abuse are coupled with framing institution deficits, the ability to weave together a narrative, language, and resources that help participants move from ‘dying from’ to ‘living with’ HIV is significantly compromised.

CONCLUSION

Consistent with research on stress-related growth among HIV-positive people, we demonstrated how respondents’ personal experiences and previous conceptions of themselves serve as building blocks for reconstituting their identities and strategies in the context of illness (Siegel & Schrimshaw, 2000). We found that, in line with Pierret’s (2007) typology of “continuity with drawbacks,” “discontinuity and reversal,” and “withdrawn” to describe the experiences of HIV positive individuals, coping trajectories are complex and change in relation to time and the discovery of new treatment. Extending this area of research, we demonstrate that while several intervening factors likely shape this process, institutions play an important role by offering *initial information* about the illness, a *conceptual framework* within which women can understand how the illness affects their lives, *language* to help women constructively describe the illness and its consequences, and *tangible resources* to help women manage their health.

Coping with HIV/AIDS with the help of framing institutions is a dynamic process in which narratives of illness are offered up, critiqued, challenged, and reformulated. These organizations speak to women's individual struggles with marginalized social and economic positions. Insofar as black women are often seen as predatory, hypersexual, and lacking social value, framing institutions can reinforce or refute these perceptions depending on how they treat respondents and address their needs (Berger, 2004). While negative framing institutions such as Stevie's prison and Roslyn's housing environment reinforce their sense of powerlessness, the most effective institutions and agents, such as Jackie's Narcotics Anonymous and HIV support groups and Monet's pastor, enable women to reframe their self conceptions and perhaps even improve their social situations.

Consider the historical context of these women's experiences with framing institutions. When the AIDS epidemic emerged in the United States, gay men and intravenous drug users comprised the bulk of reported cases, feeding a disease narrative that emphasized individual behavior and stigmatized identities. As "the modern plague" (Sontag, 2001), HIV was linked not only to "death, but also with homosexuality, sexuality and the use of illegal drugs" (Parmet & Jackson, 1997, p. 7; Alonzo & Reynolds, 1995; Dill, 1994). Limited scientific knowledge and medical intervention only underscored the "plague" narrative, casting the disease as an affliction visited upon those whose "deviant behavior" invited divine punishment (Parmet & Jackson, 1997, p. 9). When groups like the Gay Men's Health Crisis (GMHC), the AIDS Coalition to Unleash Power (ACT UP), and others mobilized to combat HIV/AIDS, they were fighting not only a medical condition but also its stigmatized associations that limited funding for research, prevention education, and treatment (Cohen, 1999; Epstein, 1996; Shilts, 1987).

Significant progress has been made to combat AIDS stigma, increase treatment options, and expand AIDS education. Nevertheless, women have had to forge their own path, as they were largely neglected as the focus of research, treatment, and education in the epidemic's earliest stages. Today most respondents are benefiting from their ties to framing institutions, accessing an expanding network of AIDS organizations that provide services to, and advocate on behalf of, women. In addition, these organizations have also helped to educate the public and their colleagues within non-HIV specific institutions. Consequently, drug and alcohol rehabilitation centers, churches, and other organizations are better positioned than ever to become positive framing institutions for HIV-positive individuals. The typical coping trajectory among women likely mirrors the developmental process that organizations themselves underwent as more marginalized women became infected and therefore demanded services, medications, and the possibility of a long life with HIV.

This analysis of the role that framing institutions play in the coping processes of HIV-positive African American women therefore not only enhances our understanding of the sociology of illness but also illuminates individuals' negotiations with institutions, especially those involving marginalized populations. Although we focus our inquiry on a single disease and a disproportionately afflicted population, the 'framing institution' concept is not restricted to HIV or African American women. *Any* organization that helps individuals manage major life disruptions could qualify because of its capacity to support coping trajectories. As we saw in the cases of Stevie, Jackie, and Joyce, the structures, policies, and climates that their framing institutions created influenced how they addressed their status while in prison, drug and alcohol rehab, and supported housing, respectively. *Framing agents* proved to be critical actors within these institutions, informing how illness is constructed and addressed and offering explicit and

implicit directives for coping. Institutions provided access points through which women met framing agents, providing legitimacy that allowed framing agents to intervene consequentially in women's lives, for better or for worse.

