FACTORS INFLUENCING CARETAKERS DECISION TO DISCLOSE THE HIV SEROSTATUS OF CHILDREN LIVING WITH HIV/AIDS IN DAR ES SALAAM, 2007.

By

Zaynab Juma Lweno

A Dissertation Submitted in Partial Fulfilment of the Requirements for the Degree Of Master of Public Health of the Muhimbili University of Health and Allied Sciences.

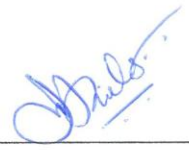
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CERTIFICATION

The undersigned certifies that he has read and hereby recommends for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled **"Factors influencing caretakers decision to disclose the HIV serostatus of children living with HIV/AIDS in Dar es Salaam 2007**." in partial fulfilment of the requirements for the degree of Master of Public Health of the Muhimbili University of Health and Allied Sciences.



Prof. J.Z.J KILLEWO

(Supervisor)

Date: 21/11/2008

DECLARATION

AND

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I, **Zaynab Juma Lweno**, declare that this dissertation is my own original work and it has not been presented and will not be presented to any other University for a similar or any other degree award.

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My appreciations also go to the caretakers of the children who participated in this study and made the data collection process a success.

DEDICATION

This dissertation is dedicated to my beloved parents, the late Engineer Juma O Lweno my father and my mother Mrs Maisara F Lweno who provided me with a good education foundation which has brought me to where I am today, my beloving children Othman Juma and Baby Maisara for their love and tolerance they have displayed during my studies.

ABSTRACT

As an increasing number of children infected with HIV live to older ages, the question of disclosure of the diagnosis to the child becomes crucial. The purpose of this study was to determine the Prevalence of HIV disclosure to infected children, the factors which could influence the caretaker's decision to disclose as well as their perception of the appropriate time for disclosure. Cross sectional survey using quantitative methods was used to answer the research objectives. A total of 285 caretakers were interviewed. The study revealed that prevalence of HIV disclosure in infected children to be 23.8%.Disclosure was highly associated with the age of the caretaker 32.9%(95% CI 22.3-43.4%) and level of education of the caretaker 31.4%(22.7-40.2%),the age of the child was also considered as important factor for disclosure to take place, as the age of the child increased so did the disclosure (p-value< 0.001 trend set chi square =47.8).Caretakers gave the age range of 10-12 as appropriate to start having discussions and disclosure to the children about their serostatus.Accessibilty to ARV regimens and reducing child's anxiety and depression were some of the factors mentioned that could influence their decision to disclose. No guidelines exist in Tanzania on pediatrics disclosure of HIV, there's need for the preparation of the guidelines as infected children are now surviving to older ages, and having knowledge of their serostatus could lead to improvement in their quality of life.

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LIST OF ACRONYMS

ARV	-	Antiretroviral
AIDS	-	Acquired Immune Deficiency Syndrome
CDC	-	Center for Disease Control
CTC	-	Care and Treatment Clinics
EGPAF	-	Elizabeth Glazer Paediatric Foundation
HAART	-	Highly Active Antiretroviral Treatment
HIV	-	Human Immunodeficiency Virus
IMCI	-	Integrated Management of Childhood Illness
IQ	-	Intelligence Quotient
MTCT	-	Mother To Child Transmission
MUHAS	-	Muhimbili University Of Health and Allied Sciences
MPH	-	Master of Public Health
NACP	-	National AIDS Control Programme
PMTCT	-	Prevention Mother To Child Transmission
RNA	-	Ribo-Nucleic Acid
TACAIDS	-	Tanzania Commission for AIDS
THIS	-	Tanzania Health Indicator Survey
UNAIDS	-	United Nations Organization on HIV/AIDS
UNICEF	-	United Nations Children's Fund

CHAPTER 1

1.0 INTRODUCTION

1.1 Background

HIV/AIDS is a major cause of infant and childhood mortality and morbidity in Africa. In children under five years of age, HIV/AIDS now accounts for 7.7% of mortality worldwide. AIDS already accounts for a rise of more than 19% in infant mortality and a 36% rise in under five mortality, thus HIV/AIDS is threatening recent gains in infant and child survival and health.[1] Of the 2.1 million children under the age of 15 years living with HIV worldwide, at least 90% live in Sub Saharan Africa.[1] It is currently estimated in developing countries 1600 children are infected daily by their HIV infected mothers.

UNAIDS estimated that in 2003 there were 630,000 new paediatric HIV infections worldwide, about 90% of which were in sub Saharan Africa. This high HIV infection rate in children in Africa results directly from the high infection rate in women of childbearing age and the high rate of mother to child transmission (MTCT). Of the 40 million people living with HIV at the end of 2003, 70% live in Sub Saharan Africa, and 60% of those infected are women .[1]

In developed countries HIV infection in children is preventable, and paediatric HIV has been largely controlled. In such settings HIV testing as part of routine antenatal care, combinations of antiretroviral (ARV) drug

regimens, elective caesarean section, and complete avoidance of breast feeding have translated into mother to child transmission (MTCT) rates of less than 2%. In Africa on the other hand, high birth rates, high rates of maternal HIV infection, lack of access to currently available and feasible interventions and the widespread practice of prolonged breast feeding translate into a high burden of paediatric HIV disease. Without prevention of mother to child transmission (PMTCT) transmission rate is about 30-40%. Thus efforts to expand care and treatment for children must go hand in hand with efforts to rapidly improve the uptake of interventions for reducing MTCT. Access to currently available, effective care and treatment remains a major obstacle.

Despite the establishment of HIV prevention, care and treatment facilities in Tanzania which provide antiretroviral (ARV) to children living with HIV/AIDS there has been a slow enrolment of children to access antiretroviral drugs (NACP).

And even the few who have been enrolled uptakes have been slow and there is non adherence to regimens; few studies have been done to assess factors which influence adherence to antiretroviral in children. The few studies of adherence to antiretroviral regimens in children suggest that only 25-50% of HIV infected children are adherent to doses of their regimens. [2] This is also true with other chronic disease in children such as anticancer regimens or diabetic drugs.

With Highly active antiretroviral treatment (HAART), adherence is a more critical issue since resistance and adverse side effects could worsen the condition and lead to poor prognosis.

The HAART has changed HIV/AIDS from a severe and acute to a chronic disease. There is increased longevity survival among paediatric patients with HIV infection.[2] Data from various studies quotes median survival age of between 8 and 13 years for children with perinatally acquired infection. [2]
This is most probably due to effect of HAART, but adherence to complex regimens of HAART is essential to achieve long-term suppression of HIV RNA load and it is now becoming a common clinical issue particularly in children and adolescents. [3]

Disclosure of the child's HIV serostatus has been identified as one of the barriers to HIV adherence. [4] the process of disclosure to infected children has received little attention in Sub Saharan Africa. Most of the health care providers and caretakers have different attitudes and practices around discussing HIV with infected children. There is a strong discussion on the optimal time as to when should the child be revealed of his/her HIV status and what sort of discussion should take place, who should reveal the serostatus to the infected child, whether it is the role of health care provider or the caretaker. This study assessed the factors which influenced the caretakers' decision to disclose HIV/AIDS serostatus to infected children, so as to address the issues of disclosure of HIV status to infected children as this

may contribute to the improved quality of long-term care for this highly vulnerable population.

There are several factors which have been associated with disclosure of HIV serostatus to children with HIV/AIDS. The factors associated with disclosure of HIV serostatus from studies done in Europe include parental depression, family environment, availability of social support, socioeconomic status, Childs age, parental HIV serostatus and disease severity.[7,8]Stigma ,lack of knowledge and skills in the disclosure and emotional unpreparedness have also been implicated as reasons which influence the caretakers decision to disclose HIV status of their infected children.[6,25]

Currently there are no available literatures which exist on the issue of paediatric HIV disclosure in Tanzania, the extent of disclosure is not known and there are no clear guidelines on the disclosure as to when and how should the infected children be informed of their HIV serostatus.

1.2 Research questions

- What is the extent of disclosure of HIV/AIDS serostatus in paediatric patients?
- When should a child infected with HIV/AIDS be informed of his/her serostatus?
- What are the parents/caretakers perceived benefits/barriers of disclosing HIV serostatus to infected children living with HIV/AIDS?

1.3 Statement of the problem

Disclosure of a child's HIV status is becoming one of the greatest challenges in the management of paediatric HIV disease particularly in this era when more and more children, are having access to antiretroviral medications, which prolong and improve quality of life.

Research indicates that parents are often reluctant to discuss disclosure to their children until adolescence or in some cases not at all [5, 6]

Delayed disclosure of HIV status has been related to non adherence to medications [4,] postponement of discussions regarding secondary risk particularly since infected children are now surviving into middle childhood and adolescence [3] and also delayed disclosure has been related to increased mental health morbidity [7]. Therefore it is desirable for infected children to know their HIV status at ages when they start to understand issues related to their health so that they can learn to adjust themselves and relate to their peers.

Infected children who have not been informed of their serostatus present a serious public health concern; there is sexual risk or re-infection, psychological problems such as anxiety "something is wrong but don't know what" and depression [4]. Behavioural problems may also arise such as "acting out" and difficult peer relationships. There's also an effect of having limited access to treatment interventions [6].

