DISCLOSURE OF HIV SERO-STATUS AND ASSOCIATED CHILD AND CARETAKER FACTORS IN CHILDREN AGED 7 TO 14 YEARS RECEIVING ANTIRETROVIRAL THERAPY, IN CARE AND TREATMENT CLINICS IN DAR ES SALAAM, 2007

Dr. Kristina Kengeri Lugangira, MBCHB (MU)

MMED (Paediatrics and Child Health) Dissertation

Muhimbili University of Health and Allied Sciences

November 2008

DISCLOSURE OF HIV SERO-STATUS AND ASSOCIATED CHILD AND CARETAKER FACTORS IN CHILDREN AGED 7 TO 14 YEARS RECEIVING ANTIRETROVIRAL THERAPY, IN CARE AND TREATMENT CLINICS IN DAR ES SALAAM, 2007

By

Dr. Kristina Kengeri Lugangira, MBCHB (MU)

"A Dissertation Submitted in Partial Fulfilment of the Requirements for the Degree of

Master of Medicine (Paediatrics and Child Health) of the

Muhimbili University of Health and Allied Sciences"

November 2008

CERTIFICATION

The undersigned certify that they have read and hereby recommend for acceptance a dissertation entitled ***"DISCLOSURE OF HIV SEROSTATUS AND ASSOCIATED CHILD AND CARETAKER FACTORS IN CHILDREN AGED 7 TO 14 YEARS RECEIVING ANTIRETROVIRAL THERAPY, IN CARE AND TREATMENT CLINICS IN DAR ES SALAAM, 2007"*** in partial fulfilment of the requirements for the degree of Master of Medicine (Paediatrics and Child Health) of the Muhimbili University of Health and Allied Sciences.

------------------------------------	------------------------------------
Prof. Karim P. Manji	Dr. Sylvia Kaaya
(Supervisor)	(Supervisor)
Date 13th October, 2008	Date 15th October, 2008

DECLARATION AND COPYRIGHT

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

Signature____________________

ACKNOWLEDGEMENT

I express my sincere thanks to my supervisors, Professor Karim Manji and Dr. Sylvia Kaaya for the tireless guidance and encouragement. I deeply value the time they allocated to me.

I am grateful to Heads of Department of Paediatrics and Child Health Dr M. Fataki (MUHAS), Dr. J.Kitundu (MNH), my course coordinator Dr A.Massawe and all the department staff. My thanks also go to Prof. E. Muhondwa, Dr S. Kamazima, Dr M. Kazaura, Mr. F. Mayunga, and Mr. C. Makwaya for their excellent in puts.

My special thanks to Dr. G. Chalamilla for the assistance extended to me in order to carry out this study, without forgetting the site managers, the staff, the children and their parents/caretakers in the HIV/AIDS Care and Treatment Clinics, for their cooperation.

I am indebted to the efforts of some special people, Mr Einar Lunde and Stromme-Foundation, Norway, for their endless support and for believing in me.

Thanks most of all to my husband, mum, sisters and brothers for the encouragement and my dear daughters Monalisa and Fifi for being patient and understanding.

Lastly but not least, my heartfelt appreciations to each one of you, not mentioned here for your enlightening inputs that have made this work a success.

I thank the Almighty God, for making things happen.

DEDICATION

To my late father, the ideal father. (R.I.P)

ABSTRACT

Background: Paediatric HIV infection continues to increase in sub Saharan Africa as a result of mother to child transmission (MTCT). With the increased availability of anti-retroviral therapy (ART), there is an increasing number of children with perinatally acquired HIV infection who are surviving into mid-childhood and adolescence. It is therefore necessary to gain more of an understanding about some of the complex issues of children and adolescents living with HIV including issues relating to disclosure. It is crucial to involve the child fully in the process of management of HIV disease. An important step in such an undertaking is to have a better understanding of child disclosure practices, and to identify the barriers and enhancers of disclosure to children with HIV

Objective: To assess HIV sero-status disclosure among children aged 7 to 14 years attending Care and Treatment clinics in Dar es Salaam.

Study design and setting: A cross sectional quantitative and qualitative study using structured and in depth interview guides respectively, at four HIV Care and Treatment Clinics in Dar es Salaam, Tanzania.

Study Subjects: A total of 280 HIV infected children aged 7-14 years and their parents/caretakers were identified to join the study as written consent was obtained. Ethical clearance was granted to carry out the study by the Research and Publication Committee of Muhimbili University of Health and Allied Sciences. Permission was also obtained from Municipal Medical Officers and site managers of the four CTCs where the study was to be conducted.

Methods: From August to November 2007, a descriptive cross-sectional study collected qualitative and quantitative data to determine HIV/AIDS diagnosis disclosure rates among HIV infected children. Proportionate samples of 272 consecutive children and their caretakers attending four HIV/AIDS care and treatment clinics (CTCs) and a convenient sample of 8 child/caretaker pair for in-depth interviews were recruited. Unstructured individual interviews informed descriptions of nuances related to treatment and disclosure experiences using descriptive summaries of narratives. Univariate and multivariate analyses determined prevalence of child diagnosis disclosure and associations with child and caretaker socio-demographic and treatment related factors.

Results: Just over 12% (12.1%) of children on treatment were formally informed of their HIV diagnosis. Factors independently associated with the diagnosis disclosure to children were older child's (p value <0.001) or caretaker's age (p value < 0.01); caretakers employment (p value 0.02). Similarities in caretaker's diagnosis disclosure concerns across qualitative and quantitative data included the child being too young; and the potential for psychological reactions and family vulnerability to stigma due to inadvertent diagnosis indiscretion in the child. Children knowing their diagnosis better understood their contribution to sustaining health despite challenges, while those not knowing, resented taking medication and depended on caretakers for drug administration (p value <0.001). Discrepancy was indicated in recognition of children's distress when children's accounts of their distress in response to diagnosis disclosure are compared to what was recognised by disclosing parent/caretakers. (sadness 10 (30.3 %), anger, one (3.0%) 22 and in-deference 22 (66.7%)

Conclusion: The prevalence of disclosure of HIV diagnosis to children aged 7-14 years is low. Strengthening of guidelines on paediatric care and treatment should include healthcare providers' roles in facilitating child HIV diagnosis disclosure by caretakers. A "right to know" perspective is recommended to enhance full participation of affected children and youths in HIV &AIDS care and treatment. A better understanding of what children mean when they say they become distressed as well as how they respond to this distress could provide information to develop strategies that increase parent/caretakers recognition of distress and appropriate supportive responses. A "right to know" perspective is recommended to enhance full participation of affected children and youths in HIV & AIDS care and treatment.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ACTG	AIDS Clinical Trial Group
ART	Antiretroviral Therapy
CD4	Cluster of Differentiation 4(T-lymphocyte bearing CD4 receptor)
CTC	Care and Treatment Clinic for HIV
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IDC	Infectious Disease Control
IDI	In-depth interviews
MDH	Muhimbil Dar es Salaam City Harvard
MNH	Muhimbili National Hospital
MTCT	Mother-to-child transmission
MUHAS	Muhimbili University of Health and Allied Sciences
NACP	National AIDS Control Programme
PCR	Polymerase chain reaction
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
RCH	Reproductive and Child Health
SD	Standard Deviation
UNAIDS	United Nations Joint Programme on HIV/AIDS
USAID	United States Agency for International Development
VCT	Voluntary counselling and testing
WHO	World Health Organization

DEFINITION OF TERMS

Adolescence	According to WHO definition, it is the period of life between 10-19 years
Antiretroviral therapy	Drugs that inhibit the replication of HIV. When given in combination, HIV replication and immune deterioration can be delayed, and survival and quality of life improved.
Caretaker	A person, who lives with the child, participates in the child's daily care.
Child	Person aged up to 18 years.
Children infected with HIV	Children who have a positive test for HIV antibodies when more than 18 months of age or a positive DNA PCR when less than 18 months of age.
Children orphaned by AIDS	Persons aged less than 18 years of age who have lost one or both parents because of HIV/AIDS.
HIV Disclosure	Having told a child about his/her HIV/AIDS diagnosis
Health care provider	One who delivers proper health care in a systematic way professionally to any individual in need of health care services.
Perception	What is believed about or considered.
Sero-status	Refers to either HIV negativity or HIV positivity.

