

**Assessing Knowledge On The Importance Of Disclosure To Adherence In Caregivers Of HIV Infected Children
On Highly Active Antiretro-Viral Therapy (HAART)**

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Keyword

HAART – Highly Active
Anti-retro-Viral Therapy.

HIV- Human immune-
virus.

BHM – Baptist hospital
Mutengene

HAMU – HIV/AIDS
management unit

THD – Tiko health district

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Abstract

Disclosure generally is telling an individual about his/her HIV status and it could involve indirectly telling the caregivers status as well. Adherence and disclosure are key ingredients in pediatric HIV/AIDS care and management. Disclosure of HIV status to children is essential for disease management but is not well characterized in resource-limited settings. This study aimed at assessing the knowledge on the importance of disclosure to adherence in caregivers of HIV infected children. A cross-sectional study was done, with HIV-infected children aged six to fourteen years randomly selected. Semi-structured questionnaires were administered to 37 caregivers of HIV infected children; evaluating their adherence to highly active antiretroviral therapy at these levels: pre, during and post-disclosure; how disclosure affects adherence, the barriers to disclosure, benefits of disclosure to adherence and other factors which could affect adherence to antiretroviral. Data analysis indicated that disclosure had great impact on HIV-infected children's adherence to anti retroviral therapy. Thus, knowledge on adherence and disclosure itself is one of the key factors in pediatric HIV/AIDS management and care and if looked into and implemented in our nation Cameroon will greatly improve the treatment outcome of children living with HIV and their families. Further studies are recommended on a larger sample size to comprehend and establish a standard in our nation Cameroon.

1. INTRODUCTION

Rachel C.V., Michael L.S., Ann M., Matthew T., Samuel O. A., Constance T., Winstone M. (2006) highlights that informing children of their own HIV status is an important aspect of long-term disease management, yet there is little evidence of how and when this type of disclosure takes place in resource-limited settings, its impact and how it affects adherence.

WHO (2010) states that, viral suppression is a key aspect in the survival of HIV infected children and this can only be achieved with good adherence. Disclosure of HIV status is an important part of the process of living with HIV, and is crucial to continuum of HIV care. Disclosure decisions are particularly complex when children are involved because of concern about children's emotional and ability to understand and cope with the nature of the illness, stigma, family relations and concerns about social support. Parents and caregivers are often uncertain how to counsel about disclosure, and opportunities to provide HIV testing and care, and to help families start the discussion about living with HIV are often missed.

WHO has developed this guidance for healthcare workers on how to support children twelve years of age and younger, and their caregivers, on disclosure of HIV status. The guidance is intended as part of a comprehensive approach to the physical, emotional, cognitive and social well-being of a developing child

following the child's own diagnosis of HIV or that of a parent of close caregiver.

Chenysa, S.A.(2006) highlights that Strict adherence to antiretroviral therapy (ART) is key to sustained HIV suppression, reduced risk of drug resistance, improved overall health, quality of life, and survival, as well as decreased risk of HIV transmission. Conversely, poor adherence is the major cause of therapeutic failure. Achieving adherence to ART is a critical determinant of long-term outcome in HIV infected patients. For many chronic diseases, such as diabetes or hypertension, drug regimens remain effective even after treatment is resumed following a period of interruption. In the case of HIV infection, however, loss of virologic control as a consequence of non-adherence to ART may lead to emergence of drug resistance and loss of future treatment options.

Many patients initiating ART or already on therapy are able to maintain consistent levels of adherence with resultant viral suppression, CD4+ T-lymphocyte (CD4) count recovery, and improved clinical outcomes. Others, however, have poor adherence from the outset of ART and/or experience periodic lapses in adherence over the lifelong course of treatment. Identifying those with adherence-related challenges that require attention and implementing appropriate strategies to enhance adherence are essential roles for all members of the treatment team.

1.1 How disclosure affects adherence to HAART

According to Bijaako-kajura (2006), forty-two HIV –infected children and their primary caregivers were assessed and concluded that full disclosure is related to good adherence. Furthermore, many studies to date have utilized cross-sectional designs and cannot adequately assess the impact of disclosure on clinical or psychosocial characteristics. Other studies suggest that HIV-infected children who know their status may be better able to seek social support, have improved coping skills and practice safer sexual practices to prevent secondary transmission but other studies describe negative effects.

Disclosure of chronic illness to a child is a controversial and emotional issue that is particularly difficult for HIV given the associated stigma and the potential for guilt in the case of vertical transmission (Wiener, 2007). Pediatric HIV clinicians generally promote disclosure as a positive influence on adherence; however, the evidence from the literature is mixed. Because disclosure typically does not occur until late childhood or adolescence, the effects of disclosure may be difficult to distinguish from those of age.

