

Research

Living with HIV/AIDS in Rural and Urban Areas of the Midwest

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Abstract

This paper utilizes interview data to understand the lived experiences of 18 persons living with HIV and AIDS (PLWHA) in low prevalence areas of the Midwest, in both urban and rural contexts. Our findings demonstrate qualitatively different lived experiences of those in rural versus urban contexts. In exploring these themes, the paper reveals that respondents in rural areas are likely to be geographically dispersed, struggle with accessing healthcare services, believe their communities are intolerant of HIV-positive people, and that respondent's fear of stigma and discrimination make them less likely to disclose their positive status or seek out social support. On the other hand, respondents who lived in urban areas were much more likely to disclose their positive status, have access to AIDS service organizations and social support, and to participate in the "HIV community." Urban respondents were more likely to challenge HIV-related stigma by becoming activists and challenging misconceptions about HIV/AIDS and negative stereotypes about PLWHAs. We conclude by drawing attention to the continuing stigmas and barriers experienced by PLWHAs in rural settings and offering suggestions to mitigate stigma and discrimination in social and healthcare settings.

"Place is not merely a setting or backdrop, but an agentic player in the game, a force with detectable, and independent effects on social life" (Gieryn, 2000, p. 466).

Background

In the third decade into the HIV epidemic, people living with HIV and AIDS (PLWHAs) continue to report experiencing HIV-related stigma within their day to day lives. Despite the advancements in the treatment of care to combat HIV and AIDS worldwide (i.e. combination anti-retroviral treatments) and the proliferation of HIV-related education across the globe, work still remains to combat stigma, prejudices, and discrimination associated with being HIV-positive. A growing body of research suggests that stigma and discrimination related to an HIV-positive status among PLWHAs act as barriers to getting tested, taking medication, and retention in care among PLWHAs (Turan et al., 2011; Vanable, Carey, Blair, & Littlewood, 2006; Holzemer et al., 2009; Vyavaharkar et al., 2010; Stringer et al., 2016) as well as having negative effects on the psychological and social wellbeing of PLWHAs (Herek & Saha, 2013). In general, the level of prejudice, stereotyping, and discrimination toward PLWHAs has decreased since the 1990s (Herek, Capitanio, & Widaman, 2002), however it still remains prevalent among some communities within the United States (Stringer et al., 2016; Zukoski, Thornburn & Stroud, 2011; Canstaneda, 2000).

The nature of HIV stigma, prevalence, and expression varies across social and cultural contexts. The experiences of stigma can vary depending on the geographic regions within a country, particularly within the United States where this varies across urban and rural contexts. Comparing research across sociocultural context in the United States demonstrates qualitatively different lived experiences of those living with HIV/AIDS in urban and rural areas.

Structural resources are more available to PLWHAs in urban settings. There are more people living with HIV and more support services through local AIDS service organizations (ASOs). ASOs typically provide individuals with case management, financial assistance for medication, housing, counseling, educational or vocational training, and numerous other related services. The characteristics of urban settings—existence of ASOs, increased numbers of PLWHAs, and increased availability of related healthcare and social support—insulates PLWHAs from negative experiences and discrimination. HIV-positive people are often able to construct an “HIV community” or support network, what Kelley (2002) refers to as an aggregation of HIV-positive friends, family members, and medical providers. This “HIV community” often serves as a great source of support for these individuals’ social and health related needs. PLWHAs in urban and rural areas both experience stigma, albeit intensity and prevalence in rural contexts is greater than in urban environments (Heckman et al., 1998; Zukoski & Thornburn, 2009).

Most notably, studies find that PLWHAs living in rural contexts experience heightened stigma, discrimination, and rejection by community and family members. They also have limited access to ASOs and other related health and social support services due to distance or lack of transportation, and can experience issues with confidentiality and involuntary disclosure among their community (Castaneda, 2000; Zukoski & Thornburn, 2009). There are fewer persons living with HIV in rural areas so it is less likely to know someone with HIV, which might increase negative views toward PLWHAs. In terms of the culture, research finds that rural areas are more likely to hold on to stereotypical beliefs about PLWHAs and present unique environments PLWHAs must navigate (Castaneda, 2000). In this paper, we explore the lived experiences of 18 PLWHAs in urban and rural areas of the Midwest including Kansas, Nebraska, and Missouri and how these individuals manage, respond, and combat HIV-related stigma in their communities.

