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HIV Diagnosis, Linkage to Care, and Retention among Men Who Have Sex with Men and Transgender Women in Guatemala City

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Abstract

Men who have sex with men (MSM) and transgender women are disproportionately affected by HIV in Guatemala, yet little is known about their experiences with diagnosis, linkage to care, and retention. We conducted qualitative interviews with 26 MSM and transgender women living with HIV in Guatemala City. HIV diagnosis experiences changed over time with increasing asymptomatic testing at non-governmental organizations. Fear of the physical and social impacts of HIV delayed testing, acceptance of diagnosis, and linkage to HIV care. These fears were driven by layered stigma and discrimination due to non-normative gender expressions and/or sexual orientation. Retention-specific determinants included HIV clinic dynamics and limited employment opportunities. There is an urgent need to improve support systems for early testing and linkage to care and to expand employment opportunities. Stigma and discrimination must be addressed at the family, clinic and contextual levels to reduce fear of diagnosis and improve access to care.

Keywords

Men who have sex with men; transgender women; HIV diagnosis; linkage to HIV care; retention in HIV care; HIV care continuum; stigma; Guatemala

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The biomedical discovery that early initiation of anti-retroviral treatment reduces transmission of the HIV virus, referred to as “treatment as prevention” (TasP), creates a new opportunity for HIV prevention.[1] Men who have sex with men (MSM) and transgender women are disproportionately affected by HIV in Guatemala. Only recently have targeted HIV surveillance data been collected to document this disparity and inform programming. While national level HIV prevalence among adults is estimated to be less than 1.0%,[2] the most recent prevalence estimate among MSM is 8.9% and transgender women 23.8%.[3] There is a need to assess how to operationalize TasP to the reality of key populations living with HIV in concentrated epidemics with limited resources.[4]

Early diagnosis is critical for optimizing the impact of TasP, as the earlier that people get diagnosed, the earlier they can commence HIV care and treatment. In the most recent integrated behavioral and biological survey in Guatemala, 59.2% of MSM and 45.1% of transgender women reported having had an HIV test in the last 12 months.[3] However, between 2011 and 2013, MSM and transgender women represented less than 1% of the HIV tests conducted by the Ministry of Health, highlighting major gaps in government-sponsored testing for these key populations.[5] In qualitative studies with MSM and transgender women in Guatemala City, the main barriers to HIV testing identified include fear, layered stigma and discrimination due to gender identity and/or sexual orientation and HIV, lack of social support, and lack of knowledge and access to HIV testing resources.[6,7] One consequence of these barriers to testing is that many MSM and transgender women are diagnosed with advanced cases of HIV, which has negative implications for their health as well as the opportunity for timely implementation and effectiveness of TasP.

In addition to experiencing a disproportionate burden of HIV and delayed testing, MSM and transgender women across the world experience barriers to getting into HIV care and staying in care, which are also critical for achieving TasP.[8,9,10] The first HIV diagnosis in Guatemala was made in 1984.[11] Up until the late 1990s, ART was extremely hard to acquire in Guatemala. Through the late 1990s and early 2000s, access to medication improved, but the supply was still insufficient and inconsistent. During this time, most medication available in Guatemala was imported by a volunteer program that imported unused HIV medications from infectious disease clinics in the US and international donors, including Doctors Without Borders.[12] Since the mid-2000s, ART is acquired through a combination of Guatemalan government funding and the Global Fund to fight AIDS, Tuberculosis and Malaria.[11] There are currently 17 HIV treatment providing units in Guatemala, mostly in public sector facilities, where ART is provided free of charge. In Guatemala City, where this study took place, 3 large public HIV clinics provide ART and also serve as referral centers. While access to treatment has improved dramatically during the last, it is estimated that only 35% of the 52,784 people living with HIV in Guatemala are engaged in HIV care, 31% receive ART, and 16% are virally suppressed (viral load <50copies/ml).[13] As a comparison, in a recent analysis of the HIV care continuum among MSM diagnosed with HIV in the US, where MSM also experience a disproportionate burden of HIV, 77.5% of those diagnosed were linked to care, 50.9% were engaged in care, 49.5% were prescribed antiretroviral therapy (ART) and 42.0% were virally suppressed.[14] The drop-off from diagnosis to viral suppression identified in these studies highlights the need for improved understanding of the continuum across settings to inform context-specific interventions that translate the biomedical advances of TasP to the reality of HIV clinics in low-income and middle-income countries.

