Silence Is Not Golden: Invisible Latinas Living with HIV in the Midwest

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Abstract This qualitative study was conducted to better understand the health needs and concerns of immigrant HIV-infected Latinas residing in the Midwest United States. Individual interviews \( (n = 18) \) were conducted in Spanish with Latinas in Kansas, Oklahoma and Missouri. Women were at different stages of acceptance about their HIV diagnosis and four common themes emerged from the data: pregnancy as a death sentence, HIV is taboo, God as their only resource, and living in isolation. Silence was an over-arching theme present throughout all the narratives and many women had never shared their stories about HIV with anyone. Depressive symptoms and suicidal ideation were common. These findings have implications for strategies to address the HIV prevention and HIV-related healthcare needs of this population of women. Results from this study further suggest that efforts are needed to break the silence surrounding HIV and to reduce HIV-related stigma in smaller Midwestern Hispanic communities.

Keywords HIV · Women · Hispanic · Immigrant

Introduction

There is no greater agony than bearing an untold story inside you
Maya Angelou

Early in the HIV epidemic, the health care systems in Western Europe and the United States tended to focus on the needs of homosexual men [1]. The fact that women were infected and affected by HIV has been only gradually acknowledged. Moreover, recognition that this population of women had special needs was even more slowly attained [2]. In recent years the need for broad HIV prevention measures across all populations has been acknowledged as has an understanding that HIV-infected racial/ethnic and gender groups have unique health needs that extend beyond access to medical care and antiretroviral therapies.

Approximately 1.2 million people are living with HIV (Human Immunodeficiency Virus) in the United States (US) and over 56,000 new infections occur each year [3]. While there is no cure, HIV disease can be successfully treated with antiretroviral medications and managed as a chronic illness for many years [4, 5]. Racial and ethnic minority populations experience disproportionately high rates of HIV disease compared to Caucasians and also have poorer HIV-related health outcomes [6].

The 44.3 million Hispanics/Latinos in the US now represent the fastest growing group of Americans, accounting for half the population increase between the years 2000 and 2006 [7]. Hispanics/Latinos experience the second highest rate of HIV infection among US racial/ethnic minority groups [8]. Latinas, who are primarily infected with HIV through heterosexual transmission, experience worse HIV-related health outcomes than Latino men and other minority females. Poor health outcomes and
lower survival rates among HIV-infected Latinas in the US have been associated with delays in diagnosis and entry into care and non-adherence to HIV treatment [9].

In the United States, Hispanics/Latinos have traditionally lived in large cities throughout Florida, California, Arizona and Texas. However, at the start of the twenty-first century the number of Latinos living in the Midwest and in smaller communities had risen substantially [10]. As the Midwestern Latino population has grown, so has the number of Latina women living with HIV. However, little is known about the specific needs of Midwestern HIV-infected Latinas [11].

Moreover, the antecedents to HIV infection and health care needs of this group of Latinas may be unique, due to immigration patterns and residence in smaller cities with less diversity and fewer community resources. Few research studies have focused on the needs of HIV-infected Midwestern Latinas living in smaller cities—in part because first-generation and recently arrived immigrants have traditionally been a challenging study population to reach [12, 13] and also because US HIV-related research studies have typically been conducted in larger cities [14].

The initial aim of this qualitative study was to better understand the healthcare needs and service gaps of a population of immigrant Latinas living with HIV in Missouri, Kansas and Oklahoma. We sought to gain information that would help improve service delivery and inform clinical practice. We expected to hear about health care system problems such as long wait times to receive health care services, financial barriers and difficulties surrounding HIV treatment regimens. But we heard little about such problems. In fact, all the women interviewed were satisfied with their health care providers, had few if any negative feelings about the health care system and indeed felt fortunate and grateful for the HIV care and treatment that each was receiving. What we did find, however, was a group of 18 women who universally had been living in silence about their HIV disease. “This is my ugly story,” they told us over and over, “but it feels good to be able to tell it to you.” Thus, while we found negative results in relation to our initial hypotheses, an unanticipated outcome of this study was to give voice to a group of Latinas who had been underrepresented in previous HIV research. The emotional, psychosocial and psychiatric needs discovered in this study represent healthcare gaps for HIV infected women.

