‘Sometimes we take a vacation’: Qualitative study on barriers to HIV treatment adherence among PLWH in Central America

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Abstract ID: 164

BACKGROUND

Eligibility criteria and sub-optimal coverage inhibit many people living with HIV (PLWH) in Central America from receiving the benefits of Antiretroviral Therapy (ART). Social, structural, and individual factors also impede effective treatment and care. In 2012, as part of the USAID-funded Combination Prevention Program, PASMO conducted formative research to explore barriers and strategies for achieving ART adherence.

METHODS

The study was conducted in Costa Rica, El Salvador, Nicaragua and Panama among male and female PLWH, with deliberate recruitment of the program’s key populations: men who have sex with men, transgender women, female sex workers, men at risk, and women from the general population. 69 life histories and 20 focus groups were used to identify key moments in the treatment continuum when adherence was compromised and to generate consensus regarding challenges in ART adherence. To document the experience of treatment successes and challenges over time the sample was segmented on time since diagnosis, using 55 months as a threshold.

RESULTS

PLWH’s relationship with ART is complex and mutable. The construct of adherence is frequently re-defined, depending on PLWH’s experiences, expectations, and evolving needs. PLWH develop alternatives to adherence, often in response to a medical system perceived as overly strict and inflexible.

These include:

- “Permissions” — Suspension of ART during short and discrete periods, usually for specific reasons like attending a social event.

“I usually take [my medications]. I remind myself that they’re the motor that keeps me going… I don’t take them when I know that I’m going out over the weekend. Some of my friends take [their medications] with a swig of beer. Not me. I respect that… If I know that I’m going out at night, I take one pill in the morning at 9 am like normal, but I won’t combine the pills with liquor. I try to follow the instructions exactly.” (MSM living with HIV, Costa Rica)

- “Vacations” — Suspension of ART for a period of time (several days, weeks or months) to take a break from the routine and re-energize.

“...you get tired of taking so many pills, thirteen years of taking so many pills. You get tired, so you give yourself a vacation. I stopped taking medication for a month. Later I regretted it because the Hospital punished me: they didn’t want to continue giving me the medicine. I felt like dying. What was I going to do? I was irresponsible; the Infectologist taught me a lesson.” (Woman living with HIV, Costa Rica)

- Self-regulation of ART — this is practiced when PLWH regulate or modify their dosage or schedule, but without completely abandoning it. PLWH who practice self-regulation consider themselves to be adherent to treatment, despite their deviations from doctors’ orders.

“...I’ve never had a lapse, and I hope not to have one. So I’m always on time [taking my medication] and I try to, every day of the week up to Friday. Because when Friday comes around it’s party time! And I forget about the pills until Sunday. On Monday I start taking them again. It’s just Friday and Saturday that I take my days off.” (Woman living with HIV, Panama)

CONCLUSIONS

The threats to treatment adherence vary throughout the continuum of ART. PLWH often develop their own strategies when integrating ART into their lives and these strategies often deviate from the prescribed protocols. These insights provide key intervention points for programs intending to improve ART adherence.

Key Terms: Adherence, Qualitative, Vulnerable Groups

Track: Antiretroviral Therapy Medication Adherence

Themes: Intervention development, implementation, and/or outcomes: Other

Key Populations/Settings: Resource limited settings, Men who have sex with men (MSM), Transgendered individuals

Other Key Populations/Settings: Female Sex Workers