

# QUALITY OF LIFE OF PEOPLE LIVING WITH HIV AND AIDS WHO ARE ON ANTIRETROVIRAL THERAPY IN SWAZILAND

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## ABSTRACT

The study was conducted to assess the quality of life (QOL) of people living with HIV and AIDS (PLWHA) who are on antiretroviral therapy (ART) in Swaziland. A qualitative, exploratory, descriptive and contextual design was used. Twenty-four PLWHA on ART were purposefully selected to participate. Methods of data gathering consisted of: (1) in-depth individual semi-structured interviews; and (2) observations in the form of field notes. Data were analysed using Tesch's descriptive method of data analysis. The study revealed that PLWHA in Swaziland are faced with many challenges concerning ART that negatively influence their QOL. The



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findings are discussed within six (6) QOL domains, namely: (1) the physiological domain is categorised as the inability to meet nutritional needs, non-adherence to ART, experience of disfiguring side effects of ARVs, and inconsistent condom use; (2) the psychological domain is categorised as stigma and discrimination, depression, difficult acceptance and coping with ART, and lowered self-esteem; (3) the spiritual domain identified as negative influence of some religions on ART; (4) the socioeconomic domain defined as lack of financial support; (5) the cognitive domain associated with poor support systems, poor understanding of ARVs, negative thoughts about ART as categories; and lastly (6) the environmental domain that deals with contextual issues, for example, the health care system, culture, and rights of PLWHA. These challenges negatively influence adherence to ART as all the participants did not achieve the 95% adherence rate required to maximise the benefits of ART, and PLWHA appeared to be powerless to deal with them. Non-adherence to ART negatively influences the QOL.

## INTRODUCTION AND BACKGROUND

Antiretroviral therapy (ART) was introduced in Swaziland in 2001 in an effort to increase the length and quality of the lives of PLWHA. Swaziland has made enormous progress towards providing ARVs, guided by the health sector response plan for HIV and AIDS 2003–2005 and the Emergency Care and Treatment Implementation Plan. In Swaziland, both the public sector and non-governmental organisations offer ART. The public sector started providing ART in 2001 at the Mbabane Government Hospital. By September 2008, about 30 337 people (48%) of PLWHA were receiving ART in Swaziland (Ministry of Health Multisectoral Strategic Framework for HIV and AIDS Multisectoral Strategic Framework for HIV and AIDS 2009–2014, 2014:49).

Although ART has a significant benefit of controlling HIV disease and extending life, research shows that ARVs have unpleasant side effects that may erode the QOL (Roberts & Dennik, 2006:191–197). Many health carers are faced with the dilemma of extending life versus improving life. In agreement with this dilemma, Burgoyne and Tan (2008:469) assert that the length of life and the QOL in this age of highly active antiretroviral therapy (HAART) are a delicate matter, difficult to keep in balance.

As a result, being on ART means participating in what is called ‘the largest uncontrolled clinical trial in the history of medical science’ (Shernoff, 2002:25). No one can say for sure what the long-term effects of the drugs will be (Shernoff, 2002:25). This argument raises concerns about the QOL of PLWHA who are on ART.

As such, treatment cannot guarantee a good QOL. On the one hand, Dudgeon (1992) argues that the ultimate goal of medicine in chronic illnesses is the improvement of the patient’s QOL. On the other hand, Fellow (1992) in Mitchell (2002:245) is of the opinion that ‘the advancement in medical science appears to have led to a decline in the art of medical science and that medical interventions may result in states of life that are worse than death’. As a result, Mitchell (2002:245) argues that treatments of certain

diseases such as cancer can be worse than the disease, and that there is no certainty that the sufferer will enjoy a longer, healthier life.

Therefore, health professionals should bear in mind that taking some of these medications is not simply a matter of popping pills a few times a day. Rather, these drug regimens may have radiating effects, which may profoundly influence the day-to-day interactions of patients taking these medications with other people in their social networks (Shernoff, 2002:25). As such, the amalgamation of these factors has an important bearing on the person's QOL.

