

Self-reported adherence to anti-retroviral therapy (ART) challenges faced by caregivers of HIV positive children

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ABSTRACT: Since 1986 when the first case of AIDS client was reported in Swaziland, HIV has spread at an alarming rate. Swaziland is leading in the Sub-Saharan Africa and globally on HIV and AIDS pandemic with an estimated prevalence of 26% among adults aged 18 – 49 years. About 6,448 children in Swaziland are on anti-retroviral therapy (ART). Poor adherence to ART results in increased opportunistic infections, increased viral load, drug resistance, poor quality of life, and reduced life expectancy among the children.

The purpose of the study was to describe ART related challenges faced by caregivers of HIV positive children. The sample comprised 25 female caregivers. The findings revealed significant correlations: between the caregiver's education and relationship with the health care provider ($r = -0.413, p < 0.05$); employment and forgotten doses ($r = 0.502, p < 0.05$); duration of being on ART and forgotten doses ($r = -0.403, p < 0.05$); side effects and forgotten doses ($r = -0.474, p < 0.05$); age of child and difficulty in taking medicines ($r = -0.529, p = 0.01$); age of care-recipient and familiarity with prescribed ART ($r = 0.461, p < 0.05$); and between age of care-recipient and relationship with health care provider ($r = 0.448, p < 0.05$).

Caregiver challenges related to adherence to ART included the care-recipient having too many drugs to take; taste of the medication; age of the care-recipient; experiencing side effects from ART; lack of disclosure and social support; and forgetting. Based on the study findings it is recommended that health care providers strengthen their relationship with caregivers; and develop strategies that will assist working caregivers to reduce forgotten doses; advocate for few drugs; assist the caregiver in disclosing the status of the care-recipient to the care-recipient and family; and advise on measures to alleviate the side effects from ART.

KEYWORDS: anti-retroviral therapy (ART), caregivers, HIV/AIDS, adherence.

1 INTRODUCTION

1.1 HIV AND AIDS GLOBALLY

According to Van Dyk 2008, the first recognized cases of Acquired Immune Deficiency Syndrome (AIDS) occurred in the United States of America (USA) in 1981, where a rare form of pneumonia; *Pneumocystis carinii*, with other conditions such as cytomegalovirus infections, candidiasis and Kaposi's sarcoma suddenly appeared simultaneously. The global AIDS epidemic had an estimation of 39.5 million people worldwide who were living with HIV in 2006 (Van Dyk, 2008). Almost 45% of the individuals living with HIV were women, estimated to be 17.2 million, while an estimated 2.3 million were children below 15 years of age, and 2.9 million of people lost their lives to AIDS in 2006 (Van Dyk, 2008).

1.2 HIV AND AIDS IN AFRICA

HIV and AIDS are a major public health concern and cause of death in Africa. Although Africa has a population of just over 14.7 % of the world's population, it is estimated to have more than 88% of people living with HIV (Avert, 2009). According to Van Dyk (2008), about 43% of all children less than 15 years of age living with HIV are found in Southern Africa where 52% of all women live with the virus.

The HIV prevalence rates and statistics of people dying from AIDS varies greatly between African countries, but the Sub-Saharan Africa region remains the worst affected region in the world with an estimated 22.5 million people living with the virus, accounting for 71% of all new HIV infections in 2008 (United Nations Programme on HIV/AIDS [UNAIDS], 2009). In 2008 around 1.2 million of people died from AIDS in the Sub-Saharan Africa and 1.9 million people became infected with HIV (UNAIDS, 2009).

1.3 HIV AND AIDS IN SOUTH AFRICA

In 2009 South Africa had an estimated 5.6 million people living with HIV and AIDS, and an estimated 310,000 South Africans died of the virus in the same year (Avert, 2009). The prevalence was 17.8% among those aged 15–49 years, with some groups particularly affected, especially women in the child bearing age. The impact of the AIDS epidemic reflects a dramatic change in South Africa's mortality rates. The overall number of annual deaths increased sharply from 316,559 in 1997 to 607,184 in 2006 (Avert, 2009).

