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Antiretroviral therapy initiation and adherence in rural South Africa: community health workers' perspectives on barriers and facilitators

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Abstract

South Africa has the largest global HIV/AIDS epidemic, but barriers along the HIV care continuum prevent patients from initiating and adhering to antiretroviral therapy (ART). To qualitatively explore reasons for poor ART initiation and adherence rates from the unique perspective of community health workers (CHWs), we conducted focus groups during May–August 2014 with 21 CHWs in rural Msinga, KwaZulu-Natal. Interviews were audio-recorded, transcribed, and translated from Zulu into English. Hybrid deductive and inductive analytical methods were applied to identify emergent themes. Multiple psychosocial, socioeconomic, and socio-medical barriers acted at the level of the individual, social network, broader community, and healthcare environment to simultaneously hinder initiation of and adherence to ART. Key themes included insufficient patient education and social support, patient dissatisfaction with healthcare services, socioeconomic factors, and tension between ART and alternative medicine. Fear of lifelong therapy thwarted initiation whereas substance abuse principally impeded adherence. In conclusion, HIV/AIDS management requires patient counselling and support extending beyond initial diagnosis. Treating HIV/AIDS as a chronic rather than acute infectious disease is key to improving ART initiation and long-term adherence. Public health strategies include expanding CHWs' roles to strengthen healthcare services, provide longitudinal patient support, and foster collaboration with alternative medicine providers.

Keywords

Antiretroviral therapy; initiation; adherence; barriers to care; community health workers; South Africa

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1. Introduction

South Africa has the largest global HIV/AIDS epidemic, with an estimated 19.1% adult prevalence (World Health Organization, 2013). In 2004, the South African government began scaling up public sector HIV resources to make antiretroviral therapy (ART) widely available, including providing ART free of charge and expanding HIV care through community programmes (South African Department of Health, 2007). Although this has improved access (UNAIDS, 2012), only 42% of people with HIV were taking ART as of 2013 (World Health Organization, 2015).

In Sub-Saharan Africa, patient drop-off occurs at each step along the HIV continuum of care (Bassett et al., 2009, 2010; Kranzer et al., 2010, 2012; Larson et al., 2010; Rosen & Fox, 2011). While suboptimal ART adherence continues to thwart community-wide viral suppression (Chaiyachati et al., 2014; Dewing, Mathews, Fatti, Grimwood, & Boulle, 2014), attention is shifting to individuals diagnosed but not yet initiated on ART. Evidence suggests that a substantial and potentially growing number of patients never initiate therapy despite being eligible (Bassett et al., 2009, 2010; Kranzer et al., 2012).

While quantitative studies and meta-analyses throughout Sub-Saharan Africa have laid the groundwork (Bassett et al., 2009, 2010; Kranzer et al., 2010, 2012; Larson et al., 2010; Mberi et al., 2015; Mulissa, Jerene, & Lindtjorn, 2010; Nachega et al., 2015; Rosen & Fox, 2011), qualitative methods have recently provided in-depth insight into the suspected barriers to ART initiation and adherence (Corneli et al., 2008; Lifson et al., 2013; Lubega et al., 2010; Mbonye, Seeley, Ssembajja, Birungi, & Jaffar, 2013; Mshana et al., 2006; Musheke, Bond, & Merten, 2013; Sanjobo, Frich, & Fretheim, 2008). The few qualitative studies conducted in South Africa have primarily focused on reasons patients drop-off the care continuum after enrolling in ART (Coetzee, Kagee, & Vermeulen, 2011; Dahab et al., 2008; Miller, Ketlhapile, Rybasack-Smith, & Rosen, 2010); the most commonly cited barriers are stigma, socioeconomic challenges, and overall difficulty accessing and navigating the healthcare system (Michel, Matlakala, English, Lessells, & Newell, 2013).

In the setting of South Africa's ART scale-up and healthcare workforce shortages, community health workers (CHWs) are increasingly recognized as potential contributors to healthcare (Global Health Workforce Alliance and WHO, 2010; Lehmann & Sanders, 2007; South African Department of Health, 2007). Working effectively in various capacities including HIV/AIDS, maternal and child health (Kipp, Kabagambe, & Konde-Lule, 2002; Lehmann & Sanders, 2007; Lewin et al., 2010), CHWs are members of the communities where they work and supported by, but not necessarily a part of, the formal healthcare system, with shorter training than professional workers (World Health Organization, 1989). In South Africa, CHWs tend to be women who serve as lay counsellors and are valuable human resources connecting patients with evidence-based medicine (Root & Whiteside, 2013; Zulliger, Moshabela, & Schneider, 2014). As community members themselves, some being HIV-positive, CHWs also possess a unique perspective on healthcare and its array of challenges.

Thus far, CHWs have been minimally utilized in research towards understanding barriers and potential interventions to improve ART effectiveness. In addition, barriers to ART initiation and adherence have been studied in isolation from each other, making it difficult to assess the degree to which they overlap and whether interventions could be developed to simultaneously address both issues. The identification of such barriers and interventions to address them are urgently needed to prevent drop-off at both the initiation and adherence stages of the care continuum, particularly in rural settings where risk of drop-off appears to be higher but research has been sparse (Bassett et al., 2010; Peltzer, Friend-du Preez, Ramlagan, & Anderson, 2010). The goal of this qualitative study was to gain an in-depth understanding, from the perspective of CHWs, of the barriers to both ART initiation and adherence in KwaZulu-Natal, South Africa.

