PUBLIC PERCEPTIONS OF ANTIRETROVIRAL THERAPY (ART) IN RELATION TO ENTRY AND RETENTION IN THE HIV CONTINUUM OF CARE: Findings from a Rural Setting of Chivuna, Zambia

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Abstract

As is the case with most of the countries in the sub-Sahara region with a high prevalence of HIV and AIDS, antiretroviral therapy has increasingly become available in Zambia. The way antiretroviral therapy (ART) is perceived by the users and potential users is important for its effectiveness. This paper is aimed at exploring how ART is perceived and how such perceptions influence people's entry and retention in the HIV continuum of care.

Data for this paper was derived from a large study in a remote rural setting of Chivuna in Southern Province of Zambia. A mixed methods approach was used and 653 participants were interviewed using a structured questionnaire to generate quantitative data while 24 focus groups, 67 in-depth interviews and 19 informant interviews informed the qualitative aspect of the study. Data analysis was done using SPSS version 20 and Atlas.ti version 7 data analysis packages.

Although people's perceptions about ART were generally evolving from negative to positive, this study indicates that negative perceptions still exist among the rural population. These negative perceptions act as barriers to people's utilisation of HIV and AIDS-related services.

The study has shown a level of association between perceptions about ART and people's entry and retention in the HIV continuum of care. In this regard, it is important for stakeholders to redress negative perceptions and harness the positive ones so as to enhance early entry and retention in the continuum of care for people living with HIV. This has the potential of contributing to reduced morbidity, reduced mortality and reduced transmission of new HIV infection cases.

Keywords: HIV and AIDS, HIV continuum of care, perceptions of ART, Zambia

Introduction

More than three decades into the HIV and AIDS epidemic, the epidemic still remains one of the major challenges affecting the world with sub-Saharan Africa bearing the heaviest burden (Sasaki, 2012; Bene and Darkohb, 2014).

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Although significant inroads have been made in the area of the prevention of new infections, which shows a reduction of about 50 per cent between 2001 and 2012, the world over (UNAIDS, 2013), treatment and care seem to pose the greatest challenge to worldwide efforts to reduce the epidemic. Evidence shows that regardless of the mainstream knowledge, policies and interventions, along with the impressive financial resources allocated to AIDS in low and middle-income countries, the HIV treatment coverage only represented about 34 per cent of the 26.8 million eligible group of People Living with HIV (PLHIV) in 2013 (Layer *et al*., 2014; UNAIDS, 2013).

In order for HIV treatment to be successful, people living with HIV need to progress through a number of stages. These stages have been collectively coined as the HIV continuum of care or a cascade of care (CoC) (Blutingera *et al.,* 2014; Layer *et al.,* 2014). It includes voluntary HIV testing and counselling, linkage to care, ART, initiation and life-long adherence and retention in care (Christopoulos *et al.,* 2013; Fox and Rosen, 2010). The CoC strategy is comprehensive because it is focused on services offered by health systems, homes and the community at large. For PLHIV to access and continue with ART, for instance, they will not only need availability of HIV testing services and ARVs but also encouragement and care from their family members as well as supportive community structures.

However, although the CoC is an important tool in bolstering HIV care and treatment, Drop Outs (DOs) along the stages have considerably been documented in the literature, especially during pre-ART initiation and retention periods (Fox and Rosen, 2010; Mugglins *et al*., 2012). The reasons for DOs in less resourced spaces are varied but they include lack of food supplements (Ntalasha *et al*., 2015), poverty and livelihood insecurity (Murray *et al*., 2009), stigma (Roura *et al*., 2008) non-disclosure of HIV zero-status to spouse (Sasaki *et al.,* 2012), lack of family support (Murray *et al*, 2009), long distance to ART centres (Blutingera *et al*., 2014) and negative effects of ART (Mills *et al*., 2006) among others.

This study seeks to extend the list of the factors contributing to DOs by exploring the role played by perceptions. Although there is a burgeoning literature in sub-Saharan Africa showing that perceptions have an important role in determining people's behaviour, including treatment-seeking behaviour (Kabatereine *et al*., 2014), the literature reviewed, that there are limited studies in Zambia on how ARVs are perceived by people and the influence such perceptions have on people's entry and retention in the HIV continuum of care.