It is the observation of the authors of this article that ART may indeed prolong life, but may only do so at considerable cost to the QOL of PLWHA. The authors argue that health workers should be more concerned about quality, rather than quantity of people receiving ART. Instead of being content that many people have been put on ART, the concern should therefore be on the QOL of these people.

QOL is to be taken as an important indicator of the efficacy of ART, compared with other indicators, such as in-patient period, length of sick leave, side effects of drugs, and mortality. QOL challenges nurses to look beyond ART and adopt a holistic approach that includes all facets of life in an endeavour to improve the QOL of PLWHA.

To increase the length and quality of survival of PLWHA who are on ART, it is essential that an evaluation of their QOL is done because in most instances, in illness, QOL becomes more important than quantity of life.

## PROBLEM STATEMENT

This study grew out of the authors' concern that no research had been carried out to assess QOL of PLWHA who are on ART in Swaziland since its inception in 2001. The authors noted with concern that the QOL of PLWHA who are on ART in Swaziland had been assessed in terms of the side effects of ARVs and CD4 cell count. The authors were concerned about the assumption held by health practitioners that since ARVs reduce the ability of the virus to replicate and improve CD4 cell count, the QOL will be improved. This clearly indicates that the QOL of PLWHA who are on ART in Swaziland has been limited to one dimension only, that is, their physical recovery, yet for a valid QOL assessment, one needs to examine all the dimensions that affect life. The authors are of the opinion that QOL of PLWHA need to be assessed from the perspective of the people on ART and that it should not be based on assumptions of health care providers.

## RESEARCH QUESTION

The statement of the research problem led to the following research question: How is the quality of life of PLWHA who are on ART in Swaziland?

## RESEARCH PURPOSE

As a result, the main purpose of this study was to explore and describe the QOL of PLWHA in Swaziland who are on ART.

## METHODS

### Research design and methods

This was a qualitative study that is explorative, descriptive and contextual in nature.

### Sampling and criteria for sampling selection

The participants of this study were adult PLWHA in Swaziland who had been on ART for more than a year. This period was considered as sufficient proof that the participant has enough experience of being on ART to participate in the study. The mean year on ART was 2.8 years. There was no discrimination of the participants in terms of being on first line or second line ARV treatment. Participants who were on other chronic medication, for example cancer, tuberculosis, hypertension and diabetes mellitus, were not included in the study.

Purposive sampling was employed by the researchers and research assistant to invite a total of twenty-four (24) PLWHA who were present at the VCT centre during data collection. The research assistant is an expert in research and had been working at the ART clinic for more than five years. The sample comprised eleven (11) men and (13) women. The majority, 11 of them, were unemployed, and only seven (7) were employed and the remaining six (6) were self-employed. In terms of religious affiliation, 22 were Christians, 1 Muslim and another 1 did not disclose his/her religion. With regard to formal education, ten of the participants had junior certificate, 6 had primary certificate, 5 had completed high school and 3 had no formal education. The participants' age group ranged from 20 to 60 years.

## ETHICAL CONSIDERATIONS

The study was approved by the following review boards: (1) University of South Africa's (UNISA) Health Studies Research Ethics Committee (HSREC), the Swaziland Scientific and Ethics Committee (SSEC), and the Raleigh Fitkin Memorial Hospital (RFMH) administrator of the RFMH VCT centre where interviews were conducted. The participants gave informed written consent, which contained the following (1) objectives of the study, (2) the nature of their participation, (3) duration of the interviews, (4) use of audio-tape recorder during interviews, (5) the option to end their participation at any given time, (6) voluntary participation, and (7) guaranteed anonymity and

confidentiality. Pseudonyms were used to identify research participants so that no responses would be linked to them. Audio-tape recordings and field notes were only accessible to researchers.

## DATA GATHERING

In-depth semi-structured individual interviews and observations in the form of field notes were used as methods of data gathering. Two months were spent in the field collecting data during 2009. Data were obtained through 24 in-depth semi-structured individual face-to-face interviews.

