

Treatment Holidays and Adherence

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Having an effective, holistic and comprehensive response to HIV in terms of treatment adherence means adopting a woman-centred and gender-equitable approach. Young women who were born with HIV have a lifetime of treatment, while women who were diagnosed later in life have also been taking medication for many years, causing a range of side effects from antiretroviral therapy, and psychological triggers of stressful and disorienting feelings of guilt and fragility related to one's own health¹. These effects raise the likelihood of taking a "treatment holiday" even more as people seek a break from the heavy emotional work of living with HIV.

I. Treatment interruption

Current HIV treatment guidelines do not recommend treatment holidays or interruptions of ARVs as it makes the virus more difficult to manage over time. There have been multiple research studies about the effects of interrupting doses, the DART study gave individuals 12-week breaks from taking the HIV treatment, but the study was stopped and all participants were recommended to return to continuous therapy after researchers found that people who had treatment breaks were more likely to develop HIV-related illnesses.² Such risks,³ that were concluded within the DART and SMART studies⁴, were the increase in viral load with a drop in CD4 making the risks of infections and opportunistic diseases higher leading to heart, liver or kidney disease - even when returning to treatment after interruptions the lymphocyte levels may not reach the previous levels. One of the most worrisome is the risk of developing resistance to ART, especially if treatment interruption is not done carefully. Other studies on treatment breaks have concluded that some monitored interruptions can reduce the risk of toxicity of treatment and lower costs; and some participants may even regain drug sensitivity.⁵ However, these benefits have always been followed by a rapid return to treatment due to an increase in viral load which causes the immune system to gradually decline.

II. Understanding Adherence

Adherence goes beyond the traditional definitions of taking a drug on the same daily schedule seven days a week, this limited conception of what adherence entails only demonstrates that there is a very narrow view of the complexities of the lives of women with HIV. In order to understand a comprehensive definition of adherence, we must include the time invested in accessing the medication and having all the financial, material, ecological, psychological and physical resources to be able to adhere to the doses. This can mean nutrition support, dealing with side effects...

There is a need to reflect on the diverse contexts and intersectional realities encountered by women with HIV, who are not the same and who may experience and approach treatment differently; for example, taking ARTs can cause trauma related to diagnosis or trigger experiences of stigma and discrimination. It's simplistic to claim that treatment a-pill-a-day. Most people with this thinking are outside of the HIV daily-routine looking in through straight glasses about what life after diagnosis should be like.

have repeatedly stated that to have a comprehensive response to HIV we must go beyond the biomedical dimensions, although they have been fundamental in terms of pharmaceutical advances, they alone are not sufficient to resolve the complex realities of women with HIV. Yet, there is little to no evidence on the effect of treatments on either toxicity levels and the long-term

¹ Jones, D., & Otros. (2017.). Adherencia a los tratamientos antirretrovirales en personas que viven con VIH en la Argentina. Dirección de Sida y ETS, Ministerio de Salud. <http://iah.salud.gob.ar/doc/Documento121.pdf>

² Peabody, R. (2021) HIV treatment breaks. NAM. <https://www.aidsmap.com/about-hiv/hiv-treatment-breaks>

³ Ibid

⁴ Egwang, T. (2008) SMART study reaffirms that HIV replication is harmful, even at CD4 counts above 350. NAM <https://www.aidsmap.com/news/apr-2008/smart-study-reaffirms-hiv-replication-harmful-even-cd4-counts-above-350>

⁵ <https://clinicalinfo.hiv.gov/en/guidelines/pediatric-arv/antiretroviral-treatment-interruption-children-hiv>

cognitive, psychological and mental health effects of childhood-initiated ARV therapy. Many children who began this regime in the early 2000s and are now young adults.

III. Lived realities - the autonomy of our bodies

ICW Latina's qualitative study on young women living with HIV found that 25 out of 58 female respondents under the age of 30 have interrupted their medication at least once in their lives, which leads young women to grow up with the feeling of "having a love-hate relationship with the pills".⁶ Other reasons that have been studied for abandoning treatment are fear of side effects, being persuaded by the medical staff, feeling of hopelessness and dislike of taking medication.⁷ Will there ever be a time when our adherence doesn't involve pills every day?

Because of treatment we can start research around breastfeeding, explore our sexuality freely, but also because of treatment we suffer panic attacks, vomiting, dizziness, insomnia, even with long term effects such as pancreatitis.⁸

The stigma that several women with HIV undergo is multidirectional, it is not only experienced by the diagnosis, but also by the decisions and directions that our diagnosis takes us. Being judged for not having enough motivation given the U=U when many find it difficult to reach undetectability or stigma around autonomy of our body by deciding to pause the treatment assuming disregard for one's health. It has been said publicly by some women about treatment holidays and the freedom to decide, "I feel free when I don't take them".⁹

There are still many underlying complexities about treatment interruption that are not analyzed beyond a biomedical perspective. The efforts of NGOs and community-led organizations working for access to ARTs are recognized, however, there are few lines of governmental interventions for adherence support related to these stratified experiences that women with HIV have.¹⁰ In terms of and comprehensive response to HIV, what does it mean for us to take ART?

If you have been considering it, always consult with your healthcare provider, explain your situation and together you can find alternatives.

⁶ <http://icwlatina.org/wp-content/uploads/2021/09/Nosotras-Sabemos-Nosotras-podemos-1.pdf>

⁷ Belmar, J., & Stuardo, V. (2017). Adherencia al tratamiento antirretroviral para el VIH/SIDA en mujeres: una mirada socio-cultural. 34(4), 352 - 358. <http://repositorio.uchile.cl/bitstream/handle/2250/149236/Antiretroviral-treatmentadherence-for-HIV-AIDS-in-women.pdf?sequence=1&isAllowed=y>

⁸ "Tengo VIH y hace 3 años que no tomo medicación" <https://www.organizacionllaves.org/post/tengo-vih-y-hace-3-a%C3%B1os-que-no-tomo-medicaci%C3%B3n>

⁹ Charlas de café III: "Qué bonita la indetectabilidad, pero qué cansada la adherencia!

¹⁰ Ibid.