Elsewhere, studies have shown that positive perceptions about ART have the potential of encouraging people to be engaged in HIV and AIDS-related services (Mitchel *et al*., 2009; Phakathi *et al*., 2011) while negative ones act as a barrier to ART (Irwin *et al*., 2003; Kerr *et al.,* 2004; Grant *et al*., 2008; Layer *et al.,* 2014). In terms of positive perceptions, ART has been constructed as life-saving in the literature. Simpson and others, for instance, report that their participants were representing antiretrovirals (ARVs) as having a Lazarus effect (after a biblical figure who rose from the dead). These perceptions motivate people to seek, access and use HIV and AIDS-related services (Simpson *et al*., 2009). Such perceptions have arisen from seeing people who were once very ill improving and being able to work again after being on ART (Grant *et al*., 2009).

Negative perceptions and beliefs about ART, on the other hand, have helped spread discontent and discouragement with respect to HIV treatment. The findings from earlier Zambian studies indicate that negative perceptions about ART have extended beyond the spheres of HIV and AIDS, to include sexuality and parenthood (Grant *et al*., 2008; Rosen *et al*., 2011). Antiretrovirals have been perceived as killer drugs in certain discourses (Mitchel *et al*., 2009) and this has somewhat challenged people's understanding and inhibited some from seeking ART.

With ARVs having been made available in Zambia for free since 2005, it is important that people's perceptions about ARVs are explored so as to identify any negative ones which can be addressed in order to improve people's desire to test early and be retained in the continuum of care for viral suppression. The way people perceive existing ART services is crucial in achieving the goals of ART – less morbidity, less mortality and reduced transmission of new HIV.

Theoretical Framework

To explore factors that influence people's entry and stay in the HIV and AIDS continuum of care and treatment, the study from which this article is extracted was guided by the social-ecological model (SEM).

The SEM is an approach to health promotion that offers a broader perspective because it recognises that most public health challenges are too complex to be adequately understood from the single level analysis (Robinson, 2008).

This models human behaviour as a function of personal and environmental factors, which include socioeconomic, political and health factors (Choi *et al.,* 1998; Roura *et al.,* 2009). Health-seeking behaviour is, therefore, not construed as something that exclusively resides in the individual but as a reflection of wider interactive situational processes (Latkin *et al*., 2005; Roura *et al., 2009).* The individual health-seeking behaviour is located in the social, institutional and physical environment and consequently, behaviour is shaped by the social environment (Roura *et al.,* 2009). Thus, individual behaviour is determined to a large extent by the social environment, such as community norms and values, regulations, and policies. The most healthy behaviour would be a combination of efforts at individual, interpersonal, organisational, community and public policy levels (Mcleroy *et al.*,1998).

The SEM situates the individual in a dynamic social ecology in which individuals adapt their behaviour to their social environment and make decisions based on information, influences and interactions available through local social networks, relationships and institutions (Roura *et al.*, 2009). This means that in analysing health-seeking behaviour, this framework looks beyond the individual by taking into consideration the social environment in which the individual exists and the influence that the social world has on the individual. This leads to the assumption that the world we live in influences our behaviour including health-seeking behaviour. Additionally, health system related and based factors are also taken into consideration (McLaren and Hawe, 2005).

This approach, therefore, avoids an exclusive focus on either the individual or the environmental factors as separate analytical factors but takes into consideration the dynamic interaction of both personal and external non-personal factors in explaining health-seeking behaviour (Choi *et al.*, 1998).

The SEM model classifies the factors influencing people's health-seeking behaviour into four main categories, namely; structural, programmatic, social and individual (Roura *et al*., 2009). Structural factors are those over which the individual has completely no control (Parker *et al.*, 2004). They include poverty, livelihoods, health policies, laws and the financing of health care systems all of which are linked to the national economy (Sumartojo *et al*., 2004). Programmatic factors are those that are related to the health system and basically, relate to the way health systems are organised and delivered including availability and accountability of services, attitudes of health providers, waiting times and distance to the health facilities (Munro *et al.*, 2007; Roura *et al*., 2009).