Methods

Narrative description was used in an effort to obtain a better understanding of the antecedents to HIV infection and the unique health needs and concerns of Latinas living with HIV in the Midwest [15]. The analysis of narratives, that is the examination of personal stories from the population of interest, has gained stature as a quality method for examining the human response to illness [16]. Narrative description has been utilized successfully by researchers to identify the health concerns of other populations of women living with chronic illnesses [17] and is useful in practice disciplines as a way to gain information about the desires of those served from their own perspective [18].

Sample

Eighteen women from Missouri, Kansas and Oklahoma participated in the study. The inclusion criteria for study participation were age 18 years age and older, diagnosis of HIV infection and Latina. Information about the study was distributed to HIV-infected Latinas through case managers in the Ryan White government-sponsored HIV case management program.

Establishing Research Relationships

Recruiting Latina women into research studies can be challenging due to cultural and social issues such as traditional sexual roles and communication with male partners, concerns about deportation, English language difficulties and transportation problems [19, 20]. The establishment of a trusting relationship between researchers, Ryan White case managers and community agencies was the basis for successful recruitment for this study. Prior to the study’s initiation, the principal investigator met individually with case managers in Oklahoma City, Oklahoma; Wichita, Kansas and Kansas City, Missouri and visited their respective community agencies several times over a 1-year period to discuss the aims and long-term goals of the research study. After it became clear to case managers and agency personnel that the goals of all parties involved were aligned, that is, to learn more about the needs of Latinas in order to develop effective ways to meet the needs of these women and their families, enthusiasm for the study soared. The case managers were anxious to “get the word out” to their Latina clients that voluntary participation in this study was an opportunity to “let their voices be heard,” and to express their health care needs and concerns in a safe setting.

Procedures

The Institutional Review Boards of the University of Missouri-Kansas City and the University of Kansas-Wichita approved the study. The case managers informed potential Latina participants about the study and offered interested women two options for scheduling an interview. Potential candidates could either contact the study nurse to schedule an interview and the nurse interviewer would
come to the woman’s home to conduct the interview, or the participant could select a time and day to meet the nurse interviewer at a local community agency. The majority of women (n = 13) had their interviews conducted at a local community agency; the remainder (n = 5) chose to have the interviewer come to their homes. Women were instructed to arrive at the local community agency on the designated interview day and follow posted signs that directed them to a conference room. These signs had no identifiers as to the nature of the interviews. The nurse interviewer did not have access to any contact information or identifiers about the women prior to the interview date/time. When a woman arrived at the conference room, a research team member explained the study and obtained written informed consent. The women each received a $25 department store gift card for their time participating in the study. A light snack was provided and transportation reimbursement was also available.

Each woman was informed that at the conclusion of the interview she would be asked to sign the consent form again to indicate that she was comfortable with the information she had shared in the interview. If she was not comfortable, she could stop the interview at any time, she would be given the audiocassette, and any information she had shared up to that point would not be used in the research. Each interview was audio-taped and lasted 50–75 min. All participants signed the consent the second time as no information she had shared in the interview. If she was not comfortable, she could stop the interview at any time, she would be given the audiotape, and any information she had shared up to that point would not be used in the research. Each interview was audio-taped and lasted 50–75 min. All participants signed the consent the second time as no woman felt uncomfortable with the information she had disclosed in the interview.

