

HHS Public Access

Author manuscript

Health Care Women Int. Author manuscript; available in PMC 2018 February 01.

Published in final edited form as:

Health Care Women Int. 2017 February; 38(2): 144-158. doi:10.1080/07399332.2016.1217863.

Women's experiences with HIV-related stigma from healthcare providers in Lima, Peru: "I would rather die than go back for care"

Dellanira Valencia-Garcia, Deepa Rao, Lara Strick, and Jane M. Simoni University of San Francisco, San Francisco, USA, University of Washington, Seattle, USA

Abstract

In Peru, HIV/AIDS is increasing among heterosexual women. This qualitative study examined HIV-related stigma among 14 women in Lima, Peru who were HIV-positive, and at least 18 years of age. A thematic analysis was used to analyze the data and indicated that women experienced stigma from healthcare providers. Three themes emerged from the data: maltreatment during health care, neglect of patients' rights to confidentiality and privacy, and the process of women speaking out. Stigma from healthcare providers had a long-term, negative impact on women's willingness to seek treatment. Future stigma reduction initiatives, on a global level, should include health care workers.

Keywords

healthcare; HIV/AIDS; women; qualitative analysis; stigma

The HIV/AIDS pandemic has devastated populations within developed and developing countries, predominantly affecting people living at the margins of society. Following closely after the first reported cases of HIV, stigma emerged as a pervasive and pernicious force that still exists today. Worldwide, over 35 million people are living with HIV (World Health Organization [WHO], 2012) many of whom face considerable stigma associated with the disease. A recent UNAIDS (2010) report noted that "stigma and discrimination, lack of access to services, and bad laws can make epidemics worse." Researchers have documented stigma's harmful effects on people with HIV, such as depression, poor quality of life, and poor health outcomes (Chesney, Ickovics, Hecht, Sikipa, & Rabkin, 1999; Rao et al., 2012). While Peru is fortunate to have received HIV funding to improve clinical HIV care (e.g., from the Global Fund for HIV/AIDS, Tuberculosis, and Malaria), the social impact of HIV, namely through stigma and discrimination, remains largely ignored as an avenue for intervention (Cáceres & Mendoza, 2009).

Correspondence should be addressed to Dr. Dellanira Valencia-Garcia, University of San Francisco, School of Nursing and Health Professions, 2130 Fulton Street, San Francisco, CA 94117-1080; dgarcia12@usfca.edu.

Dellanira Valencia-Garcia, is now at the School of Nursing and Health Professions, University of San Francisco, San Francisco, USA; Deepa Rao, Department of Global Health, University of Washington, Seattle, USA; Lara Strick, Department of Medicine, University of Washington, Seattle, USA; Jane M. Simoni, Department of Psychology, University of Washington, Seattle, USA.

Conflict of Interest Statement: The authors report no real or perceived vested interests that relate to this article (including relationships with pharmaceutical companies, biomedical device manufacturers, grantors, or other entities whose products or services are related to topics covered in this manuscript) that could be constituted as a conflict of interest.

In Peru, as of July 2010, the Ministry of Health (MOH, 2010) reported 41,638 cases of HIV. However, it is estimated that up to 79,000 Peruvians are living with HIV/AIDS, suggesting a large percentage of people are unaware of their diagnosis (Cáceres & Mendoza, 2009) and may be partly due to perceived stigma associated with having this disease. The epidemic in Peru is largely concentrated in urban areas followed by regions along the Amazon; 77% of all reported cases are in Lima and Callao (USAID, 2010). The epidemic is primarily sexually transmitted (97% of cases) and concentrated among men who have sex with men (MSM) and transgendered sex workers (MOH, 2010). However, HIV has quickly spread to heterosexual women and their children via MSM sexual networks (Cáceres & Mendoza, 2009). From 1990 to 2000, the ratio of men to women living with HIV dropped precipitously from 18:1 to 3:1 (USAID, 2010). Despite this knowledge, women in Peru remain unrecognized as a population at risk. Worldwide, women remain at high risk of contracting HIV via heterosexual partners and are a highly stigmatized group due to culturally bound gender roles (Valencia-Garcia et al., 2008; Paternostro, 1999).

HIV stigma

Across the globe, HIV-related stigma continues to be a powerful barrier to testing, disclosure, and treatment (Pulerwitz, Michaelis, Lippman, Chinaglia, & Díaz, 2008; Rajabiun et al., 2008). Researchers have documented stigma's deleterious effects on people with HIV, such as low self-esteem, depression, anxiety, and poor quality of life (Lee, Kochman, & Sikkema, 2002). Stigma results from having "an enduring condition, status, or attribute that is negatively valued by a society whose possession consequently discredits and disadvantages an individual (p.595)" (Herek, Capitanio, & Widaman, 2002). Others have defined stigma in terms of differences in power structures and social inequalities (Castro & Farmer, 2005). For example, social scientists have posited that stigma is difficult to overcome because it is embedded within basic hierarchical social structures, operating at the crossroads of 'culture, power, and difference' (Parker & Aggleton, 2003), with society's power structures enabling and perpetuating stigma (Link & Phelan, 2001).