Social factors include interpersonal relations, such as those between married partners, family members and peers that, in turn, affect individual actions (Roura *et al*., 2009). Community level factors include the relationship with and the influence of social systems, institutions like the church, social exclusion, discrimination, stigma, traditional health care systems, local illness ideologies and concepts which are all embedded in people's sociocultural systems (Musheke *et al.,* 2013). The relationship between the formal health sector and its professionals, on one hand, and the local people, on the other, is also seen as part of the social level factors and viewed as capable of influencing treatment-seeking behaviour because it is regarded as being structured by the social order (Duffy *et al.,* 2010). Individual factors are the personal determinants of health-seeking behaviour over which an individual has control. These include personal characteristics like perceived severity of the disease, wellness, interpretation of illness and attitudes towards treatment, knowledge, as well as somatic responses to medication (Duffy *et al.*, 2010).

Thus, according to this model, a more comprehensive approach to health promotion requires changing the practices of social systems that have wide spread effects on human health rather than solely changing the habits of the individual. This model shows that all these factors are interlinked and interwoven to enforce each other in influencing the individual's treatment-seeking behaviour. While at times the interplay of two factors may be involved in improving patient's adherence, such as reduced waiting times (health sector factor), and personal motivation (individual factor) sometimes a combination of several factors may be involved. For instance, pervasive stigma (social factor) or waiting times at the ART clinic (health related) may all reinforce each other leading to a lack of motivation (individual factor) and consequently, resulting in attrition from ART care (Musheke *et al.,* 2013).

Due to its comprehensive and multifaceted approach, the SEM avoids the theoretical divide between individual and structural models by treating both paradigms as complimentary and lying on the same continuum (Roura *et al.,* 2009). Used with modifications, this model was found to be useful for this study because of its multifaceted approach. It was, therefore, possible for the study to investigate not only individual factors but also other factors at all levels which make one's social environment. In the context of this article, it was possible to investigate individual and community level factors such as public perceptions of ARVs.

Data and Methods

Study Area

The study was carried out in Chivuna, a rural community located approximately 60 km South-East of Mazabuka town, 35 km from the Great North Road and about 70 km South of Lusaka, the capital city of Zambia. The main ethnic group is Tonga speaking (or *Ba*-Tonga in plural), a matrilineal and patrilocal group of people. Chivuna has a population of approximately 19,000 people scattered in an area covering about 34 square kilometres. The main source of livelihood is subsistence farming, which is seasonal and dependant on the rainfall pattern. Like most rural areas in Zambia, poverty levels are quite high, averaging more than seven people in ten being poor and having limited access to basic necessities, including food and health. While nearly all the health facilities in the area offer VCT, ART services only exist at Chivuna and Mbayamusuma health facilities, the two facilities; with a distance of more than 40 km apart. The Chivuna health facility started providing VCT and ART in 2006 and 2008, respectively.

Data Collection and Analysis

The data presented here was part of a bigger mixed methods study conducted over a period of one and half years. This component of the study explored people's perceptions of ART. To recruit study participants, purposive sampling was used for the qualitative data. The idea was to recruit people with the monopoly of knowledge on the subject matter such as PLHIV and gate-keepers at health institutions. Multistage random sampling was conducted for quantitative data in order to take care of the heterogeneity in the population distribution of the community. The total sample for the study was 653 for quantitative data. Quantitative data was collected and 24 focus group discussions, 67 indepth individual interviews, 19 key informants interviews from both the community and health facility were used for the qualitative data.

For the purpose of quality control, all the interviews that generated qualitative data were carried out by the principal researcher while the standard questionnaire was administered with the help of 12 trained research assistants. All interviews for qualitative data were transcribed and put in a word processing application and checked for clarity by the principal investigator. The analysis was done using Atlas-ti version 7. Grounded theory was adopted as a data analysis and coding approach. First, open coding was used, after which all the codes were sorted out into groups in form of axial coding and finally, selective coding which allowed for the creation of core categories relevant for analysis was performed. From these categories, themes were generated (Bryman, 2012).

Ethical approval for the study was obtained from the Research Ethics Committee in the School of Humanities and Social Sciences at the University of Zambia and was also cleared by the Ministry of Health. For all the individuals that took part in the study, informed consent was administered and they were all assured of anonymity and confidentiality.

Results

Although the data reported in this study was derived from a mixed methods study, the results will mainly focus on findings from the qualitative component. This is because the researchers generated richer information on perceptions of ART from the qualitative data compared to the quantitative data. The results are reported in an aggregated form showing the perceptions of ART for either entry or retention in the HIV continuum of care under the subheadings of positive and negative perceptions about ART.

