

HIV IN THE HEARTLAND: NEGOTIATING DISCLOSURE, STIGMA, & THE HIV
COMMUNITY

by

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Abstract

Even after 28 years the AIDS epidemic continues to affect the American population and HIV/AIDS remains a social problem. Living with HIV affects every aspect of an individual's life. It involves a personal negotiation at the onset of diagnosis, a social negotiation when one decides to disclose to others, and finally, a communal negotiation when individuals seek formal support via ASOs (AIDS service organizations), and/or informal support through family members and friends. The purpose of this research is to investigate these negotiations over the course of HIV infection, how these processes inform decisions to disclose, how stigma influences lived experiences, and the importance of the HIV community. The data come from eighteen HIV+ individuals, ten men and eight women, living in various locations throughout the Midwest. Drawing on the experiences of these men and women, I explore reactions after diagnosis, disclosure patterns, experiences of stigma, and the importance of the HIV community.

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Dedication

To those of you struggling with the virus, let your voices be heard. To Rachel.

CHAPTER 1 - Introduction

“AIDS fades in and out unfortunately,” Stan says, the final statement in his interview with me. His statement holds some truth. HIV and AIDS in the United States rises and falls in prominence as a social problem, and often its level of visibility has little to do with the toll it takes. As of 2009, the Kaiser Family Foundation reported that 1.1 million people are currently living with HIV/AIDS and that the virus has claimed close to 580,000 lives since 1981 (KFF 2009). Over the course of the epidemic, AIDS has been a source of political turmoil as a result of its early association as a “gay disease,” and later as a result of disproportionate infection rates among African Americans. Initially most prevalent in the US in groups of gay white men, injecting drug users and Haitian immigrant populations, the demographics of the affected populations have changed since the beginning of the outbreak. During the 1990’s higher proportions of prevalence were found in heterosexual women and men, African American and Hispanic populations. HIV has spread to all corners of the country and affects people from all walks of life.

Since the onset of the epidemic in 1981, HIV has become a much more survivable disease. HIV+ people are no longer dying within months or a year of being diagnosed. This is due in part to the increased effectiveness and earlier use of medications. Most notable has been the rise in the use of protease inhibitors, which prevent HIV from replicating within the body. HIV activists have fought to decrease stigma surrounding the disease and also lobbied for increased governmental funding (such as the Ryan White Care Act) for HIV related services and research. Though there is still no cure for HIV, the conditions of those living with HIV/AIDS have tremendously improved in the past three decades.

There has been a tremendous amount of research on the lives of those with HIV and AIDS. Studies have examined the process of disclosure (Black and Miles 2002, Derlega et al. 2004, Emler 2008, Kadushin 1999, Leonard and Ellen 2008, Ostrom et al. 2006), experiences of stigmatization (Herek 1988, 1999, Herek et al. 2005), how stigma is informed by social location (Berger 2004, Borchert et al. 1995, Douard 1990), stigma management (Chenard 2007, Siegel et al. 1998), and the formation of the HIV community (Amaro et al. 1995, Cameron and Yuk 1999, Crook et al. 2005, Kelley 2002). My research aims to look simultaneously at these processes over the life course of HIV infection and also how these processes act/react upon each other, by drawing on interviews I conducted with eighteen HIV+ individuals who live in various locations throughout the Midwest. My research looks at the decision making processes in a multitude of settings, how individuals incorporate an HIV+ identity, the rationale for deciding to tell others, the management of stigmatizing experiences, and the use and importance of HIV community. At each stage of this process, individuals negotiate personal decisions between a stigmatized identity and outside social conditions that both hinder and enable their participation in the HIV community. These experiences shed light on the day to day experiences of living with HIV. HIV, in a sense, becomes a managed identity.

I contribute to the literature in two ways: first I offer an analysis of a population that has been understudied in the HIV/AIDS literature - positive individuals living in low prevalence areas, specifically the Midwest, and areas with few resources available to HIV+ individuals; and second my analysis gives insight into the importance of the context underlying individual decision making processes regarding disclosure, experiences of stigmatization, and utilization of the HIV community. The experiences discussed throughout this thesis shed light on the complexity of day to day experiences of living with HIV.

CHAPTER 2 - Literature Review

Introduction

Once they are diagnosed, negotiation becomes an important daily practice for HIV+ individuals. From the onset of illness, positive individuals are constantly involved in the conscious negotiation of living with the illness. This process takes place at many different intersections. Three important social negotiations in which HIV+ individuals are involved are processes of disclosure, experiences of stigmatization, and involvement in the HIV community. In this chapter I will explore these processes to demonstrate the importance of each of these events in HIV+ individual's lives. They must negotiate personal behavior and decisions, processes of disclosure, interactions with others, and interactions among and in the community.

Disclosure

Deciding to disclose is an important process for individuals who are HIV+; it is often the first step in seeking support or help. Disclosure takes place at the intersection between the personal and social world where individuals must decide to disclose their HIV+ status to those who are closest to them – their friends and family. Deciding to disclose is a carefully considered process (Emlet 2008, Ostrom et al. 2006, Black and Miles 2002). Black and Miles (2002) suggest that individuals actively carry out a cost/rewards analysis regarding decisions surrounding disclosure (see also Emlet 2008, Ostrom et al. 2006). If individuals see more benefits than risk for their decision, they are more inclined to disclose. However, there are instances when disclosure is not beneficial. Recent research conducted by Leonard and Ellen (2008) illustrates how disclosure can complicate life instead of making it easier. They found that disclosure of HIV+ status in some contexts did not result in expected social support, but instead

resulted in more anxieties and stress (Leonard and Ellen 2008). In their case study of an HIV+ woman and her negative husband, they highlight how, after “Crystal” disclosed her status she did not receive social support, and despite her boyfriend’s knowledge of her positive status, they continued to engage in risky sexual behavior. Leonard and Ellen (2008) highlight two realms where disclosure has become problematic instead of beneficial. Instead of receiving social support, “Crystal” receives none, and instead of preventing the spread of HIV, her partner is still put at risk. Therefore disclosure of an HIV+ status can be either beneficial or harmful but the consequences are shaped by the context/setting in which one decides to disclose.

Derlega et al. (2004) expands on this notion of disclosure as contextual, pointing to two contextual factors that influence decisions. The first involves the nature of relationship (i.e., closeness, satisfaction) that the HIV+ individual has with the person to whom they wish to disclose. Thus, individuals will disclose their status to those with whom they have trusting relationships and from whom they can receive support. The second contextual factor involves the social environment that one inhabits, including cultural attitudes/beliefs of the community surrounding HIV/AIDS. Stigmatization of people with HIV/AIDS and stereotypes surrounding HIV/AIDS are still very prevalent despite widespread knowledge regarding transmission and the illness. Similarly, members of conservative communities are more likely to believe these traditional HIV stereotypes compared to those in more urban areas (Bunn et al. 2008). Surrounding community beliefs about HIV can complicate the disclosure process for individuals in these communities, who may fear that they will be stigmatized once their HIV status becomes widely known. For example, research focusing on disclosure among African American populations in the Deep South confirms this claim (Mohammad and Kissinger 2006, Sowell et al

1997, Black and Miles 2002); individuals are more likely to disclose in “safe spaces” i.e., medical settings, and less often to sexual partners due to fear of stigmatization.

Following a decision to disclose research indicates differences in disclosure patterns. Black and Miles (2002), in their study of African American women living in rural Louisiana, found that women engaged in several different forms of disclosure that ranged from secretive to full disclosure. Those who fully disclosed were HIV activists. The main reason for not fully disclosing was fear of being stigmatized because they lived in a “backwards” community, while the main reason for deciding to disclose was need for support. Type of disclosure (secretive to full) is mediated by perceived stigma and the social environment one inhabits.

Disclosure is also informed by race, class, gender, age and sexuality. These social locations inform both disclosure patterns and the support networks of HIV+ individuals. Gay men with HIV are more likely to disclose their HIV+ status to and receive support from friends rather than to family (Kadushin 1999, Ueno et al. 2001, Serovich 2006), whereas heterosexual women are more likely to disclose their HIV+ status to and receive support from family members (Lichtenstein et al. 2002, Comer et al. 2006). Heterosexual women often face decisions about whether to disclose to children. The literature suggests that women choose not to tell children about their HIV+ status out of fear of hurting the child and fear of hostile reaction by others; conversely, a decision to tell children often stems from wanting the child to know and feeling that the child should know (Ostrom et al. 2006, Black and Miles 2002). As opposed to heterosexual women, Ueno et al. (2002) found that gay men often cope with HIV collectively. As HIV progresses for gay men, they are more likely to seek and receive greater amounts of social support from family members, specifically female members of the family; male members of the family provide less support (Kadushin 1999, Ueno et al. 2002).

All of these findings point to the importance of context and the negotiation that takes place within that context (Leonard and Ellen 2008, Derlega et al. 2004). Disclosure is required before one can construct a support network and social location influences the size and type of support network. Additionally, the construction of the support network influences how HIV+ individuals cope. Differences in disclosure patterns also influence the individual's ability to seek help. Individuals may be more inclined to disclose if they feel they are in a safe environment with plenty of available support. However, in other circumstances, individuals may choose to maintain nondisclosure out of fear of being ostracized from their communities and rejected by their families. Management of potential stigma is an important mitigating factor in a decision to disclose. All of these contextualized factors - the reaction of others, the quality and type of support, and the expected material outcome of disclosure influence the decision to disclose.

Stigmatization

Despite years of activism and education surrounding HIV and AIDS, living with HIV is still highly stigmatizing (Herek et al. 2005). Stigma associated with HIV often complicates the lives of individuals living with the virus. Individuals sometimes do not disclose due to fear of being stigmatized. They may be rejected by friends or family, lose their job or housing, and often experience depression and social isolation because of discrimination and prejudice (Herek 1988, 1999, Kadushin 1999, Sowell et al. 1997, Hackl et al. 1997, Goggin et al. 2001). In the following section, I discuss how HIV+ individuals become stigmatized through social processes and how stigmatization is maintained through these same processes, how stigma is informed by social location, and finally consequences of stigma in everyday life. My point is to illustrate how social processes both inform stigma itself and the consequences that emerge from it.

Becoming Stigmatized

Stigma is a social construction. It is created in a process of imposing inequality between dominant groups and marginalized groups. Link and Phelan (2001) argue that this process has several steps. First, people distinguish and label human difference (Link and Phelan 2001). Then, dominant cultural beliefs link labeled persons to undesirable characteristics and categories to differentiate “us” from “them.” Next, labeled individuals experience status loss and discrimination, which results in unequal outcomes. Unequal outcomes, i.e., the material consequences of processes of stigmatization, mean that stigmatized people often lack access to political, economic, and social resources to better their positions (Link and Phelan 2001, Berger 2004).

Douard (1990) expands on this process of categorizing stigmatized people: “society has a method for classifying people with respect to certain attributes to facilitate social recognition and all members belong to a range of permissible categories” (38). Individuals who fall outside of the permissible categories are stigmatized. HIV+ individuals are categorized based on social location, i.e., gender, sexuality, race, but also by mode of transmission. Those who contract HIV through sex work, IV drug use, and sex between men are particularly likely to be stigmatized. The “innocent” victims in the AIDS epidemic have historically been those infected through blood transfusions, children born to mothers with HIV, or (sometimes) those who contract the disease through heterosexual sex (Patton 1994). In these latter instances, individuals are viewed as victims; Ryan White¹ is a perfect example.

¹ Ryan White could be considered the AIDS epidemic’s first highly publicized “innocent victim.” He was a hemophiliac child who was infected with HIV through a blood transfusion. He became a prominent advocate for and face of AIDS, and helped the general public realize that it could happen to “anyone.”

Gendered Stigma

Stigmatization is also shaped by gender and sexuality; HIV stigmatization of men and women normally follows the lines of traditional gender stereotypes, i.e., heterosexual women are often categorized as irresponsible, immoral or as vectors of the disease (Lichtenstein et al. 2002, Kitzinger 1994, Patton 1994). Gay men – who are often culturally feminized - are stigmatized in similar (but sometimes more extreme) ways as heterosexual women and HIV/AIDS is often associated with male homosexuality (Herek et al. 1999). Adina Nack's work on women with human papillomavirus (HPV) highlights a "gender double standard," in which heterosexual women who contract a sexually transmitted disease (STD) are often viewed as "filthy," "dirty," "stupid," promiscuous and violating gender appropriate behavior (Nack 2006: 6, Borchert et al. 1995). Heterosexual men view a diagnosis of AIDS as an attack on their masculinity (Lichtenstein 2004).

One of the most pivotal works done on AIDS stigmatization was conducted by Berger (2004). In her study of urban African American, crack/cocaine using sex workers, Berger offers the concept of intersectional stigma, which captures the ways HIV+ individuals are socially defined in terms of the interlocking oppressions of race, class, gender and sexuality (2004). Berger found that intersectional identities played a large role in the stigma African American women experienced, a stigma that looks different than stigma experienced by heterosexual white women. In the former, HIV stigmatization is constituted by inhabiting several marginalized positions simultaneously (Black, IV drug user, prostitute, a woman etc.), while in the latter, white women occupy a less marginal position and therefore, HIV stigmatization is different and may be less severe. Berger best highlights this differentiation when talking about how the marginalized positions these women occupy come together to influence their experiences:

Intersectional stigma points to the understanding that women are not only marginalized, and socially situated (shaped by their race, class, gender), but that the category of “HIV-positive person” is loaded (from the stigma standpoint) with effectively negative perceptions about groups of people with the virus (drug users, prostitutes, lower income women) (2004: 24).

For the women in Berger’s study, these situated experiences of stigmatization informed identity, resources, political participation and their roles as activists.