There are various types of stigmas that can affect people living with HIV/AIDS (PLWHA): namely, public, institutional, internalized, and intersectional. Public stigma refers to the negative attitudes held by members of the public, such as healthcare professionals, clergy, or employers, about people with devalued characteristics. Public stigma that occurs at the societal level can take the form of restrictive policies and procedures of governments, schools, hospitals, and other institutions. Hospital policies that suggest exclusion of people with HIV from accessing services are examples of *institutional stigmas* (Corrigan & Kleinlein, 2005). Once public stigma is experienced or perceived, it can be *internalized* by the stigmatized individual and have the potential to profoundly and negatively impact mental health, healthcare service utilization, medication adherence, and ultimately, health outcomes for people living with HIV (Chesney et al., 1999; Rao et al., 2012).

The severity and impact of HIV stigma on the individual appears to stem from the connection of the disease with death, morality, and the taboo subject of sexuality. HIV stigma has been linked to people living at the margins of society who often struggle with multiple stigmatizing conditions (e.g., being poor, female, and a racial/ethnic minority),

sometimes called *intersectional stigma* (Berger, 2006; Wyatt et al., 2013). Reidpath and Chan (2005) argue that the impact of multiple stigmas is additive, making the experience more severe and difficult to overcome than the experience of a singular stigma. Additionally, factors such as gender, poverty, and cultural context may make the negative impact of stigma more severe and pervasive.

Women, stigma, and HIV

Women account for half of the people living with HIV worldwide (WHO, 2012) and may experience more HIV-related stigma than men (International Center for Research on Women [ICRW], 2006). This may result from women's generally devalued status worldwide and patriarchal power dynamics evidenced in certain cultures (UNAIDS & UNIFEM, 2004). Women have had to fight for equal status within political, financial, and educational domains (Ezechi et al., 2009; Lin, McElmurry, & Christiansen, 2007).

As a group, women face additional HIV-related stigma as they are often perceived as vectors for disease transmission who spread HIV to men via sex work or to unborn fetuses (Corea, 1992). Similar to other Latin cultures, many Peruvian women who are living with HIV/AIDS have had few lifetime sexual partners and may be unaware of their male partner's high-risk sexual behaviors (Alarcon et al., 2003; Johnson et al., 2003). Furthermore, women are expected to maintain culturally defined moral traditions and adhere to gender roles that indicate that women should know little about sex (Gomez, 2011; Valencia-Garcia, Starks, Strick, & Simoni, 2008). Our prior work explained how women with HIV in Peru are silenced and lose status within society, leaving them ill-equipped to negotiate for themselves: when a Peruvian woman is known to be HIV-positive, she is often seen as the unfaithful partner in a marital relationship, responsible for contracting HIV, and thus experiences stigma within her marriage, family, and society (Valencia-Garcia et al., 2008).

The treatment experienced by people who are living with HIV/AIDS (PLWHA) by health care workers can either impede or facilitate HIV/AIDS treatment utilization. Some studies have found that due to discriminatory treatment some PLWHA will cease treatment after a negative experience (Wong & Wong, 2006; Zhou, 2009). Wong and Wong (2006) found that healthcare workers can stigmatize and discriminate PLWHA in several ways including refusing to treat someone with known HIV diagnosis, providing differential treatment, testing for HIV without consent, segregating PLWHA in hospitals, and breaching patient's confidentiality.

Despite the diversity of people infected with HIV/AIDS, this disease continues to be associated with the "immoral" sections of society, namely the homosexuals, injection drug users and sex workers (Wong & Wong, 2006; Rajabiun et al., 2008). The perception of immorality subsequently facilitates blaming and stigmatizing behaviors from others. Wong and Wong (2006) discuss the 'moral hegemony' that occurs when PLWHA are expected to behave in certain ways (e.g., disclosing their status as a way to show moral responsibility) by health care providers making them vulnerable to unequal treatment, stigma, and discrimination. In various cultures, homophobia and the association of a disease linked to

homosexual behavior is sufficient to thwart testing, disclosure, or seeking treatment (Rajabiun et al., 2008; Shedlin & Shulman, 2004).

The present study

Improving women's healthcare service utilization, including HIV testing uptake and engagement in HIV treatment, is a fundamental component of improving health outcomes for women. To date, little is known about HIV-positive Peruvian women's experiences with HIV-related stigma in healthcare settings. The purpose of our paper is to present women's experiences with HIV-related stigma within healthcare settings in Lima, Peru.