1.0 INTRODUCTION AND LITERATURE REVIEW

1.1 Prevalence of HIV infection

Human Immunodeficiency Virus, (HIV), is the greatest health crisis the world faces today. According to UNAIDS estimates, the number of people living with HIV globally in 2007, was 33.2 million (30.6-36.1 million). Of these, 22.5 million (60%) live in sub-Saharan Africa (SSA).[1] Despite improved medical treatment options and ongoing prevention efforts in SSA, the death rate from Acquired Immune Deficiency Syndrome, (AIDS), continues to grow and new infections continue to emerge, particularly in women. Among adults living with HIV infection worldwide, women accounted for 50% of adults and 61% in SSA.[2] Children continue to be born with HIV infection and with the increased availability of anti-retroviral therapy (ART), there is an increasing number of children with perinatally acquired HIV infection who are surviving into mid-childhood and adolescence. In 2007, new infections were 2.5 million, with 420,000 (350-540,000) being children under the age of 15 years. People who died of AIDS were 2.1 (1.9-2.4) million and 330,000 (310,000-380,000) were children. HIV/AIDS now accounts for 7.7% of mortality in children aged below five years and although children under the age of 15 years represented just about seven percent of 22.5 million people living with HIV/ AIDS in SSA, they accounted for 15.7% of the 2.1 million deaths in 2007.[2]

According to revised estimates from UNAIDS January 2008, using Spectrum EPP, indicate that in 2007 HIV sero-prevalence in the 15 to 49 year age group was 6.2% in Tanzania.[2] Children under age of 15 years estimated to have HIV infection were 140,000 (85,000-230,000).[3] Children constituted five percent of people living with HIV in Tanzania, in 2004. Amongst children below the age of five years, mortality attributable to HIV was estimated at 16%.[4] In Dar es Salaam, Tanzania, the HIV prevalence among sick children admitted at Muhimbili National Hospital year 2002, was 19.2 % and their mortality rate was 21.4%.[5]

1.2 HIV transverse and horizontal transmission risks in children

More than 90% of HIV infected children under the age of 15 years worldwide have acquired the infection from their infected mothers.[1] Data based on observational studies and clinical trials show that the transmission risk for a c hild born to an HIV infected mother in an African setting (transverse risk), without any interventions for prevention of mother-to-child, transmission (PMTCT) is about 30–40%. UNAIDS currently estimate that 1,600 children are infected daily by their HIV infected mothers in developing countries, 1,500 of them being in sub-Saharan Africa.[6] Surveillance report (2007/2006) on HIV and Syphilis Infections among antenatal clinic attendees, suggested the overall HIV prevalence of 8.2%.[7]

In developed countries, such as the United States, where early recognition of HIV infection amongst pregnant women is routine and ART is available, the average age of children born with HIV was reported to range from 8.6 to 13 years. Those reported to live longer than 13 years were 36-61%.[8,9] In Tanzania, there is increasing availability of routine HIV counselling and testing in antenatal care settings and access to antiretroviral therapy (ART), in both the antenatal and postnatal periods. Availability of and access to ART results in a significant decrease in mortality and morbidity.[10] This situation implies that an increasing number of children that acquire HIV infection in the perinatal period will survive into mid-childhood and adolescence, thus increasing the population of children and families living with HIV as a chronic disease. With onset of puberty, children with HIV infection can become sexually active, thus posing a risk to their sexual partners or of being re-infected by other HIV positive persons.[7, 11]

However, among adolescents, horizontal transmission plays an important role in HIV transmission. A review of studies of sexual behaviour of school based adolescents in Sub-Saharan Africa indicate an early age of onset of sexual intercourse in samples with mean ages of 12.0 to 15.5 years for males and 13.6 to 15.9 years for females.[12] One article cited four percent (n=1,751) female adolescents initiated sexual activity before the age of 10 years.

Challenges arise in interpreting this data as most studies confined themselves to vaginal penetration sexual act, leaving out other high-risk sexual practices. Some children did not interpret such practices as being sexual as reported by street children in Tanzania. Large proportions of sexually active adolescents, reported unprotected sexual intercourse and more than one life time sexual partner. [12]

In a rural North Western Tanzania cross sectional survey of primary schools pupils, with mean ages of 15.5 and 14.8 years, for male and female pupils respectively, sexual experience was reported by one fifth of the female pupils and half of all males (n=9,283).[13] Rates of HIV prevalence was reported as 0.2%. Although the prevalence of sexually transmitted infections (STI) biomarkers was relatively low, the study alerts to the reality of early-unprotected sexual activity in the Tanzanian context. Primary and secondary school pupils have been reputed to have inadequate levels of knowledge on sexual and reproductive health, including methods of preventing transmission of STI and HIV, which put them at risk of acquiring these infections. This observation is supported by data demonstrating scores on HIV/AIDS knowledge scale in young persons of mean age 14.9 years.[14]

1.3 HIV/AIDS Care and Treatment Programmes in Tanzania

Large-scale HIV/AIDS prevention and treatment programmes have been established for adults and HIV-exposed children. Nutrition counselling and management in the care and treatment of HIV/AIDS includes prompt treatment of opportunistic infections, growth monitoring and provision of micro and macro-nutrient supplements, especially multi-vitamins.[15, 16,] PMTCT and ART. Less than 10% of HIV-positive expectant mothers globally and six percent in SSA receive PMTCT services which include provider initiated counselling and testing for HIV, risk reduction counselling, short course preventive ART, counselling for safe infant feeding options and ART for the child. According to a report by Naftalin et al. (2004), in Tanzania, of 90% of pregnant mothers who accessed antenatal care, only 6.5% had tested for HIV infection.[17]

ART under the National Care and Treatment Programme were introduced in Tanzania in October 2004, for the treatment of eligible adults and children with HIV/AIDS. Treatment is offered to infants and children with confirmed HIV infection that meet the criteria for ART initiation using WHO defined indicators (Appendix i). By 31st July 2007, of the 188,264 patients enrolled into the programme, 8.8% (16,643) were children. Monitoring data from eight CTCs in Dar es Salaam, at primary and secondary levels of care showed that, as of September 2007, there were 3,586 children attending eight CTCs, with 54% (N=1,927) receiving ART. Of those on ART, 74.8% (N=1,441) were of age 7-14 year old.[18] Tanzania is one of the countries with the highest number of children (11%) on ART in East and Central Africa [19] The average duration of survival for children on ART in Tanzania has however not been established.

Early diagnosis of HIV infection and referral to CTC sites ensures timely care and treatment, including assessment of readiness to initiate ART. It also ensures support for care-providers of HIV positive children who struggle with making decisions related to disclosure of the child's and/or their own HIV sero-status to significant others; commitment to ART adherence, and implementation of adherence plans for the child. ART for HIV infected children; as is the case for infected adults, involve a process that is more than simply the prescribing of drugs. Such inputs optimize uptake of various HIV infection control options by parents or caretakers and in this way delays the progression from HIV infection to AIDS and the need for ART. Eventually the responsibility for engagement in control of disease progression needs to transfer gradually from the care-provider to the infected children/youths.

The goal of antiretroviral therapy is to maximally, suppress viral replication, preferably to undetectable levels for as long as possible, while preserving and/or restoring immune function and minimizing drug toxicity. This will prolong survival; promote optimal growth and development; preserve, enhance, or reconstitute the immune system and reduce opportunistic infections through suppressing HIV replication. Delaying HIV disease progression contributes tremendously to HIV reduction of related morbidity and mortality.[20,21] Aggressive antiretroviral therapy with at least three drugs is recommended for initial treatment of infected children because it provides the best opportunity to preserve immune function and delay disease progression. [20]

1.4 Disclosing HIV status to children

Adults living with HIV/AIDS (some of them parents) do not disclose their HIV status to their partners or children.[22, 23, 24] To date, studies to understand disclosure of HIV status that have been undertaken in Tanzania, are few and have focused on adults. A study in Tanzania, that enrolled 288 pregnant women using self-reported disclosure, documented that only 16.7% disclosed their positive HIV sero-status to their sexual partners.[24] In a prospective Tanzanian study of predictors, of HIV-1 sero-status disclosure, in HIV positive pregnant women, self-reported disclosure of own diagnosis to a partner increased from 22% to 40% over a 3-year period of observation.[25] These studies raise concern that in the absence of partner disclosure, the HIV status of a child also risks not being communicated to the child by parents/caretakers if only one parent/caretaker is aware of the child's HIV status.

