

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

Celeste Watkins-Hayes, Ph.D.

LaShawnDa Pittman-Gay, Ph.D.

Jean Beaman, Ph.D.

Northwestern University, Department of Sociology

1810 Chicago Avenue, Evanston, IL 60208

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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, we reveal how and why interactions with non-profit and government institutions help to explain variation between those who thrive and those who do not following an HIV diagnosis. We argue that 'framing institutions' shape the form and tenor of coping trajectories by offering *initial information* about one's HIV status, a *conceptual framework* to understand 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, we highlight how a diverse array of non-profit and government institutions not only play a critical part in helping women cope with HIV but also renegotiate their social identities 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.

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INTRODUCTION

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

We posit that a diverse array of non-profit and government institutions play vital and often underappreciated roles along with medical providers in the coping process for socially marginalized populations. We explore this function by examining the path by which African American women living with HIV/AIDS accept their health status and begin to adopt attitudes and behaviors meant to slow the progression of the disease. We argue that individual relationships *with* and *within* institutions facilitate and frame the interaction between a newly acquired medical status and women’s existing social statuses and identities. As we will show, the significance of ‘framing institutions’ in the lives of these women suggests that for socially marginalized groups, the adoption of healthy behaviors to fight HIV cannot be fully explained by focusing on individual resources (or challenges) or even environmental conditions. Rather, it must be placed within a context that is attentive to how shared knowledge, diverse social

networks, and de-stigmatizing social spaces fostered (or stymied) by certain organizations prove medically and socially critical for those who often lack these resources in other areas of their lives.

We begin by identifying two issues at the intersection of medical and organizational sociology literatures that deserve greater attention: (1) the development of illness coping strategies within diverse institutional environments and (2) the interaction between individuals' social locations and institutional experiences in shaping the coping process associated with a medical diagnosis. Then after providing background on HIV/AIDS among black women and outlining how data for this study were collected, we examine the interactions that respondents describe as being the most instrumental in helping them come to grips with their HIV-diagnosis and re-formulate their lives in its wake. We highlight how these women fared when they did not rely on such relationships and warn that, despite institutional involvement, some personal and institutional barriers continue to challenge respondents' abilities to come to terms with and manage their health consistent with widely-shared prescriptions for healthy living with HIV. We conclude that the *framing institution* offers a useful conceptualization for how people, particularly stigmatized populations, manage chronic illness through institutional support that includes both medical and non-medical organizations.

REVIEW OF RELEVANT LITERATURE

Since the pioneering scholarship of Parsons (1951) and Strauss and Glaser (1975), work on the experiences of those living with chronic illness has established several key findings about the coping processes or trajectories that accompany chronic illness diagnoses. Unlike acute illnesses, chronic illnesses have an “unfolding” or “emergent” quality, and as a result individuals

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 that may include working to maintain or gain a sense of control over life events and maintain emotional equilibrium as they struggle with feelings of shock, anguish, anxiety, powerlessness, incapacitation, and a sense of mortality (Pierret, 2003; Siegel & Krauss, 1991). Chronically ill individuals must interpret the meaning and significance of the illness; tolerate, adjust to, and reduce the negative aspects of the disease; maintain a positive self-image; assess and tap actual and potential resources; and continue satisfying relationships with others (Pierret, 2003; Siegel & Krauss, 1991). These adaptations are ongoing and have been shown to improve quality of life and slow disease progression (Siegel & Krauss, 1991).

While Bury (1991), Ball et al. (2002), Ingram & 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. Previous work suggests that along with personal spirituality, social support networks comprised of friends, family members, and intimate partners help build and sustain coping trajectories by offering acceptance, moral support, and caretaking (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 their specialized knowledge to name and frame diagnoses and prescribe health management strategies to help patients progress (Brown, 1995; Davis, 1960; Fox, 1974; Friedson, 1970; Parsons, 1951; Perakyla, 1998; Stewart & Sullivan, 1982).

