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## HIV in the Heartland: Experiences of Living with HIV in Urban and Rural Areas of the Midwest

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## HIV in the Heartland: Experiences of Living with HIV in Urban and Rural Areas of the Midwest

### Abstract

Scholarly research on HIV/AIDS and stigma has largely demonstrated a different experience for people living with HIV and AIDS (PLWHA) who inhabit urban and rural areas. Largely missing from this scholarship are experiences in low prevalence areas. Low prevalence areas typically have fewer resources, social networks, and HIV infection and prevalence is less common. In this paper, we examine the challenges PLWHAs in rural and urban areas of the Midwest face and how these individuals manage, respond, and combat HIV/AIDS related stigmas in their communities. This paper utilizes interview data to understand the lived experiences of 18 persons living with HIV and AIDS. This paper reveals that respondents in rural areas are likely to be geographically dispersed, struggle with accessing healthcare services, believe their communities are less tolerant, and are less likely to disclose their positive status or seek out social support. Respondents who lived in urban areas were more likely to disclose their positive status, have access to AIDS service organizations and social support, and to participate in advocacy in the "HIV Community." Our study demonstrates how social and community context are agentic players in shaping life chances, decisions, and behavior of the PLWHAs we interviewed.

### Keywords

HIV/AIDS, Stigma, Disclosure, Midwest, Low Prevalence

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## **HIV in the Heartland: Experiences of Living with HIV in Urban and Rural Areas of the Midwest**

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*Scholarly research on HIV/AIDS and stigma has largely demonstrated a different experience for people living with HIV and AIDS (PLWHA) who inhabit urban and rural areas. Largely missing from this scholarship are experiences in low prevalence areas. Low prevalence areas typically have fewer resources, social networks, and HIV infection and prevalence is less common. In this paper, we examine the challenges PLWHAs in rural and urban areas of the Midwest face and how these individuals manage, respond, and combat HIV/AIDS related stigmas in their communities. This paper utilizes interview data to understand the lived experiences of 18 persons living with HIV and AIDS. This paper reveals that respondents in rural areas are likely to be geographically dispersed, struggle with accessing healthcare services, believe their communities are less tolerant, and are less likely to disclose their positive status or seek out social support. Respondents who lived in urban areas were more likely to disclose their positive status, have access to AIDS service organizations and social support, and to participate in advocacy in the “HIV Community.” Our study demonstrates how social and community context are agentic players in shaping life chances, decisions, and behavior of the PLWHAs we interviewed. Keywords: HIV/AIDS, Qualitative, Stigma, Disclosure, Midwest, Low Prevalence*

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“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)

### **Introduction**

In the third decade into the HIV epidemic, people living with HIV and AIDS (PLWHA) continue to report experiencing HIV-related stigma within their day to day lives. With the advent of HIV medications, such as combination antiretroviral treatments (cART) and advancements in the treatment of care to combat HIV/AIDS worldwide, 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 consistency in care among PLWHAs (Holzemer et al., 2009; Stringer et al., 2016; Turan et al., 2011; Vanable et al., 2006; Vyavaharkar et al., 2010) and have negative effects on the psychological and social wellbeing of PLWHAs (Herek, Saha, & Burack, 2013).

The nature of HIV stigma, prevalence, and expression varies across social and cultural contexts (Chambers et al., 2015; Earnshaw & Kalichman, 2013; Genberg et al., 2007; Kalichman et al., 2009). In terms of contextual diversity among the United States, research reports that prejudice, stereotyping, and discrimination of PLWHAs by healthcare workers is more prevalent in the Deep South (Stringer et al., 2016); and in rural and low prevalence areas PLWHAs similarly experience higher levels of prejudice and discrimination and lesser access to healthcare and social support compared to urban areas (Castañeda, 2000; Heckman et al.,

1998; Zukoski & Thornburn, 2009; Zukoski, Thornburn, & Stroud, 2011). However, much of this research has not addressed the geographical context of the Midwestern United States as these areas have low HIV prevalence and infection rates. Living with HIV in low prevalence areas, especially rural areas provides a different set of living circumstances than those in urban areas. These struggles include lack of resources such as transportation, limited access to healthcare services, and minimal social support. Not only do PLWHAs in rural areas experience lack of material resources but generally live in areas where there is less awareness and greater misinformation of HIV/AIDS. In this paper, we explore the lived experiences of PLWHAs in low prevalence areas of the Midwest in both urban and rural contexts and how these individuals manage, respond, and combat HIV-related stigma in their communities for the purpose of providing greater insight into their struggles as well as areas for potential intervention for practitioners and policy makers.