With the expansion of HIV treatment programmes and increased accessibility to antiretroviral treatment there's need to address disclosure issues in paediatrics. In Tanzania, like most developing countries there is absence of disclosure guidelines which could help caretakers and providers in the process of disclosing the status to children. The lack of social support before the process of disclosure and post disclosure have also been implicated as factors which may hinder disclosure as parents fear what help will their children obtain after disclosure.[7] In Tanzania the extent of disclosure is unknown, hence a need for conducting research on the paediatric disclosure. Parents and caretakers have shown concern that lack of knowledge and skills in the disclosure process is a contributing factor, and they do not know when and how they should disclose the serostatus to the infected children. Cultural factors could also be a barrier to disclosure in our African setting, since traditionally there's silence in discussions around illness and disease particularly with children.

The inadequate number of health care providers who have received training on counselling children and how to address their psychosocial needs is also one of the problems that could be affecting the process of disclosure.

Few studies on parental disclosure of HIV status to children have been done in Sub Saharan Africa where the burden of HIV/AIDS is on the increase and mother to child transmission is at a higher rate. Caretakers of children infected with HIV/AIDS have been identified as a major barrier in the process of disclosure of diagnosis.[5]

Therefore there's a need to examine caretakers perspectives on the issue of disclosure, what the extent of disclosure is , what reasons they have to disclose or not to disclose and what possible consequences are there for disclosing HIV status to infected children from the caretakers perspective.

1.4 Rationale

After identifying gaps in the process of disclosure from the caretakers/parents perspective this study will enable to facilitate the development of disclosure guidelines and models for health care providers and caregivers to be used in health facilities providing paediatric care for children with HIV/AIDS. The findings of this study will also be used in the assessment of the magnitude of the disclosure problem and the factors influencing the disclosure in children so that the policymakers can address it and the people involved in the care of the HIV infected children.

1.5 Objectives

1.5.1 Broad objective

To determine factors influencing caretakers decision to disclose HIV serostatus of children living with HIV/AIDS.

1.5.2 Specific objectives

1. To assess the proportion of children living with HIV/AIDS whose HIV status has been disclosed to them by their caretakers.
2. To assess awareness among the caretakers of HIV positive children to disclose the HIV serostatus to their infected children.
3. To determine the caretakers perception on the appropriate time to disclose HIV status to their infected children
4. To determine reasons which motivate caretakers' decision to disclose HIV serostatus to infected children.
5. To assess the perceived barriers to the disclosure of HIV to children LWHA.

CHAPTER 2

2.0 LITERATURE REVIEW

2.1 Global paediatric AIDS situation

AIDS in children was first described in 1982. By June 1998, 8280 children under the age of 13 with AIDS had been reported to the Centres for Disease Control and prevention (CDC).[9] To date 25 years after the beginning of the HIV/AIDS pandemic the HIV has spread to virtually every country in the world infecting 65 million people and killing 25 million. The HIV pandemic causes over 11000 new infections and approximately 8000 deaths daily. An estimated 39.5 million people worldwide were living with HIV in 2006, among these children less than 15 years were 2.3 million; an estimated 4.3 million people became newly infected with HIV in 2006 among these children less than 15 years were 530,000. In 2006, 2.9 million people died of AIDS- related illness 380,000 were children under 15 years .[10]

Despite the progress in preventing HIV transmission from pregnant mothers to babies, approximately 1500 children under the age of 15 worldwide were infected with the virus each day in 2006.The range of infected children each year is 410,000 to 660,000.Without ART about one –third of HIV infected infants will die within their first year, and half will die before their second birthday. Lack of HIV prevention and treatment has left an estimated 15.2 million children as orphans.

The number is expected to grow to 20 million by 2010. Currently only one in ten children needing ART receives it, the remaining 90 percent face a bleak and short lived future.[10]

AIDS has hardest hit the children of Sub Saharan Africa they account for more than 85 percent of all children under 15 living with the disease. As the political leadership of the fight against HIV/AIDS is growing and global funding for HIV and AIDS programmes increasing in low and middle income countries, children have been largely missing from the picture, increasing numbers of children are entering the world infected with the virus diminishing their chances of survival, increasing numbers of adolescents and young people are contracting the virus every year threatening their hopes for the future, increasing numbers of their parents, teachers and guardians are dying, leaving infected, affected and vulnerable children including large number of orphans behind.[11]

Although AIDS is considered the most recognised disease in the world today the disastrous impact it is having on children has not been given adequate attention. Being the weakest members of the society, children infected with HIV/AIDS are crippled by having limited involvement in their care. Caregivers and health care workers decisions usually take precedence on what should be done to make children comfortable, which may not be in their interest.

Limited response to the psychosocial needs of children has rendered medical and clinical care inadequate; children who are sick with HIV/AIDS often refuse to take drugs prescribed by physicians or present with unexplained depression anxiety and isolation.[12]

2.2 Paediatric AIDS situation in Tanzania

Mother to child transmission (MTCT) of HIV in Tanzania has set a remarkable and deleterious impact on children survival. Using an estimated HIV prevalence rate of 12 percent for antenatal women and a total of vertical transmission of approximately 40 percent it was estimated that 72,000 babies would become infected with HIV from their mothers (approximately 25000 babies through breastfeeding) per year.[13]

Therefore (MTCT) accounts for the additional 64800 child deaths. Adding 64800 to the existing 150,000 child death from common childhood infections represents a 43 percent increase in infant mortality. This is a big setback to the improved infant survival enjoyed by the country in the last two decades through universal immunization and improved integrated management of childhood illness (IMCI).

By the end of 2003, it was estimated the number of HIV infected children at the age of 0-15 in Tanzania to be 140,000.The number of children who have lost their mother or father or both parents to AIDS and who were alive under

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the age 17 at the end of 2003 to be 980,000.This indicates the impact of HIV/AIDS to the infected and affected children in Tanzania.[14]

2.3 Challenges in the management of paediatric AIDS

The second decade of the AIDS epidemic has brought more effective therapeutics to children affected by HIV resulting in an increasing population of children and families living with HIV as a chronic illness. [8] The advent of HAART have resulted to children with perinatally acquired HIV to survive into their school age years and adolescence, thus families, schools and community are faced with a number of complex medical and social issues. These include adherence to the HAART regimens which are life long with potential side effects, there is an issue of treatment failure and the psychosocial issues such as disclosure of HIV status to the infected child .[15]

2.4 Paediatric disclosure of HIV serostatus

Disclosure is the process of sharing information about a person's HIV status to others. Whether it is the child or a member of the family that is HIV positive, people who are involved in the provision of care to the infected children need to think carefully about disclosure of HIV status to a child. This is because it may have a number of implications depending upon how much information is disclosed, to whom the status is disclosed (for example the child's siblings, relatives, the school, or the community) when the status is disclosed and how the status is disclosed.[16]

According to the American Academy of Paediatrics disclosure of HIV infection status to children and adolescents need to take into consideration their age, psychosocial maturity, the complexity of family dynamics, and the clinical context. As there's increased longevity among infants with perinatally acquired infection with the median survival of children after diagnosis to be between 8.6 to 13 years and 36% to 61% of infants with perinatally acquired HIV infection expected to survive to age 13 years,[2] the disclosure of a diagnosis of HIV infection/AIDS to a child is becoming an increasingly common clinical issue.

Considerable guidelines exist about the disclosure of a chronic illness to a child. In general disclosure is geared to a child's level of cognitive development.[17] and psychosocial maturity. For most illnesses children receive simple explanations about the nature of their illness and what their responsibilities are in caring for themselves. The exact diagnosis and prognosis are less important in early discussions with young children. As children mature they should be fully informed of the nature of their illness and encouraged to actively participate in their own medical care.

Children with a variety of chronic diseases including those with cancer have exhibited better coping skills and fewer psychosocial problems when appropriately informed about the nature and consequences of their illness.[18].

Some caretakers and health care professionals are reluctant to inform children about their HIV infection status. Reports from different studies in paediatric AIDS clinics done in Europe and Asia indicate that between 25% and 90% of school age children with HIV/AIDS have not been told that they are infected.[2] Some of the reasons given by caretakers for not disclosing HIV serostatus are similar to reasons expressed by family members of children with other serious diseases, which include concerns about the impact disclosure have on a child's emotional health and fear by the caretakers that the knowledge will negatively affect a child . Additional reasons given by caretakers of HIV infected children include a sense of guilt about having transmitted infection to the child, anger from the child related to knowledge of perinatal transmission and fear of inadvertent disclosure by the child. Disclosure of the status may lead to stigmatization, discrimination or ostracism toward the child and other family members.[5, 6] Health care professionals and families are also concerned about the difficulty children will have, keeping a 'secret' and limiting the disclosure to the selected persons.[2]

Families desiring to protect their children from certain problems by concealing information risk having encounters with other issues. Children may develop inappropriate and hurtful fantasies about their illness. A conspiracy of silence surrounding children infected with HIV may isolate them from potential sources of support.

In the unfortunate event of the death of a parent the opportunity is lost for children to discuss their illness with that parent. Children may inadvertently learn of the nature of their illness in a manner that is not supportive, if children find out their infection from someone other than a parent they may feel unable to confide in their parent or feel a need to conceal that they are aware of their diagnosis.