We saw the most troubling instances of risky or destructive attitudes and behaviors among women who rarely draw on institutional relationships and who minimize their institutional interactions because of poor staff quality or concerns about confidentiality. This suggests that there are institutional characteristics that differentiate negative from positive framing institutions. The most beneficial framing institutions facilitate interactions that create shared knowledge, introduce women to social ties that connect them to a diverse array of services, actively de-stigmatize HIV, and demystify what HIV/AIDS means to them.

Future research could explore other contexts in which the framing institutions framework is applicable and compare effectiveness by type of framing institution. Perhaps women draw upon particular types of institutions at distinct stages of their meaning-making processes in disease progression. The study is limited insofar as our data did not allow us to compare HIV coping based on race or gender, but future work could explore this question. Framing institutions appeal to African American women in part because they help them understand how to cope with being HIV positive while struggling at the bottom of the social hierarchy. To that end, future research could explore whether black women prefer certain kinds of institutions over others, informed in part by their trust in particular types of institutions and the role of endorsements from members of their social networks.

Given the manifest significance of positive framing institutions, policymakers should seek sufficient resources to ensure that they operate effectively. Both AIDS-specific organizations and agencies that include AIDS education and services among their offerings will

continue to be important players. Personal support networks are unlikely to offer the level of support that these organizations do, especially in the wake of recent economic shocks and rising income inequality. As a result, these women depend more than ever on the viability of non-profit and government organizations. Budget cuts have rightly prioritized funding AIDS medications over social services in recent years, but such a realignment is not sustainable given the acute needs of those infected that this paper highlights.

Works Cited

- Adimora, A.A. and V.J. Schoenbach. (2005). Social context, sexual networks, and racial disparities in rates of sexually transmitted infections. *The Journal of Infectious Diseases*, 191, S115–S122.
- Alonzo, A. A. and N. R. Reynolds. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science & Medicine*, 41, 303-15.
- Anderson, R. (1992). Families and self-help groups as key actors. In Kaplun, A. (Ed.) *Health Promotion and Chronic Illness*. Discovering a New Quality of Health. Copenhagen: WHO Regional Office for Europe.
- Ball, J., L. Tannenbaum, L. Armistead, and S. Maguen. (2002). Coping and HIV infection in African American women. *Women and Health*, 35(1), 17-35
- Barnes, D., B. A. Alforque, and K. Carter. (2000). Like I just got a death sentence': Conditions affecting women's reactions to being told their HIV antibody test results and the impact on access to care. *Research in the Sociology of Health Care*, 18, 3-33.
- Battle, S. (1997). The Bond is Called Blackness: Black Women and AIDS. Pp. 282-291 in *The Gender Politics of HIV/AIDS in Women: Perspectives in the United States*, edited by N. Goldstein and J. L. Manlowe. New York: New York University Press.
- Benford, R. and D. Snow. (2000). Framing Processes and Social Movements: An Overview and Assessment. *Annual Review of Sociology*, 26, 611-639.
- Berger, M. T. (2004). *Workable Sisterhood: The Political Journey of Stigmatized Women with HIV/AIDS*. Princeton, NJ: Princeton University Press.
- Bloom, J. S. Stewart, M. Johnston, P. Banks, and P. Fobair. (2001). Sources of support and the physical and mental well-being of young women with breast cancer. *Social Science and Medicine*, 53, 1513–1524.
- Brander, P. and V. Norton. (1993). Women living with HIV/AIDS: Issues and needs confronting women with HIV/AIDS and women who care for people with HIV/AIDS.
- Broman, C. (1996). Coping with Personal Problems. Pp. 117-129 in *Mental Health in Black America*, edited by H. Neighbors and J. Jackson. Thousand Oaks, CA: Sage.
- Brown, P. (1995). Social construction of diagnosis and illness. *Journal of Health and Social Behavior*, 35, 34-52.
- Bury, M. R. (1991). The sociology of chronic illness: A review of research and prospects. *Sociology of Health and Illness*, 13(4), 452-468.
- Bury, M.R. (1982). Chronic illness as biological disruption. *Sociology of Health and Illness*, 4, 167-182.
- Catz, S. L., C. Gore-Felton, and J. B. McClure. (2002). Psychological distress among minority and low-income women living with HIV. *Behavioral Medicine*, 28, 53-60.
- Charmaz, K. (2000). Experiencing Chronic Illness. Pp. 277-292 in *Handbook of Social Studies in Health and Medicine*. Edited by G. Albrecht, R. Fitzpatrick, and S. Schrimshaw. London: Sage.
- Ciambrone, D. (2001). Illness and other assaults on self: The relative impact of HIV/AIDS on women's lives. *Sociology of Health and Illness*, 23, 517-540.
- Cohen, C. (1999). *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*. Chicago: University of Chicago Press.
- Conrad, P. (1987). The Experience of Illness: Recent and New Directions." Pp. 1-32 in *Research in the Sociology of Health Care: The Experience and Management of Chronic Illness*, vol. 6, edited by J.A. Roth and P. Conrad. Greenwich, CT: JAI Press.

