



## Attitudes and practices of caregivers on adherence to Antiretroviral (ARV) Drugs among HIV–Infected children attending comprehensive care clinic in Kenyatta National Hospital

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### SUMMARY

**Background:** Ensuring high level of adherence to anti–retroviral medication (ARV) is a priority in treating people living with HIV and AIDS. Adherence in children cannot be fully studied if we do not recognize the involvement of primary caregivers who largely determine how well and often the ARV medication is taken.

**Objective:** To determine attitude and practices of the primary caregivers on adherence of ARV in HIV+ve children.

**Methods:** A cross–sectional study involving primary caregivers of HIV +ve children. Interviewer administered questionnaires were used to collect data from 126 primary caregivers. The data was complemented with key informant in–depth interviews with the health workers at the Comprehensive Care Centre (CCC) and two focus group discussions (FGD) of the primary caregivers.

**Setting:** Kenyatta National Hospital comprehensive care centre for HIV/AIDS.

**Results:** Adherence of 97.2 % to antiretroviral drugs was reported. The primary caregivers reported various methods they used to remind them when to give the medication e.g. clock alarms. 99.2% of the caregivers were aware of the ARV side effects. Out of the 126 caregivers interviewed, 96% of them recommended that caregivers of HIV+ve children should know their HIV Status.

**Conclusion:** This study has revealed that practices and attitude of the caregivers of HIV +ve primary caregivers of HIV+ve children influence the ARV adherence levels. Primary care givers are susceptible to or do suffer stress and HIV/AIDS Comprehensive Care Centres should consider establishment of psychosocial support groups. More studies and follow up especially in the rural settings for comparison with urban areas are recommended.

**Keywords:** antiretroviral treatment, children, primary caregivers, adherence,

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## Introduction

Treatment adherences have been closely correlated with viral suppression while non-adherence has a contributed to progression to AIDS [1]. Adherence is perceived as a significant barrier to the delivery of ARV therapy in sub-Saharan Africa [2]

Lack of adherence to highly active anti-retroviral therapy (HAART) is considered to be one of the key challenges to AIDS worldwide. Estimates of average rates of non-adherence with ARV therapy range from 50% to 70% in many different social cultural settings, and the risks associated with non-adherence are extensive at both individual and societal level [3]

The factors that affect ARV adherence in children include: shortage of appropriate paediatric formulations, the unpalatability of some paediatric antiretroviral drugs and the dependence on a caregiver for delivery of the medication. In studies conducted in South Africa and Ethiopia focusing on adherence in children, caregivers came out as one of the key factors that will determine adherence to ARV in children. The studies further demonstrated that the caregivers of African children have the potential to achieve adherence comparable to the wealthier countries if given the required support [4], [5].

**Millennium Development Goal 6, which focuses on combating HIV/AIDS, provides that, by 2015, the world will have halted and begun to reverse the global HIV epidemic by making the HIV response one of the overriding international priorities for the 21st century (UNAIDS, 2008).**

Sub-Saharan Africa remains the most heavily affected region in global HIV epidemic with 23.5 million people living with HIV residing in sub-Saharan Africa which represents 69% of global HIV burden [6]. An estimated 3.4 million children were living with HIV at the end of 2011, 91% of them in sub-Saharan Africa [6]. HIV is the underlying reason for more than one third of all deaths among children under the age of five [7]. New infections in children dropped by 43% from 2003 to 2011 [8]. This decline mainly reflects the drop in new infections in children as well as increased access to antiretroviral treatment. Research has shown that non-adherence to prescribed regimens is common, whether the disease is acute, chronic or whether the patient population is adult or pediatric [9]. The major factor determining the success of ARV is sustainable and optimum adherence to therapy [10].

As of December 2011, there were 1.6 million people living with HIV/AIDS in Kenya. The adult HIV prevalence in Kenya as of 2010 was 6.2% with women representing 58% of the prevalence among adults [11]. In 2011, 220,000 children between the age of 0-14 years in Kenya were estimated to be living with HIV/AIDS and there were an estimated 1.1 million AIDS orphans between the age of 0-17 years [8]. The access to ARV in Kenya has improved over time with 83.1% of adults eligible for ARV receiving the medication. The access to ARV for children has been challenging in Kenya with only 31.1% of those eligible for ARV receiving it [11]. Adherence to ARV has been found to predict HIV clinical outcome [12]. Pediatric adherence to ARV is not well studied in resource-limited settings. Unlike adults, children are relatively more dependent on others for their well being and care.