Although child's age has been found to play a key role in HIV disclosure [5,19] clinical observations suggest that other family and community factors may also be important determinants in communication about highly stigmatised information such as HIV infection.[20,21]. Delays in disclosure of HIV infection may potentially result in negative consequences for the child including impaired treatment understanding and participation, increased psychological and behavioural problems, decreased support services and more complicated bereavement.[22, 23]

Other factors known to predict disclosure include child's developmental awareness and cognitive development,[8] family communication style where family with greater family expressiveness have known to increase disclosure, child's intelligence and maturity also predicts disclosure [8]

Paediatric HIV disclosure is a complex issue and while guidelines on the disclosure of HIV infection among adults have received considerable attention, there are no such guidelines focusing on the disclosure of paediatric HIV[2] and in particular resource limited settings .[6, 24]

Studies done from USA and Europe have shown that when and how a parent discloses to a child can affect the provision of care for the child [24] and may influence the child's psychological adjustment and development.[24] Beyond the parent child relationship, public disclosure of a child's HIV status can have significant impact on children and families [21].

Factors influencing parental decision of HIV serostatus disclosure could be classified according to different levels involved in the care of the paediatric population. At the national level the absence of guidelines which could facilitate parents and caregivers and also health care workers in the process of disclosure .[6, 24] At the national level the absence of guidelines which could facilitate parents and caregivers and also health care workers in the process of disclosure .[6, 24]

At the facility level, the care of paediatric HIV population requires a multidisciplinary team with health care workers, counsellors, nutritionists, and psychologists who will attend to the psychosocial needs of the children including the disclosure issues.

Health care providers have less experience concerning the psychological and psychosocial aspects of long-term survivors such as HIV disclosure [15] and also in a study done in Thailand indicated they lack approach to the process of disclosure.[25]

At the family level, caretakers have shown concern that they lack knowledge and skills required in telling the diagnosis to their children as a result there' a pattern of inaccurate disclosure among children [5, 6] and also expressed a need for training on how to disclose the HIV status to infected children. [6]

Caretakers and child relationship has also been implicated as a factor influencing disclosure. Infected biological parents face more difficulty on disclosing child's diagnosis as this would simultaneously involve disclosure of their status [5, 8] and a sense of guilt for transmitting the disease to the child. Social economic status could also influence parental decision to disclose.
In a study done in Thailand parents who had financial problems were more likely to have disclosed[6].

Cultural/beliefs systems in particular in our African culture could also affect disclosure, usually adults do not talk to their children issues related to sex, death and witchcraft thus there's lack of honesty and openness in talking to children. The fact that HIV/AIDS still remains a highly stigmatised disease therefore socially unacceptable could influence disclosure. [25] Presence or absence of social support has also been implicated to influence disclosure.[7]

CHAPTER 3

3.0 METHODOLOGY

3.1 Study area

The study was conducted in Dar es Salaam region, the largest city in Tanzania. According to the 2002 National population census, it has a total population of 2,497,940 of which 1,236,864 (45.9%) are females (Population and Housing Census, 2002). Dar es Salaam has three municipalities namely Ilala, Kinondoni and Temeke. Thirty three percent (33%) of the total population is composed of children less than 15 years. Dar es salaam is one of the cities in Tanzania that has a high prevalence of HIV of 10.9 percent . The region was chosen for this study partly for convenience and partly because most of its district hospitals and health centres offer specialised paediatric care for children with HIV/AIDS unlike most other district hospitals in Tanzania.

3.2 Study design

A cross sectional study design was used to assess factors influencing the caretakers decision to disclose HIV serostatus of their children who are living with HIV/AIDS.

3.3 Study population

The study involved caretakers of children aged from 4-14 years as this is the age range in which disclosure discussions can start to take place between caretakers and their children [2] .The caretakers were of the children who were attending CTC in the three municipal hospitals of Dar es Salaam namely

Amana, Temeke and Mwananyamala hospitals and health centres offering Care and treatment services to paediatric patients which included Buguruni and Sinza health centre.

Inclusion criteria
Caretakers of children attending CTC with a child aged 4 –14 years and consented for the study.

Exclusion criteria
Those who did not consent for the study

3.4 Sample size

The sample size was calculated using the formula,

$$N= z^2p\ (1-p)/\varepsilon^2$$

Where n= expected minimum sample size

ε= margin of error (5%)

P= proportion of children who have been disclosed their serostatus taken as 26% from a study done in South Africa[24]

z= which corresponds to 1.96 (at 95% CI)

THUS $n = 1.96^2 0.26(1-0.26)/0.05^2$

The above sample size expression was used to determine the minimum number of subjects (n=295) to be included in the survey. However, due to the limitation of time a sample size of 285 was reached. The proportion was taken from a study done in South Africa since it was the only country in Sub Sahara Africa which has conducted a study on Paediatric HIV disclosure (published).

3.5 Sampling technique

Distribution of children attending CTC sites in Dar es salaam according to place of enrollment.

CTC site	Children enrolled	Percent
Mwananyamala hospital	340	20.3
Amana hospital	308	18.4
Temeke hospital	304	18.1
IDC clinic	250	14.9
Makuti clinic	233	14.0
Sinza health centre	90	5.4
Buguruni health centre	89	5.3
Mbagala health centre	61	3.6
Total	**1675**	**100**

Purposeful sampling was used to select the 3 municipal hospitals namely Amana, Temeke and Mwananyamala hospitals as they offer specialised paediatric care to HIV patients and they serve a large population. The 2 health centres of Sinza and Buguruni were randomly selected from the 5 remaining CTC sites (by tossing).Thus the number of health facilities to be included in the study was 5.

The minimum number of study participants from each facility was 57, obtained by 285/5.On reaching the site systematic random sampling was used to select participants. The total attendance was obtained through the attendance registers and participants were picked at an interval of every 2 caretakers as long as they fit the inclusion criteria.

3.6 Data collection tool and pre- testing

The data collection tool was a semi-structured questionnaire with both open and close-ended questions to collect responses from the participants (Appendix 1). The questionnaire was developed in English and then translated to Swahili language. Prior to the commencement of the study pre testing of the study instrument was done to caretakers of HIV infected children who were not included in the study, obtained from Muhimbili National Hospital paediatric clinic. The aim of pre testing was to check whether there were any misconceptions or misunderstandings, which needed to be cleared off before the main study.

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3.7 Data collection procedure

The principal researchers with the help of seven research assistants were involved in data collection. The data collection period commenced from 10th to 25th August 2007. The research assistants were nurses/counsellors with previous experience in conducting surveys. Training of the research assistants was done for one day by the principal investigator; it involved familiarization with the questionnaire and how to record the required information correctly.

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Associations and strength of relationship between the dependent and independent variables were obtained using cross tabulations and the Chi square test. Ninety five percent confidence interval around proportions were obtained by Epi info 3.3.2

3.10 Ethical issues

Ethical approval for conducting the research was obtained from the MUHAS Directorate of Research and Publication. Permission to carry out the study was sought from the relevant municipal authorities, which are Kinondoni, Ilala and Temeke municipality. Informed verbal consent was obtained prior to data collection.

The caretakers were interviewed in privacy, not in the presence of the child and they were assured that the information would be kept secret.

3.11 Definition of term

HIV disclosure – informing or revealing the HIV serostatus to a person.

CHAPTER 4

4.0 RESULTS

4.1 Socio demographic characteristics of the respondents

The study involved 285 caretakers of children who were attending the CTC clinics of Amana, Temeke and Mwananyamala Hospitals and also the Buguruni and Sinza health centres. Table 1 presents the socio-demographic characteristics of the study population.

The table shows that, 198 (69.5%) were females while 87 (30.5%) were males. The age of the respondents ranged between 20 to 70 years and the mean age was 39.2 years. Fifty one percent of the respondents were married while 16.2% were either unmarried or never married. One third of the respondents formed a special group of marital disunion that we termed disrupted marriages, which included divorcees, separated and widowed.

Forty two percent of the respondents were engaged in petty business and other related activities such as drivers and tailors. Regarding educational level, 48% had completed primary school education. For religion, 50.8% of the respondents were Muslims while 48.4% were Christians.

Table 1: Socio-demographic characteristics of the respondents
N=285

Characteristics	Number	Percent
Age (years)		
20-29	44	15.4
30-39	116	40.7
40-49	76	26.7
50+	49	17.2
Sex		
Male	87	30.5
Female	198	69.5
Marital Status		
Never married	46	16.2
Married	144	50.5
Disrupted	95	33.3
Occupation		
Peasant/not employed	72	25.2
Public/Private employee	94	32.9
Petty business/Others	119	41.9
Education		
No formal	41	14.4
Primary	136	47.7
Secondary and above	108	37.9
Religion		
Muslim	145	50.8
Christian	138	48.4
Others	2	0.8

4.2 Age and gender distribution of children attending CTC sites.

Table 2 shows the distribution of the children who were attending the clinics with their caretakers. Most of the children were in the age group of 7-9 years (46.0%). The proportion of female was (54%) while that of male was (46%).

Table 2: Age and gender distribution of children attending CTC sites with their caretakers

N=285

Characteristic	No.	Percent
Age(in years)		
4-6	71	24.9
7- 9	131	46.0
10-12	65	22.8
>12	18	6.3
Gender		
Male	131	46.0
Female	154	54.0

4.3 Prevalence of HIV disclosure to children by various characteristics of the caretakers

The overall prevalence of HIV serostatus disclosure to children by their caretakers was 23.8%. Table 3 depicts the prevalence of HIV serostatus disclosure by various characteristics of the caretakers.

