ARTICLE

ADHERENCE TO TREATMENT AND RETENTION IN CARE OF ADULT PATIENTS ON ANTIRETROVIRAL THERAPY

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ABSTRACT

The introduction of antiretroviral therapy came as a relief to people living with HIV and AIDS as it improved their quality of life and chances of survival, and delayed the progression to AIDS. Maintaining high adherence levels to antiretroviral therapy remains a challenge for many, yet strict adherence to and retention in care are critical for the successful suppression of the human immunodeficiency virus. The objective of the study was to determine factors that influence adherence to and retention in care for adult patients who are undergoing antiretroviral therapy. A qualitative research design was used. Purposive sampling was used to select 23 participants who met the specified criteria. Data were collected by means of indepth individual unstructured interviews. A thematic analysis revealed six themes, namely staff-patient relationships, adherence support networks, patients' knowledge of antiretroviral therapy, motivation to live, counselling, and factors related to medication. The study concluded that adherence to antiretroviral therapy and retention in care were facilitated by good interpersonal relationships between hospital staff and patients and efficient service delivery at the institutions.

Keywords: HAART; adherence; retention; adult patients; qualitative research



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Introduction and Background

Zimbabwe is among the countries that are mostly affected by the HIV and AIDS epidemic (UNAIDS 2013). In 2011 an estimate of 1 159 097 adults and children were living with HIV and AIDS in Zimbabwe (UNAIDS 2013), and an estimate of about 597 293 patients were in need of antiretroviral therapy (ART) as of December 2011 (UNAIDS 2013). Since the introduction of ART and the expanded coverage of patients accessing ART, the quality of life for many patients and their chances of survival have improved. It was estimated that about half of the people with a CD4 count lower than 350 cells per cubic millilitre would die within two years if they did not get ART (UNAIDS 2016).

In response to the patients' demand for treatment, the Zimbabwean Government introduced the ART programme in 2004 and since then many ART sites have been expanded throughout the country to ensure easy access to antiretroviral treatment (UNAIDS 2013). Tremendous strides were made in scaling up ART clinics such that by December 2011, 141 initiating sites and 449 follow-up sites were fully functional (UNAIDS 2013).

As access to ART increased, concerns have been raised on how to maintain optimal adherence to it. To achieve effective treatment ART requires a high adherence rate of 95 per cent and above, but the challenge now remains on how to sustain such a high percentage of adherence over the long term (Ayalu, Reda, and Sibhatu 2011). Sub-optimal adherence has been reported to cause drug resistance. Skovdal et al. (2011) also noted that ART being a complex treatment, requires not only availability of the ART sites, but also need to ensure that patients carefully adhere to the treatment regimens to prevent drug resistance and to improve on survival.

In Botswana, the emphasis was on psychosocial factors influencing adherence to ART. Do et al. (2010) identified alcohol use, depression, and non-disclosure of positive HIV status to partners as predictive of poor adherence rates found in a sample of 300 adult patients. In Nigeria, being of an older age and male gender correlated better with adherence in a sample of 253 participants (Salami et al. 2010). In Nepal, Wasti et al. (2012) in a sample of 289 participants, revealed complete adherence and a compliance rate higher than that found in North America. The major factors identified to influence compliance with ART medication were being female, being illiterate, having side effects, the travel time to the hospital, and non-disclosure of HIV status.

Antiretroviral treatment is complex and requires strict adherence to scheduled time and dietary requirements. For one to fully enjoy the benefits of the antiretroviral treatment, a minimum adherence level of 95 per cent or greater is needed to maintain undetectable viral loads among patients treated with highly active antiretroviral therapy (HAART). However, this has not been possible with some patients (Jean-Baptiste 2008). At the ART clinic, once a patient has been considered eligible for treatment, counselling on the treatment regimens and adherence is done before starting the ART. The patient is expected to adhere to all the treatment instructions but sometimes it may not be possible

therefore viral suppression may not be maintained (Ministry of Health and Child Welfare 2009).