It is therefore important to understand the perspective of the caregivers for the HIV-infected children and its effect on adherence to ARV.

## **Materials and Methods**

**Study Design:** A cross-sectional descriptive study involving both qualitative and quantitative research methods was conducted among primary caregiver of HIV +Ve children attending the HIV/AIDS Comprehensive care Centre (CCC) at Kenyatta National Hospital.

**Sampling:** The systematic sampling method was used for the primary caregivers attending the Kenyatta hospital CCC. In 2010 Kenyatta Hospital had approximately 700 children enrolled for ARV with an average attendance of 15 – 20 patients per day. The Sample size for the study was 126. Sample size determination was based on the facts according to the UNAIDS report 2008 there were 2 million people in Kenya living with HIV / AIDS, of these 180,000 were children which is 9% of the total population living with HIV/AIDS. The proportions to be used in the sample size calculations were 9% (UNAIDS WHO 2008).

**Inclusion criteria:** The primary caregivers must have been fully involved in the day to day care of the HIV-infected children between the ages of 2–12 years  
The primary caregiver must have spent at least the 6 months prior to the interview date caring for the child and attending that particular CCC. Those participants who gave written consent were the only ones allowed to participate in the study.

**Exclusion criteria:** Primary caregivers who did not consent to participate in the study or those who withdrew the consent during the interview. Pre-testing

of the questionnaire was done at Kenyatta National Hospital. The questionnaires were analyzed and any corrections or adjustments were made to the data collection tool. Those who participated in the pre-testing were not being eligible for the actual research. Their card numbers were recorded to ensure that they were skipped during the actual research.

**Ethical considerations:** Clearance was obtained from the Scientific Steering Committee and the National Ethical Review Committee. Informed consent from the study subjects was obtained. Study subjects confidentiality was maintained by not including their names on the questionnaire.

Those who declined to participate had their wish respected and this did not affect their services in the clinic. There was no direct benefit to the study participants but the information collected was analyzed and the findings will be shared with donors and the ministry of health for the purpose of improving policies and activities that will enhance the ARV therapy in children. The study participants were not exposed to any invasive clinical procedures.