The prevalence of HIV serostatus disclosure was statistically significant higher among the caretakers aged 40-49(32.9%) compared to that among the caretakers aged 20-29 (13.6%). The findings were also true with respect to the education level of the caretaker; the prevalence of serostatus disclosure was statistically significantly higher among the educated (22.7%-40.2%) compared to those with no formal or primary education (19.2%).

There was no significant difference in HIV serostatus disclosure among the study population in respect to difference in sex, marital status, occupation and the relationship of the caretaker to the child.

Table 3:Prevalence of HIVserostatus disclosure by various characteristics of the caretakers.

Characteristics	No. Studied	No. Disclosed	% Disclosed	95% CI
Age (years)				
20-29	44	6	13.6	(3.5-23.7)
30-39	116	25	21.6	(14.0-29.0)
40-49	76	25	32.9	(22.3-43.4)
50+	49	12	24.5	(12.4-36.5)
Sex				
Male	87	20	22.9	(14.1-31.8)
Female	198	48	24.2	(18.2-30.2)
Marital Status				
Never married	46	8	17.4	(6.4-28.3)
Married	144	39	27.0	(19.8-34.3)
Disrupted	95	21	22.1	(13.7-30.4)
Occupation				
Peasant/not employed	72	15	20.8	(11.4-30.2)
Public/Private employee	94	23	24.4	(15.7-33.1)
Petty business/Others	119	30	25.2	(17.4-33.0)
Education				
No formal /Primary	177	34	19.2	(13.4-25.0)
Secondary & above	108	34	31.4	(22.7-40.2)
Caretakers relationship to the child				
Parents	155	35	22.6	(15.9-29.1)
Siblings	27	10	37.0	(18.8-55.2)
Grandparents	51	13	25.4	(13.5-37.4)
Others	52	10	19.2	(8.5-29.9)
Overall disclosure	285	68	23.8	(18.9-28.8)

4.4 The prevalence of HIV disclosure in children according to their age and gender.

The prevalence of HIV serostatus disclosure to children by caretakers was highest (72.2%) among children aged over 12 years of age. Table 4 shows the prevalence of disclosure of HIV status to the children according to age and gender. It increased steeply from a low of 4.2% in the 4-6 years age group to 72.2% in the oldest group. There was therefore a statistically significant difference between the children's age group and disclosure status (p- value trend <0.001) Chi square trend =47.8.The prevalence of disclosure was slightly higher among females (24.7%) than males (22.9%) with no statistically significant difference between gender of the child and the disclosure status (p-value= 0.75).

Table 4: The prevalence of disclosure of HIV in children according to their age and gender.

Characteristics	Total No.	Disclosed		P-value
		No.	%	
Age (in years)				
4 - 6	71	3	4.2	
7- 9	131	15	11.5	
10 - 12	65	37	56.9	
>12	18	13	72.2	<0.001 trend set
Sex				
Male	131	30	22.9	
Female	154	38	24.7	0.75
Total	**285**	**68**	**23.8**	

Most of the children who knew their HIV serostatus had been informed of their status by their biological parents (54%) especially the mother, 12% had been disclosed of their status by their grandparents, while 16% had been informed by the health care providers at the clinics, the rest 18% had been informed by other family members including aunts, uncles, sisters and brothers. Most disclosure events took place at home 84% and the rest 16% occurred at the clinics.

Awareness of children's rights on HIV disclosure among the caretakers.

The caretakers of the children living with HIV/AIDS were asked whether they were aware that it is the right of an infected person (children inclusive) to know their serostatus and also about the source of information on the rights to disclose to an infected child. A total of 282 (98.9%) of the respondents knew that it is the right for the children to know their HIV serostatus.

Source of information on HIV Disclosure to children

When asked where they had obtained the information on HIV status disclosure to a child, 73.0% of the respondents reported they had obtained the information from the health care providers at the clinics while 17.7% reported to have heard from the media which included newspapers, radio and TV. Eight percent of the respondents reported to have heard the information from caretakers of infected children. Two respondents (0.71%) reported that they had heard this information from religious leaders. Figure 1 shows the distribution of the caretakers according to source of information about HIV disclosure to children.

had heard this information from religious leaders. Figure 1 shows the distribution of the caretakers according to source of information about HIV disclosure to children.

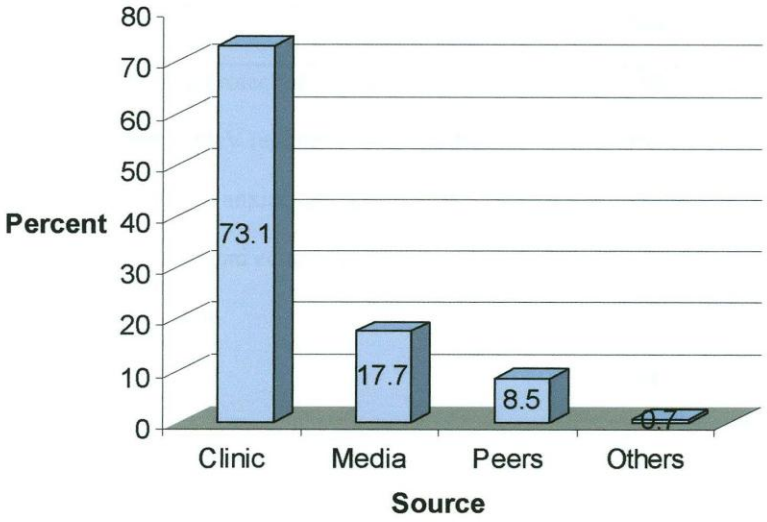


Figure 1: Sources of information on the disclosure to children

4.5 Benefits of disclosing HIV status to children

Of the 285 caretakers who were interviewed, 99.3% thought there were benefits of disclosing HIV status to children. Only less than 1% of the respondents reported that there are no benefits of disclosing to children.

Of those who responded in the affirmative regarding benefits of informing the child (281) were then asked what the benefits of disclosing to the child were.

Table 5 shows various benefits of disclosing the serostatus to the child given by the caretakers. More than half of the respondents (55.1%) reported that

the respondents stated that the feeling of anxiety and depression among the children would be reduced.

Table 5: Benefits given by the respondents for disclosing HIV status to the child

N=281

Benefits	No	Percent
Encourages self protection and prevents transmission.	155	55.1
Able to obtain ARV regimens when needed.	85	30.2
Reduce feeling of anxiety and depression.	22	7.8
Helping to assist and educate peers.	17	6.1
No benefits given.	2	0.8
Total	**281**	**100**

4.6 Reasons for not disclosing the HIV serostatus

Among the 217 respondents who had not disclosed to the child of his/her HIV serostatus were interviewed and asked for reasons for not disclosing the child's HIV status. Table 6 presents the reasons given by the caretakers for not disclosing the HIV serostatus to the child.

Majority (65%) stated that the child was too young and would not be able to understand. Others (11%) stated that the child might not be able to keep his/her diagnosis confidential.

Fear of stigma and discrimination were reported by 4% of the respondents. Some caretakers admitted that they did not have the skills to disclose HIV status to their children (6.5%).

Table 6: Reasons given by caretakers for not disclosing the HIV serostatus to their children

Reasons	No	Percent
The child too young to understand	141	65.3
The child unable to keep secret	23	10.6
The child will be worried /depressed	20	9.3
Don't know what to say and how to inform	14	6.5
Fear of stigma and discrimination.	10	4.1
Child will be psychologically affected	3	1.4
No reason given	6	2.8
Total	**217**	**100**

Explanations given by caretakers in the non-disclosure group on the frequent visits to the clinic.

When asked what explanations they usually give to the child as to why they make frequent visits to the clinic, most of the caretakers (84%) gave reasons related to other medical conditions such as having a chronic cough, tuberculosis, typhoid and allergy requiring medical attention and regular medications. However sixteen percent 16% stated that they usually don't tell anything to the child.

The group of caretakers who had not disclosed the status to their children was also asked about the best person whom they thought should disclose the HIV serostatus of the child and where they thought the disclosure event should take place. Majority 65% stated that the caretaker would be the best person while 32% reported that the health care provider would be the best person to disclose the serostatus of the child. Three percent (3%) of the respondents mentioned religious leaders and peers of caretakers as the best positioned persons to disclose the serostatus of the child. Fifty four percent (54%) stated that they would prefer the disclosure event to take place at home and the rest (46%) thought the clinic to be the right place for the disclosure event to occur.

Readiness for disclosure

Of those who had not disclosed, when asked if they would be ready to disclose to the child in the future, 99 % (215) were willing to inform the child of his/her status. However only 1% (2) were not willing to disclose for fear of being asked by the child how he/she got infected.

4.7 Reactions of the children when told of their HIV serostatus

There were 68 respondents who had disclosed HIV serostatus to the infected children. Majority of the respondents (39.7%) reported that the child received the information calmly and accepted the results. Thirty five percent (35.3%) of the respondents reported that the child was scared.

Twenty five percent (25%) of the respondents reported the child to be worried when he/she was informed of the serostatus. None of the respondents reported the child to be angered by the disclosure of his/her status. Table 7 shows the various reactions experienced by the children when told of their HIV serostatus.

