

Adherence to Antiretroviral Therapy among Older HIV-infected Persons Receiving Treatment in a Public Hospital in Gauteng Province

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Abstract

Adherence to antiretroviral therapy (ART) is a complex and dynamic process and remains an important issue in HIV care. Literature has highlighted sub-optimal adherence to ART across settings and populations, with many factors influencing the level of adherence. While older adults have been characterised as being more compliant, other studies have demonstrated at least 50% poor adherence. The aim of this study was to explore and describe own perspectives on adherence to ART among older persons receiving HIV treatment in a public hospital in Gauteng Province, South Africa. This study used a qualitative exploratory design that included a purposive sample of older HIV-infected men and women currently receiving HIV healthcare services from a public hospital in Gauteng Province. Individual interviews with 12 purposively selected older participants were conducted. The data were analysed using a thematic approach. Findings of the study revealed five main themes, namely: 1) disclosure, stigma and adherence; 2) drug-related side effects; 3) difficulties related to social factors and lifestyle; 4) support and adherence to ART; as well as 5) experience with the health system. Recommendations include empowering older persons in managing internalised stigma, monitoring of adherence by healthcare providers, and educating family and other support structures to form part of adherence enhancing strategies.

Keywords: adherence; antiretroviral therapy (ART); HIV/AIDS; older persons



Africa Journal of Nursing and Midwifery
<https://upjournals.co.za/index.php/AJNM>
Volume 22 | Number 2 | 2020 | #6989 | 15 pages

<https://doi.org/10.25159/2520-5293/6989>
ISSN 2520-5293 (Online)
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Introduction

The face of the human immunodeficiency virus (HIV) has changed in the last decades. HIV was considered to be a disease that primarily affected the young. The global HIV epidemic shows that a growing number of people aged 50 years and older are living with HIV (Mahy et al. 2014, 453; Vollmer et al. 2017, 101). South Africa has the highest adult HIV prevalence (18%) in sub-Saharan Africa and the largest adult population of PLWH in the world, estimated at approximately 7.5 million people (Statistics South Africa 2018). Studies show that this increased HIV prevalence among older adults is largely a result of successful ART over the last decade, which has dramatically improved the survival of older persons living with HIV, enabling them to live into advanced age (Sankara et al. 2011, 1187).

South Africa also has the largest government-funded national ART programme globally, providing HIV care and ART to over 4 million people (DoH 2016; Statistics SA 2018) and making treatment accessible. Access to ART is only one aspect of an effective HIV management programme; optimal adherence is another essential aspect (Moosa, Gengiah, and Lewis 2019). Adherence is a complex matter; especially that it is long term and requires commitment. The existing literature has highlighted sub-optimal adherence to ART across settings and populations, which is problematic because treatment is only effective with a strict level of adherence (Beer et al. 2012, 213; Pichon et al. 2015, 7074). Studies show that adherence to ART remains unsatisfactory and varies between 27% and 80% across different populations in various studies, in comparison to the required level of 95% (Iacob, Iacob, and Jugulete 2017, 1; Wasti et al. 2012). The literature on ART adherence among older adults is limited (Abara et al. 2016, 2674). This is particularly true in sub-Sahara where the burden of HIV among older adults is highest, and treatment and adherence challenges are greatest due to overburdened health services that are not set up to address older peoples' needs (Soomro et al. 2019, 447).

Poor adherence may lead to a number of adverse consequences on both the individual and the public domain. These include resistance to first-line treatment of ART and the burden of public health costs in resource-limited countries (Long et al. 2016, 1; Meintjes et al. 2015, 2). The older HIV patient population has more comorbidities that require consideration when choosing an ART regimen (Burgess, Zeuli, and Kasten 2015, 260). It is, therefore, necessary to consider the development of context-specific interventions to address the specific needs of older Africans living with HIV (Knight, Mukumbang, and Schaltz 2018, 2). Despite the increase in the number of older persons living with HIV, few studies have examined ART adherence amongst older persons in South Africa. In this paper narrated perspectives on ART adherence of older persons living with HIV are explored.

