

THE CHALLENGES AND PERCEPTIONS OF COMMUNITY CAREGIVERS WITH REGARD TO ANTIRETROVIRAL TREATMENT ADHERENCE OF PATIENTS: A PHENOMENOLOGICAL STUDY

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Although there is no cure for HIV and AIDS, antiretroviral treatment has transformed this disease into a manageable chronic illness. Relatively little is known about the experiences and psychosocial challenges that community caregivers of HIV and AIDS home community-based care programmes experience in ensuring patient adherence to antiretroviral treatment (ART). This article describes the results of a phenomenological study to explore these perceptions of community caregivers. Focus group discussions were facilitated with community caregivers and they made narrative reflections in journals to gain insight into their everyday world and experiences of dealing with the challenges of patients on antiretroviral treatment, as well as noting their suggestions for interventions to ensure adherence to antiretroviral treatment.

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# **THE CHALLENGES AND PERCEPTIONS OF COMMUNITY CARE-GIVERS WITH REGARD TO ANTIRETROVIRAL TREATMENT ADHERENCE OF PATIENTS: A PHENOMENOLOGICAL STUDY**

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## **INTRODUCTION AND PROBLEM STATEMENT**

South Africa has the highest number of people living with HIV and AIDS in the world. In 2012 240 000 South Africans died of AIDS-related causes. Although there is no cure, existing treatments have transformed this disease into a manageable chronic illness. Many lives have been saved through a massive scale-up of antiretroviral treatment in the last few years (WHO, 2013). At the end of 2012 an estimated eighty percent of people with HIV and AIDS received antiretroviral treatment in South Africa. However, successfully treating HIV and AIDS requires high levels of adherence to prescribed medication. There is a growing concern about adherence to antiretroviral treatment, the development of drug-resistant HIV and drug failure (Kagee, Remien, Berkman, Hoffman, Campos & Swartz 2014:413; Van Dyk, 2012:12).

The effects of HIV and AIDS have had a devastating effect on communities in South Africa. Therefore, social support structures are important for patients' adherence to ART (Dahab *et al.*, 2008:4; Kagee *et al.*, 2014:85; Nachegea *et al.*, 2006:128). Little is known about the experiences and psychosocial challenges that community caregivers of HIV and AIDS home community-based care programmers experience in ensuring patient adherence to antiretroviral treatment (ART). It is therefore imperative to explore the challenges experienced by community caregivers in order to gain insights from their perspectives and to develop community-based interventions to enhance adherence of patients to ART.

## **AIM AND OBJECTIVES OF THE RESEARCH**

This study aimed to explore and describe the perceptions of community caregivers regarding the challenges of ensuring antiretroviral treatment adherence of patients and suggestions for interventions from their perspective. The objectives for the study were:

- To explore and describe the perceptions of community caregivers regarding the challenges that HIV and AIDS patients experience in adhering to antiretroviral treatment;
- To explore and describe the perceptions of community caregivers with regard to interventions to facilitate patients adherence to antiretroviral treatment

## **RESEARCH METHODOLOGY**

A qualitative approach was used to explore the perceptions of community caregivers with regard to antiretroviral adherence of patients and suggestions for interventions to enhance adherence (Botma, Greeff, Mulaudzi & Wright, 2010:190; Nieuwenhuis, 2009:50). The research adopted a phenomenological design (Fouché & Schurink,

2011:316), meaning the focus was on people's subjective experiences and interpretation of the world. The sampling technique used for this research was purposive sampling and the sample size was determined by saturation (Greeff, 2011:367).

The sample determined inclusion criteria for the participants. The criteria included the following:

- Male and female home community-based caregivers;
- Active involvement in service delivery to patients on antiretroviral treatment;
- Serving home community-based care programmes in Potchefstroom (Bambanani Youth Project, Baptist Children's centre and Hospice Emanuel Loving Angels);
- At least one year's experience working with HIV and AIDS patients on antiretroviral treatment; and
- Ability to communicate in English.

Exclusion criteria were:

- Community caregivers who had worked for less than one year at any of the organisations; and
- Inability to communicate in Tswana, Afrikaans or English.

The participants were selected from three home community-based care centres, Permission to conduct the research was obtained from the managers of the home community-based care (HCBC) centres. They also assisted with the selection of the participants for the study. Participants were informed about the nature of the research and processes, and their willingness to take part in the study was ascertained. Willing participants were asked to give written consent to participate in the research.