1.4 HIV AND AIDS IN SWAZILAND

Since the first case of AIDS was reported in Swaziland in 1986, the virus has spread at an alarming rate. Swaziland is the leading country with the HIV and AIDS pandemic in the Sub-Saharan Africa as well as globally, with an estimation of adult prevalence of 26% (Joint United Nations Program on HIV/AIDS [UNAIDS], 2009). The prevalence rate of HIV and AIDS in Swaziland among pregnant women attending the antenatal care (ANC) between 1992 -2010 (Ministry of Health [MOH], 2010) reflects an increase of 37.2% in a period of 18 years.

Swaziland's HIV and AIDS disease burden and related co-morbidities such as tuberculosis and malnutrition has led to a reduced life expectancy from 61yrs in 2000 to 52 years in 2009, which was the lowest in the world (MOH, 2010). The decreased life expectancy leaves many Swazi children without one or both parents. Hence, contributing to the estimated 130,000 orphans and vulnerable children, that is, approximately 31.3% of all children in Swaziland (NERCHA, 2010). According to USAID/PSI (2010-2014), there are approximately 15,000 children in Swaziland between birth and 14 years living with HIV.

1.5 HIV AND AIDS MANAGEMENT

Several efforts to curb the spread of HIV have been made, which include multimedia and information campaigns for the public interventions that focus on social and behavior change communication. Programs designed to reduce the risk of contracting HIV encourage abstinence, faithfulness to partner, the practice of safe sex, circumcision and the prevention-of-mother-to-child-transmission [PMTCT] of HIV. As means of controlling HIV spread in one's body, the antiretroviral therapy (ART) program was introduced in 2003 (UNAIDS, 2009). The Ministry of Health is rapidly rolling out – decentralized ART treatment, care and support program to health care facilities throughout Swaziland.

The universal access report estimated that 89.2% of people living with HIV and AIDS [PLWHA] who needed ART were indeed receiving ART in 2009 (UNAIDS, 2009). Access to PMTCT services were also scaling up, with an estimated 69% of all HIV-infected pregnant women receiving ART to reduce the risk of transmitting HIV to the unborn baby (USAID/PSI, 2010-2014). The government has successfully supported the PMTCT programme from a base of virtually none in 2004 to 150 out of 172 ANC health facilities in 2012 (Kingdom of Swaziland, 2012)

1.6 ADHERENCE TO ART

Adherence to medication regimen is generally defined as the degree to which clients take medications as advised by the health care providers (Osterberg & Blaschke, 2005). According to Shah (2007), adherence to ART is the extent to which a person's behavior in taking medication, following dietary specifications and executing lifestyle changes corresponding to recommendations from a health care provider. In the case of children, behavior change can be related to both the child and to the caregiver. In order to achieve an undetectable viral load and reduce the risk of developing drug resistance, a person

who is on ART needs to take at least 95% or more of the prescribed doses on time (Shah, 2007). Adherence could be promoted through educating of the caregiver, motivation, and reinforcing interventions that promote adherence.

Strict adherence promotes viral suppression and quality life, while poor adherence results in further immunosuppression, resistance to ART (Shah, 2007) and poor prognosis. Thus it is very important to develop strategies to assist clients to take responsibility for their own care, adhere to drug regime and maximize the likelihood of successful ART (Machtinger & Bangsberg, 2005). Poor adherence to ART is one of the key challenges in HIV and AIDS management programmes. The aim of the study was to describe adherence to ART-related challenges faced by caregivers of HIV positive children.

2 METHODOLOGY

A descriptive correlational design was used in the study. The study was conducted at the Manzini Raleigh Fitkin Memorial Hospital, ART Department, in Swaziland. Caregivers of the HIV positive children aged between 0 and 18 years, who were on ART, comprised the sample. The study utilized an alpha = 0.05, effect size = 0.08, power = 0.80. According to Lipsey (1990) the sample was 25 participants.

The Patient Medication Adherence Questionnaire Version 1.0 (PMAQ V1.0) (DeMasi & Graham, 2001) was used to collect data from the participants. The PMAQ (V1.0) questionnaire was adapted and translated to *siSwati*. The participants were interviewed.