## Literature Review

### Conceptualization of HIV-Related Stigma

Erving Goffman (1963), one of the first social scientists to identify stigma as a social process, conceptualized stigma as a discrediting “mark” or attribute that reduces a person’s status in society. Building on Goffman’s ideas of stigma, scholars have developed conceptual frameworks specific to HIV-related stigma that emphasize the social processes involved in creating a stigmatized identity (Alonzo & Reynolds, 1995; Earnshaw & Chaudoir, 2009; Herek, 1999; Herek & Capitanio, 1998; Parker & Aggleton, 2003; Taylor, 2001). For example, Link and Phelan (2001) theorize that stigma emerges from a social process involving several stages, including labeling, stereotyping, separation, status loss, and discrimination. Though Link and Phelan’s work does not focus specifically on HIV/AIDS, it has been used widely within HIV/AIDS literature to illustrate the social process involved in othering PLWHAs. In what follows, we use HIV/AIDS to illustrate Link and Phelan’s process of becoming stigmatized. First, individuals are labeled as HIV-positive through their initial diagnosis. Then, stereotypes associated with having HIV are applied to those labeled as HIV-positive. In U.S. contexts, people may believe that they are gay, are intravenous drug users, are promiscuous, and may be fearful of touching them. The applications of these stereotypes have negative consequences for HIV-positive people that typically involve social separation, isolation, or withdrawal. Individuals may choose to or families and/or friends may force separation because of their HIV-positive status. In other instances, HIV-positive persons may lose social status or jobs due to stigma associated with having HIV or AIDS. The final stage involves discrimination, in which respondents have status loss, lose jobs, are denied housing, healthcare, or other services for being HIV-positive.

At the interpersonal level, HIV stigma encompasses the way stigma is constructed via social interaction between community members and PLWHAs. These processes typically include prejudicial beliefs and attitudes, such as feelings of anger, disgust, or fear toward PLWHAs, stereotyping, generalizing beliefs about PLWHAs to all PLWHAs, and discriminatory actions (Brewer, 2007; Earnshaw & Chaudoir, 2009). Interpersonal drivers of HIV stigma may vary in content and intensity between different sociocultural contexts and how it affects the lives of PLWHAs. Though content of prejudicial beliefs toward PLWHAs are typically negative, their degree of intensity can vary across sociocultural context.

## Sociocultural Context in the United States and HIV-Related Stigma

HIV stigma is shaped, in part, by the unique history of the HIV epidemic in a specific sociocultural context. For example, in the United States, the epidemic was largely associated with gay men, intravenous drug users (IDU), and sex workers (Herek, 1999), these stereotypes continue to persist in the present. The content and strengths of discrimination toward PLWHAs varies across sociocultural context: in some places interpersonal discrimination may be more subtle, involving social rejection, such as exclusionary or distancing practices or it may be more severe, including rejection and extreme isolation (Parker & Aggleton, 2003; Earnshaw & Kalichman, 2013; Visser, Makin, & Lehobye, 2006). Thus, experiences of stigma or severity of stigma changes over time and among the geographical diversity in the United States. In general, the level of prejudice, stereotyping, and discrimination toward PLWHAs has decreased since the 1990s (Herek, Capitano, & Widaman, 2002), however it still remains prevalent among some communities within the United States (Castañeda, 2000; Stringer et al., 2016; Zukoski, Thornburn, & Stroud, 2011).

In terms of geography, research highlights these differential experiences of PLWHAs in urban and rural areas and how it shapes their life experiences, wellbeing, and access to healthcare and social support (Castañeda, 2000; Heckman et al., 1998; Zukoski & Thornburn, 2009). In examining the urban contexts, structural resources are more available to PLWHAs. One such resource is the local AIDS service organizations (ASOs). ASOs typically provide individuals with case management, financial assistance for medication, housing, counseling, educational service, and numerous other HIV-related services. 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. Thus, 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. Ryan White<sup>1</sup> funds are generally allocated to ASOs in higher prevalence urban areas and are therefore able to provide more comprehensive services (Zukoski & Thornburn, 2009). AIDS service organizations also provide a location where PLWHAs can build social networks with other HIV-positive people. 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 for social and health related needs. In addition, to social support provided by the HIV community in urban contexts, many PLWHAs also partake in HIV education and activism (Kelly, 2002). The existence of ASOs points to an increased numbers of PLWHAs, and increased availability of related healthcare and social support, which can insulate PLWHAs from negative experiences and discrimination. Now, this is not say that PLWHAs who reside in urban areas do not experience stigma, but the intensity and the degree to which they do experience stigma tends to be lesser than those living in rural areas. Compared to rural environments, urban environments might be more tolerant of diversity, in general (Heckman et al., 1998; Reif, Golin, & Smith, 2005; Williams, Olugbemiga, Ifeyinwa, Uzezulu, & Omisbakin, 2003).