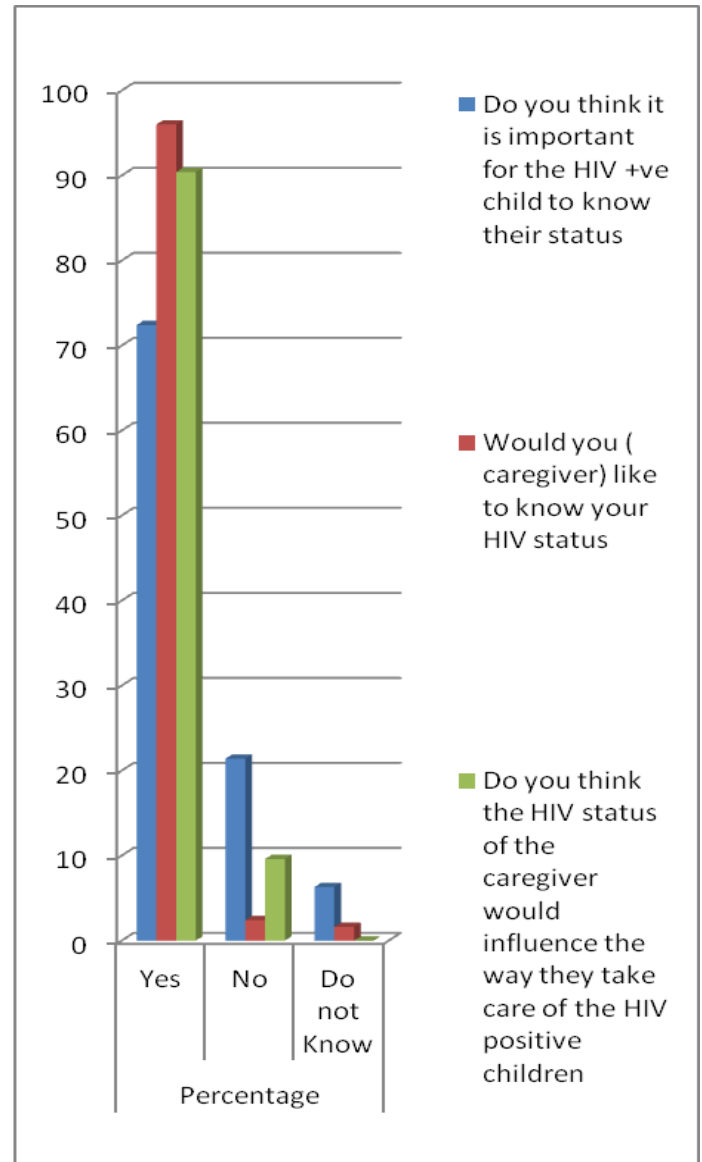
## **Results**

The Mean age of the respondents was 38 years and 5 months (age ranging from 18 – 65 years). The majority of the caregivers were between age 20 and 55 years which accounted for 96.9%. Out of the 126 respondents, 84.1% were women and 15.9% men. Of the caregivers interviewed, 99.2% said that they gave children the ARV medications at the same time every day. The caregiver reported various methods they used to remind them when to give the medication e.g. Wall clocks, alarms mobile phone and radios. The



knowledge level on adverse effects of the ARV medications was high (98%) with the majority of the caregivers (99.2%) aware of the ARV side effects. 97.6% of the caregivers interviewed were convinced that the ARV is effective and that the ARVs had helped to improve the quality of life of the children and also prolong their life span. Despite the various challenges in administration of the ARV the adherence levels remained high (97.2%). Most respondents (72.2%) felt that the children they are taking care of have a right to know their HIV status, 21.4% felt that they should not be told and the remainder (6.3%) did not know what to do. Majority of the caregivers (96%) thought it was important for caregivers to know their own HIV status.

**Figure 1: Attitude towards knowledge on the HIV status of the caregiver and the child being cared for**



**Table 1: Number of times caregivers missed to give ARV**

Number of caregivers who have not missed doses	Proportion ( out of 126 caregivers interviewed)
In the last 72 hours	95.2%
Last week	4%
Last two weeks	0.8%

**Table 2: ARV effective, caregivers' perspective**

Opinion on effectiveness of ARV	Frequency	Percentage
They are effective	123	97.6%
They are not effective	0	0%
I do know	3	2.4%

**Discussion:**

In this study the attitude and practices of caregivers were seen to greatly influence the adherence levels to ARV in children. The Study found that adherence to ARV was high i.e. 97.2 % as reported by the interviewed care givers and confirmed during the focus



group discussion. Additionally, in a study conducted in Uganda supported the fact that the caregivers play major role in establishing a medication taking routine which contributes to adherence to ARV [13].

Over 65% of the caregivers had education level above secondary and had some form of employment (formal and self-employed). This could be attributed to the fact that this study was done in an urban setting. Majority of the respondents were very knowledgeable on the times the ARV medications were to be taken and also the right combinations. 99.2% of the caregivers said that they gave children the ARV medications at the same time every day. The caregiver reported various methods they used to remind them when to give the medication e.g. Wall clocks, alarms mobile phone and radios. A study in Cape Town South Africa found that most (74.7%) caregivers used at least one method to assist with remembering and giving medication [4]. The most commonly used aids were activities of daily living reminders (40%) and treatment partners (26%). In a study carried out in USA on barriers to ARV adherence in HIV infected children and youth, forgetting to take medication was most commonly reported barrier to ARV adherence (41% for children and 33% for caregivers) [14]. Therefore the use of various methods/equipments to ensure that ARV medication is taken the right time is very important.

The key informants reported that in some instances they had challenges with multiple caregivers which were experienced mainly with children in orphanage homes. This situation was also reported in a study in Kwa-Zulu Natal that there is confusion between multiple caregivers when it comes to ARV drug adherence [15]

The knowledge level on adverse effects of the ARV medications was high (98%) on the interviewed primary caregivers. 99.2% of the caregivers said that in the event of ARV adverse effects, they would take the child to hospital for review. The majority of caregivers in this study (72.2%) felt that the children they were taking care of had a right to know their HIV status. They felt that once the child is old enough to question or comprehend their HIV status then they should be counseled and taught gradually about their condition, to understand the issue of adherence and the importance of medication in their lives. A study conducted in Zambia found that there was improved adherence with HIV status disclosure to the child, full understanding of HIV medication is important to these children [16]. In this study at Kenyatta National Hospital, over 96% of the respondents recommended that caregivers should know their HIV status. This was also supported by the key informants who said that the caregivers need to know their HIV status so that they can take appropriate steps as they care for the HIV +ve children. The key informants emphasized that when the care givers know their status it reduces stigma to child. In a study conducted in Cape Town South Africa it was recognized that stigma surrounding HIV can also lead to adherence problems if parents and caregivers are unwilling to make it publicly known that the child in their care is HIV-positive [4]. In another Study conducted in Uganda it was found that children whose caregivers had possible depression and were ashamed of their child's HIV status had poor adherence levels [13].