Methodology

Respondents were recruited via snowball sampling through AIDS service organizations. Our sample consists of ten men and eight women who are HIV-positive living in the Midwestern part of the United States. We used a semi-structured interview schedule and asked respondents about their experiences of living with HIV/AIDS. The majority of the sample identified as white, with one respondent identifying as Native American, one as Hispanic, and another as Black. The sample’s age ranged from 31-61, with an average age of 48. Length of living with HIV or AIDS varied, from two years to 26 years. All had at minimum a high school diploma, with two having taken some college courses, and only one respondent had a bachelor’s degree. At the time of the interviews, most were unemployed, living on disability and/or social security checks. Of the employed respondents, one worked for a gas station and the other worked at a sex toy shop. Respondents defined for themselves if the area they lived in constituted “rural” or “urban.” In our study, seven lived in what they considered rural areas, while nine lived in urban areas.

Qualitative research techniques were appropriate for this study because they allow researchers to grasp underlying and hidden meanings embedded in social processes (Berg, 2006; Esterberg, 2002; Weiss, 1994). Once interviews were complete, interviews were transcribed for data analysis. Consistent with the grounded theory approach, the transcripts were open coded for relevant themes and commonalities across respondent's interviews pertinent to the research question: Are there contextual differences of PLWHAs living in rural and urban areas (Berg, 2006; Esterberg, 2002; Strauss & Corbin, 1998; Weiss, 1994)? The analysis rendered four main coding categories that highlight the experience of living with HIV/AIDS in urban and rural areas in the Midwest: the geographic dispersion of respondents, how disclosure patterns are shaped by anticipated stigma from respondents' communities, experiences of enacted stigma associated with fear of casual contact, and how respondents combatted stigma through activism.

Findings

Geographic Dispersion

As is consistent with other studies on PLWHAs in low and rural prevalence areas (Zukoski & Thornburn, 2009; Castaneda, 2000) our research demonstrates that respondents often encounter structural barriers that impede their ability to seek adequate social and health related services. For instance, several respondents reported issues with inadequate or complete lack of transportation as a barrier. A Black female respondent, who has been living with AIDS for 18 years and does not have a car, receives assistance from an ASO in a neighboring town 20 miles away. If she needs a ride, she calls her case manager to set up rides through the ASO to go to appointments, group meetings, or other related social services. The ASO that provided this service shut down a few years later due to lack of Ryan White funding by the state's government. The Ryan White program allocates federal funding to local community-based organizations so that they may provide care including medical care and support services for people living with HIV who are uninsured or underinsured.

Geographical distance, especially for those living in rural communities becomes an impediment to accessing necessary health and social services. For some of the respondents in this study, health providers in rural areas did not have HIV medication and other related services readily available and therefore traveled upwards of 100 or more miles to get access. For example, one male respondent indicated issues in getting access to his medication which resulted in a four hour delay in taking his HIV medication. The most common form of medication that PLWHAs take are anti-retroviral, which prevent the replication of the HIV virus. They typically consist of a "cocktail" of several medications that have been adjusted to their individual needs. The absence of these anti-retroviral medications, either by not consistently taking, being late, or skipping medication even within a short window of 24 hours, may result in the virus replicating and evolving. If this happens, it is likely that the "cocktails" usefulness decreases and the possibility of developing resistance to their current cocktail regiment increases. Once this happens, PLWHAs must begin an entirely new medication regiment, which can take from several months, up to a year to adjust. Thus, taking medication on time and having ready access is a necessity for PLWHAs.

Similarly, in rural communities healthcare facilities sometimes do not provide all of the care PLWHAs need and they must travel to multiple locations and health facilities. One respondent shared an experience about the different locations he visits to get access to different types of medical services. He gets his blood work done at one location, his primary doctor is located at another, but he currently resides in another town. All three

locations are approximately 90 miles apart. Thus, for those PLWHAs, it is likely that those who live in rural areas must drive greater distances or visit multiple healthcare facilities in order to get their needs met.

Anticipated Stigma, Disclosure Processes, and Community “Climate”

In general, most respondents had disclosed to doctors, close friends, and family members and only two respondents reported being “out” to their entire community. One prominent pattern that became apparent is how the location of either living in a rural community versus living in a city determined the degree to which respondents had disclosed their HIV-positive status to others. Those respondents who occupied urban areas tended to be “freer” in who was knowledgeable about their status. One female respondent makes two important distinctions regarding support available and acceptance of HIV-positive individuals in rural versus urban settings. Having lived as an HIV-positive person in both of these settings, she gives insight into the qualitatively different experiences, where people experience heightened stigma, discrimination, and prejudice in rural contexts (Heckman et al., 1998; Zukoski & Thorburn, 2009). In a rural community, she describes a context where she feels there is more prejudice toward HIV-positive people and less anonymity protecting her HIV-positive status. However, in an urban community, she describes a welcoming community (i.e., “we’re a family”) as well as access to other kinds of assistance and support.