People living with HIV in rural contexts face a particularly different set of circumstances compared to their urban counterparts. PLWHAs living in rural areas and/or low prevalence areas experience transportation and confidentiality issues, heightened discrimination and prejudicial attitudes, and have decreased access to healthcare and social support (Castañeda, 2000; Heckman et al., 1998; Zukoski & Thornburn, 2009). The lack of or

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<sup>1</sup> 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.

limited public transportation can mean that access to services may be impeded either due to a complete lack of AIDS related services in their geographic area, or due to lack of transportation (Castañeda, 2000). If there is an ASO located within that community (many times there is not), these agencies must provide services to large geographic areas with limited staff and could be less comprehensive with large gaps between delivery and frequency of services (Castañeda, 2000). Less comprehensive services means potential service delivery issues; they may not have drug programs, employment services, mental health, transportation, or a women's shelter, all of which are important aspects of AIDS care and prevention services.

Rural communities are more likely to hold stereotypical views about HIV-related stigma (HIV only affects gay people, sex workers, and IV drug users), members of these communities tend to know less about HIV/AIDS (Williams et al., 2003), are misinformed about route of infection (HIV can be spread through casual contact), and have greater fear of AIDS as a contagion (Castañeda, 2000; Rozmus & Edgil, 1993). Issues of anonymity and confidentiality within rural communities can be difficult because these communities are often characterized by highly integrated social networks, where everyone knows each other, and may have a good degree of familiarity of personnel who would work directly with PLWHAs in medical or social settings (Zukoski & Thornburn, 2009). Issues of confidentiality and involuntary disclosure may actually bar PLWHAs from seeking medical, support or social services in their local community for fear of stigma; instead, they may resort to driving to a nearby urban area where anonymity is greater. Though stigma has declined in the general population since the 1990s (Herek, Capitanio, & Widaman, 2002), it remains an obstacle for PLWHAs in rural areas where community cultures and values are more traditional and community members are more likely to hold onto stereotypical beliefs and misperceptions about HIV and AIDS.

People living with HIV in rural areas compared to their urban counterparts, report significantly lower satisfaction with life, lower perceptions of social support from family members and friends, reduced access to medical and mental healthcare, elevated levels of loneliness, more community stigma, and heightened personal fear (Bunn et al., 2008; Hackl et al., 1997; Heckman et al., 1998; Reif et al., 2005). Zukoski & Thorburn (2009) highlighted that PLWHAs in a low-prevalence area experienced double stigma, or intensified experiences of stigma given their marginalized status as gay or an IV drug user coupled with their HIV-positive status. Enriquez et al. (2010) found that silence was an overarching theme, as many of the participants had not disclosed their positive status to children or extended family members, because they feared ostracism from their communities. They were also fearful, that if others in the community found out about their positive status their children would be rejected at school and by friends.

Comparing research across sociocultural context in the United States demonstrates qualitatively different lived experiences for those living with HIV or AIDS in urban and rural areas. Most notably, studies find that PLWHAs living in rural contexts experience heightened stigma, discrimination, and rejection by community and family members as well as having limited access to ASOs, other related health and social support services, and the positive benefits associated with those (HIV community). 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. In this paper, we explore the lived experiences of 18 PLWHAs in urban and rural areas of the Midwest including Kansas, Nebraska, and Missouri to see how individual's experiences may vary across geographic contexts. In particular, we explore how PLWHAs living in the Midwest manage, respond, and combat HIV-related stigma in their communities. We take a qualitative approach, to better understand how stigma manifests in sociocultural contexts and how this shapes the PLWHAs' lived experiences.

## Methodology

### State Setting

To get a sense of how individuals live with HIV or AIDS in these communities located in Kansas, Nebraska and Missouri, we first discuss the demographics of HIV/AIDS infection in these areas and the services available. HIV/AIDS services available to individuals residing in each state depend on the number of individuals living with the virus in a specific area, their assessed need, and available funding to provide services (Missouri Department of Health and Senior Services, 2017). As expected, there is more need for HIV/AIDS services in urban areas. This research was conducted in areas generally considered low prevalence, which have lower HIV/AIDS infections rates and lower prevalence of people living with HIV/AIDS. For example, in Kansas, at the time of this study in 2012 there were 2,805 individuals living with HIV/AIDS in Kansas, a rate that continues to increase each year (AIDSVu, 2012a; Kansas Department of Environment and Health, 2016a). Most cases tend to be located in metropolitan areas including Wichita, Kansas City, KS, and Topeka (Kansas Department of Environment and Health, 2016b). Kansas has divided the state into nine regions, and each region has a health department and/or AIDS organizations where PLWHAs can go and receive services (Kansas Department of Environment and Health, 2016b). In Nebraska, as of 2012, there were 1,805 individuals living with HIV or AIDS (AIDSVu, 2012b). 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 (Nebraska Department of Health and Human Services, 2017). In Missouri as of 2012, there were 11,327 persons living with HIV or AIDS an increase of almost three times the number in 2004 of 4,458 (Missouri Department of Health and Senior Services, 2012). Most individuals living with HIV/AIDS in Missouri are located in two large metropolitan areas, St. Louis and Kansas City, MO (Missouri Department of Health and Senior Services, 2017). Like Kansas, Missouri has subdivided the state into six different regions that focus on providing services to PLWHAs in the surrounding area (Missouri Department of Health and Senior Services, 2017).