Each individual interview process took approximately 45 to 60 minutes. A semi-structured interview guide using siSwati was used to gather data during in-depth semi-structured individual interviews. The interview guide comprised fifteen (15) open-ended questions based on six (6) QOL domains relevant to PLWHA who are on ART in Swaziland. These QOL domains were considered relevant since they were identified through an in-depth review of literature and further validated by nursing experts involved in the care of PLWHA who are on ART in Swaziland. The interviews were audio-recorded with the permission of participants and subsequently transcribed verbatim for data analysis.

Observations were also made during interviews as a means to understand the phenomenon of QOL of PLWHA within the natural context in which ART services are offered to clients. This was done to promote understanding of events against the background of the whole context and how such a context confers meaning to events concerned that one can truly claim to understand the events (Babbie & Mouton, 2009:278).

## DATA ANALYSIS

There was concurrent data collection and analysis. Tesch's eight step descriptive methods were used to analyse data (Creswell, 2009:177). Data was analysed based on the essential themes that emerged.

## Measures for ensuring trustworthiness of the study

Trustworthiness was ensured by applying Lincoln and Guba's (1985) model of assessing trustworthiness. The four criteria for assessing trustworthiness that were used are: credibility, transferability, dependability, and confirmability (Polit & Beck, 2008:539). Credibility was achieved through prolonged engagement with the participants, triangulation, member checking, peer examination and referential adequacy. Transferability was ensured by the use of purposive sampling of participants and thick description of methods and participants responses. The use of thick description

of methods and participants responses also ensured dependability since there can be no credibility without dependability (Babbie & Mouton, 2009:278). The use of notes, tape records and the final report ensured confirmability of this research.

## DISCUSSION OF THE RESEARCH FINDINGS

The findings of the study indicate that despite the desirable effects of ART to prolong life, there are many challenges facing PLWHA that interfere with adherence to ART and negatively influence the QOL. The findings are reflected within the six essential domains of QOL that were identified through the literature review and that were validated by a sample of expert nurses involved in the care of PLWHA who are on ART. These are the physiological, psychological, spiritual, socio-economic, cognitive and the environmental domains.

### Physiological domain

The domain of physical wellbeing pertains to individuals' perception of their own bodily functions, including disease symptomatology, side effects of medication or general physical wellbeing (Henderson et al., 2008: 369). Six (6) categories emerged related to the physiological domain. These included clinical improvement due to ART, inability to meet nutritional needs for ART adherence, non-adherence to ART, disfiguring side effects of ARVs and inconsistent condom use.

#### Clinical improvement

It is clear that ART improves the physiological aspect of PLWHA. All participants stated that they started ART when they were sick with many opportunistic infections, but they improved physically and were suffering from minor infections. Improvement was also noted with the participants CD4 cell count as most of them (22) had improved CD4 cell counts. This is the response of one of the participants:

I started the drugs with a very low CD4 cell count of 8, but it has improved to 400 after three years of treatment, but I must mention that there was a problem before I started the drugs.

The findings of the study support the fact that ART increases CD4 cell count and reduces the occurrence of opportunistic infections. Research on the influence of HAART on clinical improvement concluded that ART improves the clinical state of PLWHA, increases their CD4 cell count and decreases the viral load (Gazzola et al., 2009:328; Kumarasamy et al., 2004:11; Beard, Feeley & Rosen, 2009:1343; Fox et al., 2009:137).

### Poverty associated poor nutrition

Participants revealed that they were poor and could not provide for their nutritional needs and those of their families. This challenge negatively influences their adherence to ART and QOL. One of the participants responded as follows:

As I am unemployed, I depend on the food rations from the clinic [corn soya] and handouts from the community. We consume the food from the clinic [corn soya] within two weeks of receiving it, since everyone at home depends on it for survival and after that, survival is difficult.

In support of participants' responses that food shortage is a problem, Weiser et al. (2007:1589) contend that both food insufficiency and HIV infection are major public health problems in the sub-Saharan and food insufficiency is a major risk factor for increased sexual risk taking among women in Botswana and Swaziland.