2. Methods

2.1. Setting

KwaZulu-Natal Province of South Africa has the world's highest HIV prevalence (37.4% among pregnant women) (Republic of South Africa: National Department of Health, 2013). Its rural, resource-limited Msinga subdistrict is home to approximately 180,000 traditional Zulu people (Lehohla, 2012). The healthcare infrastructure is composed of a 350-bed district government hospital, 16 satellite primary healthcare clinics, and a local non-profit organization (NPO) providing HIV and TB services.

2.2. Recruitment and informed consent

Eligible participants were CHWs with ≥2 years of experience working with HIV patients in Msinga. From 32 eligible CHWs in the NPO's home-based care branch, 26 were purposively selected to produce a sample with at least one representative from each major Msinga neighbourhood. Twenty-one of 26 were contactable and able to commute for scheduled focus groups. After explaining our goal – to better understand challenges patients currently encounter during ART initiation and adherence, and reasons why patients delay or discontinue ART – all participants gave written consent allowing interviews to be recorded and transcribed. Participants were compensated for travel expenses.

2.3. Interview guide

Semi-structured focus groups explored CHW perspectives on: (1) the HIV continuum of care, (2) patients' experiences with testing, HIV/ART education, and ART, and (3) barriers to and facilitators of ART initiation and adherence. The interview guide first asked a key question regarding ART initiation, followed by at least one probe regarding initiation, and then a related key question regarding ART adherence with relevant probes. The interview guide was constructed based on existing literature, modified using feedback from NPO staff, then professionally translated from English into Zulu and back-translated to verify appropriate language and intent.

2.4. Data collection

Three focus groups of 2.5 hours duration with 7 CHWs each (21 CHWs total) were conducted in a private conference room. The lead researcher and a qualitatively trained, native Zulu-speaking researcher used questions and probes to promote open discussion. Participants were instructed to state their randomly assigned number prior to speaking, allowing the participant speaking to be identified on the transcript and the interviewer to facilitate equal participation among group members. Most participants were forthcoming, answering almost every question while allowing other group members to contribute. Interviews were audio-recorded and notes taken on key themes and non-verbal cues. Recordings were professionally transcribed and translated into English; interviewer notes were incorporated.

2.5. Data analysis

Transcripts were thematically analysed using a hybrid approach of deductive and inductive coding borrowed from grounded theory (Bradley, Curry, & Devers, 2007; Fereday & Muir-Cochrane, 2006; LeCompte & Schensul, 1999; Miles MB, 1994). An initial codebook was developed based on deductive (theory-driven) themes from existing literature. During data collection, transcripts and notes were reviewed to identify emerging inductive (data-driven) themes and appropriately modify the interview guide and codebook. This revised codebook was applied to the first focus group transcript, and discrepant codes were resolved by discussion with the larger, multidisciplinary research team. The final coding guide was then applied to the entire dataset using Atlas.ti software. Data displays for relevant codes and simple frequencies were used to identify patterns and prominent themes.

2.6. Ethics

This study was approved by institutional review boards at South African Medical Association (SAMA) in Pretoria, South Africa and Yale University in New Haven, Connecticut, USA.

3. Results

3.1. Sample demographics

All 21 CHWs were female, with mean age 44.3 (±11.7) years, representing 21 neighbourhoods served by 12 different clinics. Fourteen had ≥10 years of community work experience.

3.2. Patient education and the perception of “HIV normalcy”

CHWs concurred that the literacy classes required before ART initiation helped prepare patients for the realities of taking ART, thereby improving their likelihood of sustained adherence (Table 1. Quote 3.2, #1). Afterward, however, patients demonstrated variable comprehension (Table 1. Quotes 3.2, #2–3). ART literacy classes also provided an opportunity to educate patients' partners, family members, and other “treatment supporters”, enabling them to provide support and motivation. Treatment supporters were crucial to the initiation process, particularly when patients were too ill to fully engage in classes (Table 1. Quotes 3.2, #4–5).

CHWs felt that healthcare staff viewed HIV infection as a “normal” occurrence in this region, leading to inadequate education of newly diagnosed patients when counsellors assumed they already possessed basic HIV knowledge (Table 1. Quote 3.2, #6). After initiating ART, patients needed reinforcement and ongoing support to address concerns that developed over time. Both new and long-time ART patients needed to be "reminded of the importance of keeping to [taking ART on] time no matter how long you have been on the treatment…you still need to be careful".

3.3. Perspectives on HIV: the individual, household, and community

3.3.1. Denial: manifestations and effect on ART—Successful ART initiation required patients to fully accept their HIV diagnosis and commit themselves to treatment. Denial and "fear of what they are" had serious consequences including procrastinating ART initiation, not collecting refills, and lying to clinic staff regarding adherence (Table 1. Quote 3.3.1, #1). CHWs reported that men in particular tended to mistrust HIV test results and believe clinic staff were deceiving them (Table 1. Quote 3.3.1, #2). The magnitude of this denial also negatively impacted HIV-infected family members as some men prohibited wives or children from taking ART (Table 1. Quote 3.3.1, #3).