In cases in which the illness is highly stigmatizing and the resources that affected individuals have at their disposal to respond are few, some may have to go outside of their networks of family, friends, and medical professionals to determine how to 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 for individuals trying to effectively cope with their diagnoses (Anderson, 1992; Berger, 2004; Doyal & Anderson, 2005; Epstein, 1996; Jennings et al., 1988; Kobasa, 1990). However, privileging medical providers and HIV-focused support groups and social services as the most significant institutional actors involved with people living with HIV underplays the ways in which individuals access other kinds of institutional ties (Crossely, 1998).

The social meanings that people assign to illness experiences and the strategies that 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 shape the micro-processes that affect coping by arming individuals with varying levels of power and access to resources within institutions (Lutfey & Freese, 2005). This is not simply a question of observing how individuals cope with disparities in access to or the quality of medical care (Smedley et al., 2003). We need to discern how personal biographies and environments interact with institutional experiences in order to shape the *process* by which individuals come to understand and respond to a serious health diagnosis like HIV/AIDS.

Black women living with HIV/AIDS face distinct challenges that likely shape the progression of their HIV coping processes, and thus an analysis focusing on their experiences is necessary (Farmer, et al., 1996; Gilbert & Wright, 2003; Goldstein and Manlowe, 1997; Marcenko & Samost, 1999; Owens, 2003). The Centers for Disease Control (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.

The disproportionate HIV infection rates within the black community are the result of several factors. Cathy Cohen's (1999) *Boundaries of Blackness* provides one of the most comprehensive explanations. When early cases were reported in the 1980s, mainstream media, public discourse, public health interventions, and political activism focused on the experiences and needs of white gay men, a group whose hard-fought efforts to mobilize are well-documented (Epstein, 1996). This framing of HIV largely ignored African American AIDS victims in those crucial years in which groundwork was laid to battle the epidemic through prevention and treatment. Black political leaders and black media contributed to this collective silence as infection rates rose among blacks. Cohen (1999) argues that class divisions likely fueled this dynamic as community leaders who invested in a politics of racial respectability to make the case for social, political, and economic progress calculated that those most likely to be infected – gay men, intravenous drug users, low-income women, and sex workers – were a politically unattractive group to rally behind to attract greater resources to fight AIDS. Intragroup politics between the black gay men who spearheaded some of the earliest activism in support of HIV-positive African Americans and the influx of human services professionals who came later into the AIDS arena were also evident.

These political setbacks were coupled with environmental factors that also encouraged the rise in HIV infection rates among blacks. Compared with whites, blacks are more likely to live in racially 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). The lack of affordable and accessible health care, as well as a lack of trust in the system among many blacks due to prior negative interactions, also serve as barriers to 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 the high-poverty urban areas in which many blacks live are infected with HIV, a rate well above the 1% that designates a generalized epidemic.

In recent years, formal organizing through conferences, community education, and targeted interventions have increased public acknowledgment and acceptance of HIV/AIDS as a disease affecting black communities and improved basic services for those in need. Media obsession with black men who have sex with women but hide their sexual relationships with men, or “the Down Low” phenomenon, recently led to increased discussions about HIV in black communities, under the assumption that “DL men” were to blame for the increased infection rates among black women. However, there is little scientific evidence to support this explanation, and it de-emphasizes other potential HIV risk factors (Ford et al., 2007; Millett et al., 2005; Peterson et al., 1993). As new issues emerge surrounding the AIDS epidemic in black communities, HIV-positive black women continue to struggle with the question of where they fit into their communities and how they will gather the resources and emotional wherewithal to cope with their illness.

Many HIV-positive black women confront what political scientist Michele Berger terms “intersectional stigma” (2004), marginalization based on HIV status as well as race, gender, socioeconomic status and sexuality. Black women are more likely to be diagnosed with