In an Italian study of children over eight years, disclosure was associated with worse adherence (Giacomet, 2003). Studies in the US and Ethiopia found similar results when controlling for potential covariates. No effect, however, was seen for age or disclosure on adherence in US and Ugandan studies. Another US study similarly found no effect for disclosure, although age was associated with

increased non-adherence prior to multivariate analysis. Finally, qualitative studies in Uganda and Belgium found disclosure to be generally associated with improved adherence.

Disclosure is crucial to long-term disease management, yet how and when caregivers and healthcare professionals in resource-limited settings disclose to children are not well-characterized and the number of children that know their status is generally thought to be low. Moreover, many of these settings currently lack standardized, culturally appropriate guidelines and resources for undertaking disclosure. Children infected with HIV need love support, reassurance and acceptance, as well as a sense of belonging, to thrive and cope with life’s difficulties. These children are generally vulnerable to emotional distress which could come from the illness itself, loss of loved one, dysfunctional family situations, low self-esteem, and feelings of guilt and despair.

In Cameroon though it has become one of the packages in pediatric care, it still limited as many health care providers either inadequate knowledge and skills required or lack training and resources needed to carry on these activities fully.

1. METHODOLOGY

2.1 Study Area

BHM is the lone HAMU in Mutengene with about 3500 adults and about 215 children between the ages 0-19yrs of age. It is one of the health facilities in the Tiko health district found in Fako Division in the

South West Region. It shares boundaries with the three other health district in Fako Division namely Buea, Limbe and Muyuka health districts and also with Littoral region. According to statistics gotten from THD, the total population of this Health District is about 143,837 and it covers a surface area of 484 kilo meters square. This health district has 3 HAMU'S with 2 in TIKO AND 1 in Mutengene

2.2 Research Design

A cross-sectional study design was done using a random sample of care givers of HIV infected children attending pediatric clinic at BHM between the ages six to fourteen years

2.3 Target Population

The targeted population involved caregivers of HIV infected children on HAART at the HAMU of Baptist hospital Mutengene. This clinic was selected because it is one the largest clinic with the highest number of HIV infected children currently on treatment.

2.4 Sampling Size and Sampling Procedure

The sample size was caregivers of HIV infected children between the ages six to fourteen who have been on HAART for at least six months and who attended clinic during the time of research and consented to take part in the research. Participants were randomly selected from all the caregivers whose children are currently on HAART at BHM.

2.5 Data Collection Instruments

Semi-structured questionnaires with both open and closed ended questions were used to collect primary data. The questionnaire was divided into four sections:

Section A: Socio-Demographic data

Section B: Assessing caregivers knowledge on disclosure

Section C: Indefinable reasons for non-disclosure

Section D: Effects of disclosure on adherence

2.6 Inclusion criteria

The study included all caregivers of HIV infected children attending pediatric clinic at BHM who had been on HAART for at least 6months and who were willing to participate in the study and were available at the time of data collection.

2.7 Exclusion criteria

This study excluded caregivers of HIV- infected children between the ages 6-14 attending the Pediatric clinic at BHM who had not been on treatment for at least six months and also those who refused to take part in the study.

2.8 Data Analysis

Data was analyzed using Microsoft excel and exported to the Statistical Package for Social Sciences (SPSS) version 21. Frequency distribution tables, pie charts, and bar chart were used to present these data.