Despite significant advances in HIV treatment and care, there is anecdotal evidence of reluctance to HIV status disclosure of the perinatally infected child by families; such resistance is one of the clinical challenges to managing infected children. Resistance to HIV status disclosure may be part of the tremendous stigma to the disease that still exists in society. Providing HIV status disclosure and medical counselling to children living with HIV can be difficult. However, it is important and feasible if conducted in a systematic manner that minimizes psychological distress to both caretakers and the infected children. Children living with HIV/AIDS are, like other children, undergoing continued cognitive and psychological developmental changes that make the task of disclosure even more difficult. Nonetheless, there comes a stage whereby the child has to be informed about his or her illnesses in a supportive manner; this is preferable to the child so that he/she does not accidentally find out that they are infected through gossip or from peers. Attention to a process of HIV disclosure and emotional support for caretakers and children is crucial to avoid misinformation and to provide an opportunity to involve the child fully in the management of HIV/AIDS.

In order to have a smooth and gradual uptake of personal responsibility and engagement of a child living with HIV/AIDS in their own disease management, there is a stage where a child needs to be considered sufficiently mature and able to deal with information about their illness. The prevalence of and age at disclosure to a child of his or her positive HIV sero-status varies widely. Among studies reporting disclosure, there is a wide variability. Studies suggest a significant number of children have not been informed of their HIV status by their parents/caretakers and that a variety of patterns and levels of disclosure about HIV/AIDS status to affected and infected children have been employed as follows.[26, 27, 28,29]

Funck-Brentano (1997), studied the patterns of disclosure and perceptions of the HIV in infected Parisian elementary school age children. Among 34 HIV infected children of mean age 7.5 years, 83.0% were not told of their HIV diagnosis. Partial disclosure of a HIV/AIDS diagnosis (description of the symptoms, treatments, the virus, and immuno deficiency with no reference to an AIDS diagnosis or HIV infection), was reported in 40.0% of the children, while full disclosure was provided to six (17.0%) of the children. Secrecy regarding the child's sero-status was reported by 15 (43.0%) of the parents or caregivers. These parents/caregivers reported complete nondisclosure (n=8) or deception by attributing illness symptoms to another condition, medical or otherwise (n=7).[30]

A study conducted by Apateerapong,[31] amongst Thai infected children of median age seven years (ranging 2.8 to 13.0 years) between 1984 and 1993, showed that only two percent of caregivers (n=35) fully disclosed HIV status to their infected children. In the same study, an exploration of attitudes of caregivers towards HIV disclosure indicated that while 60% of caregivers intended to disclose to their children in the future, most of them were poorly prepared to do so and for a time, they were willing to lie/distort the truth if the children asked questions about their illnesses. The findings suggested a need to help both caregivers and children prepare for HIV disclosure.

In a study amongst Thai children[32], 19 out of 96 children (19.8%) of mean age 9.6 years had been told of their HIV diagnosis by their caregivers. Eighty-four percent of the disclosed children reported they perceived their illness to be HIV infection or AIDS. Common reasons for non-disclosure to children were concerns that the child was too young, could be psychologically harmed by the information, and that the child would not be able to keep the information regarding their diagnosis confidential. Out of 77 non-disclosing caregivers, about 70% (n=54) intended to inform the child of his/her HIV status in the future. However, the remaining 30% were reluctant to disclose HIV sero-status to the child.

In Benin, West Africa, a study reported reasons for and outcomes of health care professionals disclosing HIV status to children aged 6-14 years at a care unit for children exposed to or infected by HIV/AIDS. Out of the 24 children seen between June 2000 and October 2004, 14 (50%) were on ART, and 23 % were informed of their sero-status by their paediatricians in response to poor ART adherence. From the parents' perspective, similar concerns regarding risks to privacy reported by Thai parents were noted. Ninety two percent of the West African parents were concerned that should the children know of their diagnosis, they could reveal this information to the neighbours.[33]

In a South African study, focus group discussions with 17 primary caregivers of children with HIV seen for care at Chris Hani Baragwanath Hospital in Soweto, it was revealed that primary caregivers of children with HIV typically do not disclose HIV status to the infected children, despite the fact that children often asked questions about their illness.[34]

Some studies have systematically explored the perspectives of adults about what to disclose to a child living with HIV/AIDS and at what age. Analyses of narratives collected in a paediatric HIV clinic in Cape Town South Africa by Myers , reported that most healthcare providers stated that discussions with a child about their health should begin at an age of six years. The specifics about HIV infection and disease should, however, be delayed until a child attains the age of ten years. Key informants for the study reported that caretakers should lead discussions with their children, but require support of healthcare providers. Ninety-eight percent of caretakers recommended use of formal guidelines.[35] Ages of 5 to 7 years have been proposed else where as when to begin a gradual process of disclosure.[36]

Experience in the counselling of children with conditions not related to HIV indicates that children cope better when told of the disease condition, such as cancer, at an earlier rather than a later age. With disclosure, the children have higher self-esteem and parents feel less depressed.[37] Studies conducted in Uganda indicate that children who are informed of their HIV status cope with disclosure, if not better, than adults do. A study at the Mildmay Centre in Uganda demonstrated that complete disclosure and a strong parent-child relationship were related to good adherence among children taking cotrimoxazole prophylaxis and ART. The study further showed that as children to whom HIV status was not disclosed matured and suspected they might be HIV sero-positive, intentional non-adherence to ART was not unusual. Children who knew their diagnosis had better adjustment to chronic illness and less psychological distress, suggesting that open communication may enhance family functioning and adaptation to HIV disease.[38]

For a patient to have a significant fall in viral load, adherence must be high with adherence level of 95% and above, of prescribed doses of ART.[39, 40, 41] It is therefore important for health workers to understand and address issues related to disclosure of HIV status to children living with the infection, and also to consider it an important facility based ART adherence support. Intermittent exposure of HIV to ART results in development of resistant strains and an increase in viral load replication, usually followed by immunological deterioration. Unilateral decisions to increase or reduce ART and other drug doses by care caretakers or children themselves may have a major impact on drug interactions. Brief episodes of missed medication have been associated with major drug interactions, and development of HIV strains resistant to ART.[42]

Stigma has been identified as an important barrier to disclosure. In Tanzania, reported HIV stigma indicators in adults included fear of causal transmission, shame, blame, and judgment, discrimination and concerns regarding risk of own sero-status becoming common knowledge.[43] Children infected with HIV have similar needs to those of adults including access to appropriate medical treatment, confidentiality and protection from discrimination. There are, however, developmental needs and family issues that specifically affect children. In addition to the risk of discrimination, children have to cope with chronic ill health that impact on growth and educational attainment. Furthermore, taking pills every day and regular blood tests without knowing why this is necessary, risks straining relationships with caretakers in the home. Children may ask questions about illness related events or why they are different from other children; evasive responses or no response from parents/caretakers is not unusual. For some children who know their status, they have the burden of keeping this information confidential or limiting information to selected persons.[44, 45]

1.5 ARV drug adherence : In the absence of a gold standard measure for ART adherence, options for monitoring adherence include self-report, announced and unannounced pill counts, review of pharmacy refill tracking records. Additionally other measures include electronic monitoring, biological markers and health care provider assessments.[46] Self-report and announced pill counts supported by pharmacy refill tracking records are the most common strategies used for routine monitoring of ART adherence. Self-report as a measure of adherence may, however, be biased due to poor recall, and strategies to circumvent this include requiring recall of drug use over a short period (for example missed doses in the week or month prior to assessment). Pill counts at clinic visits, while a useful monitoring tool, does not guarantee that drugs removed from the container were actually taken. This limitation is also the case when using pharmacy refill records, however well maintained, to monitor ART adherence.