HIV/AIDS at later stages, experience debilitating symptoms, and die sooner than their white counterparts (CDC, 2009). There are likely several reasons for this. The psychological distress common among people living with HIV/AIDS is often compounded by the stress associated with the immediate and cumulative effects of institutional and interpersonal racism and/or economic hardship (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, or dependency on the state. When their kinship networks fail to provide tangible or emotional support due to HIV/AIDS related stigma, black women have been shown to be strongly and negatively impacted due to the lack of alternative sources of support and the strong cultural norms that emphasize family connection to overcome difficulties (Misener & Sowell, 1998; Sobo, 1995). Black women may also often contend with competing caregiving responsibilities that encourage them to delay their own care (Stein et al., 2009). Previous 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). Given that heterosexual transmission accounts for most HIV infections among women, the lack of power and dependence on men that is common in a patriarchal society may make it difficult for women to negotiate safe sex practices and to contend with disease management protocols provided by medical and social institutions (CDC, 2009; Ciambrone, 2001; Sobo, 1995; Brander & Norton, 1993; Coward, 1994). These issues suggest that black women's abilities to cope with HIV/AIDS are not simply about health management or psychological breakthroughs; they must also find ways to renegotiate their social identities as black women in the wake of receiving yet another stigmatizing social marker.

This work 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 explain how they come to grips with the realities of their conditions and adding 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, have confidence in the knowledge being provided, and have 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 be a promising place to look to explain variation between women who thrive and those who do not following an HIV diagnosis given the barriers that they face. How do African American women living with HIV formulate attitudes and behaviors to 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 long-term? What does this tell us about the role of institutions in the lives of marginalized populations as they marshal the resources they need to grapple with pivotal life events and situations?

THE FRAMING INSTITUTION

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"

that individuals rely on to 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 solely consequential for people living with HIV, but the disease's unique medical and social implications demonstrate and inform how framing institutions operate to assist people along the coping trajectory. Coping with the illness often means simultaneously managing physical demands and a stigmatized social status that obliges its carriers to grapple with 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 internally and externally 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 potentially serve as filters through which individuals interpret and address their physical symptoms and the social significance of their diagnoses.

Particularly as HIV/AIDS may not be well understood within an individual's preexisting social network, framing institutions can provide alternative means of support. They differ from other organizations in that they help facilitate or impede a “turning point” in people's lives that represent 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

“come to terms” with and begin proactively addressing a particular circumstance. Framing institutions can result in the adoption of 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 what it means to have HIV, the language used to talk about one’s condition, and the resources offered to begin restructuring one’s life in the wake of a diagnosis. However in any case they facilitate a set of social interactions that prove pivotal to individuals’ subsequent health-based decision-making.

DATA AND METHODS

Data are drawn from an ethnographic 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, due to many of the factors previously outlined in this paper. 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. The study involved two in-depth semi-structured interviews with each respondent and one participant observation session conducted at a site that is particularly meaningful to her as an HIV-positive woman.ⁱ Due to space constraints, the analysis presented here is based only on interview data. 30 HIV-positive African American women participated in the study, a group small enough to follow ethnographically over a multi-year span but large enough to generate the analytical depth necessary to show clear patterns among respondents.ⁱⁱ

Potential participants were alerted to the study through Chicago-area HIV social service agencies, healthcare providers (whether or not they specialize in treating patients with HIV), and

word-of-mouth.ⁱⁱⁱ 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) self-identified as HIV-positive (or AIDS-diagnosed) at the time of recruitment and could provide written medical documentation of their positive HIV status; (4) were living in Chicago; (5) were 18-45 years of age; (6) were not hospitalized, in hospice care, or incarcerated at the time of recruitment; (7) had received their HIV diagnoses more than six months prior to study recruitment; and (8) were English-speaking, native-born, and non-Hispanic.^{iv}

All 30 study participants self-identified as U.S. born black women 18-45 years old (average age 36). 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 are, however, impoverished, reporting yearly household incomes of less than \$15,000.^v 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 at the time of recruitment, 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. Undergraduate research assistants first coded along themes that followed the interview guide, including codes related to each of the four social domains mentioned above. 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 what is a very stressful and stigmatizing condition. We found ourselves building on extant theories of stress-related growth (Siegel & Schrimshaw, 2000), but wanting to not only *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 graduate research assistants recoded the interview transcripts using a new set of emergent codes in order to unpack the role of institutions in *how* participants adjusted to their HIV status.^{vi} Through this analysis of the data, 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 heading warnings not to abandon extant literature in drawing 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 in order to demonstrate how framing institutions are instrumental in each stage of the 'dying from' to 'living with' process. These organizations play a role along four dimensions: the *initial information* that they provide women about their HIV status, the *conceptual framework* that they offer to help women understand how HIV/AIDS will affect their lives, the *language* they impart to help women constructively describe the illness and its health and social consequences, and the *tangible resources* that they help women acquire to medically, materially, and socially manage HIV.

