

Stigma and Discrimination: Coping Strategies for Persons Living with HIV/AIDS in Rural America

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Abstract

Individuals with HIV/AIDS that live in rural areas experience significant stigma that creates psychosocial stress, depression, anxiety and reduced self-esteem. Coping with stigma and discrimination is a significant aspect of living with HIV/AIDS and has implications for the psychological and physical well-being of these individuals (Moskowitz, Hult, Bussolari & Acree, 2009). This study examined the relationship between stigma and discrimination, and coping strategies used by People Living with HIV/AIDS (PLWHA) in rural areas using a mixed method study design. HIV-positive individuals served by the Illinois HIV Care Connect in Region 5, completed the survey for the study. The results showed that self-isolation was the most preferred method of coping, closely followed by engaging in destructive behaviors or reactions. The least preferred method was seeking spiritual guidance. Results of regression analysis also revealed that spending more years in care and having more social support really do have an effect on coping with HIV stigma and discrimination among the rural population. Implications for health and human services workers such as rehabilitation counselors and health communication officers are discussed.

Keywords: HIV/AIDS, stigma, discrimination, coping, rural population

Global estimates place the number of people living with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) at about 35.5 million people (Joint United Nations Program on HIV/AIDS [UNAIDS], 2015). According to the Centers for Disease Control and Prevention (CDC), approximately 1.2 million people are currently living with HIV in the United States (US), with 50,000 new cases occurring each year (CDC, 2013). The agency reported that as of 2011, 6.1% of existing HIV/AIDS cases and 7.5% of new cases involved persons between the ages of 35–44 living in rural areas (CDC, 2014). The breakdown of HIV cases in rural America showed that the majority of HIV/AIDS cases (50%) were African-American, followed by whites with 38%, Latinos 10%, and American Indians and Alaska Natives at 2% (CDC, 2013). Nationwide, rural counties in the South, Southwest and Northeast of the U.S have the highest rate of people living with HIV/AIDS (CDC, 2008; Dreisbach, 2011). The majority of rural HIV/AIDS cases has been attributed to heterosexual activity and drug use (CDC, 2014; Gerbi et al., 2011; Gere, 2014). Rural HIV/AIDS impacts local communities and households by transforming the socioeconomic landscape: age structure, diminished workforce, increased poverty, reduced agricultural productivity, and altered household structures (Oramasionwu, Daniels, Labreche, & Frei, 2011).

However, many rural areas lag behind urban areas in HIV/AIDS related services, funding and awareness in addition to lack of accessibility to medical, mental and social services. People Living with HIV/AIDS (PLWHA) in rural areas within states with limited participation in the Medicaid expansion lack care coverage. In addition, because Medicaid and the Ryan White Comprehensive AIDS Resources Emergency Act have income eligibility requirements, as well as a waiting list to get HIV medication, many in rural areas do not have access to adequate treatment (National Rural Health Association [NRHA], 2004). Worse still, there is significant stigma and discouragement that impedes voluntary testing or treatment (Chandra, Billiou, Copen, & Sionean 2012). Chandra, et al. (2012) further noted that rural populations are particularly at increased risk for HIV/AIDS infection or transmission because of the absence of low cost free routine testing for HIV/AIDS, STD or testing as part of blood donation. Persons living with HIV/AIDS (PLWHA) in rural areas experience difficulties such as the exorbitant cost of treatment and adequate insurance coverage, isolation, disclosure of HIV status, low levels of HIV/AIDS knowledge and lack of information on access to treatment and support services (NRHA, 2004). Within their communities, PLWHA in rural areas also experience problems with resources: availability of health care facilities, support services and competent care professionals, access to health care facilities, as well cultural practices and attitudes including stigma and discrimination (NRHA, 2004; Schur et al., 2002).

Health behavior theorists cite cultural and environmental factors, including social norms, attitudes and expected cultural acceptance as motivators or barriers to uptake of health services (Kohler et al., 2014). Cultural and environmental factors such as stigma and discrimination have been identified as significant barriers to the treatment and quality of life management of PLWHA (Kohler et al., 2014). Nyblade et al. (2005) specified four distinct domains of stigma: fear of causal contact, moral values of shame, blame and judgment, discrimination and disclosure. Stigma and discrimination of PLWHA is pervasive and interfere with HIV/AIDS treatment efforts (Parker & Aggleton, 2005). Goffman (1963) defines stigma as an undesirable or discrediting attribute that an individual possesses, that reduces that individual's status in the eyes of society. Another attribute of stigma, according to Goffman (1963) is deviance: viewed as being negatively different from common or valued norms. Although stigma and discrimination are related, the former refers to attitudes and perceptions, whereas the latter encompass actions and behaviors that are directed at an individual as a result of a perceived difference (Goffman, 1963). Stigma and discrimination, therefore include negative attitudes