Table 7: Reactions of the children when told of their HIV serostatus

N= 68

Reaction	No	Percent
Scared	24	35.3
Worried	17	25.0
Others (accepted, calm)	27	39.7
Total	**68**	**100**

4.8 Factors influencing caretakers' decision to disclose.

Caretakers in the disclosure groups were also asked of the factors which influenced their decision to disclose the HIV serostatus to their infected children. The child's ability to follow his/her ARV medication was the most stated factor mentioned by 28% of the respondents. Another factor which influenced their decision to disclose was that the child would learn how to prevent transmitting the virus to others by practising safer sex after being informed of his/her serostatus stated by 20.6% of the caretakers. The fact that the child could have heard news about HIV/AIDS either through media or at schools before disclosure by caretakers was another factor mentioned which

influenced the decision to disclose as most caretakers feared their children would know the serostatus from other community members before being told by them. Table 8 shows the factors mentioned by the caretakers, which influenced their decision to disclose.

Table 8: Factors influencing caretakers' decision to disclose HIV status to the infected child

	Disclosed	
Factors	**No.**	**%**
Child able to follow his/her medications	19	27.9
Would enable child to prevent transmission.	14	20.6
Would give child access to ARV support	12	17.6
It is child's right to know HIV status	2	3.0
Would reduce child's anxiety about his/her condition.	5	7.4
Would encourage child to educate others.	0	0.0
Would embarrass caretakers if child hears before	13	19.1
Gave no influencing factor	3	4.4
Total	**68**	

The caretakers were also asked at which age of the child they would prefer to start having general discussions with their children with regard to their illness. Majority of the respondents (42.8%) reported the age range of 10-12 years as being the best age to have general discussions with the child. Similarly (40.4%) of the respondents reported the age range of 10-12 years as the best age to disclose HIV serostatus to children. The most common reason for the preferred age range was that the child could have a better understanding (72%) and the other reason stated (12%) was that the child will have matured and approached puberty.

could have a better understanding (72%) and the other reason stated (12%) was that the child will have matured and approached puberty.

The child could be able to keep his/her serostatus confidential was also mentioned by 8% of the respondents. The rest (8%) reported this age range to be the most appropriate age.

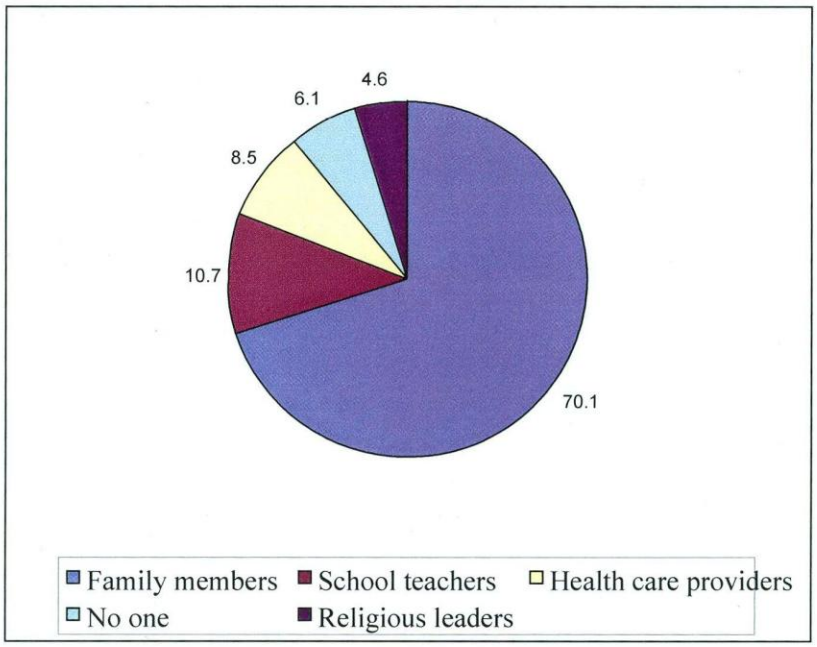


Figure 2: Caretakers' preference of other people to know the child's serostatus.

Caretakers were asked about other persons apart from them, with whom they would like to share the HIV serostatus of the child. Over 70% of the respondents stated that they would like to share the serostatus with other family members including grandparents, brothers, sisters, uncles and aunts of the children. Eleven percent (10.7%) of the respondents reported that they would share the child's serostatus with schoolteachers where their children were attending school.

Nine percent (8.5%) were ready to share the child's serostatus with the health care provider and 4.6% of the respondents were ready to share the serostatus of the child with religious leaders, while 6.1% of the respondents were not ready to share the child's serostatus with any other person (See Figure 2).

CHAPTER 5

5.0 DISCUSSION

Children with perinatally acquired HIV disease are now surviving into school age and adolescence. These children often ask questions about the illness and the complex treatments they are receiving to their caretakers and the health care providers. In such circumstances caretakers tend to avoid disclosing the diagnosis of paediatric AIDS to the child.

Little is known about paediatric HIV disclosure by caretakers particularly in Sub Saharan Africa where the magnitude of HIV/AIDS is high. Therefore, this study was prompted by this gap in knowledge and went on to explore various factors that may influence the caretakers' decision to disclose the HIV serostatus to the infected child. The factors ranged from socio-demographic characteristics of the caretakers including age, marital status, religion, level of education and the relationship to the child. The factors which influenced the decision to disclose were assessed. These factors have also been addressed in other studies were conducted in Thailand, South Africa and United Kingdom.[5,6,24,25].

The prevalence of HIV serostatus disclosure to children in this study was 23.8%. This finding is in keeping with studies from other countries in which the reported percentages of non disclosure to children ranged from 25-83%.[2,6,24] The findings also reflect that 76.2% of children aged from 4-14 years in the population studied have not been informed of their serostatus.

This is in agreement with the findings of a study done in Thailand where 80% of HIV infected children who were older than 5 years had not been told of their HIV status.[6] These findings reflect the uneasiness in letting the child aware of this potentially life threatening and stigmatising illness. This also reflects that the issue of disclosure to paediatric patients has not been given a particular attention by the people involved in their care that is the health care providers, the caretakers and the policymakers.

The age range of children in which most disclosure had occurred was among children aged above 12 (72.2%) and lowest (4.2%) in children aged 4-6 years. This signifies that willingness to disclose increased as the child's age increased. There was statistically significant difference between the disclosure and non-disclosure group with respect to the age of the child. The results are in contradiction with a study done in Thailand were most children had been told of their serostatus at an average age of 9.4 years, and there was no significant difference in the mean age between the disclosed and non disclosed group.[6,25]

The findings in this study that as age of the child increased so did the disclosure is in keeping with the findings from previous studies where the child's age has been found to be an important factor of disclosure.[5,6,24,25]

However, disclosure seems to be at a much older age compared to other studies, this could probably be due to cultural differences where in Tanzania there is hesitation to discuss with children issues related to sex, diseases and death.

Most of the caretakers interviewed were the primary caretakers of the children (95%). Similar to other studies the persons who disclosed the serostatus to the child were the primary caretakers. The caretakers' relationship to the child did not seem to influence disclosure of HIV status. This finding is in contrast to those of a study done in Thailand where infected biological parents had significant disclosure.[6]

In a study done in Thailand, 73% of the caretakers reported that the parent or primary caretaker should be a responsible person in disclosing the serostatus to the child.[25] In another study done in South Africa 83% of the respondents felt that the parent or primary caretaker would be a responsible person to disclose the serostatus to the child, while 16% felt the responsibility of disclosing the serostatus should be of the health care provider (doctor, nurse or counsellor).[25] In this study 65% reported the parent/caretaker to be a responsible person for disclosing the serostatus, while 32% reported that it is the responsibility of the health care provider. Although 32% reported the health care provider should reveal the serostatus only 8.6% of the caretakers were ready to share the serostatus with the health care provider.

The findings imply that there's no clear guidelines in Tanzania, which explains the process of disclosure to children. Since it is not clear who should disclose the serostatus to the child, whether it is the responsibility of the caretaker alone or the health care provider or in combination.

Of the interviewed caretakers who had not disclosed to the child only 12% reported to have discussed HIV with the child, this is more or less similar to the findings in the study done in South Africa were only 9% of the interviewed caretakers had discussed HIV with the child.[24] This is probably due to culture difference were usually there's no discussion with children on issues related to illness, death and sex in Tanzania.

The caretakers who had not disclosed to the child gave various explanations to the child when he/she asked why they were making frequent visits to the clinic. Eighty five percent gave reasons related to other medical conditions such as Tuberculosis, typhoid requiring frequent medical attention. The caretakers in the non-knowing group in a Thailand study gave similar reasons, 70.8% reported that they explained to the child that they had other diseases such as allergy, lung infection and pustules.[6]This implies that there's a tendency of hiding the HIV serostatus behind other medical conditions, probably due to the fact that HIV still remains a highly stigmatised condition.

Sixteen percent of the caretakers in this study reported that they usually don't tell anything to the child, therefore tending to keep the serostatus a secret to the child. Implying that there's secrecy surrounding HIV disclosure probably due to stigma and deception done by caretakers in deciding not to tell the children their serostatus. This could also be due to the fact that some parents do hesitate to disclose the serostatus in order to avoid questions, which the child could ask about how he/she got infected.[5,8]

HIV disclosure in this study was highly associated with the level of education that is those with higher education were more likely to disclose their children's HIV status than those with lower level of education. This finding is probably a result of the caretakers in the high education being more knowledgeable about HIV/AIDS than those in the lower levels. They may also probably have acquired skills in handling the process of disclosure and the emotional consequences that may arise later.