- Coward, D. D. (1994). Meaning and purpose in lives of persons with AIDS. *Public Health Nursing*, 11, 331-336.
- Crossley, M. (1998). 'Sick role' or 'empowerment'? The ambiguities of life with an HIV positive diagnosis. *Sociology of Health and Illness*, 20, 507-531.
- Davis, F. (1960) Uncertainty in medical prognosis clinical and functional. *The American Journal of Sociology*, 66(1), 41-47.
- Dill, A. (1994). Institutional environments and organizational responses to AIDS. *Journal of Health and Social Behavior*, 35(4), 349-369.
- Doyal, L., & J. Anderson. (2005). 'My fear is to fall in love again....' How HIV-positive African American women survive in London. *Social Science & Medicine*, 60, 1729-1738.
- Epstein, S. (1996). *Impure science: AIDS, activism, and the politics of knowledge*. Berkeley: University of California Press.
- Farmer, P., M. Connors, and J. Simmons (eds). (1996). *Women, Poverty, and AIDS: Sex, Drugs and Structural Violence*. Monroe, ME: Common Courage Press.
- Feist-Price, S. and L.B. Brown Wright (2003). Mental health issues among women with HIV and AIDS. *Women & Therapy*, 26(1/2), 27-38.
- Ford, C., K. Whetten, S. Hall, J. Kaufman, and A.D. Thrasher. (2007). Black Sexuality, Social Construction, and Research Targeting 'The Down Low' ('The DL'). *Annals of Epidemiology*, 17, 209-216.
- Fox, R.C. (1974). Ethical and existential development in contemporaneous American medicine: Their implications for culture and society. Milbank Memorial Fund Quarterly. *Health & Society*, 52, 442-483.
- Friedson, E. (1970). *Professional dominance*. New York: Atherton.
- Fullilove, M.T., R.E. Fullilove, M. Smith, K. Winkler, C. Michael, P. Panzer., and R. Wallace. (1993). Violence, trauma, and post-traumatic stress disorder among women drug users. *Journal of Traumatic Stress*, 6(4), 533-543.
- Fullilove, M.T., E. Golden, R.E. Fullilove, R. Lennon, D. Porterfield, S. Schwarcz, and G. Bolan. (1993). Crack cocaine use and high-risk behaviors among sexually active black adolescents. *Journal of Adolescent Health*, 14(4), 295-300.
- Gardner, L. I., G. Marks, L. R. Metsch, A. M. Loughlin, C. O'Daniels, C. Del Rio, P. Anderson-Mahoney, and J. D. Wilkinson. (2007). Psychological and behavioral correlates of entering care for HIV infection: The antiretroviral treatment access study (ARTAS) *AIDS Patient Care and STDs*, 21(6), 418-425.
- Gielen, A. C., K. A. McDonnell, A. W. Wu, P. O'Campo, and R. Faden. (2001). Quality of life among women living with HIV: The importance of violence, social support, and self care behaviors. *Social Science & Medicine*, 52, 315-322.
- Gilbert, D. J. and E. M. Wright. (2003). *African American Women and HIV/AIDS: Critical Responses*. Westport, CT: Praeger.
- Goffman, Erving. (1974). *Frame Analysis: An Essay on the Organization of Experience*. New York, New York: Harper & Row.
- Goldstein, N. and J. L. Manlowe. (1997). *The Gender Politics of HIV/AIDS in Women: Pandemic in the United States*. New York: New York University Press.
- Grinstead, O. B. Zack, and B. Faigeles. (2001). Reducing postrelease risk behavior among HIV seropositive prison inmates: The health promotion program. *AIDS Education and Prevention*, 13(2), 109-119.