3 RESULTS AND FINDINGS

3.1 SECTION A: DEMOGRAPHIC INFORMATION OF CAREGIVER

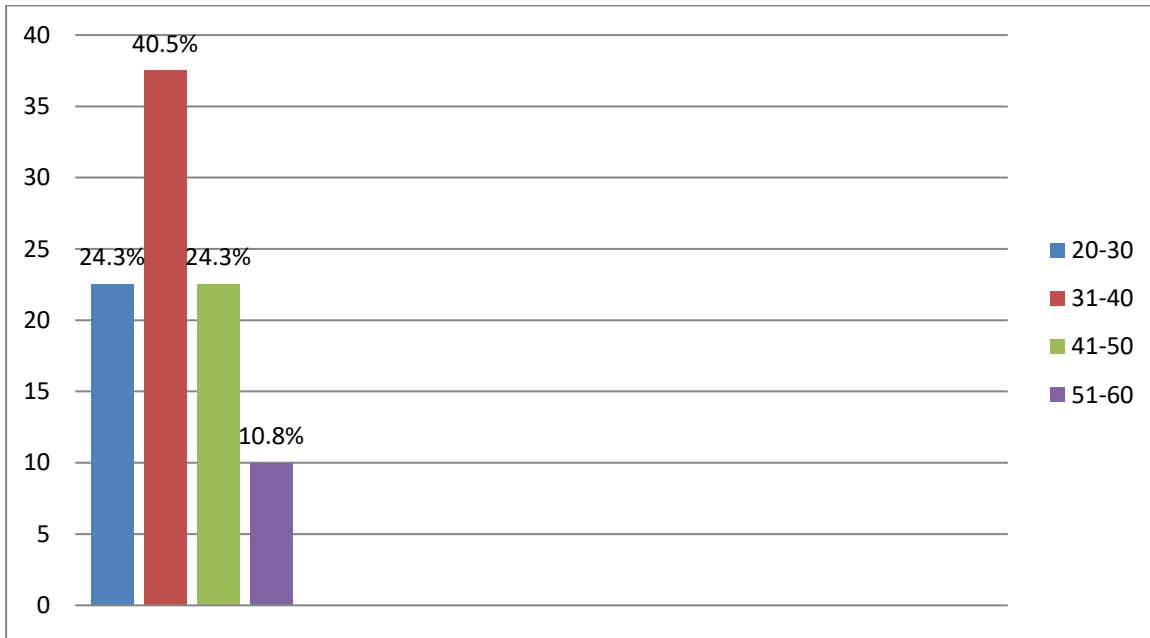


Figure 1: Bar chart showing the age distribution of the caregivers

