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The Perceptions of HIV-Positive Patients (ART Patients) on Anti-Retroviral Therapy (ART), Treatment Supporters and Health Care Workers with Regard to their Role in ART Adherence at ART Clinics in the Intermediate Hospital Oshakati, Namibia

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Abstract

This study sought to explore and describe the perceptions of patients on antiretroviral therapy (ART patients), treatment supporters and health care workers (HCWs) about their roles in antiretroviral therapy (ART) adherence. This study was carried out at the Oshakati ART clinic at the Intermediate Hospital Oshakati (IHO) in Oshana region, northern Namibia. A descriptive, explanatory qualitative design was used. Convenient sampling was used as a sampling technique and unstructured interviews were used as the data collection method. Data was analysed using a content analysis method.

The findings of this study revealed that ART patients perceived a number of factors as affecting ART adherence; these include a lack of money and transport as well as poverty, while ART clinic-related factors included negative attitudes experienced on the part of ART clinic staff, long distances that have to be travelled to the ART clinic, as well as long queues and lengthy waiting times at the clinic. The findings also revealed that ART patients, treatment supporters and HCWs perceived their roles as pivotal to ART adherence and all had positive perceptions of these roles. HCWs and treatment supporters perceived adherence as an important aspect in the success of ART.

The recommendations made based on the findings of this study include the consideration by government to decentralise ART treatment to clinics and health centres in order to increase access and reduce the costs of accessing ART treatment.

Keywords: Perceptions; Adherence; Treatment

Introduction

HIV/AIDS is a global problem and, according to a World Health Organization (WHO) report of December 2007, 33,2 million people are living with the HIV/AIDS globally. The region most affected is sub-Saharan Africa which has approximately 25 million HIV-infected people. Namibia is one of the five countries most affected by the world pandemic [1].

In Namibia, the national HIV/AIDS prevalence rate in 2008 was estimated to be 17, 8% with a 21% rate for Oshana region. According to the Health Information System for the Oshana region, in 2008/2009 approximately 10 000 HIV-positive patients were registered for antiretroviral therapy of which about 17% defaulted.

In Namibia, anecdotal reports about patients defaulting from antiretroviral therapy (ART) programmes have raised concerns about patients' adherence to lifelong ART regimens. By the end of 2005, around 14 400 patients were enrolled in ART programmes in various public health facilities. In the 2008/2009 financial year, about 10 000 HIV-positive patients were registered at the ART clinic at the Intermediate Hospital Oshakati, with about 17% defaulting from the programme in the same year, thus representing a 17% poor ART adherence [2].

Oshana region is one of 13 regions in Namibia, and is situated in the northern part of the country. In 2009, the population in the Oshana region was estimated to be 183 452. Namibia's total population is approximately 1.8 million (Namibia Population and Housing Survey, 2001). In view of the fact that HIV/AIDS is a common health problem, defaulters of ART are a problem in the Oshana region, and it is against this background that the researcher investigated the perceptions of HIV-positive patients on ART, as well as those of treatment supporters on their roles in relation to ART adherence.

Although the first case of HIV/AIDS in Namibia was reported in 1986, ART was only introduced in 2003. In 2004, ART was piloted in four regions and in 2006 the service was rolled out to all districts and regional hospitals in the country in order to make the services accessible to those in need of them. Currently, all three intermediate hospitals, 34 district hospitals and 84 health centres provide ART services in Namibia. According to the ART guidelines of 2007, the first line of treatment is zidovudine (AZT), stavudine (D4T), lamivudine (3TC), nevirapine (NVP) and efavirenz, while the second line treatment is fumarate (TDF), lamivudine (3TC), lopinavir (LPV), didanosine (ddi) and abacavir (ABC) [1]. Poor adherence results in patients developing a resistance to the first line of treatment, leading to them having to be placed on the second line of treatment, which is more expensive and has complicated side effects [2].

According to the national guidelines for ART [2], in order to qualify for ART, adolescents and adults should meet the WHO criteria for clinical stage 3 and 4 of HIV disease, irrespective of CD4 cell count. A patient will be eligible for ART when he or she has a CD4 cell count of ≤ 200 cell/mm³ and ≤ 250 cell/mm³ for pregnant women [2].

According to the Ministry of Health and Social Services (MoHSS) ART training guideline manual for health workers [2], ART adherence takes place when a patient takes his/her medication and makes follow-up medical visits according to the doctor's prescription schedule. The importance of adherence to ART treatment is that it helps the medicine to work effectively by suppressing the viral load and boosting patients' immune system. The reduction in HIV-related illness and deaths is simply because CD4 cell counts increase and viral loads decrease. ART medicine adherence is vital for the success of the highly active ART drugs, and very high levels of clinic attendance and taking at least 95% of prescribed doses are required to sustain the suppression of HIV growth [2].