According to DeMasi et al. (2001), the psychometric evaluation of the PMAQ-V1.0 used Cronbach's alpha and item-scale Pearson correlation and the reliability total score was 0.76 (DeMasi et al., 2001). The research instrument was pre-tested at the Mbabane Government hospital HIV Testing and Counseling [HTC] Unit.

Data were analyzed utilizing the Statistical Package of Social Sciences (SPSS, version 17.0). Descriptive statistics and Pearson's Correlation Coefficient were applied in analyzing data.

The study was performed in compliance with the Swaziland Ministry of Health Scientific and Ethics Committee guidelines. Permission was sought and received from the Scientific and Ethics Committee, relevant health authorities in the health facilities, and the participants.

3 RESULTS

The sample comprised 25 females who were caregivers to children on ART. The findings are presented according to the research objectives.

3.1 CAREGIVERS' SOCIO-DEMOGRAPHIC VARIABLES

The majority ($n = 11$, 44%) of the participants were aged 30 -39 years while 24% ($n = 6$) were aged between 40 – 49 years, 20% ($n = 5$) were aged 50 years and above and 12% ($n = 3$) were aged 20 -29 years. The participants' mean age was 39.7 years with a standard deviation of 12.6 years. Most ($n = 16$, 64%) of the participants reported that they resided in the rural area, 32% ($n = 8$) were from the peri-urban, and only 4% ($n = 1$) were from the urban zone. The educational level of the participants varied. The majority ($n = 7$, 28%) had high school, 20% ($n = 5$) had secondary, and another 20% ($n = 5$) had tertiary education. More than half ($n = 13$, 52%) reported that they were unemployed, 16% ($n = 4$) were self-employed and 32% ($n = 8$) of the participants were employed (summary in *Table 1*).

Table 1. Socio-demographic characteristics of family caregivers to children on ART (N = 25)

Variable	Number / Mean	Percent / SD
Age	39.7	12.6
Gender		
Male	0	0
Female	25	100
Residence		
Rural	16	64
Peri-urban	8	32
Urban	1	4
Educational level		
Not attended school	2	8
Sebenta adult literacy	2	8
Primary education	4	16
Secondary education	5	20
High school education	7	28
Tertiary education	5	20
Employment status		
Unemployed	13	52
Self-employed	4	16
Employed	8	32
Age of child on ART	7.4	4.1
Duration of child on ART	4.9	

3.2 CARE-RECIPIENTS

The care-recipients (children on ART) were from different age groups. Most (28%) care recipients were from the age group 7 - 9, another 28% ($n = 7$) were from 4 - 6, 16% ($n = 4$) were from 10 -12, 16% ($n = 4$) were from 1 - 3years, and 12% ($n = 3$) were from the age group of 13 -15 years. The mean age of the care-recipients was 7.4 years with a standard deviation of 4.1 years. The correlations between the age of the child and health care provider relationship was positive ($r = 0.45$, $p < 0.05$). This means that the increasing age of the child was accompanied

by increasing relationship with the health care provider which facilitated discussion on ART. The majority of the care-recipients ($n = 9$, 36%) were reported to have been on ART between 2- 4 years, 32% ($n = 8$) between 5 -7 years, 16% ($n = 4$) between 0 - 2 years, 8% ($n = 2$) between 8 -10 years, and another 8% ($n = 2$) had been on ART for 11years and above. The mean duration of being on ART was 4.9 years.

Research objective: To describe challenges related to adherence to ART encountered by caregivers

3.3 ART STORAGE AND TIME

The majority ($n = 23$, 92%) of the participants reported that they did not whereas 4% ($n = 1$) revealed that they had problems with storing ART. About 80% ($n = 20$) of the participants reported that they gave, while 16% ($n = 4$) reported that they did not give the child ART medication on time. Most ($n = 23$, 92%) of the participants reported that they were able to refill ART on time, and only ($n = 1$, 4%) reported that they were unable to remember to refill the child's ART prescription on time.