Understanding HIV outcomes among key populations such as MSM and transgender women requires a contextualized understanding of their daily lives and the social and structural determinants of their wellbeing. Non-normative gender identity and sexual orientations pathologized in Guatemalan society.[15] Men who have sex with men MSM and transgender Guatemalans are consistently denied basic human rights and experience disproportionate levels of violence in an already extremely violent society.[16] Violence against transgender women and general transphobia are rampant.[15,16] In our previous research, we identified fear of discrimination related to sexual and gender identity and behaviors, lack of confidentiality, fear of HIV stigma and discrimination, and distrust of service providers as barriers to sexual health services for MSM and transgender women in Guatemala City.[6] We also found that most MSM live with their families and within their home environments experience a combination of stigma related to gender, sexual orientation, and HIV, as well as support, which could have implications for staying in HIV care and adhering to treatment.[17]

Given the limited understanding on the experience of living with and managing HIV among MSM and transgender women in Guatemala, we conducted a qualitative, formative study. The purpose of this paper is to describe the factors that shape the timing or stage of diagnosis, process of linking to care, and retention experiences of MSM and transgender women living with HIV in Guatemala City.

Methods

Study design and sample

This formative, qualitative study was conducted to improve understanding of the HIV experience among MSM and transgender women to inform the design of intervention strategies to improve outcomes along the HIV continuum of care in Guatemala City. We conducted in-depth interviews using a semi-structured guide to explore experiences with diagnosis, linkage, and retention in care. Eligibility for MSM included being at least 18 years old, having received a positive HIV diagnosis, having had sexual relations with a man in the last 12 months, and not being noticeably under the effects of alcohol or drugs to give consent. For transgender women, in addition to these criteria, another eligibility requirement was that they had been born biologically male but currently identified as a woman and/or transgender. Initial recruitment was led by referrals from key informants who worked with local community-based groups and introduced the study to MSM and transgender women living with HIV and peers from the MSM and transgender communities; subsequently, study participants also made referrals to potential participants. We monitored thematic saturation, or the identification of recurring themes related to the study questions during data collection, to determine the final sample size.

Data collection

The in-depth interview guides were designed to elicit participants' HIV diagnosis and care stories using open-ended questions and probing. We developed the guide as a team using a collaborative, iterative process. We drew on our past experiences conducting qualitative interviews with sexual and gender minority populations living with HIV to inform the way we elicited narratives while still responding to our concrete interests in obtaining information to inform program development. All interviews were conducted in Spanish by one of two Guatemalan researchers, one man and one woman, in locations of convenience to the participants. Both interviewers were trained psychologists and had experience with qualitative interviewing. One interviewer had also been an HIV counselor and the other had doctoral-level training in critical sociology. Interviews were audio-recorded and transcribed by either the interviewer or a trained transcriber. In total, 26 interviews were completed (15 with MSM and 11 with transgender women); each participant was interviewed one time. While individuals were recruited as representing either MSM or transgender, their identities were more fluid and frequently crossed over between these two categories, as we have found in other qualitative research with these populations in Guatemala.[17] We used the same interview guide for both populations, modifying pronouns based on the gender preference of each participant. All participants provided written consent. They were provided with compensation for their transportation costs upon completion of the interview. The study was reviewed and approved by the Institutional Review Boards at the University of North Carolina at Chapel Hill and the Universidad del Valle in Guatemala.