Resistance of viruses to ART refers to a change in the virus that makes the virus protected and antiretroviral medicine ineffective. When the medicines are taken correctly without omission then the virus cannot multiply and make new copies [3-5].

Networking takes place between treatment supporters, community groups and health workers, that is, pharmacists, doctors, nurses and expert patients, who all help to maintain ART adherence.

In Namibia, joint planning for ART management is done every year to reach the common goal of 100% ART adherence. ART treatments are combined and are being simplified [2]. Despite this, patients on ART have been found to default. In Oshana, ART adherence has been found to be poor.

According to Machtinger and Bangsberg, various methods are used to measure treatment adherence, namely, counselling, pill count, self-report and pharmacy refill data. However, no single method is effective in achieving or guaranteeing 100% adherence [6].

Counselling services

In Namibia, counselling is done with patients and treatment supporters on the first visit and on every follow up at the clinic to reinforce adherence. Pre-ART initiation training sessions are carried out three times before the initiation of ART. Support groups such as expert patients (patients living with HIV/AIDS) are available at the health centres and HIV/AIDS support groups are available in all 13 regions, including Oshana.

Self-reports

Self-reporting involves the patient giving a drug history regarding missed or incorrect doses [7].

According to Turner [8], estimates of treatment adherence from patients' self-reports are less complex to obtain than other methods. The advantage of using self-reports are their low cost and flexibility of design and they are applicable to a variety of clinical settings [9].

Pill count

Pill counts involve counting the remaining doses of medication in a specified cycle. The return of excess pills provides tangible evidence of non-adherence [6]. Although the health care provider or pharmacist can do pill counts, the problem with this method is that it is time consuming, and determining the date when the patient commenced the current prescriptions can be difficult, especially when patients combine all their pills in one bottle [8]. Another problem identified with this method is that patients dump pills in order to appear more adherent when counts occur. Unannounced pill counts have been developed to counter this practice, and these involve the counting of pills by health care workers (HCWs) at unannounced home visits. The problem with unannounced pill counts is that they are intrusive and cumbersome for common clinical practice [6].

Pharmacy refill data

Pharmacy refill data can serve as an adherence measure by providing the dates on which antiretroviral medications were dispensed [6]. Poor adherence is noted when there are no timely refills of medications.

Problem Statement

The government of the Republic of Namibia, through the MoHSS, has focused on addressing the HIV/AIDS pandemic by increasing access to cost-effective and high-quality treatment, care and support services for all people living with or affected by HIV/AIDS. Despite these efforts, however, there is evidence that clinical teams (HCWs and treatment supporters) do not give enough support to patient through counselling and educating them about the importance of ART adherence [2]. As a result, patients on ART treatment are at risk of missing doses, which is likely to, in turn, put them at risk of developing treatment failure due to poor viral suppression eventually leading to drug resistance. This has led to the formulation of

the research question: What are the perceptions of HIV-positive patients (ART patients), HCWs and treatment supporters with regard to their role in ART adherence at ART clinics at the Intermediate Hospital Oshakati (IHO)?

Aim of the study

To explore and describe the perceptions of ART patients, treatment supporters and HCWs about their roles in ART adherence

Research objectives

The objectives were

- to explore the perceptions of ART patients, treatment supporters and HCWs about their current roles in ART adherence, and factors that can influence adherence
- to determine the knowledge gap of ART patients, treatment supporters and health care workers in ART adherence.

Significance of the Study

The study will give insights into the perceptions of HIV-positive ART patients, treatment supporters and HCWs concerning their role in ART adherence. The findings may assist the researcher to make recommendations to the relevant authorities for the improvement of adherence interventions in the future.

Research Method and Design

A descriptive and explorative study was conducted using a qualitative methodology. The study population comprised ten HIV positive patients on ART, six HCWs and ten treatment supporters at the Oshakati ART clinic. Convenient sampling was used to select the ART patients and treatment supporters from among those who came to collect their monthly supply of ART medication, as well as all the health workers who attended to them. The researcher used unstructured interviews to collect the data.

Results

Content analysis was used to organise the raw data obtained from the participants into themes and sub-themes in order to synthesise valuable information and meaning. Furthermore, the results obtained from all the participants were consolidated, thus giving a clear understanding of adherence at the ART clinic at the Intermediate Hospital Oshakati.