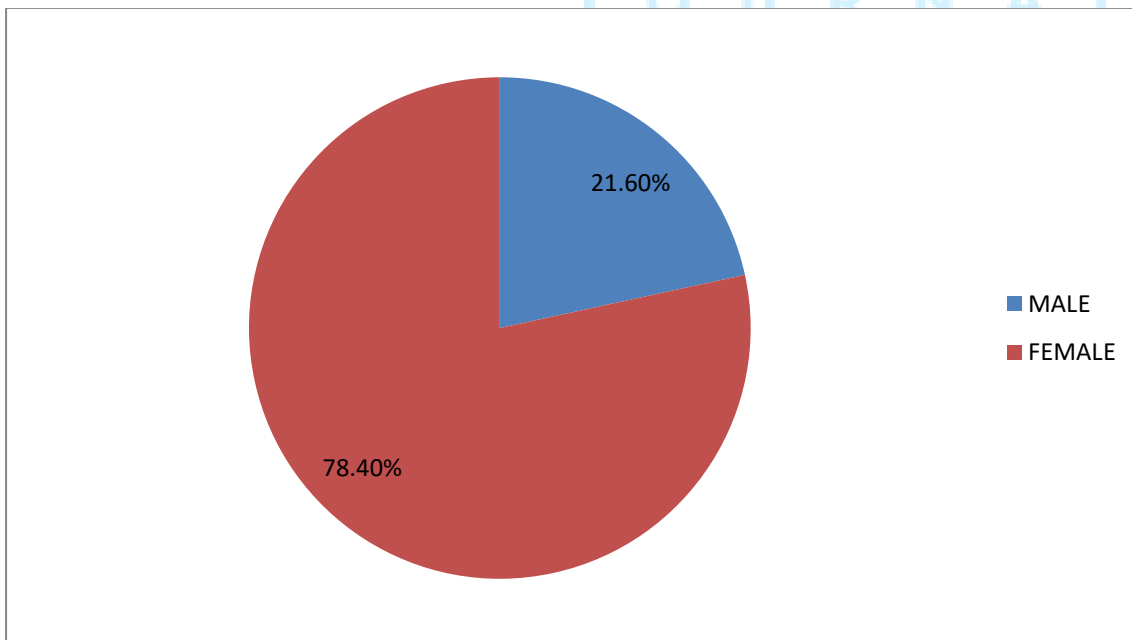


Figure 2: Pie chart showing caregiver's gender

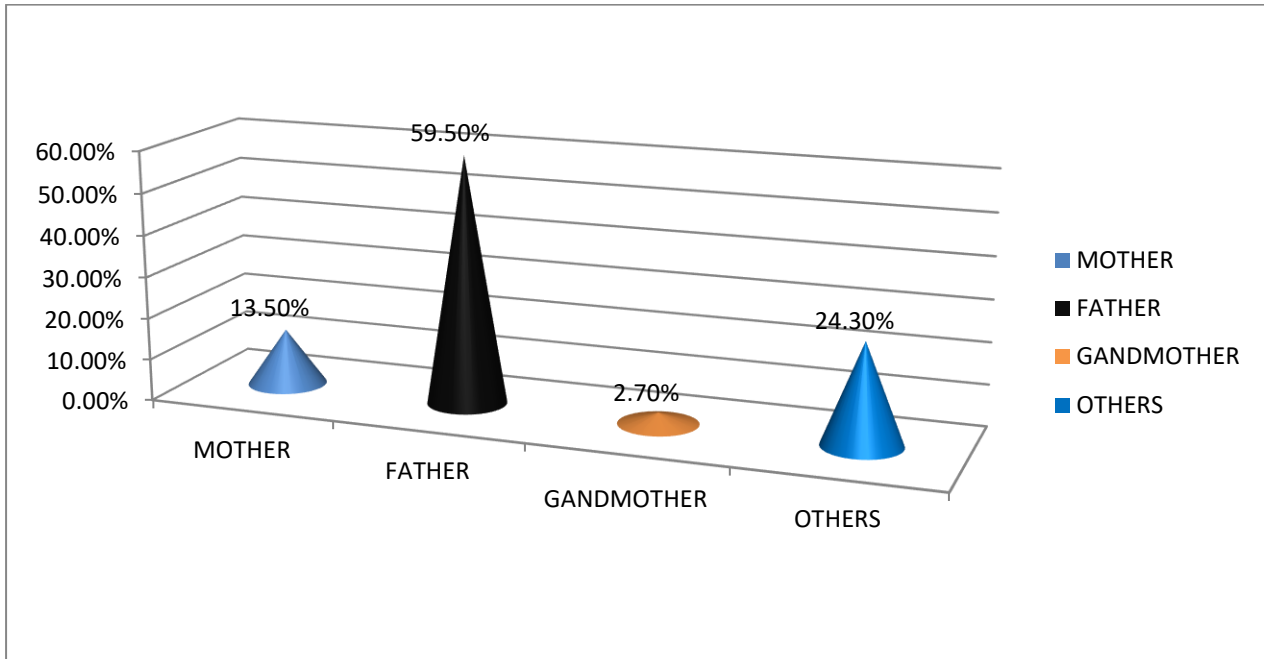


Figure 3: Graph showing the relationship of caregiver to child

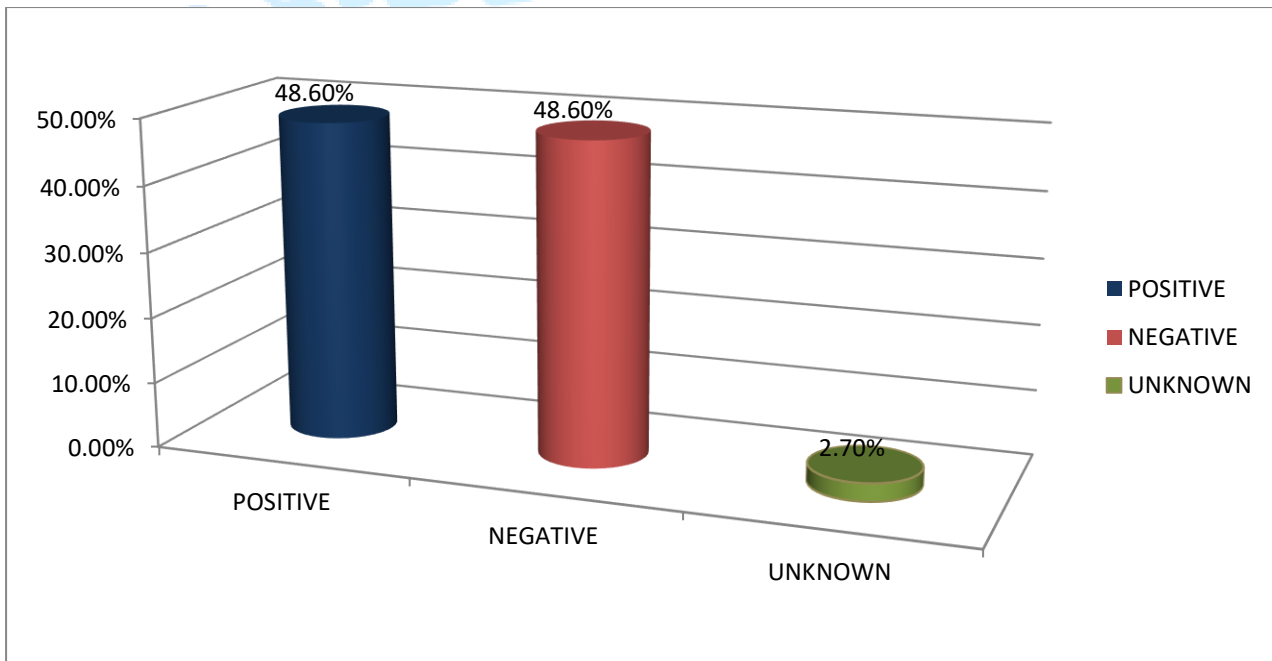