Analysis

Our analytic approach was informed by Maxwell and Miller's theory of qualitative analysis in which they distinguish between categorizing (or thematic) approaches and connecting (or narrative) approaches.[18] We drew on this distinction in order to balance our engagement with participant's rich stories while also identifying key themes within each stage of the HIV continuum. Our analytic team included one of the interviewers along with researchers from the participating universities and community-based organizations that work with study populations. We first wrote narrative summaries of each participant's HIV experiences to summarize the process of navigating the HIV continuum of care, capture the meaning of these experiences, and describe the context in which they managed life with HIV.[19,20] The research team discussed and compared the narrative summaries to inform the collaborative development of a thematic codebook. The codebook contained both descriptive codes derived from the interview guide (e.g., place of diagnosis, place of treatment) and interpretive codes derived from themes and ideas from the narrative analysis (e.g., discrimination, fear, desire to live).[20] Code definitions were collectively written and discussed until the team reached consensus. The interviews were then systematically coded using the Atlas.ti software (version 7) through an iterative process.[21] Following coding, the team developed matrices to organize and further reduce the data along the three stages of the continuum that we focus on in this paper: diagnosis, linkage, and retention in care.[22] These matrices also facilitated comparative analysis across the two strata we focus on in this paper: year of diagnosis (and study population (MSM vs transgender). Matrices were reviewed by the team and key findings were re-contextualized by returning to the narrative summaries.

Results

We first provide a description of the study population (Table 1) followed by our analysis of participants' experiences with diagnosis, linkage to care and retention. The study population provided experiences that cover over 30 years. Average age for MSM was 38 years (range 21 to 66 years for MSM) and 41 years for transgender women (range 23 to 70). Most MSM had completed high school (n=7) or some amount of college (n=4) ; only 2 transgender women had some college and 2 had completed secondary school. The majority of all participants were single; 2 MSM participants were married or in union. Only 3 MSM and 4 transgender women reported living alone. Consistent with findings from our past research with MSM and transgender women in Guatemala, most MSM lived with their families or partners while transgender women rented rooms in a house or lived with friends.[17] While both groups mentioned difficulties getting jobs, the majority of MSM had some paid work at the time of the interview (n=10) while less than half of the transgender women (n=4) reported having paid work. Involvement in sex work, currently or in the past, was common among both groups, though more so among transgender women (n=7 MSM, n=9 transgender women). All but two participant were engaged in HIV care at the time of the interview, one MSM and one transgender woman.

Diagnosis

Across the last 30 years of living with HIV represented in this study, themes related to diagnosis varied substantially over time as the social context and availability of services have evolved. One noteworthy trend over time was where participants got tested (Table 2). Among participants diagnosed prior to 2006, most were diagnosed in public hospitals or clinics (n=2 MSM, n=4 transgender women) or private laboratories or clinics (n=3 MSM, n=1 transgender woman). Only two participants, both transgender, were diagnosed at non-governmental organizations (NGO) prior to 2006. In contrast, among those diagnosed since 2007 there was more testing occurring at NGOs (n=3 MSM, n=2 transgender women) with continued use of public hospitals and clinics (n=3 MSM, n=2 transgender). Only 1 MSM participant reported getting diagnosed at a private clinic or lab after 2007. Most participants diagnosed since 2007 in both NGO and public hospitals reported receiving pre- and post-test counseling, which was not true of the earlier diagnoses in hospitals and labs.