Stigma in Everyday Life

There has been a tremendous amount of research on stigmatization among HIV+ populations. Studies of heterosexual women have focused on the impact on mental illness (Collins et al. 2008a, Collins et al. 2008b), sources of stigma (Sandelowski et al. 2004, Bunting 1996), stigma as a barrier to medical care (Carr and Gramling 2004), and stigmatization of African American women (Buseh and Stevens 2006, Clarke et al. 2003). Research on gay men has focused on the effects of stigma on sexual risk and drug use (Bruce et al. 2008, Lewis 1999), how stigma affects depression and mental wellbeing (Courtenay-Quirk et al. 2006, Frost et al. 2007), and how individuals manage stigma (Chenard 2007, Siegel et al. 1998). Courtenay-Quirk and colleagues (2006) found that HIV positive men are often treated negatively by others within the gay community, and that these experiences of stigma have negative impacts on the men’s mental health. Siegel and colleagues’ (1998) study of gay men in New York City illustrates several ways men manage their stigma. These processes involve a spectrum of management including complete concealment, attributing infection to HIV to more “acceptable” modes of transmission, and challenging the social stigma through political activism. Management of stigma is an important negotiation in which HIV+ individuals are involved, first because it acts

as a defense mechanism to counteract stigma, and second provides motivation to become politically active.

Stigmatization and Community Context

Research indicates that community context plays a role in how stigma manifests itself in the lives of HIV+ individuals. Individuals who live in rural or conservative communities may experience greater amounts of stigma (Hackl et al. 1997, Heckman et al. 1998). There are several reasons why. Members of these communities tend to know less about HIV/AIDS (Williams et al., 2003), are less tolerant of social diversity, and have negative attitudes towards people with HIV/AIDS (Zukoski and Thorburn 2009, Bunn et al. 2008). A study conducted by Zukoski and Thorburn (2009) found that HIV+ individuals living in rural areas were often rejected by friends and family and also often experienced heightened discrimination from medical professionals. Community beliefs surrounding HIV/AIDS influence patterns of stigmatization and have important material consequences.

My discussion of research on stigmatization raises important implications for HIV+ individuals. Becoming stigmatized and experiences of stigma are wrapped up in social processes of “othering.” Experiences of stigma still persist, and these experiences have negative consequences for HIV+ individuals. In light of these negative experiences, positive individuals negotiate stigma via stigma management and activism.

HIV Community

In the following section, I discuss processes involved in constructing HIV communities, how the historical context of the AIDS epidemic and the establishment of AIDS service organizations (ASOs) informs the appearance of the HIV community today, a discussion of

barriers to accessing ASOs, and finally processes that both promote and discourage the utilization of ASOs and creation of the HIV community.

Cohen (1985) postulates that the first step involved in community construction is the creation of boundaries between groups. The creation of boundaries occurs when “communities interact in some way or other with entities from which they are or, wish to be, distinguished” (Cohen 1985: 12). The second step is the aggregation of individuals who have something in common. These factors are relevant to the discussion of HIV communities. Stigmatization or the creation of boundaries between HIV positive groups and HIV negative groups (or everyone else) involves a process of “othering” (Berger 2004, Goffman 1963, Link and Phelan 2001). Processes of “othering” HIV+ individuals distinguish between “us” and “them,” creating a social divide. This divide is the first step involved in creating the “HIV-positive community,” where individuals seek refuge and find others who have “shared interest or circumstance” (Kelly 2002: 551). The social divide manifests formally and informally, and is located within the HIV community which is composed of a mixture of medical settings, institutions: AIDS service organizations (ASOs) and/or community based organizations (CBOs), and friends and family (Kelly 2002). This physical space serves as one location where the HIV community and/or individuals can advocate against and cope with discrimination and prejudice associated with being HIV positive.

History of HIV Community

On June 5, 1981 an “immune deficiency” virus was found in five gay men in Los Angeles; this marked the start of the AIDS epidemic within the United States. AIDS’ early association with gay men in urban areas influenced the course of the epidemic and the construction of HIV/AIDS communities. In these large urban areas, a gay community existed

prior to the onset of AIDS. The two most notable community based organizations (CBOs) that responded to the early epidemic were Gay Men's Health Crisis in New York City and the AIDS Foundation in San Francisco (Altman 1986). Due to lack of funding from governmental sources, these organizations relied heavily on the funds of the rich white gay population (Altman 1986). They were primarily concerned with education and prevention, and provided therapeutic and medical support for their clients. In the early 1980's, the federal government largely ignored AIDS. It provided no funding for AIDS research or CBOs. The continued rise in HIV/AIDS infection among gay men, the Hardwick decision in 1986², and the unresponsiveness of the government created hostility among the gay community. This hostility and restlessness led to the formation of ACT UP (AIDS Coalition to Unleash Power) in 1987 (Gould 2001, Halcli 1999). The creation of ACT UP – an organization involved in dramatic displays of public activism - was the first major move toward HIV/AIDS activism by the gay community. Though ACT UP was successful in drawing attention to HIV/AIDS, Ryan White's death in 1990 proved to be the most pivotal point in encouraging a federal government role in fighting the AIDS epidemic. Four months after his death, Congress enacted the Ryan White Care Act, which became the first and largest federally funded program for people living with HIV. The Ryan White Care Act is specifically meant to provide care for low-income, uninsured and under-insured individuals living with AIDS and their families (KDEH 2009). Since its implementation it has been amended several times – most recently in 1996 and 2000 - expanding its funds to include those in rural areas, women and their families (KDEH 2009).

² Bowers vs. Hardwick (1986) is a Supreme Court case that upheld the constitutionality of a Georgia sodomy law that criminalized oral and anal sex in private between two consenting adults. This decision outraged the gay community, as they saw it as an infringement against gay rights in the heat of the early AIDS epidemic.

CBOs to ASOs

In the early 1990's, the public health infrastructure serving those with HIV/AIDS began to grow. Though both are oriented towards servicing people with HIV, there are important differences that distinguish ASOs from CBOs. AIDS service organizations are non-governmental organizations that provide services to individuals with HIV or AIDS (Altman 1994). Community based organizations were formed through grassroots response during the early epidemic by HIV infected groups, most notably gay men (Altman 1994). They generally cater to a specific demographic population, but do not limit their services to that specific population (Altman 1994). CBOs are generally associated with the early AIDS epidemic, while ASOs emerged later on the epidemic. With increased federal government support HIV organizations moved away from the private sector and became more institutionalized. ASOs lack the "grassroots" flavor that CBOs once had, are more oriented towards providing services, and are federally funded (Halcli 1999: 148). As the epidemic progressed, ASOs spread beyond predominantly urban centers and were established across the entire United States. The Ryan White Care Act allowed ASOs to provide case management services to affected populations. Currently, ASOs make up the majority of HIV support outlets nationally. ASOs provide numerous services, but the services they provide depend on resources available to them, including donations from the community, governmental funding, and other monetary sources. Generally, AIDS service organizations provide individuals with case management, financial assistance for medication, housing, counseling, educational services, and numerous other HIV related services (KDEH 2009).

The existence of ASOs within communities depends on both the number of people infected with HIV or AIDS in a given community and the need for services. Both of these factors are related; communities with higher rates of HIV infection have greater need of HIV related services; hence the existence of ASOs is more likely and more necessary. Therefore the services

that ASOs provide generally reflect the number of people they are servicing and the resources that those populations need. It is through ASOs and other HIV community organizations that HIV+ individuals find and construct community.

HIV Community and the ASOs

Though the ASO is not the only space where an HIV community can form, it offers an important space where individuals can go to access services and meet other HIV+ individuals. However, this is complicated for individuals cannot access ASOs. These organizations have made and continually have to make accommodations to successfully reach and serve their marginalized clientele.

Several factors come into play in regards to how accessible ASOs are to the population they serve. Research in this area looks at who uses ASOs (Crooke et al. 2005), frequency and rationale for using ASOs (Cameron and Yuk 1999), and success at reaching target communities (Amaro et al. 1995). Cameron and Yuk (1999) looked at ASOs in various metropolitan areas in the United States and surveyed their female clients about their perception of their local ASO and the services it provided. They found that women often chose not to use services because they did not want to be associated with HIV/AIDS, felt uncomfortable in these spaces, and could not make it to the ASO due to transportation and scheduling conflicts. This study provides insight into the accommodations ASOs have made and continue to make in order to efficiently reach diverse populations they serve.

Perceptions of the ASO are another important factor that influences choices to utilize an ASO. Cain (1994) looks at how ASOs manage impressions. ASOs, like HIV+ individuals, must manage stigma associated with HIV/AIDS. He finds that these organizations attempt to negotiate their impressions in three ways: trying to appear as a non-gay organization by appealing to the

heterosexual population, appearing professional, and confronting stigma by challenging homophobia and discussing sex openly. Cain's study raises important issues ASOs must confront when trying to establish legitimacy and barriers they have to overcome when trying to reach the community they are serving.

A final factor research depicts that influences access to ASOs is the local community context. Zukoski and Thorburn (2009) point to the influence of rural community culture on individuals living with HIV/AIDS. These characteristics included less tolerance of diversity, greater fear of HIV, and less anonymity within the community. Similarly, research on ASOs in rural settings indicates other barriers individuals experience when trying to access HIV related sources. In rural areas there are fewer outlets for PLWHAs (People living with HIV or AIDS) to use and ASOs in these areas are few or nonexistent. Those that do exist provide limited social support programs and often lack comprehensive AIDS services (Castaneda 2000, Zukoski and Thorburn 2009). Other barriers to care include poverty, negative attitudes about HIV/AIDS, and misinformation about HIV or AIDS (Castaneda 2000, Hall et al. 2005, Heckman et al. 1998). This research indicates the problematic nature of constructing HIV community and assessing ASOs in the face of barriers. Additionally, this research points to the importance of two conceptions of community, first the idea of the HIV community, which is an aggregation of positive individuals and their support networks, while the second notion of community refers to the surrounding geographic community contexts (cities, towns, etc.).

Throughout this section I have discussed both the HIV community and ASOs. My point in doing so was first to highlight how HIV community is constructed. The HIV community is constructed by establishment of a boundary as "HIV+." The second step involves the aggregation of HIV+ individuals (Cohen 1985). ASOs or other HIV organizations offer one example of

physical place where an aggregation of HIV+ individuals can occur. However, as shown by Kelley (2002) the HIV community can be constructed in a multitude of other ways via HIV+ friends, family members, and medical providers, etc. Therefore, HIV community can be constructed in a multitude of ways, settings, and consist of a number of different people/institutions. Additionally, it is important to recognize the influence that community context has in the construction of the HIV community, how people access that community, the resources available in that community, and how the makeup of the community has changed over the course of the epidemic. Early on, HIV community existed in the gay community. Since then, the composition of the community has changed. This transition has meant that some individuals do not feel comfortable accessing AIDS resources because of the “gay” association of the disease. Further, barriers exist for some individuals making it harder to access the HIV community and support the ASOs offer. Overall, these findings indicate the difficulty in accessing ASOs in certain contexts. Living with HIV in these settings present unique situations for those who are positive. Although research exists on the creation and accessibility of ASOs, there is little research that captures the importance that HIV community plays within the lives of HIV+ individuals, with particular interest into how the HIV community is utilized, its benefits, and how context influences individual’s access and involvement.

Conclusion

This review establishes three themes in the literature. First, disclosure is a decision making process that is contextualized by the type of relationship an individual has to others and the environment in which they disclose. Second, stigma is still very much an important factor in the lives of HIV+ individuals. Stigma manifests in various material consequences (discrimination, rejection), and is informed by social location. Additionally, stigma becomes an

important factor in both deciding to disclose and accessing the HIV community. Finally, the HIV community serves as a space where individuals can access support and advocate on behalf of HIV; however in certain contexts there are barriers that bar individuals from accessing the HIV community. Processes of disclosure and involvement in the HIV community are ways individuals manage, conceal, and monitor their stigmatized identity.

My research explores the manageability of an HIV+ status on a personal, social, and communal level drawing on interviews with eighteen HIV+ individuals. The purpose is to explore how individuals negotiate personal decisions of disclosure, manage experiences of stigmatization in the personal realm of an “HIV+ identity” and within the social realm of the HIV community, all in the face of unequal circumstances. My research focuses on four central questions: How do decisions surrounding disclosure act as a mechanism to manage stigma? What processes (stigmatization, seeking support) inform a decision to disclose? How do HIV+ individuals experience, manage, and combat stigma? And finally, how does the HIV community function as a place where individuals manage stigma by constructing support networks, being involved and advocating for the HIV community and HIV itself?

To date, research has looked at these processes by themselves or at a given point in time. My research aims to examine these processes of negotiation over the life course of HIV infection and also the ways these processes act/react upon each other. I contribute to the literature in two ways: first I offer an analysis of a population that has remained understudied in the HIV/AIDS literature - positive individuals living in low prevalence areas, specifically the Midwest, and areas with fewer resources available to HIV+ individuals; and second my analysis gives insight into the importance of context underlying individual decision making processes regarding disclosure, experiences of stigmatization, and utilization of the HIV community.

CHAPTER 3 - Methodology

Sampling

In this research I explore patterns of disclosure, stigmatization, and the importance of the HIV community in HIV positive people's lives. Much research on these issues has been quantitative, drawing on survey methods to describe patterns of disclosure or instances of discrimination (see Black and Miles 2002, Borchert et al. 1995, Derlega et al. 2004, Herek 1988, 1999, Herek et al. 2005, Kudushin 1999). However, this project focuses on processes and meaning – the process of deciding when and to whom to disclose, the meaning and impact of an HIV+ diagnosis in people's lives, and the processes of coming to access (or not) an HIV+ community. Qualitative research is well suited to answering questions about meaning and process. I chose to conduct interviews with eighteen HIV+ respondents to explore these issues.

