East African Medical Journal Vol. 95 No. 10 October 2018
AN INVESTIGATION OF ADHERENCE TO ANTIRETROVIRAL THERAPY USING CAREGIVER REPORTS IN CHILDREN AGED 2-14 YEARS IN LAGOS NIGERIA
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AN INVESTIGATION OF ADHERENCE TO ANTIRETROVIRAL THERAPY USING CAREGIVER REPORTS IN CHILDREN AGED 2-14 YEARS IN LAGOS NIGERIA

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ABSTRACT

Background/Objective: **The introduction of antiretroviral therapy (ART) has shown a tremendous reduction in HIV-related mortality and morbidity in people living with HIV / AIDS. Adherence is essential to achieve the success of ART. In children, the caregivers play very key roles and understanding the factors that affect adherence to antiretroviral therapy is important for successful and sustained viral load suppression. The objective of the study was to evaluate the adherence to antiretroviral therapy and its associated factors using reports from caregivers of children aged 2-14 years.**

Design, Setting and subjects: **This prospective cross-sectional study involved 164 caregivers of children living with HIV and who were receiving antiretroviral therapy for more than three months. The study was carried out at the pediatric human immunodeficiency (HIV) clinic of the Lagos University Teaching Hospital (LUTH) from June to August 2017.**

Interventions: **Adherence was assessed by caregiver reports using a pretested questionnaire. Descriptive analyses including mean for numerical variable, frequencies and proportions for categorical variables were performed. Chi-square test was used to assess the association between gender, education level of caregivers and adherence. The level of significance was $p<0.05$**

Main outcome measure: **Adherence to antiretroviral therapy and its associated factors**

Results: **Ninety-one percent of the caregivers were females. Eighty two percent could read and write and sixty eight percent were mothers of the children. The caregivers felt that availability of drugs (59%) and fear of death (28%) were the commonest factors responsible for good adherence while pill burden (37%),**

stigmatization (32%) and forgetfulness (31%) were the commonest reasons for poor adherence. Gender and educational level were not significantly associated with adherence. (Pearson Chi-Square = 2.481 and p-value < 0 .05).

Conclusion: **The role of the caregiver is very important to maintain good adherence levels and therefore treatment success. Health education on the importance of adherence, antiretroviral therapy should be improved and targeted at caregivers of children to improve adherence.**

INTRODUCTION

Human immunodeficiency virus (HIV) infection is an important public health concern and it adds considerably to childhood burden of disease in Sub-Saharan Africa. Use of antiretroviral therapy (ART) has resulted in better treatment outcomes and together with good adherence are key determinants of treatment success and positive outcomes (1). Suboptimal adherence can lead to poor clinical, immuno-virologic outcomes with incomplete viral suppression, emergence of resistant viral strains, treatment failure, increased antiretroviral treatment costs, morbidity and mortality (2).

Several methods have been used to measure adherence and these include therapeutic drug monitoring (TDM), directly observed therapy (DOT), pill counts, and self-reports. In the self-report method, the patient or caregiver (in the case of children) gives information on how the drugs are taken and reports on missed doses. Paediatric adherence is challenging and relies on the caregiver providing true and accurate information (3).

Studies on the role of caretakers on antiretroviral therapy adherence and factors that affect adherence among HIV infected children are important. Various factors including caregiver, health worker, issues related to medication types and socio-cultural factors can affect adherence to antiretroviral therapy (4). A clearer understanding of the factors that influence adherence to antiretroviral treatment is important to achieve good treatment outcomes in the clinical care of HIV infected children. The objective of this study was to investigate adherence to antiretroviral therapy and its associated factors using reports of caregivers of children aged 2-14 years.

METHODOLOGY

This study was carried out in the paediatric HIV clinic of the Lagos University Teaching Hospital from June to August 2017.The study was a cross sectional prospective study. Caregivers of children aged 2-14 years receiving antiretroviral therapy who presented to the clinic were consecutively included in the study if they gave their consent.

Data collection tools and procedure: Data was collected by using a pretested and structured questionnaire administered to caregivers by three trained health care providers. The questionnaire used was adopted from previous studies (5,6). Data included socio demographic characteristics, reasons for non-adherence in their children, support level of their family and friends, adherence counselling and commonest reasons for missed doses. Adherence was measured utilizing the caregivers report following three months of treatment. Good adherence was defined as taking at least 95% of totally

prescribed doses at the prescribed times and day (7).