- Hackl, K. L., A. M. Somlai, J. A. Kelly, and S. C. Kalichman. (1997). Women living with HIV/AIDS: The dual challenge of being a patient and caregiver. *Health and Social Work*, 22(1), 53-62.
- Ickovics, J. R., B. Forsyth, K. A. Ethier, P. Harris and J. Rodin. (1996) *Delayed Entry into Health Care for Women with HIV Disease. AIDS Patient Care and STDs*, 10(1), 21-24.
- Ingram, D. and S.A. Hutchinson . (1999). Defensive mothering in HIV-positive mothers. *Qualitative Health Research*, 9(2), 243-258.
- Jennings, B., D. Callahan, & A. L. Caplan. (1988). Ethical challenges of chronic illness. *Hastings Center Report*, Feb/March, 1-16.
- Johnson, R. and S. Raphael. (2006). The Effects of Male Incarceration Dynamics on AIDS Infection Rates among African American Women and Men. Working Paper 22, National Poverty Center, The University of Michigan.
- Jones-DeWeever, A. A. (2005). Saving ourselves: African American women and the HIV/AIDS crisis. *Harvard Journal of African American Public Policy*, 11, 79-83.
- Kim, A., K. Page-Shafer, J. Ruiz; L. Reyes, V. Delgado, J. Klausner, F. Molitor, M. Katz, and W. McFarland. (2002). Vulnerability to HIV among women formerly incarcerated and women with incarcerated sexual partners. *AIDS and Behavior*, 6, 331-338.
- Kobasa, S.C O. (1990). AIDS and volunteer associations: Perspectives on social and individual change. *The Milbank Quarterly*, 68(2), 280-294.
- Lather, P. and C. Smithies. (1997). *Troubling the Angels: Women Living with HIV/AIDS*. Boulder, CO: Westview Press.
- Lutfey, K. and J. Freese. (2005). Toward some fundamentals of fundamental causality: Socioeconomic status and health in the routine clinic visits for diabetes. *American Journal of Sociology*, 110(5), 1326-1372.
- Mahon, M. (1996). New York inmates' HIV risk behaviors: The implications for prevention policy and programs. *American Journal of Public Health*, 86(9), 1211-1215.
- Marcenko, M.O. & Samost, L. (1999). Living with HIV/AIDS: The voices of HIV positive mothers. *Social Work*, 96, 36-45.
- Millett, G., D. Malebranche, B. Mason, and P. Spikes. (2005). Focusing "Down Low": Bisexual black men, HIV risk and heterosexual transmission. *Journal of the National Medical Association*, 97(7), 52S-59S.
- Misener, T. R. and R. L. Sowell. (1998). HIV-infected women's decisions to take antiretrovirals. *Western Journal of Nursing Research*, 20(4), 431-445.
- Owens, S. (2003). African American women living with HIV/AIDS: Families as sources of support and of stress. *Social Work*, 48,163-171.
- Parmet, W. E. and D. J. Jackson. (1997). No longer disabled: The legal impact of the new social construction of HIV. *American Journal of Law & Medicine*, 23(1), 7-44.
- Parsons, T. (1951). *The Social System*. London: Routledge.
- Patterson, O. (1985). *Slavery and Social Death: A Comparative Study*. Cambridge: Harvard University Press.
- Perakyla, A. (1998). Authority and accountability: The delivery of diagnosis in primary health care. *Social Psychology Quarterly*, 61(4), 301-320.
- Peterson, J. L., J.A. Catania, M.M. Dolcini, and B. Faigees. (1993). Multiple sexual partners among heterosexual African Americans in high risk cities of the United States: The National AIDS Behavioral Surveys (NABS). *Family Planning Perspectives*, 25, 263-267.

