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Exploring the Factors and Effects of Non-Adherence to Antiretroviral Treatment by People Living with HIV/AIDS

by **Jabulani G. Kheswa**

Abstract

The aim of the study was to determine how the health of people living with Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) is affected by social and structural factors conducive to non-adherence to antiretroviral treatment. In a qualitative study conducted at Victoria Hospital in Alice, a town in the Eastern Cape, South Africa, 23 isiXhosa-speaking participants (including both men and women) between the ages of 18 and 60 years were interviewed. Guided by the social-ecological framework of Bronfenbrenner (1979), which is based on the notion that the health-seeking behaviour of people living with HIV/AIDS (PLWHA) is influenced by their social, institutional and physical environments, the analysis of the data identified the following themes conducive to non-adherence to antiretroviral treatment: food insecurity, financial constraints, poor service from health workers, unfair dismissal, fear of the consequences of disclosure, and rejection by church members. Based on these findings, and given that there is no single model of best practice that can appropriately address the various social and structural factors complicating the treatment of HIV/AIDS and hence the containing of the pandemic, the study suggests the need for not only supportive community initiatives, but a collaborative approach at both local and national level, and particularly in impoverished communities, by the appropriate departments of state to promote adherence to anti-retroviral treatment by making treatment and counselling facilities more accessible to PLWHA and educating communities about the implications and prevention of the disease.

Introduction

Although antiretroviral therapy (ART) has effectively delayed the progression of HIV/AIDS from a manageable chronic illness to a terminal illness, non-adherence to antiretroviral (ARV) treatment by people living with HIV/AIDS (PLWHA) is likely to be reported (Yu, Lau, Mak, Cheng, Lv, & Zhang, 2014). Non-adherence to antiretroviral treatment refers to the non-taking or discontinuation of prescribed medication for HIV/AIDS over a given period, and tends to be a contributary factor in opportunistic infections such as tuberculosis (TB) and pneumonia (Gonzalez, Batchelder, Psaros, & Safren, 2011). Since AIDS is a complex disease syndrome when the immune system is weak, the following symptoms may be noted when there is non-compliance and non-adherence: loss of weight and appetite, fatigue, oral thrush, diarrhoea, and/or Kaposi's sarcoma, a cancer of the blood vessels affecting the mouth, skin and lymph glands due to human herpes virus 8 (HHV8) infection (Ogoina, Onyemelukwe, Musa, & Babadoko, 2012).

To date, South Africa has the largest antiretroviral treatment programme in the world, with more than 7 million currently living with HIV/AIDS, 80% of whom are on ART, and an estimated HIV prevalence five years ago already of 17.3% in the 15 to 49 year age group (Azia, Mukumbang, & Van Wyk, 2016; World Health

Organization, 2012). Antiretroviral drugs (ARVs) are the only approved medicines that can suppress viral replication, improve immunological outcomes, reduce the risk of developing drug resistance (AIDSinfo, 2015), and that have been scientifically proven to reduce HIV/AIDS-related morbidity and mortality (Anglemyer, Horvath, & Rutherford, 2013). Because HIV/AIDS is not merely a bio-medical phenomenon but a disease that comprises a number of interacting socio-economic, interpersonal, behavioural and psychological components (Katz, Ryu, Onuegbu, Psaros, Weiser, Bangsberg, & Tsai, 2013), both the stigma attached to HIV infection and alcohol consumption may hinder health-seeking treatment among the majority of PLWHA (Morojele, Pithey, Kekwaletswe, Joubert-Wallis, Pule, & Parry, 2010). Studies have found a universal tendency for PLHWA to report regimen characteristics such as forgetfulness due to alcohol abuse (Beach, Roter, Saha, Korthuis, Eggly, Cohn, Sharp, Moore, & Wilson, 2015; Martin, Kiwanuka, Kawuma, Zalwango, & Seeley, 2013) and experience impaired respiratory tract and gastro-intestinal immune systems, which, in turn, inhibit the effectiveness of ARVs in providing protection against opportunistic infections (Schneider, Chersich, Temmerman, Degomme, & Parry, 2014).