I recruited respondents in the fall of 2008 through snowball sampling. Snowball sampling is the most appropriate sampling technique because HIV+ individuals are a “hidden population” (Kadushin 1999). To find respondents, I sent a letter to case managers working at HIV advocacy groups and health departments located in Kansas, Nebraska and eastern Missouri. The letter described the research project and asked for volunteers willing to participate in the study (see Appendix A). Respondents who were interested in participating then contacted me by phone. One of my respondents also connected me with two other HIV+ individuals I interviewed for this study. The final sample consists of ten HIV+ men and eight HIV+ women who reside in several areas throughout the central Midwest.

Sample

My sample is mostly white and older than the U.S. HIV+ population as a whole. My youngest respondent is 31, the oldest respondent is 61, the median age is 48. Most had been living with HIV or AIDS for many years, ranging from two years to twenty-six years. Of the respondents seven currently report being classified as having HIV by medical professionals, while the remaining eleven report being classified as having AIDS. Respondents indicated diagnosis of HIV or AIDS depended on several factors: CD4 (T-cell) count, occurrence of opportunistic infections, and HIV or AIDS related symptoms. In general, HIV infection is defined as having a CD4 count greater than 200 and history of no opportunistic infections; AIDS diagnosis is defined by a CD4 lower than 200 and past or current opportunistic infections. The majority of respondents have at minimum a high school level of education; two have taken some college courses, and only one respondent has a bachelor's degree. At the time I interviewed them most were unemployed, living on disability and/or social security checks provided by the government. The main reason for unemployment was due to health related issues because of HIV, which made respondents unable to maintain consistent employment. Many reported that they did odd jobs for supplemental income such as babysitting, yard work, and cleaning friends' businesses. Those who did work often had not been infected with HIV for as long or had relatively good luck living with the disease (i.e., they had not experienced a lot of health problems related to HIV). Of the three who were employed, one worked at a gas station, another at an after school program, and one owned a store. All respondents except one (who was not qualified because his income was too high) have access to case management services through their local health department or a local AIDS service organization (ASO) via the Ryan White program. Table 3.1 summarizes the demographic characteristics of the sample.

Table 3.1 Sample Characteristics³

Name	Age	Race/Ethnicity	Sex	Status	Yrs. Infected	Infection Route
Joe	51	Native American Background	Female	AIDS	>8	Heterosexual sex
Michelle	36	White	Female	HIV	10.5	Sex work
Bert	50	Black	Female	HIV	18	Heterosexual sex
Courtney	38	White	Female	AIDS	>22	Heterosexual sex
Cynthia	48	White	Female	AIDS	>26	Heterosexual sex
Deb	59	White	Female	AIDS	24	Heterosexual sex
Stacy	44	White	Female	HIV	22	Heterosexual sex
Valerie	40	Hispanic	Female	HIV	2.5	Heterosexual sex
Kent	55	White	Male	HIV	>20	IV Drug use
Brad	48	White	Male	AIDS	15	Homosexual sex
Jim	46	White	Male	AIDS	22	Homosexual sex
Sal	31	White	Male	HIV	5.5	Homosexual sex
Phil	49	White	Male	AIDS	>20	Homosexual sex
Drake	43	White	Male	AIDS	22	Homosexual sex
Chris	58	White	Male	HIV	8	Blood exposure
Ralph	60	White	Male	AIDS	30	Blood transfusion
Stan	61	White	Male	AIDS	12	Homosexual sex
Ted	53	White	Male	AIDS	18	Homosexual sex

State Setting and Ryan White Program

To get a sense of how individuals live with HIV or AIDS in these communities (located in Kansas, Nebraska and Missouri), it is important to provide a brief description of the demographics of HIV/AIDS infection in these areas and the services available. Due to issues of confidentiality I do not use actual names or locations of organizations. HIV/AIDS services available to individuals residing in each state depend on the number of individuals living with

³ The “>” indicates the approximate years respondents thought they had been infected with the disease. Many lived several years without ever knowing when they had contracted HIV.

the virus in a specific area, their assessed need, and available funding to provide services (DHSS 2004). As expected, there is more need for HIV/AIDS services in urban areas. Kansas and Nebraska are low prevalence states; Kansas ranks 37th, while Nebraska ranks 43rd for total number of individuals infected with HIV/AIDS per state (data includes districts and territories of the United States). Missouri ranks higher – at 22nd – largely due to the presence of two large urban areas in the state (KFF 2007). As of December 2008 in Kansas there were 1,344 individual living with AIDS and 1,259 individuals living with HIV, with the majority of the cases located in the metropolitan areas of Kansas City and Wichita (KDHE 2008). Kansas has divided the state into nine regions, and each region has a health department and/or AIDS organizations where PLWHA's can go and receive services (KDHE 2009). As of 2006, Nebraska had 1,379 individuals living with HIV or AIDS, with the majority of cases located in Omaha (DHSS 2006). Nebraska's services are structured somewhat differently than those in Kansas. As the majority of PLWHAs are in the eastern portion of the state, the majority of services are located in this region as well (DHSS 2007). In Missouri as of 2004, 4,458 individuals are living with HIV, whereas 4,771 are living with AIDS, with the majority of cases located in two large metropolitan areas, St. Louis and Kansas City, MO (DHSS 2004). Like Kansas, Missouri has subdivided the state into six different regions that focus on providing services to PLWHAs in the surrounding area (DHSS 2009). Each of these regions has several health departments and/or AIDS organizations that provide case management services to their clients, funded through the Ryan White Program. People living with HIV or AIDS (PWLHAs) have access to case management services, drug assistance programs, dental care, medical services, mental health care, substance abuse programs, help with transportation, payment of medications and housing options (KDHE 2009, DHSS 2009, DHSS 2007).

Interview Methodology

I began interviewing respondents in the spring of 2009. The majority of the interviews took place in respondents' residences; I also conducted two interviews at a public library, one at the respondent's place of employment, another interview at a restaurant, and one by phone. I used a semi-structured interview schedule that consisted of thirty-five open-ended questions (see Appendix B). The topics covered include general information regarding the respondent's HIV infection, information about the surrounding community, perceptions of being HIV+, experiences of stigma, disclosure of HIV+ status, involvement in HIV advocacy groups, and available support. The interviews ranged from thirty minutes to two and one half hours. I recorded the interviews and produced verbatim transcriptions. All respondents have been given pseudonyms to maintain confidentiality.

As a background for the analysis that follows, it is important for the reader to know that I am a white woman, and a typically aged graduate student. Most respondents noted that I was young and often treated me as such. However, this also may have aided in the data collecting process as I appeared young and naïve, which meant that respondents might have provided even more information than they may have otherwise. In general, the respondents seemed open to answering my questions even though HIV is a sensitive topic.

Data analysis in qualitative research focuses on the emergence of relevant themes. After transcription, I coded the interviews using NUD*IST 6, software designed for use with qualitative research, to identify patterns, themes, and meanings (Berg 2007). I began by reading each transcript line by line and identifying relevant themes. By doing this with each interview transcript I began to capture patterns that emerged in the data. At this point, my analysis became focused on identifying these recurrent themes. I then constructed a coding tree that outlined patterns I found in the data (see Appendix D). The themes that emerged during analysis included

processes of disclosure, experiences of stigma, quality and availability of support, perceptions of and involvement with the HIV community, and activism.

CHAPTER 4 - Findings

Introduction

In this chapter I explore the themes that emerged during my interviews. Overall the themes fall into a general time line of important events that happened over the respondents' lifetimes of living with HIV. The first important event was learning of their positive diagnosis. For many, a positive diagnosis acted as a catalyst for change; respondents reevaluated their current living situations and adopted an identity as an "HIV+ individual." Following diagnoses, respondents opted to reveal their positive status to some but not to others, hence I discuss processes of disclosure, decisions to disclose, and consequences of disclosure. Though many received positive support from family and friends after disclosure, many reported negative experiences. This is where the importance of the third theme comes into play, that of stigmatization. In this section, I discuss respondents' stigmatizing experiences, and how respondents both cope with and manage these experiences. Finally, I look at the importance of the HIV community in respondent's lives, the factors that influence their choice to be involved or not be involved, and how they utilize the community through various activities such as support groups, activism, and education. Throughout this analysis, I highlight the decision-making processes, personal choices, and social processes underlying each of these phenomena. Living with HIV involves a negotiation by HIV+ individuals with themselves, the actors (friends, family, etc.) in their lives, and finally, the HIV community itself. The aim here is to capture the problematic and sometimes contradictory nature of being HIV+ and how positive individuals negotiate this existence and carry out their everyday lives.

Diagnoses

Diagnosis of a positive status is the first step involved in the process of becoming a marginalized individual. By exploring the process of learning one is HIV+, I illustrate how respondents react after they learn of their positive diagnosis, how this reaction eventually turns into motivation for substantive life changes (often for the better), and I illustrate how these changes manifest in the acceptance of their positive diagnosis and adoption of an “HIV positive identity.”

Of those I interviewed, fifteen respondents decided to get tested after hearing a former sex or drug-using partner was infected, the remaining three respondents (all gay men) got tested routinely every six months. An HIV+ diagnosis from medical professionals spurred a multitude of emotions and reactions from respondents. Some reported feeling disappointed by their diagnoses, regretful, and ashamed they had been infected with HIV. Others reported feeling initially indifferent about their positive diagnoses.

Most of the respondents in this sample were tested and diagnosed with HIV in the mid-1980s to early 1990s. During this time, life expectancy was still very low for those living with HIV/AIDS. Hence, several respondents reported feeling that an HIV positive diagnosis was a death sentence:

I figured I was going to die immediately. Got all my paperwork ready, like who I wanted to have what, and I went through the house and wrote on everything. It was kinda like, your death sentence, you just had so many days to get it. (Joe, 51, Native American)

Being diagnosed HIV+ makes death more realistic. In a sense, death becomes a part of everyday life. In other instances respondents simply gave up on caring about their own life. Michelle reported that she didn't care whether she lived or died after finding out about her positive diagnosis:

Oh my gosh. At first, when I first found out I was very, I didn't care whether I lived or died. My kids don't need to know who I am. Because I had been in and out of prison and to where my kids didn't really know me anyway. So I was like I'll just go on the street and smoke myself to death, which I almost did. I was trying to smoke myself to death, which I did, my counts went real low and I got really sick and I decided to come home.
(Michelle, 36, white)

Michelle initially reacted by not caring about her own life and even went to lengths to end it (smoking herself to death with crack cocaine). As the interview progressed, Michelle went on to describe a negative experience she had with her drug dealer. Michelle and her drug dealer had been high on drugs for three days. On the final day, she was riding in the car and they had planned to go and kill someone. While in the car, her drug dealer held a gun to her head several times threatening to shoot Michelle. She cites this experience as a "wake up" call for turning her life around. Following this experience, Michelle decided to get sober. In conjunction with getting sober, Michelle began to take better care of herself, manage her HIV, and resume her role as a parent.

Other respondents described similar situations in which they decided to make substantive changes in their lives. In these instances, an HIV positive diagnosis served as a catalyst for change. Here, respondents reevaluated their lives. This reevaluation involved deciding how they should manage living with HIV, reconsidering the direction their life was going, and contemplating what life meant to them:

What uh, when I found out that I had it, you know decided that I wanted to, you know I wasn't going to live life like I'd been living, [I decided] I wasn't going to let a man try to

take over my life, you know, and try to ruin my life, and tell me how, what I could and couldn't do. (Deb, 59, white)

I came home and sobered up and just was like I don't want to die, I want to live. Well if you want to live these are all the changes you got to make. So I started taking medication, and doing what I gotta do. I've been on almost all the pills they have. But it has also made me appreciate life more. Holy cow, I might not have much time, which I think I will. So it's like you know, do what you can, be there for your kids, do the right shit instead of that shit. (Michelle, 36, white)

It's forced me to make sure I sleep better, make sure I take care of myself better, make sure I'm doing multivitamins, make sure I'm exercising, it's just made me be more vigilant about my health because I don't have the luxury of slacking off. So I am much more in tune with my body and aware of making a healthier choice than I was before. (Sal, 31, white)

Being diagnosed HIV+ was a sobering moment (sometimes literally) for these respondents. It made them appreciate life more and figure out what was important to them. Deb's, Michelle's, and Sal's experiences each illustrate how HIV+ individuals reevaluated their lives and make changes accordingly. Reevaluation involved personal changes (getting sober, becoming healthier) and changes in social roles (parents, people in general). Through these changes, respondents begin to accept their positive their diagnosis. Additionally, following a positive diagnosis these individuals sought out informational support at their local ASO. This informational support often empowered respondents to take charge of their illness and informed

the life changes they describe. For these respondents an HIV+ diagnosis served as a catalyst for change.

Becoming an “HIV+ person”

Alongside accommodating life and lifestyle to being HIV+, respondents began to forge identity as an “HIV-positive person.” Stacy best describes this process:

Well, I don’t take life for granted like I used to. Becoming HIV+ really makes you think, you’re not the same person you were, but at the same time you still are. But now you’ve got this new thing going on, HIV. You almost become something totally different than you were before. So that makes it really hard. (Stacy, 44, white)

Stacy captures this transition by recognizing the boundary that separates her past self and her current HIV+ self - a process that involves holding onto some part of a former self but at the same time adopting a new identity as a person with HIV. Similarly, Stacy highlights the process Link and Phelan (2001) describe in which HIV+ individuals are differentiated as “us” and “them.” Cynthia describes the impact that this distinction from “us” and “them” has within an HIV+ individual’s life:

HIV doesn’t show on the outside, so? It’s a huge bigger stink bomb. We always talk about the letters. I apostrophe M, H-period, I-period, V-period, plus. A whole lot of punctuation and not many letters, whole lot of big stink in the air. Just like you talk about a mushroom cloud. A lot of people really move back at times. They really do. “I’m HIV positive.” (49, white)

Despite the simplicity of the phrase “I’m HIV+,” the weight that it carries and the meaning behind it far surpass the statement. It is with the construction and acceptance of an identity as “I’m HIV+” that individuals begin creating a boundary that separates themselves from others and

their former selves. Both Stacy and Cynthia are involved in a process of “othering,” they are no longer view themselves as “normal” but now occupy a marginalized status (Berger 2004, Goffman 1963, Link and Phelan 2001). Through this distinction HIV+ individuals begin to construct their social world around this new identity.