Electronic medication monitoring devices have limitations including inability to assure that pills taken out when opened are used; furthermore, the use of this adherence measurement approach in the context of developing countries is limited due to prohibitive costs. The logistics of unannounced pill counts pose implementation difficulties for routine monitoring although periodic operations research using an unannounced pill count method could be one way of both determining the validity of routine adherence monitoring activities and evaluating new formal adherence supports initiated at CTCs. For the child, measuring of adherence is made more difficult due to their dependence on caretaker reports for drug administration.

Despite the above limitations in measurement of ART adherence, some useful information can still be gathered using a combination of methods to measure adherence. Assessment of ART adherence, in one study in the USA found that 84% of 2088, HIV infected children and adolescents aged 3 to 18 years had complete adherence. [47] In addition to drug related factors such as complex regimens, with multiple drugs, high pill burden and sub optimal formulations, particularly for children, HIV/AIDS related social stigma may be an important environmental factor that may influence adherence through its association with HIV sero-status disclosure.

Article 13 of the UN Convention in part states that every child has a right to expression and a right to receive information and ideas. Children have the right to get and to share information, as long as the information is not damaging to them or to others. Also, they have a right to express their feelings, to be given home care support and offered required medical care.[48] Following disclosure regular supportive counselling is important to help young people with HIV infection to cope with the emotions and challenges they experience when they discover they are infected with HIV.[48] Furthermore, it helps the children make choices and decisions that will prolong their lives and improve the quality of life including adapting their life styles to accommodate daily pill taking and cope constructively with drug side effects. In these processes, each child should be gauged individually according to the child's age, maturity level and intellect. In the Tanzanian context, several questions arise that relate to management of HIV infection in children and adolescents such as; at what age should HIV/AIDS related information be provided to infected children? What is the appropriate age for HIV sero-status disclosure for a child to comprehend the information? What is the best way to disclose HIV status to the child who is infected? How and who should disclose? At what age should adherence counselling with children as direct recipients be initiated?

2.0 PROBLEM STATEMENT AND RATIONALE THE STUDY

2.1 Problem statement

Unabated high rates of HIV infection among pregnant women and the high rates of MTCT in Tanzania continue to result in perinatal HIV infection in children. Use of ART as well as prevention of opportunistic infections result in decrease of morbidity and mortality for HIV infected children. Among identified HIV infected children who access ART services at CTCs, preliminary routine data indicate improved short-term (18 months) survival rates and it is likely to be sustained through adolescence. Children are characterized by physical, emotional and cognitive changes as well as significant changes in the relationship between themselves, their family/care givers and peers. The consequences may be greater in the context of coping with HIV positive sero-status and adhering to the restrictions imposed by management of HIV disease in surviving children faced with multiple medical challenging issues of medical regimens and drug adverse events. Studies show that large proportions of sexually active adolescents practice unprotected sexual intercourse and have more than one lifetime partners. Furthermore, inadequate knowledge on sexual and reproductive health will put them at risk of rapid disease progression in addition to infecting others.

Strict adherence is mandatory for effective ART and this requires shared information between health care providers and caretakers and eventually between healthcare providers, family and the child. A number of healthcare providers in Tanzania are better trained in adult than child medical counselling. Often parents/caretakers lack adequate information and communication skills or are fearful about of the impact of disclosure and fear that the child will reveal the diagnosis to others, which makes them unwilling to work actively with their children towards shared responsibilities for HIV/AIDS care and treatment.

There are critical gaps in our knowledge on the extent to which children attending CTCs understand the illnesses they are being treated for and their awareness of their HIV positive sero-status, both of which are important pre-requisites for the child's constructive engagement

3.0 OBJECTIVES

3.1 Broad objective

To assess HIV sero-status disclosure among children aged 7 to 14 years attending Care and Treatment clinics in Dar es Salaam.

3.2 Specific objectives

1. To determine proportion of HIV infected children disclosed to by selected child characteristics.
2. To determine the process of disclosure of HIV status among HIV infected children.
3. To determine the effect of different parental/caretaker characteristics on HIV diagnosis disclosure to infected children.
4. To determine drug administration among HIV infected children.
5. To describe perceived risks, benefits and barriers amongst parental/caretakers towards discussing illness matters with the HIV infected children and children's experiences.

4.0 METHODOLOGY

4.1 Study design

Using a mixed designed study methodology, a cross-sectional descriptive hospital based study was carried out, whereby combined qualitative and quantitative data collection methods were employed to generate information from children and their parents/caretakers.

4.2 Study setting

This study was conducted in four paediatric HIV/AIDS Care and Treatment Clinics within three Municipal hospitals of Dar es Salaam. The three hospitals were Mwananyamala (Kinondoni Municipality), Amana (Ilala Municipality) and Temeke (Temeke Municipality). The fourth clinic was at the Infectious Disease Control Centre (IDC) situated in Ilala Municipality. The Municipal Hospitals are public hospitals that serve the inhabitants of Dar es Salaam Region. Dar es Salaam being the largest city of Tanzania, has a population of more than three million people, 32% of whom are children under the age of 15 years.[50] A prevalence of 19.2% of HIV infection has been reported among admitted children in a tertiary hospital in Dar s Salaam.[5] The study sites were selected because they house large HIV/AIDS Care and Treatment Clinics and would be representative of the HIV infected children accessing care and treatment in Dar es Salaam.

4.3 Study population

The study focused on children of age group 7 to 14 years, attending CTCs and receiving ART, in the Kinondoni, Ilala and Temeke Municipals in Dar es Salaam. This group covered the middle school age period (7-10 years) and young adolescents (11-14 years). From age of seven years, most children can express themselves well. and from a cognitive development perspective, are developing abstract thinking and therefore enabling them to shift between the general to the particular and vice versa when thinking through concepts and situations.[51, 52] Hence, at this age, information on issues related to a specific situation can begin to be used in novel situations such as preventive and health promoting behaviours. With the selected age range of 7 to 14 years, a substantial contribution was expected in terms of information gathered to assist in future development of clinic-based interventions that are particularly appropriate and relevant to this age group.

4.3.1 Inclusion criteria

The inclusion criteria were HIV infected children between ages of 7 and 14 years who were attending the CTC as outpatients and had been on ART for at least 6 months and whose parents/caretakers provided written informed consent to participate in the study. Furthermore, additional data was collected from the primary caretakers/parents of a child participating in the study.

4.3.2 Exclusion criteria

Children who were not accompanied by a parent or caretaker or whose parents/caretaker did not consent to participate in the study and children with mental retardation were excluded. Likewise, children who were under the care of orphanage homes were excluded, as they did not have specific caretakers. Most orphanages in Dar es Salaam belong to certain communities or organizations and the children are under the immediate care of a supervisor.

4.4 Study duration

The duration of the study was four months, from August to November 2007.

4.5 Selection of key informants and sample size estimation

Key informants were selected as they came in the clinic.

4.5.1 Qualitative formative interviews

Child key informant

At recruitment at each clinic, the first two children aged between 10 and 14 years, one of whom had been informed of the HIV status and the other who had not, were recruited for the individual in-depth interview (IDI). The criteria employed for their selection was parental consent and child's assent to participate after being provided with information on what participation would entail. The age and assent was deemed essential as IDI participants need to be able and willing to provide the necessary information. Older children (10 years and above) would perhaps have a longer experience of use of ART and hence more likely provide the comprehensive information required on their experiences with illness and ART use.

Adult key informant (parent/caretaker

At each clinic, two consenting caretakers/parents were invited to participate in the parent/caretaker IDI. It was anticipated that attitudes would vary by HIV diagnosis disclosure to the child. The selection criteria for formulating the parents/caretakers/ IDI key informants were hence non-disclosure or disclosure of HIV diagnosis to children. Non-disclosure is defined for this purpose as when a parent/caretaker was not willing or being unable to provide any information to the child about the HIV status or illness or if she/he attributed illness to some other disease. Disclosure of HIV serostatus is when the child had been told that he/she is infected by HIV or has AIDS. Two participants were recruited per selection criteria, hence eight adult key informants were recruited across all four clinics for the in-depth interviews. Selected child and adult key informants for in-depth interviews were not recruited for the quantitative survey to avoid contamination of that sample, as a prior in-depth interview encounter would result in differential exposure to research subject matter in in-depth interview key informants when compared to strictly subjects that had not been subjected to the same.