### Non-adherence to ART

The majority of participants were not conversant with the concept of adherence. To them, it meant just taking your medication anytime as long as you take them daily. Adherence was explained to them. When the participants were asked if they were adhering to their medication schedule, they pointed out many challenges they face and that resulted to non-adherence. These include non-disclosure of status, lack of reminders from family and friends, lack of food and the tiring, lifelong ART routine. It became clear that all the participants had not reached the 95% adherence rate necessary for maximising the benefits of ART as all of them reported missing more than three doses per month and not taking the drugs on time. Adherence to treatment is critical to obtain full benefits of ART, including maximum and durable suppression of viral replication, reduced destruction of CD4 cells, prevention of viral resistance, promotion of immune reconstitution and slowed disease progression (Steel et al., 2007:4).

### Perceived disfiguring side effects

Some participants were more concerned about perceived disfiguring side effects of ARVs as these serve as a marker for HIV infection and ART. They mentioned that they had disfiguring side effects, which interfered with adherence and their self-esteem. One of them stated that:

I don't know which is better, to continue with the drugs and not feel happy as I am, because of this enlarged abdomen that I have because of the drugs [or to stop taking the drugs]. I explained it to the doctor, but he said that I should be patient, because they cannot change the drugs just because of the abdominal enlargement. You can easily tell if someone is on the drugs – thin legs and broad shoulders. I am ashamed, because I know I am noticed by everyone.

According to Kinlaw and Marsh (2004:484), the prevalence of lipodystrophy in patients on HAART is approximately 40% and has been attributed to the use of protease

inhibitors and a nucleoside analogue called stavudine. This condition includes both the loss of facial and limb fat and central obesity. The participants' responses indicated that lipodystrophy is a major concern for PLWHA in Swaziland. This research clearly shows that although ART prolongs life, PLWHA are more concerned about their appearance and self-image than they are about prolonged life. So far there is no treatment of lipodystrophy in Swaziland.

### Inconsistent condom use

Participants mentioned that they use condoms every time they had sex. These participants mentioned that though they use condoms, they face some challenges that include the perception that condoms reduce the pleasure of sex, misconceptions about condoms, expressed desire to have children and ARVs perceived as increasing sexual desire. Some openly stated that they do not use condoms every time they have sex. There was a perception that if one is on treatment; there is no need for protection. Other participants also perceived ARVs to increase their sexual desire. One participant said that:

Condoms can't reduce AIDS; they are okay in boosting lust and sexual immorality, and to control childbirth. I cannot imagine myself living on that thing [a condom] for the rest of my life.

The above participant's response indicates that there are myths and misconceptions that hinder condom use in Swaziland. Although nurses encourage condom use, some religious and traditional leaders describe condom use as un-Swazi and inconsistent with Swazi manhood. Many Swazis believe that the flow of fluids involved in sexual intercourse represents an exchange of gifts of self, and for that reason they do not use condoms.

### Psychological domain

Neuman (1995) in George (2002:343) defines the psychological domain of a person as 'the mental processes and relationships'. Six categories emerged pertaining to the psychological domain, namely: the constant experience of stigma and discrimination, experience of depression, difficult coping with illness and treatment, lowered self-esteem and self-image due to ART, and negative perception of illness and treatment.

### Experience of stigma and discrimination

Regarding the perception of HIV and AIDS as a stigmatising condition, the majority of participants revealed that when they were diagnosed with HIV, they were stigmatised in some way by their family members, friends and community. In addition to HIV stigma, participants felt that ARVs have exacerbated the stigma of HIV and AIDS. This is what one participant said:



Even if I never disclosed my [HIV-positive] status, I cannot hide the drugs [the ARVs]. Eventually people will find out that I have the virus [HIV]. You cannot hide the tablets [the ARVs]. I wish there was a monthly injection. At least no one would know that you have the virus. It gives us a problem because you stop taking the drugs [the ARVs], you get sick. You take the drugs [the ARVs] and face ridicule from society.