Figure 4: Bar Chart showing caregiver's HIV status

3.2 CHILD'S DEMOGRAPHIC INFORMATION

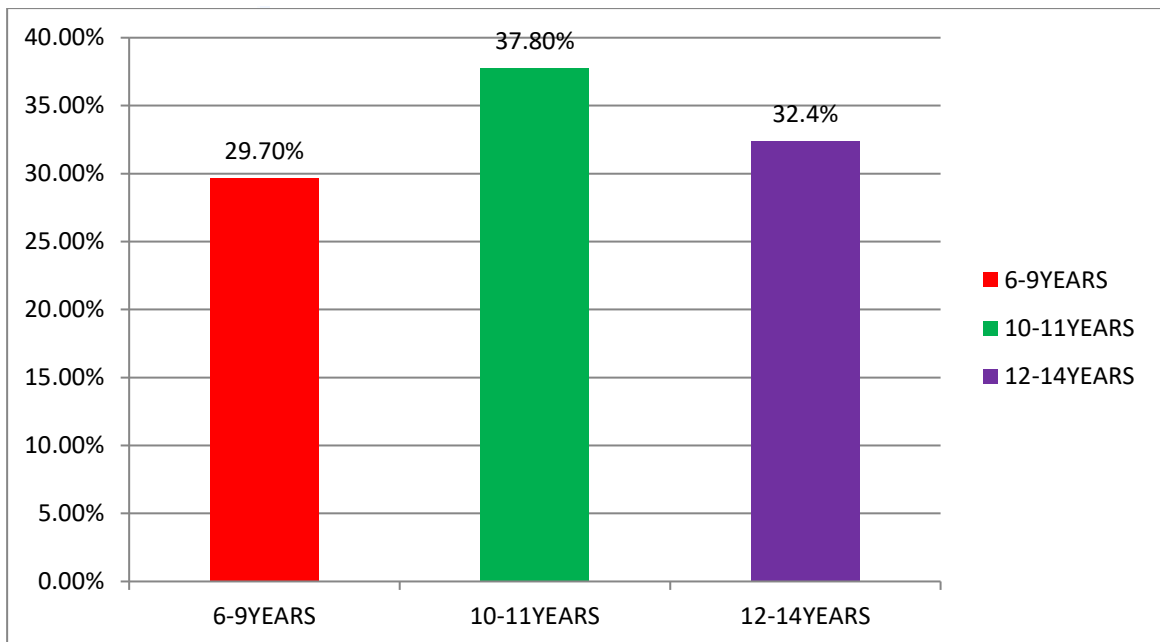


Figure 5: Graph showing the children's age distribution.