For the purpose of this study data were collected using focus groups (Botma *et al.*, 2010:190; Bryman, 2008:475; Greeff, 2011:348; Nieuwenhuis, 2009:50; Smith, 2009:118). These groups explored not only community caregivers' perceptions of patients' challenges in adhering to antiretroviral treatment, but also their suggestions for interventions. The focus group schedule was pre-tested by means of a pilot study to ensure the questions were relevant and understandable to the participants. These participants were excluded from the main study. The schedule was adjusted based on feedback from the focus group.

By means of journal descriptions and narrative storytelling, participants described their experiences of patients' adherence to antiretroviral treatment. According to Alaszewski (2006), the aim of journals in social research is for participants to narrate their thoughts about a certain phenomenon, giving them the opportunity to return to the written text and supplement it with additional thoughts or information. The instructions for journal views were pre-printed in the journals and were collected after a month. Guidelines included:

- Describe your daily challenges with your patients on antiretroviral treatment.

- Based on your daily experiences, why do you think patients are not adhering to antiretroviral treatment?
- What suggestions do you have to improve adherence of patients to antiretroviral treatment?

The methods of ensuring trustworthiness proposed by Lincoln and Guba (in Babbie & Mouton, 1998:276) were utilised during this research. The aspects of credibility, transferability, dependability and confirmability were taken into account. The following methods were used to increase trustworthiness of the study, namely that no potential harm to participants be done, informed consent and voluntary participation and confidentiality (Strydom, 2011).

Creswell's data analysis spiral process indicates that the process moves in analytic circles (rather than in a linear way) comprised of planning for recording the data, data collection and preliminary analysis, managing the data, reading and writing memos, generating categories and coding the data, testing emergent understandings and searching for alternative explanations, interpretation and developing typologies (Creswell, 2013:182). Data were described and classified, and interpreted and categorised for identification of similarities. Thereafter the data were organised according to different themes. Additional extracts from the narratives in the journals were checked against the themes that emerged from the focus group discussions to identify new themes. Emerging themes were revised until no further themes could be identified.

## **DISCUSSION OF FINDINGS**

The discussion on the research findings will be presented in three sections as follows:

- Geographical area where the study was conducted;
- Demographic data of the participants;
- A discussion of the themes and sub-themes which emerged from the processes of data analysis.

### **Geographical area where the study was conducted**

The study was conducted in Potchefstroom with three home community-based care organisations, namely, Bambanani Youth Project, Baptist Children's centre and Hospice Emanuel Loving Angels.

### **Demographic data of the participants**

A total of 16 participants took part in four focus group sessions. The ages of the community caregivers ranged from 24 to 40 years. Eleven of the participants were female and five were male. All community caregivers were actively involved in service delivery to patients on antiretroviral treatment.

## Discussion of themes and sub-themes

**TABLE 1**  
**THEMES AND SUB-THEMES REGARDING THE PERCEPTIONS OF**  
**COMMUNITY CAREGIVERS OF PATIENTS' ADHERENCE TO**  
**ANTIRETROVIRAL TREATMENT AND THEIR PERCEPTIONS OF**  
**INTERVENTIONS TO ENHANCE ART OF PATIENTS**

<b>Category A: Psychosocial challenges and ART adherence of patients</b>	
<b>Themes</b>	<b>Sub-themes</b>
<b>Theme A1: Psychological challenges</b>	<ul style="list-style-type: none"> <li>▪ Feelings of hopelessness</li> <li>▪ Anger and non-acceptance of HIV status</li> <li>▪ Patients lack motivation</li> </ul>
<b>Theme A2: Physical challenges</b>	<ul style="list-style-type: none"> <li>▪ Patients experience difficulties with self-regulation and self-efficacy</li> <li>▪ Knowledge and beliefs about physical complications of ART</li> </ul>
<b>Theme A3: Social challenges</b>	<ul style="list-style-type: none"> <li>▪ Alcohol and drug abuse</li> <li>▪ Risky sexual behaviour</li> <li>▪ Cultural and traditional practices and beliefs influence the patients' adherence to ART</li> <li>▪ Discrimination and stigma influence adherence to ART</li> <li>▪ Non-disclosure as a barrier to ART adherence</li> <li>▪ Lack of social support</li> <li>▪ Lack of family support</li> </ul>
<b>Theme A4: Socio-economic challenges</b>	<ul style="list-style-type: none"> <li>▪ Lack of food influences ART adherence</li> <li>▪ Social grants as a barrier to ART adherence</li> <li>▪ Unemployment as a barrier to ART adherence</li> <li>▪ No transport as a barrier to ART adherence</li> </ul>
<b>Category B: Community caregivers perceptions of ART interventions</b>	
<b>Theme B1: ART Interventions</b>	<ul style="list-style-type: none"> <li>▪ Psychological interventions</li> <li>▪ Interventions on a physical level</li> <li>▪ Social interventions</li> <li>▪ Socio-economic interventions</li> </ul>