Data Collection

All interviews were conducted in Spanish by a bilingual/bicultural masters prepared nurse with previous experience in the care of adults with HIV disease. A demographic data and health form was completed prior to the beginning of the interview. Each interview began by asking the woman “what is it like being a Latina living with HIV in Oklahoma, Kansas or Missouri?” and content flowed from the responses. At some point in the interview, each woman was specifically asked if she had any concerns about her health, if her concerns were being addressed, and if her health needs were being met. If a woman stated that particular needs were not being met, she was asked to talk more about each specific concern that she felt was not being addressed. The interview concluded by asking the woman if there was anything else she would like to say or if she had any advice for other Latinas living with HIV. Saturation or repetition of the same information became evident by the fourteenth or fifteenth interview when it was apparent that no new data was being collected. To ensure that data saturation had been reached, three additional interviews were conducted beyond the point at which no new data was being collected.

Data Analysis

The audio-taped interviews were transcribed verbatim in Spanish and then translated and transcribed into English by a certified bilingual Spanish/English interpreter. Characteristics of voice inflection and emotion were added to the transcriptions. Three investigators performed the data analysis: two were bilingual/bicultural Spanish–English and one was an English speaker. The investigator who conducted the interviews did not participate in the data analysis. Data were analyzed using content analysis [21] to identify categories and themes that were discussed by the women. Data were analyzed in both Spanish and English. Analysis in both languages helped assure that no meaning was lost or changed in the translation from Spanish to English. The investigators coded the women’s responses independently. Results, themes and categories that emerged from the independent coding were reviewed and any discrepancies in coding were discussed until 100% agreement was reached among the investigators. The majority of data analysis discrepancies involved issues of translation and cultural language nuances that were challenging to capture in English. To enhance trustworthiness of the data, two of the women who participated in the study were asked to review an overall description of the findings to be certain that they also agreed with the themes as identified; their suggestions were integrated into the final analysis.

Results

The 18 Midwestern Latinas with HIV infection who participated in this study were all first generation immigrants whose dominant language was Spanish; many had limited or no English proficiency (Table 1). The women ranged in age from 26 to 55 and had an average of 9 years of education. Half were married or lived with a male partner, half were employed, and all but one had children living at home. All of the women considered themselves to be in good health and were actively engaged in HIV care and treatment, with the majority (72%) taking antiretroviral medications for their HIV disease, however, many (66%) could not articulate their key HIV laboratory marker numbers, CD4 cell count or their PCR/HIV viral load, except to state that their “labs were good” or “my doctor says I am doing fine.”

The women willingly gave detailed descriptions of their experiences as Latinas living with HIV in the Midwestern US. Without prompting, almost every woman gave an account of the day she was given her HIV diagnosis. The majority of the women had learned about their HIV infection through screening while pregnant, had little
knowledge about HIV prior to their diagnosis, and had not felt at risk for HIV prior to the diagnosis.

Four themes and two sub-themes emerged from the data analysis (see Table 2), with silence as an over-arching theme that prevailed throughout all the narratives. Every woman expressed feelings of stigma and talked about present or past barriers faced due to limited English proficiency. All spoke about feelings of depression, rejection or suicidal attempts; few had received any type of mental health care intervention. For over half of the women, God was their primary source of emotional support.

Table 1 Demographic characteristics of participants (n = 18)

| Characteristic                        | No. (%) |
|--------------------------------------|---------|
| Age                                  |         |
| 26–40                                | 15 (83.3%) |
| 41–55                                | 3 (16.7%) |
| Marital status                       |         |
| Single/Divorced                      | 9 (50%)   |
| Married/Lives with male partner      | 9 (50%)   |
| Employment status                    |         |
| Full-time                            | 8 (44.4%) |
| Part-time                            | 1 (5.6%)   |
| Unemployed                           | 9 (50%)   |
| Taking ARV treatment                 |         |
| Yes                                  | 13 (72.2%) |
| No                                   | 3 (16.7%)  |
| Did not respond                      | 2 (11.1%)  |
| CD4 cell count                       |         |
| 200–500                              | 4 (22.2%)  |
| >500                                 | 3 (16.7%)  |
| Doesn’t know                         | 12 (66.7%) |
| Did not respond                      | 1 (5.6%)    |
| HIV viral load                       |         |
| <50 (undetectable)                  | 4 (22.2%)  |
| <5,000                               | 1 (5.6%)   |
| Doesn’t know                         | 12 (66.7%) |
| Did not respond                      | 1 (5.6%)   |
| Have children living at home         |         |
| Yes                                  | 17 (94%)   |
| No                                   | 1 (6%)     |
| Number of children living at home    |         |
| Range                                | 0–6      |
| Mean                                 | 3.0      |
| SD                                   | 1.5      |
| Years of education                   |         |
| Range                                | 2–16     |
| Mean                                 | 9.81     |
| SD                                   | 3.6      |