As a response to the real or perceived stigma or prejudice PLWHAs may experience, many respondents modified their disclosing patterns to minimize these negative experiences. This modification typically involved not telling anyone outside their doctor and immediate friends and family. Most practiced this process of “selective disclosure” because of the fear of community backlash. Two female respondents indicated that they did not disclose for fear of being ostracized by the community. Both respondents are not sure how their community would react, but assume it would be negative. One of the ways in which respondents avert experiences of hostility, discrimination or prejudice is through keeping their HIV-positive status completely secret.

Respondents indicated the “feel” of their rural community and a social environment where HIV-positive people were not accepted, were fearful of harassment and discrimination as well as afraid for their personal safety. One Native American female respondent indicated being fearful because of the general hostility she witnesses towards other marginalized groups of people in her community, particularly persons who are Black and are non-English speakers. She wondered what the community would think of a person with HIV. Her experience illustrates the creation and maintenance of boundaries between who belongs and who does not belong.

Similarly, another respondent describes his community as a “redneck” town. It is noteworthy that the respondent uses the term “redneck” to describe the place in which he resides. In American culture the word “redneck” is associated with specific characteristics, and his use of the word gives sense to the qualities of his community: traditional, intolerant, conservative, and farm-based economy. Invoking the term “redneck town” implies that those who do not “fit in” to this stereotype would probably be considered outsiders and therefore not welcome in the community, as well. Both respondents describe the “climate” and what this means for those living with HIV or AIDS in these communities.

The “Myth” of Casual Contact and Enacted Stigma

We also explore what happened to the respondents in this study after disclosing their HIV-positive status. Post disclosure, respondents often experienced mixed reactions from family members, friends, and medical providers. They ranged from complete support, to being exiled and rejected by family, friends, and community (Herek, 1999). Upon disclosure one respondent was rejected by family, which prompted her to move away from her family. She explained that being disowned by her family hurt for a while, but where she is living now (urban area) is much better for her. She is able to receive the medical services she needs.

Despite widespread knowledge about how HIV is transmitted, one common “myth” that still plagues PLWHAs is that HIV/AIDS can be transmitted through casual contact (e.g. sharing a drink, touching someone) with someone who is infected. The fear of casual contact remained one of the more common reasons why respondents were treated poorly in their day to day lives (Herek, Widaman, & Capitanio, 2002). The majority of the respondents indicated having past and current experiences where they experienced fear of casual contact by their family members, healthcare providers, and strangers. This is one of the reasons why some of the respondents chose not to disclose their positive status to deter negative experiences of discrimination and harassment. However, non-disclosure is not always an option, such as in healthcare settings. The “myth” of infection through casual contact persists even in healthcare settings. One male respondent reported experiencing stigmatization when seeking care in a hospital setting. The respondent described being left in the emergency room for six or seven hours and hearing nurses saying “I’m not touching him.” Finally, a doctor noticed that he had been laying there for a long time and inquired what was wrong, after explaining the issue, the doctor remedied the situation. The persistence of these myths and resulting negative treatment of HIV-positive persons points to a breakdown or lack of adequate education in rural contexts involving HIV transmission and infection. Even when disclosing their status in mandatory settings, respondents still experienced stigmatizing interactions.

Activism and Combatting Stigma

The experience of HIV-related stigma motivated some to figure out ways to combat stigma. One way of doing this was through becoming a target, challenging stereotypical beliefs, and becoming involved in activism surrounding HIV and AIDS issues. In this study, women were more likely to be involved in activism, in part, because they had greater access to opportunities at ASOs located in urban areas. The types of activism respondents participated in varied from participating in AIDS marches, giving speeches to medical professionals and students about prevention, fundraising, attending benefits, participating in support groups, and involvement on councils regarding Ryan White funding allocations for medical care and support services for PLWHAs. For the respondents who were politically active, the main motivation behind activism was to better the lives of HIV-positive individuals living within their communities, spread awareness about HIV, and to combat ignorance and stigma surrounding the disease.