The antiretroviral medications consisted of fixed dose combination therapy of zidovudine, lamivudine and nevirapine administered in two strengths of 60/3050 mg and 300/150/200mg according to the World Health Organization (WHO) weight band dosing (8).

Statistical analysis: Descriptive analyses, was done, including frequencies, and proportions for categorical variables. Chi-square tests were used to assess the association between gender, education level of caregivers and adherence. The level of statistical significance was $p<0.05$.

Ethical consideration: This study was approved by Health Research Ethics Committee of the Lagos University Teaching Hospital, Lagos, Nigeria (ADM/DCST/HERC/APP/1758). Each caregiver was adequately informed about the purposes of the study and written informed consent was obtained. Caregiver information was treated as confidential and they were not identified by name.

RESULTS

A total of 164 caregivers of children aged between 2 and 14 years who were on antiretroviral therapy for at least three months were included in this study. Table 1 shows socio demographic characteristics of caregivers. One hundred and fifty (91%) of the caregivers were females. One hundred and thirty-four caregivers (82%) could read and write. Sixty-eight percent (112) were biological mothers of the children.

Table1

Socio-demographic characteristics of caregivers

Characteristics	Frequency	Percentage
Gender of caregivers		
Female	150	91%
Male	14	9%
TOTAL	**164**	**100%**
Education of caregivers		
Can read and write	134	82%
Cannot read and write	30	18%
TOTAL	**164**	**100%**
Relationship with child		
Aunt	10	6%
Brother	4	3%
Guardian	2	1%
Cousin	4	3%
Father	13	8%
Grandmother	15	9%
Mother	112	68%
Sister	2	1%
Uncle	2	1%
TOTAL	**164**	**100%**

Marital status of caregiver		
Married	146	89%
Divorced	2	1%
Single	16	10%
TOTAL	**164**	**100%**

Table 2 shows the proportion of caregivers who gave adherence counselling to their children. Of the respondents, sixty-nine (42%) does not give adherence counselling to children undergoing antiretroviral therapy. Of the patients who gave adherence counselling, a great proportion of them (71%) gave adherence counselling every day of the week as directed by the physician. According to the caregiver's report, the proportion of children who took 95% or more of prescribed doses (good adherence) in this study was 58% (95). Amongst those with poor adherence (42%) the commonest reasons given by the caregiver's, for missed doses were caregiver's forgetfulness (32%) and social stigma (22%) (Didn't want others to notice) (Table 3). In the general study population caregivers felt that availability of drugs (95%) was a factor that ensured good adherence to antiretroviral drugs while pill burden (37%) was appeared to encourage poor adherence. (Table 4)

Table 2

Proportion of caregivers who give adherence counselling to their children and frequency of counselling

Adherence counselling (n= 164)	**Frequency**	**Percentage**
Caregivers who gave counselling	95	58%
Caregivers who did not give counselling	69	42%
TOTAL	**164**	**100%**
Frequency of counselling (n= 164)		
Always (every day of the week as directed by the physician)	67	71%
Almost always (at least six days in a week)	26	27%
Sometimes (between three to six days in a week)	2	2%
Rarely between one to three days in a week	0	0%
TOTAL	**95**	**100%**

Table 3

Commonest reasons for missed doses by caregivers of children with poor adherence (<95%)

Reasons	Frequency	Percentage
Simply forgot	22	32%
Too many pills to take	10	14%
Wanted to avoid side effects	0	0%
Did not want others to notice	15	22%
Change in daily routine	0	0%
Drug was toxic	0	0%
Fell asleep	6	9%
Fell sick	0	0%
Fell depressed	7	10%
Timing problem	8	12%
Ran out of pills	0	0%
Felt good	0	0%
Away from home	1	1%
TOTAL	**69**	**100%**

Table 4

Response of caregivers on factors responsible for good or poor adherence in the study population