4.5.2 Quantitative survey

Sample size estimation

For quantitative data, the following equation for single proportion was used to calculate the sample size.

$n= 4p\,(100 - p)/\,d^2$

Where: - n = minimum sample size

4 = approximated squared value of standard normal distribution of 1.96 to 2 (at 95% CI)

p = estimated proportion of disclosure (18.5%, mean of disclosure in 2 studies of Funck Brenteno and of Thai children [30, 31]

d = maximum likely error (5%)

The minimum calculated sample size, n = 241. Having a sample with stigmatised disease, an assumed 13% drop out of the study was used to give an estimated sample size of 272 children. For each child, a parent participant/caretaker accompanying the child on day of interview was also involved.

Sampling procedure

A proportionate sampling technique was used to recruit consecutive children attending CTCs at the four sites. The number of children to be recruited from each clinic was proportional to the total number of children attending that particular clinic. Thus, the clinic with a large number of children was correspondingly represented by a larger number of children in the study sample. Likewise, a clinic with less number of enrolled children had lower representations in terms of number of children in the sample. With 1505 registered HIV infected children across all sited as of June 2007, a sampling proportion of 51.5% was used to determine the minimum number of children at each clinic. Using this guideline, 90 eligible children were recruited from Amana Hospital CTC, 78 from the Mwananyamala Hospital CTC, 57 from the Temeke Hospital CTC and 47 from the IDC.

Children meeting the inclusion criteria were continuously enrolled as they came to the clinics until the required sample size were obtained. At the CTCs, paediatric visiting day is once a week and falls on same day of the week. Thus, data was colleted from one site until the required number of participants for the particular clinic was obtained before the researcher moved on to another CTC. On average, 15-17 children were recruited per week. In order to avoid double recruitment, files of enrolled participants in both qualitative and quantitative surveys were identified by a sticker. Participants were told that participation was once, for both the child and the parent/caretaker and at each interview session, the researcher asked the parent/caretaker if she/he had recently participated in similar study.

4.6 Study Procedures

Upon enrolment and recruitment into the study, the procedures for data collection were initiated starting with identification of the disclosure status, followed by qualitative data collection through IDI, and lastly quantitative data collection by use of structured guides for assessment of HIV diagnosis disclosure and ART adherence. In addition, information was obtained from consenting accompanying parent/caretaker of each of the selected children for the study.

4.6.1 Data Collection instruments

Pilot testing

Interview guides with structured interview schedules were pilot tested in a group of eight children and eight parents/caretakers, revised and then used for the quantitative interview.

Training of research assistants and translation of instruments

At each clinic one nurse, experienced in working with HIV infected children, was recruited and trained. The training covered the purpose of the study, data collection techniques, familiarity with data collection tools and strategies for quality assurance. Structured and unstructured interview schedules were translated from English into Kiswahili, (Appendices iv and v) the national language that is well known especially in urban setting like Dar es Salaam. The main researcher conducted all IDI observed by the nurse research assistant who also documented non-verbal events related to the interview. The main researcher and research assistant administered the quantitative structured interview schedules. Interview guides were checked for completeness before the participant left the clinic and the researcher checked filled forms daily for consistence to ensure good quality.

A trained clinical staff identified the targeted children from appointment records. Files for children 7 to 14 years who were on ART for a period of at least 6 months were retrieved and the children were earmarked for enrolment. A registration log book summarised information on the child's identification number, site registration number, and the child's initials, age, and day of recruitment The recruitment log book provided information for quality assurance of data collection (Appendix vi).

The attending staff approached all eligible parents/caretakers of the selected children to describe the study. Parents/caretakers who agreed to participate were escorted by the nurse to meet the researcher who completed the consenting process and determined study eligibility. Participants meeting study eligibility criteria were enrolled and those that were not legible were excluded with an apology and an explanation as to why they were excluded was provided. The parents/caretakers were assured that they would receive the routine medical services as provided at the facility. Enrolled parents/caretakers were asked about the child's knowledge of his/her disease prior to the interview. For the children who did not know their HIV sero-status, the interview questions referred to general health issues without any reference to HIV.

The children and the caregivers were interviewed individually and parents/caretakers were requested to reassure the child both for the parental/caretaker interview and for the child interview sessions. During parental/caretaker interview the child was left playing in the company of other children in the waiting area. Likewise, during child interview the parent/caretaker waited in the waiting area. Interviews were carried out during the time study participants were waiting for or after their routine clinic attendance, in a private room at the CTC facility.

4.6.2 Interviews: Individual in-depth interviews

For the qualitative data collection, semi-structured in-depth interviews guides with open-ended questions and probes were used to collect information from eight children and eight caretakers/parents individually. The participants were asked to clarify the information they gave throughout the interview. There were three different interview guides: one for the children, one for disclosing parents/caretakers and another for non-disclosing parents/care takers.

Child in-depth interviews

At each of the four CTCs, two children (one having been disclosed to and another undisclosed to) aged 10-14 years were interviewed using IDI interview guide to provide qualitative data. The interview duration lasted 10-20 minutes. The child's demographic data included age and sex. The three key thematic areas explored, included awareness of the child of his/her illness that required regular and daily medication, the child's perceptions of what illness she/he had, the medication used, and the child's views on how the illness affected his/her relationships with other people.

Care-taker/parents in-depth interviews

Similarly, two parents/caretakers participated in the IDI at each of the CTC. They comprised equal numbers of parents/caretakers who had and who had not disclosed HIV diagnosis to their children. The duration of parent/caretaker interviews was between 25 to 30 minutes. A short demographic interview was also administered to parents/caretakers for age, sex, relationship to the child and if they had disclosed to the child or not. A series of open ended questions and probes in these sessions were used to collected information surrounding three key thematic areas including; perception towards child disclosure, disclosure experiences and future plans for the child. The guide specifically probed for enhancers and barriers to disclosure of HIV diagnosis.

4.6.3 Quantitative surveys

Parents/caretakers and child versions of structured interview schedules were administered to collect quantitative data. The structured interview schedules collected information on:

Child Demographic and selected child medical characteristics:

Variables included age, sex, education, who the child was living with. Medical records were reviewed to extract medication regimen.

Caretaker/parent demographic and HIV related characteristics:

Included variable of age, sex, marital status, relationship to the child, HIV testing and HIV sero-status, education level and employment status.

Assessment of HIV Diagnosis Disclosure

Disclosure was assessed by asking a series of questions to the child and parent/caretaker. Parents/caretakers were asked whether HIV sero-status had been disclosed to the child. Further questioning was on how long the child had been on ART, reasons for having disclosed or not having disclosed the diagnosis, appropriate age for disclosure, who should disclose the HIV diagnosis to the child, communication within the family and outside the family. Specifically for the parents/caretakers who had disclosed, they were asked questions in relation to who told the child of the HIV diagnosis, post disclosure reactions of the child, age at disclosure, reasons for disclosure, advantages and disadvantages of disclosure. Non-disclosing parents were asked how they had managed not to disclosure. Inquiries were also made on communication about the child's HIV diagnosis to persons in and out side the family.

All interviewed children were asked about reasons for frequent hospital attendance. For those who acknowledged their HIV sero-status, they were asked how they came to know, who told them, what they were told and how their relationships at home, at school and with peers had been affected by the disease. Their communication about the disease to others (social disclosure) was also assessed. In this study, HIV disclosure is defined as a parent/caretaker sharing information on the child's HIV sero-status with the infected child.

Drug Adherence Assessment

In this study adherence to ART was assessed by self-reports of parents/caretakers and children. Adherence in HIV treatment is defined as managing and maintaining a given therapeutic combination of medication regimen to control viral reparation and improve immune function. It means taking the drugs exactly as agreed with health care provider (on time, all pills, no missed doses, every day). Inquiries were made on the timing and taking adherence. Right timing is when the doses are taken within one hour of the scheduled time. All doses of drugs in the existing ART regimen at CTCs are supposed to be taken every 12 hours except for Efavirenz, which is taken once in the evening. Four day self-reports were obtained probing specifically for two dimensions, timing and taking of ART. Child adherence to ART was assessed using a modified Swahili version of self reported adherence assessment tool developed by the Adult AIDS Trials Group, (ACTG).[53] Parents/caretakers were asked to report on the number of doses the child was supposed to take and number of missed doses on each day of the 4 days prior to assessment.