3.4 ART TOLERANCE

The majority ($n = 21$, 84%) of the participants reported that the care-recipients were able to swallow the medication, while 12% ($n = 3$) revealed that their children had difficulty swallowing the medication. Most ($n = 20$, 80%) of the participants reported that the child did not have difficulty, while 20% ($n = 5$) revealed that the child had difficulty in taking medication because of unpalatable taste. There was a negative ($r = -0.529$, $p = 0.01$) relationship between the age of the child and difficulty in taking ART because of unpalatable taste. This means that with increasing age of the child, there was a decline in having difficulty taking ART with unpalatable taste.

3.5 EXHAUSTION AND EFFECTS OF ART

The majority ($n = 23, 92\%$) of the participants reported that the child took ART when he / she (child) was tired, while ($n = 2, 8\%$) stated that the child did not take medication when tired. Most ($n = 19, 76\%$) of the participants revealed that they (caregivers) gave ART even when the child experienced side effects, while 16% ($n = 4$) reported that they (caregivers) stopped giving the child ART when experiencing side effects. Furthermore, the results revealed a negative ($r = -0.474, p < 0.05$) relationship between side effects and forgotten doses. This means that with increased side effects there was a decline in forgotten doses.

Most ($n = 24, 92\%$) participants reported that having the child taking ART resulted in better health of the child. However, 4% ($n = 1$) reported that ART did not give their children better health.

All ($n = 25, 100\%$) the participants reported that they continued to give ART even when the health of the child had improved.

3.6 FAMILIARITY WITH ART AND THE USE OF SUPPLEMENTS

Most participants ($n = 15, 60\%$) reported that the child was familiar while 36% ($n = 9$) reported that the child was not familiar with the prescribed ART medication. Furthermore, correlations between age of the child and familiarity with prescribed regimen was positive ($r = .461, p < 0.05$). That is, with increasing age of the care-recipient (child) there was also an increase in familiarity with prescribed ART regimen.

Most participants ($n = 21, 84\%$) reported that the child was taking only ART medication prescribed and dispensed in the hospital. However, 12% ($n = 3$) of the participants reported that the child was taking ART prescribed by the doctor and also supplements.

3.7 STIGMA

The majority ($n = 11, 44\%$) of the participants reported that they felt uncomfortable with people knowing that the child was taking ART. On the contrary, 44% ($n = 11$) revealed that they did not feel uncomfortable with people knowing that child was taking ART. Forty four percent ($n = 11, 44\%$) of the participants were not willing to disclose the HIV status of the child. Forty four percent ($n = 11, 44\%$) of the participants reported that the HIV status was not stigmatized by having to take ART. On the contrary 48% ($n = 12$) reported that the HIV status was being stigmatized by having to take ART.

3.8 SOCIAL SUPPORT

The majority ($n = 23, 92\%$) of the participants reported that the child was able to take ART, however, 8% ($n = 2$) revealed that their children had difficulty in taking medications when she (caregiver) was away from home. The majority ($n = 21, 84\%$) of the participants reported that they received and only 4% ($n = 1$) revealed that they did not receive social support from the family on the use of ART.

3.9 FORGETTING

Most ($n = 24, 96\%$) participants reported that they were giving the child ART even when they (caregiver) were busy. However, 4% ($n = 1$) of the participants reported that they had difficulty giving medications to the child because they (caregiver) were busy. There was a positive and significant ($r = 0.502, p < 0.05$) correlation between employment and forgotten doses. This means that being employed was accompanied by frequent forgotten doses. It is most likely that the employed caregivers get tired and forget to administer ART to the child.

Most ($n = 19, 76\%$) participants reported that they did not have difficulty remembering to take ART for my child when leaving their (caregiver's) places of residence, while 24% ($n = 6$) revealed that they had a challenge in remembering to take ART for the child when travelling.

Sixty percent ($n = 15$) of the participants reported that having more ART medication to give to the child caused more frequent forgotten doses. In addition, there was a negative ($r = -0.403, p < 0.05$) correlation between duration of being on ART and forgotten doses. This means that the longer period the child was on ART the lesser were the forgotten doses.

3.10 RELATIONSHIP WITH HEALTH CARE PROVIDER

The majority ($n = 24$, 96%) of the participants reported that they had established rapport with the health care provider, and only 4% ($n = 1$) reported that they had poor relationship with the health care provider. In addition, there was a negative ($r = -0.413$, $p < 0.05$) correlation between the caregiver's level of education and having a relationship with the health care provider that facilitated discussion of ART. This meant that, with increasing caregiver's level of education, the relationship with the health care provider that facilitated discussion about ART declined.