Among all participants and time periods, the most commonly identified reason for getting tested was being sick, in some cases gravely ill (Table 2). More recently, however, there was increased use of voluntary HIV testing as a preventive behavior or in response to perceived risk. In the group diagnosed prior to 2006, three MSM participants were diagnosed asymptomatically while donating blood or during a check-up for a work physical. However, only 1 MSM identified asymptomatic testing motivated by risk perception prior to 2006. Three MSM in the more recently diagnosed group were tested asymptomatically. One 46-year-old gay man diagnosed in 2009 described getting tested as a preventive measure for his health because he had seen many of his friends die:

> I experienced seeing my friends die of HIV. And I was afraid that I might have it. We had potentially shared the same people, we had had sex with the same people… I saw a friend, and he was very skinny, and I thought, I have it too. So [I] was afraid

> of getting tested. But I went before I got to that [bad state of health]. I went before that and did the test and came out positive. (MSM, age 46, diagnosed 2009)

As reflected in this quotation, many participants expressed feeling fear related to testing. While this participant got tested before having symptoms, for many others fear was a driver of delayed testing.

There was also a shift over time with regard to who participants were with when they got tested. Individuals who got tested because they were very sick were frequently accompanied by a family member because they could not physically go alone. In contrast, both MSM and transgender participants who got tested as a form of prevention at an NGO were frequently with friends. Several participants across both time periods intentionally got tested alone, as described by a 46 year-old- transgender woman diagnosed in 1999:

> No, with no one, with no one, no because, I don't trust those women, and I didn't tell anyone afterward either, only I know. Only I know and no one else. I don't even want to tell my mother because she will cry and be worried and, so I don't tell her, just I know…because sometimes, let's say I tell someone, then that person can go and get drunk and talk about it, and say, hey look they have HIV. So it's better it is just me. (transgender woman, age 46, diagnosed 1999)

This quotation reflects how lack of trust within the transgender community in the late 90s led to this participant getting tested alone. This lack of trust transcended time and other spheres of the participant's life, leading her to opt for not disclosing her status to anyone. Another transgender women, diagnosed in 2008, echoed this sentiment saying that she got tested alone fearing that "someone would find out."

The diagnosis experience was frequently quite traumatic, especially among those who were diagnosed in the late 1990s and early 2000s before testing and counseling was widely available. Participants described feelings of fear, guilt, anguish, and depression in response to their diagnosis. Many of those diagnosed at hospitals or labs before 2006 were unaware that HIV test was even being done; some received the news briskly from a doctor or were simply handed an envelope with the results. A 39-year-old transgender woman diagnosed in the 1980s described how little was known about HIV when she was tested and how little infrastructure existed:

> It was horrible! We didn't even know what they were talking about, you know? It was a boom in the U.S. It was a boom for the whole world, and we knew nothing. Not what was happening, not why it was happening, you know? It was very difficult, there weren't support groups or lectures or pre-test counseling, none of that existed. The word HIV didn't even exist. Imagine, what it sounded like to hear them tell you that you had AIDS. (transgender woman, age 39, diagnosed 1986)

The combination of how participants found out their status and the lack of services, or knowledge about services, created anxiety and depression for many during the diagnostic period.

Linkage to care

We identified several barriers and facilitators to getting linked to HIV care. The time from diagnosis to enrollment ranged from immediate (for those who were diagnosed in hospitals with serious health complications related to HIV) to seven years. Barriers to linkage to care for those who were not diagnosed when already sick included fear, denial, and lack of symptoms.

Overall, linkage was a salient topic for both MSM and transgender women who were recently diagnosed. Participants diagnosed with a poor health status were much less likely to have a significant lapse between their diagnosis and linkage to care; in these cases, poor health status paradoxically acted as a facilitator to HIV care, especially if they were diagnosed in a hospital setting. A 44-year-old MSM man diagnosed in 2002, who initially refused immediate treatment, was linked into care in under a week because he was diagnosed with such severe health problems that he couldn’t walk and was nearly blind. However, when his doctor tried to admit him to the hospital, he said “If I’m going to die, I’d rather die at home.” After a few days at home, his family took him back to the hospital. This example highlights the important role of social support, in this case family support, in timely linkage to care.