### **Category A: Psychosocial challenges and ART adherence of patients**

Theme A1 focuses on psychosocial challenges associated with ART. The analysis revealed a number of psychosocial dimensions influencing ART adherence. According to Wouters *et al.* (2014:146), merely initiating life-saving ART in all eligible HIV and AIDS patients is not sufficient. As a chronic illness, HIV and AIDS require life-long treatment adherence, and thus sufficient attention needs to be devoted to the psychosocial dimensions of care and support needs of community caregivers to encourage ART adherence of patients.

### ***Theme A1: Psychological challenges Mpungu***

Studies by Nakimuli-Mpungu *et al.* (2012:2115) and Yeyi *et al.* (2014:1485) found that people with HIV and AIDS are subjected to numerous stressors that can impact on their mental health. These psychological stressors manifest themselves in feelings of hopelessness, depression and other severe mental health problems, anger and non-acceptance of their HIV status and other life stressors. From this study it became evident that psychological problems manifest themselves in different ways as expressed by the following comment: *“Some patients who drink medication want to get well but inside they are wounded.”*

#### ***Sub-theme A1.1: Feelings of hopelessness***

According to Nakimuli-Mpungu *et al.* (2012:2115), depression is associated with feelings of hopelessness and with the loss of the will to care for the self. The systematic review by Nakimuli-Mpungu *et al.* (2012:2115) indicates that HIV-positive individuals with depression symptoms are less likely to adhere to ART compared to those without depression symptoms. This view is supported by this study, based on the responses of the community caregivers. According to them, depressive behaviour of patients is a major barrier for optimal adherence to medication. The following comment was made: *“Some patients do not want to go to the clinic ... they get depressed, just stay at home and do not want to look after themselves.”*

#### ***Sub-theme A1.2: Anger and non- acceptance of HIV status***

The study by Hardon, Davey & Gerrits, (2006:80) on the challenges of antiretroviral treatment found that anger and non-acceptance of HIV status constrain adherence to antiretroviral treatment. In this study anger and non-acceptance of HIV-status were particularly perceived by community caregivers as a major barrier to adherence of patients to medication. Most caregivers agreed that individual acceptance of HIV-positive status is required for optimal adherence to ART. However, patients experienced difficulty accepting their HIV status as expressed by the following statement: *“Patients cannot accept their status...”*

A participant said: *“They [patients] are angry of taking pills every day ... they want their life back before they were drinking the pills.”* Interventions are needed, since this influences their ability to take their medication as required from them. Other community caregivers stated the following: *“Many patients who are on antiretroviral treatment don’t accept that they are sick and they don’t take their medication as described ... For example when they take medication at 8h00 in the morning, they make it 10h00 and that is not good, because the treatment will fail.”*

#### ***Sub-theme A1.3: Patients lack motivation***

According to community caregivers, lack of self-motivation leads to low ART adherence, as one focus group participant explained: *“The patients have a lack of motivation ... They are not positive ... They don’t have self-motivation ... They will say I will die at any time.”* Others expressed it in this way: *“Some patients who drink medication are ignorant, because when you check it, by the end of the day they did not take the pills ... They have the information and the knowledge, but they are just*

*ignorant.*” According to WHO (2003:146), the motivation to adhere as prescribed is influenced by the value the person places on the treatment and the confidence he or she has to follow instructions as indicated. When the value of the treatment for a person’s daily functioning is pointed out during routine check-ups, motivation is enhanced.

### ***Theme A2: Physical challenges***

Physical challenges emerged as difficulties in dealing with self-regulation, as well as knowledge and beliefs about the physical complications of ART. The participants highlighted the following challenges.