3.3.2. Disclosure and social support—Patients who accepted their HIV diagnosis were still afraid to disclose to family members and sexual partners (Table 1. Quotes 3.3.2, #1–3). Disclosure discouraged ART use when it resulted in blame for one's HIV infection or threat of expulsion from the home (Table 1. Quote 3.3.2, #4). Family members' poor understanding of HIV and its transmission routes led to stigmatization at home and pressure to visit traditional healers (Table 1. Quotes 3.3.2, #5–6). Thus, ongoing communication between patients, family members, and CHWs both before and after ART initiation was essential.

Nevertheless, disclosure could facilitate ART use by strengthening social support and motivating both patient and treatment supporter. Family members – in one case a child for his HIV-positive mother – helped collect monthly refills and provided daily adherence reminders (Table 1. Quote 3.3.2, #7). The desire to live to care for one's children also strongly motivated ART initiation (Table 1. Quote 3.3.2, #8). Patients who relocated risked failing ART if the move isolated them from their social support network.

3.3.3. Stigma—Despite many patients understanding the steps necessary to initiate and adhere to ART, shame and fear of being associated with HIV/AIDS kept some from attending clinics, particularly stand-alone HIV clinics (Table 1. Quotes 3.3.3, #1–2). Fear of acquaintances identifying them there or co-workers seeing them take their medications at work was enough to deter patients from even initiating ART (Table 1. Quotes 3.3.3, #2–5).

3.4. Socioeconomic factors

3.4.1. Poverty, unemployment, and lack of resources—Lack of funds for food and transportation were two common manifestations of socioeconomic hardship affecting ART. Household breadwinners felt forced to choose between personal health and providing for family (Table 2. Quote 3.4.1, #1). Food insecurity was a strong predictor of suboptimal ART use; patients without access to food failed to initiate or discontinued ART after experiencing nausea from taking ART on an empty stomach (Table 2. Quote 3.4.1, #2).

Patients borrowed money just to make the initial clinic visit to initiate ART and, in desperation, even turned to CHWs for help with expenses (Table 2. Quote 3.4.1, #3).

3.4.2. Substance abuse—The use of alcohol, tobacco, marijuana, glue, and "whoonga" (an addictive illicit substance derived from the antiretroviral agent Efavirenz) (Grelotti et al., 2014) was problematic for patients initiating ART who clung to their substance-using social networks and for patients who overlooked their medications while under the influence (Table 2. Quotes 3.4.2, #1–3). Some used substances to cope with their diagnosis (Table 2. Quote 3.4.2, #4). A case of long-term domestic abuse of an HIV patient and the recent development of strict clinic policies to prevent individuals falsely claiming HIV infection from accessing Efavirenz exemplify ways in which whoonga impedes ART adherence (Table 2. Quotes 3.4.2, #5–6).

3.5. Perspectives on lifelong ART and side effects

The prospect of lifelong medication so intimidated patients that they avoided ART or waited to become severely ill before initiating (Table 2. Quotes 3.5, #1–2). Another barrier was fear of experiencing ART side effects (e.g., lipodystrophy) and fear that these effects (e.g., physical changes) would make them identifiable as HIV-positive (Table 2. Quotes 3.5, #3–4). Experiencing side effects often cast doubt on their diagnosis, leading to ART discontinuation (Table 2. Quote 3.5, #5). Others blamed ART for side effects such as changes in sex drive that complicated their sexual partnerships and created social pressure to stop ART (Table 2. Quote 3.5, #6). Nevertheless, some patients were encouraged to initiate by seeing others improve on ART and learning about simpler regimens including the single daily fixed drug combination tablet (Table 2. Quotes 3.5, #7–8).

3.6. The healthcare environment

3.6.1. Interactions with the healthcare system—Clinics could encourage ART through strong initial counselling, positive interpersonal interactions, and ART pre-packaging programmes to reduce collection wait times. However, negative healthcare experiences impacted both initiation and adherence. Perceptions of poor treatment by staff discouraged patients from revisiting local clinics. Frustration with poor organization, misplaced patient files, long wait times, medication shortages, and lack of access to mobile clinics during the rainy season discouraged ART initiation and led to poor patient adherence (Table 3. Quotes 3.6.1, #1–3).

Certain healthcare policies, such as mandating a primary care clinic referral letter prior to hospital level evaluation, presented inconvenient and sometimes dangerous barriers to care. This policy became problematic in emergency settings, especially for patients with limited transportation funds (Table 3. Quotes 3.6.1, #4–5). The transfer-of-care referral process was also confusing to patients and even some CHWs, presenting obstacles for patients who were relocating (Table 3. Quotes 3.6.1, #6–7).

3.6.2. Alternative medicine—CHWs felt that the influence of traditional healers and religious leaders undermined the evidence-based medical community's efforts to initiate and retain patients on ART, with dire morbidity and mortality consequences (Table 3. Quotes

3.6.2, #1–3). Patients in denial of their diagnosis or the existence of HIV altogether first sought help from traditional healers rather than HIV care providers. Even after ART literacy classes, traditional beliefs outweighed faith in the healthcare system (Table 3. Quotes 3.6.2, #4–5). The promise of a short-term, “curative” traditional remedy was more attractive than lifelong ART (Table 3. Quotes 3.6.2, #6–7). Furthermore, traditional healers' services were perceived by patients to be more attentive and individualized than clinic care, creating competition that discouraged ART (Table 3. Quote 3.6.2, #8).