Aside from the health condition at diagnosis, the other main factors driving delayed linkage to care, which transcended time periods, included depression, denial, fear and confusion. Depression and denial both created barriers to taking action towards linkage to care. Others diagnosed in a healthy state who were not linked into treatment in a timely manner were fearful, especially of involuntary disclosure as a part of getting into care and also of the treatment itself. A 23-year-old transgender woman diagnosed in 2010, waited nearly three years to enter into care after her diagnosis, due to fear. She cited depression, suicidal ideation, and fear of involuntary disclosure for delaying her linkage. Three years after her diagnosis, she noticed small declines in her health and realized that deteriorating health could also could also reveal her status, which pushed her to get into care. Another transgender woman who was diagnosed in 2008 had still not been linked to care at the time of the interview,

> I am afraid [to get into care], because I feel healthy. Also it is obvious that I’m not sick and I don’t get sick…I promise, my scars heal in three or four days, but I’m afraid of taking a fucking medicine, and ugh, what is it going to do to me, I’m going to take medicine that is going to make me sick? I don’t know, I don’t know. That is my reaction. (transgender woman, age 31, diagnosed 2008)

This quotation reflects the synergistic influence of fear of the unknown, fear of treatment side effects, and some denial (“I don’t get sick”) working together as barriers to care.

While fear of involuntary disclosure was a major barrier to seeking out HIV care, for most participants, disclosure led to support for getting into care. A young gay man diagnosed in 2013 who delayed getting into careand was very adamant that his family not find out about his sero-status described disclosing to another HIV-positive friend:

> Sometimes I would think [after my diagnosis], what is happening? What did I do? I would see there was no way out. No solution. But finally, I told an old friend of mine who is also positive, and she said, ‘look, you have to keep living, we will not die of this, we have to live,’ to take this as an opportunity to live….she asked if I was taking medicine. No I said, I don’t want to take medicine, she said, you have to do for your health, and so your family doesn’t find out, because otherwise you will get sick and they will find out. I stopped and thought about it, and then I had to go, we had to go, and I went. I went [to start treatment]. (MSM, age 21, diagnosed in 2013)

Supportive relationships played an important role in linkage to care by helping participants see past their fears, appreciate the value of their health, and understand the importance that treating HIV can have for their lives. In addition to the importance of support from a friend living with HIV, this participant again highlights how fear of poor health being an indicator of HIV was a motivator to get into care.

Retention in care

Key determinants of retention in care overlapped with determinants of linkage, including supportive relationships and health status. Retention-specific determinants included clinic dynamics, economic resources, and stigma and discrimination. Participants who had disclosed their HIV status to their families, roommates, friends, or coworkers often received support to stay in care and adhere to treatment. Many participants reported that friends who were living with HIV gave them advice on where to seek care, what organizations ran good support groups, and links to informal support groups. These relationships provided key information and resources to support staying in care. Among MSM participants in particular, families provided support by cooking for specific dietary requirements, giving rides to appointments, and providing care during health crises. These forms of family support facilitated retention in care by helping participants to attend their appointments and follow their prescribed diets.

While many participants reported emotional support from disclosure, not all experiences with disclosure were positive, especially when coupled with disclosure of sexual orientation. Among MSM, many described situations where their family did not support or accept their sexuality, but would offer instrumental or material support related to their HIV status. For example, one 42-year-old gay man who had been homeless when he was diagnosed, moved back in with his family after disclosing his HIV status. They did not support him in his sexual orientation, however, and told him,

> I don’t want any faggots coming to knock on my door looking for you, understand? …You can live in your world, we respect that is who you are, but no one will come to my door saying they want to talk to you, or watch TV with you, none of that. (MSM, age 42, diagnosed in 2013)

The isolation of living with his parents and being denied contact with his social world was difficult. However, his parents provided critical support related to his HIV. Before moving in with them, he walked long distances to his appointments but after moving back home, his father drove him at 4 a.m. so that he could be the first one in line for care, which is important given the large number of patients seen at the two main HIV clinics in Guatemala City on a daily basis. His parents also made sure that his basic needs were covered, cooked him appropriate food, and made sure he was physically comfortable. This challenging dynamic of families not accepting or approving of a participant’s sexual orientation or gender identity, but giving them support related to their HIV care, was mentioned by several participants.