In this study majority of the caregivers believed that HIV positive caregivers are better suited to provide better care to HIV positive children because they are going



through the same thing or experience. Similar findings were reported in a study conducted in Uganda that caregivers taking ARV themselves may have established effective means for adherence, which can be passed on to the children[13]. Another study at Sinikithemba HIV/AIDS Clinic, McCord Hospital, Durban, South Africa showed that more than half of the HIV +ve children in the Sinikithemba cohort are cared for by at least one HIV-positive caregiver, these caregivers showed a protective effect against mortality in HIV +ve when compared with caregivers who were untested or HIV negative[15].

In order for the caregivers to succeed in continually supporting children on adhering to their medications, this study found that the primary caregivers needed social-economic support to help them improve their quality of life. Similar findings were also seen in a study of the Sinikithemba cohort in Durban South Africa [15] where adherence issues could put an enormous strain on the daily lives of parents and caregivers who are usually responsible for administering treatment. Additionally this study found that even though the cost of providing ARV drugs is theoretically free (covered by government and donor sources), potential clients still have to find money to pay for the high costs of transport, and drugs to treat opportunistic infections, in addition to the opportunity costs of time spent seeking care instead of earning money to feed and support other household members. Majority of the caregivers interviewed were convinced that the ARV is effective and that the ARVs had helped to improve the quality of life of the children and also prolong their life span. 96% the caregivers stated that it was important know their HIV status and 90.4% agreed that the HIV status of the

caregiver influences the way they care for the HIV+ve children.

The caregivers were also aware of the appropriate actions to take when adverse drug reaction is suspected. Despite the various challenges in administration of the ARV the adherence levels remained high (97.2%). In case of adverse effects like vomiting, primary caregivers reported that they gave a repeat doze after 30 minutes. Also the challenge of cold storage of some forms of ARV was addressed by keeping the ARV medications that required cold storage in water. The caregivers were also aware of the appropriate actions to take when adverse drug reaction is suspected.

In this study, conducted at Kenyatta National Hospital, the caregivers advocated for more supportive counseling, spiritual and social support to help them cope with and manage the challenges that come with caring for a HIV+ve child. This support should include more knowledge on ARV, adherence, nutrition and any other issues dealing with ARV care for HIV positive children. Comprehensive treatment literacy for the caregivers is very important and impacts on adherence to ARV Key informants in this study (KNH CCC) noted that little has been done on developing educational materials like pamphlets, educational aid materials, and take-home booklets related to ARV in children.

The importance of joining or belonging to a support group both in the hospital and outside the hospital setting was affirmed by an overwhelming majority (92.9%) of the primary caregivers for psychosocial support. This was also supported by the key informants and focus group discussion informants who agreed that



support groups are avenues to release stress and forums to talk about experiences and challenges. In these support groups the members can also benefit from others by getting knowledge on how to undertake income generating activities. In study conducted in South Africa [17] community-based adherence support was seen be an effective way to improve patient retention amongst children receiving ART in low-income setting. Support groups at Kenyatta National Hospital are short term and are set up for the purpose of research and disbanded once the particular research is over.

Key limitation to this study was the fact that this was done in the urban area (Nairobi city) and there is no comparison data for rural setting. Health workers supported data collection and this may have skewed the data to the high levels of adherence. Nevertheless, adherence levels to ART in Sub-Saharan Africa have been found to be present adequate median to ART for viral suppression [13].

## Conclusion

This study has revealed that practices and attitude of the caregivers of HIV +ve primary caregivers of HIV+ve children influence the ARV adherence levels. The appreciation by the caregivers that ARV medication prolongs life and improved quality of life of the children greatly contributed to the high level of adherence. The caregivers ensure that they put in place measures to remind them when to administer medication is very important to ensuring adherence. Majority of the caregivers were aware of the ARV side effects and took the children to hospital when any of those side effects were observed. The access to ARV has greatly

improved due to the attention by the Ministry of Health and Non-governmental organizations. Support for the caregivers of HIV+ve children has not been prioritized and therefore there is need to focus on caregivers' in order to achieve high adherence levels.

## About the Authors

Mbiyu JW is a student pursuing Masters of Science in Public Health at Jomo Kenyatta University of Science and technology, Kenya. The concept of this study was developed by Josephine. Dr. Kikui and Dr. Amukoye are Josephine's supervisors who have worked with her in the proposal writing, data collection, analysis and the finally the thesis.

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