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 Highly Active Anti-Retroviral Therapy (HAART) was not widely available until 1996, years after the diagnosis of Sheila and approximately 55% of our sample. Consistent with previous literature, many women engaged in harmful behaviors upon receiving the news—failing to properly manage their health with medication, diet, rest, exercise, and regular doctors' visits; ignoring depressive symptoms; and returning to (or

initiating) risky behaviors, including those that may have led to infection in the first place (Barnes, et al., 2000; Broman, 1996; Hackl et al., 1997).

During the diagnosis experience, 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 the multiple and often conflicting messages that they have received 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 affects how women conceptualize their plight in those first crucial minutes and hours. 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 awe, 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?” . . . But I’m still back at, “You’re HIV positive,” . . . And I was just so shocked and I wanted to leave. They wouldn’t let me leave right away. I told the lady I’d register for a program. So first thing I did—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, “who would do this to [her],” presumably was meant by medical staff to help trace the epidemiology of the illness, it reinforced the message that HIV represented not only a medical condition but also

some sort of violation, complete with nameable “culprits.” When merged with the initial shock of diagnosis, the framing experience left Jackie feeling ashamed.

Traditional hospitals and clinics are not the only framing institutions providing initial information and conceptual frameworks that shape what HIV will mean for women. While incarcerated for drug possession, prison offered Stevie the first tools to understand and address her diagnosis. Although she voluntarily took an HIV test in 2002, Stevie was not prepared for the shock of the results: “So when I took it and I’d say about two weeks later she called me back down to the infirmary. And when 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 was shameful and required silence in order 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 HIV-positive inmate whose status was known, offered Stevie explicit and implicit messages for coping with her diagnosis. In trying to explain why she avoids medication against the advice of her doctors even outside the prison walls, Stevie still talks about seeing that HIV-positive inmate being ostracized. “I am half a woman because I got something they can’t cure and I can’t shake,” she maintains. Since her diagnosis was initially framed by the belief that she cannot ‘live with’ HIV,

Stevie effectively relies on what got her through her two-year prison sentence as an HIV-positive woman: silence. Stevie feels depressed and laments her self-imposed isolation from others, including her own family. Turning inward, she seems unable to figure out how to accept, productively talk about, or positively address her health status, demonstrating the power of a negative framing institution for someone who already struggles to cope with difficult life situations.

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:

Oh, the first words out of my mouth was, "God's punishing me." But then [my] doctor said, "God doesn't punish us." The doctor must have been a Christian . . . And he started talking to me from a Christian's point of view. 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 the way that her framing agent actively contested her immediate move to shame and offered a counter-narrative for how she should interpret 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 that they may gravitate towards following diagnosis.

The experience of being diagnosed, and the institutional interlocutors in this interaction, shaped how study participants 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. As so many of our respondents were diagnosed prior to the advent to HAART, the messages of framing institutions competed with the wave of AIDS-related deaths at the time and the public's understanding of AIDS as a terminal illness against which there were few possible interventions. The examples presented also highlight that there is a 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. For Dani, the medical establishment was a positive framing institution as her doctor directly challenged her immediate movement toward the belief that HIV was a punishment. Using spiritual language to speak to Dani gave her a framework within which to wrestle with the implications of her condition even after her initial contact with the institution. Years later, Dani still remembers being told, "No, God loves you," whenever she might be tempted to believe the worst about her situation. On the other hand, Jackie's medical providers reinforced her beliefs about the shame of her situation and failed to convince her that the appropriate response would be to enroll in a recommended HIV treatment program. Both the prison health providers and fellow inmates shaped Stevie's understanding that she should be silent about her HIV status, and that core belief has contributed to limited compliance with her prescribed drug regimen and a reluctance to seek the support of others.