#### ***Sub-theme A2.1: Patients experience difficulties with self-regulation and self-efficacy***

Heyer and Ogunbanjo (2006:7) explain self-efficacy as a person’s belief in his or her ability to take the medication as prescribed to manage their condition. Self-efficacy or the sense of being empowered to change factors affecting one’s life also affects adherence behaviour. Community caregivers found that patients do not want to take responsibility for their own treatment. They stated: *“Some patients will throw the pills away ... You will teach them not to do it, because they drink the pills for themselves and not for the caregiver.”*

#### ***Sub-theme A2.2: Knowledge and beliefs about physical complications of ART***

A person’s knowledge and beliefs about HIV and AIDS and ART can influence adherence (Miller *et al.*, 2010:50; Nachega *et al.*, 2005:198; WHO, 2003:99). Community caregivers stated that patient’s fears and beliefs about the physical complications of ARVs and the treatment discourage them from taking the medication. They stated that patients have different beliefs about the treatment, which influences their adherence to treatment. For example, they say: *“Some patient’s believe if they take ART, they are going to be malformed ... Sometimes they don’t go to the clinic.”* Community caregivers reported a lack of self-esteem of the patients because of the side-effects. Some community caregivers reported the following: *“They (the patients) said ARV gives side effects like glands, so they don’t want to go to the clinic because of that.”* The literature confirms that for patients without proper education and support side effects may be so severe that they may discontinue their treatment in favour of more immediate relief. Therefore, people on antiretroviral treatment must be educated about the potential adverse side effects they may experience and be advised on how to handle them (Hardon *et al.*, 2006:289; WHO, 2003:98).

### ***Theme A3: Social challenges***

The data that emerged on social challenges are divided into three sub-themes, namely alcohol and drug abuse, risky sexual behaviour, challenges regarding social support and challenges regarding family support. These are presented in the discussion below.

#### ***Sub-theme A3.1: Alcohol and drug abuse***

According to the literature, high-risk behaviour such as abuse of alcohol and other drugs has been associated with poor or no adherence to ART (Coetzee *et al.*, 2011:148; Morojele *et al.*, 2014:522). Community caregivers stated the following about alcohol



abuse: *“The main problem is alcohol ... If you tell them (patients) to stop drinking alcohol they will say it is my life and I know I will die ... and that is not good.”*

Community caregivers confirm this and said: *“Some patient’s repeat the same mistakes ... my client defaulted because she does not take the pills when she is drinking alcohol ... Most of them (patients) they abuse alcohol ... So they don’t have time for their medication.”* This was echoed by another respondent who said: *“Because of alcohol abuse the patient will go to bed drunk ... They don’t want to drink the pills the next day ... It causes them to default.”*

Non-adherence to ART may be associated with the chaotic lifestyle of people who abuse drugs and alcohol (Coetzee *et al.*, 2011:148). One of the respondents describes this as follows: *“When my patient drinks, her boyfriend gets abusive ... He beats her up in front of the children ... The client does not want to listen to advice ... She does not have ID and the children do not have birth certificates.”*

Based on the narrative reflections of the community caregivers in this study, alcohol seemed to be a major factor in patients’ non-adherence to ART. However, in a qualitative study done with 25 HIV-positive youths, aged between 17 and 25 years, the main objectives were to examine the attitudes that the youths with HIV had to the antiretroviral treatment and to explore the barriers to adherence to medication that faced them. This study by Rao *et al.* (2007:31) found that 77% of respondents were drinking alcohol even when taking their medication for HIV. Other studies have demonstrated that a history of substance abuse is unrelated to adherence issues, although active substance abuse is one of the stronger predictors of non-adherence (Chesney, 2000; Gill *et al.*, 2005).

### ***Sub-theme A3.2: Risky sexual behaviour***

In many instances substance abuse may lead to sexual risky practices and health-compromising behaviour. A study done by Hahn *et al.* (2011:5) on alcohol’s effect on the HIV epidemic in Sub-Saharan Africa indicated that alcohol consumption is associated with risky sexual behaviour and an increased risk of HIV infection. Alcohol consumption reduces a person’s ability to make informed choices about safer sex and protection from HIV infection (Inungu & Karl, 2006:4). The following comments describe the problem from the view of the community caregivers. *“Some girls participate in unprotected sex knowingly and spread the virus ... They say they cannot die alone ... In that way they are spreading the virus ... If you take part in unprotected sexual activities you will not drink your medication regularly.”* Other respondents stated that *“They (men) will use the girls and give them drugs (Tik) to sleep with them and spread the virus. They say nothing will happen because they who are HIV positive will live longer than other people.”*

### ***Sub-theme A3.3: Cultural and traditional practices and beliefs influence the patient’s adherence to ART***

Cultural and traditional practices and beliefs, discrimination and stigma as well as non-disclosure are social factors that influence adherence from the perspective of the community caregivers, as discussed below.