Disclosure

Deciding to Disclose

Following an HIV+ diagnosis, individuals at some point or another will have to tell others about their positive status. The rationale for deciding to disclose is the need for support. However this decision is contextualized and varies depending on whom the person is telling and the setting in which they are telling. Further, anticipation of a negative reaction also influences a disclosure decision. With these factors in mind, I discuss how individuals decide to disclose, the contextualized nature of disclosure, and finally the consequences of disclosure.

Some respondents opted for disclosing immediately, while others waited, at times several years, before disclosing to others. For this sample disclosure patterns ranged from full disclosure to partial disclosure. Full disclosure indicates that respondents disclose to their entire social circle, those who partially disclose only make certain aware of their HIV+ status (Black and Miles 2002). None of the sample reported that no one knew of their HIV status; most of the respondents had disclosed to their family, close friends, and within medical settings.

Some respondents were adamant about disclosing their status while others were reluctant. For instance, when asked who knew about her HIV+ status Joe responded, “Like I said I don’t want anyone to know, I don’t want any sympathy and I don’t want things thrown at me.” Joe perceives a potentially volatile reaction from others, and this fear influences her decision to maintain nondisclosure to others. On the other hand several respondents indicated disclosing

their status rather freely. Cynthia, who is very politically active, is adamant about making her HIV+ status known to those around her (Black and Miles 2002): “The fact that I am totally 100% flat out, that everyone knows I’m the blind woman living with AIDS. I put myself in that light, I don’t mind that, I can take it.” She puts herself in that light for the benefit of others and her own needs and fully discloses her HIV+ status. Similarly, Stacy says: “I’m very open; you know what I’m saying. I don’t care who knows. I’ve never lost any friends. Nobody’s ever pushed me away.” She also indicates that she has not experienced negative treatment from others after disclosing. Sal also describes how he is open with his HIV+ status: “Pretty much everyone I know knows. My immediate family knows, a couple of cousins know, anyone in my immediate circle of friends who know me since becoming positive all know.” For these respondents openly disclosing their HIV+ status is in part an outgrowth of their activism and a feeling that they are in more accepting environments where fewer people would judge them. A distinct pattern emerges here, activism informs a decision to disclose; others who continually fear stigmatization do not openly disclose. Personal comfort within one’s social environment becomes a determining factor in decisions to disclose.

As mentioned in chapter 2, disclosure is a decision making process for respondents, meaning that respondents weighed the potential benefits and consequences of revealing their positive status to others (Black and Miles 2002). All respondents engaged in this sort of cost benefit analysis to some degree. Michelle best highlights this process:

What’s the worst possible scenario and what’s the best possible scenario if you tell them? Like kinda, do a pros and cons list and see what if anything can come back on you, and are you willing to take that risk for that person to know. Or is it that important for that person, you know? It depends on if you’re going to sleep with that person, because they

definitely need to know. Or are you going to live in close quarters, you're going to have to tell whether you want to or not. And if you don't want to then you don't need to do that. (36, white)

Michelle highlights the decision making process involved in deciding to disclose a positive status. HIV+ individuals contemplate the possible outcome of disclosure and whether they will put someone at risk. Michelle's experience depicts the personal negotiation in which individuals engage when deciding to disclose. They speculate both on the reaction of others and the outcome after disclosure.

Contextualized Disclosure

In understanding disclosure as contextualized, several factors come into play, including the type of relationship one has with others, the environment where one is disclosing, and the perceived reaction from others following disclosure (Derlega et al. 2004). Social distance also becomes an important factor in disclosure; positive individuals are more likely to disclose to family and friends in an attempt to get support instead of those with whom they have tangential connections. Respondents described situations where these factors played an important role when deciding to disclose. For respondents who described situations where they could put others at risk disclosure is a necessity, most notably in settings where others would come into direct contact with bodily fluid, e.g., through sex or in medical settings. As these respondents observe:

If you're going to sleep with somebody you have to tell them. It's only fair to that other person, so they can make the decision, on what they want to do. (Courtney, 38, white)

But it's one of those things where, on a lot of the other social networking sites I'm on, they are more hook up services, so usually the first thing on my profile is "pos," just

putting that upfront because it leaves out the bullshit. Plus it saves my ass, you know getting into it that this is what I am and this is what I'm about. If it goes any further than this, then you have already been warned. (Sal, 31, white)

When you go to the hospital, immediately, when the paramedics come to work on you, [disclose] immediately, you need to disclose to those people so that, there already is a universal precaution, but that way that they know that they need to definitely be cautious when working with you so that they don't get infected. (Jim, 43, white)

All three respondents describe contextualized disclosure. These are situations they define as those in which disclosure of an HIV+ status is a necessity, instances where others will come in direct contact with infected bodily fluids: sexual contact and in medical settings. However, though many respondents discussed the necessity of always openly disclosing in these settings, some did not follow through in their personal lives, particularly in sexual situations. This gives insight into the disconnect between belief and behavior in regards to HIV and sexuality. Several respondents opted not to tell "one-night stands" but would tell others who became regular sexual partners. Whether they disclosed or not, all stressed the importance of using condoms and other forms of protection during sexual encounters.

Not all respondents remained sexually active after being diagnosed HIV+, however. In instances in which there was no risk of others coming into contact with bodily fluids, respondents pointed to a different type of disclosure. Courtney describes two different instances where she chose to maintain nondisclosure on the basis of not putting others at risk and fear of how they would react if they found out. In the first instance, she chose to maintain nondisclosure from an employer after overhearing a negative conversation the employer had with another

person about HIV+ children. In the second instance, she maintained nondisclosure because she was not putting anyone at risk:

And I heard her [my employer] talk to someone while I was there cleaning, and watching how she reacted when they asked if she would take HIV kids. She's very, "eww," she'd freak out. But I'm not putting her at risk. Actually, my salon, my hair stylist, asked me. I figured I'm not putting her at risk either, so I wasn't comfortable telling her so I didn't. (38, white)

Courtney highlights a decision to maintain nondisclosure based on a perceived negative response from others. Later on in the interview she describes how she has chosen not to tell her employer because she is afraid she would lose her job. She further justifies the maintenance of nondisclosure based on the fact she is putting neither individual at risk of infection. In both instances, Courtney uses nondisclosure as a form of stigma management because she is unsure of the direction of the outcome.

Similarly, Jim describes a situation where disclosure is not based on putting someone at risk, but based on assessed needs.

You need a support team, once you find out you're HIV positive, you need a team of support. A group of people who will care about you, not judge you, whatever. Maybe you have to figure out which friends, which family members you want to be on that team, that you can trust won't run away from you. (43, white)

Jim highlights a decision to disclose based on an assessment of the relationship with a potential support person (Derlega et al. 2004). Jim also highlights the importance of building a support network consisting of trusted individuals to provide support. Both Jim's and Courtney's experiences highlight the relationship between social distance and disclosure. Social distance is

an important determinant for disclosure. Individuals often tell people close to them in an effort to obtain social support, but protect/conceal their positive status in the presence of others socially distant from them.

Involuntary Disclosure

As discussed in the literature, disclosure is not always beneficial (Lenoard and Ellen 2008), and can be harmful. One such instance is the involuntary disclosure of an HIV status. In these instances, the choice to disclose is taken out of a one's hands. Several respondents reported having their status involuntarily disclosed by others. Courtney and Bert illustrate how their former husbands often used their HIV positive status to be hurtful.

My ex is doing that right now. Is telling everybody actually here in [...]. "A lot of people know Courtney has AIDS". Although they don't believe it. I mean, I always tell them how my ex-husband was abusive, I left him, and now he's spreading rumors. The ones I don't want to know, they, you know, accept the story. With so many people it's still a stigma (laughter). (Courtney, 38, white)

My husband is the one who let everybody know that I was positive, he tries to keep these guys from talking to me and stuff. Just about everyone around here knows. (Bert, 51, Black)

Courtney manages her potentially compromised status by discrediting her ex-husband; noting that he was abusive and is seeking retribution. By doing this she gives herself legitimacy. At the same time, Courtney is also managing potential stigmatization that could result disclosure. Bert's husband, on the other hand, attempted to control her behavior by disclosing her HIV+ status. As a result of Bert's compromised disclosure, she is treated negatively by others in her community.

Stigmatization

Manifestations of Stigma

Despite years of activism in HIV+ communities, stigma is still present in the lives of HIV+ individuals. In the following section I highlight various experiences of stigmatization provided by the respondents. In these situations respondents were rejected by immediate family members and openly discriminated against (Herek 1999). I illustrate how experiences of stigma are informed by gender and sexuality, and explore the mechanisms respondents utilize to cope and manage experiences of stigma.

Post disclosure, respondents often experience mixed reactions from family members, friends, and medical providers. These can range from complete support and sympathy to being exiled and rejected by family, friends, and community (Herek 1999). Often initial negative reactions changed once family members learned more about the disease. In other instances respondents remained estranged from these family members. In one instance Valerie, after being rejected by her family members, moved out of her small town in Arkansas to a larger urban area in the Midwest.

I pretty much decided to leave after the reaction I got from my family. They were really mean to me about it, pretty much disowned me. That really hurt for awhile. But now I live up here and it's better. I mean, there is a lot more medical stuff and services for me, but I sometimes miss seeing my family. (40, Hispanic)

Valerie's experience parallels stigmatization as described by Herek (1999). Valerie was rejected by her family, and as a consequence she relocated. The relocation was not an entirely negative experience as she now has better access to medical and other HIV related services. Her experience gives insight as to how consequences of stigmatization unfold in real life.

The most reported experience of stigmatization was via fear of casual contact, where others feared coming into direct contact with HIV+ individuals (Herek 2005). Situations in which respondents were stigmatized involved fear of contamination of food, fear of being touched, and fear of sharing personal items. The majority of the respondents indicated having past and current experiences with this type of stigmatization. Following several respondents describe situations where they experienced fear of casual contact by others.

Well like the one time I was at China Buffett and I was there before them and my sister and brother-in-law came and they said “Oh God, we can’t touch the food, after she’s touched it” so they turned around and left. That made me feel really low. (Joe, 51, white)

I have one friend I went to coffee with him at his family's house because he wanted to tell them he had AIDS. So, we drive up the street for it one day, and we go in there and drink coffee, and just as we left, his dad grabbed a [bottle of disinfectant] and a rag and threw our coffee cups in the trash with rubber gloves. And, it was shocking. And people do these things because they don’t know about it. People are spiteful. (Ted, 53, white)

I went in with pneumonia, and didn’t know it was pneumonia. And they left me laying in the emergency room for six or seven hours and I could hear the nurses saying “I’m not touching him, I’m not touching him.” They wanted to do a spinal tap because they thought it might be meningitis. At that point, they still hadn’t even diagnosed. Finally this one doctor came in and said, “I see you have been laying here for a long, long time”, and I was crying and he asked “what’s wrong?” And I explained to him some of comments that I had heard and he’s like “this is bullshit” and he started getting the tests done and

everything. And then they finally admitted me, because I had pneumonia, but even during that four days, there were nurses that refused to touch me, there were nurses that were nasty to me. (Jim, 43, white)

These experiences capture just a fraction of actual stigmatization respondents reported experiencing. Joe's family became fearful of food touched by Joe or being near her because of "contamination" by HIV. Similarly, Ted identified experiences of fear of casual contact by a friend's father after he accompanied him to disclose his positive status. And finally, Jim highlights an experience of fear of casual contact by medical professionals. In this case, Jim's health was potentially compromised because medical professionals at the hospital were afraid to touch him. Jim's example also highlights how stigmatization via casual contact can also take place in institutional settings. Similarly, both Joe and Jim highlight how these experiences affected them emotionally, resulting in crying or feeling "low." Ted on the other hand taps into how misinformation about HIV transmission fuels negative reactions by others, which causes these experiences of stigmatization. Fear of contracting HIV via touch is a common rationalization that others used to justify discrimination against people with HIV (Herek 2005). This rationalization also reinforces continued stigmatization of HIV+ individuals. Additionally, experiences of stigmatization constrain and shape the directions of people's lives, e.g., in Valerie's decision to move away from her family. Positive individuals negotiate living with a fatal illness, maintaining their health status, social responsibilities as parents, workers, and being productive members of society, all within the constraining context of HIV stigmatization.

One respondent shed light on how experiences of stigmatization act as constraining forces. Kent describes material consequences of HIV stigmatization (job loss) after his positive status was involuntarily disclosed.

Yeah, I got fired from my job because of a prickhead in AA that thought he was too good for everybody else. Took it to the boss, because I was open [disclosed his HIV+ status] in a meeting which is supposed to be confidential. I've never been back to AA. (Kent, 55, white)

Kent's quotation illustrates an experience at an Alcoholics Anonymous meeting where his disclosure was compromised, which resulted in a job loss, and solidified his choice to discontinue attending AA meetings (Herek 1988, 1999). His experience highlights stigma's manifestation in material consequences and as a constraining force.