While there were examples of support from family and friends related to HIV, participants also described experiencing social isolation and rejection, which could make staying in care challenging. A 66-year-old gay man diagnosed in 1998 was thrown out of his house when he told his family about his HIV status. They also burned his clothes because they feared infection. This family’s fears reflect a combination of HIV stigma and lack of knowledge. Another example of social rejection was the experience of a 42-year-old gay man diagnosed in 2013. His partner left him when he disclosed his status and his family isolated him, again out of fear of infection:

> Now they understand the situation of, of what HIV is because I’ve also… I’ve opened their minds a bit, because there were very closed minded when I came here [to live with them]. They separated my plates, they separated everything, they said, ‘here is your bathroom, and your apartment, you don’t have to even come downstairs.’ They closed off this little world, but now, I’ve talked to them, and little by little they’ve been opening up, opening their eyes. (MSM, age 42, diagnosed in 2013)

This quotation reflects a process of communication and adaptation within families, led by the participant, which slowly led to provision of the support that was critical to remaining in care.

Having trusting relationships with HIV clinic staff and providers enabled participants to stay in treatment and adhere to care and treatment in interesting ways. Care providers included not only doctors, but also nurses and other clinical staff. For instance, several participants, both MSM and transgender women, discussed feeling comfortable enough with the clinic staff to be able to call and change appointments when needed. One MSM participant noted that clinic staff trusted his history of adherence, which facilitated communication and flexibility with his appointment schedule. This flexibility was important as it allowed participants to avoid missing appointments and then fearing negative reactions by clinic staff, which could lead to dropping out of care. Participants also described asking to be scheduled with doctors they felt treated them well or avoiding those doctors who they didn’t have a good relationship with to improve their care experience.

While some participants discussed developing trust with clinic staff, many also described experiencing discrimination related to their sexual orientation and/or gender identities in the HIV clinics where they received care. Discrimination acted as a barrier to care as by creating distrust of providers and making participants fearful of getting care. While there were examples of discrimination among both the MSM and transgender women, discrimination was more salient for transgender women. Transgender women experienced discrimination by staff who refused to use their female names, an experience described by a 23-year-old transgender woman diagnosed in 2010:

> "One day I arrived dressed [as a women] and they call me by my name, my legal name, and it made me feel bad and it was in front of all the people waiting in the hospital. It made me feel bad, but I let it go and I didn't want to say anything. (transgender woman, age 23, diagnosed in 2010)

Only one transgender participant who experienced this type of treatment described addressing it with her provider; most reacted as the woman quoted above and did not do anything. Another way transgender women experienced discrimination in care settings was being stared at, pointed at, and watched by other partients, and clinic staff. These experiences undermined transgender women's trust in the clinics, which could negatively impact their retention. Some participants highlighted receiving good treatment and high quality HIV care but negative experiences in other health care settings. For example, a 42-year-old MSM diagnosed in 2013 described seeking care for a foot injury and the doctors did not want to touch him because he was a gay man living with HIV. This participant had a positive relationship with his HIV doctor to whom he turned to get help accessing the care he needed for his foot, highlighting the importance of a good relationship with the primary HIV doctor for services beyond HIV.