ART patients' perceptions on their role in ART adherence

The patients' perceptions of their roles in ART adherence were found to be positive. Sub-themes that emerged from the study included taking medication daily, collection of medicine

and follow-up care from the ART clinic, diet and medication, and the support in ART treatment.

Taking medication

Most of the ART patients perceived taking medication daily as a personal responsibility. This was because they realised the negative effects of not taking medication consistently, that is, drug resistance, as well as the benefits of taking the medication consistently, namely, increased CD4 counts on follow-up visits. This was expressed as follows:

"I take it as my responsibility for life and I feel good for it because there is a health benefit in it."

"I accept it as my responsibility for life to take medicine that rescued me from death, because I was seriously sick."

In addition, the study participants perceived taking ART medicine daily to be one of the pillars of ART treatment effectiveness: they indicated the need to ensure that there is always enough medication in the blood to suppress the HIV virus. The following is an extract from the some of the participants' responses:

"I decided to join the programme (ART) in order to drink medicine daily which will suppress the virus down in my blood and I will live longer, do my work as well."

Moreover, participants perceived not skipping doses as one of their responsibilities in ART adherence. Some of the participants stressed that skipping doses would result in resistance to medication.

"Not skipping doses is good ... I feel good that I am healthy and live longer, to help my children because they are young."

These findings are further supported by Van Dyk [10], who states that it is very important to develop strategies to help patients take responsibility for their own treatment, adhere to ART and maximise the chances of successful treatment.

Collection of medicine and follow-up care at the ART clinic

Participants seemed to have accepted that the collection of ART medicines and going for follow-ups as the role they have to play in ART adherence. Many of the participants emphasised that the collection of medication and the follow-up visit is of paramount importance in ART adherence. They mentioned that a sufficient supply of medication ensures that no doses are missed, which in turn will ensure maximal viral suppression and the avoidance of drug resistance. They also referred to the benefits of follow-up visits, including being able to be clinically and immunologically evaluated by nurses and clinicians. Follow-up visits also give them the opportunity to be treated for any other illness, as well to receive valuable reinforcement counselling. The following are extracts from the transcripts of the interviews with participants:

"Though in the rain season flooding causes me to walk very long distance to the alternative bus stop ... I try to come a day

before so I will make time to come for follow-up visit and collect my medication!”

The findings of this study are similar to those of a study conducted by Mohammed and Sarki [11] in Abuja, Nigeria, which revealed that long travelling times to the clinic were claimed to be one of the factors that interfered with adherence.

Diet and medication

Most of the study participants perceived eating healthily as one of their roles in ART adherence. All participants reported that they eat before taking their medication. To explain the importance of food in ART treatment, some of the participants expressed gratitude to relatives who bought or prepared food for them. Some even appealed to government to provide drought relief food to assist those who are affected by natural disasters such as drought or flood. ART patients affected by disasters use to receive that drought relief food. Some of the participants mentioned that they sometimes had adverse drug interactions, which they perceived as occurring when they took their medication without eating first. Below are some of the extracts from participants' responses:

“I eat first after 20 minutes I drink medicine. It helps to prevent dizziness.”

“It could be good if government can source an organization that can provide food to patients on ARVs. I am just surviving in my disability grant and my mother's pension to fulfil all our needs including food.”

In a similar study by Dzinza [12], it was reported that some patients on ART in Botswana revealed that because of their poor financial status, they failed to obtain proper food, thus adherence to treatment was affected. Hardon, et al. [13] found that in most parts of Africa a shortage of food has been reported as a major reason for non-adherence to ART, as these drugs are said to increase appetite. The importance of food security and nutrition is seen as being crucial to adherence, and particularly in the early stages of ART. In some cases the view is that people may not even start treatment when they are not sure about their source of food.

Support in the ART treatment

Most of the participants highlighted sourcing a treatment supporter as one of their perceived roles in ART adherence. They explained that if their families accepted them after knowing they were HIV positive, it gave them the strength to continue with ART. Most of the participants mentioned that they had good relationships with their close families who in return had become their treatment supporters. Some also mentioned the satisfactory interaction they had with HCWs.

Although a few said they did not want anyone to help them, this study revealed that a treatment supporter is valuable in ART adherence. Some stated that during the first two months of their treatment they experienced side effects; as a result they felt like stopping treatment, but with the encouragement and counseling of a treatment supporter they continued.

Some indicated that the treatment supporter collected their medicine when they were too unwell. They also received psychosocial support from these treatment supporters. Below are some extracts from participants' responses:

“The relationship with my mother and my sister is still good. They are my support in everything; they remind me and cook for me!”

“I had my sister already who is reminding me to take medicine. I need her to prepare food for me also. She is the one that put alarm for me, just to remind!”