Positive Perceptions about ART

Positive perceptions about the ART were reported to facilitate peoples' decisions to be tested for HIV, commence ART and adhere to treatment. For many, this was as a result of seeing some of their colleagues who were once bedridden recover. For others, it was a combination of what they had personally experienced and messages received about the efficacy of the ARVs from other community members. Antiretroviral therapy was thus viewed as highly efficacious as can be attested to by the statements from different sources indicated below:

> People used to die before the introduction of ARVs. After the introduction of the ARVs, the beds were empty at Monze hospital. That is how we thought of starting ART services at Chivuna clinic. Even here in the villages, burials were a weekly thing but now we go for months without hearing of a funeral in the community. There is no doubt ARVs are working. This has encouraged many people to accept taking medicine once eligible (Female Health Care Provider, Chivuna Health Center).

> The benefit of taking ARVs is to reduce the impact of AIDS, but I don't know if the drugs could cure the disease completely. The other benefit is that all problems related to HIV and AIDS would be cured. In addition, we also hear that the drugs can make the virus sleep. We have seen a lot of people on their feet again after taking the ARVs. So the benefits are there, as some people say, they are miracle tablets because they have managed to bring people back from the graves. All this encouraged me to start taking these medicines, (Middle-aged Male, Clinic-based FGD).

The survivors often commented that they were once dead and they credit ART for bringing them back to life. During a focus group discussion with members of a support group, a middle-aged widower amidst laughter and agreement from the other participants poignantly narrated:

> I started taking the medicine, I became fine and very strong. I was very sick and my voice was so faint that for one to hear what I was saying, there was need to bring their ear close to my mouth. I would call for *'keele' (*porridge) in a very faint voice (laughter from other participants). But now as you can see, I am okay, at that time even lifting a small container of water was a very big problem. It is only unfortunate we have no photographs of how we were before we started taking drugs; you could have seen how some of us who are here used to look like. I wish we were like white people who keep photographs. If you were to see those photographs, you would not believe it is us seated here speaking to you. We were moving graves. Those who saw us then and see us now really get encouraged to accept the medicines.

Views on the efficacy of ARVs were also expressed by several care givers as shown in the comments below:

> My daughter (referring to the researcher), these drugs are really effective. You should have seen how this girl was looking before she started taking drugs. She was completely finished and she had lost so much weight. This child you see here was very sick, she was finished. But shortly after the medicines, she became okay. You can see how she is looking; you do not have to be told. I have come to respect this medicine. It is really effective (Grandmother and Care-Giver to an Orphaned 4-year-old Girl).
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> This boy was very ill but now he is very strong. He is one of those holding ploughs and helping in the field. He plays with other children you can't even notice that he was once bedridden (Uncle to an HIV-positive nine-year-old boy orphaned by AIDS).

It was also interesting to note, especially from the health care providers, that positive perceptions have not always been the case as far as ART is concerned. The health care provider maintained that people's perceptions about the drugs had evolved over time because of what people had witnessed. One health care provider stated that in the past, people used to view them as killer drugs. He recalls:

> In the past, people used to think of ARVs as killer drugs because a number of people actually used to die upon starting treatment. This was, maybe, because of the cost that was attached to the medicines, a number of the people used to start taking medicines very late. Adherence was also very difficult because of the same cost. But this is no longer the case, yes people may still face other barriers but at least the cost of medicines is not there anymore (Male Health Care Health Care Provider).

Because of the evolution of people's perception concerning the medicines, it was reported that people wanted to test as soon as possible and avoid becoming sick and associated with a deadly disease. According to the health care providers, this was a new trend that had come with the evolution in the perception of the efficacy of ARVs and their free availability. Expressing this view, a 36-year-old female care provider shared her experiences when she explained that:

> Most people now want to be tested early and get medicines. You find when you tell them about their CD4 count being too high and that they would get medicines later, they start complaining saying: 'Sister that will be too late, I want to start taking medicines immediately,' Some do not want to fall sick or start losing weight so they want to test early and start taking medicines as soon as possible to avoid suspicion. People are now in a hurry to test and get the medicines as soon as possible before they become sick.

Apart from encouraging people to test and start taking their medication, positive perceptions equally motivated people to consistently take their medication and hence remain in care and treatment. This was because of the positive conviction that people had in the efficacy of the drugs. When asked what they thought about the medicine, a common response, particularly, among users was, *'RVs* (*or ma RR,* as they were usually referred to by the elderly)*,* are our life.'