4. Discussion

To our knowledge, this is the first study in South Africa to simultaneously explore barriers to and facilitators of ART initiation and adherence from the community perspective. Thus, this study contributes to the growing body of qualitative literature aiming to better understand reasons for poor ART initiation and adherence rates in Sub-Saharan Africa. Our results suggest that ART non-initiation and non-adherence share similar etiologies and may benefit from similar interventions. Furthermore, shifting to a chronic disease model of HIV care and facilitating ART initiation in both symptomatic and asymptomatic patients would benefit long-term engagement in care. Through the expansion of home-based care interventions (Decroo et al., 2014; Grimsrud, Lesosky, Kalombo, Bekker, & Myer, 2015), CHWs are uniquely positioned to help mitigate barriers to care such as stigma, denial, inadequate patient education, poor social support (Root & Whiteside, 2013; Zulliger et al., 2014), and patient preferences for alternative medicine (Appelbaum Belisle et al., 2015; Peltzer, Friend-du Preez, Ramlagan, Fomundam, & Anderson, 2010).

Barriers to initiation have a lingering impact on adherence efforts later in the HIV continuum of care and, likewise, barriers to adherence tend to feedback by deterring newly diagnosed patients from initiating (Figure 1). From the perspective of the CHWs interviewed, factors relevant to both initiation and adherence are patient education (HIV/ART literacy and counsellors' perception of “HIV normalcy”), individual and community perspectives on HIV (denial, fear of disclosure, social support, and stigma), socioeconomic factors (poverty and substance abuse), perspectives on ART (fear of lifelong treatment and side effects), and dissatisfaction with the healthcare environment (negative interactions with the healthcare system and seemingly viable alternative therapies). Fear of lifelong therapy is a barrier exclusive to initiation whereas substance abuse primarily impedes adherence. Through frameworks such as Auerbach's socioeconomical model, these factors can be conceptualized as acting at the level of the individual patients, their relationships with others, and the broader healthcare environment (Figure 2) (Auerbach, 2009; Mantell, DiVittis, & Auerbach, 1997).

Patients who commit to taking ART and proactively seek guidance from CHWs are more likely to initiate ART. Strong motivators for initiation and adherence include children and family (Dahab et al., 2008), seeing others improve on ART, positive interactions with healthcare staff, comprehensive counselling at time of diagnosis, and learning about less complex ART regimens (Bogart et al., 2013). Similarly, witnessing improved health with ART and death in those who stop ART can also impact adherence.

Patients who overcome personal barriers such as denial are still faced with extensive community barriers including stigma, poverty, and challenges navigating the healthcare environment (Abrahams & Jewkes, 2012; Dahab et al., 2008, 2011; Miller et al., 2010). Barriers along the care continuum necessitate long-term guidance and reinforcement of ART that is not readily available. CHWs can mediate conflict prompted by status disclosure and support families as they navigate the care continuum (Root & Whiteside, 2013; Zulliger et al., 2014). Given recent advances in ART regimens, patients with clear expectations regarding lifelong treatment and knowledge about ART side effects may be more successful. Ongoing HIV/ART education reinforcement from CHWs and healthcare staff may combat societal pressures and reconcile conflicting health information that discredits ART (Knight, Van Rooyen, Humphries, Barnabas, & Celum, 2015; Root & Whiteside, 2013).

In resource-limited settings, patients have many competing priorities; employment and providing for family are often paramount (Michel et al., 2013; Miller et al., 2010). Mitigating socioeconomic strain by recognizing patients' limitations is key to improving HIV/AIDS outcomes (Auerbach & Coates, 2000; Geng et al., 2010). Evidence suggests that subsidizing transportation costs (LIFT II, 2015) and expanding CHW roles to include ART distribution to medically stable patients would improve linkage to routine care and reduce drop-off (Decroo et al., 2014; Grimsrud et al., 2015).

Abuse of substances such as whoonga is a growing problem in South Africa (Grelotti et al., 2014; Rough et al., 2014) and appears to be partly responsible for poor ART adherence, particularly among young males (Michel et al., 2013). As substance use disorders can be a form of “escapism” from the reality of one's HIV diagnosis (Michel et al., 2013), HIV/ART interventions must be modified to better address substance abuse, mental health, and other medical co-morbidities.

Our findings corroborate recent reports suggesting that patient satisfaction plays a substantial role in ART use (Bogart et al., 2013; World Health Organization, 2010). As initial patient–provider interactions lay the groundwork for patients' decisions whether to initiate and continue ART, cultural and organizational changes could ameliorate several healthcare system-related barriers (Gilvydis et al., 2015). Healthcare facilities can be more sensitive to patients' needs and the role of stigma by modifying service provision, including providing more thorough individualized pre- and post-test counselling (Knight et al., 2015) and avoiding HIV stand-alone services in favour of integrated primary care. A system for systematically identifying and triaging care for patients with especially restrictive socioeconomic circumstances may also be beneficial.

The interplay between religious and health-related beliefs has considerable influence on ART (Dahab et al., 2008; Lubega et al., 2010; Michel et al., 2013). Patients who subscribe to traditional healing or Christianity are likely to turn to these beliefs in times of crisis, including HIV diagnosis (Appelbaum Belisle et al., 2015; Peltzer, Friend-du Preez, Ramlagan, Fomundam, et al., 2010). When these belief systems contradict HIV/ART education or create social pressure against ART, patients are forced to choose between alternative medicine and ART. At this crossroad, collaboration between healthcare providers and key community figures such as traditional healers could improve ART use. In an overburdened healthcare system, integrating alternative and evidence-based medicine may also improve patient satisfaction while eliminating perceived competition between treatment approaches (Appelbaum Belisle et al., 2015).