Non-adherence to ARV treatment has been found to be attributable to factors such as lack of employment opportunities, migration, cultural and religious beliefs, intimate partner violence, and inaccessibility of health care centres such as in Uganda, South Africa, Kenya and Zimbabwe (Coetzee, Kagee, & Vermeulen, 2011; Reniers & Armbruster, 2012). Furthermore, non-adherence is exacerbated by lack of accurate knowledge about either HIV/AIDS or ARVs, which is fuelled by traditional healers in most African countries, leading to many HIV/AIDS patients holding false beliefs about having been bewitched (Oku, Oku, & Monjok, 2013). Alongside cultural beliefs, some PLWHA tend to be led astray by religion, believing that it is only through prayer that they can hope to be cured (Kim et al., 2016). In terms of gender role strain theory, which is based on the assumption that male sexual behaviours conform to cultural norms, HIV positive women are likely to report non-adherence to the ARVs, non-condom use for fear of being rejected, and fear of physical assault by their sexual partners, and consequently opt for non-disclosure of their status (Naidoo, Peltzer, Louw, Matseke, Mchunu, & Tutshana, 2013). In the same vein, in a South African quantitative study by Murray, Semrau, McCurley, Thea, Scott, Mwiya, Kankasa, Bass, and Bolton (2009), 39.9% of the women who skipped their ARVs indicated being afraid that their husbands might accuse them of being responsible for the HIV infection. Morfaw, Mbuagbaw, Thabane, Rodrigues, Wunderlich, Nana, and Kunda (2013) noted that non-adherence amongst women often occurs when their sexual partners are around at the time of taking the ARVs or on the day they should be going to the clinic for check-ups and to collect the treatment drugs. In support of this, Mepham, Zondi, Mbuyazi, Mkhwanazi, and Newell (2011) found in KwaZulu-Natal, South Africa, that violent male sexual partners suspected that their women were having extramarital affairs when they (the males) picked up their partners' cellphones and found that male staff nurses had called to ask why their partners had not come to the clinic. Because depression tends to becomes inevitable in such instances owing to lack of emotional and social support (Slabbert, Harvey, Brink, & Lubbe, 2015), Plummer, Watson-Jones, Lees, Baisley, Matari, and Changalucha (2010) found that impaired memory, fatigue and feelings of helplessness often lead to discontinuation of the ARVs and development of opportunistic infections, including cryptococcal meningitis (Rabkin, 2008). Given that, as a mood state, depression is characterized by feelings of worthlessness, sadness and despair, and social withdrawal (Durand & Barlow, 2002/2016), Nell and Kagee (2011) are of the opinion that patients living with HIV/AIDS should receive therapy to enable them to be intrinsically motivated to remember to take their medication on time and to be hopeful about the future.

To facilitate adherence to the ART regime, the majority of PLWHA employ problem-focused coping strategies of some kind, such as belonging to support groups, relaxation techniques, and asking others to collect their medication for them from the clinics since they are unemployed and cannot afford the cost of transport (Coon & Mitterer, 1976/2010). Since regular visits to the clinic could be beneficial to the psychological well-being of PLHWA, given that the support groups and trained volunteers provide new knowledge on how to prevent opportunistic infections, it was suggested by Kheswa (2014) that the official introduction of mobile clinics or transport from the villages could serve to contain the HIV pandemic more effectively. Owing to the dearth of research on non-adherence to ARV among people from 18 to 60 years living with HIV/AIDS and attending hospitals in the rural Eastern Cape, this qualitative research study expands on exploring the factors implicated in non-adherence to ARVs, with the participants including individuals with no history of treatment interruption as well as those whose treatment had just begun.