Perceived efficacy of the medicines was not only held by the direct beneficiaries but was a commonly held view even among community leaders. Referring to what motivated people to adhere to ARVs, the area Chief had this to say:

> Belief in the effectiveness of the medicine actually encourages many to continue taking them because they are able to remember how they were before they started taking them. Some of them were as good as dead, but immediately they started taking the medicines, they recovered completely. Many, actually, do believe that ARVs are their life.

These views were also shared by many other key informants, particularly those from the health facility who also had an opportunity of directly interacting with people on ART as one of them intimated:

> I think many people now know that ARVs work because it is something they have seen for themselves. There are people in the community who really were gone but the ARVs have brought them back to life. That acts as a confirmation for others to trust the medicine (Male Health Care Provider).

The actual beneficiaries, most of whom had been on medication for a long time, also shared their experiences as reflected from the statements below:

> For me, it was like you were almost in the grave and then somebody just comes to take you out. It is really a second chance to live. That is why even when some people call us names "eh... those who depend on medicines or those whose life was in the bottle," we have continued taking our medicines (58-year-old-female ART User Clinic Based IDI, on ART for More than 3 Years).

Reiterating these sentiments, another ART user narrated:

> From the time I started getting the medicine, I have come to respect the ARVs. I actually compare this medicine with soap which is able to clean a dirty piece of cloth, so I feel this medicine has really cleaned up my whole body from the disease and that is why I will never stop taking it at all. I will stick to my medicine all the way. I will only die from some other natural illness and not from AIDS (47-year-old Widower, Community-Based IDI, ART User).

This conviction was re-enforced further among those who had tried other remedies which never brought any health relief. This was the case with those who had once sought consultation with some healers or had earlier gone for spiritual healing. Some of the sentiments are reflected in the statements below:

> From the time I started taking the medicine; I started feeling better by the day; now I can walk again. I believe that this medicine works, when I remember how I was. I was as good as dead. I consulted so many traditional doctors who used to tell me that I had been bewitched but immediately I started taking these drugs I got better. Now I even think of my money I used to give those traditional healers because now I have a good appetite, I could be buying myself food using that same money (Female ART User, Community-Based IDI).

Nearly all study participants were of the view that ARVs could allow positive women give birth to healthy children. As a result, despite the many barriers they experienced in accessing PMTCT, most women embraced it.

Positive perceptions about ART were also demonstrated by the concerns expressed by the users about the sustainability of supplies in terms of both manufacturing and continued free provision by the government. Most of the users could not imagine a life without the medicines. They hoped that the government would continue with the free supply of the medication because they were poor people who could not afford to buy medicines. Referring to the possibility of the government withdrawing free provision, common statements were as follows:

> That is when we shall all die; that will be the end of our journey because these medicines are our life. If the government fails to supply us with free medicine, we shall not survive (ART User).

Additionally, this study discovered that ART had changed the way people living with HIV were regarded in the community. It was reported that in the past, people living with HIV were viewed as 'the dying'. As a result, some people were reluctant to even lend them money for fear of losing their money through imminent death by the borrower. This situation is, however, no longer the case due to the transformative nature of ART. This change was summarised by one of the PLHIV who was also the Chairperson of one of the support groups when he stated:

> ARVs have changed people's attitude towards us. Before ARVs came, some people would not even dare lend money to somebody who was suspected to be an AIDS patient for fear that they would die before they paid back. Even the way people now treat somebody who is sick is very different because now, everyone knows that you still have a life ahead of you even if you are HIV positive. In the past, people would just wait to die. The sick have also had a different approach towards life now because in the past, some people would even want to commit suicide once pronounced positive while others would squander all their property knowing that they were going to die anytime, but now all this has changed.

Likewise, ART had changed the way many HIV people viewed themselves as most of those on ART no longer considered themselves as 'the dying' even if HIV was still linked to death. This was a major shift in thinking compared to the time before ART.