Notably, framing institutions do not merely deposit information or dictate women's behaviors from on high. Individuals exercise agency in how they will understand, implement or challenge the initial information and conceptual frameworks that these institutions offer. As we

will see in the next section, the women themselves ultimately decide how they will respond to their diagnoses in the longer term, often engaging again with framing institutions in order to do so.

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

The contributions of framing institutions do not end with women’s initial diagnosis and the formation of an early conceptual framework regarding their status. Institutions often prove to be the vehicles through which individuals integrate the reality of their health status into their everyday lives through both the *language* that the institutions impart and the *resources* that they offer. In these instances, framing institutions move into the realm of organizing not only women’s understanding of HIV but also how they talk about it and proactively connect to resources that may help them cope. In addition, as respondents confront the additional stigmatizing marker of HIV/AIDS, the most effective framing institutions and agents devise ways to address the potential influence of black women’s intersectional marginality on disease management. In other words, in order to assist black women in moving from ‘dying from’ to ‘living with’ the disease, these framing institutions move beyond providing general information and encouragement to take into account the many social circumstances that accompany respondents’ seropositive status. In this sense, the ‘dying from’ to ‘living with’ process becomes not only internal but external, as respondents align their sense of themselves as black women living with HIV who are nevertheless worthy of an investment in self-care with the tools of their environments.

After periods of inertia or engaging in unhealthy behaviors immediately after diagnosis, the coping process was propelled for most respondents by a later medical or emotional crisis that

sent them to another framing institution that could offer messages that might not have been delivered by their first framing institution (or fully absorbed and implemented by the women during diagnosis). The interventions of these organizations and their agents effectively discouraged a downward spiral of behaviors.

The eight years following Jackie's diagnosis were mired in drug and alcohol abuse. She describes that dark period as the "ugly part of my life," anesthetizing the pain of her diagnosis with a new and growing addiction. "I would have to say that [the diagnosis] played a major part [in my addiction]," Jackie explained, "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 the most immediate mechanism for coping with her diagnosis. She began to accept her health status only after an unusual institutional intervention: 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 stimulated her acceptance of being HIV-positive, as she began to construct a new conceptual framework within which to understand her experience, adopt a language of acceptance, and access information and resources to aid in the management of both HIV and alcohol abuse (Tangenberg, 2001). "It wasn't until I attended these groups, seeing women and men say that they were addicts, telling their story . . . I became like a sponge, absorbing everything I heard."

Substance abuse programs with a 12-step framework served as important framing institutions for 17 of our 30 respondents. As program emphasis is on individual responsibility rather than structural intervention, coping with social disadvantage and its health implications such as drug and HIV exposure is constructed as a personal pursuit that is 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 some of the most significant events in their lives. The tools of substance abuse treatment merge with strategies and practices to manage HIV, offering individuals the language and resources to address their multiple statuses. Respondents often discuss balancing a sense of personal agency with spiritual surrender, acknowledging past mistakes, and learning to live a healthier life under a new code of behavior, describing HIV and drug addiction interchangeably. To keep moving forward along the coping trajectory, respondents describe needing to avoid “people, places, and things” that threaten their progress, borrowing the language of drug and alcohol rehab and applying it to the management of HIV as well as their post-diagnosis lives.

For respondents who did not require drug and alcohol treatment, a diverse array of institutions proved to be important for teaching women how to 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 proved to be a positive framing agent. She finds in the church both a spiritual framework through which to understand her condition as well as specific health management tools because her pastor happens to be a physician. Her pastor is an example of how framing agents may go beyond their prescribed roles to help individuals understand

significant life changes. Although she had reservations about sharing her status with other parishioners, her pastor created a safe space for her to seek advice and acceptance:

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, how you take care of yourself, what you eat, how much rest you get, are you taking your medicine? 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.”

For Loren, a homeless shelter in which she was working as a cook brought her into contact with relevant resources and information to help her live with HIV. Through the shelter’s ties to a clinic with an outreach program targeting people living with HIV/AIDS, she met an advocate who challenged her approach to HIV. Loren had largely been ignoring her health but credits the advocate with helping her accept and manage her health status:

She made me go to the county HIV Center. And she made me listen to her; she made me believe in her. . . I got a doctor, I got on medication, I started helping myself and living with it and dealing with it . . . I started going to support groups then . . . reading on [HIV] myself, just the stuff you pick up, you know, little literature, little pamphlets, I educated myself on it and the support group helped me a lot . . .