Theoretical Framework

This study adopted the social-ecological framework pioneered by Bronfenbrenner (1979) as it provides a comprehensive understanding of health-seeking behaviour (Joint United Nations Programmes on HIV/AIDS, 1999). The premise underpinning this framework is that the PLWHA's health-seeking behaviour is located in social, institutional and physical environments, with adherence to the ARV treatment regime consequently largely influenced by the social environment (Roura et al., 2009). The social-ecological model views social factors (i.e., interpersonal relationships with marital

partners, family members, church) and structural factors (i.e., poverty, health systems, livelihood and living circumstances) as inextricably linked and in some ways mutually reinforcing (Duff, Kipp, Wild, Rubaale, & Okech-Ojony, 2010). Skinner's operant conditioning (behaviour modification) affords a crucial complement to the social ecological framework (Donald, Lazarus, & Lolwana, 1997/2010), since adherence to ARVs is strengthened through positive reinforcement (social and emotional support) or weakened through adverse consequences (punishment, rejection, or discrimination) (Simoni, Amico, Pearson, & Malow, 2008). It is against this background that the researcher sought to investigate the following research questions: (i) What contributes to non-adherence to ARVs by PLWHA? (ii) How do PLWHA cope with the side-effects of the ARVs?

Research Method

A qualitative, explorative, descriptive and contextual design was followed to determine the challenges faced by PLWHA as far as adherence to ARV treatment is concerned, with the study conducted at one of the public hospitals located in rural areas of the Eastern Cape, South Africa. Qualitative research allows data to be collected in the form of written or spoken language which is then analysed by identifying and categorizing themes (Babbie, 1975/2010; de Vos, Strydom, Fouche, & Delport, 1998/2011). Purposive sampling was used to recruit PLWHA at the clinic when they came to collect their monthly ARV treatment. The sample consisted of 23 participants (10 males and 13 females) who speak isiXhosa and whose ages ranged from 18 to 60 years.

Data Collection

Focus group interviews were conducted to collect data since they offer participants the opportunity to describe their experiences in their own language and from their own perspective (Creswell, 1994/2009; de Vos et al., 1998/2011). It is important to note that this study took place in September 2014 following endorsement by the Ethical Committee of the University of Fort Hare. Thereafter, the researcher sought permission in writing from the Superintendent of the Victoria Hospital in Alice, highlighting the aims and objectives of the study, ethical considerations, and the method of data collection to be implemented. The following questions were asked of each participant:

- *Can you identify the factors which lead you to non-adherence to the ARVs?*
- *How do PLWHA cope with the side-effects of the ARVs?*
- *How do PLWHA cope with discrimination?*

To facilitate the focus group interviews, the manager of the clinic and a sister in charge arranged one of the consultation rooms as the venue. The venue was well ventilated, free of hazards, and the tables were arranged in a horse-shoe style for the participants to maintain eye contact. The researcher used communication skills such as reflection, questioning, nodding and clarification to facilitate and encourage the participants to share their experiences until the themes were identified. Field notes were also taken during the interviews, which each lasted for 50 minutes.

Data Analysis

Tesch's (1990) method was applied to analyse the data qualitatively. This procedure being aimed at capturing patterns, the researcher listened to and transcribed the audiotapes, and read the verbatim transcripts several times in order to familiarize himself with the data (Braun & Clark, 2006). Similar ideas were grouped together and identified as codes and further categorised as themes (Creswell, 1994/2009).

Trustworthiness

To establish the trustworthiness of the research study, four alternative constructs proposed by Lincoln and Guba (1985) and also cited in Krefting (1991) were adopted: credibility, dependability, confirmability and transferability. To ensure credibility, all the participants were taken through the same questions and interviewed to the point at which it was evident that data saturation, marked by prolonged engagement with the same themes, had been reached. Dependability was achieved through dense description of the research methodology employed and by conducting a code-recode procedure on the data during the analysis phase (Krefting, 1991, p. 221). Confirmability was ensured by audit trial of the verbatim descriptions and themes (Krefting, 1991). To achieve this, the researcher validated the transcripts by consulting a few participants after completing the data analysis. In this regard, it should be noted that, for the purpose of reaching an international audience, some of the transcripts had to be translated from isiXhosa to English. Transferability was ensured through a literature control review after analysis of the data collected, where similar findings of previous studies were reported.