Participants were asked to discuss culture in terms of how it might influence adherence of patients to ART. Denial of the existence of HIV and denial of an HIV-positive diagnosis as illustrated in the studies of Dahab, Charalambous, Hamilton, Fielding, Kielmann, Churchyard and Grant (2008:3) and Aspeling and Van Wyk (2008:6) were also reflected by community caregivers as a major problem. According to community caregivers, patients indicated that they would rather revert to traditional medication. *“Some patients will use medication from the traditional healers ... It is not good for them.”* Other patients prefer not to take the medicine or use both, which will compromise their health, as expressed in the following statement:

*“Others say that ARV’s is not for them ... They say they believe in traditional medication to heal them ... Some of the patients use both ... Patients have beliefs that ART has complications and feel that traditional medicine is better.”*

Patients will not take their treatment, because they do not believe that HIV is the cause of their illness. They believe they were bewitched and that the HIV virus has nothing to do with their illness. According to community caregivers, more patients are resorting to explanations such as witchcraft for their sickness. Community caregivers echoed this in statements like the following: *“The patients don’t want to find out that they are HIV positive. They say it is witchcraft ... They are not HIV positive.”*

#### ***Sub-theme A3.4: Discrimination and stigma influence adherence to ART***

Fear of being stigmatised and not disclosing HIV status are factors that negatively influence adherence in Sub-Saharan Africa (Frank & Duncan, 2009:4; Inungu & Karl, 2006:2; Nachegea *et al.*, 2005:200). Participants revealed that patients are affected by stigma at home and in the community. This affects their adherence to ART. Many patients experience fear of being recognised as an AIDS patient and do not want to access services because of the stigma. This is summarised by community caregivers as follows:

*“Some patients don’t go to the clinic, because they are afraid of stigma, so they don’t collect medication at all ... They say that other people notice that you get medication from the clinic, because they group people at the clinic.”*

This is supported by literature studies which found that stigma can, among other things, discourage people from being tested, impede access to treatment and other health care services, undermine adherence to treatment and discourage disclosure (Inungu & Karl, 2006:2). Respondents agreed that as patients do not feel accepted, this may lead taking the medicine secretly. Some respondents perceived the integration of ART with other health services as exposing them to the likelihood of being stigmatised.

*“Some patients are going to the hospital and are worried about who will see them going there ... Some of them say the caregivers must fetch the medication for them.”*

#### ***Sub-theme A3.5: Non-disclosure as a barrier to ART adherence***

One important psychosocial factor facilitating ART adherence is the patient’s decision to disclose their HIV status and need for ART to others (Cornett, 2008:48; Dahab *et al.*,

2008:3; Frank & Duncan, 2009:4; Nachega *et al.*, 2005:200). HIV-positive people may be shunned by their family and friends and the wider community (Inungu & Karl, 2006:2). According to Hardon *et al.* (2006:80), patients who disclose their status to others close to them do not have to take their pills secretly. Secrecy is something that can lead to treatment defaults. Non-disclosure emerged as a barrier to adherence. When the patients are in a state of denial, it is difficult to disclose to others and medicines are hidden from friends and family, as observed by community caregivers, who said: *“You will find that some patients will hide their medication from the family.”* Failure to disclose could be because of fear of stigma, fear of being discriminated against and abandonment. Respondents stated that: *“At home the patients are stigmatised and are blamed for being HIV positive ... family members will say to the patient: if you were not irresponsible you would not have been HIV positive ... It is mostly stigmatisation from home which makes it difficult for patients to take their pills.”* Others stated: *“Some patients are also ignorant, because they don’t want their partners to know their HIV status.”* This confirms the study by Vu *et al.* (2012:136), who found a lack of disclosure of patients’ HIV status to their partners.

### ***Sub-theme A3.6: Lack of social support***

Some of the community caregivers’ narrative reflections included comments such as: *“Some patients have a lack of support ... The treatment has side-effects ... The patients don’t have support ... Some only have children in the house ... The children don’t know how to help them ... Some of them are still small ... They look to us caregivers for support ... If you go through the side-effects you need somebody to support you and take you to the clinic.”* This is consistent with the findings of the study by Cornett (2008:58) in Uganda, where it was found that some patients only have children as treatment support and they are alone at home.

One community caregiver reflected in the journal: *“Some patients don’t have care ... so I give them support so that they feel accompanied by someone and not feel alone.”* Caregivers described their duties as follows: *“We make sure they get the medication. If necessary we collect the medication for them at the clinic ... The clinic gives us a list of the defaulters and we go and look for them ... Sometimes we come along with the card and get the medication.”* Community caregivers specified other services rendered: *“We assist them (the patients) not to forget to drink their pills ... We do lay-counselling ...”* *“We tell them about the treatment and adherence.”*

### ***Sub-theme A3.7: Lack of family support***

The family plays an important role in adherence. According to researchers, family support, communication between family members, parental involvement, family dysfunction, and stable living situations are factors that affect adherence. In a family where there is poor communication and little support, especially for HIV-positive children, adherence is influenced negatively. Families must therefore be included in discussions to improve adherence (Bhana *et al.*, 2014:8).

