

Barriers to HIV testing in Guatemala: A Qualitative Study

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Abstract:

Background: Early detection and treatment decreases HIV transmission rates and leads to risk reduction in those who are diagnosed. HIV-infected Guatemalans typically present with late-stage disease. **Objective:** We employed qualitative methods to explore barriers to HIV testing in Guatemala. **Methods:** In depth, qualitative interviews were conducted in an HIV testing and treatment facility in Guatemala City. These were analyzed using the methods of Grounded Theory. **Results:** Four major barriers impeded HIV testing in our subjects: psychological factors, stigma/discrimination, gender roles/machismo, and systemic barriers to care. Many of our patients' fears were grounded in a reality of discrimination, while the systemic problems of the healthcare system reflected misunderstandings and fears on the part of healthcare workers. **Discussion:** Our findings are consonant with the international literature. Our narrative suggested potential inter-

ventions; presenting HIV testing as a way to “save one’s life” instead of an “automatic death sentence” might foster HIV testing and earlier diagnosis.

Background

The benefits of HIV treatment for both individual patients and public health are now well established, yet many patients continue to present late for care.¹ Late presentation is a clear risk factor for death. One Spanish study found that 12 per cent of late presenters died within three months of diagnosis.² Why individuals present later for testing – and how to get HIV-infected persons in for testing and treatment – are key issues in the public health agenda. Easing barriers and facilitating access to HIV testing can lead patients to earlier diagnosis and treatment, which can in turn lower transmission rates, increase HIV treatment using HAART, and lower HIV-related mortality.

There is an extensive literature in diverse populations looking at factors that either facilitate or serve as barriers to voluntary HIV counseling and testing (VCT). Spielberg and colleagues have conceptualized these factors into three general categories: individual beliefs, systemic policies and programs, and testing technology/counseling options.³ Individual beliefs that impede testing include: believing that one is not infected or at risk, fear of the HIV diagnosis, fear of stigma or discrimination, and lack of knowledge regarding HIV and HIV testing.⁴⁻⁶ Structural factors impeding VCT include: not having health insurance or a regular medical provider⁷, lack of access to HIV testing¹, not being offered routine testing⁶, scarcity of human resources⁸, and lack of outreach to at-risk groups.⁹ Characteristics of the testing/counseling process that are thought to encourage testing include: no cost testing, the use of

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rapid oral tests, and confidentiality of VCT process.^{9, 10}

Little has been published regarding barriers to VCT in Guatemala. One qualitative study of 30 male clients of female sex workers looked at barriers to risk reduction. Many men chose not to use condoms because they felt they could assess their partner's HIV risk and felt reassured by the existence of a public HIV/STI clinic for sex workers.¹¹

Given the lack of specific information about VCT barriers and facilitators in Guatemala, we undertook this study to understand the barriers to HIV testing in Guatemala. We employed qualitative methods to generate hypotheses that might guide practical responses and further research. We hoped to develop new strategies to encourage VCT.

Methods

Setting

The study took place at the Clinica Familiar, an urban HIV specialty clinic associated with the Hospital General San Juan de Dios in Guatemala City. The clinic provides both inpatient and outpatient HIV specialty care. Inpatient care is provided at the Hospital General San Juan de Dios, one of Guatemala's two national hospitals.

Methodology

Semi-structured qualitative interviews were conducted among individuals attending the clinic's outpatient testing and treatment center.

Eligibility and Recruitment

All adult patients at the clinic who were capable of providing consent were eligible for the study. The study contained two groups. One cohort consisted of HIV positive patients recruited from the waiting room by clinicians and HIV counselors at the Clinica Familiar; the second cohort consisted of patients of unknown HIV status who are coming to the clinic to be tested. Patients verbally consented to be interviewed and taped. No identifying patient information was recorded and the interviews were conducted without access to patient medical records. Interviewing continued until no new themes were uncovered (theoretical saturation).