Problem Statement

The researchers noted with concern that there was an exponential increase in the number of people in need of ART after the WHO recommended ART to HIV patients with a CD4 cell count of 350 and below regardless of their WHO clinical staging (Ministry of Health and Child Welfare 2009). Zimbabwe recorded one of the highest rise in enrolment, with an increase of almost 50 per cent in the number of people receiving treatment between December 2009 and December 2010 (WHO, UNICEF, and UNAIDS 2011, 98). The problem was, however, how to maintain high levels of adherence required for maximum viral suppression. The majority of studies done on ART adherence focused on factors that contribute to compliance with medication (Do et al. 2010; Salami et al. 2010; Wasti et al. 2012) and this study purports to close that gap by looking at the factors that contribute to the motivation for ART adherence and retention in care for adult patients on ART in Zimbabwe.

Research Question

What are the factors promoting adherence to and retention in care for adults patients attending ART clinics in Zimbabwe?

Research Objective

The objective of the study was to explore the factors that promote adherence to and retention in care for adult patients attending ART clinics in Zimbabwe.

Definition of keywords

Adherence: Medication adherence is typically defined as a ratio of the number of drug doses taken to the number of doses prescribed over a given period, i.e. as the medication possession ratio (MPR) (Morrison, Stauffer, and Kaufman 2015, 893). In this study adherence means to achieve ART treatment at an adherence rate of 95 per cent and above.

Adult patient refers to someone who is older than 18 years of age and who is able to give consent to participate in the study.

Antiretroviral therapy (ART) is the combination of several antiretroviral medicines used to slow the rate at which HIV makes copies of itself (multiplies) in the body. These are the drugs that specifically work to suppress HIV replication (Mwale 2016, v).

Motivator is a person or thing that makes someone enthusiastic about doing something (https://dictionary.cambridge.org/dictionary/english/motivator).

Retention in care is the ability to adhere to critical aspects of care, such as attending regular follow-up appointments, scheduled laboratory tests and other monitoring activities as prescribed by the healthcare provider (Mwale 2016, v). In this study, retention in care refers to a patient attending all the scheduled follow-up appointments.

Research Design

This study utilised a generic qualitative research design that is explorative, descriptive and contextual. This design was chosen because it provides a picture of a situation as it happens in the natural context (Streubert-Speziale and Carpenter 2003). Qualitative research focuses on individuals' perceptions of their lived experiences while emphasising the complexity of those experiences.

Study site and research sample

Data were collected at the Beatrice Road Infectious Disease Hospital (BRIDH) which is a public health institution owned by the City of Harare in Zimbabwe. The hospital has an opportunistic infection and ART clinic that was established in 2006 and since then the hospital has been offering ART services to adults and adolescents. The decision to choose this institute was because the hospital caters for a high number of people on treatment for HIV and AIDS within the suburbs of Harare. An estimate of about 150– 200 patients are seen at the clinic on a daily basis from Monday to Friday during normal working hours. The inclusion criteria were as follows: older than 18 years, attending the ART clinic at BRIDH, a confirmed HIV-positive diagnosis, currently receiving ARV treatment, have been taking ARV treatment for at least three months, and able to provide informed consent. Twenty participants who met the inclusion criteria were purposively selected.

Ethical clearance of the study

Permission to conduct this study was granted by the Health Studies Research Ethics Committee at the University of South Africa, the Institutional Review Board, and the Medical Research Council of Zimbabwe (MRCZ), which is the controlling body that regulates all medical research in Zimbabwe. The Zimbabwean Ministry of Health and the City of Harare also granted permission for the study to be conducted in the chosen hospital. Each participant was informed about the purpose of the study. Issues of confidentiality, voluntarism and the right to withdraw from the study at any time during the data collection process were emphasised before the informed consent was signed.

Data collection

Data were collected using in-depth individual unstructured interviews. Interviews were conducted in the private room allocated for the study in the study hospital. Each interview lasted between 45 to 60 minutes. Pseudonyms were used instead of participants' names to ensure privacy and anonymity. Each interview started with a broad question: "Please tell me about the various motivators for ART adherence and retention in care." In accordance with principles of qualitative interviewing this broad question was followed by the use of facilitative communication skills to encourage the research participants to talk and express their views (Mavundla 2000). A tape recorder was used to capture the dialogue between the interviewer and each participant. Interviews were conducted until data saturation occurred. This means that the researcher continued interviewing participants until no new information was obtained (Creswell 2007).