Methods

Participants

A subset of HIV-positive women who were participating in a cross-sectional quantitative study (*N*=150) at the *Asociación Civil Impacta de Salud y Educación (Impacta)* were recruited for our study. Participants' eligibility criteria included being HIV-positive, 18 years of age or older, and not known to be pregnant at the time of enrollment. Purposive sampling, a type of non-random sampling was used to select and invite women to participate in the study based on the knowledge of the population, demographic characteristics, and the purpose of the study. We purposively invited women to participate who were of varying socioeconomic levels, who were on and off antiretroviral (ART) medications, resided in rural or urban areas in and around Lima, were of varying ages, and had different relationship status (e.g., married, single, etc.). A total of 15 women were asked to participate in a face-to-face interview and only one participant declined participation due to transportation difficulties. Participants were compensated *S*/.15 *soles* (approximately \$5 U.S. dollars) for their participation.

Procedures

Individual face-to-face interviews took place in September 2005 over a one-week period. All interviews were conducted at the *Impacta clinic*, a sexually transmitted disease research clinic located in Lima, Peru. The study was approved by the Institutional Review Board at the University of Washington and *Impacta*. After women were identified as potential participants based on the purposive sampling criteria (stated above) women were contacted via phone by a Spanish-speaking clinic female staff counselor and asked if they were interested in participation and informed about the purpose of the study. After obtaining informed consent, participants were interviewed in Spanish by a bilingual, Latina doctoral student using a semi-structured, open-ended interview guide. Interviews ranged from 30 to 120 minutes and were audio-recorded. The interview guide, originally in English, was translated through a back-translation technique to ensure linguistic and cultural equivalency (Marín & Marín, 1991). Interview items inquired about women's social support, becoming infected, perceptions and experiences of HIV-related stigma, and disclosure of HIV status.

Interview digital audio files were transcribed verbatim by Spanish-speaking-Latinaundergraduate research assistants. All interviews were reviewed by a second research assistant to confirm accuracy of the transcribed data. The data were then entered into Atlas.ti

V5.0, a qualitative statistical software program used for coding and data analyses. All transcriptions were kept in Spanish during the coding process to decrease translational effects and were coded by at least two independent Spanish-speaking individuals from the research team. Selected quotes are translated for publication purposes. Pseudonyms are included after each quote for anonymity.

Analysis

A thematic analysis framework was used to analyze the data. Thematic analysis assists in identifying, organizing and understanding the data rather than focusing on counts or frequencies (Braun & Clarke, 2006; Taylor & Bogdan, 1998); it is a systematic method for analyzing and reporting patterns or themes in your data.. This paper will address one of the major themes that arose from the analysis, stigma-related to women's experiences from healthcare providers. After the interviews, we developed general themes evident in the data for a general qualitative coding framework. The "stigma" theme was defined as "a negative event that occurred, and/or a perception of differential treatment based on HIV diagnosis." Six sources of stigma were identified: partners, family members, health care providers, employers, friends, and the community. Additionally we identified verbal (gossip), physical, psychological, and other types of stigma. During coding, either the source (e.g., medical provider) and/or the type of stigma were recorded (e.g., verbal).

Results

Participant demographics

Interview participants resided throughout Lima, 50% of women lived in the North, 14.3% in the South, 21.4% in the East, and the remaining 14.3% resided in Central Lima. Women were between the ages of 20 and 47 years (M= 33), identified as heterosexual, had at least one child (range 1–5) and were all living with their children at the time of enrollment. Women resided in households with extended kin (2 to 12 people), as is customary in Latin American countries; none lived alone. The majority (71%) of women lived with their parents; 21% indicated living with a male partner. Half of the participants were employed, usually in low-wage menial and temporary jobs, and their education ranged from 4 to 16 years (M= 11). The majority of participants self-identified as *mestiza* (or "mixed") ethnicity. Fourteen percent of women endorsed wanting to have more children in the future. Only 36% of women indicated receiving HIV/AIDS-related information from their doctors.

All of the participants reported becoming infected with HIV via heterosexual transmission from a main male partner (e.g., husband). Women stated two primary reasons for testing, their husband's diagnosis of HIV or pregnancy. Many women were the primary caregivers of their husbands before their death. The majority of women (79%) indicated that they perceived being treated different because of their HIV serostatus. Interestingly, while the majority of women stated perceiving differential treatment, none used the word "stigma" in their personal accounts.

Themes

In our analysis of the interviews women discussed stigma experiences from various sources (i.e., family and community), however indicated that the most frequent and distressing experiences of stigma came from healthcare providers (e.g., doctors and nurses) when accessing treatment, especially during childbirth and after care. Women communicated that while stigma was distressing from any source it was "worse" coming from a health care provider who, as one participant noted, "should know better." Additionally, because testing and treatment are vital to decreasing the spread of HIV, service barriers are especially useful to identify. The data revealed stigma from healthcare providers that were categorized into three themes: 1) maltreatment during care, 2) neglecting patient's rights to confidentiality and privacy, and 3) the process of women speaking out. Selected quotes from these themes are highlighted and discussed.

Maltreatment during care: "They hated me as though I had something on me."

The following quote highlights the thoughts and feelings of a participant who discussed feeling "marked" and alludes to the idea that her chart was flagged to alert providers about her HIV status.