The state health departments and/or AIDS service organizations in each of these regions provide HIV/AIDS related services to their clients and are funded through the Ryan White Program, the Center for Disease Control, or the Office of Minority Health. PLWHAs have access to case management services, drug assistance programs, dental care, medical services, mental healthcare, substance abuse programs, help with transportation, payment of medications and housing options (Kansas Department of Environment and Health, 2016b).

Two issues emerge for respondents who live in rural areas that are isolated from social support and medical support. First, access to ASOs, depended on a number of things including access to transportation and geographical distance. Several of the respondents in our study did not own a car, have access to other forms transportation, or lived far away from the nearest organization that provided social and health services to HIV-positive individuals. The respondents who lived in what they considered rural areas had to drive an average of 45 miles to access the nearest healthcare facility that provides services to PLWHAs. Sometimes, one location does not provide all of the care PLWHAs need and they must travel to multiple locations and health facilities. Second, geographic distance and access to adequate healthcare becomes important when considering HIV/AIDS medication regimes. Anti-retrovirals, which prevent the replication of the HIV virus, are the most common form of medication that PLWHAs take and must be regularly taken. With 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 regimen increases. Once this happens, PLWHAs must begin an entirely new medication regimen, which can take several months up to a year to adjust.

## Research Design

Our research project was exploratory in nature, in part because we were interested in gaining more insight into the lived experiences of PLWHAs in rural and urban areas of the Midwest—a context not systematically covered in HIV/AIDS scholarship. Similarly, because we were interested in understanding lived experiences, we used an interpretive phenomenological approach (IPA) to analyze our data (Larkin & Thompson, 2012). IPA, in the Heidegger tradition, understands lived experience as *being* in the world (1962; McConnell-Henry, Chapman, & Francis, 2009). IPA is interested in understanding a “person’s relatedness to the world (and the things in it which matter to them) through the meanings they make” about their experience (Larkin & Thompson, 2012, p. 102). Because of its experiential nature, IPA is frequently used in qualitative health research aimed at understanding how individuals make sense of experiences with illnesses (Biggerstaff & Thompson, 2008). IPA is a suitable methodological approach for our study because we are interested in understanding how having HIV/AIDS affects individual’s lived experiences and other related aspects of their lives. All ethical standards were met and maintained throughout the course of this research and ethical approval was obtained from the first author’s University Institutional Review Board.

## Researchers’ Positionality

A feature of IPA is being self-reflective, thus it is important for us to discuss our positionality as researchers in our interpretation of this data (Lavery, 2003). At the time of this study, the first author was in pursuit of a PhD in sociology. The first author became interested in this topic after regularly volunteering at an ASO in the Midwest. During her graduate program, she became interested in doing research on the lived experiences of persons living with HIV and AIDS in the Midwest, hence the current study. All data were collected and analyzed by the first author with consultation from other qualitative experts. The second author is a current colleague of the first author. The second author became interested in this project given her background in HIV/AIDS advocacy and medical sociology. The second author has collaborated with the first author on writing this current paper. The purpose of this intended research is to give practitioners, policy makers, and other interested parties more insight into the lived experience specific to PLWHAs in the Midwest.

## Participants

Respondents were recruited via purposive sampling. PLWHAs are a hidden and marginalized population, thus we contacted HIV/AIDS case managers and advocates who worked at the county health department or ASOs in Kansas, Nebraska, and Missouri to get direct access. Case managers were identified by searching for them online. Typically, case managers are in charge of certain geographic regions of each state. Their caseload typically depends on the number of infected individuals in their specific region. We contacted all case managers we could find contact information for in Kansas, Nebraska, and Missouri. The first author would call each case manager and described the study to the case managers. From this, the case managers would contact their clients and provide information on the study. If clients were interested in participating, they contacted the first author via phone.

The sample consists of ten men and eight women who are HIV-positive living in the Midwestern part of the United States. The majority of the sample identified as White, with one



respondent identified as Native American, one as Hispanic, and another as Black. The youngest respondent is 31, the oldest respondent is 61, the median age is 48. Participants reported living with HIV or AIDS between two and 26 years. At the time of the interviews, three respondents worked and the remaining respondents did not work, receiving disability and/or social security checks provided by the government. Respondents who did not work reported that the main reason was due to health related issues associated with HIV and indicated inability to maintain consistent employment. 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. We let respondents define for themselves if the area they lived in constituted “rural” or “urban” because definitions of “rurality” or “ruralness” vary greatly within the literature (Zukoski & Thornburn, 2009). In their self-definitions, respondents tended to talk about the “feel” of the area as rural being more traditional and urban areas being more progressive. Similarly, population and geographic isolation was also used as a determinant for being considered rural or urban. With rural areas being those areas less populated and lacking comprehensive social services, businesses, and grocery stores, with urban settings being the opposite. The flexibility in our definitions of rural and urban allows us to better gauge how the “feel” of a sociocultural context affects the lived experiences of the PLWHAs in our study. Seven respondents lived in what they considered rural areas, while nine lived in urban areas.