Ethical Considerations

To safeguard the human dignity of the participants, strict adherence to ethical principles was necessary. The participants were asked to give their informed consent and, as suggested by Babbie (1975/2010), they were assured of their right to confidentiality, privacy and anonymity. Accordingly, the participants were not asked to identify themselves during the interview, and they were assured that their responses would not be shared with anyone in a way that would breach their privacy. Along with the consent of each having been obtained for the interview to be audio-recorded, the participants were also promised by the researcher that, once the data analysis had been completed, all the audio-recordings would be deleted. Considering the sensitivity of the research topic, debriefing took place after the interviews, conducted by the researcher (a trained counsellor).

Results

In order to give an overview of the main challenges of PLWHA, the individual, social and structural factors that emerged from the interview data are presented first. This is then followed by the presentation of the themes that specifically relate to non-adherence to ARVs.

Demographic Details of the Participants

A total of 23 PLWHA receiving ARV treatment was included in the analysis. The majority of the respondents (n=13) were women and nearly half (n=11) were aged between 18 to 24 years. More than half (n=14) were single and not working, while nine of the respondents had employment. Six of the respondents were divorced, and only three were still married. In terms of treatment history, five respondents had received more than five years of treatment each as opposed to eighteen who had started their treatment less than five years previously.

Categories and Themes

The categories with sub-themes identified following Tesch's method of qualitative data analysis as conducive to non-adherence to ART are: poverty, violation of human rights, unprofessionalism, gender-based violence, and discrimination.

Poverty

Food Insecurity

Food insecurity was a recurrent theme related to non-adherence to ARV treatment that emerged as both a day-to-day barrier to adherence to ARV treatment and an underlying factor for ARV interruption. Participants frequently mentioned that lack of adequate food actually compromises the effectiveness of the ARV drugs, given the side-effects. One participant cited the following:

> *"There are times when I lack food at home and that makes it difficult to take my treatment on an empty stomach because they could aggravate your health. Taking ARVs on an empty stomach results in headaches, weak body, and diarrhea."* [Male participant, aged 54]

Financial Constraints

Another important theme that impacted on adherence to ARV treatment was financial constraints. Participants pointed to unemployment and staying far from the clinic as resulting in some of them missing their medication refill appointments or follow-up examinations by the medical doctors. For example, one female participant explained that, given the cost of transport, she has no option but to walk a long distance in order to reach the hospital owing to financial constraints:

> *"My village is far from town so we struggle to get to the hospital. The transport requires cash. I then end-up walking to the hospital."* [Female participant, aged 38]

Another participant concurred that the cost of accessing treatment centres impacts adversely on ARV adherence:

> *"The reason for not taking treatment correctly is the cost of reaching treatment centres."* [Female participant, aged 30]

Childheaded Households

Participants also highlighted that being unemployed and living in child-headed households contributed to their skipping of treatment, because at times they needed to seek temporary jobs to ensure that their siblings had food.

> *"The reason for not adhering to treatment apart from living far from the hospital is that I should do either gardening or painting for my neighbours in order to get money for food for my two young sisters who are still at school, because we do not have parents."* [Male participant, aged 19]

Violation of Human Rights

Deprivation of Sick Leave

Participants reported that their employers refuse to grant them leave to collect their treatment despite knowing their health status and that that impaired their immune systems. Moreover, participants expressed that their employers had threatened to fire them and employ other people should they be absent from work.

> *"I am working in the bushes, so sometimes I take my treatment after the scheduled date because the bush manager does not give me a day off and he says that I am not sick. And I have been working for him since 2008 ..."* [Male participant, aged 39]

Unfair Dismissal

Another participant, who had been on ARV treatment for 6 years, reported that, after having been fired, she took her employer to the Commission for Conciliation, Mediation and Arbitration (CCMA) for having refused to give her days off to go to the clinic for her ARV treatment. The CCMA is the South African statutory body which arbitrates labour disputes and mitigates damages caused by unfair dismissal either by awarding compensation or by calling for re-instatement of the employee (Constitution of the Republic of South Africa, 1996).