Statement of the Research Problem

Adherence to antiretroviral therapy (ART) is critical to viral suppression and maintaining health status and quality of life among people living with HIV (Genberg et al. 2015, 85). Medication adherence is a complex process that has been linked to many aspects, such as patient-related factors, therapy-related factors, social factors, the healthcare team and the healthcare system (Kardas, Lewek, and Matyjaszczyk 2013, 1; Pagès-Puigdemont et al. 2016, 707). Although it appears that adherence is better among older populations (Ghidei et al. 2013, 806), some studies have reported contradictory evidence; where there was at least 50% poor adherence among older women (Bianco et al. 2011, 1438). Despite data suggesting more favourable adherence to prescribed ART regimens in older HIV patients, vision loss, cognitive impairment, limitations in health literacy, complex regimens, comorbidities associated with ageing with an increased number of medications, medication cost, depression, and decreased expectations of health status can all negatively impact adherence (Burgess et al. 2015, 261; Cahill and Valadéz 2013, 7; Gleason, Luque, and Shah 2013, 750; Mpondo 2016, 2). The literature review suggests that there is no specific ART behavioural intervention that supports adherence in sub-Saharan Africa that is exclusively focused on older adults. Despite the evidence that people infected with HIV are living longer, the perspectives of older persons on adherence to ART have not been explored.

Research Question

What are the perspectives on ART adherence of HIV-infected older persons receiving treatment in a public hospital in Gauteng Province?

Purpose of the Study

The purpose of this study was to explore and describe adherence to ART by older HIV-infected persons who are receiving treatment in a public hospital in Gauteng Province.

Objectives of the Study

The study intended to explore and describe the perspectives of older persons living with HIV on their adherence to ART.

Definition of Concepts

Adherence

The World Health Organisation defines adherence as following the recommendations made by the treatment provider on timing, dosage and frequency of medication-taking (WHO 2016).

Antiretroviral Therapy

Standard ARV therapy consists of a combination of ARV drugs to maximally suppress the HIV virus and stop the progression of HIV to AIDS and also prevent the onward transmission of HIV in the population (WHO 2016).

Human Immunodeficiency Virus

Human Immunodeficiency Virus (HIV) is a retrovirus that destroys the body's ability to fight off infection and disease, eventually causing AIDS (UNAIDS 2011, 16).

Older Person

Patients over 50 years old are commonly considered “older persons” in HIV literature, owing to management considerations that are unique to this group of patients as they age (Burgess et al. 2015, 251).

Older Person living with HIV

These are people aged 50 years and older who are infected with HIV.

Research Methodology

This study used a qualitative exploratory design that included a purposive sample of older HIV-infected men and women currently receiving HIV healthcare services from the treatment centre in a public hospital in Gauteng Province. This approach was determined to be appropriate as a means of gaining access to the inner world of older men and women in order to understand the issues affecting their medication adherence (Streubert and Carpenter 2011, 90). Based on the day and time preferences of participants, interviews were conducted in a private room in the hospital by two research assistants; one female, and one male. The gender preference of interviewers was left to participants.

Study Setting

This study was conducted in a public academic hospital in Tshwane district, situated in the northern part of Gauteng Province. All interviews were conducted in a private room within the hospital or at the university, depending on the participants' preference.

Recruitment

Recruitment was achieved with the assistance of healthcare professionals treating older persons at an AIDS treatment centre in a public hospital in Gauteng Province. The head of the treatment centre, a senior professional nurse, approached older HIV-positive individuals and requested their permission for a referral to the researcher who had experience in collecting qualitative data. The researcher determined whether the

referred patients met the study's inclusion criteria, informed them about the study, and obtained their written consent to participate.

Population

The target population in this study were all older persons (females and males) who were infected with HIV and taking ART.

Sampling Technique

The population of this study was purposively selected to include older persons (male and female) as they would best contribute the information needed for the study (De Vos et al. 2011, 392). The researcher recruited 12 participants (see table 1); seven women and five men met the study's inclusion criteria. Participants had to be over the age of 50, diagnosed with HIV, and have been on ART for at least six months. Individuals over 50 years old are commonly considered "older adults" in HIV literature, owing to management considerations that are unique to this group of patients as they age (Burgess et al. 2015, 251). Participants who had only recently been diagnosed, that is, within a period of less than six months, were excluded because of the possible emotional impact of discovering that they were HIV-positive.

