

Stigma Related to HIV among Community Health Workers in Chile

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Abstract

Purpose: When healthcare workers have stigmatizing attitudes toward people living with HIV it may lead to discriminatory behavior that interferes with prevention, treatment, and care. This research examined the HIV-related stigmatizing attitudes reported by health workers in Santiago, Chile.

Methods: The study used focus group data from the first phase of a larger study to develop and test a HIV prevention intervention for Chilean health workers. Ten focus groups were conducted with health workers in two communities in Santiago, Chile. Content analysis was used to analyze the data.

Results: Two central themes emerged: Societal stigma and discrimination towards people living with HIV and healthcare system's policies related to HIV. Both inaccurate fears of transmission among the general public and Chilean Health workers and societal prejudices against homosexuals contributed to stigmatization and discrimination.

Conclusions: Health workers did not recognize their own stigmatizing attitudes or discriminatory behaviors, but their discussion indicated that these behaviors and attitudes did exist. Healthcare system issues identified included problems with confidentiality due to the desire to inform other health workers about client HIV status. Health workers must be sensitized to the current stigmatization and misinformation associated with HIV and its negative impacts on persons living with HIV and the general community.

Implications: All clinical and non-clinical workers at community clinics need mandatory education for HIV prevention that focuses on changing attitudes as well as sharing knowledge. Also, the Chilean law protecting people living with HIV and the confidentiality of their medical care needs to be publicized, along with guidelines for its enactment in clinics and other health facilities.

Keywords: Chile, community, health workers, HIV, stigma

Introduction

The HIV pandemic has severely affected people all over the world. In Latin America, more than 1.7 million people are estimated to be living with HIV and 100,000

new cases were reported in 2007. While this region has often been overlooked, there is now a growing awareness within the international community that the HIV epidemic in Latin American countries demands more attention than it has received in the past [Joint United Nations Programme on HIV and AIDS (UNAIDS), 2008]. Health workers are considered key players in the prevention and management of HIV (Hentgen, Jaureguiberry, Ramiliarisoa, Andrianantoandro & Belec, 2002) and they have a crucial role in fighting

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the steady increase in the prevalence of HIV infection (Bluespruce *et al.*, 2001; Ezedinachi *et al.*, 2002).

Global research has shown that health workers have not achieved their potential as HIV prevention leaders (McCaughey, 2006). However, the scarcity of qualitative research concerning HIV related stigma in Latin America indicates that more research must be conducted in order to understand this phenomenon and to develop strategies to overcome it. The few qualitative studies that exist have been conducted in Peru, Costa Rica, Mexico and Brazil (Lama, 2000; Aggleton, Morrison-Melke & Bronfman-Pertsovsky, 2003; Infante-Xibille, Zarco-Mera, Cuadra-Hernandez, Morrison-Melke & Bronfman Pertsovsky, 2004; Frasca, 2005; Abadía-Barrero & Castro, 2006). These studies reported that HIV-related stigma is one of the major barriers to fighting HIV in Latin America because fear of stigma often prevents people from accessing testing and treatment. In addition, health workers were also mentioned as perpetrators of HIV stigma. In this literature review, no qualitative research on this topic was found in Chile. It is therefore evident that Chile, like other Latin American countries, needs to investigate further the increasing problem of HIV and the attitudes of Chilean health workers that affect HIV prevention and AIDS care.

Stigma has marked the history of HIV and AIDS, leading to suffering and human rights' violations against people living with HIV (DeBruyn, 2002; Parker & Aggleton, 2003). In general, stigma is characterized by the rejection of a person with a specific mark or sign (e.g., age, sexual orientation, race, religion) that is not accepted according to social-moral standards (Goffman, 1986; Kass, Faden & Fox, 1992). HIV is an example of a disease that generates stigma (Foreman, 2003). The misunderstandings, myths, and fears of the disease, as well as negative social attitudes towards people living with HIV and the behaviors associated with transmission, all promote stigma relating to HIV. In this paper, *stigma* is used as an inclusive term referring to stigmatizing attitudes and discrimination toward people living with HIV. Individual and social factors play a central role in the continuation, enactment, and experience of stigma and its effect on discrimination (Guajardo, 2000). This situation is worse in a community where health workers provide trusted sources of health information and yet are not appropriate role models for effective HIV prevention (Cianelli, 2003; Rahlenbeck, 2004; Ferrer *et al.*, 2009).

