

Challenges and Opportunities for Improving Early Initiation of ART: A Thematic Analysis of Experiences among Individuals Recently Diagnosed with HIV

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Background

Clinical guidelines in the province of British Columbia (BC), Canada, advise individuals diagnosed with HIV to initiate antiretroviral therapy (ART) immediately to improve long-term health outcomes and decrease the likelihood of transmission. ART and related care are provided at no direct cost for persons living with HIV (PLHIV) in BC.

Despite these clinical guidelines and the widespread availability of ART, delaying ART initiation remains a persistent issue for recently diagnosed PLHIV, and creates gaps in the **HIV cascade of care*** at both individual and population levels.

This thematic analysis explores individuals' experiences of and attitudes towards ART initiation to better understand how time between HIV diagnosis and treatment initiation may be decreased.

*The **HIV cascade of care** refers to the percentage of people living with HIV, and of those people how many are HIV-diagnosed, linked to HIV care, retained in HIV care, on ART, and have achieved viral suppression (≤ 200 copies/mL).

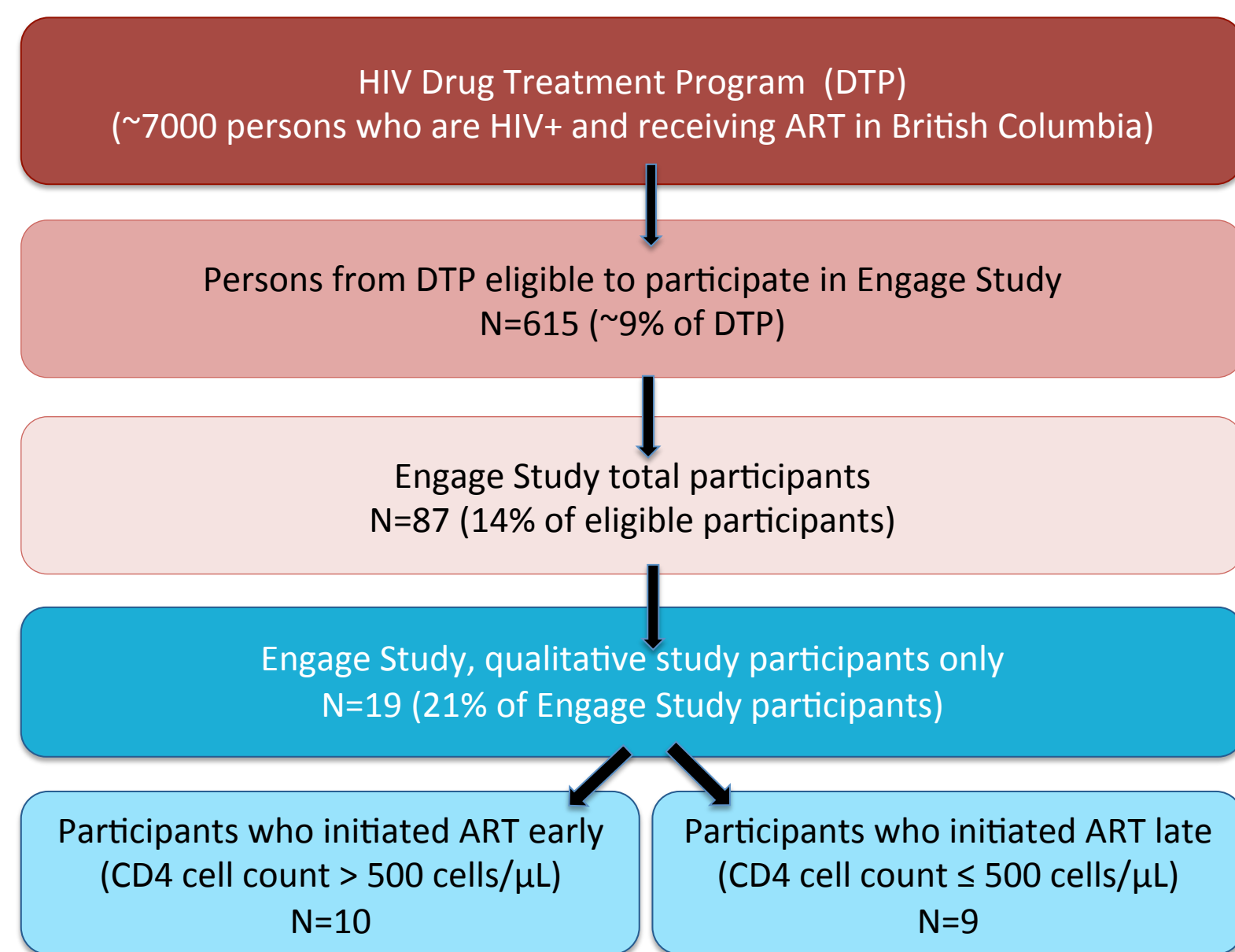
Methods

Data for this analysis were obtained from the Engage Study – a prospective cohort of new ART initiators linked to clinical data in the provincial Drug Treatment Program at the BC Centre for Excellence in HIV/AIDS. Engage participants completed baseline and follow-up surveys on their experiences initiating ART. Individuals were eligible if: over the age of 19; living with HIV; a BC resident; able to complete the survey in English; and initiated ART for the first time ever within the study enrollment period (December 2013 - December 2015).