This study's main limitation was a language barrier, mitigated by the presence of a qualitatively trained, Zulu-speaking researcher who conducted interviews and helped create the codebook, and the use of professional transcription and translation services. Also, the sample was exclusively female, making it representative of the CHW population with the unavoidable consequence that male patients' experiences were described from a female CHW's perspective. Finally, some CHWs interviewed may be HIV patients themselves or have loved ones with HIV, and may have biased the data by supplementing their patient anecdotes with their own life experiences. Nevertheless, the perspectives of these uniquely positioned community members provide meaningful insights into current barriers to ART and suggest areas for intervention.

Our findings speak to the need to view HIV/AIDS as a chronic disease requiring a lifelong treatment and management plan, rather than an acute infection. Longitudinal education and counselling for patients and their treatment supporters is essential. Another important component of this shift includes refocusing HIV/AIDS interventions from the individual patients (Michel et al., 2013) to include the social and structural conditions that compromise individuals' abilities to engage in ART (Auerbach, Parkhurst, & Caceres, 2011). This will require renewed efforts with support from CHWs to strengthen education and counselling, enhance support at clinics, and work alongside patients' traditional and religious beliefs to provide noncompetitive, holistic healthcare services.

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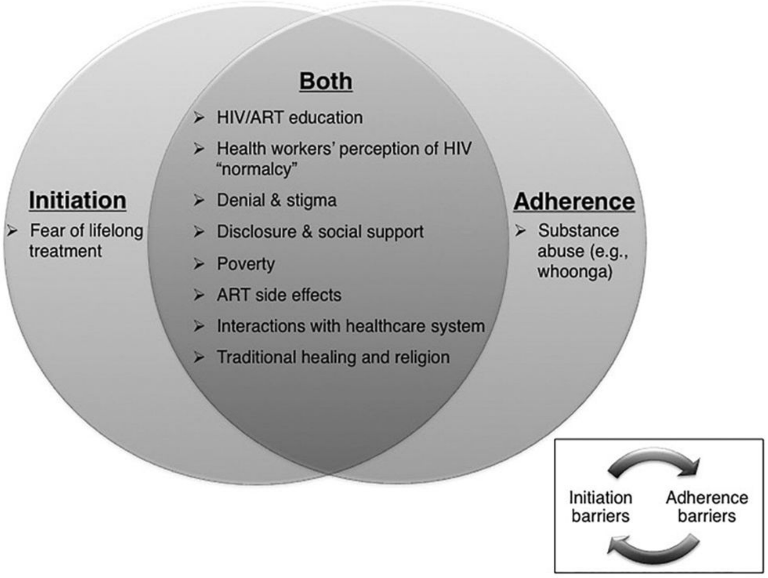
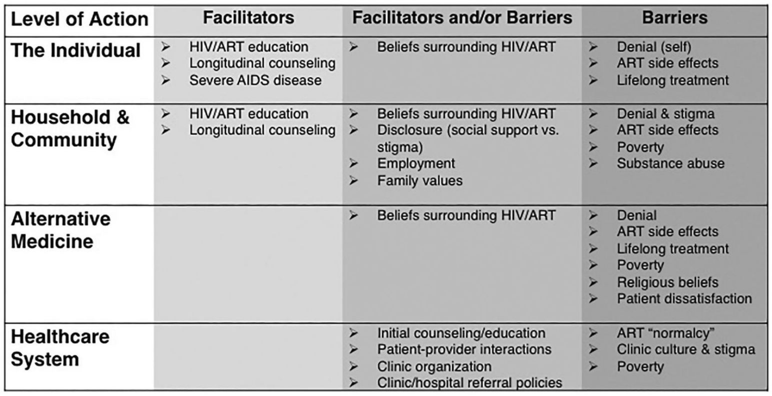


Figure 1.

The intersection between barriers to ART initiation and adherence.



Level of Action	Facilitators	Facilitators and/or Barriers	Barriers
The Individual	➢ HIV/ART education ➢ Longitudinal counseling ➢ Severe AIDS disease	➢ Beliefs surrounding HIV/ART	➢ Denial (self) ➢ ART side effects ➢ Lifelong treatment
Household & Community	➢ HIV/ART education ➢ Longitudinal counseling	➢ Beliefs surrounding HIV/ART ➢ Disclosure (social support vs. stigma) ➢ Employment ➢ Family values	➢ Denial & stigma ➢ ART side effects ➢ Poverty ➢ Substance abuse
Alternative Medicine		➢ Beliefs surrounding HIV/ART	➢ Denial ➢ ART side effects ➢ Lifelong treatment ➢ Poverty ➢ Religious beliefs ➢ Patient dissatisfaction
Healthcare System		➢ Initial counseling/education ➢ Patient-provider interactions ➢ Clinic organization ➢ Clinic/hospital referral policies	➢ ART “normalcy” ➢ Clinic culture & stigma ➢ Poverty

Figure 2.

Multi-level factors that act as facilitators and/or barriers to ART initiation and adherence.

Table 1

Quotes related to HIV/ART education (Theme 3.2) and perspectives on HIV (Theme 3.3).