- Pierret, J. (2007). An analysis over time (1990-2000) of the experiences of living with HIV. *Social Science and Medicine*, 65, 1595-1605.
- Pierret, J. (2003). The illness experience: State of knowledge and perspectives for research. *Sociology of Health & Illness*, 25(3), 4-22.
- Remien, R. H., T. Exner, et al. (2006). Depressive symptomatology among HIV-positive women in the era of HAART: A stress and coping model. *American Journal of Community Psychology*, 38(3-4), 275-285.
- Scambler, G. and A. Hopkins. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health & Illness*, 8(1), 26-43.
- Serovich, J.M., J. A. Kimberly, K. E. Mosack, and T. L. Lewis. (2001). The role of family and friend social support in reducing emotional distress among HIV-positive women. *AIDS Care*, 13, 335-341.
- Shilts, R. (1987). *And the band played on: Politics, people, and the AIDS epidemic*. New York: St. Martin's Press.
- Siegel, K. and B.J. Krauss. (1991). Living with HIV infection: Adaptive tasks of seropositive gay men. *Journal of Health and Social Behavior*, 32(1), 17-32.
- Siegel, K. and E. W. Schrimshaw. (2000). Perceiving benefits in adversity: Stress-related growth in women living with HIV/AIDS. *Social Science & Medicine*, 51(10), 1543-54.
- Simoni, J. M., H. D. Montoya, B. Huang, and E. Goodry. (2005). Social support and depressive symptomatology among HIV-positive women: The mediating role of self-esteem and mastery. *Women & Health*, 42, 1-15.
- Small, M. L. (2009). 'How many cases do I need?' On science and the logic of case selection in field based research. *Ethnography*, 10(1), 5-38.
- Small, M. L. (2006). Neighborhood institutions as resource brokers: Childcare centers, interorganizational ties, and resource access among the poor. *Social Problems*, 53(2), 274-292.
- Smedley, B. D., A. Y. Stith, A. R. Nelson, and Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. (2003). *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington D.C.: National Academies Press.
- Sobo, E. J. (1995). *Choosing unsafe sex: AIDS-risk denial among disadvantaged women*. Philadelphia: University of Pennsylvania Press.
- Sontag, S. (2001). *Illness as metaphor and AIDS and its metaphors*. New York: Macmillan.
- Stein, M.D., S. Crystal, W. E. Cunningham, A. Ananthanarayanan, R. M. Andersen, B. J. Turner, S. Sierler, S. Morton, M. H. Katz, S. A. Bozzette, M. F. Shapiro, and M. A. Schuster. (2000). Delays in seeking HIV care due to competing caregiver responsibilities. *American Journal of Public Health*, 90, 1138-1140.
- Stewart, D. and T. Sullivan. (1982). Illness behavior and the sick role in chronic disease: The case of multiple sclerosis. *Social Science & Medicine*, 16(15), 1397-1404.
- Strauss, A. and Glaser, B. (1975). *Chronic Illness and the Quality of Life*. St. Louis: Mosby.
- Strauss, A and J. M. Corbin (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Thousand Oaks, CA: Sage Publications.
- Tangenberg, K. M. (2001). Surviving two diseases: Addiction, recovery, and spirituality among mothers living with HIV disease. *Families in Society*, 82(5), 517-524.
- Tewksbury, R. (1994). 'Speaking of someone with AIDS . . .': Identity constructions of persons with HIV disease. *Deviant Behavior*, 15(4), 337-355.