ARV antiretroviral

Table 2 Themes and sub-themes

| Theme                        | Sub-themes                      |
|------------------------------|---------------------------------|
| Pregnancy as a death sentence|                                 |
| HIV is taboo                 |                                 |
| God as the only resource     |                                 |
| Living in isolation (two sub-themes) | No one to talk to |
|                               | Someone to talk to              |

Silence

Silence about their HIV infection dominated the actions of the women in this study, who cloaked themselves in secrecy about their illnesses. For most of the women, only a handful of people knew about their HIV status, and in some cases they had only talked with God about their diagnosis. Those women who were married or partnered had told their husband/partner, most often because the partner was also HIV-infected. Only one woman had disclosed her HIV diagnosis to her children and few had told even close family members. In fact, most stated that informing family members, in general those with whom they were closest on all other issues, was not an option, because relatives not only would not understand but also would reject the woman. Furthermore, it was believed that an HIV diagnosis would pose too great a burden for the family. Several had experienced severe symptoms of depression or even suicidal ideation, yet had spoken to no one, about these symptoms. In addition to this silence about HIV at the individual level, many women talked about the fact that HIV was not discussed in their families or social networks. Most felt that they were “the only woman living with HIV in (their) community,” and the majority had never spoken with another woman who was HIV-infected. Living a life of silence, filled with shame, stigma, and depressive feelings in essentially complete isolation, had become the “norm” for these women.

Pregnancy as a Death Sentence

Most women learned about their HIV diagnosis during routine HIV screening while pregnant and described this event as a “traumatic experience.”

It is something one does not expect. I went in for treatment of the flu and they told me I was pregnant. They started doing a lot of laboratory tests which showed I was infected with HIV.

Regardless of the circumstances surrounding the HIV diagnosis, the news came as a shock for every woman and most had immediate thoughts of death and dying.

When they tell you that you have HIV, this is an experience one can never forget. I still remember in
detail the face of the doctor that told me. When you hear this diagnosis, you feel you don’t want to live, the first thing you think is ‘I’m going to die.’ I’m going to suffer a lot and die.

When I found out what I had (HIV), I tried to commit suicide, do things I shouldn’t, I tried to commit suicide twice.

One reason for the shock was that most women had little, if any, accurate knowledge about HIV prior to being informed about their diagnoses.

I didn’t know how people became (HIV) infected, there are many myths…there is a lot of ignorance.

HIV is Taboo

Every woman talked about the constant stigma that surrounded HIV and each of them was certain that family members and friends believed that all HIV-infected individuals had done “bad things.” Hence, the women kept their HIV diagnoses to themselves and feared rejection by or social ostracism from their communities if the truth was discovered. Women were concerned that their child(ren) would be rejected at school and by friends if anyone learned about her/her husband’s HIV diagnosis.

“The (Hispanic/Latino) people accept all diseases except this one. They (Hispanics) believe that people with HIV are homosexuals or prostitutes. If I were to tell anyone about my disease, they would say I had been with everyone in the world.” “Latinos have a closed mind about HIV, it’s taboo.”

God as the Only Resource

Almost every woman talked about her relationship with God, her dependence on God for guidance and her belief that God would give her the strength to deal with HIV. For some women, God was the only source of emotional support.