"I don't want anything to do with the hospital because supposedly the personnel there are supposed to be the best prepared in these sort of cases and they are the ones that treat you the worst ... I am not the only one that is treated poorly, there are various women in this [HIV] group that go to the hospital, they get there first and they see them last, when they arrive they [healthcare providers] don't want to treat them ... they treat them with total discrimination ... I don't know maybe they put a stamp [on the chart]that reads "I have AIDS" just like that ... I have no desire to go to the hospital, for what, if I know that they are going to treat me bad."

[Elena]

Feeling "marked" was a common occurrence discussed by women in this study. The thought that they would be discriminated against and treated poorly was enough to discourage seeking medical treatment. Additionally, maltreatment at certain hospitals and clinics travelled quickly via word-of-mouth and women "knew" where not to go. Most women indicated that they would only go to the doctor when they or their children were severely ill and even then, many indicated that they would not go due to fear of discrimination or maltreatment.

During the interviews, many of the women discussed receiving poor treatment during labor and delivery. While the primary goal of testing pregnant women is to reduce vertical transmission, the treatment and psychological sequelae of receiving this diagnoses is largely ignored.

"When I was pregnant they [hospital staff] treated me very bad. It was a bad experience [sobbing]. They didn't want me to shower, they didn't want anyone to enter my room, they didn't want to hold my daughter, they would come in upset and grab my daughter to change her. Because I had a cesarean section they didn't

want to tend to my wound, they would come in a bad mood and against their will, you could feel it and see it, and that would make me more depressed."

[Lorena]

Lorena was not alone in noticing that she and her baby were treated differently. Women discussed the extreme shame and discomfort they felt during their hospital stay. The next participant compares the treatment she received in the hospital when she was HIV-negative to the treatment she received when she was HIV-positive with her second child. She recalled being physically isolated and treated as though she were contagious by touch.

"When I had my [first] baby they had me in a room with the other women, when I had my other baby they put me in a separate room, away from others. They did not treat me appropriately. They hated me as though I had something on me ... when they [nurses and doctors] entered my room they wore facemasks and gloves. I felt alone and I was in a separate room. At times when my husband would come they would look at him as though he was strange and not a normal person. It hurt my husband a great deal. There are people who hate us." ... After that I felt hopeless, I wanted to leave the hospital because they were treating me bad, they threw food at me as though I were an animal ... we were not human to them... why do they treat us this way?"

[Beatriz]

The same participant recalled how frightened she was to have her mother visit her at the hospital after giving birth since she had not disclosed her HIV status to her family. She believed that the way in which she was being treated by the medical staff and her physical separation from the other women would make her HIV diagnosis obvious to her family.

"I was terrified that my mom would arrive at the very moment that they were bringing me lunch, I was fearful that she would see them bringing me food when they wanted to, wearing gloves and a face mask ... I was fearful that she would know what I had."

[Beatriz]

Another woman discusses her experience with childbirth and aftercare and the negative impact she had from this experience. As she recalled this experience, she wept the entire time.

"I struggled so much, and at that moment I was not doing well at all [after childbirth], I noticed that they put me in an isolated room. I did not want to see anyone. The doctors were mean ... I couldn't take it anymore, I broke down and I cried."

[Carissa]

The same woman discussed another experience she had during a routine operation.

"I was in the hospital and was victim to awful discrimination. They prepared me for an operation three separate times and they offended me terribly just so that they

wouldn't have to operate ... afterwards they sent me to a room that was a storage room ... it was horrible, horrible."

[Carissa]

Another participant indicated receiving severe stigma from nurses and reported that they were fearful of touching her. She highlights the need to educate medical providers as a way to decrease stigma and increase access to treatment.

"At times when people hear that you have this disease, there are times that they don't even want to touch you. They say don't touch them or this and that, the nurses say this ... what is needed is information for the hospital personnel, information, because supposedly they should be the ones who know and they are the ones who treat you the worst."

[Susana]

Neglect of patient's rights to confidentiality and privacy: "I will never come to this hospital again."

Eva shares an experience she had with a doctor when taking her ill baby in for an appointment. She cried as she recalled how her confidentiality was violated which angered her and subsequently turned her away from wanting any type of medical treatment for herself or her baby.

"I went to the appointment, and he [the doctor] asked me "What problem is the baby having?" I didn't want to explain because they had already told me what we had, I remained quiet and I didn't answer him, he then looked at my medical chart and asked me "Why did you not tell me you have AIDS?" he spoke to me in a loud and harsh voice, there were people in the waiting area that heard him ... one woman came after me and found me crying, I told her I will never come to this hospital again because I am ashamed and embarrassed ... I will never come here again. I left and I didn't return. I told myself if death should come, then it will take me, what am I to do? It is far worse to be treated this way. After that, I wouldn't go to the hospital ... my baby continued with fevers, I would give him things to soothe him and that is how I cared for him."