It was clear that HIV and AIDS stigma still exist in Swaziland. This is supported by a study conducted by Holzemer et al. (2007:1002) on HIV and AIDS stigma in five countries, Swaziland included. They noted that AIDS stigma and discrimination is continuing to affect PLWHA and their health care providers, particularly in the southern Africa where the burden of AIDS is significant. It also became clear that ARVs have increased stigma. Participants stated that they were better off without the ARVs. They base their arguments on the idea that ARVs are a positive marker for the infection. They also raised a concern that the frequent visits to VCT centres make people suspicious that they have AIDS. Authors noted that most PLWHA, when given the pills, will discard the original pill boxes. Some will even empty all the pills into new containers. These people are afraid of being seen with ARVs, which are used by stigmatized people.

A study done by Uys et al. (2009:1059) concluded that stigma is higher for people who are on antiretroviral drugs than those not on ARVs. According to Gerretsen (2008:4), these life prolonging antiretroviral drugs have been fingered for contributing to HIV-positive people being stigmatised in their communities.

### Experience of depression

Due to the constant experience of stigma and discrimination associated with HIV and AIDS and ART, participants reported that they suffered depression due to the perception of HIV and AIDS as a disease for gays and lesbians with ARVs as a constant reminder of status and lack of proper counselling by health workers. One participant who suffered severe depression stated that:

They say HIV and AIDS is an issue for all of us. It is not true. Every time you go to bed or you are alone, it haunts you, and you are alone and it [HIV and AIDS] is no longer a general thing. It's a personal thing. You alone suffer the effects of ARVs, and you alone have to take ARVs every day. You ask yourself questions such as Why me? Who brought this thing, and why? How much time do I have left in this world? Who will take care of me when I am sick? Who will take care of my kids?

Research has identified an association between HIV and AIDS, ART and depression (Thom 2009:8). Rabkin et al. (2000:4130) conducted a study on the psychological effects of HAART and concluded that depression declined after two years of ART. In this study, it became clear that depression continues even after two years of HAART because the ARVs themselves contribute to depression. Though there was no evidence of a formal diagnosis of depression, participants mentioned that being on lifelong ART depresses them and ARVs were constantly reminding them of the infection.

### Perceived lowered self-esteem and self-image

Although some participants reported improved self-esteem, the majority were suffering from lowered self-esteem. Self-esteem is characterised by feelings of confidence, and a feeling of being appreciated and valued.

I sometimes ask myself what kind of human being lives by the bottle [ARVs]. There is no life like this [life on ART]. I don't feel like a human being anymore but a patient, and will feel like this as long as no cure is found or for the rest of my life.

Although Power, Tate, McGill and Taylor (2003:62) state that HAART may have a negative impact on self-esteem and QOL, especially for those young and the newly diagnosed individuals, this study revealed that it is not only the young and newly diagnosed who suffer lowered self-esteem but also adults.

### Negative perception of illness and treatment

With regards to perception of illness and treatment, participants perceived HIV and AIDS as an illness that is different from other illnesses. They mentioned that HIV and AIDS is not perceived like other infections by society. One participant mentioned that:

To me HIV is different from any other illness. You are stigmatised because of it. There is no treatment, and it is a disease that is associated with shameful behaviour and a disease that you are not proud to reveal. We were told that AIDS was for those who were behaving badly [prostitutes]. We accepted that. It [that perception] is now very hard to change, despite the fact that it [the disease] is now affecting everyone.

### Spiritual domain

Apart from the psychological domain, this study also explored the spiritual aspect of participants. Participants' responses identified two categories related to spirituality of PLWHA. It was identified that spirituality can serve as a source of (1) support for PLWHA and (2) conflict with ART.

#### Spirituality as a source of support

Participants emphasised the importance of religion in coping with HIV and adherence to ART. Participants' responses varied from increasing spiritual beliefs (n=16), emotional support (n=18), material support (n=2) and source of strength to carry on (n=11). This is what one of the participants had to say:

Church members donate money and food for those who are sick in my church every month, and I was encouraged to attend prayers, and I don't think I would have survived without their support. They don't have a problem with the HIV-positive status. Actually, they are encouraging people to come out and disclose their status, so that they can be helped.

Clearly, this study indicates that spirituality serves as a source of strength and an antidepressant for PLWHA in Swaziland. This study also showed that spirituality has both direct and indirect positive effects on participants' lives.