Negative Perceptions about ART

Despite the many benefits from ARVs and also the evolution of perceptions from negative to positive ones, negative perceptions have not been diminished. Many key informants from both the community and the health facility affirmed that misconceptions were still prevalent mainly, in some of the very remote communities where community sensitisation was still limited as elucidated by the statement below:

> There are still many people lacking knowledge because of the size of the chiefdom and some communities being very remote. Some of the people in these remote communities know nothing about the medicines. And also, you find that very few people are on medicines in such communities and have not seen anyone taking ARVs so they do not know the effectiveness of these drugs. Those who have seen people recover, some of whom were almost dying, do believe that ARVs are very effective because they have seen it with their own eyes. So, for these people, when they are advised to start taking ARVs, they immediately do so because they do believe in the medicines working. (Area Chief).

Misconceptions contributed to delay in testing, starting to take ARVs upon ART prescription and also treatment interruptions. For instance, in one of the community discussions, some women indicated ARVs interfere with family planning pills and that if ARVs were taken while a woman was using family planning pills, family planning pills would not work and she would end up being pregnant. Whenever this question was asked, some women were emphatic as they explained that, '*ma mapilusi a family planning inga alazundwa ku ma ARVs*' (family planning pills become non-effective because of ARVs).

The concerns of ARVs causing impotence and infertility especially for men also came up in a number of group discussions. The understanding was that the use of ARVs results in them having low sperm counts which subsequently makes them unable to make women pregnant. Key informants were emphatic that on the basis of such misconceptions, a number of people still delayed in testing and consequently, delayed people in accessing the other services that came after one was found with HIV. Key informants elucidated on this point as follows:

> There is a belief which does not seem to go away in the communities…that ARVs men fail to perform in the bedroom. We don't know where this is coming from but it has an effect on people's decisions to enrol in ART (Health Care Provider).

Similar sentiments came up from other sources. For instance, during one of the male community-based FGDs with a community very close to the health centre, a middle-aged man expounded:

> Some people say ehh RR (referring to ARVs) can kill you, ehh they can make you mad, you can die if you forget to take your medicines even for one day. Those who listen to such stories are discouraged from taking the medicines even when they are advised to do so after being tested (Male-participant, Male Community-Based FGD).

It was also clear from the findings that although stigma associated with people living with HIV has over the years reduced significantly, it is still problematic in rural communities. People living with HIV are still conceived as people who engaged in perverted sexual activities and AIDS is construed as a disease for sexual perverts. This finding appeared consistent from all sources including youths. For instance, during one of the community-based focus group discussions with youths aged between 15 to 24, when they were asked about what they thought of HIV positive people in their community, nearly all of them stated that it was '*buhuule'* (prostitution) and that, 'even for the baby who is positive, we say, their parents were prostitutes.'

A number of those who had tested, and in particular women, indicated that they took a long time hesitating before going for testing for fear of being discriminated against; 'I was fearing embarrassment in case the disease was found because this disease causes embarrassment'. This was confirmed further by the reported reluctance among some community members to openly talk about HIV and AIDS. It is almost regarded as a taboo with the sanctions of isolation and being a topic for private gossip.

Other negative issues associated with ARVs which equally affected entry and retention in the continuum of care included life-long adherence, too many pills to be taken in a day, the size of the tablets and the fact that the medicines were in tablet form instead of liquid form. These were also found to contribute to negative perceptions about ART and thus, affect people's decisions to enter and remain in the HIV continuum of care.

Discussion

The findings from this study revealed that both positive and negative perceptions about ARVs exist and that they are influential in people's decision to enter and successfully progress along the continuum of care. In this study, similar to some previous studies as well (Grant *et al.,* 2008), there was an evolution of perceptions about ARVs from negative to positive ones. The evolution resulted from personal experiences and observations from other people regarding the efficacy of ART. Because of these experiences, most of the people in the community strongly believed in the efficacy of ARVs as life-saving drugs.

Most people were able to testify how the number of beds had become empty at the local health facilities and how funerals had reduced in the community. Those on ART, some of whom were bedridden themselves before starting ART, made comments like, 'We were moving graves'. This is an indication that ARVs were generally perceived as life-saving and life-prolonging drugs which had given many positive people who should have been dead a second chance to live again and also to be able to continue working for their families, particularly, those with small children.

Other authors (Simpson *et al.*, 2010) also observe the perceived efficacy of the ARVs and note that they had an effect similar to the Lazarus effect as cited in the Bible. In the present study, the efficacy of the medicines was also reflected by the local concepts for ARVs such as *musamu,* (the medicine), *mukabuumi, (*life-giver) and *mbusha bafu, (*bringing back the dead to life). Similarly, Phakathi *et al.,* (2011) also observed that because some people had witnessed someone on ART recover, ART was perceived as bringing hope and prolonging life and that this acted as a driver not only for testing but adherence as well. This was a drastic change because as confirmed by findings from this study, an observation that was also made by earlier studies (Mitchel *et al.,* 2006), ARVs were in the past perceived as killer and poisonous drugs.