4 DISCUSSION

Consistent with previous research with increasing care-recipients' age there was an increased in familiarity with ART (Roux, 2002). The longer period the child was on ART the lesser were the forgotten doses. It might be that with time the child and caregiver gradually become familiar with the different periods at which ART has to be taken hence, fewer doses forgotten. In addition as the child grows older, she/ he is likely to remind the caregiver each time the next dose has to be taken.

A unique finding was that with increasing caregiver's level of education, the relationship with the health care provider that facilitated discussion about ART declined. It may be possible that health care providers are threatened by educated caregivers. It is important therefore that health care providers be prepared to collaborate as partners with clients regardless of the client's level of education. Much as the client may be educated but the client may still be ignorant about some aspects of health care particularly in the area of HIV and AIDS which is a dynamic disorder together with its management. There is need for further research to determine rationale for the poor relationship between health care providers and educated caregivers

Consistent with previous research (Beach, Keruly, & Moore, 2006; Schneider et al., 2004) good client-health care provider relationship improved adherence to ART. It is likely that the established rapport between the client and health care provider improves trust on any advice that is shared between the client and health care provider, and the client is more willing to share any barriers that she or he encounters with ART.

Contrary to previous research (Ammassari et al., 2001) the current study findings demonstrated that despite side effects from ART there was decline in forgotten doses. Probably the participants assumed that side effects were a result of poor adherence, and that good adherence to ART will alleviate the symptoms. It is recommended however, that in each and every follow-up visit health care providers encourage clients to reveal any side effects experienced since there may be need to change the client's ART regimen.

Consistent with previous research (Ammassari et al., 2001) busy caregivers e.g. employed caregivers reported more forgotten ART doses. This is an unfortunate scenario because more forgotten doses are accompanied by drug resistance, poor quality of life, increased morbidity and mortality in the care-recipient. Working caregivers need to be advised on strategies that could assist them in remembering the ART administration intervals. In addition, caregivers and care-recipients need to be empowered with knowledge about how ART works and consequences of more forgotten ART doses.

Consistent with previous research (Davies et al, 2008), some children had difficulty in taking ART because of the unpalatable taste. Unpalatable ART have increased likelihood on being skipped decreasing the child's quality of life and promoting the development of drug resistance. Yet, palatable ART regimens have been reported to be associated with better adherence, and consequently improved quality of life. Health care workers need to advocate for palatable ART for children so as to reduce the likelihood of poor adherence related to unpalatable ART.

Some participants reported that their family members and relatives were not aware that the child was HIV-positive and was on ART. Lack of disclosure made it difficult to administer ART to the child in the presence of family members who were not aware of the child's condition, lest they question the reason for the child to always take medication. Rujumba et al. (2010) reported that caregivers had several issues that ranged from unwillingness and difficulty to disclose the HIV status of their children, Disclosure plays a major role in curbing the spread of HIV and also in promoting adherence to ART. Disclosure can be accompanied by several benefits, including, helping one to reduce the stress of coping on your own; and receiving social support from the family and reducing missed doses when the caregivers is away from home. Openness about the child's HIV-positive status may help in reducing stigma, discrimination and denial that surround HIV and AIDS; and promote responsibility (Roux, 2002).

5 RECOMMENDATIONS

It is recommended that this study be replicated on a larger scale, to validate the findings and that physiologic measures be utilized to measure adherence in the care-recipient. Health care workers need to be trained on techniques which this special group of children and adolescents might be supervised, and supported in terms of understanding and accepting their HIV status and ART regimen.

The caregivers should be given the adequate guidance as to when to begin to disclose the HIV status to their children. There is need for the children to be involved in the explanation and discussions about ART in order to obtain mutual understanding, which will enhance adherence.

6 CONCLUSION

Caregiver self-reported challenges related to adherence to ART included: forgetting, age of the child, poor client-health care provider relationship, care-recipient having too many drugs to take; unpalatable taste of ART; experiencing side effects from ART; lack of disclosure and and poor social support.

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