

“What Will Become of Me if They Take This Away?” Zimbabwean Women’s Perceptions of “Free” ART

Clara M. Gona, PhD, RN, FNP-BC*

Eileen McGee, PhD, RN

Rosanna DeMarco, PhD, RN, ACRN, FAAN

The evolution of antiretroviral therapies (ART) has redefined HIV infection from a life-threatening disease to a chronic manageable condition. Despite ART, HIV infection remains a serious health burden in Zimbabwe, particularly among women of reproductive age. In this interpretive phenomenology study, we interviewed 17 women with advanced HIV infection to uncover and understand their experiences of living with HIV infection in the ART era. Two themes (knowing the restorative power of ART and the heavy burden of being infected with HIV) reflected the women’s experiences. ART brought physical and mental relief, but did not change the sobering reality of poverty or the challenges posed by the infective nature of HIV. The heavily donor-funded Zimbabwean ART program has been a success story, but there is uncertainty over its long-term sustainability. In resource-limited countries, clinicians and other stakeholders should continue to focus on HIV prevention as the cornerstone of HIV programming.

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Widespread use of antiretroviral therapy (ART) together with behavior modification has been credited with stabilizing Zimbabwe’s HIV prevalence rate from a peak of 26.5% in 1997 to 15% in 2013 (Zimbabwe Ministry of Health and Child Care

[MOHCW], 2014). HIV infection continues to be a major health crisis, with 1.4 million people estimated to be living with the disease in Zimbabwe (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2014). Women bear the biggest burden of HIV infection, comprising at least 59% of adults living with HIV infection in 2013 (MOHCW, 2014). In Zimbabwe, women are the major beneficiaries of the ART distribution program. Mutasa-Apollo et al. (2014) reported that women accounted for 64% of patients started on ART between 2007 and 2010.

The advent of ART has changed the HIV infection landscape from being a deadly disease to a chronic illness that can be routinely managed (Campbell, Skovdal, et al. 2011). ART has been available in Zimbabwe since the early 2000s and has been credited with the reduction of annual HIV infection-related deaths from 115,117 in 2011 to 61,476 in 2013. Unfortunately, not all people currently in need of ART have access to medications, with only

*Clara Gona, PhD, RN, FNP-BC, is an Assistant Professor, MGH Institute Health Professions School of Nursing, Boston, Massachusetts, USA. (*Correspondence to: cgonamghihp.edu). Eileen McGee, PhD, RN, is an Associate Professor of Practice, School of Nursing and Health Sciences, Simmons College, Boston, Massachusetts, USA. Rosanna DeMarco, PhD, RN, APHN-BC, FAAN, is a Professor and the Chair, Nursing, College of Nursing and Health Sciences, University of Massachusetts, Boston, Massachusetts, USA.*

77% of adults and 44% of children in need of ART actually on treatment in 2014 (UNAIDS, 2014).

ART in Zimbabwe is available through a “cost-free” program funded by donor agencies and the government (UNAIDS, 2014). Currently, Zimbabwe is facing serious economic and political problems and is heavily reliant on donated medications for HIV treatment; there are reports that up to 92% of all medications used in 2014 were donor-funded (Nleya, 2014). So concerning is the current health-sector dependence on donors that the donors themselves have started to publicly voice those concerns (Mbanje, 2015). Meanwhile, stories of ART shortages in the government program abound in the local media (Chipunza, 2012; Chitagu & Tunhira, 2013; Mambo, 2014). The Zimbabwe National Statistics Agency (2012) reported that approximately 72% of the population lived below the poverty line in 2012, resulting in most patients being forced to depend on “free” medications for their survival.

The predominant culture also plays a crucial role. The country is largely a patrilineal society where a woman’s success is defined by her roles as wife and mother. Zimbabwean women are expected to be married and have children (Gona & DeMarco, 2015; Kambarami 2006; Mungwini, 2008; Schmidt, 1996). Living with HIV infection superimposes the expectation that a return to a normal life not only depends on the assurance of uninterrupted access to ART, but also the ability to get married and bear children. Although psychological, social, and economic improvements in the lives of women on ART (Campbell, Scott, Madanhire, Nyamukapa, & Gregson, 2011; Campbell, Skovdal, et al., 2011; Mutasa-Apollo et al., 2014; Patel et al., 2009; Skovdal, Campbell, Nyamukapa, & Gregson, 2011) as well as clinical biomarker improvements (Mutasa-Apollo et al., 2014; Patel et al., 2009) have been reported, it is also true that husbands, upon discovering that their wives were taking ART, interfered with the wives’ care by forbidding them from doing so (Skovdal et al., 2011). Although ART has successfully reduced mortality in Zimbabwe, HIV disease remains a major health crisis requiring continual evaluation as well as new treatment and prevention interventions. To be effective, treatment and prevention interventions should take the patient’s

experiences into account. The purpose of our study was to describe the experience of being diagnosed and living with HIV infection for Zimbabwean women. The women’s experiences of being diagnosed with HIV infection have been reported elsewhere (Gona & DeMarco, 2015).

We report here on Zimbabwean women’s experiences of living with HIV infection while on ART. We aimed to provide a deeper understanding of what it was like for these women to be on ART and also to give voice to women living with HIV in Zimbabwe. Gaining a deeper understanding of women’s experiences will inform health care providers and policymakers as they develop sustainable HIV prevention, treatment interventions, and policies.

Methods

The setting and design of our study has been described previously (Gona & DeMarco, 2015). Briefly, interpretive phenomenology as described by van Manen (1997) was used to study the women’s lived experiences. We conducted in-depth, individual, face-to-face, open-ended interviews. Data interpretation began during the interview process and continued throughout the course of the study.

Sampling

Purposeful sampling was used (Patton, 2001). The study was nested within an ongoing ART clinical trial at the University of Zimbabwe Clinical Research Center. To participate in the clinical trial, participants were required to meet the World Health Organization (2002) AIDS diagnosis criteria. We recruited volunteer participants from the ART trial support group. Inclusion criteria for the study included: (a) older than 18 years of age, (b) confirmed HIV diagnosis for at least 12 months, and (c) fluency in the local Shona language. Women with mental and cognitive conditions or who were too ill to withstand an interview were excluded. We interviewed participants until data saturation was achieved (Lincoln & Guba, 1985). Data saturation occurred after interviewing 17 women, and we were no longer getting new information.

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