HIV and AIDS care and support activities extend well beyond the needs of the HIV-positive person and often includes dynamics involving the whole family (Wouters *et al.*,

2014:146). According to community caregivers, family members sometimes demonstrate negative attitudes and refuse to provide care for a family member with AIDS. A number of challenges were reported by community caregivers. The lack of family support was described as a big challenge. Community caregivers said: *“The family is not supportive ... Support should start with the family, sometimes the family is there other times not.”* However, participants agreed that family support plays an integral part in a patient’s adherence to ART and specifically in understanding of the patient’s treatment regimen.

#### ***Theme A4: Socio-economic challenges***

Lack of food, social grants, unemployment and transportation emerged as challenges for patients’ adherence to ART.

##### ***Sub-theme A4.1: Lack of food influences ART adherence***

In this study lack of food was cited as a main problem that affected adherence. According to the community caregivers, lack of food complicated adherence and led to non-adherence. Community caregivers observed that patients have a lack of food: *“As a caregiver sometimes when I visit a patient they are alone ... they don’t have food and they cannot take medication.”* Others stated: *“Most of the times they (patients) complain about not having food and cannot take the medication ... When they see us they want food parcels ... Now we are busy helping them with food gardens so that the patient can adhere to ART.”* The literature, (Kagee *et al.*, 2014:85; Skovdal *et al.*, 2011:303; Tuller Bangsberg, Sekunga, Ware, Emenyono & Weiser, 2010:780) confirms that socio-economic factors play a substantial role in people’s decisions about their health. Patients who struggle with food and attend monthly consultations are less likely to adhere and therefore more likely to experience opportunistic infections (Hardon *et al.*, 2006:9; Kagee *et al.*, 2014:4).

##### ***Sub-theme A4.2: Social grants as a barrier to ART adherence***

Research studies also found that disability grants are sometimes the only source of income for some people on ART. Research done by Kagee *et al.* (2014:86) and Leclerk-Madlada (2006:251) found that the qualifying criteria for the disability grant for people on ART poses a major challenge. Community caregivers reflected the following: *“Poverty also makes the patients not to drink the medication ... They don’t have much to eat ... Also others do not even receive the grant.”*

Some caregivers are concerned that some patients do not want to drink the medication because they are scared they will lose the grant. This is described in comments like the following: *“Some patients don’t want to drink the pills ... they want to default so they can get the disability grant.”* However, some community caregivers regard the grant as having a positive effect for improving the life circumstances of patients. They stated: *“Some patients don’t misuse the grant ... If they don’t have the grant they will apply for the grant.”*

### ***Sub-theme A4.3: Unemployment as a barrier to ART adherence***

Community caregivers stated that patients are not in a position to work, because of their condition. *“This influences them negatively ... They can’t work ... They only rely on grants.”* Others said that patients reported that taking the medication influences their ability to work. They stated: *“Some patients say you can’t work and also drink medication, because it is difficult to do, so you forget about the pills.”* Research studies done by Barnighausen *et al.* (2007:8) and Coetzee *et al.* (2011:148) revealed that loss of a job and wages is of great concern for patients on antiretroviral treatment. Individuals with employment may have to choose between attending clinic or paying rent and feeding their children, and therefore do not disclose their status to the employer.

### ***Sub-theme A4.4: No transport as barrier to ART adherence***

Two of the most commonly reported ART-related expenses across sub-Saharan Africa are transportation and additional food requirements (Kagee *et al.*, 2014:85; Skovdal *et al.*, 2011:303; Tuller *et al.*, 2009:780). The study by Kagee *et al.* (2014:85) on structural barriers to ART adherence in South Africa found problems in accessing transport as a major barrier. In this study lack of transportation was established as a barrier for both community caregivers and the patients. Community caregivers described the problem as follows: *“Sometimes the clinic does not have medication, so they refer you to the local chemist, but that time you don’t have transport.”*

## **Category B: Community caregivers’ perceptions of ART interventions**

Community caregivers’ perceptions of and suggestions for ART interventions are important in planning services to this vulnerable group in society. From this category the following themes with some sub-themes emerged, namely psychological interventions, interventions on a physical level, social interventions and socio-economic interventions.