- U.S. Centers for Disease Control and Prevention (2009). *HIV/AIDS Among African Americans* CDC HIV/AIDS Fact Sheet. Washington, DC: U.S. Government Printing Office.
- U.S. Centers for Disease Control and Prevention (CDC) (2010). New CDC analysis reveals strong link between poverty and HIV infection: New study in low-income heterosexuals in America's inner cities reveals high HIV rates. Press Release, July 19, 2010. <<http://www.cdc.gov/nchhstp/newsroom/povertyandhivpressrelease.html>> (accessed July 29, 2010).
- Weitz, R. (1990). Living with the stigma of AIDS. *Qualitative Sociology*, 13, 23-38.
- Wyatt, G.E., H. F. Myers, J. K. Williams, C. R. Kitchen, T. Loeb, J. V. Carmona, L. E. Wyatt, D. Chin, and N. Presley. (2002). Does a history of trauma contribute to HIV risk for women of color? Implications for prevention and policy. *American Journal of Public Health*, 92(4), 660-665.
- Zierler, S. and N. Krieger. (1997). Reframing women's risk: Social inequalities and HIV infection. *Annual Review of Public Health*, 18, 401-436.

ⁱ The two interviews with study participants were scheduled approximately 30-60 days apart and lasted approximately two hours each. Interviews took place in an enclosed room in an HIV social service agency (or other private location agreed upon by the participant) and were conducted by the first author or a research assistant. In addition to the four social domains of interest, interviews also covered respondents' HIV diagnosis experiences, HIV-related and overall health, experiences receiving medical and social services, neighborhoods, childhoods, educational experiences, and general attitudes about HIV/AIDS. The participant sample size is consistent with theory generation but not hypothesis testing. We limited our sample to 30 participants when we attained saturation (Small, 2009).

ⁱⁱ In order to protect confidentiality, individuals interested in participating were asked to call the phone number of the study's research office for eligibility screening. Per IRB guidelines, potential participants were informed of the voluntary nature of this study and the potential risks of participating, and informed consent was obtained from each participant.

ⁱⁱⁱ The 18-45 age range is consistent with a vulnerable target adult population in terms of HIV/AIDS infection rates. This age group also represents a time in the life cycle when most individuals are actively and independently making choices pertaining to employment and training, child bearing, child rearing, intimate relationships, social networks, and other domains of interest to this study. We chose not to include women who were in hospitals, hospice care, or incarcerated at recruitment (although some respondents had resided in such facilities prior to enrollment) because we wanted to find respondents who could actively participate in shaping their lives in the context of the social domains of interest. Respondents had to have known their HIV positive status for at least six months to participate in the study to protect recently diagnosed individuals who may have been at greater risk for emotional harm. Respondents were restricted to English-speaking, native-born, and non-Hispanic women in order to maintain some level of cultural homogeneity among the sample. We did not include any transgender individuals in the study as their experiences are distinct and require strong representation within the respondent sample in order to make any robust analytic claims.

^{iv} The large number of low-income women in our sample is consistent with national AIDS trends (CDC, 2010).

^v Coding was cross-checked across research assistants to ensure reliability, and the Principal Investigator did a final check of the coded dataset.

^{vi} Prior to HAART, the antiretroviral AZT began being used to treat people with HIV in 1987.