Published in final edited form as:

AIDS Care. 2020 January ; 32(1): 72–75. doi:10.1080/09540121.2019.1614521.

“A way of escaping”: a qualitative study exploring reasons for clinic transferring and its impact on engagement in care among women in Option B+

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Abstract

Clinic transfers among women in Option B+ are frequent, often undocumented, and may lead to suboptimal engagement in care and HIV outcomes. The reasons women move between HIV clinics are not well understood. We conducted four focus group discussions FGD among HIV-infected pregnant women in Option B+ and four FGDs and five in-depth interviews among healthcare workers (HCWs) at two large ART clinics in Lilongwe, Malawi. Mobility and fear of inadvertent HIV disclosure, particularly due to seeing neighbors or acquaintances at a clinic, were key drivers of transferring between HIV clinics. Women were aware of the need to obtain a formal transfer, but in practice this was often not feasible and led women to self-transfer clinics. Self-transferring to new clinics frequently resulted to re-testing and re-initiating ART and concerns about disruptions in ART. Strategies to monitor women's engagement in HIV care without requiring a formal transfer are urgently needed.

Keywords

engagement in HIV care; clinic transfer; Option B+; default; pregnancy; HIV

Introduction

The scale-up of antiretroviral treatment (ART) to all pregnant and breastfeeding women, known as Option B+, has the potential to improve maternal health and end mother-to-child HIV transmission.(WHO, 2013) However, lack of engagement in HIV care threatens to limit the advances of Option B+.(Knettel et al., 2018) In Malawi, over 25% of women default

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Presentation: A version of this work was presented at the 22nd International AIDS Conference in Amsterdam, Netherlands, July 23–27, 2018.

Declaration of Interest: The authors report no conflicts of interest.

from Option B+ programs within three months of starting ART.(Hauser et al., 2018) For Option B+ to improve HIV outcomes, sustained engagement in HIV care is essential.

For women in Option B+, clinic transfers may influence engagement in HIV care. Recent estimates from Malawi and South Africa suggest 30% or more of women who default from Option B+ programs, have self-transferred (e.g. moved without a formal transfer) to a new clinic.(Clouse et al., 2017; Tweya et al., 2014) Self-transferring leads to underestimates of retention in ART programs and may lead to gaps in HIV care and treatment.(Wilkinson, Skordis-Worrall, Ajoye, & Ford, 2015) However reasons for transferring between clinics are not well understood.(Buchberg et al., 2015; Ferguson et al., 2014; Guga et al., 2017; Mitiku, Arefayne, Mesfin, & Gizaw, 2016; Muhumuza et al., 2017; Tweya et al., 2018) The aim of this qualitative study was to explore the reasons for clinic transfers and how transferring affected engagement in care among HIV-infected pregnant women.

Methods

We conducted a qualitative study including HIV-infected pregnant women in Option B+ and healthcare workers (HCWs) at two large urban clinics in Lilongwe, Malawi between October and December 2017. We conducted a total of eight focus group discussions (FGD) and five in-depth interviews (IDI). Four FGDs were conducted with HIV-infected women and four with HCWs. Among HIV-infected women, FGDs were further stratified between women newly initiating ART (n=2 FGD) and those re-initiating ART (n=2 FGD). All participants were 18 years of age and living in Lilongwe District, Malawi.

FGD and IDIs were conducted by a trained research assistant fluent in English and Chichewa, the local language in Malawi. Interviews were conducted in Chichewa, translated into English, and checked for accuracy before being entered into Nvivo v.11. We used deductive and inductive coding to identify key themes. (Bernard, 1995) All participants provided written informed consent and ethical approval was provided by the University of North Carolina and National Health Sciences Research Committee.

Results

Nine HIV-infected women participated in two FGD for women initiating ART and ten women participated in two FGD for women re-initiating ART (n=19 women total). Women initiating ART for the first time were slightly younger than women re-initiating ART (median age 26.5 versus 28). The majority of women (53%) completed primary school (S1-S7) and were either a housewife/caretaker or a small business owner. All but three women were married (2 divorced and 1 never married). Twenty-five HCWs from a range of roles completed four FGDs and five HCWs completed IDIs.

We identified two broad internal factors – mobility and disclosure—that played key roles in shaping women’s decisions about when to transfer HIV clinics and impacted engagement in HIV care.

Mobility

Nearly half of all women in FGDs discussed mobility as a factor influencing ongoing engagement in HIV care, and in some cases the choice to transfer clinics. Key drivers of mobility for women included changes in residence, employment, and relationship status.

There are some women who come here (Lilongwe) for a short while because their husbands are doing temporary work and they may get pregnant during that time. They start ANC and may find out that they are also HIV-positive yet they are not staying around for long. When the husband's contract expires, ... They may have to move with very little notice and so they do not even come to the clinic to inform us that they are moving back to the village. -FGD 4, mentor mother

For women, mobility often presented challenges in accessing HIV care. In Malawi, formally transferring clinics requires a patient to obtain their 'master card', or clinic health record, and a letter from her original clinic. In practice, obtaining one's master card and a letter before moving was often not feasible.