Gendered Stigma

Other respondents indicated experiences of stigmatization informed by their social location, specifically gender. For two respondents, these manifestations resulted in experiences of gendered stigma (Nack 2006; Lichtenstein et al 2002; Kitzinger 1994; Patton 1994), and stigma management associated with mode of transmission. In the first example, Joe experienced gendered stigma while at the same time managed this stigma by disassociating herself from behaviors normally associated with HIV transmission:

I feel stupid for getting it; it just makes you feel dirty, filthy. I don't know it's not something I went out to get. I mean I don't sleep around, I don't do drugs. (51, Native American)

Bert also reported being stigmatized along the same lines.

I feel bad because when they get mad at me or something like that, they throw it in my face. They call me a slut or a tramp, or a no good drug addict. And I go home and isolate myself, crying and stuff, drink, do drugs, anything, I get depressed and I'm taking depression pills. It's hard on me. (Bert, 50, Black)

Women HIV+ respondents experience stigma that is rooted in socially defined gendered expectations (Berger 2004). For women, stigmatizing experiences are informed by a socially based gender double standard (Nack 2006). These women describe experiences that highlight the gendered nature of HIV related stigma, as they stereotype themselves or are stereotyped by others as being “stupid,” “dirty,” “being a slut,” due to their HIV+ status (Lichtenstein et al. 2002; Kitzinger 1994; Patton 1994). These women’s experiences also give insight into coping mechanisms and ways to manage stigma. Joe internalizes HIV related stigma, whereas Bert was stigmatized by individuals within her surrounding community. Bert describes how she copes with stigmatization by turning to substance use, crying and isolation (Hackl et al. 1997). Both of these passages indicate the negative impact that self stigmatization and stigmatization by others can have on HIV+ individuals. Additionally, Joe calls attention to wider held HIV/AIDS stereotypes. She does this in two ways, 1) by identifying types of individuals who are generally associated with having HIV, those who “sleep around” and “do drugs” and 2) by identifying two types of behavior that are associated with HIV transmission, drug use and promiscuity. She separates herself from these categories by saying she does not participate in these behaviors. Both mode of transmission can be a stigmatizing attribute as well as having HIV itself, but the mechanism in which individuals are stigmatized is informed by gendered processes of stigmatization. These respondents are actively involved in a negotiation process. They negotiate potential stigmatization alongside managing stigma associated with mode of transmission.

Managing Stigma

Two other respondents, Chris and Ralph, serve as negative cases within this sample. Both claim to have contracted HIV from nontraditional routes. Chris says he contracted HIV after he cut his finger with a contaminated scalpel, while Ralph contracted HIV via a blood transfusion.

Though both respondents attribute their HIV infection via these routes, both also participated in other behaviors during their lifetime that could have led to HIV infection; Chris identifies as gay and Ralph is a former IV drug user. Though it is not my place to discredit these men, their examples do provide insight into how powerful HIV stigma related to mode of transmission is. People who are infected with HIV via non-stigmatizing modes are often seen as victims, whereas those who contract HIV through traditional modes of transmission are seen as at fault for contracting the disease (Kitzinger 1994). Stigma associated with mode of transmission is powerful in the fact that it could lead some to disassociate themselves from traditionally stigmatizing modes of infection instead opting for more accepted modes of transmission: blood contamination or blood transfusion (Chenard 2007, Siegel et al. 1998).

HIV Community

Two Conceptions of Community

For this research I use two distinct conceptions of community. The first involves the idea of the “HIV community.” Like Kelly (2002), I refer to “HIV community” as a manifestation of AIDS service organizations (ASOs), medical providers who provide services to HIV+ individuals (formal sectors), and support available for HIV+ individuals via friends and families (informal sectors). Following diagnosis, HIV+ individuals begin seeking out medical services, ASOs and other HIV related organizations. This is where individuals begin to construct community. The spaces, services, and people available to individuals I interviewed varied depending on the resources accessible in their communities and their perceived (negative or positive) reaction of their friends and family. The conception of “HIV community” that I use is very general and nonexclusive, therefore many actors and institutions are parts of the community. The second conception of community that I use refers to the geographic community

respondents inhabit (town, city etc.) and their perception of the surrounding community. Many respondents perceived their community as “a kind of a redneck town” and that “you [HIV+ people] just aren’t accepted around here.” Both of these ideas give insight into the community context some of the positive respondents face. They are not necessarily the most friendly or accepting to HIV/AIDS and HIV+ individuals.

In the following section I begin by discussing three distinctive features of the HIV community, and then I discuss the importance of surrounding community context. The first distinctive feature of the HIV community is the physical makeup of respondents’ support networks, and how this differs and changes over time. Second, I discuss reasons for being involved or not involved with the HIV community. Third, I discuss the importance of the HIV community as it acts as an outlet for individuals to construct community, advocate on behalf of HIV, and challenge stigma. Following my discussion of the construction of HIV community I discuss how respondents’ perceptions of their surrounding community (geographic community: town, city, neighborhood etc.) influence the existence/involvement with the HIV community, and how the HIV community differs depending on community contexts (urban vs. rural).

Support Networks

Many respondents indicated that the makeup of their support network changed over the duration of their illness. For most, in the early years of diagnosis support networks consisted primarily of friends and family. This was the case post disclosure. Friends and family members provided emotional support, monetary support, and other material help such as transportation, childcare and food. The family becomes an important place where HIV+ individuals find support and “community” in the early years of their diagnoses. Michelle illustrates the importance that her family has played as a source of support throughout the duration of her illness.

They go to the groups with me, Jasmine [my daughter] participates in them. It's really cool and she supports me, I have notes all over the house, to take my pills, and to take care of myself, you know all kinds of stuff. They'll put notes up for me, and stuff, I don't know, she's just really good. And if I get sick, she totally takes care of me..... And if I start talking, because I'm kind of morbid, sometimes I'll say you know when I die you can have that. She's like mom "shut up". She's pretty funny with that. (36, white)

For some, like Michelle, the family was the most important source of support. Her children attend support groups and perform primary caregiving roles for her. For heterosexual women who were mothers, children were an important source of support.

In other circumstances, HIV has acted as the unifying catalyst that both created friendships and maintained those friendships. For instance, Courtney, Cynthia, and Stacy, who live in an urban area, have been "best friends" for approximately 10 years. They met while attending support groups several years ago and have remained close friends since. Stacy puts it best when describing their friendship: "Yep, if it wasn't for HIV we wouldn't be friends." Stacy attributes her friendship with the other two women to their shared positive status. The three women get together at each other's houses on a weekly basis, celebrate each other's birthdays and often attend ASO functions together. Stacy recently lost her daughter, and relies on Cynthia and Courtney for emotional support. Stacy, Courtney and Cynthia's example shows what a support network between HIV+ friends looks like.

Among those I interviewed, support networks looked different for men and women. The majority of the male respondents in my sample were gay, and their support networks consisted primarily of their partners and friends (Kadushin 1999; Ueno et al. 2001; Serovich 2006), whereas for the heterosexual women in this sample support networks consisted of family

members, including significant others, children, and their parents (Lichtenstein et al. 2002). Though most heterosexual women relied on support from family, some did have friends who supported them. This is consistent with the literature, and demonstrates the influence of gender and sexuality in shaping support networks. Ted describes his two biggest supporters, his partner and a friend:

So, who would you say is your biggest supporter? John and Deb. Yeah. Deb's, we've been through a lot with Deb, and she's been through a lot with us. You know, she's just always been there. We may not talk for a month, but then we may talk every day, ten times a day. (white, 53)

Ted describes two individuals in his life who serve as his main supporters. Ted does not receive support from his family because his mother and father have passed away. The two individuals that Ted mentions have HIV as well. Again, HIV serves as a unifying catalyst in relationships that would not necessarily exist otherwise. John, Ted and Deb all met at the local health clinic and have remained friends for several years.

Later on during the interview Ted goes on to describe the "old timers group" a group of his HIV+ friends who have all had HIV over fifteen years. This group meets weekly for lunch and communicates on a regular basis. Recently, one of the group members passed away. Ted described how hard his death was on all of the friends in the group. Ted's description of his supporters and the "old timers group" give insight into how support networks are constructed for older gay men. Age is a relevant factor, as Ted has aged and his parents have passed away. Construction of a support network in this case is shaped by age, gender and sexuality.

To be involved or not involved?

Beyond family and friends, HIV+ individuals have another outlet for HIV community: their local ASO. ASOs offer a variety of services; however these services varied depending the size of the community. It is important to discuss the availability of resources characteristic of the communities represented in the sample. Of the respondents in my sample, eleven reside in various metropolitan areas throughout the Midwest, while the remaining seven live in smaller communities (fewer than 50,000 people). Of the three metropolitan areas represented in this sample, two cities had two ASOs each, while the third city had one ASO. Of the seven smaller communities represented only one community had an ASO, the remainder had none. The ASO in the smaller community, provided fewer services as compared with ASOs in urban settings. The biggest difference between the ASOs was the type of services they provided. In smaller communities the (only) ASO was oriented toward spreading awareness about HIV through prevention and education programs, marches, HIV testing services, and provided fewer services directly to HIV+ clientele. For case management services, HIV+ individuals in smaller community contexts utilized their local health departments. Urban ASOs offered all of these services on site. In smaller communities where there was no ASO, HIV+ individuals sought these services at their local health department. However, for four respondents to receive AIDS related services they must travel to a neighboring urban center. By discussing the availability of resources depending upon community context, it gives us insight into what options HIV+ individuals have, and how availability informs choices of involvement or no involvement.

For different reasons individuals may or may not decide to seek outside support. Those who chose not to access ASOs indicated no need for this type of support, did not want to be associated with HIV and desired anonymity, felt that support groups offered by the ASO didn't provide what they needed, and found their support elsewhere (family/friends). Some respondents

also described situations where they could not participate in ASO services due to extenuating circumstances. In these instances, individuals did not have an ASO within their community, lacked adequate transportation to access it, and did not qualify for services provided by ASOs. What follows is a discussion of the different personal reasons and structural barriers that barred access to ASOs for respondents.

Bert indicated that she simply did not want to attend support groups:

I don't want to go. I ain't shy, but I just don't want to participate. Like in [...] at the clinic there, I see more and more with the condition I got, they have all of us coming around at the same time, so you mainly get to see different type of people that got it, even little kids too. It really hurts to see that. They get it through pregnancy and stuff, little kids get it, so they must have had it longer than I have. (51, Black)

Bert highlights the toll that seeing other individuals with HIV has on her, and as a result she chooses to stay away from these spaces. Joe says she does not need support from a formal group because she receives it elsewhere:

I don't go, I more or less deal on my own. I've got my kids; they help me, a lot. And my sister in law I talk to her. I do have certain people I talk to; I just don't go out and visit the groups. (51, Native American)

Like Michelle, Joe receives much of her support from her children. Later on in the interview, I asked Joe if she had ever been involved with the [ASO]. She stated that her case manager had tried to get her to walk with them [in a march], but she didn't want to because she thought that if she had been seen with them [ASO members] people would assume she had [HIV]. Due to a perceived need for a degree of anonymity and fear of disclosure by association Joe chooses to remain inactive. Her experience also demonstrates reluctance to be involved with the HIV

community that is fueled by fear of association with HIV because of compromised disclosure (Cameron and Yuk 1999).

Several respondents described having transportation issues that barred them from both accessing and participating in ASOs and events in the HIV community. After being asked why she does not participate more actively within the ASO in a neighboring community, Bert responded: “I don’t do it. For one thing I don’t got no ride over there to [.....].” (51, Black). When asked if they participated in services provided by the ASOs, other respondents indicated similar transportation issues:

No, because I have a problem with transportation because I don’t have my own car. And if I do go out, even if I did have my own car I would have to take an aide with me that’s on duty. (Drake, 43, white)

Well I tell you what; most of the people here are on Medicaid or Medicare. That’s why I have to go to [...] because there is nothing here for me. (Chris, 60, white)

These respondents indicated having trouble accessing ASOs and other medical services due to lack of transportation and availability of resources (Cameron and Yuk 1999). Rationale for not being able to access ASOs indicate a mixture of personal choices to stay away from ASOs and structural barriers that bar access. For instance, Bert stays away due to personal choice, but also cites she lacks adequate transportation to get to the ASO. For her, poverty acts as a barrier. Drake indicates a similar experience. Drake is the only respondent who lives in an “assisted living” facility where he is under constant surveillance by the staff who serve as physical barriers that bar him from coming and going as he pleases. Finally, Chris indicates the complete absence of HIV medical services in his own community so to access other services he must travel an hour to

a nearby metropolitan area. Not having ready access to all of these services poses a threat to the health and wellbeing of HIV+ individuals. In dire circumstances, these positive individuals have to travel great distances to receive needed support but often lacked the ability to do so, again pointing to the heightened disparities of living with HIV in communities that have fewer services available to HIV+ people. The above experiences also highlight how poverty can act as a barrier to care for these individuals (Heckman et al. 1998).

One respondent indicated being unable to access ASO services offered because his cumulative income surpassed the cut off for case management services provided by the state. This was the case for Stan, who did not qualify for Ryan White services:

Basically I go there every year, you fill out your profile. With me they can't provide any services, because basically they're services are dealt with the Ryan White [Act]. You have to be, make a certain amount of money. You have to be below, this year, I believe it's below \$33,000 dollars in order to for you to get any support. Between my long term disability and my social security disability, I make too much money to get help from any of them. I become a middle class person, who can't get help anywhere. (Stan, 60, white)

Stan is the only respondent among those I interviewed who identified as "middle class" and as a result is unable to receive case management services provided by the state. Stan's experience provides insight into how accessing services for individuals who do not qualify for state aided services can be problematic. Gaining access to services, qualifying for disability, seems to be a difficult process despite what class respondents inhabit.