When asked of their perception for the appropriate time to have general discussions regarding the child's illness and the best age to inform the child about his/her HIV status, the caretakers gave an age range of 10-12 years this is in keeping with the median age of 11 years as the best time to have general discussion about the illness and 12 years as the age to tell a child about his/her HIV infection according to the study done in S.Africa.[24]

This age range of 10-12 years stated probably reflects the high percentage of 72.2% of children aged over 12 years who had been disclosed of their status, since most caretakers thought the appropriate age to be from 10-12 years.

The most common reason for the preferred age, was that the child could understand better mentioned by 72.2% of the respondents, the other reason was that the child was maturing at this age and approaches puberty. This is in agreement with the American Association of Paediatrics guidelines for disclosure, were child's developmental awareness, cognitive development and maturity predicts disclosure.[2,8,17] It also explains the trend seen in this study were as the age of the child was increasing so was the increase in disclosure, particularly in those aged over 10 years. This is when the child is considered to have developed cognitively and matured.

In the group of caretakers who had disclosed the HIV status to the children, forty percent (40%) of the respondents reported the most common response of their children when told of their HIV/AIDS status was that of calm and quiet acceptance. The findings are somehow in keeping with the responses of the caretakers in the Thailand study, but at a higher percentage were the most common response was acceptance (71%). This contradicts findings in the literature were the parents have been reported to be reluctant to disclose the HIV status for fear that the knowledge will negatively affect the child's will to live.[5,6]

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This finding also implies that children when told at an age where they start to understand, and hearing news about HIV as in the media they usually accept the diagnosis.[25]

The caretakers mentioned various benefits of disclosing the HIV/AIDS status to the child, the most stated reason mentioned by 55% of the respondents was that after knowing the diagnosis the child would be able to self protect and prevent transmitting the virus to others. This finding contradicts the perceived advantage reported by caretakers in Thailand study who reported that disclosure might help the child adhere well to HAART.[6] Probably this could be due to the fact that HAART have been recently been made available to patients in this country and thus the issue of adherence to the regimens in paediatric patients has not been given much attention. Reducing the child's anxiety and depression was another factor mentioned by 8% of the respondents. This puts emphasis on the need to address the psychosocial needs of children living with HIV/AIDS, as many perinatally infected children are surviving longer.

Perceived barriers for disclosure that were stated in this study included the child being too young to understand (67.1%) this was the most stated barrier, the caretakers not knowing how and what to say to the child was mentioned by (7%), fear of stigma and discrimination was also mentioned as another barrier. These barriers are the same as the barriers explained in other studies.[6,24,25]

The barriers explains the factors which make the caretakers to be reluctant to disclose to the child, age being an important factor followed by psychosocial factors such as anxiety, depression, stigma and discrimination. The lack of knowledge and skills in disclosure has also been mentioned as an important barrier, the fact that (62.1%) of the respondents had low level of education or that they had no skills in disclosure could explain why they mentioned lack of knowledge and skills in disclosure as a barrier. Therefore there's need to address these barriers when considering developing guidelines which can assist the caretakers and health care providers involved in the care of paediatric HIV patients.

The caretakers when asked about other persons apart from them whom they would like to share the HIV serostatus of the child over 70% reported that they would like to share the diagnosis with other family members. The finding imply that the child's serostatus is still considered a family issue, and that the serostatus should be kept within the family, thus the importance of involving other community members such as school teachers and spiritual leaders who also contribute in the care of the child has not been realised by the caretakers.

Reducing the child's anxiety and depression was an important factor stated by the caretakers that could influence their decision to disclose. This implies that not only medical issues are of concern in infected children but psychological well being need also to be taken into consideration in the care of the children,

and that people involved in caring for paediatric HIV patients should consider their psychosocial needs such as disclosure.

Another factor mentioned that could influence the caretakers' decision to disclose was the child's ability to adhere to ARV regimens. This finding emphasises the finding in the literature that as children are surviving into middle age and adolescence there's need to address the issue of disclosure so that the children could have better adherence to ARV regimens which are lifelong with potential side effects.[1,2,4]

There are a number of limitations in this study, first the information collected was only in a limited period of time of data collection and thus patients included in the study were chosen conveniently as long as they met the inclusion criteria, secondly the disclosure status was at the period of study and more children might have had their status disclosed as time passed. Some children were attending the clinic without their caretakers although they did fall in the age group to be studied and thus they were not interviewed.

CHAPTER 6

6.0 Conclusion

This study revealed that the prevalence of HIV serostatus disclosure to infected children aged 4-14 years by their caretakers was 23.8%. Although 76.2% of the children did not know of their HIV serostatus, a high proportion of their caretakers were aware that it was the child's right to know his/her serostatus and they were responsible and willing to disclose the serostatus to the child.

Disclosure was highly associated with the level of education of the caretaker as well as the age of the child, and both were considered to be important factors for disclosure to take place. Caretakers gave an age range of 10-12 years as the appropriate time to start having general discussions with children about their HIV serostatus and also the same age of 10-12 years as appropriate to disclose the HIV serostatus to the infected child.

Reducing the child's anxiety and depression and accessibility to ARV regimens were some of the factors mentioned, that could influence caretakers' decision to disclose.

6.1 Recommendations

1. There is need to address barriers to paediatric HIV disclosure particularly by the people involved in their care. The Ministry of Health and Social Welfare should facilitate the preparation of guidelines for disclosure, which are appropriate to our country and could assist the caretakers, health care providers, when disclosing the serostatus to the child.
2. There is need to train caretakers of paediatric HIV patients who are attending the CTC clinics, by conducting training sessions and seminars so that they can acquire skills for disclosing the serostatus to the child. And also continuous psychological counselling sessions should be offered to the caretakers and their children so that they can be able to deal with the process of disclosure.
3. As more children continue to be enrolled in CTC sites and have access to HAART there's need to address the HIV serostatus disclosure in order to achieve adherence to ARV regimens and helping the children adjust psychologically.
4. More research is needed in children to determine their perceptions about their illness and challenges they face living with HIV/AIDS. This could be used in the preparation of the guidelines and assist the caretakers and the children to deal with the difficult process of disclosure.

Questions that need further research include:

- What is the impact of disclosure to the child and the family.
- What should be the best approach to HIV disclosure in our setting, as most caretakers seem to be reluctant to share and discuss disclosure with the healthcare provider.

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8.0 Appendices

APPENDIX 1: ENGLISH VERSION QUESTIONNAIRE

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APPENDIX 1: ENGLISH VERSION QUESTIONNAIRE

SEMI STRUCTURED QUESTIONNAIRE

GENERAL INSTRUCTIONS

1. This is a questionnaire which has been designed to gather information from caretakers of children who are living with HIV/AIDS.
2. Any information collected will be strictly confidential.
3. Do not write names of interviewee on the paper.
4. Circle or tick number of an answer corresponding to the response
5. Write fully given responses in the spaces provided for the open ended questions and on "others".

PART I BACKGROUND INFORMATION

QUESTIONNAIRE NO_____

NAME OF THE INTERVIEWER_____

DATE OF INTERVIEW _____

PART II: DEMOGRAPHIC DATA:

INFORMATION OF THE CARE TAKER:

1. Age of the Caretaker ..... (in years)

2. Sex
   1. Male ☐
   2. Female

3. What is your current marital status?
   1. Never married
   2. Married
   3. Divorced ☐
   4. Widowed
   5. Separated
   6. Cohabiting.

4. What is your current occupation?
   1. Peasant
   2. Unemployed ☐
   3. Government employee
   4. Employee in private sector
   5. Petty business

6. Others specify .....

5. What is your highest level of formal school education you have attended? (Number of years in School)
.....

6. What is your religion?
   1. Muslim
   2. Christian ☐
   3. Pagan
   4. Others specify .....

7. What is your relationship with the child?
   1. Mother
   2. Father
   3. Sister ☐
   4. Brother
   5. Grand mother
   6. Grand father
   7. Aunt
   8. Uncle
   9. Others specify .....

8. Are you the primary caretaker of the child?
   1. Yes
   2. No ☐

9. For how long have you been the child's caretaker?..... (years).

10. What is your HIV serostatus?
   1. Not tested
   2. Not infected ☐
   3. Infected

INFORMATION ABOUT THE CHILD:

11. How old is the child? ..... (Years)

12. Sex of the child?
   1. Male ☐
   2. Female

13. When was the child diagnosed to be HIV positive?
.....

14. Has the child started taking antiretroviral medications?
   1. Yes ☐
   2. No

15. If yes for how long the child been on antiretroviral medications?
……

16. What reason has brought you to the clinic today? ……..
……..

PART III: ASSESSMENT OF THE AWARENESS AMONG CARETAKERS ON DISCLOSURE TO INFECTED CHILDREN.

17. Do you know what it is a right for people to know about their HIV serostatus?
    1. Yes ☐
    2. No

18. If yes, how did you come to know this information?
    1. Medical clinics ☐
    2. Health care provider
    3. Media
    4. Peer parent with an infected child.
    5. Others specify ……..