I give thanks to God, He is the one who is helping me be emotionally stable, I ask Him for this (through prayer), that he not let the disease attack me, and I think He is listening.

For me there have been two miracles (from God), I am here, my daughter was born fine (not HIV-infected) and up until now we are both fine… I have a lot of faith.

Even the few women who had received professional mental health services still felt that God was in control. In a discussion about her recovery from alcohol addiction one woman stated,

God lifted me up so that I entered a Christian rehabilitation program, my life changed and I stopped drinking. I have been sober for one year.

Living in Isolation

No One to Talk to

Feelings of isolation resounded throughout the narratives, with numerous vivid descriptions of loneliness and symptoms of untreated depression. For some, these feelings were always present while for others the thoughts were intermittent. Several women gave detailed accounts of past suicidal ideations or suicide attempts.

I am alone in the world.

…I thought about killing myself, throwing myself in front of a car on the road, I felt my life was not worth anything and I felt like a parasite had entered my body and was eating me… When I was diagnosed there was no one to tell me ‘I have had this and I survived and you can too.’ I touched bottom with this disease.

…Sometimes one has ugly thoughts… a desire to end your life…I took a lot of pills while pregnant, then I was sorry, but I’d already done it, thanks to God my son is fine.

…I feel sad and alone, even though I have my family and they know (about my HIV) but there is no other person who has this disease except me…I would like to talk with other women who have HIV.

Language barriers were an important factor that heightened the experience of isolation. Every woman described experiences in which the inability to speak, understand, read or write English had caused distress for her. Language barriers appeared to be more problematic for women who were recently diagnosed, for those who had little or no English proficiency, or both. Problems associated with limited English language ability ran the gamut from simply not understanding instructions to not being able to access needed health care services because of less than competent translations.

…Yes, she (the counselor) spoke Spanish - but not much. She did not help me and I felt like it was a waste of time.

Women also talked about the challenges surrounding their HIV care due to their inability to speak English, despite the availability of interpreters.
When you get there (to the hospital) they don’t have an interpreter until you are with the doctor, then they give you an interpreter. I always have to make my husband take off work; he is the one who speaks some English. I don’t want to ask anyone else for help because I don’t want them to know about my disease.

Although interpreters were generally available, the women expressed a degree of reluctance when it came to sharing their true feelings with health care providers via an interpreter. The exchange of sensitive information via a third person was problematic for some of the women. In addition, several feared that the interpreter might be judgmental. One woman stated that she felt the experience of receiving her HIV diagnosis was made worse because the doctor gave her the news via an interpreter.

I thought they had made a mistake on the blood test. There were so many things I did not understand. I had many questions. Instead she (the interpreter) took me outside and started talking to me about God.

**Someone to Talk to**

All women expressed gratitude for the opportunity to participate in this study and to be given the opportunity to speak with a nurse, in their own language, about feelings, needs and concerns surrounding HIV. For many, this study provided the first chance to speak one on one, in Spanish, with a health care provider.

This interview is lovely. I always ask for an interpreter, but I don’t like it. It’s better [to discuss this] in my language.

Women related that participation in this study was also their first opportunity to openly discuss the experience of living with HIV. Quite a few women felt that being a part of this study was therapeutic.

I should be paying you, instead of you giving me a gift (card) for study participation.

The women thanked us for conducting the study.

… quiero darles las gracias por preocuparse por nosotros, existen gentes que se preocupan por nosotros, les agradezco y pido a Dios que los ayude…. …[I want to thank you for worrying about us, people do exist who care about us, I appreciate it and I ask God to help you.]

**Discussion**

All of the women in this study experienced profound stigma and shame with regard to their HIV diagnoses and all agreed that, in their culture, HIV was considered to be the result of extremely negative behavior. The women were at different stages of acceptance of their diagnoses and had variable levels of ability to disclose information about their HIV disease to others. Some had struggled or were still struggling with acceptance of the diagnosis and had told no one about their situation while others had shared their HIV diagnosis with a selected few individuals. Our original aim was to better understand service gaps. Instead, an unanticipated result was the role this research played in giving voice to a group of HIV-infected Midwestern Latinas that had been underrepresented in research and the discovery that deep emotional healthcare gaps exist for this group.