Content of the Interviews

Interviews were semi-structured and were guided by the following questions: 1) Why did you choose to come in for an HIV test? 2) Is there anything that could have helped you come in sooner for an HIV test? 3) When was the last time that you saw a healthcare provider? Did they recommend that you come in for HIV testing? 4) What do you know about treatment for HIV? 5) Do you know any specific groups that are at-risk for HIV? Do you belong to one of these groups? 6) How far did you have to travel for your HIV test? How much does your travel to the clinic cost? Will it interfere with your ability to return, if necessary?

Interviews were conducted in Spanish. They were audiotaped and transcribed. All identifying data except for gender was removed from the audiotapes and transcribed text.

Analysis

Following the qualitative research method (coding) outlined by Auerbach and Silverstein, the interviews were independently read by three people and reviewed for common and repeating themes.¹² The themes were then grouped into broader conceptual categories (theoretical constructs). Each reader combed through the interviews for relevant quotes for each theoretical construct, which were then further organized into subcategories based on the repeating themes. Psychologists at the clinic who had not participated in the analysis reviewed the final narrative and offered additional comments on the identified themes.

Ethical Concerns

This study was approved by the Research Committee at the Hospital General San Juan de Dios and the Committee on Clinical Research at Albert Einstein College of Medicine.

Results

Description of the Subjects

Twenty-three interviews were conducted. 15 of 22 subjects (68%) were women.

The terrible triad: Misconceptions, Fear, Denial

Interviewees reported a number of misconceptions concerning HIV transmission, progression,

diagnosis, and treatment. Individuals expressed confusion regarding modes of transmission of HIV: some believed the virus could be carried and transmitted by mosquitoes, and many told of family and neighbors who thought HIV could be passed on by touching or sharing a water bottle with an infected person.

What scared me were the mosquitoes, because they would sting me, and I would say “No! Now they’re going to sting my children!” (Interview 1, female)

People say that someone can be contaminated (with HIV) by talking or being near others with the disease. (Interviewee 11, female)

[A friend who frequents prostitutes] is called “sidoso” (sufferer of HIV/AIDS) in his household. His sisters look down on him. They won’t share a glass of water with him. If they’re drinking something, they don’t want to give him any. (Interviewee 11, female)

Generally, interviewees stated that sex workers, homosexuals, and individuals with many sex partners were at heightened risk of contracting HIV, but individuals who did not belong to those groups – including sex partners of people within those groups – did not necessarily have heightened risk for contracting HIV.

People think that [HIV] only strikes homosexuals, or people who work as...I think they call them “servidoras” (sex worker), and they say: “They’re not going to give it to me.” (Interview 1, female)

Progression and treatment of HIV were also areas of misconceptions among interviewees. Many individuals were confused regarding the course of HIV infection; some appeared to doubt that “portadores” (carriers) could transmit the disease without it seriously affecting them.

The truth is, I only know that it’s a sickness you get through physical contact, either sexually or with a needle or whatever. The idea I had was

this: that’s what they call HIV, and yes, it’s a type of illness, and there is a carrier of HIV. I have doubts about that. For a person who is an HIV carrier, how much time does it take for the disease to develop? (Interviewee 12, female)

You can have these people who take the test: it comes out positive; they don’t feel anything different; and they say “I’m not sick.” (Interviewee 15, female)

With respect to treatment, seropositive interviewees expressed a common sentiment: before receiving a positive test, they believed antiretroviral drugs and other forms of HIV care were either too expensive or too difficult to obtain in Guatemala.

[My husband] told me: “No, I don’t believe that (we have HIV) because for that illness, they say that there is no medicine, and if there is medicine I’ve been told it is expensive.” (Interviewee 9, female)

Before I didn’t know anything about treatment (for HIV), and thought that there’s no cure. But yes, with treatment one can have a better life. You can live longer, but before I didn’t know there was medicine. (Interviewee 13, female)

These misconceptions contributed to a general fear of HIV. The greatest fear regarding HIV was that contracting the virus would result in a prompt and painful death.

A person’s afraid of getting tested (for HIV)...because it was my thinking that if someone’s sick, that person is going to die. That was my thinking – that they were going to tell me I am sick and I’m going to die later. (Interviewee 13, female)

Individuals reported a correlated concern: HIV-related illness or death would mean they could not care or provide for children and other family. Most interviewees also expressed a fear that an HIV diagnosis would destroy one’s life in myriad ways. Rejection by family, friends, neighbors, or a significant

other; loss of one's job or livelihood; discrimination against one's children or family; despair regarding the possibility of future prospects or relationships were among the negative consequences of an HIV diagnosis.