The Chilean healthcare system is a mix of public and private organizations for care. Approximately 70% of Chileans are enrolled in the public sector. Of these, over 45% are classified as low-income, which severely limits their healthcare options [Ministerio de Salud (MINSAL), 2005; FONASA, 2006]. The Chilean

Ministry of Health (2009) has reported 18,552 confirmed cases of HIV since 1984, and it is estimated that this number will rise to 38,000 once unreported cases have been included.

The first Chilean law related to HIV (No. 19.779) was promulgated in 2001 to protect people living with HIV (Ministerio de Justicia, 2004). This law guarantees equality without discrimination of any nature, as well as the implementation and evaluation of healthcare policies for prevention, diagnosis, and treatment (Vivo Positivo, 2004). By law, Chileans diagnosed with HIV who are enrolled in the public system are guaranteed access to healthcare. This access includes coverage for highly active antiretroviral therapy, medical care, blood tests, and hospitalization (MINSAL, 2005). In contrast, the private health sector provides limited coverage of expenses related to HIV.

In spite of this law, situations of stigma still exist in Chile. Chilean people living with HIV have reported high levels of stigma among health workers (Vidal, Carrasco & Pascal, 2004; Vidal, Carrasco & Santana, 2005). This finding is particularly alarming because of the need for Chilean health workers to be effective and their potential impact as HIV prevention leaders. While available studies of people living with HIV serve to validate the existence of stigma towards them from health workers, little information is available on the underlying causes of these beliefs and behaviors. In Chile, stigma towards people living with HIV is a result of inadequate knowledge in the general population (Arredondo *et al.*, 2000), and beliefs of HIV linked to commercial sex work, multiple sexual partners, and homosexuality; all of which are considered socially reprehensible by Chilean society. Together with inaccurate media messages, this prejudice and misinformation have resulted in erroneous beliefs (Rajevic, 2000; Cianelli, Ferrer & McElmurry, 2008), which impede effective prevention of the disease. Therefore, the purpose of this study was to understand the attitudes and experiences that Chilean Health Workers have with HIV-related stigma in the community where they work.

Methods

Design

This study was the first phase of a larger study to adapt a HIV prevention intervention for Chilean health workers and then test its effectiveness for improving their HIV prevention knowledge, attitudes, and practices (NIH/Grant R03 TW006980). The first phase of the study was a qualitative investigation of Chilean health workers HIV prevention needs. This paper

reports on the stigma-related qualitative findings of Phase I.

Qualitative research is focused on the quality of entities, processes, and meaning, emphasizing the socially constructed nature of reality (Denzin & Lincoln, 2000; Patton, 2002). It is particularly useful to understand a phenomenon about which little is known, by obtaining a detailed view from the participant's perspective (Creswell, 2007).

Focus groups were selected as the data collection method for this study. Focus groups provide insight into the shared norms, values, and experiences of a particular relatively homogeneous group. The researcher obtains information from guided group discussions among participants to disclose an aspect of the phenomenon that is less accessible. Focus groups give rich information about participants' common experiences (Freeman, O'Dell & Meola, 2001; Van Eik & Baum, 2003; Duggleby, 2005).

Qualitative content analysis was used to identify and describe the major themes and concepts that emerged from the focus group discussions. Content analysis is a method used to recognize, code, and categorize patterns from text data (Patton, 2002). With this analysis, the researcher establishes a set of precise categories that allow different coders to reliably identify the same codes using the same data. The purpose of the content analysis was to search for cultural symbols that were included in large categories or domains, looking for the qualities they shared that were similar.