and behaviors directed at PLWHA, their partners, friends and families as a result of their condition (Lyimo et al., 2014). These attitudes and behaviors reinforce social differences in class, race and gender (Parker & Aggleton, 2003). For instance, ostracism and violence against PLWHA are common consequences of stigma (Parker & Aggleton, 2005). In addition, individuals that experience stigma also end up applying the public stigma to themselves, resulting in self or internalized stigma. Internalized stigma has been reported to result in low self-esteem and anger (Lyimo et al., 2014).

PLWHA deal with and respond to the condition in different ways (Franks & Scott, 2006; Lyimo et al., 2014). Coping is a significant aspect of living with HIV/AIDS and has implications for psychological and physical well-being (Moskowitz et al., 2009), medication adherence and treatment outcomes (Lyimo et al., 2014). The absence of effective coping strategies may cause PLWHA to resort to self-isolation, substance abuse and indiscriminate sexual behavior (Franks & Scott, 2006). However, the environment in which the individual lives is a significant determining factor in both the availability and the type of coping used by PLWHA (Bolton & Talman, 2010).

The latest 2013 estimate for persons living with HIV/AIDS disease in Illinois is conservatively placed at 36,064 people with 2,189 or 6% living in rural areas (Illinois HIV/AIDS Epidemiology Profile [IHEF], 2014). As at 2011, the state ranked eighth among 50 states in cumulative reported AIDS cases (Illinois Department of Public Health, 2011). The highest prevalence rates were found in Johnson, Fayette, and Alexander counties (IHEF, 2014). Among these populations, individuals' greater than 50 years of age, youth 13–24 years, and injection drug users constituted the largest number of people living with HIV/AIDS in the rural areas. In addition, non-Hispanic (NH) whites made up a majority (51%) of individuals living with HIV/AIDS in rural areas in 2013 (IHEF, 2014). According to the Illinois Department of Public Health (2015) HIV/AIDS incidence plateaued in rural counties in 2013, although there was almost a one third decline in death rate among HIV positive persons for the period.

Generally, research has shown that PLWHA in rural areas experience elevated levels of stigma (Lyimo et al., 2014; Simbayi et al., 2007). Factors which perpetuate stigma among the rural population include but are not limited to: lack of accurate knowledge on how the epidemic spreads gender and cultural issues, religious teachings and taboos surrounding sexuality (Kalichman & Simbayi, 2003). Rural population with HIV often experience discrimination and violence and incidences of unfair treatment within their families, workplaces, communities and treatment facilities (Kalichman & Simbayi, 2003). These attitudes and behaviors negatively impact the attitude of PLWA towards treatment, self-care and coping behavior (Moskowitz et al., 2009). Stigma and discrimination against PLWHA has been reported to lead to increased internal stigma, excessive stress, reduced self-esteem and low self-esteem, isolation, avoidance of health services and support services, and non-disclosure of status (Pharris et al., 2011). The impact of stigma and discrimination might be particularly difficult for PLWHA in rural areas and further constitute a barrier to treatment and prevent efforts (Simbayi et al., 2007), as well as an increase in the HIV epidemic and mortality rates ([DFID], 2007; IHEF, 2014). Addressing the barriers associated with HIV/AIDS stigma can improve disclosure, use of services and the overall quality of life among rural PLWHA. However, there have been relatively few studies that have examined HIV/AIDS related stigma and coping strategies in rural areas exclusively, as this paper does. In looking at the coping strategies used to buffer the effects of stigma and discrimination, and the factors that act as barriers to eliminating these from HIV discourse, the following research question was the focus of this study: For people in

rural areas: What coping strategies are used to buffer stigma and discrimination for HIV-positives?

Rural Population and HIV Stigma

With the rise of new infections in the United States, it is not uncommon for most infected people to move from the urban to the rural areas in order to avoid the added hassles of urban living. This has created a rural-urban dichotomy with HIV-positives, where the rural people encounter more barriers to care than their urban counterparts (Kalichman, 1998; Pellowski, 2013). Pellowski (2013) outlined several barriers that people with HIV/AIDS face in rural settings, most of which will be addressed in this study, including social support stigma and discrimination, poverty, confidentiality, and transportation. This is contrary to findings from Eastwood, Fletcher, Quinlivan, Verdecias, Birnbaum, and Blank (2015), which established that people living with HIV in urban areas report barriers to care more frequently. However, the authors noted that reporting less frequently did not imply lack of barriers in rural settings, but rather the presence of accounting factors. They highlighted social support as one such factor that might be responsible for why people in urban areas reported barriers less frequently. This study looks further into this claim as well.