Study findings also show that ARVs had changed the way PLHIV viewed themselves and how they were viewed by other community members. For instance, because of ARVs, many of those on ART no longer viewed themselves and were no longer viewed by others as dying instantly. All these positive beliefs about the ART encouraged not only those tested to start taking medication and those on ART to continue taking the drugs but also those who had not tested to do so, so that they could access the life-saving and life-prolonging drugs.

Results from the study have revealed, however, that much as perceptions were evolving from negative to positive ones, negative ones had not completely been diminished in this community. For instance, though most of the respondents believed that ARVs could help a pregnant woman deliver a healthy baby, some believed that it could lead to impotence and that ARVs could kill as well as make one more sick. Similarly, Fox *et al.*, (2010) also noted of negative perceptions about the benefits of treatment negatively influencing adherence to ART.

Like earlier studies (Grant *et al.*, 2009), discussions with community members showed that some people still viewed ARVs as negatively affecting parenthood. For instance, some people still believed that ARVs could make men impotent while others felt that ARVs would make family planning pills ineffective. Consistent with other studies in the region (Roural *et al.*, 2008), the study findings also show that a new type of stigma was emerging because of ARVs. It was reported that people on ART had become more difficult to identify as they even appeared healthier than those without HIV. In this context, ARVs were viewed as bringing more HIV risks in the community.

It was also clear from the findings that AIDS in rural communities was still a subject of stigma as it was linked to perverted sexual activities. Antiretroviral therapy was, therefore, directly linked to a disease for sexual perverts or prostitutes. This is an indication that despite being more than 30 decades into the HIV and AIDS epidemic, the disease was, as observed by much earlier studies (Caldwell, 1999), still linked to promiscuity. Such views all dissuaded some people from accessing and benefiting from the available HIV and AIDS-related services.

Other negative issues with ARVs that equally affected entry and retention in the continuum of care and also found to be consistent with other studies, included the need for ARVs to be taken for life (Murray *et al.*, 2009). This was an issue because people were culturally used to medicines that heal and not to be taken for one's life time and so comments like '*This medicine works but we are tired of taking tablets on a daily basis*,' were very common among those ART. In this study, people were also concerned as in previous studies, about intolerable effects (Chesney, 2000; Bangsberge *et al.*, 2001), too many pills to be taken in a day (Maman, 2001), the size of the tablets (Schumacher and Bond, 2008) and the fact that the medicines were in tablet form instead of liquid form (Layer *et al.*, 2014). All these, whether anticipated or actual, acted as predictors for the late entry, linkage to care, ART initiation and non-adherence to ART.

Using the SEM, this study had a broader approach and understanding of individual health-seeking behaviour as not only being a result of personal factors but of multiple multilevel factors such as public perceptions of ARVs from the community level.

Conclusion

The results from this study show that negative perceptions about ARVs were evolving to positive ones and that this evolution acted as a predictor for the uptake of available HIV and AIDS-related services. As opposed to being viewed as killer drugs, as was the case in the past when the medicines had just been introduced, ARVs were now seen by many people as life-saving drugs and as a source of life. This calls for the need for information, education and communication, through which health care providers and other stakeholders can provide adequate and updated information about ARVs and communicate the positive perceptions about ARVs so that many can know that these medicines were a source of life and not a killer drugs. This can contribute to increased uptake of the life-saving and life-prolonging drugs and other related services.

The study has also shown that negative perceptions about ARVs had not been completely wiped out. So, while the positive perceptions act as a predictor for people's entry and continued participation in the continuum of care, the negative ones were a barrier. Therefore, there is a need for sensitisation so as to deal with the negative perceptions and in order to enhance HIV positive people's early entry into and stay in the continuum of care. This can contribute to the achievement of the goals of ART of reduced morbidity, reduced mortality and less transmissions of new HIV and AIDS cases. Additionally, there is need to address not only personal factors but also external non-personal environmental factors such as the community where perceptions originate from if health-seeking behaviour for HIV and AIDS-related behaviour is to be improved.

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