Sample Size

The sample size was determined by data saturation, which was achieved after 12 individual semi-structured interviews with older persons.

Data Collection

Data were collected using face-to-face interviews from November 2018 to February 2019. After obtaining informed consent from participants, two experienced gender-segregated research assistants interviewed participants in a private room in the hospital; the research assistants were not involved in the main study procedures to limit biases. Interviews were conducted in the African languages preferred by participants. A semi-structured interview guide included open-ended, exploratory questions and additional follow-up probing questions that allowed participants to discuss the topics that were relevant to their experience. Domains of inquiry included issues of adherence, disclosure, support and experience with the health system. Data saturation was reached at the twelfth interview when no new categories or themes emerged.

Data Analysis

Thematic analysis was then conducted on the data in order to identify themes (Nowell et al. 2017, 2). This was conducted by the author and a co-coder (an expert in qualitative research) who read the transcripts independently and jointly reviewed emerging themes in order to reach consensus on the interpretation of the data. The data were then analysed manually to identify emerging themes and subthemes that reflected the participants'

adherence perceptions. This was followed by developing a code list that was used to establish themes.

Ethical Considerations

The study protocol was reviewed and approved by the Sefako Makgatho University Research Committee (Ethics no. SMUREC/H/132/2017:IR). Approval to conduct the study was obtained from the superintendent of the hospital. Informed written consent, which ensures participants' self-determination, was obtained after the study had been explained to potential participants, including potential risks and benefits. The principle of veracity, which embeds honesty and truthfulness, was the basis of information given to participants. Participants were informed of the voluntary nature of the study and their ability to stop the interview at any time or not to answer specific questions. Right to privacy was ensured as all interviews were conducted in a private room within the hospital or at the university, depending on participants' preference (Polit and Beck 2006, 91). Participants consented to the recording of interviews, which were subsequently anonymised. Beneficence, which imposes a duty to minimise harm, was applied by making data anonymous (Streubert and Carpenter 2011, 63). Standard precautions were undertaken to assure the confidentiality of the data. Codes were used in place of participants' names; this was done to ensure confidentiality. Only the researcher and interviewers had access to the data. Interviews were collected by research assistants who were not involved in therapeutic care or clinical care and had no relationship that would influence their care. This was done to ensure the principle of justice, which is based on the right to fair treatment (Polit and Beck 2006, 91).

Findings

Demographic characteristics of the 12 purposively selected participants are presented in table 1. Participants were asked their age, gender, relationship status, education, and employment status. In addition, participants reported the number of years they had known their HIV status. Participants were also asked to indicate whether they suffered any other condition for which they were taking medication in addition to ART.

Table 1: Participants' demographic data

Participant	Gender	Age	Marital status	Education	Employment	Number of years diagnosed	Comorbidities
1	Female	53	Widowed	Lower primary	Unemployed	6 months	Hypertension
2	Female	55	Divorced	Lower primary	Unemployed	5 years	Hypertension
3	Female	56	Widowed	Lower primary	Unemployed	8 years	Diabetes and kidney failure
4	Female	69	Never married	Lower primary	Unemployed	11 years	
5	Male	53	Cohabiting	Primary education	Unemployed	7 years	
6	Male	54	Never married	Secondary education	Unemployed	6 years	Tuberculosis
7	Male	56	Never married	High School	Unemployed	6 years	
8	Male	59	Married	Primary education	Self-employed	15 years	Kidney disease on haemodialysis
9	Female	62	Cohabiting	Primary Education	unemployed	7 years	
10	Female	63	Widowed	Primary education	Unemployed	10 years	Diabetes
11	Female	67	Widowed		Unemployed		Hypertension
12	Male	72	Married	Secondary Education	Part-time employment	13 years	Hypertension and Diabetes

The analysis of the data yielded five main themes, namely: 1) disclosure, stigma and adherence; 2) drug-related side effects; 3) difficulties related to social factors and lifestyle; 4) support and adherence to ART; and 5) experience with the healthcare system.

Disclosure, Stigma and Adherence

Participants narrated that disclosure and internalised stigma influenced their adherence to ART. Some mentioned the need to hide their medication from family members, as they were ashamed of their status and did not want to disclose it to their families.