Setting and Sample

Participants were recruited from nine community clinics that provided a broad range of health services (e.g., maternal, child, adult, dental) in two communities in southeast Santiago, Chile. These large communities were chosen because they are two of the communities in Santiago most affected by HIV. The selected communities are comparable in terms of socio-demographics and include socially disadvantaged neighborhoods, low household incomes, low levels of education, and a high incidence of violence, substance use, and HIV (MINSAL, 2009).

Recruitment of participants at the community clinics consisted of posting study flyers and having trained members of the research team on site to personally invite Chilean health workers to participate in the project during their regular work day. Prior to recruitment, permission was obtained from the nine clinic administrators, who also provided time for the Chilean health workers to participate in the study.

To be included, health workers had to be working at least 22 hours per week in one of the two communities

selected, and give voluntary consent to participate in the study. We used Talashek, Jere, Mbaba, McCreary & Norr's (2007) definition of health worker: a *healthcare worker* is any individual employed in the health system, with direct, indirect, or no patient contact. This definition was selected because community members view all health system employees as sources of health-related information.

Data Collection

Eight focus groups with a total of 84 participants (eight to 10 participants per group) were led by facilitator trained by the principal investigator. Before each focus group, refreshments were provided. This broke the ice and provided time to talk informally with the facilitator. At the beginning of each focus group, the facilitator read the consent form to the Chilean health workers, asked them to follow along with the reading, and informed them to ask any questions they may have before agreeing to be in the groups. Once they agreed to participate, the facilitator asked them to sign the consent form. This study was approved by the Institutional Review Board (IRB) from the University of Illinois at Chicago and by the IRB from the Universidad Catolica de Chile.

The facilitator conducted the focus groups in Spanish using a semi-structured discussion guide. Questions were developed by native Spanish speakers. This guide included several questions related to stigma, such as: *What is the health workers' risk of HIV infection at work? What can health workers do to reduce this risk? Do you think that negatives attitudes to people living with HIV are present among health workers? How do health workers provide care to people who come to the clinic to ask about STI or HIV prevention?* Probes were used for questions that were not clearly discussed by participants. Discussions lasting between 60 and 90 minutes were recorded using digital technology to assure clarity of responses to facilitate the accuracy of transcriptions.

Data Analysis

Focus groups were audiotaped, transcribed, and translated into English by the bilingual team using the consensus method (Jones, Lee, Phillips, Zhang & Jaceldo, 2001). Data were imported into N6 (NUD*IST 6) to facilitate data storage, coding, and retrieval.

Transcripts were coded by three investigators, all of whom identified broad themes. As part of this process, sub-categories were developed for each theme and a codebook was developed, with a corresponding coding sheet to assure reliability. Three transcripts were separately coded and then reviewed by two investigators. In addition, one external reviewer coded the same three focus groups. Comparison of coding was done to identify similarities and differences. The inter-rater

agreement coefficient was 0.95. Differences between the coders were discussed and resolved by discussing the meanings of the categories and themes with the quotations from participants. Modifications were made to the codebook and coding sheet to incorporate the suggestions until full agreement was reached on the appropriate categorizations and themes (Krippendorff, 2004).

Results

Demographic Participant Characteristics

The mean age of participants was 38.0 years old (SD = 9.1). Seventy percent of the participants were women. Forty-six percent held a baccalaureate degree (nurses, midwives, physicians, nutritionist, and psychologist). The remaining 54% had completed high school and training courses (auxiliary nurses, administrative personnel, cleaning personnel, and guards). All the participants had health insurance provided by their employer.