Support groups are important sites where participants exchange ‘insider’ rather than ‘outsider’ views of illness (Conrad, 1987; Crossley, 1998). Loren’s framing agent gave her the

confidence and information to seek out other institutional connections that could provide resources to help her understand, talk about, and live with the disease.

In summary, after the initial shock of an HIV-positive diagnosis, framing institutions prove influential again by bringing respondents into contact with framing agents that either reinforce or revise the messages of the initial framing institution. Those who initially or eventually found a more “positive” framing institution progressed along their coping trajectories, responding to a productive set of strategies to manage their physical and emotional health. This was likely largely aided by the increased access to HAART in the late 1990s, allowing women the possibility of a long life despite being HIV positive. Framing institutions’ contributions (1) help the women address health crises by providing medical information and care or drug and alcohol treatment; (2) encourage them to finally accept being HIV-positive by providing a language, shared knowledge, and a support structure in a de-stigmatizing setting; (3) and initiate connections to resources that support the coping process over the long term. They can be networked and resourced to offer a range of information and introductions to other agencies, thus further strengthening their vital role as resource brokers (Small, 2006; 2010). While these women are ultimately responsible for navigating their own coping processes, framing institutions offer a structured and safe environment where they can move away from beliefs and behaviors that suggest that physical, social, and emotional death are imminent and toward beliefs and behaviors consistent with 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 associated with HIV.

However, the majority of respondents describe HIV as a chronic but manageable condition rather than a physically, emotionally, or socially debilitating disease or ‘death sentence.’ More than any other source in their lives, they credit framing institutions for giving them the information and motivation to visit their doctors regularly, manage their diets, take prescribed medications, attempt to reduce and manage stress, avoid drugs and alcohol, and become knowledgeable about symptoms and medications.

The distinct social meanings related to HIV – the ways in which observers assign statuses of guilt or innocence to those infected based on attitudes towards sex, sexuality, and illicit behaviors such as drug use – makes managing the emotional turmoil associated with HIV an ongoing process. For these women, dueling feelings of internal shame and external stigma threaten to throw them “off course” at any time. In the following quote, Monet’s description of acceptance highlights the significant role played by both her spirituality and her therapist.

I’ve accepted the fact 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. I have to get to a happy place. 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 directly or indirectly led to women's exposure to HIV. Not surprisingly, the difficult experiences that are the result of extreme poverty, racial exclusion, and limited opportunities for 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 strategies that they might have once used to anesthetize themselves from pain. 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 pick up the phone and just vent. You know, I can just vent to them 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 . . . you know, to help me?" And, you know, I get feedback.

Framing institutions therefore help respondents with the ongoing project of viewing themselves and their situations as black women positively, regardless of the personal and environmental struggles that they may confront. The organizations reinforce the ideals of perseverance through adversity. By giving women leadership roles among their peers, they challenge dominant narratives that construct black women as powerless, socially dysfunctional, and irresponsible in ways that caused their exposure to HIV and render them unable to contribute. In short, the support network offered by these institutions offers assistance to help

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

Once many of their physical, emotional, and social 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 them re-interpret the implications of their HIV status, and these women are now able to participate in activities that can actually *bolster* rather than undermine their social status and offer them a greater sense of control in their social milieu (Berger, 2004).

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

Perhaps we should not be surprised at the success with which women in this study appear to be thriving and taking care of their physical and mental health. After all, in the U.S., where access to HAART is much greater than in many other countries and people living with HIV are more visible and, by many accounts, quite healthy, it would make sense that so many of these women eventually 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,' even sometimes years after being diagnosed. We saw the most troubling instances of risky or destructive attitudes and behaviors among women who rarely draw on institutional relationships, those whose institutional interactions do not enable them to overcome multiple and

ongoing barriers, and those who minimize their institutional interactions because of poor staff quality or concerns about confidentiality.