## Data Collection

We used a semi-structured interview schedule with 18 respondents living in various locations in the Midwest: Missouri, Kansas and Nebraska. To uphold ethical standards of research, before the interview began interested respondents were told the research objectives of the study, informed that participation was voluntary, and that they could discontinue the interview at any time. All respondents gave their written informed consent, none discontinued their interview, and none sought psychological counseling after their participation. To ensure confidentiality, pseudonyms are used for respondent’s names, locations, and organizations throughout this paper.

The first author interviewed the respondents. Respondents were allowed to select the location of the interviews, the first author and respondent would agree upon a time and meet for the interview. The majority of the interviews took place at in the respondent’s residence. However, there were two interviews at a public library, one at the respondent’s place of employment, another at a restaurant, and one by phone. The interviews ranged from 30 minutes to two and one half hours.

We used a semi-structured interview schedule. There were a standard set of questions that were followed, however it remained flexible to allow for probing and further elaboration on important topics during the interview. The purpose of the semi-structured interviews was to gain greater insight into the experience of living with HIV/AIDS, thus our questions were modeled after studies conducted by Zhou (2010) and Baumgartner (2014) who had similar research goals. Our interview schedule was composed of questions that asked respondents about their HIV infection (e.g., *Can you tell me about how you found out you were HIV-positive?*); information about care available in the surrounding community (e.g., *What sorts of care and/or support are available in the community?*); perceptions of being HIV-positive (e.g., *How has living with HIV changed your life?*); experiences of stigma (*Has anyone ever treated you differently because of your HIV-positive status?*); disclosure of HIV-positive status (e.g., *How did you decide to disclose your HIV+ status? What factors influenced your decision to tell others? How did you decide who to tell?*); involvement in HIV advocacy groups (e.g., *Are you involved in any type of HIV advocacy or HIV support groups? What is that like?*); and

other available support (e.g., *What other kind of support do you get? Where does it come from? How does it help you?*). With permission from the respondent, interviews were recorded and later transcribed verbatim by an external transcriber. Upon transcription completion, we had 204 single-spaced pages of interview transcripts for data analysis.

## Data Analysis

Interpretive phenomenological analysis involves “multiple stages of interpretation that allow for patterns to emerge, the discussion of how interpretations arise from the data, and the interpretive process itself are seen as critical” to data analysis (Laverly, 2003, p. 23). Below we describe our data analysis process. Following the completion of data collection, NVIVO, a qualitative data analysis software, was used to assist with data analysis. NVIVO allows the researcher to digitally label parts of interviews during open coding, write notes and conceptual memos, and organize open codes into more complex coding trees. The purpose of the analytic process in IPA is to uncover the experiential claims, concerns, and understandings of respondents through a “free” coding process (Larkin & Thompson, 2012). “Free” coding is a process used during qualitative data analysis to code text line-by-line for experiential themes related to the research question (Larkin & Thompson, 2012). During this process, the first author read interview transcripts in search for themes related to understanding the lived experiences of being HIV-positive. Themes are “patterns of description that repetitively recur as important aspects of a participant’s description of his/her experience” (Thomas & Pollio, 2002, p. 37). As thematic units were developed in the interview transcripts, the first author digitally labeled quotations from the respondent’s interviews and were placed under broader “code nodes” in NVIVO. Once this process was repeated on each individual interview transcript, the first author began to look for emergent patterns that indicate commonality and nuance across interview transcripts (Eatough & Smith, 2008; Larkin & Thompson, 2012). The focus of data analysis was to gain understanding of the lived experiences of PLWHAs. Respondents in this study described living with HIV as a linear process from first diagnosis to their current living circumstance. Thus, as data analysis progressed, we organized themes around the significant stages of living with HIV (e.g., “diagnosis,” “deciding to disclose,” “experiences of discrimination/stigma,” “involvement in social support,” and “involvement in activism”). As our analysis progressed, we began to code for sub themes within our broader themes (Eatough & Smith, 2008; Larkin & Thompson, 2012). To get a clearer example of how we operationalized our thematic codes, we provide an example. In our broader theme of “experiences of discrimination/stigma,” we began to be more specific and code for subthemes of discrimination respondents experienced, and “fear of casual contact” became a more specific subtheme. After data analysis, it became apparent that certain experiential “stages” in the HIV experience were more significant to understanding how respondents lived with HIV/AIDS in the Midwest, thus in the remainder of this paper we focus on further understanding PLWHAs’ decisions to disclose, experiences of stigma, and involvement in HIV advocacy.