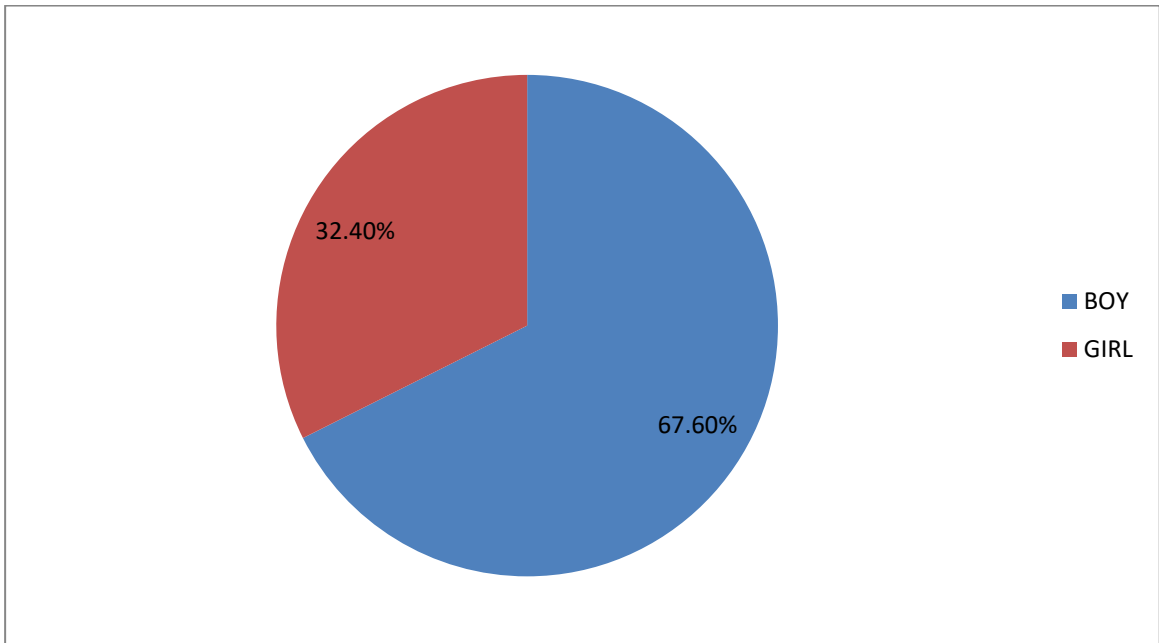


Figure 6: Pie chart showing child's sex

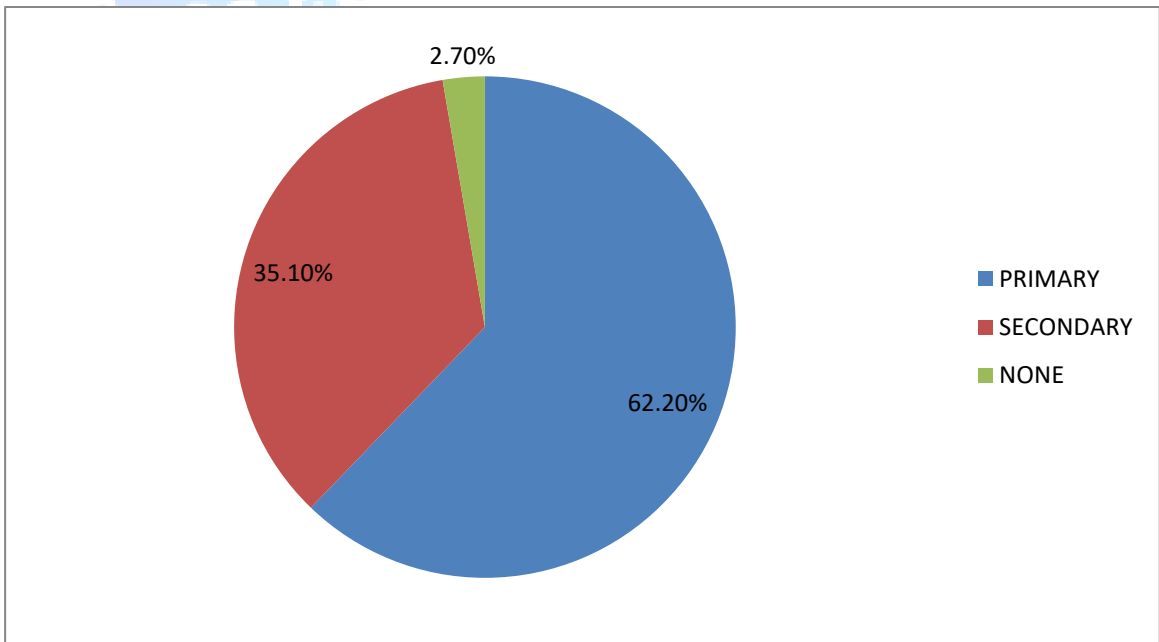


Figure 7: Pie chart showing the child's level of education

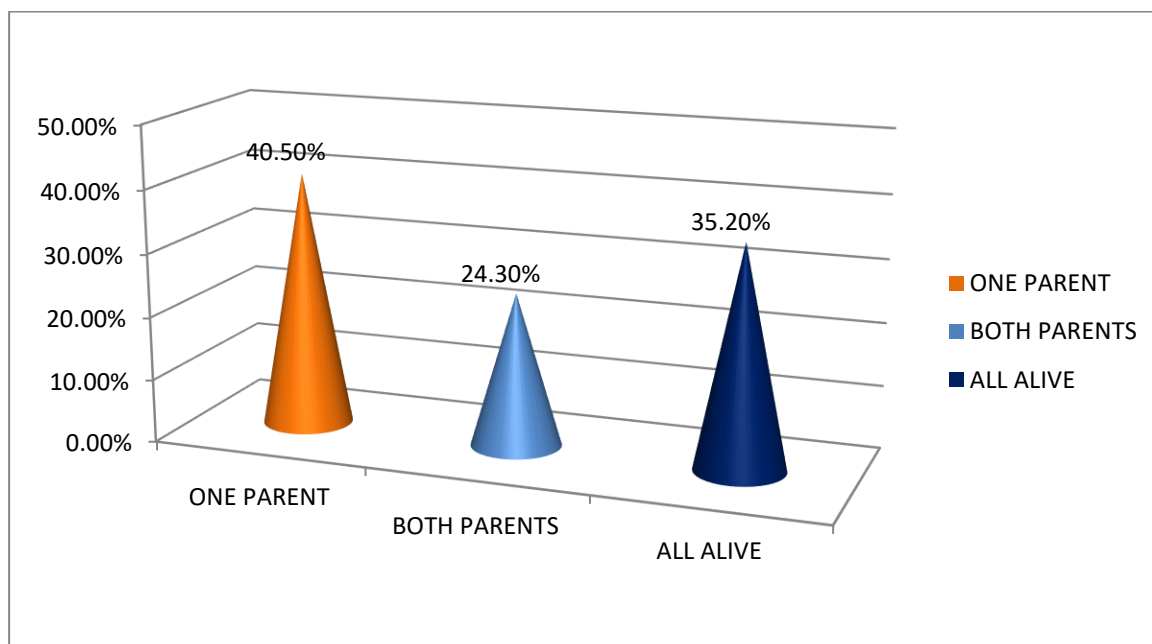


Figure 8: Graph showing child's family dynamics



3.3 SECTION B: Knowledge on disclosure

Table 1: Assessing caregivers' knowledge on disclosure

QUESTION 1	RESPONSES			
	YES	NO		
Disclosure is telling a child about His/her HIV status	(34)91.89%	(3)8.11%		
QUESTION 2	RESPONSES			
	6-9 YEA RS	10-13YEARS	>14 YEARS	DON'T KNOW

At what age do you think it is appropriate to tell	(2) 5.41%	(16) 43.24%	(13) 35.14%	(6) 16.22%
QUESTION 3	RESPONSES			
	NOTHING	PARTIAL	COMPLETE	
What level has your child been disclosed	(5) 13.51%	(15) 40.54%	(17) 45.95%	
QUESTION 4	RESPONSES			
	YES		NO	
Do you know what to tell a child during disclosure	(30)81.08%		(7) 18.92%	

Table 2: Frequency distribution showing indefinable reasons for non-disclosure

SECTION C: Reasons for non disclosure

QUESTION 6	RESPONSES					
	Inadequate Knowledge	Lack of skill	Fear of the unknown	Fear of stigma	Fear of negative emotion	Potential guilt
what are/ were some of the barriers you had to disclosure:	(1)2.70 %	(1) 2.70%	(11) 29.73%	(19) 51.35%	(3) 8.11%	(2) 5.41%

QUESTION 8	RESPONSES				
	Depression	Rebellion	Negative emotional consequences	Child being too young to understand	Stigma and discrimination