Involvement with the HIV Community

For those who chose to and can be involved with the HIV community, ASOs play a very important part of their lives and provide a mixture of services. They provide a space where

individuals can access support groups, medical providers, case management services, education and prevention services, and HIV testing. These formal settings also provide HIV+ individuals with the opportunity to meet other positive people, spaces where they can advocate, fundraise and spread awareness, provide valuable information about new medications, funding opportunities, and countless other things that are important to HIV+ people. The majority of the respondents had access to an ASO; some who lived in more densely populated cities had access to more than one. Among those I interviewed, urban respondents were more likely to be involved in the ASO and/or activism, while respondents who lived in smaller towns/cities were less likely to be involved. Smaller communities were simply less likely to have an ASO, or spaces available for HIV+ individuals. Below I offer a description of what the respondents saw as the benefits of involvement.

The importance of other HIV+ people

A very important thing that ASOs provided to other HIV+ individuals was access to other HIV+ individuals. The HIV+ community consists of a diverse group of people: heterosexual women, IV drug users, former/current prostitutes, gay men and children. Cynthia, one of the most politically active respondents, best highlights how the demographic variation within the HIV community influences the construction of community:

Because we still pick and choose carefully, there is still a lot of our community [who are] addicted, either addicted to either some drug, or some alcohol, or some behavior that we don't want to be aligned with. It's just a big of struggle for my gay friends than it is for my straight friends who really have nowhere to be with HIV positive people unless they are a woman and make it to the woman's group or something like that. So just by virtue

of how the epidemic has impacted different groups not only age wise but also gender makes a huge difference on where you are going to find community too. (49, white)

Cynthia acknowledges how the demographics of the HIV epidemic have affected the construction of community (Altman 1994). She also acknowledges the struggle that certain groups, addicted individuals, heterosexual women, and gay men have in finding community. Cynthia also highlights how demographic variables such as age and gender influence the construction of a social network. People who have these demographic qualities in common are more likely to establish bonds with others who are like them. All of this indicates the importance that social location plays in forming a support network. At the same time, HIV+ individuals carefully choose the types of people with whom they want to be associated. Later on in the interview Cynthia elaborates more on the process of choosing “certain kinds of people.”

I often tell my friends we still pick the energy we need, we attract the people who we enjoy being with, we don't hang out with the people we don't like. So we really do gravitate towards people that meet us where we are at, in some cases help us grow in some cases help keep us stuck just depends on the kind of friends we are attracting. I don't know what I would do without them, because I know if I got a really big problem even if it is all made up in my own head. I'm far better served calling one of them and dumping it out... It's really my friends that are the ones that help me feel the most balanced.

For Cynthia the most important aspect in selecting friends or the individuals is the type of connection she has with them. She indicates that this is the case with her current circle of friends (the majority of who are HIV+), and the importance that they play in keeping her “balanced.” As

Cynthia indicates her social network of HIV+ friends provides a safe outlet where she can go to find support.

HIV Collectivity

Other respondents indicated finding a similar sense of security and belonging within the HIV+ community.

And here, there is a lot more support for one, and services and just more like, I can call the [ASO] and I know everybody, it's like we're a family. I can call and say I need help with this, where would I go? Kind of networking, I think it's a lot cooler and a lot more people are infected in [this community] than in [a rural area where I lived previously]. And it's more of kind of, people with something in common and kind of an understanding. (Michelle, 36, white)

It's this family, this brotherhood that kind of you find out everyone kind of bands together. (Sal, 31, white)

Both Sal and Michelle illustrate the connectedness they feel within the HIV+ community as a “brotherhood,” “family,” and “common understanding.” The descriptors used by the respondents provide insight into how the collectivity of “being HIV+” provides a safe space for individuals to exist as HIV+ individuals and cope in a collective setting (Ueno et al. 2001). Because of their involvement in the HIV community they have access to support and friendships. Michelle also points to the importance of living within a community that has a greater number of HIV+ individuals – more available people with whom to construct a network. She does this by comparing a more “rural” area to her current residence. Similarly, she highlights this urban vs. rural divide, 1) fewer services are available in rural areas; 2) fewer HIV+ people in rural areas.

Activism

One of the most important activities that ASOs provide is the ability for positive individuals to engage in political activism around HIV/AIDS. Among those I interviewed, more women were involved in activism than men. Several factors underlie this difference. Women had greater access to spaces where they could be activists. A large portion of the men in my sample lived in communities that lacked these spaces. Activism or “caring for others” is associated with femininity. By becoming activists, women respondents adhere to gendered expectations. Involvement in activism ranged from speeches to medical professionals and students, participating in AIDS marches, fundraising, attending benefits, participating in support groups, and involvement on councils regarding Ryan White allocations. Individuals attended support groups out of personal need and some participated in the mentorship of newly diagnosed positive individuals. HIV+ individuals engaged with the HIV community by their involvement in advocacy, support groups and other activities they enjoy with HIV+ friends. For the respondents who were politically active, the main motivation behind activism was to better the lives of HIV+ individuals living within their communities, spread awareness about HIV, and to combat ignorance surrounding the disease. Ralph best captures his role as an HIV activist:

Basically, being a representative, and getting out and doing things. I’ll get up and make myself a target to whoever and whatever, because I know that sometimes they need a target to think that, and they’ll see that target. (61, white)

Ralph points out an interesting idea, that as an activist he serves as a “target” on behalf of HIV/AIDS and those living with HIV. In this instance, he realizes the controversial nature of HIV and serves as a target for those who might not otherwise be activists.

Similarly, Cynthia describes her role as an activist and the importance of advocating on the behalf of others with HIV+.

The other things besides my speaking, I was going to go on and talk about some advocacy. I think that is the other part of me that is yearning to break free. I don't know what that means yet, and it's not like I haven't advocated right here in my own community for things like HOPWA which is Housing Opportunities For People With AIDS, we have those funds here now. That's something that I couldn't get necessarily ever directly benefit from, but tons of people have. And that's the key, I think that's the truth of being any kind of advocate for anything. It's the outcome, if it's pure of heart, it's the outcome you want to ultimately have come your way. And we needed that money here in the state and it's a damn good thing ... Then you say to yourself, "there's got to be other things you can advocate about." And, I think that the political climate right where it is right now there is a lot of opportunity for someone with a voice. I'm not quite sure what that means, maybe for me it will ultimately be advocating around changing something to do with us [People living with HIV/AIDS] being viable people again.

(white, 49)

Cynthia highlights what motivates her activism and the things she has done in her role as an activist by aiding in getting funding for HOPWA. She then highlights the importance of being active, doing things for others so that they can have a better existence. Finally, she highlights how her role as an activist has changed over the course of her life as an HIV+ individual.

Unlike Cynthia, Jim has opted to start his own foundation where he raises money to help support people who are in the process of transitioning from work to disability. He did this after personally having a hard time getting on disability.

I started this [foundation] and it was just going to be for HIV/AIDS but then I decided anybody that is fighting for disability whether its cancer, whether its diabetes, whatever

they're going through the same thing so why not advocate for everybody. I don't care about race, I don't care about sex, I don't care about sexual identity, I don't care about religious belief, political belief, none of that you know people are people regardless. And no matter how they got to whatever status they are in life we all deserve to be treated with dignity, courtesy, and respect and everyone needs a little hand once and a while..... And that's what makes this world so unique is our differences. (Jim, 48, white)

Jim's decision to be active arose out of a past negative experience; several years prior to this Jim struggled to secure disability funding. This past experience acted as a catalyst for Jim to become an activist, showing how past experience matters. As an activist, it is important for Jim not only to help others with HIV, but others who suffer from similar disabilities. He illustrates his non-judgmental attitude by highlighting that all individuals should be treated equally regardless of who they are.

Valerie, similar to Jim, advocates by pressing for equality for HIV+ people and others who are disabled.

There's a lot of people out there cutting down people because they have HIV, or they have cancer, or they're handicapped. I look at them and I tell them that one of these days they're going to wind up like us people that going to have HIV or AIDS or cancer – you're gonna wind up like them. God works in mysterious ways. And they stop being mean in front of them. I preach a lot to a lot of people. (Valerie, 40, Hispanic)

All three respondents stress the importance of advocating on behalf of not only other HIV+ individuals, but others with disabilities. Similarly, they recognize the negative social perception of people with HIV or disabilities. As a result they have put themselves out as “targets” to combat ignorance, prejudice and discrimination. They continually bring attention to unequal

circumstances in their communities, while at the same time supporting and maintaining the HIV+ community by engaging with it and for it. Another salient theme emerges in the respondent's descriptions is the importance of gender. Both women respondents frame their roles as activist along the lines of doing something for others, while the male respondents give a more agentic account. They have taken on a leadership role (becoming a target) or created something (Jim's foundation). Male respondents see themselves as actors, in charge and taking on prominent roles, whereas women focus on advocating on behalf of others. These accounts fall in line with traditional gender expectations of men and women.

Community Context

Community Perceptions of HIV

A common theme that arose during interviews was respondents' perceptions of how those in their geographic (rather than social) community viewed HIV. Here I am referring to "community" in the sense of geographic location. These perceptions created a fear of negative treatment by community members among my respondents, fostered misconceptions about mode of transmission, and finally in some instances resulted in direct discrimination against HIV+ individuals. Additionally, these perceptions often influenced respondents' decisions surrounding disclosure and involvement with activism. In these instances, individuals perceived negative reactions from their surrounding community and drew on this as a rationale for maintaining nondisclosure and/or no involvement with HIV organizations. Chris described how he perceives his surrounding community as unwelcoming:

A lot of my friends are straight friends and they don't know anyone who has HIV, so I can't just talk to any of them and being in a small town like it is, if you did it would be like a disease. Spread so fast, and its nobody else's business, as long as I'm not doing

stupid stuff to infect somebody else but I haven't done any of that since, when my companion left so... (Chris, 58, white)

Chris uses qualifiers such as "small town" and "spread so fast" that give insight into the characteristics of the community in which he lives. It is both "small" and personal information is not necessarily private.

Similarly, respondents highlighted community misperceptions about HIV transmission. Bert describes how community members are ignorant about the existence of HIV and do not think they could get infected with HIV.

They are stupid, they're ignorant. They just look at you like "not me". They are aware of it, but they don't think it can happen to them. [They say] "Oh no not me, I only got one partner." I mean I guess I get upset at them, because they don't want to listen and understand it, they just ignorant with it. (Bert, 51, Black)

Chris highlights ignorance within the community about mode of transmission:

I just feel like, some of the reactions I have had from some other people, if you're HIV+ you have some kind of dreaded disease and you're like that they can catch it from you or whatever because they don't have any idea of what it's all about. I've called it, uneducated about it. (Chris, 60, white)

Both respondents highlight ignorance surrounding beliefs about HIV transmission and prevalence. These examples illustrate the continued misperceptions about HIV and how these beliefs fuel discrimination.

Sometimes this fear of being treated negatively was just a fear, more often it reflected actual experiences. Chris indicates this when describing an experience within the community where he lives:

This is kind of a redneck town, there is probably a group of us, we get together at different houses and have supper and stuff. There is too much, I call it redneck, like the high school kids or college kids, they find out [about being HIV+] and they do vandalism and stuff. (60, white)

As the interview progressed Chris highlighted how he thought his community was not the place for HIV activism: “I don’t think, like marching around for AIDS day, this is just not the community for it.” Chris’s experience offers the best illustration of what living with HIV in an unaccepting environment can be like. Communities are still hostile toward HIV+ individuals, and this hostility has material consequences: being discriminated against and ostracized. These consequences could lead positive individuals to forgo seeking out support services out of fear that could result in compromised physical and mental wellbeing. The effects of this kind of fear are twofold. First fear acts as a mechanism of social control in it keeps fearful HIV positive individuals from being able to openly disclose their status. Second, community fear based in misconceptions about HIV and discrimination of HIV+ individuals reinforces the continued stereotyping and stigmatization of positive people.

Rural vs. Urban

Research indicates that there is a divide between urban and rural areas for people living with HIV. Discrimination is heightened, there are barriers to medical services, and fewer medical services exist for HIV+ individuals to utilize (Heckman et al. 1998). Several respondents highlighted this divide by drawing comparisons between urban and rural areas:

Oh yeah, it’s better for me, if I was in [...] everybody would know and I would have a lot more, because it’s smaller, I would have a lot more crap to deal with from people.

Prejudice or whatever you want to call it, people know before I told them and shit like that. And here, there is a lot more support for one, and services. (Michelle, 36, white)

Joe who lives in a rural community, offered the same line of reasoning:

Well I know that if they live like in [.....], [.....], there is a lot more gay people and you're more accepted. And here you're just not accepted if you're gay, I'm sorry to say that because they are nice people, they really are. But you just aren't accepted around here. They are nicer people than a lot of 'em. (51, Native American)

Both of these experiences clearly highlight important distinctions between urban and rural contexts, which in turn affect perceptions of fear surrounding stigmatization, fear of involuntary disclosure, access to resources, and comfort within the community. Michelle describes her current urban residence as an environment that has more support, services, and more HIV+ people, creating a more HIV friendly environment. Coming from a rural community, Joe describes how urban contexts would be both more accepting of gay people and people with HIV. At the same time, Michelle and Joe both describe a rural context that seems more problematic. For Michelle possible compromised disclosure and ostracism from the surrounding community, while Joe highlights an environment that is not accepting of gay people or HIV.