The time I started medication, before I realised the importance I did stop. I stopped for 4 months and then I thought about it and got pregnant for this child. Well, how I stopped? I had moved from Blantyre and I didn't take my thing [master card]. – FGD 3, woman re-initiating ART

Disclosure

Inadvertent disclosure of HIV status was a strong motivator for women to transfer HIV clinics. Inadvertent disclosure of one's HIV status was common when women unexpectedly saw friends or acquaintances at the clinic. Seeing the acquaintance triggered fear that the person would either know or assume they were HIV infected, and prompted concerns about stigma.

There are some neighbours especially those who are not HIV positive, when they learn of your status, it's a burden. They insult you and tell other people to not associate with you and so everyone then knows your status. So you decide not to tell anyone... – FGD 3, woman re-initiating ART

To protect themselves from inadvertently disclosing their HIV status, some women used two health passports (one for HIV appointments and one for everything else), provided false contact information so they could not be traced, or chose to transfer to a different clinic.

For example, let's say I am a client and I see my neighbor on the queue for collecting ARVs; I will not join the queue but I will just be walking about the building... I make a decision to change clinics and when I get to the ART clinic, I tell the staff there that I want to move to [a different] clinic just because I have seen my neighbor there. -FGD 4 mentor mother

Concerns about disclosure were particularly acute for women newly initiating ART and struggling with decisions about disclosing their status to their family, friends, and partner.

Some [women who are diagnosed with HIV] do not take it well. They may decide not to tell their husbands. Some even refuse to start treatment. They eventually

come when they are very sick and for the drugs to start working at that point it's a little late... – FGD 1, women initiating ART

Implications of clinic transferring on HIV care

Women who moved frequently reported being away from their home clinic for several months at a time. The ability to maintain an adequate treatment supply during their time away was a concern.

It would be possible if she explains at her current clinic that she is traveling and will be away for several months or a year... If the clinics are only able to give out drugs for a month or two, then it might not be possible and she may be required to explain her situation to the clinic at the place she is visiting. – FGD 1, woman initiating ART

For women moving to a new clinic, not having a formal transfer letter was a barrier to continuity in HIV care. For example, of the ten women in our study who had previously defaulted from HIV care and were re-initiating ART, six described barriers in receiving care when transferring clinics.

... they told me to go back home and said I was not serious about my life. They told me to find another clinic and that maybe the other clinic would be able to handle me better. They told me that they would not give me any [patient identification] number ...or file.–FGD 5, woman re-initiating ART

When women moved clinics and presented without a formal transfer letter or used a different name, the most common outcome was that they were re-tested for HIV and re-initiated on ART treatment.

...these women who are already on ART, they have been re-tested. So I don't know why they would like to cheat us because we have seen some women who come in, they are already positive but they hide and start as if they're new – FGD 8, nurse

Discussion

In this qualitative study, mobility and fear of inadvertently disclosing one's HIV status were important drivers of the decision to transfer clinics among HIV-infected pregnant women. Women were aware of the need to obtain a formal transfer, but in practice this was challenging and in some cases limited access to HIV care. Self-transferring frequently resulted to re-testing and re-initiating ART, and in some cases disrupted access to HIV care.

For HIV-infected pregnant women, non-disclosure is associated with a range of sub-optimal HIV outcomes, including delayed ART initiation and detectable viral load at delivery. (Jasseron et al., 2013; Onono, Cohen, Jerop, Bukusi, & Turan, 2014) Fears of stigma, abandonment, or intimate partner violence are barriers to disclosing to a partner. (Medley, Garcia-Moreno, McGill, & Maman, 2004; Naigino et al., 2017; Tam, Amzel, & Phelps, 2015) In our study concerns about disclosing to family and friends was an important driver of transferring clinics. In addition, nearly half of all women in our study discussed mobility as a factor influencing access to HIV care. (Clouse et al., 2018) Mobility is associated with

an increased risk of sub-optimal ART adherence, and gaps in HIV care in non-pregnant populations.(Clouse et al., 2017; Lima et al., 2009; Tanser, Barnighausen, Vandormael, & Dobra, 2015; Taylor et al., 2014) Our study suggest mobility may also adversely affect engagement in HIV care among pregnant women.

As lifelong ART becomes standard of care, women will continue to transfer clinics. A clear understanding of how transferring clinics affect HIV outcomes and strategies to accommodate transfers without disrupting care are needed to support sustained engagement in care.

Acknowledgements:

We thank the women and healthcare workers who participated in this study. This work was supported by the National Institute of Mental Health [grant number K99MH112413] and the University of North Carolina at Chapel Hill Center for AIDS Research [grant number P30 AI50410].

Funding: This work was supported by the National Institute of Mental Health [grant number K99MH112413] and the University of North Carolina at Chapel Hill Center for AIDS Research [grant number P30 AI50410].

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