> *"I used to skip my treatment because my employer would not allow me to take my days*

to go to the hospital. I had to choose between work and my life and I did not report to work this other day. On my arrival at work the next day, she fired me and I took her to CCMA." [Female Participant, aged 46]

Unprofessionalism

Poor Service from Health Workers

Inadequate counselling for patients upon receiving their health status may account for non-adherence, since the patients are still in shock and denial. One respondent highlighted that the nurses had not given her time to accept her status, but instead put her on the treatment just a week later. She said:

"Before I moved to Kwa-Gqumashe, I used to stay in Cofivamba. At the hospital where I got tested, I was never given counselling and prepared for the side effects, and I did not take my medication regularly because I had heard that certain pills cause one to experience bad dreams." [Female Participant, aged 26]

Unacceptable Attitude and Conduct

The majority of the participants also expressed the view that nurses needed to be educated to respect patients' human dignity. They recounted incidents where persons who had not adhered to the ARV treatment, for reasons such as relocating to another village, marital conflicts or securing admission for children's education, were ridiculed by nurses and told that they were no longer on the treatment programme. The extracts below provide evidence of unacceptable conduct by health workers:

"The nurse shouted at me in front of other patients after I told her that my reason for not adhering to my treatment was after my husband threw away my pills and beat me." [Female Participant, aged 34]

"If it had not been for my parents who gave me support to re-adhere to the ARVs, I should have died seven years ago because the nurse that should have given me counselling, told me that I have a low CD4 count and she doubted if I would live." [Male Participant, aged 25].

Expressing the view that health workers needed to be trained to treat patients approproriately, another male respondent, aged 29, commented that their general level of respect for confidentiality is low and that they fail to treat patients with care or consideration. In this regard he pointed out that patients would be left unattended for a long time even when they arrived on time.

Gender-Based Violence

Fear of Disclosure

Married female participants who were in cohabitation stated that they skipped their treatment, especially when their spouses were around, due to fear of disclosure. As a result, they would neither practise nor negotiate safe sex, for fear of being physically abused.

"I do not take my pills every day because I am afraid to tell my abusive husband about my status ... . I think he is the one who infected me as I never had any sexual partners before." [Female Participant, aged 33]

Risky Sexual Behaviour

Some married female participants reported that they had unknowingly infected their babies with sexually transmitted infections through breastfeeding, due to the risky sexual behaviour of their spouses, who would not sleep at home for days and upon returning demand sex.

"Right now my baby's weight is low and she has been sick, and I was asked by the doctor if I was married and practised safe sex." [Female Participant, aged 28]

Discrimination

Derogatory Remarks

Discrimination had been experienced by some of the participants in the form of rejection by their family members, employers and also community members, who would also pass derogatory remarks. They cited that family members hurt their feelings by refusing to allow them to cook or to eat meals prepared by them. For example, a 23-year-old female participant said:

"My family is scared of me and claims that I am going to infect them with this disease, and they do not even want to eat the food that I have cooked. They talk bad things about this disease and associate HIV/AIDS with sexual promiscuity ... . Even when I was on TB treatment they did not even want to come near me. I even drink alcohol because no one really cares about me."

Stigma

A female participant said that it had become difficult even to come to the clinic to collect the ARV treatment because some of her spouse's colleagues had seen her there and had started to be discriminatory towards her.

"I once defaulted because even my husband was being stigmatized by his colleagues who saw me in the ward meant for HIV/AIDS patients." [Female Participant, aged 56]

Rejection by Church Members

Another female participant cited that discrimination and rejection by the church had stopped her taking the ARVs. She expressed the following:

> *"Having disclosed my HIV status to the church members, I began to experience aloofness and the attitudes of the choristers became different.*" [Female Participant, aged 22]