Percentage of the proportion of required doses taken within an hour of the prescribed time was obtained. All who missed a dose in the 24-hour period were treated equally to those who had incorrect dosing interval. Accepted anti retroviral adherence is when level of adherence is at least 95% of the pills taken. Hence, the cut off point of 95% was used to categorize participants as non-adherent (less than 95 used) or adherent (95% or more used. The level of adherence was calculated as a percentage of the prescribed doses taken, (e.g. if two doses were omitted in four day period of a daily regimen level adherence would be 6/8 x 100% = 75%). In this context, the percentage of adherence refers to the percentage of medication doses taken. For reliability of participants' responses, parent/caregiver interviews were compared with children's reports if dissimilar, the worst-case scenario was taken as valid. Drug adherence was analysed in both disclosed to anf non-disclosed to children.

4.7 Ethical clearance

Ethical clearance to conduct the study was granted by the Research and Publication Committee of Muhimbili University of Health and Allied Sciences. Permission to conduct the study was obtained from Municipal Medical Officers and site managers of the four CTCs where the study was to be conducted.

Ethical Considerations

Prior to recruiting participants for the formative and survey phases, parents/caretakers were subjected to an informed consent process. The purpose of the study was described and participants were invited to participate. They were informed of the study procedures, and assured that no invasive procedures would be used and that the study team would not disclose the HIV diagnosis to a child. The parents/caretakers were told of the potential benefits of participation, although not immediate. However they were informed that information they provided would help interventions to improve the quality of care and treatment of HIV in children Parents/caretakers were provided with opportunity to ask questions prior to consenting and at the end of each data collection session. Participants were informed of the voluntary nature of participating and that they could opt out at the beginning or during the study. For those who decided not to participate, assurance was given that they would continue receiving the routine medical services as provided at the facility. Requesting for permission to access medical records was part of the consent process. At the end of the session participants continued with activities of scheduled visit.

Participants were assured of confidentiality and only initials of names and unique identifying numbers appeared on the interview guides/schedules. Inadvertent disclosure to children was avoided through training and regular debrief with research assistants. Information gathered during data collection was handled with strict confidentiality by the researcher alone, locked in a safe place and utilized for the purpose of this study alone.

Information on how participants with concerns related to their rights as study participants was provided by giving participants phone contact numbers and referral addresses of the research team and the chair of the Research and Publications Committee of Muhimbili University of Health and Allied Sciences was provided in the consent form. Consenting parents/caretakers provided written consent for their own and their child's participation in the study (*Appendix ii)*. Children 10 years and above, where available, verbal assent to participate was requested. During the study any participant identified with a psychological or physical health problem were referred to the facility counsellor or a clinical doctor.

4.8 Data processing and analysis

Summaries were used to describe emergent patterns from narratives of experiences with HIV/AIDS diagnosis disclosure and non-disclosure to children. Common themes and differences in illness experience, responses and patterns of disclosure to children were summarized and are described.

Quantitative data were coded prior to data entry. The data were entered into a computer, cleaned to ensure accuracy of all entries and analysed using Statistical Package for Social Science (SPSS) software, version 10.[54]

4.8.1 Univariate analysis

Categorical variables were described using simple frequencies Comparisons between categorical variables were performed using the chi square test when comparing quantitative variables and Fishers exact test was used when the number was less than five. Statistical level of significance was set at p-value ≤ 0.05. Odds ratios (OR) were used to assess the strength of associations and were considered statistically significant when the surrounding 95% confidence intervals (CIs) excluded 1.00. All analyses were performed with SPSS.

4.8.2 Multivariate analysis

Based on the univariate analysis results, HIV diagnosis disclosure was regressed on all predictive factors of interest using multivariate logistic regression models. The models were used to determine the independence and strength of associations of demographic measures and predictive factors of interest, using the diagnosis disclosure status as an outcome variable. The models hence controlled for possible confounders within predictors. HIV diagnosis disclosure was regressed on factors associated with disclosing HIV diagnosis to children (parent/caretaker and child factors) that in univariate analysis varied at p value ≤ 0.05. Furthermore, variables identified in the literature to be associated with HIV diagnosis disclosure to a child or health outcomes in children (theoretical criteria) were also included in the models. A full factorial effects method was used whereby all socio-demographic and other predictors of interest were entered together in the first block of the logistic regression model in order to establish those that were independently associated with disclosure of child's HIV diagnosis. Variables were retained in the final adjustment if the 95% confidence interval of the OR excluded 1.00. In this way, effects of characteristic variables on disclosure were removed. Parameters of prediction in a final model are reported as odds ratios with their 95% confidence intervals. Similarities and contrasts in the qualitative and quantitative findings are discussed.

4.8.3 Study Variables

Independent variables: Characteristics of HIV infected child included sex, age (dichotomized as 7-10 years and 11-14 years), and education as to whether the child is in school or out of school/unregistered. The ART variables included the ART regimen, which was categorised according to the base of drug, (nevirapine or efaviranz) or if a protein inhibitor was included. Period of medication for which the child had been on ART was described as short duration if duration of less than 12 months and long duration if had duration of twelve months and above

Parent/caretaker variables included age (dichotomized as parents/caretakers of age less than 40 years and those of age 40 years and above), sex and religion. Only two types of faith were practiced, thus, religious denomination is summarised as Christian and Muslims. Children were under the care of parents or other close relative, thus relationship to the child is described as biological parents or kin caretaker. The education level attained by the parent/caretakers summarized as none/low education status if there was no formal education or the individual attended school up to primary seven and medium/high educational level for those who had attained education beyond primary school. The marriage status is reported as: in unison if were married or cohabiting and not in unison if were single, divorced or widowed/a widower.

Dependent variables: Diagnosis disclosure was dichotomized (categorized as non-disclosing when child was not informed that she /he is infected with HIV, and disclosed, when the child was told that he/she is infected with HIV/AIDS). ART taking adherence was dichotomized (categorized as 95% and above or below 95%); while taking adherence was also dichotomized as good if taken at time required (+/- one hour) or poor if not taken at time required.

5.0 RESULTS

From an eligible population of children, 283 children receiving ART were identified, the study objectives were explained to the caretakers and after informed consent was granted, the children were recruited into the study. Later on three children were dropped from the study. Two of them were deaf and one who cried uncontrollably during the interview was referred to the clinic counsellor. Data from 280 (98.9%) children were hence available for these analyses, 272 participated in quantitative survey and eight participated in IDI interviews for qualitative data. Since the plan was to interview one parent/caretaker accompanying the child, there was a corresponding data available from 280 parents/caretakers.

5.1 Quantitative survey results

Sample description

Characteristics of Children:

Table 1 summarises the characteristics of children that participated in the study. Of 272 children, the mean age was 9.8 (SD = 2.2) years. Females were 133 (48.9%) with mean age 10.0 years (SD = 2.3) which did not differ significantly from that of 9.7 years (SD = 2.1) of males. Children in school were 245 (90.1%) and 162 (59.6%) lived with caretakers. All the children caretakers were relatives and are referred to as kin caretakers.

Table 1 Characteristics of children attending HIV/AIDS Care and Treatment Clinics in Dar es Salaam, 2007 (n=272)

Characteristics	Number (%)
Sex	
Male	139 (51.1)
Female	133 (48.9)
Age group (years)	
7-10	171 (62.9)
11-14	101 (37.1)
Current school status	
Out of/unregistered	27 (9.9)
In school	245 (90.1)
Child living with	
Biological parent	110 (40.4)
Grand parents (kin caretaker)	47 (17.3)
Other kin caretakers	115 (42.3)

The CTC clinical chart for each patient showed that all the recruited children were on a combination regimen of two nucleoside reverse transcriptase inhibitors (NRTIs- lamivudine, stavudine, zidovudine,) and one non-nucleoside reverse transcriptase inhibitor (NNRTI-nevirapine, efavirenz) or two NRTIs and one protease inhibitor (PI-Ritonavir, Nelfinavir, Kaletra). During the study, 225 (82.7%) children were on a nevirapine (NNRTI) based regimen, 44 (16.2%) were on efavirenz (NNRTI) and the remaining three (1.1%), were receiving a protease inhibitor.