Another important structural determinant of retention was lack of economic resources and job opportunities, especially among transgender women. Lack of economic resources impacted retention by limiting access to transportation to get to their appointments. Another way limited economic opportunities impacted retention was through food. A 42-year-old transgender women explained,

> Also, not having a job, partially because there are less possibilities since I'm older. But we need to have a good diet, eat your four times a day, if possible, and sometimes I can't do it, because I'm bad economically and I can't go house to house asking because I would be ashamed to ask. But I always try to find something [to eat], like a piece of bread. (transgender woman, age 42, diagnosed in 1984)

Both MSM and transgender women experienced economic marginalization due to their gender identities and sexual orientation. Their HIV status further limited employment opportunities and exacerbated their lack of financial resources. In a few cases, participants, mostly MSM, had jobs doing work related to HIV that were both a source of economic and also emotional support. A 25 year-old gay man diagnosed in 2008, described receiving such support even when he tried to push people away:

> Some of the people I work with currently know my status, and they are the ones that most often tell me, hey, take your medicines, don't stop going to your appointments, read about HIV, and more. Sometimes they come up to me and say, 'hey are you ok? You don't look well' if I'm not doing well I'll tell them to go away and stopping to me and they will say, 'hey what's up? Are you ok? Finally I'll tell them I took my medication last night and I'm in a bad mood, and they will say

> to me, 'ok we will make sure no one bothers you, if anyone comes looking for you we will say you aren't here.' (MSM, age 25, diagnosed in 2008)

This participant also discussed being able to ask for time off for appointments, which facilitated his ability to get to his appointment.

Discussion

Based on our in-depth qualitative analysis, we described the historical context of HIV testing and linkage to care among MSM and transgender women in Guatemala City. We identified several important factors that shape experiences with HIV diagnosis, linkage to HIV care, and retention and, ultimately, create the context for achieving treatment as prevention (TasP) with MSM and transgender women in Guatemala City. Fear, of disclosure, death, and the impact of HIV in participant's lives, weresalient factors affecting all three stages of the HIV care continuum.. Fear of the physical and social impacts of HIV had a notably negative effect on early testing, acceptance of diagnosis, and enrollment in HIV care. These fears were frequently driven and/or exacerbated by the layered stigma and discrimination that participants experienced due to their non-normative gender expressions and/or sexual orientation. These findings echo previous findings of fear as a barrier to HIV testing MSM and transgender women in Guatemala City and highlight the salience of the debilitating impact of layered stigma.[6,7] As further evidence of the impact of stigma related to sexual orientation, in the most recent integrated behavioral and biological survey with MSM in Guatemala City, individuals who had not disclosed their sexual orientation to anyone were less likely to have been previously tested.[23]

By obtaining a sample of participants whose diagnoses ranged over three decades, we were able to identify shifts in the availability and use of HIV testing services, which appear to be contributing to earlier diagnosis. We found that delayed testing, or getting tested in response to serious medical complications, was especially common among the participants who were diagnosed in the late 1990s and early 2000s. These participants were not "linked to care" as they usually required immediate treatment related to HIV and other conditions. In contrast, for those who were diagnosed since the mid-2000s, getting into HIV care required more effort to enroll in HIV services, including overcoming the aforementioned fears. Paz-Bailey et al. found that MSM in the US who were diagnosed the first time they were tested experienced delayed linkage,[24] highlighting the need to integrate linkage support systems into early testing efforts.[25] A few participants mentioned benefitting from the support and experience of a peer who was also living with HIV, though there was no evidence of any programs to help recently diagnosed individuals navigate the psychological, physical and logistical challenges of the HIV care system. Earlier diagnosis and immediate linkage to care is critical for promoting TasP by getting individuals onto anti-retroviral therapy early. While the trend towards early testing we observed in this sample is encouraging, there is a clear need to continue improving access to HIV testing and linkage to care among MSM and transgender women in Guatemala City.[26] Peer navigation models could be effective in helping individuals to manage the fear and psychological impact of the diagnosis as well as facilitate timely linkage to care.[27,28]