Coping with HIV Stigma among Rural Population

Coping serves two major functions among PLWHA: managing the problem that is causing distress, and regulating the individual's response to the distress (Folkman et al., 1991; Heckman et al., 2008). Strategies for coping with HIV/AIDS related stigma among individuals with the condition in general include direct action and positive reappraisal, religious coping, substance use, denial, concealment of HIV/AIDS status as well as social support (Lyimo et al., 2014). Further, the ability to cope is determined by several factors such as individual effort, family support, socio-cultural environment and the amount of coping resources available in the environment (Heckman et al., 2008).

Method

Participants

All study procedures were approved by the Institutional Review Board (IRB) at Southern Illinois University Carbondale and the Jackson County Health Department HIV Services Division. Participants for the study were recruited from the Illinois Surveillance Region 5, which caters to nineteen (19) counties. The 43 participants ranged in age from 30 to 68 years. Participants included people who had been diagnosed HIV-positive, and those who resided in any of the nineteen counties catered to by the Illinois HIV Care Connect. As an inclusion criterion, the respondents must be an HIV-positive, must reside in any of the nineteen counties served by the Illinois HIV Care Connect in Region 5, and must be receiving HIV-related health services from this region. Limitations were not placed on age, gender, sexual orientation, education, or economic background, in order to include the entire population of people living with HIV/AIDS in this region.

Participants also received a \$10 gift-card from Wal-Mart as an incentive for participating in the study. Participants who completed the survey received the card at the end of data collection. The incentive was necessary in order to garner a high participation rate, which was needed to reach a high enough sample size to allow for generalization of results into the larger HIV-positive population in the region.

Procedure

A concurrent mixed method design was used in the collection and analysis of data (Creswell & Clark, 2007). A cross-sectional survey design was mixed with a brief interview (Dillman et al., 2009). The surveys were distributed to participants at the Jackson County Health Department HIV Services Division. A waived-signature informed consent and a cover letter were attached to the surveys. Participants completed the survey only after both the consent form and cover letter were read and approval was given by the participant. Surveys were then collected immediately upon completion. All responses were kept confidential. Additional qualitative brief interviews were conducted with the respondents concurrently to corroborate and aid in the interpretation of the quantitative findings and highlighted ways in which respondents coped with HIV-related stigma and discrimination.

Instruments and measures

Data collection was achieved using a survey and a brief interview. The two-part survey consisted of 14 questions designed to assess instances of stigma and discrimination, and explore the coping strategies used to buffer the effects of these on the HIV-positives who experienced them. The first ten (10) unique questions collected demographic data relating to respondents' age, gender, sexual orientation, economic and educational background, employment status, the current Illinois Surveillance Region 5 in which they reside, and their marital status. The second part of the survey was specific to stigma and discrimination. Respondents were asked about their experiences with stigma and discrimination, and asked to qualify such experiences by stating such experiences and the coping strategies used in mitigating instances of stigma and discrimination. The interview involved semi-structured questions on coping methods used for HIV related stigma and discrimination.

Analysis

The Statistical Package for Social Sciences (SPSS version 22.0) was used in the analysis of demographic, stigma and coping strategies related variables. Audio files from the interviews were directly transcribed and thematically coded by one of the first authors using QSR NVivo which is a qualitative data analysis software for windows 11®. Another of the first authors served as a co-coder and consensus on the themes that emerged were achieved after further discussions between the two first authors. Consistency was ensured via an audit trail, maintaining neutrality and ensuring that the co-coder followed the same procedures in the data analysis.

Results

Sample description

The 43 participants ranged in age from 30 to 68 years ($M = 50.84$, $SD = 10.08$). Of the 43 participants 32 (74.4%) were male and 11 (25.6%) were female. Among the participants, 11 (25.6%) identified themselves as Black/African American, 1 (2.3%) identified themselves as Hispanic, 30 (69.8%) were White/Caucasian, and 1 (2.6%) were other or not in the previous categories. Participants averaged 3.51 years of education. Seven (16.3%) completed middle school, 15 (34.9%) had completed high school, 11 (25.6%) held a college degree, 1 (2.3%) had an associate degree and 9 (20.9%) had completed some type of education other than the aforementioned. The majority of participants ($n=16$, 37.2%) were single, 10 (23.3%) were separated, 6 (14.0%) were married and 3 (7.0%) were widowed. Seven (16.3%) of the participants were in paid employment, 24 (55.8%) were unemployed, 11 (25.6%) were on disability income and 1 (2.3%) was self-employed. In terms of sexual orientation, 22 (51.2%) identified as homosexual, 13 (30.2%) identified as heterosexual, 5 (11.6%) were bisexual and 2 (4.6%) identified as asexual. The majority ($n=30$, 69.8%) of the participants had an