## Trustworthiness

This study’s rigor was upheld throughout data collection and analysis. To confirm study credibility, respondents were contacted by the first author to allow for further clarification in interviews. Though not as thorough as member checking, this process allowed respondents the opportunity to clarify responses. During the coding process, the first author utilized the memoing feature in NVIVO to define codes as well as make notes of interesting observations or relationships between themes. An audit trail was utilized to keep a detailed record of the data analysis process. An outside researcher, who observed the initial codes, was consulted

throughout the coding process, and participated in conversations about code meaning, classification, and organization checked coding reliability. When disagreement occurred between code meaning, author one sought further consultations from other qualitative experts who were overseeing the project. This process of engaging with the data, being reflexive during data analysis, and consulting with qualitative experts continued during the entire data analysis process (Laverty, 2003). Once all of the data was coded, the final coding schema was reviewed by three expert qualitative researchers. Triangulation between respondents, researchers, and outside qualitative experts help to ensure this study's methodological rigor and trustworthiness

## Results

Through an in-depth understanding of the meaning of lived experiences of PLWHAs in urban and rural areas of the Midwest, we are able to gain greater insights into their daily obstacles, struggles, and triumphs. Three interrelated experiential processes were identified that illustrate what it is like to live with a stigmatized, chronic illness. The remainder of this paper focuses on further elucidating and understanding the processes involved in decisions to disclose, experiences of stigma, and involvement in HIV advocacy.

### Community Context and Decisions to Disclose

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 smaller community versus living in a city determined the degree to which respondents had disclosed their HIV-positive status to others. For instance, respondents, who occupied urban areas tended to be "freer" in who was knowledgeable about their status. For example, one respondent discusses this divide and how it shapes her willingness to disclose her HIV-positive status.

Oh yeah, it's better for me, if I was in Lexing 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 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 Oak Town than in Lexing. And it's more of kind of, people with something in common and kind of an understanding.

In this example, the respondent compares and contrasts what it is like to live in two communities that have varying degrees of population and services available to PLWHAs. She makes two important distinctions regarding support available and acceptance of HIV-positive individuals. For the former, she describes a context where she feels there is more prejudice toward HIV-positive people and less anonymity protecting her HIV-positive status. For the latter, she describes a welcoming community i.e., "we're a family" as well as access to other kinds of assistance and support. 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).

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 his or her doctor and immediate friends and family. Most practiced this process of “selective disclosure” because of they feared community backlash. As two female respondents indicate below, both did not disclose for fear of being ostracized by the community:

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.

Only my family and doctors know. I thought about telling some of my friends, but I imagine it would get out quickly. I don't know how the community would react, they'd probably want me out of here. Who knows, at this point, I'd rather just continue to keep it to myself. Easier that way.

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.

The following two respondents describe in greater detail what this community “looks” like and “feels” like. They describe a social environment where HIV-positive people were not accepted, were fearful of harassment and discrimination as well as for their personal safety.

I'm afraid here. You got these people who hate the gays, hate the black people, hate people who don't speak English. What do you think they would think about someone with HIV? Oh I must be an IV drug user. Well, hey guess what I'm not! I imagine if people knew, I'd probably have to move out of this place. I'm only here really, because of my mother.

Another respondent describes her community as a “redneck” town:

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-positive] and they do vandalism and stuff.

Both respondents describe the “climate” and what this means for those living in these communities. In the first example, the female respondent describes a situation where she is fearful for her personal safety and the general hostility toward other marginalized groups of people in her community. Her experience illustrates the creation and maintenance of boundaries between who belongs and who does not belong within her particular community—if you are not white and heterosexual, you do not belong. This feeling of “not belonging” in the community resonates so strongly with some respondents, they completely move out of the community, seriously consider moving out, but are constrained because of other responsibilities for families, etc. It is noteworthy that the second 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 words gives sense to the qualities of his community: backwards, traditional, intolerant, conservative, and a farm-based community. 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. In addition, as both respondents describe, PLWHAs would likely experience some form of threat to personal safety, vandalism to their property, or harassment.

## The Enduring “Myth” of Casual Contact and Experiences of Stigma

The previous section detailed how anticipated HIV-related stigma from unwelcoming friends, family, and communities shaped respondent’s decision of how, to whom, and when to disclose their HIV-positive status. Next, we explore what happens to the respondents in this sample 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). The rejection by her family, after her disclosure lead this respondent to move away from her family:

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 a while. 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.

Despite widespread knowledge about how HIV is transmitted, one common “myth” that still plagues PLWHAs is the fear of casual contact. Meaning that HIV/AIDS can be transmitted through casual contact (sharing a drink) with someone who is infected, and the persistence of this belief despite evidence to the contrary. 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, & Capitano, 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. As a female respondent describes:

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.

Another respondent shares a similar experience:

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.