Because if I tested positive...I don't know, maybe I wouldn't have been able to continue with my family. (Interviewee 1, female)

Where I work...they want to know: why do I go to the hospital? And I can't say, because look, things have happened; I've been fired from my job (for having HIV). (Interviewee 7, female)

I'm afraid for my children, because now all the world is saying I have [HIV]...they're just kids, they're starting out, and other people have started to look down on them. (Interviewee 1, female)

I cannot have children because I cannot have a spouse; it scares me because... why should a man fall in love with me and he is (HIV) negative and I'm capable of spreading it to him? (Interviewee 22, female)

For interviewees who were being tested for their HIV status, these remained legitimate fears; for seropositive interviewees, these fears contributed to them not coming in for testing earlier.

Both misconceptions and fear fed a sense of denial that was common amongst interviewees: they could not be at risk of contracting HIV. Because they did not belong to a group associated with a higher risk of contracting the virus (sex workers, homosexuals, individuals with many sex partners), they did not consider themselves to be at risk.

People said the woman (my first husband was sleeping with) had AIDS...Yes, I knew. People told me but I didn't believe it. Until I saw with my own eyes I didn't believe it. But it happened. (Interviewee 15, female)

[My husband] went to lots of towns because he worked in highway construction and he'd go all over Guatemala...but look, no, I didn't suspect anything, well, with him I didn't know, right?

And it never crossed my mind that he had [HIV]. (Interviewee 9, female)

Interestingly, few interviewees asked sex partner(s) if they were engaging in behavior the interviewees considered risky. Multiple individuals, especially females living with their children, reported that they had not been sexually active for many years and thus did not consider themselves at risk.

Discrimination/Stigma

Nearly all interviewees indicated an enormous amount of discrimination and stigma associated with an HIV diagnosis. Seropositive interviewees reported multiple instances of termination of employment and ostracism from family because of their status as "sidosos" (sufferers of HIV/AIDS). Individuals stated that if they lost weight or suffered multiple illnesses, neighbors or coworkers would suspect they were HIV-positive, and would avoid them.

If people know that someone has HIV, they don't want to be near him, or talk with him, or shake hands with him. That's the problem here in Guatemala. (Interviewee 6, Male)

It's very difficult for a normal person to accept someone with AIDS, I think, yes. There's a lot of discrimination because of this in Guatemala. There's an expression people use: "You are sidoso," and that's like saying "you might have AIDS"...you're the worst, you're bad, trash. (Interviewee 20, male)

Virtually all of the HIV-positive interviewees only shared their status with a spouse, significant other, or (rarely) with immediate family.

Another source of discrimination was a societal stigma that seropositive individuals were "responsible" for their infection with the virus. Interviewees noted that this stigma was compounded by the sense that HIV is associated with sex workers and homosexuals: if one was infected with HIV, that individual contracted the disease through sex with a sex worker or through a same-sex relation. Traditional elements of Guatemalan society scorn these groups,

thus creating a sense that seropositive individuals “deserve” their diagnosis.

First the religion is condemnatory too...for example a man who has HIV, the first thing that's said is that he's gay. (Interviewee 19, female)

Some interviewees said that most Guatemalans considered an HIV diagnosis as a punishment for one's behavior; at least two female interviewees referred to a seropositive status as a type of punishment from God.

In Guatemala there's a lot of taboo with respect to [HIV]. And a person with it is only going to be someone ... we'd say is like ..., prostitutes and homosexuals...I used to think that [HIV] was a punishment for people who went around having extramarital partners, and my ignorance, it was the same...that [HIV] was for people like the homosexuals...in the past, I would say it was a punishment from God. (Interviewee 16, female)

Gender roles and machista culture

Many of the seropositive females interviewed reported infection from a spouse or significant other who had numerous sex partners, was often missing, refused to be tested for HIV, and who may not have sought treatment until very late in the course of illness. The women stated that these behaviors were common to the machista culture, which favors male control and dominance within the context of sexual, familial, and social relationships. Women related that they were afforded very little power within this dynamic; they faced pressure to stay within the household and care for children. However, some interviewees noted that condom use was often determined by the woman.