I disclosed to my daughter and not my son. I thought if I tell him he's going to disrespect me. My son is also HIV positive and we drink the same treatment but I will never tell him openly that I am positive. If we were to have an appointment on the same day, I will ask the clinic to change my date or refer me to another clinic instead (Female, 69 years).

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Right now my wife and I are sick but my adult children do not know. I decided that it's between me and my wife (Male, 59 years).

I didn't even tell the nurses in the local clinic where I take treatment for diabetes that I am also HIV positive and taking ARV (Female, 63 years).

Drug-related Side Effects

Most participants had other age-related comorbidities in addition to being HIV positive. Some participants experienced toxic side effects of ART, to the extent that their medication had to be revised for them to remain compliant.

I complained about the rash that was on my skin; I told her that I suspect that am having side effects on me (Female, 55 years).

I was taking different regimen; some after I drink them I was vomiting and swelling; they changed them (Female, 54 years).

Because of the kidney problem; they changed my ARV regimen. I was taking 1 pill a day and it was changed to liquid 3 times a day and two pills (Male, 59 years).

Difficulties Related to Social Factors and Lifestyle

Participants reported the difficulties they experienced in terms of their personal relationships and lifestyle, which influenced their adherence to treatment. The participants explained:

The reason for me to default it's because I was drinking a lot; my sister-in-law was stressing me and I decided to default on my treatment. When she's drunk, she insults me; that pushed me to alcohol abuse (Male, 56 years).

My husband has been dead for 13 years. I have been on treatment for 11 years, neither does my 40-year-old son nor my 30-year-old daughter know about my HIV status. I think they will take me cheap. They will say; it means that our mother was not faithful. I'd rather die with the secret. My grandchildren think I am taking high blood pressure medication ... I didn't even tell the nurses in the local clinic where I take treatment for diabetes that I am also HIV positive and taking ARV (Female, 54 years).

I missed Saturday and Sunday, we stayed until late at the social club. I tell myself that we are going to come back early, and end up coming back late; the reason being we went far from home and we are using one car (Male, 54 years).

Support and Adherence to ART

Participants found that by disclosing their HIV status either openly or by selectively choosing individuals with whom to share the diagnosis, this enhanced the level of

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support they received from significant others, including spouses, friends and family members.

Because my daughter knows about my status, she's the one who makes sure that she reminds me about taking my pills (Female, 53 years).

Yes, well I came here with my brother, after they diagnosed me HIV-positive. I was asked to come with one family member; so I asked my brother to accompany me; even today I came with him and he supports me to take treatment (Male, 54 years).

My children are the ones who took the decision to take me to the doctor. They did all the payments, they took responsibility for everything, they gave me support (Female, 55 years).

Experience with the Healthcare System

Participants narrated positive experiences with the hospital when they collect their ART. Most preferred to collect their ART from the hospital, rather than their local clinic where they are treated for other chronic conditions.

The treatment there where I take medication for blood pressure is not good. In most cases when you go there, they tell you that there is no medication. We were spending long hours in the queues; when you arrive at the clinic in the morning, the nurses were very slow (Female, 63 years).

At the local clinic, they don't care about the patient, they don't speak to people well, and then they don't have confidentiality. I'm not comfortable about that, that is why I feel I must come here [for] ARV (Male, 72 years).

Every time when I go to hospital, they give us education. These young nurses are very friendly; they greet us; the service is also good; you don't wait for a long time. That is why I do not want to change and go collect treatment at the clinic near my house. I am fine, I have my own transport and I don't complain (Male, 56 years).

Discussion

This qualitative study explored narrated perspectives on ART adherence among older persons infected with HIV, who are attending a treatment centre located in a public hospital in Gauteng Province. Multiple factors were cited to be contributing to non-adherence, including stigma and disclosure. Internalised stigma prompted participants to avoid disclosing their status for fear of rejection by their friends and family members. This affected the support that participants in this study were able to receive from family members. Some participants opted to keep their status a secret, even to the extent of hiding their medication from family, friends and healthcare providers at the local clinic. This fear of stigma (and associated lack of disclosure) is not unfounded, as research has demonstrated that many who disclose their status have experienced adverse reactions

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from others, negatively affecting their self-esteem and future reliance on others for support (Hult et al. 2012, 187). HIV-related stigma compromises ART adherence, primarily by undermining the level of social support that is available (Katz et al. 2013, 19).