We found that low-income women who did not use institutions as a significant source of support were at a disadvantage, as their combined economic and social support needs were so great. They frequently relied on family members instead, but this support often came with constraints. The tangible resources available were limited, and family members often knew too little about HIV to provide the language and conceptual frameworks that institutions were providing on a continuing basis. For example, Christine reports no ongoing institutional involvement and relies solely on her sister's limited help to deal with her health status and other traumas. Although Christine's 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 ASPs, Christine experiences a healthy regimen only briefly through repeated health crises when she is hospitalized. Emergency room staff admonishes her during each visit about her need to take care of herself, but they are ultimately able to address only her short-term needs rather than providing the more transformative frames that might encourage Christine to make significant changes. Unfortunately, her HIV diagnosis in 1988 was added to a list of traumatic experiences in Christine's life, and she has not yet marshaled the resources to effectively address them.

Ongoing traumas that compound the difficulties of their HIV status 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 must find its place on 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 by drawing upon organizational ties.

Unaddressed histories of trauma, untreated co-occurring illnesses, and stymied personal motivation can all interfere with effectively leveraging framing institutions. But some respondents' stories suggest that ineffective organizations can 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 that may affect her. In addition, the clientele do not trust most staff members to create a healthy environment in which confidentiality and service quality are prioritized, 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:

Because [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. When we're having groups, you're not supposed to come in and out. It's no respect here.

Other women vacillate in their coping processes, experiencing temporary success at managing their physical and emotional health but soon finding 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 when it went against 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 consequences of her disconnection from the institutions that seemed to help her deal with her depression manifested through Dani's 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 quite 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 alongside their HIV disease. The factors that reduce the likelihood of 'living with' HIV effectively take over, and their relationships with framing institutions (such that they exist) threaten to crumble under the weight of the women's life histories or the agency's own missteps. When HIV/AIDS and other stressors such as violence, poverty, mental illness, and drug abuse are coupled with deficits in framing institutions, 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, this paper 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). However, this paper extends this area of research by demonstrating the important role that institutions play in this process and teasing out their multi-faceted role in offering *initial information* about illness, a *conceptual framework* to help women understand how the illness will affect their lives, *language* to help women constructively describe the illness and its health and social consequences, and *tangible resources* to help women medically, materially, and socially 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. While addressing the physical and psychological toll of HIV, these organizations also speak to women's individual struggles with marginalized social and economic positions. Given their position within the societal opportunity structure and the prevailing views of Black women as predatory, hypersexual, and having little social value, framing institutions have the power to reinforce or refute these perceptions through the ways in which 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 social identities and perhaps even to improve upon their social situations.

It is critical to place these women's experiences with framing institutions in historical context. 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 identities outside of the mainstream. 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” led to a kind of divine punishment (Parmet & Jackson, 1997, p. 9). As a result, 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 the medical condition but also its stigmatized association that led to limited funding for research, prevention education, and treatment (Cohen, 1999; Epstein, 1996; Shilts, 1987).

Significant progress has been made over the last several decades to combat AIDS stigma, increase treatment options, and expand AIDS education. Nevertheless, women have had to forge a path within the movement, as they were not the focus of research, treatment, and education in the epidemic’s earliest stages. Part of what respondents are now benefiting from through their ties to framing institutions is the expansive network of AIDS organizations that now provide services to, and advocate on behalf of, women. In addition, these organizations have also made strides in educating the public and their colleagues within non-HIV specific institutions. As a result, drug and alcohol rehabilitation centers, churches, and other organizations are better positioned to become positive framing institutions when confronted with clients, parishioners, and charges who are HIV positive than in previous decades. In fact, the coping trajectory among women likely mirrors the developmental process that organizations themselves had to traverse as more women became infected and therefore demanded services, medications improved and the possibility of a long life with HIV came into the picture, and the groups most infected were increasingly economically and racially marginalized.