The previous section detailed how respondents chose to not disclose their positive status to deter negative experiences of discrimination and harassment. However, this choice is not always available; non-disclosure is not an option, such as in healthcare settings. The “myth” of infection through casual contact persists even in seemingly unlikely places—healthcare settings. A male respondent reported experiencing this kind stigma when seeking care in a hospital setting.

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.

Experiences of enacted stigma point to the persistence of "myths" about HIV. As our findings demonstrate, PLWHAs demonstrated that they continue to be discriminated against by friends and family members who believe misperceptions about the transmission of HIV through casual contact. These experiences happened more often among our respondents who identified themselves as living in rural contexts compared to those living in urban areas. The persistence in 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 despite being 35 years into the epidemic, educational campaigns dedicated to dispelling these misperceptions, and countless studies that provide evidence to the contrary. Even more surprising is the persistence of misperceptions about HIV in healthcare settings. Even when disclosing their status in mandatory settings, respondents still experienced stigmatizing interactions—ones that could potentially lead to negative health outcomes when someone is "left lying in the emergency room for six or seven hours" without treatment.

### **Activism and Challenging Stigma**

The experience of HIV-related stigma motivated some to figure out ways to combat stigma. The most notable ways of doing this was through becoming a target, challenging stereotypical beliefs, and becoming involved in activism surrounding HIV and AIDS issues. In this sample, women were more likely to be involved in activism, in part, because they had greater access to opportunities at AIDS Service Organizations located in urban areas. The types of activism respondents participated in included speeches to medical professionals and students about prevention, participating in AIDS marches, fundraising, attending benefits, participating in support groups, and involvement on councils regarding Ryan White allocations. Similarly, individuals attended support groups out of personal need and some participated in the mentorship of newly diagnosed positive individuals. 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 respondent 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.

This respondent becomes a "representative" or "target" for individuals who might be ignorant or hold prejudicial beliefs about people with HIV/AIDS, he positions himself as readily able to respond and challenge dissent from opposition. Other respondents challenged stigma in similar ways. Another respondent did this by "preaching":

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.

As these two respondents demonstrate, their main way of combatting stigma is to call people out on their ignorant beliefs or intolerant attitudes. The first does this by becoming a “target” while the second “preaches.” Other respondents were more involved within activism and the HIV community. For instance, one respondent held similar beliefs about tolerance for all individuals regardless of their health or social status, started 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.

His decision to be active arose out of a past negative experience; several years prior to this he struggled to secure disability funding and realized the similar situation that many others might find themselves in when dealing with health issue. This difficulty with finances served as the catalyst for this respondent’s activism. Respondents, in their activism, encourage a message of tolerance and treating everyone equally regardless of health and social status.

Another respondent took on a more traditional and involved role as an activist such as giving speeches and advocating for the access to resources. One respondent we interviewed has played a prominent role within the HIV community in the city she currently resides in. In the following explanation, she 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 [the AIDS Housing Project], 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.

This respondent provides a more nuanced explanation of her activism and its development overtime. In particular, she has been involved in securing social services that PLWHAs might need, such as housing. She expresses her motivation for this activism as being able to do things

that she might not necessarily benefit from, but other people would benefit. 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 in treatment regimes, yet this belief still lingers. Dispelling this notion will likely challenge negative stereotypes and myths, and will likely lead to more positive beliefs surrounding PLWHAs and their ability to continue to be valuable members of society, who can work, carry on relationships, and have families.

## Discussion

This study looked at the lived experiences of people living with HIV or AIDS in urban and rural contexts of the Midwest—an understudied geographic region. Our findings indicate that PLWHAs across diverse contexts in the Midwest experience stigma and discrimination similarly, though the severity largely depended on context. In addition, there is a lack of accessible healthcare and support services in rural areas. The findings were consistent with previous research. The respondents in this study indicated they were more likely to be socially isolated and be rejected by community members, in healthcare settings, and among family and friends when living in rural contexts compared to urban contexts (Bogart et al., 2008; Lekas, Siegel, & Schrimshaw, 2006; Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007; Zukoski & Thornburn, 2009).

Access and availability of healthcare and support services differ greatly for those living in rural contexts compared to urban areas. Consistent with previous research, we found that HIV/AIDS-specific doctors and health services were not available in many rural respondents' communities, and therefore, many traveled upwards of 90 miles to access these health services and sometimes, traveled to multiple locations. Similarly, the context of this study—Midwestern states including Kansas, Nebraska, and Missouri—are considered low prevalence and therefore organizations that provide services to PLWHAs may be far and few between. The Ryan White Program allocates funds to organizations serving PLWHAs and their families, and therefore not residing nearby one can pose issues for access. During the time of this study, an ASO that served multi-municipalities and counties closed down and some of our respondents utilized the services, including rides to doctor's appointments and attended some of the ASO's social events and support groups. The lack of availability and access to HIV-related health and social services in rural and low prevalence areas is becoming direr given cuts to government spending on healthcare program such as Medicaid and some states refusal to expand Medicaid to the 33 percent poverty line. 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 healthcare facilities.