### ***Theme B.1: Psychological interventions***

The following psychosocial interventions emerged from the study.

#### ***Sub-theme B1.1: Emotional care***

According to community caregivers, patients are in need of emotional support. More emotional support programmes should be offered. Based on literature, motivation is associated with adherence-related behavioural skills and these skills directly predict adherence to ART (WHO, 2003:141). Community caregivers in this study see motivation as an empowerment tool. Community caregivers said: *“We must teach them that there is life after HIV and AIDS and they must drink their pills.”* Motivation must be at the core of all programmes. Another intervention is to start support groups. They summarise this as follows: *“We must open support groups ... By opening up support groups you bring different people together so they can learn from each other so they can share problems from hearing others.”* However, support groups do have some disadvantages and caregivers said: *“We also wanted to start with the support groups, but they (patients) don’t tell the family they are HIV positive ... You will see the sister, aunt or brother come with them to support them ... Then they will be afraid that that person will find out that they have the disease ... They also say the other family members will*

*ask why they are going to the group.*” Kagee *et al.* (2014) proposed in his interventions that addressing mental health needs is important for improved ART adherence.

### ***Theme B2: Interventions on a physical level***

Interventions on a physical level included providing information about ART as well as support for the patient in developing self-efficacy.

#### ***Sub-theme B2.1: Information about ART and administering of treatment***

According to community caregivers, there is a lack of education on ART. They stated: *“There is less education about the treatment ... that is why patients default ... There must be more information on medication.”* Based on the UNGASS RSA Progress Report (2013), lack of information about ART is one of the challenges. Remarks from the community caregivers show intervention is needed. Community caregivers are in agreement that the community and patients should be empowered about ART adherence. Caregivers feel that patients must be trained on how to administer treatment. Educating the community and the patient about ART is essential. Educational programmes on ART will promote the efficacy of the patient and also make families and the community more involved in the care of the patient. Information about disease progression and treatment is less prevalent in these initiatives and is one of the challenges highlighted in the UNGASS RSA Progress Report (2013).

#### ***Sub-theme B2.2: Support in developing self-efficacy***

The term self-efficacy represents a person’s confidence in his or her ability to achieve a specific goal in a specific situation. According to the theory of self-efficacy (Kalichman *et al.*, 2008:683), one is competent and capable of accomplishing a specific behaviour such as adherence. Community caregivers stated: *“Patients must be trained to go to the clinic and talk about their illness and ART with health personnel ... we must teach them to take responsibility for their own treatment.”*

### ***Theme B3: Social interventions***

Community caregivers regarded interventions focused on alcohol abuse, risky sexual behaviour and HIV and AIDS prevention and life skills programmes as important. These issues are discussed below.

#### ***Sub-theme B3.1: Interventions on alcohol abuse***

Community caregivers proposed certain intervention strategies to improve ART adherence of patients as set out in this section. Community caregivers agreed that alcohol abuse should be addressed. Appropriate interventions, targeting the risk of alcohol use and high-risk sexual behaviour that increases the risk for HIV infection should be developed and implemented (Morojele *et al.*, 2014:522). They stated: *“We should address the problem of alcohol .... We need to teach people to adhere so they should not drink ... We should advise them on the dangers of using alcohol and medication at the same time.”*

### ***Sub-theme B3.2: Sexual behaviour change, life skills and prevention programmes***

Efforts aimed at preventing the spread of HIV are at the core of many HIV response strategies. Prevention strategies seek to bring about behavioural change by encouraging people to learn their HIV status, to take precautions not to transmit HIV to others if they are positive, and to protect themselves against HIV infection if they are negative. From the caregivers responses it is evident that sexual behaviour change programmes are needed in the community. They stated: *“We want programmes on abuse, prevention and life skills.”*

Social support and family support were considered important interventions on a social level.

### ***Sub-theme B3.3: Need for social support structures***

Social support is a critical aspect of living with HIV and AIDS in order to improve the patient’s quality of life; therefore a higher level of social support is associated with a higher degree of ART adherence. Studies done in Uganda by Gilbert and Walker (2009:1127) and Cornett (2008:58) show social networks to be important. This is supported by the views of community caregivers, who consider a social support network as highly important to people on ART. They stated that: *“If people care for you, the person will feel loved and drink the medicine to survive.”*

### ***Sub-theme B3.4: Need for family support***

The effects of family dynamics on physical and mental health have been studied for many years. Only a few studies (Rotheram-Borus *et al.*, 2010; Wouters *et al.*, 2014) explored the potential role of family dynamics in the impact of peer adherence support on clinical treatment outcomes. The study outcomes demonstrated interaction affect between peer adherence support and levels of family functioning. The studies associate better family functioning with better quality of life and better adherence levels. According to these studies, it is vital to explore ways to ensure the training of peer adherence supporters, enabling them to adequately tailor their activities to different family contexts. Training should include family counselling and family skills.