[Eva]

Eva experienced an array of emotions including shame, embarrassment, sadness, and anger and claimed that she and her baby "would rather die" than return for treatment. The doctor appeared angry that she did not immediately disclose her HIV status, yet they were in a crowded waiting area. Like many women, she found it difficult to immediately disclose her status for fear of discrimination or rejection. Disclosing her HIV status to the doctor at that moment would have left her vulnerable to stigma or discrimination from those in the waiting area, who were often people she knew from her community. This example illustrates the disregard for her privacy and confidentiality and highlights that PLWHA are sometimes expected to disclose their status immediately. It is also possible that Eva and other PLWHA may become more sensitive to how they receive treatment and may indeed feel more vulnerable given their HIV serostatus. Eva, like many other married, monogamous mothers,

became infected with HIV via sexual contact with her husband (see Valencia-Garcia et al., 2008), making disclosure and communication about their status more difficult due to perceived stigma, further marginalization, and community shame. This woman felt so disrespected and angry that she rejected all future treatment for herself and her ill child.

HIV counseling should ideally be provided to any individual who seeks testing, but certainly when they return to receive a positive test result. In Peru, like many other countries, HIV/AIDS is still regarded as a disease afflicting the immoral sections of society, namely prostitutes and homosexuals. A woman shares how she received her positive HIV test results.

"I went there [to the hospital], and he grabbed me and he told me, he didn't even explain anything to me, nothing, he told me, 'You know what, you have AIDS ... I left and I began to cry ... that is how he told me."

[Maria]

Maria received her positive test results in a public space; her privacy was discounted. She also did not receive appropriate counseling or education about HIV/AIDS or how this would impact her health and well-being. After this incident, the participant reported that she did not want to know more about the disease. Most of the women in our study reported that they had little knowledge about the disease prior to their diagnoses. This woman felt as though she was handed a death sentence and for many months she isolated herself and stayed in her home, not sharing the news with anyone. She learned that the hospital was not a safe place. If women experience stigma from one of the few perceived spaces where they can receive support, where are they to go for care?

The process of women speaking out: "... just because I have this [HIV] doesn't mean that you can treat me that way."

While the majority of women indicated stigma from various sources including their families, friends, and from the community the most severe discrimination came from members of the medical profession. All 14 participants discussed some form of HIV-related discrimination and/or maltreatment, but only three women reported that they spoke out when they were treated poorly. However, this did not happen immediately, rather women discussed how this was a process and that they believe that they have the right to be treated fairly and receive nondiscriminatory medical treatment.

"When they discriminated against me in the hospital, I complained to the doctor. I told her 'Doctor they treated me this way, why? I do not have a disease that they can contract, they viewed me as though I were strange and they treated me bad, they would not change my sheets, they treated me different... I consider myself to be a <u>normal person</u>, I don't know why they treated me this way. Why did they discriminate against me?' This is what I told the doctor. I also told her that I think she should provide training to the nurses so that they are prepared ... because if a person is infected there is no reason why they [nurses] would become infected."

[Beatriz]

The same participant shares how she reacted when she was treated poorly.

"A nurse in particular treated me poorly. I asked her 'Why are you treating me this way? 'You are wrong,' I told her, I am not an object nor an animal for you to treat me this way. I am going to complain to the doctor'... she got an attitude with me, 'well complain then' she replied."

[Beatriz]

The next woman discussed her experience with speaking-up after being treated poorly by a nurse and was happy when she felt heard.

"I had a problem with a nurse who treated me bad during a gynecological exam ... I am the type of person that will complain when something is unjust ... I went to put in a complaint at the office. Before I left I told her 'look just because I have this [HIV] doesn't mean that you can treat me that way' ... Because not only can she do this to me but she can do this to others that come here also. We went to the nurse supervisor and she reprimanded her, I told her she is the one, right in her face, I said she is the one, and she reprimanded her."

[Monica]

This participant expressed how she has seen her friends treated and how she believes that PLWHA should be treated.

"For some of my friends that have died [of AIDS] they had them separated, just because they have HIV. It's like everything about them <u>stinks</u>, everything about them bothers the doctors and the nurses ... they need to have personnel that are kind at a minimum ... and acknowledge that they [PLWHA] are like any other person."

[Ana]

While some of the participants were able to speak up about maltreatment and stigma, many others were not. These quotes highlight the disconnect HIV-positive women experience, those that should be caring for them (doctors and nurses) who understand their illness are the ones that are stigmatizing them. It is unclear why some women felt that they had the right to speak up while others did not. The women stated that when they spoke up they felt empowered and some received an apology from the person they complained about, however, they all reported feeling upset and sad that they were treated negatively.