Major Themes

Two major themes related to stigma emerged from the qualitative analysis: *Societal stigma and discrimination towards people living with HIV and healthcare system's policies related to HIV.*

With respect to societal stigma and discrimination towards people living with HIV, Chilean health workers did not recognize personal stigmatizing attitudes or discriminatory behaviors. However, the focus group discussions indicated that these behaviors and attitudes did exist. Fear was the most common feeling expressed by Chilean health workers and was mentioned in all of the focus groups: *It is like people still have fear. They say the name AIDS to them and the people are afraid. Or if a person has HIV, it's like they push them away.* Fear was also related to the fact that AIDS is seen as a fatal illness that will destroy the person. *I think that they associate AIDS with death or AIDS means that one is going to die right away.*

The Chilean health workers discussed the general public's fear as leading to rejection and isolation of people living with HIV, or those who are assumed to have the disease. The fear associated with HIV not only affects the individual but also the family. One health worker said:

It's your family that probably prefers you to stay silent, so hidden because, to have a brother or an uncle or a cousin with AIDS, the rest of your co-workers or people around you probably are going to stigmatize you.

They also expressed personal fear of HIV, especially the personal risk of occupational exposure. This was related to a lack of confidence in standard precautions as well as their inconsistent use. They described inconsistent and inadequate use of standard precautions and connected it to attempts to identify persons likely to be infected with HIV based on their own stereotypes. As one health worker explained, healthcare workers might have greater concern than the general public:

The risk must be similar, but I think that it is very different to work with body fluid from a person who potentially has AIDS, than to work in a restaurant peeling potatoes, that is to say the person who is peeling potatoes is not exposed to the virus.

Chilean health workers considered that clients should tell them in advance if they were HIV positive, but they realized that because of stigma, clients might conceal their HIV status.

After I treated a wound, the woman told me she has AIDS. It really had an impact on me, and I turned pale. My colleague asked me what happened. It's that she is telling me she has AIDS. But you know how you—it can be transmitted, right? Yes, I said. But the impression that I had ... because this woman should have already told me quietly that she has AIDS and what is needed here is education; there is a lack of education for the community.

Another Chilean health worker mentioned how this fear affects his work regardless of the use of standard precautions: *I am a dentist and when extracting a molar, if you tell me that this person has AIDS, I would be afraid, and [despite] all the methods [standard precautions] and all that I can do.* Fear can also trigger erroneous behaviors in terms of the use of standard precautions and procedures related to providing care.

Well, we take precautions when we have contact with infected blood, and always if we know that it is a patient with AIDS . . . we use two pairs of gloves and separate the instruments, from those we use with other patients.

Because of the fear that health workers have when providing care to people living with HIV, they devised a strategy to help them decrease their anxiety. This strategy involved informing colleagues when a person living with HIV is being treated in the community clinic. This can be done orally or by notations on the outside of the chart.

In fact, if one patient arrived [to the health care center] and I find out he is HIV positive, and he doesn't tell the other Chilean health workers, I have to inform them. The

objective that we also have is to know with whom we are working.

Homosexuality continues to be strongly stigmatized in Chile. During the focus groups, stigmatizing views of homosexuality were discussed. An example of this was the use of slang words with negative connotations used to refer to homosexual men, increasing stigma towards this group. Society continues to see homosexuals as the most important vector for HIV transmission: *The most important thing, I think, is that (Chilean health workers think) only homosexuals have AIDS. Not all people... they don't talk about them like people. They talk about the fags or the gays.*

Although in the last few years there has been more discussion about male homosexuality in Chile, this topic continues to be full of myths: *There are a lot of myths and a lot of cultural things that interfere and at the same time justify high-risk behaviors. The myths associated with infected persons are mostly homosexuals. Concerns about the judgmental attitudes in Chile toward homosexuals and people living with HIV were expressed in the following comment:*

It has to do with judging the attitude of others. We are not judges, and this is what we have to start doing, because it's easy to say (that we will not judge)...but in practice, they keep doing the same stupid things all the time, there has not been a change in society, they treat them [people living with HIV] horribly.