In this study, most common comorbidities were hypertension and diabetes mellitus (as indicated in table 1), subjecting participants to multiple medications in addition to ART. They mentioned experiencing side effects, confirming that polypharmacy is common in the older adult population infected with HIV (Gleason et al. 2013, 751). According to Iacob et al. (2017, 5), all medication has side effects. Similarly, a study by Koochak et al. (2017, 117) reported that 94% of ART-exposed patients exhibited adverse effects; the discomfort created by various side effects is an important factor that diminishes patients' adherence or leads to treatment discontinuation.

Older adults' ability to metabolise ARVs is diminished and may result in increased toxicity (Burgess et al. 2015, 251). Side effects contributed to non-adherence in some participants, resulting in doctors having to change their regimen. At least three participants suffered side effects of ART and could not adhere to taking the regimen as prescribed. Switching to different regimens improved these participants' adherence. This supports findings by Beer et al. (2012, 221) which suggest that simplifying ART regimens by decreasing dosing frequency improve adherence. Kardas et al. (2013, 2) are of the opinion that treatment which is not patient-friendly, or a longer duration of treatment, or the presence of adverse effects, will cause patients' adherence to drop.

Male participants reported that their medication regimens interrupted their leisure activities where alcohol was involved. The use of recreational alcohol has been shown to lower adherence to below 70% in the elderly population (Gondalez, Barinas, and O'Cleirigh 2011, 226; Kekwaletswe and Morojele 2014, 402). The consumption of alcohol is thus considered among the social factors that can affect adherence (Katz et al. 2013, 8).

Stress and depression among some participants reduced their adherence to ART. This finding that feelings of depression are associated with non-adherence is consistent with other studies (Beer et al. 2012, 222; Durvasula 2014, 98). Participants reported different sources of social support, which assisted them in adhering to their ART regimens. Specifically, participants described spousal or familial support as being critical in enabling them to successfully adhere to their treatment plan. The fact that they disclosed their status openly or selectively granted them access to much-needed support structures. It is, therefore, important that individuals who are infected with HIV realise the personal benefits that are available when they disclose their serostatus to others, as this enhances their access to social support (Atuyambe et al. 2014, 2). Other studies have shown that social support is positively related to better health outcomes in several

disease contexts and it is a critical determinant of participants' ability to successfully adhere to ART (Pichon et al. 2015, 7075; Wasti et al. 2012, 9).

Finally, the healthcare system was perceived as a barrier for participants in terms of collecting their ART from their local clinic. All participants stated they would rather collect their ART from the treatment centre located at the hospital, instead of their local clinic where they collect medication for their other chronic conditions. Reasons cited included long queues, unfriendly staff who disrespect them, and fear of the staff divulging their HIV status to others. Kardas et al. (2013, 5), in their systematic review, also cited factors affecting adherence to include access to a healthcare facility, long waiting times, queues, lack of privacy, and inconvenient appointment times. Participants mentioned good relations with the staff at the hospital as an important factor in their ART adherence. Trusting and positive working relationships with the healthcare system may be a powerful tool to increase ART adherence among HIV-positive individuals (Martinez et al. 2012, 111).

Conclusion

This qualitative study showed that adherence is a complex and dynamic process that has been linked to many aspects, such as psychosocial factors, therapy-related factors, stigma and disclosure status, and the healthcare system. This study found that participants experienced internalised HIV-related stigma and participants opted to selectively disclose their seropositive status to others, compromising significant social support. Stress and depression had a negative effect on ART implementation, lowering participants' adherence. Furthermore, side effects made it difficult for some participants to adhere to their ART. Most participants reported receiving support from partners, families and friends after disclosure. All participants preferred to collect their ART from the hospital, indicating good relational factors as the staff educated them about treatment and respected them; participants were thus satisfied with the healthcare system.

This study recommends the empowerment of older persons in managing stigma of any form. Good communication and psychotherapy may be needed to reduce perceived or internal stigma. A permanent monitoring of adherence by healthcare providers is emphasised, along with educating family and other support structures to form part of adherence enhancing strategies.

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