undetectable HIV/AIDS, viral load, 10 (23.3%) had a detectable load and 3 (7.0%) had an almost undetectable viral load. Twelve (27.9%) were currently enrolled in Medicare, 9 (20.9%) were enrolled in Medicaid, 9 (20.9%) had a dual enrollment in Medicare/Medicaid, 1 (2.3%) had a supplementary insurance plan, 5 (11.6%) were on disability insurance and 6 (14.0%) had other types of insurance. With regard to yearly household income before tax, 20 (45.5%) had a household income less than \$10,000, 18 (41.9%) reported household income that ranged from \$10,000-\$24,000 and 5 (11.6%) had household incomes that ranged from \$25, 000- \$49,000.

Coping Strategies

Quantitative analysis

For descriptive purposes, we first examined the frequencies of responses to the coping with stigma items. Table 1 provides insight about coping strategies that are used by persons living with HIV/AIDS against related stigma. To explore the concept of coping, seven items or questions about how respondents coped with HIV/AIDS related stigma were posed. Results showed that the self-isolation 31 (37%) was the most preferred method, closely followed by engaging in destructive behaviors or reactions, 16 (20.2%). The least preferred method was seeking spiritual guidance, 2 (2.4%).

Table 1

Coping Strategies that are used by persons living with HIV/AIDS against related stigma.

Variable	Frequency	Percentage (%)
Physical Activity	3	3.60
Seeking Spiritual guidance	2	2.40
Isolation	31	37
Seeking Social support	16	19.40
Advocacy	8	9.52
Providing Positive Reassurance to self	7	8.33
Making/ engaging in destructive reactions/behaviors	17	20.24

Regression analysis was also conducted to test the relationship between demographic variables (age, gender, sexual orientation, year in care, employment status, income level, race/ethnicity, social support) and coping. Specifically, the relationships between each of these variables and coping scores were examined using one-way ANOVA procedures. Year in care was found to be statistically significant, $F(18, 24) = 2.291, p = .029$. Similarly, Social support was also found to be statistically significant $F(27, 15) = 3.199, p = .011$. None of the other demographic variables were found to be statistically significant. Scheffe post-hoc analysis revealed that the mean of individuals with that have been in care for more than 5 years were significantly higher

than all other groups; those with 5 years were higher than those with less than 5 years. Similarly, the means of individuals with more support were higher than those with little social support; those with little social support were higher than those with no social support. Taken together, these results suggest that more years in care and having more social support really do have a positive effect on coping with HIV stigma and discrimination among the rural population.

Qualitative analysis

From the analysis of the interview conducted as part of the data gathering process on stigma and discrimination, two distinct coping strategies that encompassed the seven major coping strategies emerged and were described by the respondents. The identified coping strategies were *emotional* coping strategies (e.g. isolation, engaging in destructive behaviors, providing positive reassurance to self, engaging in physical activity) and *problem* focused (seeking social support, seeking spiritual guidance, and advocacy) (Julawong, 2009; Makoae et al. 2008).

Emotional coping strategies. This category referred to personal, social and religious measures that were used to mitigate against HIV related stress or conflicts and to stabilize emotions as reflected in the following statements:

I usually take the dog out for a walk or go outside to work in the garden whenever I have a conversation with my partner. Whenever we have a conversation on my condition . . . which are often initiated by her, tone of voice and reprimands often lead to arguments and make me feel as though I should be in control of my condition. I often feel overwhelmed with emotions after such arguments and would simply step outside for a walk (Rural HIV infected Male).

I don't usually drink but sometimes I would rather live in that state of numbness than live in the reality of reality of dying daily. At least, I can hasten the process and find some peace (Rural HIV infected female).

Problem-focused strategies. These strategies focus on seeking some type of solution such as seeking social support, finding a purpose or engaging in behaviors that are geared towards advancing the lot of persons with HIV/AIDS.

I enjoy my weekly visits to the health center as they provide me with an opportunity to make new friends and to interact. Some of these individuals have become my strongest support (Rural, HIV-infected female).

Sometimes the only way people get to know more about HIV is when we talk about it. People at the Health Center know that I am always willing and available to talk about my experiences living with HIV/AIDS whenever, there is a program in the community to enlighten people about HIV/AIDS. Certainly, you can see by a person's reaction that there is a lot that they do not know about the condition (Rural, HIV-infected female).