This analysis of the role that framing institutions play in the coping processes of HIV-positive African American women therefore provides lessons not only for our understanding of the sociology of illness but also for how we interpret individuals' negotiations with institutions, especially 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 a major life disruption could qualify because of its power to help individuals in their 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, as they inform how illness is constructed and addressed, offering explicit and implicit directives for coping. Notably, respondents rarely referenced individuals who did not have an institutional affiliation as critical to their 'dying from' to 'living with' trajectory. Institutions provided the access points for women to meet framing agents, and they offered the legitimacy that allowed framing agents to make important interventions in women's lives, for better or for worse.

Our advancing of framing institutions as a sociological concept is predicated on the notion that, within these agencies, individuals receive critical news about a life-changing condition or circumstance, learn a new conceptual framework and language through which to think and speak about this event, and access a set of resources that directly or indirectly assist them in managing this new state. We saw the most troubling instances of risky or destructive attitudes and behaviors among women who rarely draw on institutional relationships, those whose institutional interactions do not enable them to overcome multiple and ongoing barriers,

and those who minimize their institutional interactions because of poor staff quality or concerns about confidentiality. This last point suggests that there are characteristics of institutions and their approach to providing services to consumers with HIV/AIDS that reduce their capacity to operate as positive framing institutions. Poor staff quality and concerns about confidentiality stymied the characteristics that were found in the most effective framing institutions: interactions that create shared knowledge, introduce women to social ties that connect them to a diverse array of services, actively de-stigmatize HIV by surrounding them with role models, and demystify what HIV/AIDS will mean for their lives.

Future research could explore other contexts in which the framing institutions framework is applicable and whether the type of framing institution shapes the coping process. It may be the case that women draw upon particular types of institutions at different stages of their meaning-making process with illness or the actual progression of the disease. One limitation of the study is that we did not have the data to offer comparisons of HIV coping on the basis of race or gender, but future work could explore this. Part of the appeal of framing institutions for African American women is that 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 have preferences for seeking support from 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 to facilitate such choices.

Given their significance, policymakers and the public should ensure that positive framing institutions have the resources necessary to survive. Both AIDS-specific organizations and agencies with broader missions that have components dedicated to AIDS education and services will continue to be important players. HIV infection rates in the US have leveled off but not

declined, people are living longer with HIV, and groups that are marginalized on the basis of multiple markers such as race, gender, class, and sexuality make up the lion's share of those living with HIV. Their personal support networks are less likely to have the wherewithal to offer the kind of support that these organizations do, and the issues faced by these individuals are likely to be massive given the declining fortunes of many in the wake of recent economic downturns and rising income inequality. As a result, these women are much more dependent on the viability of non-profit and government organizations to facilitate HIV coping than their wealthier counterparts who are also HIV positive. Budget cuts have rightly prioritized funding AIDS medications over social services in recent years, but this realignment is not sustainable given the particular needs of those infected that this paper highlights.

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ⁱ Each encounter with study participants was scheduled approximately 30-60 days apart, allowing the interviewer to interact with each respondent regularly over a 3-6 month period. Each interview and participant observation session lasted approximately two hours. 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. The choice of which two of the four social domains to focus on during each interview was based on the participant's own assessment of what areas were the most significant in her life at the time of the interview. 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 site options presented to study participants for the participant observation session were a social service agency visit, a doctor's appointment, an HIV/AIDS activism event, or an HIV/AIDS support group meeting. These site options were chosen so as to guard against the possibility of a participant's HIV status becoming revealed to those who would not otherwise know.

ⁱⁱ The sample size participants is consistent with theory generation and not hypothesis testing. We limited our sample to 30 participants when we attained saturation (Small, 2009).

ⁱⁱⁱ 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 over the phone. No one was screened in a face-to-face encounter. Per IRB guidelines, potential participants were informed of the volunteer nature of this study and potential risks of participating, and informed consent was obtained for each participant.

^{iv} The age range of 18-45 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 the other domains of interest for this study. We chose not to include women who were in hospitals, hospice care, or incarcerated at recruitment (although some respondents resided in these facilities prior to study 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 status for at least six months in order to participate in the study to protect recently

diagnosed individuals who may have been at greater risk for emotional harm through participation as the study probes the shock and trauma that one might have experienced after diagnosis. 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.

^v The high number of low-income women in our sample is consistent with national AIDS trends (CDC, 2010).

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