This study is supported by that of Beals et al. [14], who argue that successful ART provision requires not just medical attention but also long-term social and psychological support, which includes encouragement and monitoring for adherence.

Treatment supporters' perceptions on their roles in ART adherence

Treatment supporters' perceptions on their roles in ART adherence were found to be positive. Responses were divided into the following sub-themes: follow-up visits and collection of medication, psychosocial and emotional support, giving medication and food, and encouraging personal hygiene.

Follow-ups and collection of medication

Most of the treatment supporters perceived follow-up visits and collection of medication as an important responsibility to maximise ART adherence. They felt it was their responsibility to ensure that their patients attend all follow-up visits without fail to minimise dose skipping and hence drug resistance. Treatment supporters perceived the hard task of walking long distances as being purpose driven. Though they felt the pain of walking long distances, it was evident from their explanations that it was important for their patients to be reviewed by HCWs. The role of accompanying patients for follow up is not an easy one, as shown below.

“The long distance becomes worse during the rainy season. It makes me to carry my son and pass through pools of water, but I notice the improvement of the health condition of my son ... I am encouraged to continue to take care and walk + 45 km to reach the ART clinic at Intermediate Hospital Oshakati.”

“We are footing sometimes because of lack of transport money.”

The findings of this study are similar to those of a study conducted by Dzinza [12] in Botswana, where it was reported that some patients on ART revealed that going for follow up visits would require financial means, which many did not have, as patients have to travel long distances to rich hospitals. Therefore, some failed to go for follow up, which resulted in non-adherence.

Many of the treatment supporters explained that that when patients start to feel better they are encouraged to continue with treatment, but some revert to their old negative habits. These negative patient habits may result in patients defaulting

from their treatment. So treatment supporters perceived their role in psychosocial support as reinforcement of positive behaviour to increase ART adherence. This was alluded to by one of the treatment supporters as follows:

“Some of my patients do not adhere to the treatment, or some continue to use alcohol, so I have to try to talk to them ...”

Some of the treatment supporters reported that they have to resort to giving health education to reinforce positive behaviour in patients showing full signs of recovery.

Giving food and medication on time

Giving food and medication on time was perceived to be critical role in ART adherence by most treatment supporters.

Almost all treatment supporters reported that preparing food was one of their chief responsibilities, as their patients were often too weak to do household chores. Many reported that eating healthily every day before medication helps minimise drug intolerance. Forgetting to take medicine was one of the factors highlighted by treatment supporters as an obstacle to ART adherence. In order to minimise default due to forgetfulness some bought alarm clocks or programmed the times for taking medication into their cell phones. This they said it will make them less likely to skip one of the requirements for taking ART medicine, and if it was not for the treatment supporters, their treatment adherence would not be possible. Some of these sentiments are expressed below:

To assist my cousin where needed, remind her to take her medication and her follow-up date in mind, support her psychologically and emotionally if needed.”

“... to give medicine at 7H00 and 19h00 ... prepare food for the child and lunch pack.”

These study findings concur with those of Hardon et al. [13], who found that in most parts of Africa, a shortage of food has been reported as a major reason for non-adherence. Food and nutrition are seen as crucial for adherence, particularly in the early stages of ART. In some cases people may not even start ART when they are not sure about their source of food [15]. In a study conducted in Uganda, food security was identified as a barrier to sustainable ART adherence [16].

Health care workers' perceptions on their roles in ART adherence

HCWs' perceptions on their role in ART adherence were found to be positive. Their responses were divided into the following sub-themes: monitoring patients, pill count to monitoring adherence; and questioning and counselling patients on adherence.

Most of the HCWs perceived follow-up visits as critical, and said they check patients' weight and health status and for the presence of opportunistic infections. This they say enables them to see if the patient is physically responding to treatment. They also assess for any possible side effects of

medication such as a rash. Most of the HCWs felt that if the patient is not monitored clinically, predictions of possible default will be difficult to make on time. This will then bring about drug resistance. HCWs felt loss of weight or development of opportunistic infections in patients on ARVs holds possible dangers of default or resistance. HCWs also reported that they monitored their patients immunologically which involved collecting blood to measure viral load, CD4, ALT, creatinine and haemoglobin (Hb). The HCWs perceived this as a critical component of their role in ART adherence. HCWs report that under normal circumstances one would expect CD4 count to go up and viral load to go down in patients on ART. In addition they reported that if this normal pattern is not observed it will alert them of pending danger of either resistance or default. This, they say, helps them screen patients who really need adherence counselling. HCWs also reported one of the challenges of ARV treatment as being that of hepatic toxicity in reaction to some of the medication. They monitor this by doing ALT and creatinine tests.