I talk to my kids, family or friends whenever I need some type of encouragement or support. I realize that sharing my concern with close family members gives me some peace of mind. I know I can always count on them (Rural HIV-infected male).

Discussion

The purpose of this mixed method study was to examine the relationship between the HIV/AIDS-related stigma and coping methods among the rural population with HIV/AIDS. The results showed that self-isolation was the most common type of coping strategy used among respondents. This result is consistent with the findings of Audet et al. (2013) where the majority (75%) of participants used self-isolation from friends, families, and community members as a coping mechanism for HIV/AIDS related stigma. Because rural communities tend to be small and people knew one another in an intimate way, many stigmatized individuals are likely to avoid increase contact with others resulting in an inability to develop new friendships, or seek employment or social experiences. This suggests that the more prevalent the level of perceived stigma, the more likely individuals living with HIV/AIDS are more likely to seek help concerning their condition or live integrated in the community.

Second, the results of the study showed that coping strategies can be either emotional or problem focused. The extent to which one approach is used compared to the other is likely to depend on personal characteristics of the individual. For instance, few respondents were willing to seek religious support, whereas a large number of respondents are willing to either seek some form of social support or engage in destructive or harmful behaviors. This suggests the changing attitude or views of rural people with HIV towards seeking spiritual or religious guidance. In the past, religion was viewed as a highly efficient way to buffer against incidences of stigma and discrimination than in recent times; many individuals are dealing with their stigma away from the judgement of the church (Mahajan et al., 2010; Pulerwitz et al., 2008). Third, the results of the study with respect to the use of high use of social support is also consistent with previous studies. Galvan et al. (2008) noted that individuals' high levels of perceived social support are more likely to develop more effective coping skills that can be utilized when confronting specific situations related to HIV/AIDS related stigma. Specifically, the sense that close family members and friends are available to provide assistance can result in enhancing one's ability to cope with the stigma.

Lastly, the result of the study also showed that more years in care and having more social support really do have an effect on coping with HIV stigma and discrimination among the rural population. This has implications for the provision of support systems for HIV/AIDS individuals that are experiencing stigma and discrimination. Specifically, as these individuals continue in treatment, they develop better social relationship and learn better coping strategies to deal with stigma and discrimination (Makoe, 2008).

Implications for Health and Human Services Workers

Given the findings about the use of isolation as a coping method, it is imperative for health care officials working in the rural areas to address socio-cultural barriers that perpetuate stigma. One way through which this can be achieved is through mass sensitization and enlightenment programs. In particular, health communication officers at the local level may need to provide a factual description of the disease, modes of transmission and methods of risk reduction. Health care workers in rural areas need to be oriented to the rights of these individuals to treatment, respect and privacy. Privacy laws that provide these individuals from stigma need to be respected and observed. The confidentiality of HIV-related information, particularly HIV test results, should be guaranteed at the local or county level. Attention should also be devoted to programmatic interventions, which attempt to change attitudes and behaviors towards persons with HIV/AIDS.

Limitations

The study used a convenience sample of HIV-positive people from the Illinois Surveillance Region 5, which caters to 19 counties. Hence, we are not able to generalize from these findings to the population of HIV-positive individuals in the entire state or country. In addition, the study was cross-sectional in nature. Thus, we are not able to make causal inferences with regard to the associations that were obtained among the variables in the results.

Conclusion and Future Research

In the history of infectious diseases, stigma and discrimination borne of fear of the unknown has been a recurring human reaction to diseases that have been highly infectious. From leprosy, to mental illness, to venereal diseases, stigma and discrimination have been a normal human reaction. Without understanding the epidemiology of a particular disease, people are much more likely to react in a negative manner than be accepting of people suffering from that disease. The aftermath has been years of setback in eliminating diseases from our public sphere, as these negative reactions continue to bar improvements in disease eradication and management.

For rural settings where access to health facilities are usually far and between, stigma and discrimination of HIV/AIDS and people living with the disease has contributed to the abysmally low numbers of people adopting positive health behaviors in order to avoid risk of contracting the disease at a later time. People make the choice to steer clear of testing centers, most of which provide tools to encourage healthy sexual behaviors, including free condoms, free health literacy classes and materials, as well as access to health care providers trained to give optimum guidance and care to people most at risk of infection. Future research should examine the role that family and other social support play in the coping strategies used against HIV/AIDS stigma among persons living with HIV/AIDS in rural America. Such an examination will determine the extent to which differences in the types and nature of social support, intervene on the coping strategies among these populations.

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