People living with HIV or AIDS also discuss experiencing different type of stigma due to their health status. The majority of their stigmatizing experiences 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. In healthcare settings, one respondent indicated being refused medical treatment after the nurses learned he was HIV-positive; it was hours before a doctor finally came and assisted him with his pneumonia. This finding, taken together with other studies, (Baunach & Burgess, 2013; Boehme et al., 2012; Currey, Johnson, & Ogden, 1990; Stringer et al., 2016), suggests that the



actions and behaviors of healthcare workers can affect the healthcare experience and wellbeing of PLWHAs. The fear of casual contact raises several concerns. It points to the general persistence of myths about HIV infection, misconceptions about HIV, and the adverse effects on PLWHAs. Thus, continuing education programs or events about HIV and AIDS are important for medical providers and the general community, particularly, on how HIV infection occurs. 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.

Second, these misperceptions 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 continually reinforced by anticipated stigmatization, geographic isolation, and lack of social support. A state of being that creates heightened stress, general anxiety for PLWHAs, and largely shape how respondents went about their day-to-day lives. 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).

Previous research has looked at the varying experiences of those living with HIV in rural areas compared to those living in urban contexts (Heckman et al., 1998). One difference we did notice among the various contexts in our study is differences in patterns of disclosure. For those who identified themselves as living in rural settings, though most respondents had disclosed to family members and doctors, they had not disclosed to their communities; while those in more urban areas were more likely to be “out” to the community. Respondents in this study were actively engaged in decision-making processes about who, how, and when to disclose to others. Anticipated or perceived stigma from the community, internalized shame, and past experiences of discrimination prevented many respondents in this sample from disclosing their HIV-positive status, particularly in rural areas (Brickley, 2007; Kingori et al., 2012; Vanable et al., 2006). As many chose not to disclose their status because of fear of anticipated stigma, their chances of meeting someone else who shared a similar experience was very low. Social isolation was further exacerbated by rural respondent’s geographic isolation and lack of access to social support.

Accessibility to support groups and social networks is an important aspect providing connections to other PLWHAs, finding different types of resources, and overall feeling of being connected to a “HIV community.” However, this can be extremely difficult for PLWHAs in rural and/or low prevalence areas to connect to support groups and social networks. Online support groups for PLWHAs may be an alternative to finding 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 group. Similar typed groups can also be found on social media sites such as Facebook. There are also many dating websites available for HIV-positive persons, such as *Positive Singles* and *Poz Personals*.

Our research contributes to the understanding about how PLWHAs in the Midwest combat stigma. Consistent with other research respondents identified advocating for themselves as a mechanism that tended to alleviate HIV-related stigma (Kelley, 2002; Zukoski & Thornburn, 2009). Our research expands on this area by exploring PLWHAs advocacy and activism more in depth, particularly in the various roles they take as activists. One of the main mechanisms that PLWHAs in this study challenged HIV-related stigma, stereotypes, and prejudicial beliefs was countering intolerant, ignorant, or misinformed beliefs regarding people with HIV by becoming “targets” or “representatives.” In doing so, they put themselves out there to challenge commonly held stereotypes about PLWHAs. The second way respondents

combated stigma through activism was by challenging the usual negative cultural narrative of being HIV-positive by offering an alternative narrative. In U.S. culture, an HIV diagnosis is commonly seen as a death sentence and HIV-positive people are viewed as immoral. In this study, respondents challenged this notion and instead offered the narrative of HIV-positive people as viable and productive persons who can continue to work, have families, and participate in society. Some respondents reported that they were “out” with their HIV-positive status among their community, and their positive status was well known in the community they inhabited. Directly knowing someone who has HIV is likely to challenge HIV-related stereotypes and other misinformation surrounding HIV that individuals may hold.

Though this research contributes to our understanding on the lack of accessibility and availability of healthcare, the stigma surrounding PLWHAs, and the social isolation experienced by PLWHAs living in a rural and/or low prevalence area, it is not without limitations. One of the limitations of our study is our sampling strategy. Snowball sampling is a nonprobability sampling technique and therefore any conclusions generated from this study cannot be generalized to a wider population. However, given the nature of the topic under study, using a probability sampling technique would be almost impossible given the issues of confidentiality surrounding HIV-positive persons’ identities. Similarly, since our sampling is based on snowball sampling and relied on respondents to contact us, it is possible that we only heard from respondents who are open about their HIV-positive status. Other respondents may have not participated for fear of stigmatization or status disclosure and therefore we may not have those types of perspectives and experiences in this research. How we operationalized “urban” versus “rural” might also be considered a limitation, as there are varying perspectives on what constitutes “rural” and “urban” and may differ between respondents.

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### Author Note

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