Discussion

Financial constraints affecting adherence to treatment were reported by a number of participants, especially in relation to transport costs for collection of ARVs from the clinic. Participants attributed not adhering to the treatment regularly to experiencing food shortage at home and so fearing side effects such as diarrhea and dizziness if they were to risk taking the treatment on an empty stomach. Considering that the majority of the participants indicated that they were unemployed, it is self-evident that it must be a common problem for the immune systems of such PLWHAs to suppress the viral load and opportunistic infections when they cannot afford the three meals a day required for boosting their memory and general well-being. These findings accord with those reported by Palar, Wagner, Ghosh-Dastidar, and Mugyenyi (2012) in respect of what they referred to as food insecurity (FI) among PLWHA in sub-Saharan countries due to unemployment and poverty. The findings are also consistent with the observation of Wasti, Randall, Simkhanda, and Teijlingen (2012) that there are limited ART sites in rural areas, with PLWHA therefore having to travel long distances to and from treatment sites, resulting to non-adherence to treatment. What the findings regarding the impact of financial constraints and food insecurity on treatment adherence suggest is that effective strategies to promote food access by unemployed PLWHA should be implemented in the Eastern Cape in order to curtail the side effects of ARVs. For example, at some clinics in KwaZulu-Natal, most PLWHA were given vouchers to the value of R120 (approximately $15 USD) towards improving household food security and covering the cost of transport to the clinic (Lutge, Lewin, Volmink, Friedman, & Lombard, 2013).

Pill burden was found to be another barrier, given that the participants chose not to carry their tablets with them when travelling to seek employment or to their place of work. In this context, a 19-year-old male participant reared in a child-headed household mentioned that his non-adherence to ARVs is largely due to the casual jobs he takes on, such as tending neighbours' gardens, in order to be able to buy food for his younger siblings. Holborn and Eddy (2011) assessed that, as poverty has escalated, 47% of South African child-headed households had come to depend financially on less than R1300 monthly to cover household expenditure. The majority of adolescents in childheaded households are therefore likely to drop out of school before completing matric in order to augment the household's income by working odd jobs (Ngonyama, 2013). This is in contravention of the intent of the South African Children's Act 38 of 2005 (Republic of South Africa, 2006), insofar as it deprives adolescents in child-headed households, who are still in need of appropriate care and protection, of their social developmental rights as set out in section 28 of the Constitution (Constitution of the Republic of South Africa, 1996). Owing to lack of knowledge about HIV/AIDS and a combination of risk factors such as the dysfunctional family and disorganized environment in which the 19-year-old male participant lives, he may drink alcohol and cohabitate if his locus of control is externalized, and therefore be prone to reinfection and non-adherence. This could be explained by Bandura's learning theory, especially in communities in which there are no positive role models for youth (Coon & Mitterer, 1976/2010).

Other adherence barriers mentioned in the interviews included gender-based violence and unprofessional conduct on the part of health workers. In this study, female participants seemed to be submissive and to lack assertiveness, some having conveyed that they had stopped taking their ARVs and continued to engage in unsafe sex despite being both physically and emotionally abused by their sexual partners. These findings accord with previous studies (Naidoo et al., 2013; Ndzombane, 2012) which found that, in culturally embedded societies characterised by hegemonic masculinity, it is deemed acceptable for men to engage in risky sexual behaviour. The consequence of ARV treatment interruption, which fosters the emergence of drug-resistance (Adefolaju, Theron, & Hosie, 2014), was illustrated by the report of one female participant that her breastfed baby was ill as a result of her having had unprotected sex with her partner, who had multiple sexual partners. Caterino-de-Araujo, Magri, Costa, and Manuel (2010) point out that, in such cases, both the mother and the child might suffer from Human T-cell lymphotropic virus type 1 (HTLT-1) and die of cancer. HTLT-1 is transmitted through blood transfusion, sexual intercourse and from mother to child through breastfeeding (ibid.). In addition to the adverse consequences of gender-based violence, the participants expressed experiencing some form of dehumanization and sense of worthlessness when the health care providers shouted at them instead of taking their circumstances into account and thus providing counselling and clinical support for patients on ARVs in order to facilitate adherence. The findings indicated that it is important for health care providers to inform patients in advance about the side effects to expect from the ARVs and to suggest strategies on how to handle taking their pills secretly, especially in the case of those who may not be ready yet to disclose their status.

