“In five years I will look more elegant, much better than today:” Barriers and motivations to treatment adherence among TW in Central America.

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BACKGROUND

Transgender women (TW) in Central America are the population most affected by HIV/AIDS in the region. Country-level prevalence estimates range between 7.96-28.69% and far exceed estimates among other groups. Antiretroviral Therapy (ART) coverage and adherence in TW is assumed lower than existing national estimates because TW face additional barriers to care, greater stigma, and limited family and social support.

METHODS

To inform a USAID-funded Combination Prevention Program in Central America, PASMO conducted a qualitative study to explore the barriers to adherence faced by people living with HIV (PLWH), including TW. This study examines a subset of 30 life history interviews and 2 focus groups conducted with HIV positive TW across 3 countries in Nicaragua, El Salvador, and Costa Rica.

RESULTS

At the time of diagnosis and treatment initiation, TW may face parallel and overlapping processes such as addiction recovery, overcoming depression, gender identity transitions, loss of livelihoods from sex work, or loss of housing. This additional burden may often interfere with or supersedes disclosure of HIV and adherence to Antiretroviral Therapy (ART) as a priority. HIV stigma is perpetuated by both the internal and external stigma of TW identity, leading to barriers to adherence or delays in drop-out from care because of provider discrimination, lack of family support, and a reduced self-efficacy or interest in self-care.

“[Things will change if I tell my family my diagnosis] because they already hate me for what I am—[for my sexual orientation]. It will be worse if I tell them the rest. So I better not.” In-depth interview, El Salvador.

“There used to be no medication and PLWH would get skinny, their hair fall out. All of that. At this day in age, the person who dies, dies because she wants to. At this day in age, it is not the disease that kills you, it is all this discrimination.” In-depth interview, El Salvador.

“I’m more worried about my addiction than I am about my disease… that I could become ill as a consequence of my addiction. It worries me, for my recovery. Taking pills and falling back all the time…” Focus Group, Costa Rica.

Factors contributing to treatment adherence include familiarity with AIDS death within the TW community, positive family support, and expectation of an improved/maintained appearance.

“I’ve seen my friends die of HIV—all bones, muscular atrophy. You should see that terrifying sight.” Focus Group, Costa Rica.

“If I am adherent because I don’t want to look, let’s say, bad—with sores and weight loss. Everyone knows me, they know this is my weight.” In-depth interview, Costa Rica.

Some TW develop specific and simple strategies to aid in treatment adherence and overcome the factors of lacking family support or fear of discrimination. Living in a context with other HIV-positive residents creates a supportive environment where they check-in and remind one another about medication.

“My roommate was taking them at 6, so we became accomplices. Sometimes he forgets to remind me, but I’m always like “It’s 6 am already!”

Finding ways to hide the medication (by removing labels) or discuss treatment in an indirect way is also described as a strategy to overcome stigma of being on ART.

“[Discrimination worries me because If they see the bottles they will say “the sidoso (derogatory term for PLWH) is taking medicine” So, it’s because of discrimination. That’s why I peel off the labels.” In-depth interview, El Salvador.

Also, considering the emotional status should be key in the acceptance and development of effective adherence strategies, and could be considered one of the first steps into treatment adherence.

“I consider very important and fundamental that this type of research focus on improving the quality of life of people living with HIV, I consider there is plenty to do in the emotional aspect, because it is the main axis for adherence…” In-depth interview, Nicaragua.

CONCLUSIONS

This study identified challenges faced by TW within the experience of diagnosis and treatment initiation that must be addressed prior to or as part of a holistic treatment regimen. This includes addressing and creating supportive environments for overcoming substance abuse, providing counseling services that address both HIV diagnosis and also gender identity and sexuality, and creating safe spaces where PLWH can support one another.

Key Terms: Adherence, Transgender Women, Stigma

Themes: Intervention development, implementation, and outcomes; Other

Key Populations/Settings: Transgendered individuals