Of the 87 Engage Study cohort participants, the research team sought to purposely recruit 20 individuals to participate in qualitative interviews. Recruitment was based on ART initiation time, whereby participants were categorized as either “late” (CD4 cell count of ≤ 500 cells/ μ L at time of ART initiation) or “early” (CD4 cell count of > 500 cells/ μ L at the time of ART initiation). 19 participants were successfully recruited. Dichotomization based on CD4 count was used as a proxy to indicate persons who have delayed accessing treatment or care, given that researchers were only able to document date of diagnosis (i.e. when the individual sought testing), rather than date of infection.

A peer research associate (PRA) – a PLHIV trained in data collection – conducted in-depth qualitative interviews from March to August 2015. The interview guide was structured to elucidate participants' HIV-related experiences (e.g. testing, diagnosis, treatment). Interviews were recorded and transcripts and imported into qualitative software, NVivo 10.2, for coding and thematic extraction. Three members of the research team met regularly to discuss themes emerging from the data and develop the coding structure for analysis.

Figure 1. Participant Inclusion Cascade



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Conflict of Interest Disclosure: The authors have no conflicts of interest to declare.

For more information please visit:

www.cfenet.ubc.ca/research/engage-study

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Results

Table 1. Demographic Profile of Qualitative Participants (n=19)

Total Qualitative Participants (N=19)			
Variable	(Q1-Q3) or n (%)	Variable	(Q1-Q3) or n (%)
CD4 cell count before date as first ART initiation	510 (200-670)	Age at time of interview	
Cells/ μ L		Years	41 (30-48)
Time from HIV diagnosis to 1 st ARV		Monthly personal income	
Months	3 (1-8)	CAD\$	1050 (600-2600)
Gender		Ethnicity	
Male	17 (89.5)	Indigenous	3 (15.8)
Female	1 (5.3)	Caucasian	14 (73.7)
Transgender/Other	1 (5.3)	Asian	2 (10.5)
Ever injection drug use		Ever incarcerated	
No	15 (79.0)	No	18 (94.7)
Yes	4 (21.1)	Yes	1 (5.3)

90% of participants were male, 16% reported Indigenous ancestry with median age of 41 years. There was no significant difference in key socio-demographics between participant groups. **The range of individuals' experiences of and attitudes towards ART initiation is described below and supported with selected quotations.**

Reasons reported for seeking treatment or care immediately included:

- Participants were well informed about ART and wanted to achieve an undetectable plasma viral load (pVL) to minimize transmission
- Minimal concern around medications impacting daily life
- ART considered to be a standard medical practice for treating HIV

“I wanted to drop my viral load to undetectable level to protect my partner who I wanted to continue having.” – Participant 4

“Having access to medication right away is of prime importance, and that it gives people a feeling of control, which I think is half the battle for people feeling emotionally more at ease with themselves.” – Participant 13

Reasons reported for avoiding or delaying seeking treatment or care included:

- ART considered a last resort once symptoms provided no alternative
- Lack of understanding around the individual benefits of ART
- Stigma impacting decision-making (i.e. denial or fear of others knowing their status)
- Some doctors presenting ART initiation as optional depending on CD4 cell count and pVL levels
- Participants feeling overwhelmed or fearful about HIV and the complexity of HIV care

“I was in really good health, I was in good shape. I didn't have to worry about anything. Like I knew a lot of other people who had HIV and they didn't take meds and they're fine...If I had never gotten pneumonia, I would never have gotten on meds.” – Participant 20

“[The doctor] took me in and just kept on testing me and seeing where my load was, where my T-cells were, and they were still pretty good, they were still pretty strong. So they didn't put me on any medication right away.” – Participant 15

Discussion

Education related to ART efficacy was the most common factor impacting perceptions of both persons seeking and avoiding treatment. These results suggest that additional interventions are needed to improve awareness of early ART initiation, and existing HIV educational interventions should be scaled-up across populations.

Stigma emerged as a cross-cutting theme for reasons to delay seeking treatment or care, suggesting that fear and/or denial associated with HIV-related stigma may prevent participants from seeking treatment or care despite knowing the benefits.

ART education interventions that communicate both individual and population level benefits should be scaled-up in order to increase early ART initiation and accelerate the proportion of PLHIV along the cascade of care. Efforts to minimize HIV-related stigma should remain an important focus throughout the development of these interventions.