Chilean health workers reported stigmatizing attitudes and rejection of people living with HIV similar to those held by society in general. *They know that they are not contagious, but anyway they feel this same distance for the person. An even more negative attitude expressed was: That one, I hope he explodes from AIDS, because he went to bed with whomever he wanted. Some Chilean health workers expressed more ambivalence or mixed feelings and reactions to people living with HIV. One of them said:*

I have a close experience of a family which is burdened by the disease, and yes, we have mixed feelings, compassion, anger, of course the person was asking for it, and also we say, Poor person—what is he or she doing now? ...and there are a mix of things.

Chilean health workers realized that their colleagues discriminate against people living with HIV and that this could affect Chilean health workers themselves. One participant pointed out: *And it made me think, for example, if I had HIV, and thinking about my colleagues, maybe I wouldn't continue (working) in this center.* Another health worker recognized how painful disclosure might be in the face of such discrimination,

And to tell this, for example, if I were to tell Juanita and say listen, Juanita, you know that (I have HIV), because it would be something complicated. It's certain that we can talk nicely [about HIV] but in the critical moment [for example, if I have HIV], things change.

Healthcare System's Policies Related to HIV

The Law in the Prevention of HIV (No. 19.779) has been in effect in Chile since 2001. Despite this, few Chilean health workers knew of its existence. Chilean health workers identified the health system policies as responsible for perpetuating stigma towards people living with HIV. They were especially concerned about policies related to maintaining confidentiality during referral and HIV testing. They pointed out that confidentiality issues were related to the way HIV testing and treatment were handled. Persons who want to take an HIV test must follow several steps that force them to go from their local community clinic to a referral hospital where they must go to a clinic for sexually transmitted infections. During this referral process, confidentiality is an issue since these clinics are located in the community where people know each other. One health worker mentioned,

It's that this exam is confidential, then I need a referral, the referral is sent to the emergency community clinic service to scheduling, in the end the whole community will know that the person wants to have an HIV test because she has a risk consult, then after that they must go to the hospital to the STI Clinic, and show this referral. A lot of people don't do it for that reason.

Chilean health workers also identified many confidentiality concerns regarding the way records were handled. One participant said: *The patient's record goes to the foot of the bed and it is highlighted in red, underlined. ... You put AIDS, and then what happens is that all the world (can see).*

Even when a patient protested, one health worker reported that the staff was not responsive to the confidentiality issue,

They put the diagnosis on the cover, and the man begged us not to put the medical diagnosis. So for the physician, it was very difficult not to put it. We asked him to put that it was only tuberculosis, but he said no, if he couldn't (put the correct diagnosis) he wouldn't do it (complete the form). And we had to go to another physician who could maintain the confidentiality of the diagnoses.

Finally, Chilean health workers also felt changes were needed in the policies specific to continuing education about HIV to allow them to be trained in special aspects related to the disease. They acknowledged that they shared the same lack of knowledge about HIV that

leads to the stigmatizing attitudes of the general public. They felt that this lack of knowledge was perpetuated by the absence of continuing education programs about HIV, especially for non-professional staff. One health worker affirmed,

People that are not professionals, or people that have limited access to information, have a lot of fear of HIV. That's what happens to us, everybody, probably when we had the first contact to the news of HIV's arrival to the hospital. Then if you don't know what it means, how it is transmitted, you are going to be very, very afraid, and that means you reject. If the human being naturally has fear, the fear makes him behave aggressively and destroy what he doesn't know.

Discussion

This focus group study of 84 Chilean health workers contributes to the current state of knowledge by providing an in-depth qualitative analysis of the experiences and perspectives that Chilean health workers have with HIV-related stigma in the healthcare community. Participants recognized that stigmatization against people living with HIV is present among Chilean health workers. They viewed HIV stigmatization as deeply rooted in both societal attitudes towards people living with HIV and the healthcare system's policies related to this disease.