Discussion

HIV-related stigma continues to impact this pandemic and while our study was specific to Lima, Peru the experiences shared by the women we interviewed may likely resonate with women all over the world. To our knowledge, this is the first qualitative study documenting the experiences of stigma among Peruvian women living with HIV. Results from our study highlight women's perceived and actual experiences of stigma from healthcare providers (e.g., nurses and doctors). Women discussed a range of emotions though most were feelings of sadness, depression, anger, withdrawal and isolation. The women in our study spoke about feeling "marked", "different", "not human" and having others perceive them as "abnormal" or "an animal", which is a common experience for someone who has

internalized stigma (Goffman, 1963). While we cannot ascertain whether the women in this study were truly discriminated against, their recollection of experiences were vivid and painful. We highlight women's experiences with stigma not to vilify or condemn the healthcare system but rather to bring to light the need for education and to acknowledge the perception of stigma and maltreatment these women experienced.

HIV/AIDS is increasing in Latin and South America, especially among women (WHO, 2012). Data from these 14 women provide insight into their daily life struggles and about their experiences living with HIV/AIDS in an environment where the diagnosis is still highly stigmatized and associated with immoral and unethical behavior. It is possible that these women had expectations of a medical setting, like a hospital or clinic, to be free of stigma and discrimination and as a result the impact of the experiences they had had a greater negative effect compared to stigma they experienced from other sources. Whether or not the perceived stigma was exaggerated or not, it had a direct impact on clinical care. Many women resorted to staying within the confines of their homes in order to avoid "evil looks" or maltreatment from others, including avoidance of going to the doctor even in the face of death for fear of ongoing maltreatment. While speaking up about the maltreatment seemed to help some of the women feel heard it did not rectify the situation and undo the damage that was already done.

Worldwide, there is a dire need to develop interventions for HIV-positive women, especially when many women face various forms of marginalization including poverty, lack of health insurance, gender inequality, and class oppression (Rao & Valencia-Garcia, 2014). Future interventions, regardless of geographical location, need to take into account women's gender roles and power inequality in sexual relationships (Amaro & Raj, 2000; Gupta, 2000). Men's gender roles, their sexual risk taking behavior, and their specific prevention needs should also be addressed given that men play a significant role in the context of HIV risk and infection among Latinas on a global scale. Moreover, Li and colleagues (2009) examined HIV/AIDS-related stigma among service providers in China and found that in order for stigma reduction to occur we must address both individual attitudes and societal norms, stereotypes, and prejudice towards people living with HIV.

Stigma reduction can happen on two levels, the societal level or the individual level. Activists and policy makers can help remove institutional stigmas from government, business, or hospital policies (Corrigan & Kleinlein, 2005). Other ways of working to reduce stigma on the societal level would be to focus on microfinance programs to help demonstrate women's economic independence and worth in society, and ultimately uplift their status (Sen, 1995). On the individual level, researchers suggest several ways to reduce internalized stigma. First, information-based approaches can provide education and basic facts about HIV/AIDS. Second, contact between people living with and without HIV, and involving them in meaningful activities, can help to reduce stigma. Finally, helping teach people mechanisms to cope with the stigma they perceive and experience can help to reduce stigma (Allport, 1954; Brown, Macintyre, & Trujillo, 2003).

While this study is the first to elucidate the experiences of stigma among women living with HIV in Peru, there are some limitations to address. The sample was small and may not

adequately represent the experiences of stigma by other PLWHA who are women in Peru. Experiences with stigma may differ in more rural areas; some data suggests that stigma is likely worse outside of larger cities due to less exposure to and knowledge about HIV (Heckman et al., 1998). The sample was derived from women participating in an on-going health study and a self-selection bias may have occurred. Women who may have had weaker coping mechanisms or more severe experiences with stigma may have been less likely to have participated in the study. Therefore, the cases presented may have minimized the experiences with stigma among women in Peru. On the other hand, women who regarded themselves as marked or different may have perceived or translated ambiguous interactions with others as more stigmatizing.

It is also important to contextualize the timing of this study in relation to the availability of antiretroviral treatment. The Peruvian Ministry of Health established the National ART Program in May, 2004. Soon after, the Global Fund for HIV/AIDS, Tuberculosis, and Malaria began funding HIV-related programs in Peru. When the women in this study were interviewed in September, 2005, access to antiretroviral therapy was just beginning to increase, and few of the women in the study were on HIV treatment at the time they were interviewed. It is possible the discrimination of people living with HIV, particularly among medical providers, decreased in Peru as HIV infection became a treatable condition and not a near-universal death sentence. However, the stigmatization of people living with HIV persists even in the age of highly active antiretroviral therapy (HAART). We would hope that over time stigma of PLWHA has improved within the Peruvian medical community and globally.

Health care service utilization continues to be a challenge faced by many PLWHA across the globe. Early detection of HIV infection may have significant positive outcomes for both the individual and society such as early access to treatment and behavioral interventions and education to reduce the risk of transmission to others (Bonjour et al., 2008). We hope that the personal accounts of the women presented will shed light on their negative experiences, inspire researchers to tailor prevention messages and interventions, encourage ongoing education among healthcare providers, and motivate them to change practice in order to reduce stigma in this population.