The period for which children had been receiving ART ranged between six and 48 months with a mean of 19.3 (SD = 9.6) months. One hundred and fifty two (55.9%) children had

Table 2 **Characteristics of parents/caretakers of children attending HIV/AIDS Care and Treatment Clinics in Dar es Salaam, 2007 (N=272)**

Characteristic	Number (%)
Sex	
Male	63 (23.2)
Female	209 (76.8)
Age group (years)	
Less than 40	160 (58.8)
40 and older	112 (41.2)
Religious denomination	
Christian	124 (45.6)
Muslim	148 (54.4)
Marital status of parent/care-taker	
Not in union	134 (49.3)
In union	138 (50.7)
Education	
None/low	192 (70.6)
Medium/high	80 (29.4)
Employment status	
Unemployed	84 (31.0)
Self/Casual employed	143 (52.5)
Employed – Salaried	45 (16.5)
Testing for HIV	
Never Tested	179(65.8)
Ever Tested	83.(34.2)

Univariate analysis of disclosure of HIV diagnosis to children and associated factors

Based on parents/caretaker reports, the prevalence of disclosure of HIV diagnosis to children aged between 7-14 years old was 12.1%. The mean age of children to whom parents/caretakers reported they had disclosed HIV diagnosis in this study was 11.8 (SD = 1.75) years, while that of children in the non-disclosed parents/caretaker group, was 9.56 (SD = 2.1) years. Child related factors associated with parents/caretakers reporting disclosure of HIV diagnosis are summarised in table 3.

Table 3 Proportion of HIV diagnosis disclosure to HIV infected children by selected characteristics of the child

Characteristic	N	Number (%) disclosing	p-value
Age group of children (years)			
7-10	171	8 (4.7)	
11-14	101	25 (24.8)	<0.001
Sex of child			
Male	139	13 (9.4)	
Female	133	20 (15.0)	0.15
School status of child			
Not in formal school	27	1 (3.7)	
In school	245	32 (13.1)	0.84
Child's duration on ART			
Short (less than 12 months)	105	12 (11.4)	
Long (at least 12 months)	167	21 (12.6)	0.27

Twenty-five (24.8%) older children (11 - 14 years) had been disclosed their HIV diagnosis compared to eight (4.7%) of younger children (7-10), this variation being significant (p-value <0.001). Disclosure of HIV diagnosis to children was independent of child's sex; duration on ART or whether the child was in or out of school.

Table 4 summarises the characteristics of parent/caretaker that were associated with disclosing HIV sero-status to children. HIV diagnosis disclosure to children was associated with the parent /caretaker's age, employment status and whether or not they had tested for HIV. A higher proportion of older (19.6%) than younger (6.9%) (p-value 0.002). parents/caretakers disclosed child's HIV diagnosis. Furthermore, a higher proportion (16.7%) of earning parents/caretakers (employed or self employed) disclosed HIV sero-status to their children than those that were unemployed (4.1%) (p-value 0.02). Finally, (14.5%) of parents/caretakers that had ever tested for HIV, disclosed HIV diagnosis to their children, compared to only 7.5% (p –value 0.09, of parents/caretakers that had never tested. This finding was of marginal significance.

Parental/caretaker's sex, education, relationship to the child and HIV sero-status were not associated with HIV diagnosis disclosure. Similarly, HIV diagnosis disclosure to the child was independent of the parent/caretakers reported religious affiliation and current marital status.

Table: 4. Proportion of parents/caretakers disclosing to HIV diagnosis to children by selected characteristics

Characteristic	N	Number (%)		p-value
		Disclosing	Non-disclosing	
Sex of parent/caretaker				
Male	63	9 (14.3)	54 (85.7)	
Female	209	24 (11.5)	185 (88.5)	0.55
Parent/caretaker's age (years)				
Less than 40	160	11 (6.9)	149 (93.1)	
40 and older	112	22 (19.6)	90 (80.4)	0.002
Religious denomination				
Christian	124	14 (11.3)	110 (88.7)	
Muslim	148	19 (12.8)	129 (87.2)	0.70
Current marital status				
In union	148	19 (15.2.8)	106 (84.8)	
Not in union	134	14 (9.5)	133(90.5)	0.15
Employment status				
Unemployed	84	4 (4.1)	94 (95.9)	
Employed *	188	29 (16.7)	145 (83.3)	0.02 †
Education level				
None/low	192	22 (11.5)	170 (88.5)	
Medium/High	80	11 (13.8)	69 (86.3)	0.60
HIV screening				
Ever tested	179	26 (14.5)	153 (85.5)	
Never tested	93	7 (7.5)	86 (92.5)	0.09
HIV sero-status				
Positive	94	10 (10.6)	84 (89.4)	
Negative	85	16 (18.8)	69 (81.2)	0.12
Relationship to child				
Biological parent	143	19 (13.3)	124 (86.7)	
Kin caretaker	129	14 (10.9)	115 (89.1)	0.54

* Employed include: self, casual and salaried employment

† Fisher's Exact Test

Factors associated with disclosure: a multivariate analysis

Disclosing HIV diagnosis to a child was regressed on a number of child and parent/ caretakers characteristics. The choice of characteristics to include in the regression model was made based on statistical evidence that include univariate analysis outcomes, empirical research as well as other evidences; for example, Mellins et al.[28] reported higher disclosure of diagnosis to the child when the parent/caretaker was HIV sero negative. Variation in disclosure by HIV sero-status of parent/caretaker in these analysis though not significant (p = 0.12) were included in the regression model for conceptual reasons. Many child health problems in the developing world have been related to educational level of the parent/caretaker; hence, level of education is also included in the model. It is often assumed that biological parents would have a greater commitment to the care of their children, hence whether the primary caretaker was a parent or not was included in the model for theoretical reasons.

Self reported disclosure of diagnosis to a child was regressed on these factors using a full effects model. Predictors included in the regression model were: sex of child, age group of child, duration on ART, parent/caretaker's sex, age group, employment status, marital status and relation to the child.

In the unadjusted model, both parent/caretaker and child's ages and parent/caretaker's employment status were predictors of paediatric disclosure. For example, older children (11-14 years) were about seven times (OR = 6.7, 95%CI = 2.9-15.5) more likely to be disclosed of their HIV sero-status as compared to younger ones. Parents/caretaker age of at least 40 years increases the likelihood of disclosing HIV diagnosis to children by more than 3-folds (OR = 3.3, 95% CI = 1.5, 7.1). Furthermore, employed parents/caretakers were almost five times (OR = 4.7, 95% CI = 1.6-13.8) more likely to disclose HIV diagnosis to a child.

Table 5 also summarizes adjusted factors associated with parents/caretakers reported HIV diagnosis disclosure to a child. In addition to the aforementioned factors in the unadjusted variables, a history of parent/caretaker testing for HIV (OR 3.0 95% CI 1.0-8.6) was also associated with paediatric disclosure, increasing the likelihood of diagnosis disclosure to the child three folds. The strength of the associations between diagnosis disclosure and the age of the child increased further after adjustment, with older age (11-14 years) being independently associated with eight times (OR = 8.0 95% CI = 3.2, 20.3) more likelihood of parental/caretaker disclosure of HIV diagnosis as compared to the child being younger (7-10 years). Some confounding factors between predictor variables is evidenced by higher effect sizes in the adjusted model for older age of parent/caretaker (40 years and above) compared with younger age (OR 4.1, 95% CI=1.6-10.4) and caretakers employed (OR 5.1, 95% CI=1.6-16.7) or unemployed status each increasing the likelihood of diagnosis disclosure four and five fold respectively.