3.2 Patient education and the perception of “HIV Normalcy”	
Quote 3.2, #1	“They are giving [you] a chance while getting counselling classes so that, by the time you are initiated on the programme, you are well prepared.”
Quote 3.2, #2	“They understand very well but the first time when they start taking it [ART], there is some confusion.”
Quote 3.2, #3	“Some do understand well what needs to be done. On the other hand, some do not have sufficient knowledge…[They think] maybe they can miss the day and take it on the following day, which shows the lack of knowledge as to when and how the treatment needs to be taken.”
Quote 3.2, #4	“They can not be on the [ART] programme without being educated. They are firstly educated. If there is a treatment supporter that the patient brought – it may be that a man brought his wife or someone from home – they need to agree that if the patient cannot learn, then the treatment supporter should learn on behalf of the patient about how treatment should be taken and the process that needs to be followed for a patient to adhere to treatment.”
Quote 3.2, #5	“If the patient cannot take the lessons, they ask someone who is going to…take the lessons on behalf of the patient. It can also be a person from home but it has to be someone who is going to be patient until the patient is able to do it on his own. At the end, they do learn.”
Quote 3.2, #6	“Mostly now these days I think this disease has become more common. Maybe it [the patient counselling] was better before…[Now] if you are coming to get tested, when you enter, the person [counsellor] is just sitting there and will ask you, `Okay come, do you know about the disease?' If you say that you know, the person [counsellor] will start testing you and that will be all. But when we were [first] taught counselling, it was deep education.”
3.3.1 Denial: manifestations and effect on ART	
Quote 3.3.1, #1	“Even if the family knows and tries to show their support and motivate the person…it becomes difficult for the individual to accept the situation. That is the problem when the person is starting to take the treatment; even if they do start, it will be with shame, not acceptance.”
Quote 3.3.1, #2	“Sometimes it happens [with] the married couples. If it is a woman, because women are easy to talk to, they easily accept it. A man will be so defensive, even if [the] woman has been initiated on the treatment, [the] man will refuse everything, and he will not accept it.…Men will deny and say they are negative.”
Quote 3.3.1, #3	“He is going to ask you where you got it [HIV] because he has not yet been tested – He does not know his status, nothing shows that he may also be infected. He will say, `You are going to be taking this treatment on your own and in my house. I do not want anyone who is taking this treatment.' Then it will be difficult for the woman to continue [taking ART]… She will take these tablets after collecting them and throw them away.”
3.3.2 Disclosure and social support	
Quote 3.3.2, #1	“The main problem that sometimes people face is being secretive. They do not want to talk about their problem…After you [the CHW] have left, and said your goodbyes, and given the family some education, the person will come slowly after you and say, `I want to tell you that…I am also infected.'”
Quote 3.3.2, #2	“Let me make an example of a girl … she is not married…She goes to work in Durban and meets a partner there where they are living together.… The girl was already on treatment but was afraid to tell the partner, so during the time that the girl has to take treatment she will go and take it in the toilet because the partner does not know anything about it…. Others hide it under the mattress to make sure that the partner does not see it. So that makes it difficult because, if the partner finds out, they will separate.”
Quote 3.3.2, #3	“When the person leaves the clinic, they just throw it [the medication container] outside the gate. By the time the person gets home, she changes the container and keeps the tablets in another container, not the original.”
Quote 3.3.2, #4	“We can try and sort out the situation within each family, maybe like educating the household heads. If we can educate the adults first, maybe things will be better for the children so that they can be free [to take ART]. You find that the child is already infected but is afraid to tell the parent. Sometimes the parent knows, but the man of the house is a typical Zulu man and is operating according to Zulu culture. He is going to tell the child, `If you ever go there to the clinic, you will see me.' Let me make an example with my patient that was pregnant … the patient said, `My husband said you must not test me. If you get me tested he is going to chase me away from our home.' That is why I am suggesting … the situation is first sorted with the parents/household heads.”
Quote 3.3.2, #5	“Some people do not believe that they or their children have these diseases. Even after being told [they have HIV], they believe that it is a umbhulelo (bewitchment). You need to clearly explain to the person that even if they think that it is umbhulelo … you must allow them to get help…If you do not give the person the support to take treatment, that would make them afraid of taking it. But if you as a parent allow your child to get help, the child would be free [to live] and be like any other person.”

Quote 3.3.2, #6	“The other thing that becomes a problem is stigma. Maybe the person has disclosed at home about the problem, now the person will eat on a separate plate, everything that the person uses will be separated from the rest. They do not remember what they were educated on, because they are educated on how the disease is spread to other people, how they [can] get infected…Then the person will not get enough support from the family, but [will experience] the stigma.”
Quote 3.3.2, #7	“In a certain family the child was a treatment supporter of the mother. The child would just tell the mother when it was 8 o'clock and the mother would know that it was the time to take her treatment.”
Quote 3.3.2, #8	“My other patient said, `I saw I almost died. I nearly left my children whom I love so much. If I die who will I leave my children with? I saw the need to be with them when I was very sick so I need to ensure that I am adhering to my treatment.'”
3.3.3 Stigma	
Quote 3.3.3, #1	“They understand it [the ART initiation process and the importance of ART] but it is very hard for them to practice it as they are ashamed [because] of other people.”
Quote 3.3.3, #2	“When you enter the clinic through the gate, once you walk and take this side, everybody knows [exactly] where you are going. You are like a written book …That means `I have a stigmatized disease.' … Everytime I go through that corner, people will say they have seen me [at the HIV clinic].'”
Quote 3.3.3, #3	“I wish they can be like any other sick person and not focus on being afraid to be seen by other people when they are going up there to collect their ART. I wish they can … not be separated from others. … When they are making their own separate line, it is clear to everyone … that they are going to collect the ART. So it is stigma-related, it makes them afraid to be seen there at the ART clinic.”
Quote 3.3.3, #4	“The health workers in the clinics, when they are raising their three fingers all the patients standing in the line know what you have come to do. Secondly, the cards are different from other patients' cards and they are also complaining about that. From there they are taken to another room to be kept separately. That is where you are going to collect your ART treatment. They say it is like they are showing off about the illness that they have.”
Quote 3.3.3, #5	“When they are going to collect their card it is different from the other patients' cards … they are taken to the separate room. When coming out from that room everyone is looking at them and [knows] that it was true about the three fingers.”