The shame and stigma experienced by these women appeared to be so profound that they had in effect sentenced themselves to lives of silence and isolation. Language barriers and limited English proficiency also seemed to amplify these feelings. Many yearned to return to their native country but could not. The thought of losing access to state-of-the art HIV treatment available only in the United States, coupled with the fear of having to disclose their HIV diagnosis to their family if they returned home, kept them in the Midwest. For these Latinas, life seemed to be passing them by in a land far from home. Despite the increasing prevalence of HIV infection among this population [6], these women repeatedly expressed a sense of ‘being alone,’ felt invisible and unacknowledged.

Other researchers have reported higher feelings of stigma among HIV-infected women when compared to HIV-infected men [22]. Further stigma and shame among Hispanics has been found to be higher, compared to other populations, for other chronic diseases such as mental illness. In particular, Hispanics who are less acculturated, earn low incomes and/or have low education levels, such as the women in this study, have been reported to experience high levels of mental illness-related stigma [23]. Perhaps HIV-related stigma was also higher for these Latina women, compared to HIV-infected women from other cultures.

There were limitations to this study. Because the study was conducted with a small group of women, all who were receiving HIV care and who lived in similar geographic locations, the findings of this study cannot be generalized. The perceptions of other HIV-infected Latinas who are not engaged in care or who live in other areas may be different. There were also challenges with capturing the feelings and expressions of the women in the English language. The investigators felt that some of the cultural nuances expressed may have been lost in translation. Simply stated, some data could not be expressed in English in the same manner as articulated in Spanish, or at least these investigators could not agree that upon translation, the meaning was identical. In addition, the emotional aspects of the
women’s stories—such as the agony that was heard in their voices, the sobbing that occurred as the women told their stories and the sad women’s facial expressions—was challenging to convey in a narrative format.

Despite some limitations, findings from this study have important implications. This study provided a look at the health needs and concerns of HIV-infected Midwestern Latinas through the lens of the women’s life experiences. Only by examining what was reflected back from the women’s stories can researchers, public health officials and health care providers begin to address the unique HIV prevention and treatment needs of this population [24]. The lack of awareness about the risk factors for HIV among the Latina women in this study, particularly among women of childbearing age, is noteworthy. Our findings suggest that more work is needed in the Midwestern Hispanic community to increase awareness about HIV risk factors, to promote HIV prevention efforts and to encourage HIV testing.

The Latinas in this study described a number of unmet emotional health needs. Barriers existed that impaired their abilities to access mental health care. There was reluctance to discuss sensitive issues such as depression and suicidal ideation with health care professionals. The women stated that conversing about these sensitive matters via an interpreter was problematic. Hence, these barriers may have contributed to missed opportunities for mental health intervention that could have enhanced emotional health outcomes. Strategies are needed in clinical practice that can increase access to culturally sensitive mental and emotional health care for HIV-infected Hispanic individuals and especially for those with limited English proficiency. Moreover, the lack of attention to unmet emotional needs, such as depressive symptoms, may contribute to the fact that Latinas currently experience some of the poorest HIV-related health outcomes in the US [9].

Conclusion

Findings from this study indicated that a need exists for innovative intervention programs that can engage Midwestern HIV-infected Latinas in social support networks with other HIV-infected women to enable them to cope with HIV disease and reduce their feelings of isolation and stigma. Previous research has shown that HIV-infected women benefit substantially from interaction and participation in such social networks [25]. In addition, the development of scientifically based behavioral interventions that aim to enhance emotional health outcomes and programs that can address the unique emotional and psychosocial health needs of this group of women seem warranted. Further, findings indicated that more efforts are needed to break the silence surrounding HIV and help reduce HIV-related stigma in smaller Midwestern Hispanic communities.

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