Data analysis

Audiotaped interviews were transcribed verbatim and narratives compared with the recordings to establish the trustworthiness of the data. The narratives were translated from Shona (the local language spoken at the study setting) into English by a linguist from the University of Zimbabwe who is conversant with both languages. The analysis of the data was through inductive analysis, which includes reading the transcripts, open coding, and creating categories and abstracts (Elo and Kyngäs 2008). The interview transcripts were also given to a colleague who is experienced in qualitative research to independently code the data. A consensus discussion was held between the researcher and the independent expert who coded the data to agree on emerging themes and categories.

Rigour

The four criteria for trustworthiness are: truth value, applicability, consistency and neutrality. The truth value was ensured by applying the strategy of credibility, and applicability by applying strategies of transferability. Consistency was ensured by strategies of dependability, and neutrality by strategies of conformability. In qualitative research, credibility is based on the consistency of the answers collected over time and by asking questions differently to ensure uniformity of the evidence. The researcher conducted the interviews to ensure that there was consistency. In applying the strategies of member checking and peer examination, the researcher used an independent expert to code the data, and a consensus discussion was held between the researcher and the independent expert to arrive at emerging themes. Structural coherence was ensured through focusing the interview discussions on motivators for adherence to antiretrovirals (ARVs). Lastly, triangulation was applied through the use of multiple data sources, researcher and independent coder, and literature control of findings.

Research Findings

Participants were aged between 28 and 58 years, and had been on ART for six months to nine years. Thirteen of the participants were female and seven were male. All the participants had 12 years of education and above. Six themes emerged, namely staff-patient relationships, adherence support networks, patients' knowledge levels of HIV, AIDS and ART, the motivation to live, counselling, and factors related to medication. These themes are discussed in the sections below.

Staff-patient relationships

A unique finding of this study was the effect that staff-patient relationships have on improving adherence. Patients who related well with hospital staff reported a higher level adherence than those who mentioned negative attitudes of staff members to them. This was supported by the following extracts:

I wish I can continue taking my pills at this hospital. Counsellors are very good, they treat us with respect and all the staff at this hospital is very supportive. (Female, 37 years)

Ever since I relocated here I have had reason to adhere because the hospital staff are so encouraging and treat us humanely. (Female, 34 years)

Similar findings were found in a study by Chizanga (2010), Do et al. (2010), and Ross et al. (2011) that a friendly and trusting relationship between patients and healthcare providers enabled patients to cope with their illnesses and also encouraged patients to adhere to ARV treatment. The findings also concur with those of Campell et al. (2011) that a friendly atmosphere displayed by nurses which entailed greeting, listening to patients' problems and focusing on patient's religious beliefs, were some of the factors that facilitated adherence to ART. The study findings also revealed that if patients are served within a reasonable time they are likely to adhere, and concur well with the study by Maokisa (2011) and Campbell et al. (2011) that patients who experienced long waiting hours were discouraged from going to the clinics for their monthly reviews and refill medication.

Adherence support networks

Patients who were fully supported physically, psychologically, socially, emotionally and spiritually maintained high adherence levels. Social support networks played a vital role in encouraging patients to adhere to their antiretroviral treatment. Below are some expressions from the participants:

I appreciate the morning peer interactions; we support each other and learn from others through their testimonies on how they have managed to adhere to ARV. The testimonies also help to reduce stigma and I could see that I was not alone.

I frequently miss doses, because of family problems that are stressing me, my husband deserted me and I got depressed.

The above responses show that there is an existing gap in dealing with psycho-emotional problems that influence adherence to ART. The findings concur with those of Jean-Baptiste (2008) that support is one of the psychological factors that motivates adherence. Skovdal et al. (2011) had similar findings where some men were not supportive of their spouses as they did not want to be associated with HIV, perceived HIV and AIDS as a threat to their masculinity, and believed that the illness would belittle their sense of manhood. This led to non-adherence.

Adherence support networks also facilitate people living with HIV (PLWH) to disclose their HIV status. Disclosure of one's HIV-positive status remains a motivator for adherence to treatment as revealed in this study. Some patients who did not want to disclose their status were not compliant with the ARVs as compared to those who had disclosed their HIV-positive status. This assertion is supported by the following extract:

In 2004 when I disclosed my HIV status to my relatives they stigmatised me, my sister did not even want to share a bed with me but now they have changed and they are very supportive.