We also explored retention in care and found that the salient themes related to retention were mostly interpersonal, in particular family, clinic and provider dynamics, and contextual, including stigma and discrimination, poverty, and employment. Family support, even when the family was not accepting of the participant's sexual orientation and/or gender identity, was critical for many participants to stay in care and take care of their health. This finding echoes our previous research on the dual experience of social rejection and social support within family networks among MSM and transgender women in Guatemala.[17] Strengthening the link between clinics and families could be an important way to improve long-term retention in care and adherence.[29] While having trusted relationships with providers was an important facilitator of retention in care, stigma and discrimination related to HIV, sexual orientation, and/or gender identity created barriers to staying in care, as has been found in other settings.[10] There is a need for ongoing sensitization and capacity building with all staff and clinical care providers in order to continue improving the overall environment of the clinics for these key populations.[30]

Many participants also discussed their lack of employment and dire economic situation as barriers to staying in care and adhering to their treatment regimens. Transgender women were especially vulnerable to mistreatment in clinics as well as unemployment and poverty, highlighting the need for improved support services to promote holistic wellbeing and the opportunity to live productively with HIV. Based on research with MSM and transgender women living with HIV in the Dominican Republic, we developed a conceptual model for the role of unemployment as a mediator between HIV stigma and HIV outcomes.[31] We found that MSM and transgender women living with HIV did not have jobs because HIV stigma led to them getting fired, not getting hired, and not even applying out of fear of disclosure of their HIV results. Participants who were under or unemployed experienced mental health problems, extreme poverty, interrupted care and treatment, and changed HIV clinics, which can lead to poor HIV outcomes. In contextualizing these potential links, it is important to recognize that the trajectories of vulnerability among MSM and transgender women, starting with early life stigmatizing and discriminatory experiences related to gender, and sexual orientation, may limit work opportunities later in life. Based on our findings, we believe this conceptual model applies to the experiences of MSM and transgender women living with HIV in Guatemala and highlights the need to address employment as a social determinant of HIV outcomes, including retention in care, among these key populations.

This study has several limitations. Most of the participants were currently engaged in HIV care. While this allowed them to reflect on the process of getting diagnosed and into care, it also meant they had effectively overcome the barriers they experienced and may not have represented the full range of barriers and challenges. While their experiences may not be reflective of all individuals in Guatemala City, we believe the themes they identified are important to consider in future programming. Recall may have also been compromised for some due to the long time (up to 30 years) since diagnosis.

Conclusion

Men who have sex with men and transgender women are disproportionately affected by HIV in Guatemala City. Despite recent improvements in the documentation of these disparities through rigorous HIV surveillance, the response is still lagging. There is an urgent need to improve support systems for early testing and linkage to care and to expand employment opportunities for MSM and transgender women living with HIV. Across all stages of the HIV continuum, layered stigma and discrimination related to HIV, sexual orientation, and gender must be addressed to reduce fear and improve access to all stages of care.

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Table 1

Description of the study population of men who have sex with men and transgender women living with HIV in Guatemala City

	MSM (n=15)	**Transgender women (n=11)**
Average age (range)	38 (21-66)	41 (23-70)
Education		
Primary		2
Middle school	3	5
Secondary	7	2
University	4	2
Civil status		
Married/In union	2	
Single/Divorced	13	11
Currently has paid work	10	4
Has done sex work (past or present)	7	9
Living arrangement		
Alone	3	4
Lives with others	12	7

Table 2

Description of the location of HIV testing and diagnosis among men who have sex with men and transgender women living with HIV in Guatemala City

	Diagnosis prior to 2006			Diagnosis since 2007		
Study population	**MSM**	**Transgender**	**Total**	**MSM**	**Transgender**	**Total**
Location of test[*]						
Public hospital/clinic	2	4	6	3	2	5
Private clinic or lab	3	1	4	1	0	1
NGO	0	2	2	3	2	5
Location totals	5	7	12	7	4	11
Reason for testing[*]						
Sick	2	4	6	4	2	6
Prevention	1	2	3	3	2	5
Donate blood or work requirement	3	0	3	0	0	0
Reason totals	6	6	12	7	4	11

[*] Data missing for 3 participants.