Various studies have examined the role that spirituality plays in helping patients cope with life threatening illnesses and these studies are in agreement with the participants views that religious beliefs and practices are powerful sources of comfort, hope and meaning of life, adherence and empowerment (Scarinci, Griffin, Grogoriu & Fitzpatrick, 2009:69; Delgado, 2007:233).

### Spirituality as a source of conflict for taking ARVs

Although most participants felt that spirituality offered them support, others felt that spirituality caused conflict with the taking of ARVs. One participant mentioned that:

Most Christian pastors insist on praying and healing an individual with HIV. They [the pastors] usually say, "We will pray for you and you will be healed, if you bring your tablets, so that we can burn them." One thing that people need to understand is that in church we are offered spiritual healing, and not physical healing. Physical healing is taken care of by medicine, and I will never stop taking these pills [ARVs], because they are the reason that I am still alive.

The negative influence of religion is confirmed by Flannelly, Ellison and Strock (2004:1232) who posit that religion may cause coping styles in which individuals surrender control or responsibility of problems to a higher power.

### Socioeconomic domain

The socio-economic domain deals with social support, community roles, and employment. In this domain only one category emerged during data analysis. Out of the twenty-four participants interviewed, only seven were employed, eleven were unemployed and six were self-employed. This leads to lack of financial resources for PLWHA. All the participants stated that due to their low socioeconomic status, they were unable to meet travelling and food expenses. This low socio-economic status has a negative impact on HIV and AIDS. One participant had this to say:

The situation in Swaziland is survival of the fittest. No one is assisting anyone, because everyone is poor and is struggling to feed their family. There is no compassion for anyone anymore. Everyone is minding their own business. No one cares about us. Not even government cares about us.

The participants in this study revealed that with their current low socio-economic status, it becomes very difficult to adhere to their medication. With the participants' information, it became evident that the low socio-economic status has a negative impact on HIV, AIDS and QOL.

## Cognitive domain

Concerning the cognitive domain, two categories emerged from data analysis. These are, namely: (1) poor understanding of ARVs, and (2) negative thoughts about HIV and AIDS and ART.

### Poor understanding of ARVs

Concerning the knowledge of the action of ARVs, almost all participants knew that ARVs were not a cure for HIV and AIDS. Six participants were not knowledgeable about the actions of ARVs. Concerning the knowledge of ARV drug names, the majority did not know the drugs they were taking by names. They mentioned that this was due to the difficult drug names. One participant responded as follows:

I do not know by name the two drugs that I am taking. The names of these drugs are difficult [to pronounce]. I only know zidovudine. It's like I am calling the king of demons (laughing). Just listen to that! Zidovudine! What is that? Why did they give it a difficult name like that?

Although clients receive HIV- and AIDS-related education at the study clinic, this research study showed that misconceptions still existed among PLWHA. There is a need to scale up community awareness of HIV, AIDS and ART.

### Negative thoughts about HIV and AIDS and ART

When the participants were asked what was constantly on their minds concerning the illness and the drugs, the majority of them did not have any destructive thoughts, but some (3) had something that was constantly bothering them. Incurability of the infection, lifelong treatment, short supply of the drugs and a sudden attack of opportunistic infections and side effects of treatment were causes for concern for these participants. Constantly having negative thoughts about HIV and AIDS, and ART negatively influences QOL.

## Environmental domain

The environment for PLWHA includes the health care systems, support systems, culture, policies and rights. Categories related to the environmental domain that emerged from data analysis include unsatisfactory health care delivery system, negative influence of culture on HIV and AIDS and ART, and violation of the rights of PLWHA.

### Poor health care system

All the participants mentioned that they were not happy as there were some problems that needed urgent attention. These include lack of privacy resulting from mixing of

patients in one consultation area, nurses and doctors shortage, resulting in long queues and availability of a lot of drugs purported to treat HIV and AIDS.

The right to confidentiality and privacy was not respected at all times at the study clinic as the consultations were sometimes done in the nurses' duty room. One of the participants mentioned that:

The consultation area is public, and there is no privacy. Even if you want to reveal your secrets, it is difficult. You are asked a sensitive question in front of all the others, and you are ashamed to answer. You end up leaving with your problems [unsolved].