Questions	Frequency	Percentage
If your child complies to the drug regimen regularly which one of the reasons listed below is responsible for good adherence		
1. Availability of drugs	56	59%
2. Presence of motivation and family support	12	13%
3. Fear of death	27	28%
TOTAL	**95**	**100%**
If your child /ward don't comply to the drug regimen regularly which one of the reasons listed below is responsible for poor adherence?		
1. Forgetfulness	21	31%
2. Afraid of people seeing him/her	22	32%
3. Pill burden	26	37%
TOTAL	**69**	**100%**

Table 5 shows caregiver's response on perspective, believes and family support. Majority (60%) of the caregivers were somewhat satisfied while fifteen percent were very satisfied with the overall support from friends and family members. Chi-Square analysis showed gender and educational level were not significantly associated with adherence. (Pearson Chi-Square = 2.481 and p-value < 0 .05).

Table 5

Caregiver's response on perspectives, believes and family

Questions	Number	Percentage
In general, how satisfied are you with the overall support you get from your friends and family members?		
Very satisfied	25	15%
Somewhat dissatisfied	41	25%
Somewhat satisfied	98	60%
TOTAL	**164**	**100%**
To what extent do your friends or family members help you remember to give the medication to the child?		
Not at all	35	21%
A little	14	9%
Somewhat	54	33%
A lot	61	37%
TOTAL	**164**	**100%**

DISCUSSION

Caregiver issues related to adherence may be the most important factors in care and treatment of children living with HIV. This study used caregiver reports to assess children's adherence to antiretroviral therapy and factors which affect patient adherence to antiretroviral therapy. Because children are usually unable to access health care without the help of their caregivers, the caregiver commitment to the child's antiretroviral therapy is an important factor which has an effect on the child's adherence therapy (7, 9).

The proportion of children who had good adherence in this study was 58%. This is similar to reports from previous studies, (7, 9 - 11) but is higher than the rate in another study (12). Generally, adherence to antiretroviral agents varies between 37% and 38% (13). Good adherence in which the patient takes greater than 95% of prescribed doses is recommended for optimal virologic suppression and reduction of treatment failure rates (14). To encourage the caregivers and reduce missed doses, health care providers should strengthen and reinforce adherence counselling and proper usage of medication reminders. Adherence has been documented to be higher in patients whose biological parents are the caregivers (4). However, in this study, majority of the caregivers were mothers yet adherence was not optimal. Frequent change of caregivers as documented elsewhere could be responsible for lower adherence levels (15). In another study, institutionalized children have been shown to adhere better to treatment than children who live with their biological parents (16).

In this study the reasons why children missed their medication, include caregiver's forgetfulness, social stigma and pill burden. In a previous study, social stigma was a major issue in HIV treatment and care (17). Factors that are related to socio-cultural influences such as stigma and discrimination, disclosure of one's status as HIV-positive, concerns about confidentiality affect adherence to therapy. The support of family members

noted in this study was encouraging. It goes a long way to reduce caregiver concerns about stigmatization especially in the immediate family. A link between social or psychological support and increased adherence has been established and documented in a previous study (17,18). Age and education level have been identified as important predictors of compliance to ART therapy (4). As in a previous study (16), this study found that the level of education of caregivers did not affect adherence. There was no statistically significant association between the gender or educational level of caregivers and adherence to antiretroviral therapy by the children ($p>0.05$ in both cases). This finding is similar to many studies, which found that gender and educational attainment were not linked to antiretroviral adherence (19,20).

Based on the findings of the study, we recommend improvement of the adherence level by intensifying health education with campaigns that address caregiver perception, practice and caregiver related factors that improve adherence to antiretroviral therapy. It is important to promote and sustain family and community support for children living with HIV and their caregivers. Continuous monitoring of adherence and these caregiver factors will help improve adherence therapy. Adequate feedback to the caregivers on the importance of good antiretroviral therapy outcomes, especially the fact that good adherence prevents sub therapeutic plasma levels, selection for mutation and subsequent development of viral resistance will improve adherence.

CONCLUSION

The caregiver is important and plays a major role in ensuring adherence in children. The proportion of poor adherence (<95%) observed in this study was high. The role of the caregiver is very important to maintain good adherence levels and therefore treatment success. Efforts should be made to improve caretaker understanding of antiretroviral therapy and the importance of adherence. Health education, regular information and prompt feedback should be increased and targeted at caregivers. Involvement of the family in the care and management of the children will improve support.

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