PART IV: ASSESSMENT OF THE PROPORTION OF CHLDREN WHO KNOW THEIR SEROSTATUS.

19. Has the child been informed of his/her serostatus?
    1. Yes ☐
    2. No

    If no, skip to question 28.

20. If Yes, at what age was the child told of his/her status?..... years.

21. Who told the child of his/her serostatus?
    1. Father
    2. Mother
    3. Uncle
    4. Aunt ☐
    5. Grand mother
    6. Grand father
    7. Brother
    8. Sister
    9. Doctor
    10. Nurse
    11. Others specify ……..

22. Was the child told that he/she has HIV/AIDS?
    1. Yes ☐
    2. No

23. If no, what information was the child provided with? .....

24. What was the response of the child when told of his/her serostatus?
    1. Angered
    2. Worried ☐
    3. Scared
    4. Others Specify

25. Where did the disclosure event occur?
    1. At home
    2. at the clinics ☐
    3. School
    4. Others Specify.....

26. Do you think this was appropriate? (The place where you disclosed)
    1. Yes ☐
    2. No

27. If no. which place is appropriate? .....

FOR THOSE WHO HAVE NOT DISCLOSED

28. Why have you not disclosed to the child of his/her serostatus?
    .....

29. Will you ever disclose the serostatus to the child?
    1. Yes ☐
    2. No

30. If yes, at what age will you do so?
    .....

31. If no, why not? .....

32. Have you said anything to the child about the illness?
    1. Yes ☐
    2. No.

33. What did you say about the child's illness.....
    .....

34. Which place do you think is appropriate for the disclosure event to occur?
    1. At home ☐
    2. At the clinics
    3. School

4. Others specify .....

35. How many times have you come to the clinic since the child was diagnosed?
.....

36. What explanation do you give to the child on the frequent visits to the clinics?
.....
.....

PART V: DETERMINATION OF THE CARETAKERS PERCEPTION ON THE OPTIMAL TIME FOR DISCLOSURE OF HIV STATUS TO INFECTED CHILDREN.

37. In your opinion when is the best age of the child to have general discussions about the illness?.....
(Age in years).

38. In your opinion when is the best age to disclose to the child?
.....
(Age in years)

39. Why?.....

40. Who do you think should carryout the disclosure event?
1. Health care provider
2. Teachers ☐
3. Religious leaders
4. Caretakers
5. Peers who have disclosed to their children
6. Others specify .....

PART VI: REASONS WHICH MOTIVATE CARETAKERS DECISION TO DISCLOSE HIV STATUS TO INFECTED CHILDREN.

41. Do you think there are any benefits of disclosing HIV status to infected children?
    1. Yes ☐
    2. No

42. If Yes, what are the benefits of disclosing HIV status to children living with HIV/AIDS?
    .....

43. What reasons made you disclose to the infected child of his/her serostatus?
    .....

44. Are there people with similar situation (Caring for infected child) whom you have access?
    1. Yes ☐
    2. No

45. Do you interact with them?
    1. Yes ☐
    2. No

46. If Yes, how often? .....

47. Has the (presence of peer support) have an influence on your decision to disclose the child status?
    1. Yes ☐
    2. No

48. Who else would you like to share the diagnosis of the child with?

    .....

49. We are approaching the end of our interview what advise would you give on disclosure?.....

Thank you for your cooperation

APPENDIX 2: SWAHILI VERSION QUESTIONNAIRE

DODOSO YA KISWAHILI

MAELEKEZO

1. Huu ni usaili ambao umekusudiwa kukusanya taarifa miongoni mwa wazazi/walezi wanaoishi na watoto wenye virusi/UKIMWI.
2. Taarifa zote zitakazokusanywa zitakuwa ni siri sana.
3. Usiandike jina la msailiwa kwenye karatasi hii.
4. Zungushia mduara au alama ya pata kwenye jibu lililotolewa.
5. Andika jibu lililotolewa kwenye nafasi ya swali lililo wazi (pana) na "mengineyo"

SEHEMU I: TAARIFA ZA MSINGI

KARATASI YA MASWALI Na; ----------
JINA LA MSAILI ----------
TAREHE YA USAILI ----------

SEHEMU II: TAKWIMU ZA HALI YA KIJAMII

TAARIFA ZA MZAZI/MLEZI

1. Una umri gani? ---------- (miaka)
2. Jinsia
    1. Mme ☐
    2. Mke

3. Nini hali yako ya kindoa? (Weka vema panapohusika)
    1. Sijaoa/sijaolewa
    2. nimeoa/nimeolewa
    3. mtalaka
    4. mjane ☐
    5. tumetengana
    6. tunaishi kinyumba

4. Ni shughuli gani uifanyayo kila siku kukupatia kipato? (Weka vema katika kisanduku husika)
    1. mkulima
    2. sina ajira
    3. mtumishi wa serikali ☐
    4. mtumishi wa sekta binafsi
    5. mfanya biashara mdogo
    6. mengineyo (eleza) ----------

5. Nini kiwango chako cha juu cha elimu? (Miaka aliyokuwa shule)
---

6. Dini yako?
   1. Muislam
   2. Mkristo ☐
   3. Mpagani
   4. Nyinginezo (eleza) ----------

7. Nini uhusiano wako na mtoto huyu?
   1. Mama 5. bibi
   2. Baba 6 .babu
   3. Dada 7. shangazi ☐
   4. Kaka 8. mjomba
   9 mengineyo (Eleza) ----------

8. Wewe ndiye mlezi mkuu wa mtoto huyu?
   1. Ndiyo
   2. Hapana ☐

9. Umekuwa mlezi wa mtoto huyu kwa muda gani? ----------

10. Je, umeshawahi kupima virusi vya UKIMWI?
    1. Ndiyo
    2. Hapana ☐

11. Kama ndiyo, ni ipi hali yako ya maambukizo ya UKIMWI?
    1. nimeathirika ☐
    2. sijaathirika

TAARIFA ZA MTOTO

12 .Nini umri wa mtoto? ---------- (miaka)

13 .Jinsia ya mtoto
   1. Mme ☐
   2. Mke

14. Lini mtoto aligundulika kwamba ana virusi vya UKIMWI?
    ---------- (Miaka)

15. Je mtoto ameanza kutumia dawa za kupunguza kasi ya ugonjwa?
    1. Ndiyo
    2. Hapana ☐

16. Kama ndiyo mtoto amekuwa anatumia dawa za kupunguza kasi kwa muda gani? ----------

17. Sababu zipi zimekufanya umlete mtoto kliniki leo?

SEHEMU III: UFAHAMU WA WALEZI KUHUSU KUMFAHAMISHA MTOTO HALI YAKE YA UAMBUKIZO

18. Je unafahamu kuwa Ni haki ya mtu mwenye virusi vya UKIMWI (pamoja na mtoto) kufahamishwa hali yake ya maambukizi?
    1. Ndiyo
    2. Hapana ☐

19. Kama ndiyo ni mahali gani ulifahamu taarifa hii?
    1. kliniki
    2. mtumishi wa afya
    3. vyombo vya habari ☐
    4. wazazi wengine wenye watoto walioambukizwa
    5. mengineyo (eleza) ----------

SEHEMU IV; KIWANGO CHA WATOTO WANAOFAHAMU HALI YA UAMBUKIZO WA VIRUSI VYA UKIMWI

20. Je mtoto amefahamishwa kuhusu hali yake ya maambukizi ya ugonjwa wa UKIMWI?
    1. Ndiyo ☐
    2. Hapana

    Kama jibu ni Hapana, nenda kwenye swali no. 29

21. Kama ndio, mtoto aliambiwa akiwa na umri gani?---------- (miaka)

22. Nani alimwambia mtoto kuhusu hali yake ya maambukizi?
    1. Baba 5. Bibi
    2. Mama 6. Babu
    3. Dada 7. shangazi ☐
    4. Kaka 8. mjomba
    9. Daktari 10 . muuguzi
    11. Mengineyo (eleza) ----------

23. Mtoto aliambiwa kuwa yeye ana virusi/UKIMWI?
    1. Ndiyo ☐
    2. Hapana

24. Kama hapana ni taarifa gani ambayo mtoto alipewa?

    ---

25. Aliipokeaje taarifa ya kuwa ameambukizwa virusi vya UKIMWI?
    1. Alichukia
    2. Aliogopa ☐
    3. Alionyesha wasiwasi
    4. Mengineyo (Eleza) ----------

26. Tukio la kumfahamisha mtoto hali yake ya uambukizo lilifanyika wapi?
    1. Nyumbani
    2. Kliniki ☐
    3. Shule
    4. Mengineyo (eleza) ----------

27. Unafikiri mahali hapo palikuwa muafaka (mahali ambapo mtoto alifahamishwa hali yake)
    1. Ndiyo ☐
    2. Hapana

28. Kama hapana ni sehemu gani unafikiri muafaka?

KWA WALE AMBAO HAWAJAWAFAMISHA WATOTO

29. Ni sababu zipi za kutomfahamisha mtoto hali yake ya uambukizo?

    ----

30. Je unakusudia kumfahamisha mtoto baadae?
    1. Ndiyo ☐
    2. Hapana

31. Kama ndiyo, utamfahamisha mtoto akiwa na umri gani?
    ----------(miaka)

32. Kama hapana ni kwanini? ----------
    ----

33. Je umezungumza chochote Na mtoto kuhusu ugonjwa wake?
    1. Ndiyo ☐
    2. Hapana

34. Je, ulimwambia nini kuhusu ugonjwa wake?

---

35. Unafikri ni mahali gani panafaa (muafaka) ambapo taarifa hii inaweza kutolewa kwa mtoto?
1. Nyumbani
2. Kliniki ☐
3. Shule
4. Pengine (taja) ----------