Acknowledgments

We would like to thank the International AIDS Research and Training Program at the University of Washington. We would also like to thank the fourteen women who participated in this study, as well as Jorge Sanchez, Aldo Lucchetti, Rosa Infante, and the Impacta Clinic staff. We would like to acknowledge our research assistants, Wendy Radillo, Natividad Chavez, Maria Acosta, and Katheryn Conde.

References

Alarcon JO, Johnson KM, Courtois B, Rodriguez C, Sanchez J, Watts DM, Holmes KK. Determinants and prevalence of HIV infection in pregnant Peruvian women. AIDS. 2003; 17(4):613–618. DOI: 10.1097/01.aids.0000042973.95433.22 [PubMed: 12598782]

Allport, GW. The nature of prejudice. Oxford, England: Addison-Wesley; 1954.

Amaro H, Raj A. On the margin: Power and women's HIV risk reduction strategies. Sex Roles. 2000; 42(7–8):723–749. DOI: 10.1023/A:1007059708789

Berger, M. Workable sisterhood. Princeton, NJ: Princeton University Press; 2006.

Health Care Women Int. Author manuscript; available in PMC 2018 February 01.

Bonjour MA, Montagne M, Zambrano M, Molina G, Lippuner C, Wadskier FG, ... Tami A. Determinants of late disease-stage presentation at diagnosis of HIV infection in Venezuela: A case-case comparison. AIDS Research and Therapy. 2008; 5(1):6.doi: 10.1186/1742-6405-5-6 [PubMed: 18416849]

- Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006; 3(2):77–101. DOI: 10.1191/1478088706qp063oa
- Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma: What have we learned? AIDS Education and Prevention. 2003; 15(1):49–69. DOI: 10.1521/aeap.15.1.49.23844 [PubMed: 12627743]
- Cáceres CF, Mendoza W. The national response to the HIV/AIDS epidemic in Peru: Accomplishments and gaps—a review. JAIDS Journal of Acquired Immune Deficiency Syndromes. 2009; 51(Suppl 1):S60–S66. DOI: 10.1097/QAI.0b013e3181a66208 [PubMed: 19384104]
- Castro A, Farmer P. Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. American Journal of Public Health. 2005; 95(1):53–59. DOI: 10.2105/AJPH.2003.028563 [PubMed: 15623859]
- Chesney MA, Ickovics J, Hecht FM, Sikipa G, Rabkin J. Adherence: A necessity for successful HIV combination therapy. AIDS. 1999; 13(Suppl A):S271–S278. [PubMed: 10885784]
- Corea, G. The invisible epidemic: The story of women and AIDS. New York: Harper Collins; 1992.
- Corrigan, P., Kleinlein, P. The Impact of Mental Illness Stigma. In: Corrigan, P., editor. On the Stigma of Mental Illness. Washington, DC: American Psychological Association; 2005.
- Ezechi OC, Gab-Okafor C, Onwujekwe DI, Adu RA, Amadi E, Herbertson E. Intimate partner violence and correlates in pregnant HIV positive Nigerians. Arch Gynecol Obstet. 2009; 280(5): 745–752. DOI: 10.1007/s00404-009-0956-9 [PubMed: 19242706]
- Goffman, E. Stigma: Notes on the management of spoiled identity. New York: Simon and Schuster Inc; 1963.
- Gomez CA. Preventing HIV in U.S. women and girls: A call for social action. Womens Health Issues. 2011; 21(Suppl 6):S287–S294. DOI: 10.1016/j.whi.2011.07.012 [PubMed: 22055680]
- Gupta, G. Approaches for empowering women in the HIV/AIDS pandemic: A gender perspective. Paper presented at the expert group meeting on the HIV/AIDS pandemic and its gender implications; Windhoek, Namibia. 2000 Nov.
- Heckman TG, Somlaj AM, Peters J, Walker J, Otto-Salai L, Galdabini CA, Kelly JA. Barriers to care among persons living with HIV/AIDS in urban and rural areas. AIDS Care. 1998; 10(3):365–375. DOI: 10.1080/713612410 [PubMed: 9828979]
- Herek GM, Capitanio JP, Widaman KF. HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991–1999. American Journal of Public Health. 2002; 92(3):371–377. DOI: 10.2105/AJPH.92.3.371 [PubMed: 11867313]
- International Center for Research on Women. HIV/AIDS stigma: Finding solutions to strengthen HIV/AIDS programs. Washington, DC: International Center for Research on Women; 2006.
- Johnson KM, Alarcon J, Watts DM, Rodriguez C, Velasquez C, Sanchez J, ... Holmes KK. Sexual networks of pregnant women with and without HIV infection. AIDS. 2003; 17(4):605–612. DOI: 10.1097/01.aids.0000050785.28043.b9 [PubMed: 12598781]
- Lee RS, Kochman A, Sikkema KJ. Internalized stigma among people living with HIV-AIDS. AIDS and Behavior. 2002; 6(4):309–319. DOI: 10.1023/A:1021144511957
- Li L, Liang L, Wu Z, Lin C, Wen Y. Individual attitudes and perceived social norms: Reports on HIV/AIDS-related stigma among service providers in China. International Journal of Psychology. 2009; 44(6):443–450. DOI: 10.1080/00207590802644774 [PubMed: 20090857]
- Lin K, McElmurry BJ, Christiansen C. Women and HIV/AIDS in China: Gender and vulnerability. Health Care for Women International. 2007; 28(8):680–699. DOI: 10.1080/07399330701465010 [PubMed: 17729127]
- Link BG, Phelan JC. Conceptualizing Stigma. Annual Review of Sociology. 2001; 27:363–385. DOI: 10.1146/annurev.soc.27.1.363
- Marín, G., Marín, BV. Research with Hispanic populations. Newbury Park, CA: Sage; 1991. Ministerio de Salud. 2010. Retrieved from http://www.minsa.gob.pe

Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. Social Science & Medicine. 2003; 57(1):13–24. DOI: 10.1016/S0277-9536(02)00304-0 [PubMed: 12753813]

- Pulerwitz J, Michaelis AP, Lippman SA, Chinaglia M, Díaz J. HIV-related stigma, service utilization, and status disclosure among truck drivers crossing the southern borders in Brazil. AIDS Care. 2008; 20(7):764–770. DOI: 10.1080/09540120701506796 [PubMed: 18767210]
- Rajabiun S, Rumptz MH, Felizzola J, Frye A, Relf M, Yu G, Cunningham WE. The impact of acculturation on Latinos' perceived barriers to HIV primary care. Ethnicity & Disease. 2008; 18(4):403–408. [PubMed: 19157242]
- Rao D, Feldman BJ, Fredericksen RJ, Crane PK, Simoni JM, Kitahata MM, Crane HM. A structural equation model of HIV-related stigma, depressive symptoms, and medication adherence. AIDS and Behavior. 2012; 16(3):711–716. DOI: 10.1007/s10461-011-9915-0 [PubMed: 21380495]
- Rao, D., Valencia-Garcia, D. Stigma across cultures. In: Corrigan, PW., editor. The stigma of disease and disability: Understanding causes and overcoming injustices. Washington, DC, US: American Psychological Association; 2014. p. 283-296.
- Reidpath DD, Chan KY. A method for the quantitative analysis of the layering of HIV-related stigma. AIDS Care. 2005; 17(4):425–432. DOI: 10.1080/09540120412331319769 [PubMed: 16036227]
- Sen, A. Inequality Reexamined. Oxford, NY: Oxford University Press; 1995.
- Shedlin MG, Shulman L. Qualitative needs assessment of HIV services among Dominican, Mexican and Central American immigrant populations living in the New York City area. AIDS Care. 2004; 16(4):434–445. DOI: 10.1080/09540120410001683376 [PubMed: 15203412]
- Taylor, SJ., Bogdan, R. Introduction to qualitative research methods: A guidebook and resource. Hoboken, NJ, US: John Wiley & Sons Inc; 1998.
- UNAIDS. AIDS scorecards overview: UNAIDS report on the global AIDS epidemic. Geneva, CH: UNAIDS; 2010.
- UNAIDS & UNIFEM. The gender dimensions of HIV/AIDS challenges for South Asia. New Delhi, India: UNAIDS South Asia; 2004.
- USAID. Peru: HIV/AIDS health profile. Washington, DC: USAID; 2010.
- Valencia-Garcia D, Starks H, Strick L, Simoni JM. After the fall from grace: Negotiation of new identities among HIV-positive women in Peru. Culture, Health & Sexuality. 2008; 10(7):739–752. DOI: 10.1080/13691050802213563
- Vanable PA, Carey MP, Blair DC, Littlewood RA. Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. AIDS and Behavior. 2006; 10(5):473–482. DOI: 10.1007/s10461-006-9099-1 [PubMed: 16604295]
- Wong V, Wong L. Management of stigma and disclosure of HIV/AIDS status in healthcare settings. Journal of Health Organisation and Management. 2006; 20(2):95–114. DOI: 10.1108/14777260610661501
- World Health Organization. HIV/AIDS and other STIs: Data on the size of the HIV/AIDS epidemic. 2012. Retrieved from http://apps.who.int/gho/data/node.main.618?lang=en
- Wyatt GE, Gómez CA, Hamilton AB, Valencia-Garcia D, Gant LM, Graham CE. The intersection of gender and ethnicity in HIV risk, interventions, and prevention: New frontiers for psychology. American Psychologist. 2013; 68(4):247–260. DOI: 10.1037/a0032744 [PubMed: 23688092]
- Zhou YR. Help-seeking in a context of AIDS stigma: Understanding the healthcare needs of people with HIV/AIDS in China. Health & Social Care In The Community. 2009; 17(2):202–208. DOI: 10.1111/j.1365-2524.2008.00820.x [PubMed: 19040695]