These findings are congruent with previous research documenting that stigmatization is an issue among health care workers (Cianelli, 2003; Talashek *et al.*, 2007; Ferrer *et al.*, 2009). Fear of contracting the disease and stereotypes related to HIV have been shown to be the primary causes of stigma towards people living with HIV (Ferrer, Issel & Cianelli, 2005). Chilean health workers fears about HIV also fostered their incorrect use of standard precautions, which is consistent with what was observed by Ferrer *et al.* (2009) in these same Chilean community clinics. In this study, healthcare workers reported being afraid to tell their co-workers their personal serostatus due to fear of discrimination and isolation in their workplace, a finding that is congruent with the study by Alves and Ramos (2002). Stigma is a complex phenomenon and as suggested by Foreman (2003), if this phenomenon persists, it will cause psychological, physical, social and spiritual problems for the increasing number of persons living with HIV, and these problems will continue to be a barrier to effective prevention and treatment. Health workers' continued use of heightened precautions for people living with HIV is likely to increase stigmatization and contribute to the clients' perception of discrimination (Carmona & Del Valle, 2000; Vidal *et al.*, 2004; Vidal *et al.*, 2005).

This study had several limitations. The health workers were from community clinics, so these findings regarding stigma, discrimination, and inconsistent practice of standard precautions may be unique to community clinics. In community clinics, treating a person known to be living with HIV is rare, and the exaggerated precautions taken may not occur in settings where healthcare workers have more experience with HIV. The study is also limited because it includes the views of only a small number of health workers in only 10 clinics. More research is needed related to HIV stigma, especially since this is the first study conducted in Chile that explored this phenomenon among Chilean health workers.

Implications

More than 20 years have passed since the first case of HIV was identified in Chile, and multiple campaigns by the national government and other organizations have been implemented. However, HIV-related stigma continues to occur within the Chilean healthcare sector, the segment of society that should be the most informed about HIV and the least stigmatizing in its attitudes. Chilean health workers must be sensitized to the current stigmatization and misinformation associated with HIV, and how that stigma negatively affects the lives of people living with HIV.

Another important finding of this study is the recognition that all workers at community clinics need mandatory education for HIV prevention, regardless of their job category. Chilean health workers need interventions that will help them increase their knowledge, reduce their stigmatizing attitudes, increase their comfort in talking about HIV prevention, and reduce the risk of HIV infection in their work and personal lives. Programs to help individual workers deal with these issues should be integrated into health workers' initial training and ongoing support for HIV prevention.

There are no requirements for continuing education specifically related to HIV in Chile. Therefore, Chilean health workers can go through their entire professional careers without receiving HIV in-service education or knowing the importance of protecting the identity and confidentiality of their clients. The situation is even worse for administrative personnel, security, and cleaning staff, who are not required to have any continuing education.

Our results also indicate a clear and urgent need for system-wide changes in healthcare policy and practices to protect confidentiality of medical information, including diagnosis and treatment of HIV. Although Law No. 19.779 was approved in Chile in 2001 to specifically address confidentiality, the mechanisms of implementation have not been adequate. An example of this is the continued practice of segregating services

for HIV, which increases issues related to lack of confidentiality and access to care, and stigmatizes clients seeking testing and treatment services (Muula, 2005). As the study found, it is important for the Chilean Ministry of Health to provide mandatory HIV training for Chilean health workers to ensure that workers at all levels understand the Law and are provided with specific guidelines to protect clients. This knowledge is needed not only by professional Chilean health workers, but also for all personnel who encounter or discuss sensitive and confidential patient information.

The community clinic is uniquely important because they are gatekeepers to specialized services for HIV testing and care. Interventions focused on both knowledge and attitude change for Chilean health workers are needed in both their initial training and continuing

education, and all levels of workers should be included. Efforts to expand awareness and enactment of Chilean laws protecting people living with HIV in daily practice are also needed. Together, these are important first steps to establishing non-stigmatizing and non-discriminatory care for all.

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