What are some of the fears of disclosure	(8) 21.62%	(4) 10.81%	(13) 35.14%	(8) 21.62%	(4) 10.81%

3.4 SECTION D: Effects of disclosure

Table 3: Table showing the effects of disclosure

QUESTION 5	RESPONSES					
	Rebellion	Increase bonding	Acceptance	Denial	Good adherence	Increased self esteem
what is(if currently) or what was(if completely disclosed) the Childs reaction	(4) 10.81%	(4) 10.81%	(6) 16.22%	(1)2.70%	(19)51.35%	(3) 8.11%

to the diagnosis:						
QUESTION 12	RESPONSES					
	Positively	Negatively				
How has disclosure affected you Childs adherence to ARVs	(30) 81.08%	(7) 18.92%				

Table 4: some visible benefits of disclosure

QUESTION 9	RESPONSES			
	Increased self esteem	Healthy communication	Good adherence	Good compliance
what are the benefits of disclosure you have experienced	(10) 27.03%	(12) 32.43%	(9) 24.32%	(6) 16.22%

Table 5: Table showing other factors that could affect adherence

QUESTION 11	RESPONSES			
	Ill health	Stressful life events	Poverty	Schooling
Apart from non- disclosure what are other factors that hinders adherence in your child	(10) 27.03%	(7) 18.92%	(14) 37.84%	(6) 16.22%

3.5 Discussion

In this study, 32.4% of the children were between the ages of 12-14, 37.80% between the ages 10-11 and 29.70% between the ages 6-9. Approximately 48.60% of these children were diagnosed between the ages 6-9.