Conclusion

In the previous section I have illustrated how four processes, diagnosis, disclosure, stigmatization, and involvement in HIV community both reinforce and act upon each other via personal, social, and communal negotiations. When diagnosed, individuals begin to make substantive changes in their lives and through this accept their positive status. Positive individuals enter the social world once they have disclosed their status. However, this decision is managed by several factors: fear of stigmatization, social distance, and a potentially hostile

environment. Stigmatization is still a big part of the respondent's lives. All reported past and ongoing experiences of stigmatization at the hand of others. Respondents stigmatized by their family members often had estranged relationships, and in one instance a respondent moved to another state. Stigma also kept some respondents politically and socially inactive with others who were HIV+. They chose to remain inactive and uninvolved in the HIV community out of fear of being associated with HIV/AIDS and a desire for anonymity. In other instances respondents were inactive because they lacked physical means to access spaces where they could be active. HIV+ individuals are faced with countless social and physical barriers they must negotiate on a daily basis. When individuals did decide to become involved in the HIV community, they found a space where they could advocate on behalf of others, while at the same time both avoiding experiences of stigma, and educating others in an attempt to combat stigma. All of these processes point to the importance of context in shaping these decisions and the outcomes that emerge from them.

HIV+ individuals occupy a marginal status within society. Though the social climate has improved over time, positive individuals still struggle on a day to day basis with discrimination and inability to access adequate resources. This struggle is exemplified when looking at living with HIV in different contexts. Respondents living in urban areas have better access to support and resources, which allows them to improve their mental and emotional wellbeing and health status, while respondents living in smaller communities struggle to do the same in the face of barriers. These findings give insight into the inherent inequality HIV+ individuals face, the underlying decision processes and social negotiations HIV+ individuals undertake to deal with and overcome inequality, and the processes that inform experiences of inequality.

CHAPTER 5 - Discussion and Conclusion

Discussion

This research provides insight into the daily lives of HIV positive individuals - how individuals reevaluate changes in their lives after a positive diagnosis, how they negotiate disclosure of their positive status, their experiences and management of stigma, and the importance of HIV community involvement. Taking these four processes into account, I illustrate the manageability of an HIV+ status on a personal, social, and communal level and how context informs these processes.

For many of my respondents an HIV positive diagnosis was initially synonymous with a death sentence. This makes sense considering the mortality rates of people with AIDS during the early epidemic. People often died shortly after they were diagnosed. However, the respondents in this sample were some of the lucky few, as many of them have lived longer than they ever suspected they would. Diagnosis for these individuals was a traumatic life experience. At first this diagnosis was met with shock, regret, disappointment etc., but eventually individuals began to forge an HIV+ identity. Change was something all respondents had in common. For women, this change often involved obligations to social responsibilities (parenting, not letting men take advantage of them), while for men it involved becoming a healthier individual (taking medication, working out). By making substantive life changes, individuals both accepted and adapted to their new positive diagnosis. Diagnosis was their entry into a life as a discredited individual.

In regards to disclosure, my findings parallel previous research, most notably the idea of disclosure as contextualized (Leonard and Elliot 2008, Derlega 2004) and the result of an explicit

decision making process (Black and Miles 2002). As indicated by my research, context influences a person's decision to disclose, to whom they disclose, how their positive status is disclosed, and the outcome of disclosure. Disclosure was a necessity in relationships where others would come directly into contact with infected bodily fluids (though sometimes respondents themselves did not follow through). However in relationships where this was not the case, respondents rationalized decisions to disclose based on other factors. Most notably they depended on the perceived reaction of the individual to whom they wished to disclose and their social distance from that person. In instances where individuals maintained nondisclosure it was out of an attempt to manage potential stigma. Respondents in this sample shared their positive status with family members and friends more often than with people from whom they were socially distant (bosses, school teachers etc.).

A noteworthy finding is how respondent's community perceptions influenced their decisions to disclose. Those who perceived a hostile reaction from the surrounding community were less likely to disclose. At the same time, this indicates how negative beliefs and misperceptions about HIV act as a mechanism of social control on HIV+ individuals. Because they fear stigmatization, they do not disclose, and do not receive help. Negative beliefs persist about HIV and at the same time the individual who does not disclose jeopardizes their own wellbeing.

The women in my sample disclosed more openly to friends than previous research demonstrated, while gay men's disclosure patterns paralleled previous research (Kadushin 1999). However women mostly disclosed to family members (Lichtenstein et al. 2002, Comer et al. 2006). Disclosure is also related to activism. The more politically active an individual is, the

more frequently they disclose. Both women and men who were involved in activism also disclosed more frequently than those who chose to remain inactive (Black and Miles 2002).

My findings also indicate the process of becoming stigmatized that Link and Phelan (2001) describe. There are five steps in this process. The first is the process of “othering.” Respondents realized that they were now different; their marker of difference was an HIV positive diagnosis. Following this respondents often experienced status loss through processes of self stigmatization and internalization of negative views about HIV/AIDS surrounding them. External reactions also mattered. Kent’s experience of losing his job after his status was compromised in an AA meeting best serves as an example material status loss. Chris and Bert have both been discriminated by their surrounding community. The third aspect of becoming stigmatized involves individual’s ability to access resources to better their positions (socially, economically, politically). For the respondents in this sample, this process occurred when respondents could not access ASOs, either because of personal choice or an inability to do so. Joe did not access the ASO because of fear of potential stigmatization. Other respondents could not because of transportation issues. This became more apparent when looking at access in different community contexts (metropolitan vs. smaller communities). Not having access or choosing to not access these resources poses a threat to the wellbeing of HIV+ individuals. Individuals miss out on potential support outlets and meeting other HIV-related needs. The final aspect in the stigmatization process is the reinforcement of current dynamics of power. Experiences of overt discrimination against respondents illustrate this process. The majority of the respondents indicated past and continued experiences of stigmatization via discrimination. Their experiences reveal that HIV stereotypes deployed by others which sustain relations of

power. Through this process, HIV+ individuals are marginalized, may lose access to resources that would help them, and continually have to deal with these negative experiences.

Additionally, my findings indicate experiences of gendered stigma (Nack 2006; Lichenstein et al 2002; Kitzinger 1994; Patton 1994). Both Joe and Bert reported being stigmatized via traditional gender stereotypes. This underlines Berger's (2004) idea of "intersectional stigma," particularly with regard to class. The lower class status of those I interviewed affected their lives in substantial ways; in several instances individuals lacked adequate transportation to access medical services and ASOs. In other instances, respondents did not have enough money to pay for medication and everyday living expenses. The majority relied on outside sources of funding (disability and social security checks from the government). All respondents except Stan relied heavily on resources made available to them via Ryan White funding. The majority of respondents were too sick to hold steady employment, again indicating the irony of being sick and poor. Respondents were too sick to work, but needed to work in order to make ends meet; the money that the government provides is not enough to sustain a healthy lifestyle. In looking at these individual's experience through an intersectional lens, we see that class, gender, and sexuality inform both processes of stigmatization and access to resources. The idea of intersectional stigma gives insight into the paradoxical nature of living with HIV.

As indicated by my findings and Herek et al. (2005) HIV is still highly stigmatizing. Misinformation about HIV transmission and denial about the possibility of contracting AIDS persist even in the face of three decades of public health campaigns aimed at conveying accurate information. The majority of the respondents indicated past and current experiences of others being afraid to touch them, demonstrating that misinformation about HIV transmission still has a powerful hold.

For the men and women in this sample, the first attempt at beginning to construct an HIV+ community involves accepting an HIV+ identity (Cohen 1985). From there, individuals seek out other HIV+ individuals, friends, family members, support groups, and AIDS services organizations in an effort to construct their community and support network. Support groups, the HIV community, and ASOs provided spaces where individuals could manage and conceal HIV-related stigma. These respondents constructed community in both formal and informal settings. Formal settings consisted of their involvement in the ASO and other HIV related organizations via support groups and activism, while informal settings involved support network construction with friends and family members. Those who had greater access to family members and friends were less likely to use formal settings, however use of formal settings as a source of support was determined by the community the respondent inhabited. Another pattern emerged here, specifically when looking through a metropolitan vs. smaller community frame. Respondents living in smaller communities were more likely to utilize informal settings because their communities lacked spaces where the HIV community could thrive and/or ASOs did not exist within the community. Additionally, due to the hostile community context respondents were less likely to disclose out of fear of potential stigmatization. Therefore, even if HIV community did exist within the smaller community contexts, respondents were not apt to become involved because they feared association with HIV. This process gives insight into how negative perceptions of HIV within smaller community contexts hinder individual's choices and abilities to participate in spaces/activism that could improve their status, thus reinforcing the cycle of silence of HIV+ individuals living in smaller community contexts.

In formal settings, the HIV community also provided a sense of collectivity, as many respondents indicated feeling as if they belonged to an HIV "family" or "brotherhood" (Ueno et

al. 2001). This collectivity became/is very important to respondents as it provided a “safe space” for them to exist as HIV+ people. Housed within this “safe space,” individuals are able to combat and manage stigma, advocate for HIV, and continue to make their situation and others’ better. Activism in the HIV community proved to be an effective way for individuals to better their situations. As stigmatizing as HIV remains, individuals combat this stigma in a multitude of ways and settings, most notably through the HIV community. Many of the respondents openly advocated on behalf of HIV by giving speeches, participating in marches, fundraisers, and government committees. Their main motivation for doing so was recognizing the continued inequality in their communities and wanting to do something about it, not only by advocating for individuals with HIV but also those who are marginalized in other ways (i.e. disabilities, sexual orientation etc.).

In the informal settings, the makeup of the HIV community consisted of family and friends. Reasoning for wanting/not wanting to be involved in the larger HIV+ community differed for respondents. Many reported barriers that hindered their ability to access the HIV community. Both men and women feared negative reactions by their surrounding community (non-HIV+ community) such as ostracism and being discriminated against. In a particular instance, Chris attempted to establish community by getting together with other HIV+ friends at a local park; however this ceased once they were harassed. Establishing an HIV community in certain contexts is problematic because of the continued hostility and prejudicial attitudes toward those with HIV. In other instances, respondents were unable to access HIV community due to lack of transportation. These findings suggest the importance that community context plays in not only the construction of the HIV community, but how individuals manage living with HIV, and discrimination associated with having HIV. In accordance with previous research these

findings illustrate the various mechanisms at work that hinder/promote the establishment, access, and utilization of the HIV positive community (Hall et al. 2005, Heckman et al. 1998).

Respondents constructed community through interactional processes with other HIV+ individuals. HIV+ spaces allow positive individuals to opportunity to meet and network with others who are similar to them. Construction of community is a twofold process the first involves the interactional process required to create community, the second involves a physical space necessary that houses interactional processes. This “HIV+ space” exists in both formal (ASOs) and informal settings (family, friends).

Manageability of an HIV+ status is mitigated by several factors. Disclosure is always the first step to obtain support, however some individuals opt out of doing so due to fear of stigmatization. Similarly, disclosure is required to access and establish an HIV community. In this “safe space” and through their involvement with activism, education and support groups via the HIV community, positive individuals combat misinformation, discrimination and stigma, while at the same time strengthening collectivity as “HIV+ individuals.” In instances where individuals have a harder time accessing the HIV community they may miss out on this opportunity to construct a “safe space” to shield them from stigmatization and other opportunities for support due to unaccepting environments. As this analysis illustrates, stigma is biggest component in managing an HIV+ status. Stigma can works in ways that keep some people both uninvolved and quiet, but for others serve as the motivation for activism.

Though my research is not generalizable to all HIV+ individuals, it gives insight into implications that individuals face when living with HIV. First, the stories of these respondents reveal that having HIV is complicated by several contextual factors including barriers to care, lack of support outlets, and unaccepting attitudes towards HIV/AIDS. Second, HIV

stigmatization still prevails despite years of activism. Finally, my research gives some insight into the disparities that exist between living with HIV in rural and urban areas. There are things that we can do to improve the standing of HIV+ individuals. First, increasing awareness about the existence and transmission of HIV is crucial. As indicated by my research common HIV stereotypes are still persistent (Herek 1999). Eradicating these would be the first step in making a less hostile environment for HIV+ individuals. In the presence of this kind of environment, HIV+ individuals might feel more inclined to move about their communities freely. They would be less likely to hide their status, feel more comfortable seeing their doctors and talking with others in their communities about HIV. My research indicates a general need for more education surrounding HIV existence, transmission and prevention, so that 1) stigmatizing beliefs about HIV can be diminished, 2) individuals can be more comfortable in their communities living with HIV.

Conclusion

This thesis illustrates the negotiations in which HIV+ individuals engage on a daily basis, through decisions surrounding disclosure, experiences of stigmatization, and involvement with the HIV community. Findings point to the importance of context and its influence on these processes, and the outcomes that emerge from them.

Future analysis is needed within institutional settings of ASOs to see how community is constructed within HIV+ spaces. This could be beneficial in that this research is based on individual perceptions of community. Looking at HIV community from an organizational angle could give insight into the mechanisms that create and maintain the underlying organizational framework of HIV communities. With the success of anti-retroviral drugs, those with HIV/AIDS

are an increasingly an aging population. Considering these developments, it makes sense that age would become a relevant factor when studying HIV+ individuals.

Keeping the Story Alive

It has been almost three decades since HIV was discovered. Since then we have lost millions of lives, made tremendous advances in treatment regimes, and made the quality of life much better for those living with HIV. However, the epidemic still exists and people are still dying. From these stories we can see the struggle of living with HIV. Unfortunately, we have yet to discover a cure. What now? I leave the final words to one of my respondents, Stan – there is hope: “As long as somebody keeps the story alive.”

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Appendix A - Volunteer Letter

Dear potential volunteers,

My name is Sarah Donley and I am a Master's student of Sociology at Kansas State University. I am interested in writing a Master's thesis on the experiences of individuals living with HIV in the Kansas/surrounding area. The research project involves interviewing HIV+ men and women. I am looking for 20 volunteers, 10 men and 10 women.

The reason I am contacting you is to see if you would be interested in participating in this project. The interview would not take that long, approximately an hour tops. **I am happy to travel and make accommodations for those of you that are willing to be interviewed for this project.** I have university approval for this study through the Institutional Review Board at K-State, and the project is supervised by my major professor Dr. Dana Britton. **Your anonymity and confidentiality would be maintained throughout the duration of the research project.**

If you are willing to participate, or have any questions, please contact me at sdonley@ksu.edu or 785-452-2571. Also, if you know of anyone else would might interested in participating, please pass this information on.