36. Ni muda gani sasa umekuwa ukija kliniki tokea mtoto alipogundulika na ugonjwa? ----------

37 Unamueleza nini mtoto kuhusu safari za kliniki mara kwa mara?

SEHEMU V; MUONO WA WALEZI KUHUSU MUDA MUAFAKA KUWAFAHAMISHA WATOTO HALI YAO YA UAMBUKIZO

38. Kwa maoni yako ni umri gani unaofaa kufanya majadiliano na mtoto kuhusu ugonjwa?
---------- (miaka)

39. Kwa maoni yako ni umri gani unafaa kumfahamisha mtoto hali yake ya uambukizo wa UKIMWI?

---------- (miaka)

40. Kwa nini? ----------

41. Unafikiri nani angefaa kumfahamisha mtoto?
1. mhudumu wa afya
2. waalimu
3. viongozi wa dini ☐
4. Wazazi/ walezi wa watoto
5. Walezi ambao wamekwisha wafahamisha watoto wao
6. Mengineyo (eleza)----------

SEHEMU VI; SABABU ZA WALEZI KUWAFAHAMISHA WATOTO HALI YAO YA UAMBUKIZI WA VIRUSI/UKIMWI

42. Unafikiri kuna faida coyote kutokana na kumfahamisha mtoto kuwa ameambukizwa?
    1. Ndiyo ☐
    2. Hapana

43. Kama ndiyo ni faida zipi za kumfahamisha watoto walioambukizwa kuhusu hali ya kuwa na virusi/UKIMWI?

    ---

44. Sababu zipi zilikufanya/ zitakufanya umfahamishe mtoto hali yake ya kuambukizwa?

    ---

45. Je unapata fursa ya kuwa Na watu wenye hali Kama yako (wazazi wanaolea watoto walioambukizwa)?
    1. Ndiyo ☐
    2. Hapana

46. Huwa unajumuika nao?
    1. Ndiyo ☐
    2. Hapana

47. Kama ndiyo, ni kwa kiasi gani?

    ---

48. Je kuwepo kwa umoja wa walezi wa watoto wenye virusi kuna motisha yoyote iliokufanya umfahamishe mtoto?

    1. Ndiyo ☐
    2. Hapana

49. Nani mwingine ungependa kuchangia nae taarifa ya hali ya afya ya mtoto?

    ---

50. Tunakaribia mwisho wa mahojiano yetu, ni ushauri gani ungetoa juu ya mchakato wa kutoa taarifa kwa mtoto muathirika?

ASANTE KWA USHIRIKIANO

APPENDIX 3: CONSENT FORM (ENGLISH VERSION)

MUHIMBILI UNIVERSITY COLLEGE OF HEALTH SCIENCES

DIRECTORATE OF RESEARCH AND PUBLICATIONS, MUHAS

A SAMPLE OF INFORMED CONSENT FORM

ID-NO ☐☐☐☐☐ ☐☐☐☐

☐

Consent to Participate in INTERVIEW

Greetings! My name is ..... And I am .....working on this research project with the objective of **Assessing factors influencing parents/caretakers decision to disclose HIV serostatus to children who are living with HIV/AIDS in Dar es Salaam**

Purpose of the study

The study is expected to collect information from parents/caretakers on factors which influence their decision on disclosing HIV serostatus to their children who are living with HIV/AIDS. The findings from the study will help the principal investigator to write a dissertation which is a partial fulfilment of Master of Public Health for academic year 2006/7.

What Participation Involves

If you agree to participate in the study, you will be required to answer questions. You should not hesitate because in this interview there is no RIGHT or WRONG answers.

Confidentiality

All information we shall collect on the forms will be entered into computers with only the study identification number. Confidentiality will be observed and unauthorized persons will have no access to the data collected.

Risks

We do not expect that any harm will happen to you because of joining this study.

Rights to Withdraw and Alternatives

Taking part in this study is completely your choice. If you choose not to participate in the study or if you decide to stop participating in the study you will continue to receive all services that you would normally get from this hospital. You can stop participating in this study at any time, even if you have already given your consent. If you miss some visits for any reason but wish to come back into the study, we will be ready to accept you continue giving you our services as usual.

Refusal to participate or withdrawal from the study will not involve penalty or loss of **any** benefits **to** which you are otherwise entitled.

Benefits

If you agree to take part in this study, the information you will provide will help us to understand the parents/caretakers perspective on disclosure to children in our community, and the findings will be disseminated to the policymakers so as to help in addressing the issues of disclosure to children

Who to contact

If you ever have questions about this study, you should contact the study Coordinator or the Principal Investigator...**ZAYNAB J LWENO..... Muhimbili University College of Health Sciences**, P.O.Box 65001, Dar es Salaam. If you ever have questions about your rights as a participant, you may call Prof. **J. Z J KILLEWO** supervisor of this study, and **Prof E.F.LYAMUYA**, Chairman of the College Research and Publications Committee, P.O.Box 65001, Dar es Salaam. Tel: 2150302-6.

Signature:

Do you agree?

Participant agrees..... Participant does not agree .....

I _____ have read the contents in this form. My questions have been answered. I agree to participate in this study.

Signature of participant _____

Signature of witness (if mother/caretaker cannot read) _____

Signature of research assistant _____

Date of signed consent _____

APPENDIX 4: CONSENT FORM (SWAHILI VERSION)

MUHIMBILI UNIVERSITY COLLEGE OF HEALTH SCIENCES

DIRECTORATE OF RESEARCH AND PUBLICATIONS, MUHAS

FOMU YA RIDHAA

ID-NO ☐☐☐☐☐

Ridhaa ya ushiriki katika tafiti.....

Habari! Mimi ni Dr Zaynab Juma Lweno, ni mwanafunzi wa shahada ya pili (udhamili) katika chuo kikuu cha sayansi za afya Muhimbili, ninafanya utafiti kama sehemu ya masomo yangu, kuhusu **Sababu zinazowafanya walezi kuamua kuwafahamisha watoto walioambukizwa virusi vya UKIMWI kuhusu hali yao ya uambukizo.** Utafiti huu unafanyika katika hospitali na vituo vya afya katika mkoa wa Dar es salaam.

Umuhimu wa utafiti huu

Matokeo ya utafiti huu yatasaidia kuelewa sababu zinazowafanya walezi wa watoto kuamua kuwafahamisha au la watoto walioambukizwa virusi vya UKIMWI hali yao ya uambukizo,ili kuweza kufahamu idadi ya watoto wanaoishi na virusi wanaofahamu hali yao ya uambukizo.Na pia itasaidia kuelewa iwapo walezi wanapata ugumu wowote katika kuwafahamisha watoto na ni matatizo gani wanayoyapata.

Ushiriki unahusisha nini

Ushiriki unahusisha kukubali kujiunga na utafiti huu kwa hiari na kujibu maswali kama yalivyo katika dodoso la utafiti huu.

Usiri

Taarifa zote utakazo jaza katika dodoso ni siri na wala jina lako halitaingizwa katika kompyuta isipokua namba ya dodoso.

Uwezekano wa kutokea jambo la hatari.

Si tarajii kama kuna jambo lolote baya linaweza kutokea kwa kushiriki katika utafiti huu.

Haki ya kujitoa na mambo mbadala.

Ushiriki wako katika utafiti huu ni wa hiari. Unayo haki ya kukujibu au kukataa kujibu swali lolote katika dodoso. Kukataa kujibu swali lolote hakuna adhabu yoyote wala haupotezi haki zako kama mshiriki.

Faida kwa Mshiriki

Endapo utakubali kushiriki katika utafiti huu, majibu yako yatakuwa mchango mkubwa katika matokeo ya jumla ya utafiti huu, ambayo yanatarajiwa kuleta mapendekezo yatakayosaidia katika kutayarisha maelekezo ya kuwasaidia walezi kuhusu jinsi ya kuwafahamisha watoto hali zao za uambukizo wa virusi vya UKIMWI.

Wasiliana na

Endapo utakuwa na swali lolote kuhusu utafiti huu tafadhali wasiliana na msimamizi wa utafiti huu Prof Killewo JZJ au mtafiti mkuu Dr Zaynab Juma Lweno, Chuo Kikuu Kishiriki cha Sayansi za Afya, P.O.Box 65001,Dar es Salaam.
Endapo una swali lolote kuhusu haki zako kama mshiriki katika utafiti huu , wasiliana na Prof. E .F .Lyamuya, Chairman of the College Research and Publications Committee, P.O.Box 65001, Dar es Salaam. Tel: 2150302-6.

Sahihi

Je unakubali kushiriki?

Ninakubali kushiriki ☐ Sikubali kushiriki ☐

Mimi _____ nimesoma na kuyaelewa vyema maelezo yaliyomo katika fomu hii. Maswali yangu yamejibiwa. Ninakubali kushiriki katika utafiti huu.

Sahihi ya Mshiriki _____

Sahihi ya Mtafiti _____

Tarehe ya kusaini _____