Similar results were also found in a study done in Nigeria which revealed that good adherence was associated with adherence support networks that encouraged people to disclose their HIV status (Charurat et al. 2010; Ross et al. 2011). This is supported by Do (2011) and Skovdal et al. (2011) who stated that ART adherence can be optimised in the contexts where there was openness and acceptance of one's HIV-positive status. Marukutira (2012) also found that most participants who did not disclose their HIV-positive status owing to the fear of being stigmatised failed to adhere to treatment. Nyambura's (2009) study revealed that some women failed to disclose their HIV-positive status and failed to disclose that they were taking ART as they feared being victimised by their husbands.

Patients' knowledge levels of ART

The findings of the study indicated that in-depth knowledge on ART motivated participants to make a decision of optimal adherence to and retention in care. Most of the participants were quite knowledgeable about the names of the ART they were taking, how they work and were quite conversant about the benefits of adhering and the consequences of not adhering. Furthermore, some responses had detailed information about how ART works, the side effects, and the effects of HIV on the CD4 cell count as reflected by some of the participants' narratives below:

We were taught that there is no cure for HIV, once the virus gets into your body it will stay there for life, the only treatment available is ARV drugs.

Health education given to us reinforce information on HIV and AIDS and ART. We are also given a chance to ask what we do not understand.

The findings concur with those of Maokisa (2011) that continual education to improve patients' knowledge levels of ART promotes adherence to treatment.

One of the findings from the study was that some individuals did not discontinue ART when they experienced severe side effects as they had adequate information on how to manage the side effects. They also had the knowledge that some less severe side effects would disappear over time. Timely management of the side effects was also identified as a factor that facilitated adherence. This finding is in contrast with that of Maokisa (2011) which reported that patients discontinued ART when they experienced severe side effects, and with that of Do (2011) which revealed that side effects from antiretroviral medication was one of the most common factors that contributed to non-adherence to ART. Sometimes patients may not have a clear understanding of side effects and tend to associate any illness that occurs to them while on treatment as side effects of ART.

Counselling

Counselling played a key role in disseminating information on HIV, AIDS and ART. The information given through a series of counselling sessions provided emotional and psychological support and also assisted patients and caregivers to make informed decisions about ART. The researchers found that at this hospital all patients undergo a minimum of three counselling sessions before starting the treatment. An adherence counselling session is offered again to those who fail to adhere. Some patients testified as below:

Counselling sessions helped me more than the pills; I managed to accept my status and to adhere to my treatment. I had so many counselling sessions and they were very helpful. Initially I failed to adhere to my treatment because I was stigmatised by relatives but because I had series of counselling sessions it really helped me.

Counselling sessions have really helped me to reduce my stress and to understand the importance of adhering to my treatment.

The findings of this study are in accord with what was found by Mendelsohn et al. (2012) that quality counselling from trained counsellors is a key requirement for successful ART adherence. Hansana et al. (2013) also identified counselling and education as effective interventions towards ART adherence. However, in this study the researchers noted that despite good counselling sessions and patients showing commitment to ART, some patients discontinued treatment after negative advice by their religious leaders. This is supported by Amico et al. (2009) whose view is that the possession of knowledge levels only does not translate into action, but also relates to one's behavioural skills. When HIV-positive results are revealed the person may experience stress and will struggle to

live with the stress and may search around for a cure. In this study the researchers found that some religious leaders advised the patients on ART to stop medication completely under the belief that the prayers from the church could have cured the virus, and that if they continued with medication it implied that they lacked faith in God. However, the same patients, after noticing relapses in opportunistic infections came back for restarting the ART treatment as reflected in the responses below:

I have been taking ARVs religiously for two years and I never missed a dose but then when I joined one faith healing churches the pastor asked me to stop ARVs and believe in God that I have been healed. Three months after I had stopped ARVs I became very sick. I came back here, I had sessions of adherence counselling from the counsellor and I was recommenced on treatment. And now I am on second line therapy, I gave my testimony to others that we must not stop ARVs. (Male, 45 years)

My church discourages us from taking pills, so I did not disclose to them that I take ARVs, but because I also have faith in the holy water they give me I now use the water to take my ARVs. (Male, 55 years)

Motivation to live

Participants who had enjoyed the benefits of ART were quite motivated to maintain high adherence levels as they kept appointment dates and scheduled treatment times as reflected below:

ARVs are very helpful. I was very sick, was treated for TB but there was no improvement, I was tested for HIV then was commenced on ARVs. Since then my health has improved. I came here (at this ART clinic) in a wheelbarrow, I could not walk, but after taking ARVs I have noticed a speedy recovery. I had lost weight, my weight was 65 kg, then I reduced to 46 kg, but look at me now I managed to gain 11 kg in a few months after commencement of ARV treatment. (Male, 40 years)

I was very sick, I was very thin, I could not walk or do even household chores, but look at me now I now fit and am now back at work. (Female, 47 years)

Adhering to scheduled times was noted as a challenge to most participants. As a way of dealing with the challenge, the study participants designed their own convenient times for taking their medication. Different innovative strategies such as the use of cell phone alarms as reminders, designing own treatment plans, adjusting one's social life to fit into ART, the use of meal times and carrying the pills when one is not at home, assisted patients to make them adhere to dosing times as indicated below:

I never missed a dose, I set my phone alarm. I always carry a few tablets with me if I anticipate delay so that I take my pills on the prescribed time. (Male 40 years)

I always carry a few tablets with me in my handbag, sometimes I finish work late or I fail to get transport early, then I take my tablets even at the bus stop. (Female, 38 years)

I used to smoke and drink but I stopped when I was commenced on ARVs as I realised that I would not be able to take my ARVs properly if I continued to drink alcohol. (Male, 45 years)

My ARVs are part of my daily meals – breakfast and dinner, I follow my meal time, 8 am and 8 pm and this helps me not to miss my dose. Female, 39 years

This finding is similar to that of Mbirimtengerenji et al. (2013) that patients on ART who noted an improvement of their general health status were motivated to adhere to treatment, and they kept all the appointments and did not miss a dose as they could see that ART made a difference in their quality of life.

Do (2011) also reported that factors such as being too busy, special events changing the daily schedule, travel and oversleeping, among others, are factors that prevented PLWHIV from taking their ART. Jean-Baptiste's (2008) study also identified forgetfulness, being occupied by other things, and the client not being at home during the scheduled time as some of the common reasons for non-adherence to treatment.

Factors related to medication

The study revealed that maintaining a regular supply of ART promotes treatment adherence. As a way of preventing an interrupted supply of ART, patients were given an extra three-day supply of ART during every clinic visit to cater for unforeseen emergencies. Below are two participants' responses:

This hospital has never run short of ARVs, every time when I come I always get my supply of ARVs except for co-trimoxazole which we are asked to buy. (Female, 37 years)

I missed my appointment last month after I travelled to my rural home when my wife urgently told me that our daughter was sick. However, I managed to come back two days after the appointment date but I did not miss any dose since I had extra doses. (Male, 47 years)

The findings concur with those of the study done in Zambian rural areas which revealed that adherence was strongly associated with the availability of ART (Nozaki et al. 2011). This was also supported by Posse et al. (2008) that an interruption of supply of ART owing to financial constraints negatively affects adherence.

However, some participants expressed that it was not easy to take tablets on a daily basis and were suggesting an injection or a one-dose treatment as reflected by these excerpts:

A monthly injection or a daily dose of one tablet would further enhance my adherence. (Female, 34 years).

The pills are too many, find a cure, taking ARVs for life is not easy, can they introduce one fixed dose tablet. (Male, 28 years)

Limitations to the Study

This study was conducted in one setting, in the urban area of Zimbabwe, and this might have excluded the rural populace who may perceive different factors as motivators to treatment adherence to and retention in care, hence the study cannot be generalised. Some of the participants have been taking ART for more than five years while others have been taking them for less than a year. This difference was not considered part of the investigation and is therefore a limitation to the study.

Conclusion and Recommendations

This study explored motivators to treatment adherence and retention in care for adult patients on ART in Zimbabwe. This study has closed an existing gap in literature where most studies had focused on the causes of non-adherence rather than what motivates PLWHIV to stay on treatment, and hence made a contribution to ART adherence literature. The overarching theme that came out of this study was the good interpersonal relationships between the hospital staff and the PLWHIV that serve as a motivator for treatment adherence and retention in care. The pill burden should also be dealt with so that participants can take just one pill a day, which would be manageable, by most participants.

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