A female respondent who has played a prominent role within the HIV/AIDS community in the city she currently resides has been involved in securing social services that PLWHAs might need, such as housing. Most notable, however, is this respondent’s discussion of where her activism is going: “changing something to

do with us [PLWHAs] being viable people again” to combat HIV-related stigma. This undermines HIV-related stigma in a few ways. Early in the epidemic, due to the high death rates, being diagnosed with AIDS was synonymous with a death sentence. This is no longer the case given developments of treatment regimes, yet this belief still lingers. Dispelling the notion that an HIV diagnosis is a death sentence will challenge negative stereotypes and myths and will likely lead to more positive beliefs surrounding PLWHAs and their ability to continue to be a valuable member of society, who can work, carry on relationships, and have families.

Discussion and Implications

Our findings indicate that people living with HIV across diverse contexts in the Midwest experience stigma and discrimination similarly, though the severity largely depended on context. The respondents in this study indicated they were more likely to be socially isolated and rejected by community members, in healthcare settings, and among family and friends when living in rural contexts. In the majority of their stigmatizing experiences, it was others’ fear of casual contact with the PLWHAs that lead to family or friends avoiding the person or to the respondent modifying their behavior to prevent further negative experiences caused by others. This finding raises several concerns. It points to the general persistence of myths about HIV infection and misconceptions about HIV, despite the countless local, national, and global educational campaigns designed to correct misinformation regarding HIV/AIDS infection. Second, it is these misperceptions that are the catalyst to stigmatizing beliefs towards and actions against PLWHAs. The greatest concern here is how stigmatizing beliefs can maintain a consistent state of forced social isolation that is further exacerbated by anticipated stigmatization, geographic isolation, and lack of social support. These findings demonstrate the relational nature of stigma, its manifestations in sociocultural contexts and the damaging effect stigma has on the wellbeing of PLWHAs (Earnshaw & Kalichman, 2013; Link & Phelan, 2001).

Our findings suggest that interventions are needed to mitigate stigma and discrimination in both social and healthcare setting, more so in rural contexts. Myths regarding infection still persist and have adverse effects on PLWHAs. Thus, continuing education programs or events (such as World AIDS Day) about HIV and AIDS are important for medical providers and the general community, particularly, on how people are infected with HIV. One way to provide accurate information about HIV/AIDS in rural areas is to recruit practitioners or case managers who have expertise in this area to provide educational programs at community centers or local schools to provide continued education and information surrounding HIV and AIDS.

Our findings indicate that PLWHAs advocating or participating in spaces where they have access to other PLWHAs and ASOs was a positive experience and helped to combat internal and external HIV-related stigma. Our findings also show that PLWHAs and ASOs are not easily accessible in rural contexts. Online support groups for PLWHAs may be an alternative to find support in a geographically isolated location. Online groups and counselors have the potential to provide support as well as allow for more confidentiality. Currently, such websites as *The Tribe* have HIV/AIDS specific support groups. Similar groups can also be found on Facebook and MySpace. There are also many dating websites available for HIV/AIDS positive persons, such as *Positive Singles* and *Poz Personals*.

The findings also indicate there is lack of availability and access to HIV-related health and social services in rural and low prevalence areas. This becomes direr given cuts to government spending on healthcare

programs such as Ryan White, Medicaid, and some states' refusal to expand Medicaid to the 33% poverty line under the Affordable Healthcare Act. Given the rigid medication schedule PLWHAs must maintain to keep healthy, availability of medications in cases of emergency needs to be adequately addressed. There needs to be more funding or designated funding for those in rural areas. There is also the possibility of collaborating with existing social agencies in these communities to provide commonly needed resources in rural areas, for example transportation services and health care facilities.

Conclusion

Three decades into the HIV epidemic, PLWHAs continue to experience stigma associated with being HIV-positive. Although research documents that stigma has decreased, it still remains prevalent for PLWHAs in rural contexts (Herek, Capitanio, & Widaman, 2002; Stringer et al., 2016; Zukoski, Thornburn & Stroud, 2011; Canstaneda, 2000). Despite the numerous educational materials and campaigns to inform the general population about the transmission of HIV, myths about the HIV transmission persist. Thus, there is still work which needs to be done to combat stigma, prejudices, and discrimination associated with being HIV-positive. Our research offers a glimpse into some mechanisms that may work to address the disparaging effects of HIV stigma and discrimination in rural contexts among the United States.