Community caregivers indicated a need for the implementation of family empowerment programmes. They stated: *“Support must come from the family ... we must teach the family how to care for the patient.”* These interventions are in line with previous research studies, such as the qualitative interview study of Sanjabo *et al.* (2008) in Zambia. In this study patients and health care providers said that disclosure is a critical factor, usually linked to the support they receive from their families.

## ***Theme B4: Socio-economic interventions***

The following socio-economic interventions were proposed by the participants.

### ***Sub-theme B4.1: Food security and social security programmes***

According to community caregivers, food security programmes are a facilitator of optimal adherence to ART. Research studies confirm the importance of nutrition in antiretroviral treatment adherence (Hardon *et al.*, 2006:9; Kagee *et al.*, 2014:4; Nachega

*et al.*, 2006:131). According to WHO (2013:179), nutritional support increases the success of ART. Research studies also found that disability grants are sometimes the only source of income for some people on ART (Kagee *et al.*, 2014:86; Leclerk-Madlala, 2006:251). Community caregivers agreed that “*We must assist with application for grants.*”

#### ***Sub-theme B4.2: Support programmes for income-generating activities***

Income-generating projects were seen as an important strategy, as stated by community caregivers, who said: “*We must start more food gardens so that patients can adhere to taking medication*” and “*Patients should be encouraged to take responsibility for their own lives and they and their families should become involved in these projects.*” This is consistent with the findings of Campbell *et al.* (2011) stating that ART patients are in need of income-generating programmes.

## **DISCUSSION**

The present study applies a qualitative approach to explore community caregivers’ experiences and challenges in dealing with patients on ART. Based on the themes generated, the challenges concerning ART in this research confirm previous research literature on this issue. As seen in this study, community caregivers perceived many challenges in improving ART adherence of patients. In particular these challenges can be described as those relating to high-risk behaviour, health beliefs, social problems, socio-cultural challenges and socio-economic challenges. The use of alcohol has been associated with poor adherence. Motivation and self-efficacy were highlighted as the main facilitators of adherence to ART. Failure to disclose leads to non-adherence as the patient has to seek ways to secretly take the medicine. Socio-economic factors such as a lack of food influence adherence to ART. According to this study, cultural beliefs play a role in the patient’s knowledge of ART and can have a negative impact on adherence to ART. The study also highlighted the perceptions and suggestions of participants for possible interventions to improve adherence of patients to ART. The study showed that interventions on a psychological, physical, social and socio-economic level are needed to enhance adherence. The findings of this qualitative study are valuable and can inform the design of interventions to promote ART adherence for patients from the perspective of community caregivers.

## **LIMITATIONS OF THE STUDY**

- Qualitative research is context-specific and the findings of this study cannot be generalised to other settings.
- The study was limited to only three home community-based care organisations. This means that the results of this study may not be applicable to other settings and different factors may be identified that influence adherence of patients, as well as the need for empowerment programmes.
- Some new data may emerge when similar research is conducted in other home community-based care facilities; however similar studies need to be undertaken with community caregivers and ART adherence of patients.



## RECOMMENDATIONS

Based on the research findings, the following recommendations can be made:

- The challenges of community-based caregivers to ensure ART adherence is important for future research and the development of community-based ART interventions;
- Studies to explore the psycho-social challenges in improving ART adherence should be encouraged;
- Research on community-based interventions for ART adherence should be enhanced;
- The use of community caregivers in ART services is seen as a valuable strategy to support adherence of people on ART; therefore more research is needed on ART empowerment programmes for community caregivers.

## CONCLUSIONS

- The results of this qualitative study showed many psychosocial challenges with regard to ART adherence of patients from the perspective of community caregivers.
- The findings of the study suggested that adherence is influenced by many psycho-social factors and are important for the development of community-based ART interventions.
- The role of community caregivers was seen as vital in supporting patients on antiretroviral treatment.
- Community caregivers also highlighted intervention strategies to enhance ART adherence of patients.
- The findings of this research can guide community-based interventions for patients on antiretroviral treatment, as well as their families and the broader community.
- Further guidance, support, skills development and training are needed to provide and enhance the development of community caregivers in improving ART support.

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