During analysis we I saw that 34(89%) of the caregivers had and understanding of the term disclosure, while 3(8.11%) either did not understand or knew nothing about the disclosure process. Also 43.24% of them taught that the best age to disclose between 10-13years, this could be attributed to the fact that most parents believe that at this age the children are more emotionally and cognitively mature. This is in line with AM Butler et al (2009) who in their study ascertain that the age of disclosure has

gradually declined with time from 16years in 1985, to approximately 5 years in 1998 and that the median for full disclosure is 11 in 365 HIV – infected children. Similarly some caregivers preferred disclosing to their children when they are above 14years as most think that they can better cope with post disclosure problems at this stage. This could be the reason why in this study only 17 out of the 37 children were fully disclosed. Giacomet, (2003) in this same light concluded that disclosure typically does not occur until late childhood or adolescence, the effects of disclosure could be difficult to distinguish from those of age.

More so, 30 of the caregivers accepted that they actually knew what to tell during disclosure. This might be attributed to the fact that some staff have been trained in the psychosocial care of children living

with HIV and they started impacting the knowledge to these caregivers.

In trying to answer the question what are barriers to disclosure, we saw that 51.35% feared stigma, 29.73% feared the unknown, while 8.11% feared negative emotional reactions while on the other hand only 2.70% lacked skill and 2.70% had inadequate knowledge to carry on disclosure. This is to say that, fear of stigma and potential for guilt can be correlated to the fact that 48.60% of the caregivers are HIV positive themselves and in disclosing to the child they might be indirectly disclosing their own status and cannot say with certainty how this information will be safe in the children's mouths. In addition, potential of guilt could be because the caregivers feared the children might blame them for being negligent and allowing them go through this situation. Those who feared the unknown and/or feared negative emotional reactions could be because they could not foretell how these children will receive the diagnosis or might have witness or heard some negative reactions of other children to whom the caregivers had disclosed.

Furthermore, some caregivers feared that some children my experience depression (21.62%), rebellion (10.81%) and that disclosure might have negative emotional consequences (35.14%) on the child. This is in line with the Disclosure process for children and adolescents living with HIV: Practical Guide (2009), which highlights that most caregivers tend to blame themselves or feel guilty about their child's status. It is

even more difficult if the caregiver is HIV- Positive themselves as they fear stigma and discrimination

More so, during the study we identified some reactions of children who were in the process of disclosure (currently) or fully disclose (past). 16.22% demonstrated acceptance of their status, 51.35% began adhering well to the ARVs, and 8.11% of them had good self esteem. Probable reasons for this reaction could be, because the parents or caregivers themselves either were infected or underwent the sessions on how to disclose. That notwithstanding, a fewer percentage of the children rebelled (10.81) and 2.70% suffered from denial.

Even though there has been some hindrances in disclosure, caregivers put forth that disclosure has generally impacted the health and wellbeing of the children to an extend; 27.03% of the children developed increased self esteem, 32.43% became more and more closer to their caregivers while 40.54% developed good adherence and compliance to their meds.

51.35% of the caregivers confirmed that disclosing to their children either partially or completely improved their children's adherence to ART and of this number) 81.08% those fully disclosed demonstrated at least 95% adherence rate. This could be due to the fact that these children better understand their disease condition and opt for positive living. This goes in line with Bijaako-kajura (2006), who measured the adherence outcomes in

forty-two HIV –infected children and their primary caregivers. He ascertained that full disclosure was related to good adherence as majority of the HIV infected occasionally missed doses or did not miss at all.

Though knowledge on disclosure and disclosure has a positive effect on adherence and wellbeing of the HIV infected children, other factors were identified which could hinder adherence in one way or the other namely: - ill health (27.03%), stressful life events (18.92%), and poverty (37.84%). Similarly, Chenysa (2006) highlighted that adherence to ART could be influenced by a number of factors, including the patient’s social situation, clinical condition prescribed regimen and the patient-provider relationship.

3.6

Conclusion

It has been proven that children who are disclosed either partially or completely tend to live healthier and more fulfilling lives as they adhere well to treatment. Even though this trend exist, from the study it has been proven that disclosure be it partially or fully does not necessary imply good adherence as shown that only 24.32% practice good adherence following disclosure. Moreso, 18.92% of the caregivers to which their children were being disclosed either partially or completely confirmed that disclosure affected their children negatively. This could be attributed to the lack of adequate knowledge and skill on the disclosure process.

In conclusion, knowledge on disclosure and disclosure itself is one of the key factors in pediatric HIV/AIDS management and care and if looked into and implemented in our nation Cameroon will greatly improve the treatment outcome of children living with HIV and their families.

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