Immunological monitoring includes viral resistance tests especially in patients who show signs of treatment failure. HCWs said they will then ask for the laboratory to assess the mechanism of resistance as well as the particular medications involved so as to change medications to more effective ones. These sentiments are expressed clearly in some of the quotations below:

“Do monitoring adherence by ordering laboratory tests as well as viral load to detect poor adherence.”

“We monitor clinically, immunologically e.g. viral load and CD4 cell count.”

“The clinical and immunological picture of the patient tells us a big story behind ART resistance, without it we will be walking in complete darkness.”

Pill count in monitoring ART adherence

It was apparent from the findings of this research that participants accepted their role in pill counting to monitor ART adherence.

All the HCWs reported that they monitor ART adherence through pill counts. HCWs reported that they do pill counting for the first three months after patients have started the treatment. After six months, when the patient show good adherence, the HCWs relax pill counting.

“We do pill counting and see how many pills were given before and how many they come back with, then we tell the difference ...”

In a similar study conducted in Botswana [12], one physician emphasised that assessing adherence is a complex issue but it is unfortunately a very essential component of HIV treatment.

This role of pill counting to monitor ART adherence was perceived by some HCWs as a challenge. “Pill dumping” was the most raised concern in this regard. HCWs are of the opinion that some patients throw away pills to appear to be

more adherent. This limits the reliability of this assessment method. The following were some of the reports.

“A patient can also be clever, then can remove and throw away pills.”

“But you know somebody can still throw away the tablets.”

This finding agrees with findings observed by Dzinza [12] in Botswana where physicians who reported doing pill counting for every patient during interviews were observed to be doing pill counting for every patient during consultations as a measure of assessing adherence.

Self-reporting

Some HCWs therefore think that enquiring from the patient about the number of times they take treatment and asking whether they have ever missed treatment (self-reporting) is helpful. Most HCWs use patients' self-reporting as one of the methods to assess patients' adherence to ART, and explained that this is done by sitting down with the patient and asking how they have been taking the medication. If communication skills are good, the HCWs believe that the patient will feel free to even include their wrongdoings. The following are quotations from HCWs that illustrate the use of patients self-reporting.

“And when you sit down with the patient and try to talk to them some admit that they skipped treatment.”

“We just talk to them; you know a patient should be free to tell you really the correct thing. You should not be watching over him like a policeman.”

HCWs reported some of the problems associated with self-reporting, including relying solely on the information from the patients and the fact that patients sometimes do not tell the truth. HCWs were quoted as saying:

“They tell us they are adherent, they have never missed a pill and we believe.”

Counselling of patients

Most of the HCWs identified ongoing counselling as one of the most effective interventions in ART adherence. Participants responded as follows in this regard:

“We usually encourage them to stop drinking alcohol if drinking alcohol is the problem.”

“We also go to the pastor, we talk to them if they can also teach, if they can give correct information in the churches about HIV/AIDS.”

These findings are similar to those of a study conducted in Nigeria by Igwebe, et al. [17], on the prevalence and determinants of non-adherence to antiretroviral therapy among HIV-positive pregnant women in Nnewi. The study found that knowledge of the determinants of non-adherence factors should be properly applied and addressed during adherence counselling programmes. That finding is consistent with this study in that adherence counselling is being done on

a regular basis and in a sustainable manner for all patients on ART as it has been found to have significant benefits.

Conclusions

It was evident from the findings of this research that ART patients perceive a number of factors as affecting ART adherence, including lack of money and transport and poverty, while ART clinic-related factors included negative attitudes on the part of ART clinic staff, having to travel long distances to the ART clinic and the presence of long queues and lengthy waiting times at the clinic.

Recommendations

The following recommendations are made based on the findings of this study:

- Adequate manpower should be provided in all departments of the ART clinic to allow for proper adherence assessment and continued monitoring and counselling by HCWs.
- HCWs must be provided with customer care training to establish the provider–patient relationship essential for ART adherence.
- Government should decentralise ART treatment to clinic health centre level to ensure easy access and reduce the costs involved in accessing ART treatment.

Recommendations for future research

A research study could be conducted to explore the influence of religion and tradition on ART adherence.

Limitations of the Study

Given the sensitivity of HIV, it is possible that some participants may not have expressed their views freely. Apart from English, Oshiwambo was also used to collect the data for this study and the responses were interpreted into English. Accordingly, it is possible that some of the original ideas of the participants may have been lost in during the interpreting process.

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Competing interests

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

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