Others participants were concerned with long queues resulting from staff shortage. One participant stated that:

Every time I come here I have to ask for permission from my employer and promise to come back [to work] soon. Now, with the long queues, it is impossible to come back to work soon. We need more nurses to work here, because we will end up not taking the drugs as a result [of these long queues].

Staff shortage, which resulted in work overload, was observed by the researcher. The clinic was short staffed with only seven nurses per day. Understaffing is a problem that results in reduced quality of nursing care and may jeopardise patient safety. This is supported by Mkhabela, Mavundla and Sukati (2006:70) who identified that there was a staff shortage in VCT centres in Swaziland. Staff shortage is accompanied by overcrowding. Overcrowding makes it difficult for a short staffed facility to provide quality care, which often leads to frustration and stress for the nurses (Mkhabela, Mavundla & Sukati 2006:70).

In addition to poor staffing, participants were concerned about the Swazi government's failure to control drug markets in Swaziland. This result in the availability of many unproven and unlicensed drugs marketed to PLWHA. One participant stated that:

There are a lot of drugs that are available for us to buy anywhere. One wonders if those drugs work. We just buy because they are widely marketed. If they are dangerous then why are they allowed?

Participants felt that the availability of the unproven and unlicensed drugs that are marketed to them gave them an option not to take ARVs.

## Culture and its influence on HIV and AIDS and ART

Participants mentioned that the Swazi culture has a negative influence on them concerning the way they view HIV and AIDS and ART. They mentioned that even after intensive education, they still exist in Swaziland with its traditional cultural practices, some of which are detrimental to their health. This is what one research participant said about their culture:

Even if you are educated about HIV and AIDS and the drugs [ARVs], there is a lot that is being said around us that disturbs us, because we are traditional Swazis, and we are still attached to our traditions. Sometimes I feel tempted to take traditional medicine, because when we were young our parents relied mostly on herbs.

## Violation of the rights of PLWHA

When asked about the rights of people living with HIV and AIDS, all participants mentioned that most of the time their right to confidentiality and privacy were violated. This is one of the participants' responses:

One Member of Parliament mentioned that we [PLWHA] should be branded on our buttocks, so that we are easily identified and do not infect others. This means violating my right to my illness. We should emphasise that everyone must protect himself or herself and not expect to be protected by HIV branding.

A study done by Kohi et al. (2006:404) on HIV and human rights revealed that the human rights of people living with HIV and AIDS are violated in a variety of ways, including denial of access to adequate or no health care/services, and denial of home care, termination or refusal of employment, and denial of the right to earn an income, produce food or obtain loans and also verbal and physical abuse.

## LIMITATIONS

The study was qualitative and was conducted on a limited sample. The nature and sample size of this study means that the findings can only be contextualised among PLWHA in Swaziland.

## IMPLICATIONS FOR NURSING PRACTICE

Despite the mentioned limitations of the study, the findings have important implications for nursing practice and research.

- ART services in Swaziland need to be decentralised to ART accredited facilities to scale up ART services. There is also a need for immediate implementation of the task shifting strategy as was recommended by the WHO in 2008. This will broaden the nurses' scope of practice, and they can prescribe for manageable patients and refer complex patients to medical practitioners.
- All new ART patients should be screened by nurses to determine those at risk of poor nutrition. Assessment is conducted to ascertain a baseline nutritional status and to determine the nutritional needs of the patient, so as to offer tailored nutritional assistance, treatment and management based on the results of the assessment.

- The churches should be encouraged to play a major role in disseminating HIV and AIDS information and promoting ART.
- HIV and AIDS, ART, trans-cultural nursing, nutrition for HIV and AIDS, and counselling courses are offered in pre-service nursing education.

## CONCLUSION

The study revealed that although ART improves some aspects of the life of PLWHA, there are challenges that interfere with adherence to ART and that negatively influence their QOL. This study revealed that PLWHA are powerless to deal with the above challenges and as such have a poor QOL.

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## COMPETING INTERESTS

The authors declare that they have no financial or personal relationship(s), which may have inappropriately influenced them in writing this paper.

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