Here society is excessively machista; it discriminates a lot and turns its back on you, there is no help from other people. (Interviewee 19, male)

My husband...how do I tell you? He leaves, and I don't know – that's how the situation is right now. He's not going to tell anything to me, but

maybe a person already has the sickness and one doesn't know anything. (Interviewee 4, female)

Because at times the woman decides (condom use)...and at other times no. (Interviewee 11, male)

Gender roles also appeared to play a role in the stigmatization of female rape victims. One interviewee did not report an incidence of sexual abuse because of fear and embarrassment; in another incident of sexual abuse, police only appeared to provide limited assistance to the victim.

I was embarrassed (about the sexual assault) and was afraid to tell my employer. (Interviewee 22, female)

Systemic barriers, and lack of access to care

While most of the interviewees stated that they had adequate access to HIV/AIDS testing and care, some noted that opportunities for testing and treatment may be unavailable to Guatemalans living in remote towns or rural areas. Similarly, interviewees reported deficits or misinformation regarding HIV/AIDS and sex education, with limited access to informational materials particularly for teenagers and for those living in rural settings.

No, there's not much over there (in my town), they arrived to do a free (HIV) test but it's very little. (Interviewee 18, female)

I think that in Guatemala, information hasn't been expanded much – that is, there hasn't been information by way of national agencies, through the state, or government. (Interviewee 20, male)

Individuals blamed these deficits on traditional attitudes toward sex, as well as the stigma surrounding HIV.

Interviewees also faced barriers or poor health outcomes because of inadequate care by health service providers. A seropositive interviewee who worked in healthcare noted that health service providers sometimes provided wrong information about HIV; he also showed signs of chronic illness for six

months before health providers considered administering an HIV test:

The way [health workers] do things, for me, I think it provokes more fear amongst people. (Interviewee 5, male)

Female interviewees reported uneven HIV-related care during pregnancy; physicians tested for HIV during some pregnancies and not others, and provided little to no counseling regarding safe sexual practices or contraception. One seropositive male with a history of mental health issues believed he acquired HIV during a stay at a psychiatric institution; male and female patients shared poorly supervised open wards, and many of the patients engaged in unsafe sexual practices.

The Guatemalan legal system was seen as one of the greatest structural barriers to proper HIV testing, treatment, and care. As noted, the police appeared to provide little assistance in at least one case of sexual abuse amongst the interviewees. Perhaps more important, no seropositive interviewees indicated that legal recourse was available when they felt themselves to be victims of HIV-related discrimination. Many seropositive interviewees were terminated from employment as a result of their HIV diagnosis; none of them reported taking any legal action against an employer. It was unclear if individuals were unaware of the existence of laws against HIV-related discrimination or if interviewees did not consider a lawsuit or other legal recourse worth the effort.

Discussion:

Our interview data identified four major themes that impeded HIV testing in our subjects: psychological factors, stigma/discrimination, gender roles/machismo, and systemic barriers to care. While these conceptual themes are useful to organizing information, there is clearly overlap among them. Many of our patients' fears were grounded in a reality of discrimination, while the systemic problems of the healthcare system reflect misunderstandings and fears on the part of healthcare workers. While these studies reflect a specific Guatemalan reality, they are broadly consonant with the international literature on barriers to VCT.

One of the strengths of our study was that we were able to obtain rich descriptions from people who had either been HIV tested in the past or were presenting for HIV testing. However, this study did not include the most important target group: those at risk for HIV who have not come in for testing. Presumably, this group shares concerns that are similar to the patients we interviewed. However, it is certainly possible that this group has other concerns. We plan to replicate this study in at-risk populations.

Given the fear and misconceptions concerning HIV testing and infection that we found amongst our subjects we felt that it was important for public health messages concerning HIV in Guatemala to concentrate on positive images. If HIV testing could be associated with "saving lives" instead of "immediate death" it is possible people would be less reluctant to be tested.

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