Table 2

Quotes related to socioeconomic factors (Theme 3.4) and perspectives on ART (Theme 3.5).

3.4.1 Poverty, unemployment, and lack of resources	
Quote 3.4.1, #1	“He was the only one working, bringing food. Now this patient has to go and collect treatment while at home there is nothing, nothing. This patient does not know what to do. He does not know how he is going to travel to get to the clinic. He was the one providing for the family…You [as the CHW] get disappointed and you wonder what is going to happen. You tell the person that `On this date I would like you to please go and collect your treatment.' The patient just tells you that `I do not have anything. When you look at the [cooking] pots there is nothing.' The mother of the patient has to go out and try, sometimes she will borrow the money on the patient's behalf so that the patient can go to the hospital …The doctor will not refer the patient for a sick pension (disability grant). Sometimes when the doctor refers the patient for the pension, he will give an [appointment] date that is far so all the while the patient would be struggling to survive.”
Quote 3.4.1, #2	“As the homebased caregivers we are encouraging the patient to take tablets. If the patient does not have anything to eat, you have to go to your house and get something for the patient or you go to the clinic and ask for the porridge. Sometimes they do not have it in stock, and the patient has to take the treatment. Those are the challenges that we come across in the community … challenges of hunger.”
Quote 3.4.1, #3	“We started going to the clinic. At the clinic they said it was too much for them, the patient needs to go to the hospital …I was forced to take the last money [from] my pocket and stop the cars that were passing by to assist me with this patient. There is a problem even here at [the nearest clinic] if the patient is critically ill, it is very far.”
3.4.2 Substance abuse	
Quote 3.4.2, #1	“They will stop the ART treatment and carry on with the glue even if their parents are telling them to quit it. They think they are older than their parents because of this glue.”
Quote 3.4.2, #2	“[For] others it is the Marijuana … it is mostly the youth. Maybe the time is about 4:00 and the person has to take medication at 7:00. At around 4:00 the person will go and chill with his friends, maybe they are meeting in the shop and smoking marijuana …It [becomes] a habit…[He] will remember the following day that he did not take the treatment.”
Quote 3.4.2, #3	“Some have a problem of not wanting to quit taking alcohol. At the time when the person is supposed to be taking treatment, he is drunk. That person will forget the time of taking treatment, the following day will be the same problem.”
Quote 3.4.2, #4	“Some people who are having problems are those that are drinking alcohol, and taking a lot of drugs. People who cannot stay away from alcohol. The person will start well on their treatment but when meeting friends he will drink again and decide to stop [treatment] and join his friends in drinking. At the end, some commit suicide.”
Quote 3.4.2, #5	“In Johannesburg nowadays they do not just give treatment if the patient does not have the [clinic] referral letter- they said that people are selling treatment and making drugs (whoonga).”
Quote 3.4.2, #6	“After the child passed away, she came out and said, `That is why I am not getting any better. It was because my child was hitting me and taking my ART to make drugs.'”
3.5 Perspectives on lifelong ART and side effects	
Quote 3.5, #1	“The first [reason] will be, `I was told that I am ready to start, but I am not going to start because they said when I start I have to take it for the rest of my life, so I am not going to start.'”
Quote 3.5, #2	“After testing, they will tell the person that `You can now start taking the treatment.' The person will say 'No, because I am still fine, I am not going to start immediately. I have no pains in my body so let me leave it.'”
Quote 3.5, #3	“Some [men] develop breasts like a girl. Some say, `I am not going to continue with this treatment because of the side effects. I cannot have breasts like a woman.'”
Quote 3.5, #4	“A woman will change at the back of the legs and the top body part will be big. So when somebody else is sick [with HIV] like the neighbour or in the family, the person will [say to] themselves …`Okay, as I am sick, now I need to start this treatment. [But] that means I will also become like that person as they look now. I [would] rather stop taking [or not take] this treatment than become like that.'”
Quote 3.5, #5	“Other people do come up with those stories, saying, `They did not identify my disease well, that is why this medication is making me sick – they falsely identified my disease. I would not be this sick if it was the right disease.'”
Quote 3.5, #6	“They will say, `I have decided to stop taking treatment because it is not going well at home with my wife, she is going away. I am not able to satisfy her sexually.' He will tell you that he has decided to stop because he can see that he is going to be single now.”
Quote 3.5, #7	“Others are encouraged to continue [ART] by looking at their CD4 count results when they are coming to collect treatment and getting the results showing that the CD4 count is high. The patient can see that the [health] status is getting better.”