Your participation in this project would be greatly appreciated!

Thanks!

Sarah Donley
Graduate Research Assistant
Department of Sociology Anthropology and Social Work
Kansas State University
sdonley@ksu.edu
785-452-2571

Appendix B - Interview Schedule

Introduction/Background:

1. How were you contacted about this study?
2. How long have you been coming to the [respondent's health provider]**?
3. What kind of services do they provide for you?
4. How did you learn about this medical provider?
5. Can you tell me a little bit about yourself? Do you have children? Are you employed? Probes for other demographic information will follow.

Community:

6. What is life like here?
7. How long have you lived here?
8. Can you tell me about the neighborhood?
9. What do you do for fun?
10. What community organizations are available for people who live here? Are you involved in any of these? Can you tell me about them?
11. How would you describe this community to someone who has never been here before?
12. What sorts of care and/or support are available in the community?

HIV infection/perceptions:

13. Can you tell me what was going on in your life at the time you found out you were HIV+?
14. How has living with HIV changed your life?
15. Do you know other people who are also living with HIV?
16. What does it mean to you, to be a woman with HIV?
17. Does living in [town]** have any impact on living with HIV?

HIV and disclosure:

18. Who knows about your HIV status? Can you tell me about the first person you told? What was her/his reaction?
19. Was there a specific moment when you knew you wanted to tell someone, if so, can you tell me about that?
20. How did you decide to disclose your HIV+ status? (If you have told others) What factors influenced your decision to tell others? How did you decide who to tell?
21. Can you tell me about specific reactions these people have had?
22. Can you describe any situations where people have treated you differently because you have HIV?
23. If you have not told many people, what things do you do to manage your nondisclosure?
24. How has your social network changed over time?
25. How have these experiences influenced your life?
26. If you could do it all over again, would you do anything differently?

27. What would you advise other people who are living with HIV about whether and how to tell others about their HIV status?

Support:

28. Are a member of any type of social group? If so, what groups are they? Do they know about your HIV+ status? Why did you decide to tell them or not to tell them?

29. Are you involved in any type of HIV advocacy or HIV support groups? If so, can you tell me what it's been like to be a member of these groups? What kind of support do they provide?

30. What influenced your choice to be involved or not be involved in HIV advocacy or HIV support groups?

31. What other kind of support do you get? Where does it come from? How does it help you?

32. How has the care/support you've received changed over time?

33. How would your experience change in the absence of care?

Conclusion:

34. Is there anything else I can tell you about the project? Or anything that I didn't cover that you think is important?

35. For someone really trying to understand the experience – is there anything more I need to know or understand?

**changed for respective respondent

Appendix C - Informed Consent Statement

1. Name of Researcher: Principal Investigator: Dana Britton, Professor of Sociology, Kansas State University, Co-Investigator: Sarah Donley, Graduate Student, Department of Sociology, Anthropology and Social Work, Kansas State University

2. Title of Study: HIV in the Heartland: Men, Women and Intersectional Stigma.

3. Objectives of Study: The objective of this research project is to explore how race, class, and gender intersect with possible stigma associated with being HIV+ in the Midwest.

4. Description and purpose of procedures: This section of the research involves interviews with fourteen men and ten women who are HIV+ in the Midwest (Kansas, Nebraska and Missouri). There is one interview per person, and the interview will last approximately 45-60 minutes. With your permission, I will tape record this interview. The questions asked throughout the interview will involve basic demographic information, questions about disclosure of HIV status to family and friends, discussion of living with HIV, experiences of stigma and/or discrimination associated with HIV, and involvement in HIV advocacy or support groups. Information gathered throughout the research process will be used to better understand the interactions between intersectionality and stigma of men and women who are HIV+.

5. Use of results: Data collected will be used for a master's thesis. The data may be presented at a future sociological meeting. Your name will never be used in any published or unpublished report.

6. The risks and discomforts: Discussion of illness can always be emotional. None of the questions I will ask will be extremely personal or intimate, however. I am interested in the experiences of day to day life only. I do not anticipate that the interview will create emotional distress. If you are uncomfortable at any time you may end the interview.

7. Possible benefits to you or to others from participating in this study: Being interviewed may offer you a time to reflect on personal experiences and feelings about HIV/AIDS. Your participation in this research will also contribute to the body of knowledge of AIDS research within sociology.

8. Reducing potential risk: You may terminate your participation in this study at any time. Your name will never be used in any published or unpublished report based on this study. With your permission, I will tape record our interview, but I will keep this recording separate from this consent form at all times. The tape will be erased immediately after it is transcribed. If this interview creates any distress for you, the [.....] can also provide you with counseling and other resources. If you need to access these resources please call this phone number: [....].

9. Debriefing: The main purpose of this study is to gain greater insight into lives of men and women with HIV. The information gathered here will be used for a master's thesis at Kansas State University. In the future, I may present a paper from this research at sociological meetings. If you would like, I can give you a copy of the completed research.

10. Rights as a research participant: Your participation in this study is completely voluntary and you may **REFUSE** to participate at any time without penalty. If you have any questions regarding this interview, please contact me, Sarah Donley, at 785-452-2571 or sdonley@ksu.edu. If you have questions about the research project, you should contact the professor supervising the project, Dana Britton, at (785) 532-4968 or brittn@ksu.edu. Questions about the role of the university or your rights as a participant in this research should be directed to Rick Scheidt, Chair, Institutional Review Board, Kansas State University, (785) 532-3224.

Signed Consent Portion – TO BE RETAINED BY INTERVIEWEE

I understand my role in the study “HIV in the Heartland: Men, Women and Intersectional Stigma” as explained to me. I consent to participate in this study, and my participation is completely voluntary. I understand that the research information given during interviews is strictly confidential and that my identity will not be exposed in any reports. I understand and I can stop participating at any time without explanation, penalty or prejudice.

(Respondent Signature)

(Date)

(Researcher Signature)

(Date)

=====

Signed Consent Portion – TO BE RETAINED BY RESEARCHER

I understand my role in the study “HIV in the Heartland: Men, Women and Intersectional Stigma” as explained to me. I consent to participate in this study, and my participation is completely voluntary. I understand that the research information given during interviews is strictly confidential and that my identity will not be exposed in any reports. I understand and I can stop participating at any time without explanation, penalty or prejudice.

(Respondent Signature)

(Date)

(Researcher Signature)

(Date)

Appendix D - Coding Tree

- 1= Index Tree
- 2=(1) Diagnoses
 - 3=(1 1) reaction after diagnoses
 - 4=(1 1 1) death sentence
 - 5=(1 1 2) coping mechanisms
 - 6=(1 1 3) negative reaction
 - 7=(1 1 4) indifference
 - 8=(1 1 5) denial
 - 9=(1 1 6) disappointed
 - 10=(1 1 7) change life
 - 11=(1 1 8) what am i going to do
 - 12=(1 1 9) celibacy
 - 13=(1 1 10) in control
 - 14=(1 1 11) keep on living
 - 15=(1 1 11 1) be positive
 - 16=(1 1 12) isolated
 - 17=(1 1 13) regretful
 - 18=(1 1 14) no reaction
 - 19=(1 1 15) benefits of HIV
 - 20=(1 2) going on in life around diagnoses
 - 21=(1 2 1) hospitalization
 - 22=(1 3) how infected with HIV
 - 23=(1 5) reason for getting tested
- 24=(2) Disclosure
 - 25=(2 1) Contextual Disclosure
 - 26=(2 1 1) at risk
 - 27=(2 1 2) not at risk
 - 28=(2 2) Who knows
 - 29=(2 3) reasons for disclosure
 - 30=(2 3 1) type of relationship
 - 31=(2 4) Reaction of Others
 - 32=(2 4 1) no cure for AIDS
 - 33=(2 4 1 1) fear of casual contact
 - 34=(2 4 1 2) degraded
 - 35=(2 4 1 3) throw it in face
 - 36=(2 4 1 4) gendered stigma
 - 37=(2 4 1 5) come unglued
 - 38=(2 4 1 6) rejection
 - 39=(2 4 1 7) denial
 - 40=(2 4 1 8) job loss
 - 41=(2 4 1 9) upset
 - 42=(2 4 1 10) no reaction
 - 43=(2 4 1 11) positive
 - 44=(2 4 1 12) discriminated
 - 45=(2 4 1 13) questioned sexuality
 - 46=(2 4 1 14) anger
 - 47=(2 5) Management of disclosure
 - 48=(2 6) fear of disclosure
 - 49=(2 7) reasons for nondisclosure
 - 50=(2 8) deciding to disclose
 - 51=(2 9) involuntary disclosure

- 52=(2 9 1) gossiping
- 53=(2 9 2) by medical professionals
- 54=(2 10) no disclosure
- 55=(2 11) how to disclose
 - 56=(2 11 1) be prepared with info
- 57=(2 12) illegal not to disclose
- 58=(2 13) men disclose more
- 59=(3) Community
 - 60=(3 1) Maintenance of community
 - 61=(3 1 1) Activism
 - 62=(3 1 1 1) reasons for not being active
 - 63=(3 1 1 1 1) no transportation
 - 64=(3 1 1 1 2) depressing
 - 65=(3 1 1 1 3) mental illness
 - 66=(3 1 1 1 4) job
 - 67=(3 1 1 1 5) no money
 - 68=(3 1 1 2) speeches
 - 69=(3 1 1 3) need for continued activism
 - 70=(3 1 1 4) mentorship
 - 71=(3 1 2) Support groups
 - 72=(3 1 2 1) no one attends
 - 73=(3 1 2 4) reasons for not going
 - 74=(3 1 2 5) prospective support groups
 - 75=(3 1 2 6) changes in support
 - 76=(3 1 3) activities
 - 77=(3 2) Past vs. present comm.
 - 78=(3 2 1) medical care
 - 79=(3 2 2) governmental funding
 - 80=(3 2 3) disclosure
 - 81=(3 2 4) isolated
 - 82=(3 2 5) activism
 - 83=(3 2 6) type of people
 - 84=(3 2 7) perception of HIV
 - 85=(3 3) gay community
 - 86=(3 3 1) denial about HIV
 - 87=(3 3 2) non disclosure
 - 88=(3 3 3) don't practice safe sex
 - 89=(3 3 4) no network for HIV+ men
 - 90=(3 3 4 1) all dead
 - 91=(3 3 4 2) no activism
 - 92=(3 3 5) previous support groups/activism
 - 93=(3 3 6) same old people
 - 94=(3 3 7) gossiping
 - 95=(3 3 8) close knit
 - 96=(3 3 9) built in support network
 - 97=(3 3 10) wanting to be HIV+
 - 98=(3 3 11) having sex/hooking up
 - 99=(3 3 11 1) positive vs. negative guys
 - 100=(3 4) perceptions/characteristics of community
 - 101=(3 4 1) urban
 - 102=(3 4 1 1) same old people
 - 103=(3 4 1 2) anonymity
 - 104=(3 4 2) suburban
 - 105=(3 4 2 1) community culture

106=(3 4 3) ignorance about HIV
 107=(3 4 3 1) discriminatory
 108=(3 4 3 11) perception about transmission
 109=(3 4 4) rural
 110=(3 4 4 1) travel for services
 111=(3 4 4 2) characteristics
 112=(3 4 4 3) no support
 113=(3 4 4 3 1) want support
 114=(3 4 4 4) community culture
 115=(3 4 4 4 1) homophobic
 116=(3 4 4 5) no medical available
 117=(3 4 5) urban vs. rural
 118=(3 4 6) current AIDS
 119=(3 5) no community
 120=(3 5 1) no community for middle class
 121=(3 5 2) no community for straight men
 122=(3 7) constructing HIV community
 123=(3 7 1) our people
 124=(3 7 2) choosing certain people
 125=(3 7 3) friends because we have HIV
 126=(3 7 4) common understanding
 127=(3 7 5) being HIV+
 128=(3 8) Physical manifestation of community
 129=(3 8 6) Support Network
 130=(3 8 6 1) Family
 131=(3 8 6 1 1) problematic relationships
 132=(3 8 6 2) Friends
 133=(3 8 6 2 1) friends are useful
 134=(3 8 6 2 2) don't socialize w/ other HIV+ individuals
 135=(3 8 6 2 3) stay away from gay people
 136=(3 8 6 2 4) only certain people
 137=(3 8 6 2 5) other HIV+ people
 138=(3 8 6 2 5 3) old timers
 139=(3 8 6 3) Institutional support
 140=(3 8 6 3 1) governmental funding
 141=(3 8 6 3 2) doctor
 142=(3 8 6 3 2 1) HIV kept quiet
 143=(3 8 6 3 2 2) free services
 144=(3 8 6 3 3) ASOs
 145=(3 8 6 3 3 1) dissatisfaction
 146=(3 8 6 3 3 2) loss of funding
 147=(3 8 6 3 3 13) ASOs throughout the state
 148=(3 8 6 3 4) case management
 149=(3 8 6 3 4 1) informational support
 150=(3 8 6 3 4 2) mental support
 151=(3 8 6 3 4 3) beneficial
 152=(3 8 6 3 5) counseling
 153=(3 8 6 3 6) AA meetings
 154=(3 8 6 3 7) problematic services
 155=(3 8 6 3 7 1) no help
 156=(3 8 6 3 7 2) denied services
 157=(3 8 6 3 8) medical insurance
 158=(3 8 6 4) Religiosity

159=(3 8 6 5) significant other
160=(4) Living with HIV
161=(4 1) medications etc.
162=(4 2) Changes from beginning to now
163=(4 3) consequences of living with HIV