Reflecting the work of Lazarus and Folkman (1984),

which derives from the psychological theories of stress and coping, the male participants had experienced less discrimination and prejudice from their partners and family members in comparison with the women. To be seen at the HIV/AIDS clinic by community members could, however, have adverse consequences, as reported by a participant whose spouse was subsequently stigmatized in the work place. This is in line with the study on discrimination towards patients with TB in KwaZulu-Natal, where Daftary, Padayatchi, and O'Donnell (2014) found that respondents had been alienated from relatives who became afraid to visit or share physical space with them because they were identified as suffering from a dangerous disease. Given this, it is thus not surprising that Kalichman et al. (2012) found that patients who stopped taking their ARVs, engaged in drinking alcohol and reported significantly more AIDS symptoms were those who lacked emotional support. In this regard, it would seem incumbent on health care providers to exercise empathy and treat their patients with dignity. The importance of emotional support was illustrated by the acknowledgement of four of the participants that their parents encouraged them to adhere to the ARV treatment. Another two of the participants highlighted having received financial support from their employed parents. Hence, in cases where family support is evident, adherence efficacy is high as opposed to non-adherence as a consequence of experiencing depression. In Brazil, a high prevalence (25.8%) of depressive symptoms was reported among women living with HIV/AIDS when compared with the general female population owing to lack of social support, and, in particular, rejection by sexual partners upon disclosing their status (Reis, Haas, Santos, Teles, Galvão, & Gir, 2011).

Contrary to the Bill of Rights (Chapter 2 of the Constitution of the Republic of South Africa of 1996), it is apparent from the findings that it is still difficult for some employed PLWHA to enjoy fringe benefits such as cumulative leave. As highlighted by one male participant, aged 39, whose employer of eight years had refused to grant him days off for clinic appointments, he might consequently have started experiencing weight loss, fatigue and constant coughing, given the unduly long hours of strenuous work that the majority of farm workers are exposed to. In contrast, in a study conducted in ten HIV clinics supported by the Foundation for Professional Development (FPD) in four South African provinces – Gauteng, Mpumalanga, Limpopo and North West – it was found by dos Santos, Kruger, Mellors, Wolvaardt, and van der Ryst (2014) that, in the case of those participants who experienced violation of human rights, more than half (54.7%) tried to obtain legal redress, as opposed to the 33.3% who had feared intimidation. In this regard, economically productive citizens should be empowered and educated regarding their human rights.

Conclusion and Recommendations

Even though ARVs are now freely available in public hospitals around South Africa, the potential benefits are impeded by non-adherence to the treatment regime. It is therefore evident that, in order to curb non-adherence to ARV treatment and consequent high rates of opportunistic infections and mortality, which further impact the economy, efforts from multiple sources are required, especially in poverty-stricken environments. The Eastern Cape being one of the poorest provinces in South Africa, community members and the church may, for instance, be urged to collaborate in organising soup kitchens for PLWHA and child-headed families, rather than to reject them by stigmatizing their condition.

Although new information has emerged to contribute towards expanding the body of knowledge on HIV/AIDS management, it is important to note that this study has limitations, given that the target population comprised only Xhosa-speaking people from rural areas in the Eastern Cape and followed a qualitative approach. Furthermore, considering variations in terms of the biographical details of the participants (i.e., source of livelihood, length of treatment, and marital status), it cannot be assumed that PLWHA from other race groups (i.e., Indians, Coloureds and Whites) in other provinces experience the same challenges. Therefore, there should be collaboration between government departments (Social Development and Health) to ensure the provision of social grants or food parcels to indigent PLWHA. The government should ensure that all employers are acquainted with the HIV/AIDS policies pertaining to the workplace in order to avoid exploitation of workers. This study further points to the need for mobile clinics in the villages, given the hardship caused by the physical distance between the nearest hospital and rural communities, as well as door-to-door campaigns by trained health workers in order to monitor compliance and adherence. To destabilize patriarchy in culturally embedded communities, the government should involve the chiefs of the villages in programmes aimed at addressing gender-based violence and encourage men to go for voluntary testing and counselling for HIV/AIDS. In conclusion, this study advocates that sex education should be introduced as part of the school curriculum, given that most of the participants in this study were below age 24 and might have contracted HIV due to the dominant influence of cultural and religious factors, poor role models, and the lack of appropriate education and guidance by educators while at school.

Referencing Format

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