Quote 3.5, #8	“Others, when they get better due to taking treatment, they decide never to stop as they can see that they are now well.”

Table 3

Quotes related to the healthcare environment (Theme 3.6).

3.6.1 Interactions with the healthcare system	
Quote 3.6.1, #1	“Others are defaulting because there are so many queues at the clinic. Even if you are asked to come to go to the hospital, the nurses shout at you, they shout at us. Patients do say all these things – the shouting and that no [one is] caring. When you arrive, no one cares for you, you just have to wait, they say the nurses are gone for lunch. It is irritating.”
Quote 3.6.1, #2	“I met one women who was collecting treatment on behalf of the grandchild …Whenever she comes to the clinic on the date for treatment collection that was given by them, she will find that they are out of stock. As a result she has to travel and come hereto the hospital…She has to go and borrow the money …She said this has happened on two occasions, it has happened for two months [that] when coming to collect treatment she only [then] learns that the clinic is out of stock …They need to make sure that treatment is here on time to prevent people from going back home from the clinic without any treatment.”
Quote 3.6.1, #3	“It happens sometimes that the mobile clinic does not come when it is raining. Maybe it was that patient's date for collecting treatment …when it rains the mobile clinic does not come. The patient is unable to get treatment and that person does not have the money to travel to the hospital. It is a problem.”
Quote 3.6.1, #4	“If the person is sick on a Saturday and you take him to the hospital, they will tell you to go to the clinic [first] but the clinics are closed on Sunday until Monday.”
Quote 3.6.1, #5	“I brought the patient but was given another date. When I returned on that date, they still did not transfer the patient … at night they had to call the ambulance to come and take the patient to the hospital. When we got to the hospital they were asking about the referral letter from the clinic. I told them I did not have a referral letter. I was asked to wait until the morning so that I could be able to go to the clinic and get the referral letter. My God, that man passed away on our way to the clinic because he did not have that letter.”
Quote 3.6.1, #6	“You find that some people are in Johannesburg but they are collecting their treatment from KwaZulu-Natal, and you find that the person is unable to collect the treatment … because of work …the person did not ask for the transfer [of care].”
Quote 3.6.1, #7	Those patients coming back from Johannesburg … they are very sick …He was already on the ART programme, but when the patient was leaving he did not tell you that he was going away. The following day you wake up and you visit the patient only to find that the patient has left …In that way, the patient will default and by the time the patient comes back, he is very sick. The patient does not even know when was the last time he has taken his treatment. When the patient comes back again, he has to start afresh with the counselling classes … The patient will just say, `I stopped because I did not know that I was not going to get it [ART] on that side [Johannesburg].' You now have to take the patient back to the clinic, the patient has forgotten how to take treatment.”
3.6.2 Alternative medicine	
Quote 3.6.2, #1	“Things do happen even to a patient who is already on treatment when they meet church people saying, `I will pray for you and you should stop taking the tablets.' …A patient that was under my care … stopped taking treatment as she was prayed for. I tried begging her but she refused and said she had been prayed for so `I am no longer taking this treatment.' The patient took the treatment and threw it in the toilet.”
Quote 3.6.2, #2	“You make a follow up on the patient and they are doing well adhering to the treatment. Afterwards you find that the patient no longer goes to the clinic as they are supposed to – they have stopped. Then you meet the patient wearing the red bhayi (initiation cloth). The patient will say, `I was told that this is not the HIV that I thought I had, they told me that I am being initiated into traditional divining.'”
Quote 3.6.2, #3	“There is an herbalist … or a healer that made the whole area of Msinga rise…He was telling the patients to stop taking ART treatment, even those who were already on the treatment. People were scared … and people did stop taking [ART]. They were sick, some died, and some were defaulting.”
Quote 3.6.2, #4	“The person will say, `I am sick, as my sister has said that it is amandiki (a condition like an illness that indicates that you need to be initiated to become a diviner. It presents itself as if you are possessed by ancestors).' The person will want to go and start the initiating process for becoming a traditional healer or they want to go vomit as part of cleansing. They [family members and traditional healers] will mention a lot of things that will prevent the person from starting the treatment…”
Quote 3.6.2, #5	“Some do understand and some do not because of their beliefs, because you find that the person is taking the ART but still believes that the ancestors want some rituals. …But they will not understand exactly what is going to help them, the ART or the rituals for the ancestors. The person will hold on to the ancestors a lot …Those are the things that make them not adhere to their ART treatment.”
Quote 3.6.2, #6	“They just say, `When I will die taking this treatment, it is better not to start taking it. Maybe it is better to start taking traditional medicine.'”
Quote 3.6.2, #7	“The ART treatment is taken for the rest of your life, while … the people who are selling the traditional medicine do not tell the person that the medicine will be for the rest of their life – they just say, `This medicine is going to cure your illness.' That is why people prefer taking traditional medicine, as it will cure them.”
Quote 3.6.2, #8	“We are taught that if the person has a problem we must not encourage that person to go to the traditional healers but to go to the clinic and the hospitals. This is making us liars in front of the community, because … when the patient arrives at the hospital, they do not attend to the patient. While the patient is very sick, they will just make the patient sleep on the

benches. The following day … if you make a follow-up on that patient asking if the patient did visit the clinic, the patient will simply tell you that `I went to your people …They did not attend to me at the hospital. `What are you expecting us to do? This is really worrying us within the community, we do not know how we should … explain to them why is it done that way.”