References

- Berg, B.L. (2006). *Qualitative research methods for the social sciences, 6th edition*. Long Beach: Pearson.
- Castaneda, D. (2000). HIV/AIDS-related services for women and the rural community context. *AIDS Care, 12*, 549-565. doi: 10.1080/095401200750003743.
- Earnshaw, V.A., & Kalichman, S.C. (2013). Stigma experienced by people living with HIV/AIDS. In P. Liamputtong (Ed.), *Stigma, discrimination and living with HIV/AIDS: A cross-cultural perspective* (pp. 23-38). Dordrecht: Springer Science + Business Media.
- Esterberg, K.G. (2002). *Qualitative Methods in Social Research*. Boston: McGraw-Hill.
- Gieryn, T.F. (2000). A space for place in sociology. *Annual Review of Sociology, 26*, 463-496. doi: 10.1146/annurev.soc.26.1.463.
- Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. New York: Simon & Shuster.
- Heckman, T.G., Somlai, A.M., Peters, J., Walker, L., Otto-Salaj, C.A., Galdabini, & Kelly, J.A. (1998). Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care, 10*, 365-375. doi: 10.1080/713612410.
- Herek, G.M. (1999). AIDS and stigma. *American Behavioral Scientist, 42*, 1106-1116. doi: 10.1177/0002764299042007004.
- Herek, G.M., Capitanio, J.M., & Widaman, K.F. (2002). HIV-related stigma and knowledge in the United States: prevalence and trends, 1991-1999. *American Journal of Public Health, 92*, 371-377. doi: 10.2105/AJPH.92.3.371.
- Herek, G.M., Saha, S., & Burack, J. (2013). Stigma and psychological distress in people with HIV/AIDS. *Basic and Applied Social Psychology, 35*, 41-54. doi: 10.1080/01973533.2012.746606.
- Holzemer, W.L., Human S., Arudo J., Rosa, M.E., Hamilton, M.J., Corless, I., Robinson, L., Nicholas, P.K., Wantland, D.J., Moezzi, S., Willard, S., Kirksey, K., Portillo, C., Sefcik, E., Rivero-Méndez, M., &

- Maryland, M. (2009). Exploring HIV stigma and quality of life for persons living with HIV infection. *Journal of the Association of Nurses in AIDS Care*, 20, 161–168. doi: 10.1016/j.jana.2009.02.002.
- Kelley, A. (2002). Making community: Individuals and families living with affected by hemophilia and HIV/AIDS and other blood borne viruses. *Culture, Health & Sexuality*, 4, 443-458. doi: 10.1080/1369105021000041052.
- Link, B.G., & Phelan, J.C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 24, 363-385. doi: 10.1146/annurev.soc.27.1.363.
- Stringer, K.L., Turan, B., McCormick, L., Modupeoluwa, D., Nyblade, L., Kempf, M.C., Lichtenstein, B., & Turan, J.M. (2016). HIV-related stigma among healthcare providers in the Deep South. *AIDS Behavior*, 20, 115-125. doi: 10.1007/s10461-015-1256-y.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*, 2nd ed. Thousand Oaks, CA: Sage Publications.
- Turan, J.M., Bukusi, E.A., Onono, M., Holzemer, W.L., Miller, S., & Cohen, C.R. (2011). HIV/AIDS stigma and refusal of HIV testing among pregnant women in rural Kenya: results from the MAMAS study. *AIDS Behavior*, 15, 1111–1120. doi: 10.1007/s10461-010-9798-5.
- Vanable, P.A., Carey, M.P., Blair, D.C., & Littlewood, R.A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS Behavior*, 10, 473–482. doi: 10.1007/s10461-006-9099-1.
- Vyavaharkar, M., Moneyham, L., Corwin, S., Saunders, R., Annang, L., & Tavakoli, A. (2010). Relationships between stigma, social support, and depression in HIV-infected African American women living in the rural Southeastern United States. *Journal of the Association of Nurses in AIDS Care*, 21, 144–52. doi: 10.1016/j.jana.2009.07.008.
- Weiss, R.S. (1994). *Learning from strangers: The art of and method of qualitative interview studies*. New York: The Free Press.
- Zukoski, A.P., Thorburn, S., & Stroud, J. (2011). Seeking information about HIV/AIDS: a qualitative study of health literacy among people living with HIV/AIDS in a low prevalence context. *AIDS Care*, 23, 1505-1508. doi: 10.1080/09540121.2011.582077.
- Zukoski, A.P., & Thornburn, S. (2009). Experiences of stigma and discrimination among adults living with HIV in a low HIV-prevalence context: A qualitative analysis. *AIDS Patient Care and STDS*, 23, 267-276. doi: 10.1089/apc.2008.0168.