The model explained 34% variability in diagnosis disclosure, which is good in that the model was able to capture the variances. Model applied Omnibus Tests and Hosmer and Lemesh tests (-2 Log Likelihood 148.4, X^2 52.6 df 10 and p less 0.01)

Table: 5. Logistic regression output of predictors of parents/caretakers HIV diagnosis disclosure to children

Characteristics	Number disclosed (%)	Unadjusted OR (95%CI)	Adjusted* OR (95%CI)
Sex of child			
Male	13 (9.4)	Reference	Reference
Female	20 (15.0)	1.7 (0.8, 3.6)	1.7 (0.7, 4.2)
Age group of child (years)			
7-10	8 (4.7)	Reference	Reference
11-14	25 (24.8)	6.7 (2.9, 15.5)‡	8.1 (3.2, 20.3)‡
Duration on ART (months)			
Short duration (< 12)	12 (11.4)	Reference	Reference
Long duration (12+)	21 (12.6)	1.1 (0.5, 2.4)	1.1 (0.5; 2.9)
Sex of parent/caretaker			
Male	9 (14.3	Reference	Reference
Female	24 (11.5)	1.3 (0.6, 2.9)	1.1 (0.4, 3.1)
HIV test (parent/caretaker)			
Never tested	7 (7.5)	Reference	Reference
Ever tested	26 (14.5)	2.1 (0.9, 5.0)	3.0 (1.0, 8.6)†
Employment status			
Unemployed	4 (4.1)	Reference	Reference
Employed	29 (16.7)	4.7 (1.6, 13.8)†	5.1 (1.6, 16.7)†
Education level (pc)			
None/low	22 (11.5)	Reference	Reference
Medium/High	11 (13.8)	1.2 (0.6, 2.7)	1.1 (0.4, 2.9)
Relationship to index child			
Kin care-takers	19 (13.3)	Reference	Reference
Biological parent/s	14 (10.9)	1.3 (0.6, 2.6)	1.9 (0.5, 6.9)
Parent/caretaker's age (years)			
17 – 39	11 (6.9)	Reference	Reference
40 – 74	22 (19.6)	3.3.(1.5, 7.1)‡	4.1 (1.6, 10.4)‡
Current marital status			
Not in union	14 (9..5)	Reference	Reference
In union	19 (15.2)	1.7 (0.8, 3.6)	2.2 (0.6, 8.2)

* = Adjusting for all variables included in the model with forced entry of all variables

† = $p < 0.05$;

‡ = $p < 0.01$

OR = Odds ratio; CI = Confidence Interval

Process of HIV Diagnosis Disclosure and Communication on HIV Treatment

Circumstances Surrounding Disclosure

Descriptive quantitative information from parents/caretakers was available on the processes involved in HIV diagnosis disclosure to the child. Among the disclosing parents/caretakers, 14 (42.4%) had been assisted by health care providers who had informed the child about his/her illness. Eight (24.0%) biological parents and eight caretakers had each disclosed HIV diagnosis to their children on their own without being assisted by anyone. The remaining three (9.I %) parents/caretakers had been assisted by persons other than heath care providers to disclose. Twelve parents/caretakers (37%) reported they had been alone with the child at the time of diagnosis disclosure, 15 (47.0%) reported a health care provider had been present, while five (15.6%) reported other persons had been present.

Parents/caretakers were also requested to provide information on their perceptions on who best should disclose HIV diagnosis to a child. In response, 157 (57.7%) suggested disclosure to the child should be done by a parents/caretaker. Others, comprising 97 (35.7%) preferred disclosure to be done by health care provider and 18(6.6%), suggested whoever is willing to disclose can do so. Just over half of the 33, parents/caretakers who had disclosed 17 (51.5%), preferred disclosure to be done by healthcare providers. They believed the health care providers are in better position to know the technique, what and how much to tell the child. While 12 (33.4%), and four (12.1%) preferred a parent/caretaker or any other person to do the disclosure respectively.

Children's Responses to HIV Diagnosis Disclosure: Emotional reactions of the child following disclosure, as reported by the parent/caretaker, varied from 22 (66.7%), reporting the child accepted the information, 10 (30.3%), reported the child was sad and one (3.0%) mentioned anger being the child's response. However, from children's own accounts, a larger proportion reported distress. From the children's structured interviews, amongst those that knew their HIV diagnosis, 15 (51.7%) had felt sad, four (16.8%) had felt anxious, and two (6.9%) reported anger; over a fifth, that is nine children (26.5%) reported indifference.

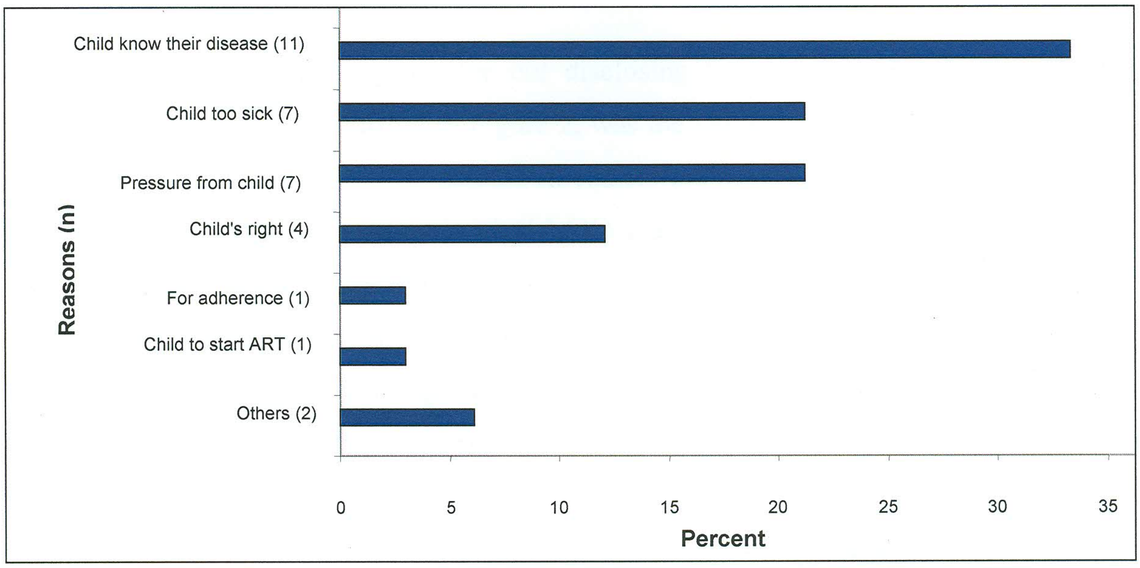
Despite the high rates of reported distress, most children did not report any changes in relationships with family members, peers school life as result of their HIV diagnosis.

Perceptions of Appropriate Age for Disclosure: Both disclosing and non-disclosing parents/caretakers responded to the questions on the most appropriate age for disclosure to a child. The overall mean (SD) appropriate age suggested was 13.5 years (2.2), (p value = 0.8). Non-disclosing parents/caretakers reporting a higher mean age of 13.7 (2.1) years compared to 11.9 years (2.2) reported by the disclosing parents/caretakers.

Disclosure and Duration of Child's use of ART: Twenty (60.6% of all disclosing parents/caretakers) of the children had disclosed to their children after the child had commenced use of ART. For children whose parents/caretakers had reportedly disclosed HIV diagnosis, 12 (36.6%) had been on ART for 12 months or less, (termed short duration) and 21 (61.4%) had been on ART for 13 months or longer (termed long duration in this study). Similar proportions for duration on ART for children of non-disclosing parents/caretakers were 93 (38.9%), and 146 (61.1 %) respectively (not statistically significant, P = 0.27).

Reasons for HIV Diagnosis Disclosure: The disclosing parents/caretakers were asked to provide their reasons for deciding to disclose HIV diagnosis to their child. The most frequent reason mentioned, was the desire for the child to know his/her health problem hoping that such knowledge would help the child to care for him/herself through increased motivation to use medication. This reason was reported by 11 (33.3%) of the disclosing parents/caretakers. Seven parents/caretakers (21.2%) mentioned they disclosed in response to pressure from the child's consistent questions about his/her illness. Seven parents/caretakers (21.2%) disclosed because the child was very sick and they felt it was wise to tell. Other parents/caretakers believed in the child's right to know his or her health status. This was mentioned by four (12.1%), parents/caretakers. (See Figure 1 below)

Figure 1. **Distribution of reasons given by parents/caretakers for disclosing HIV diagnosis to children**

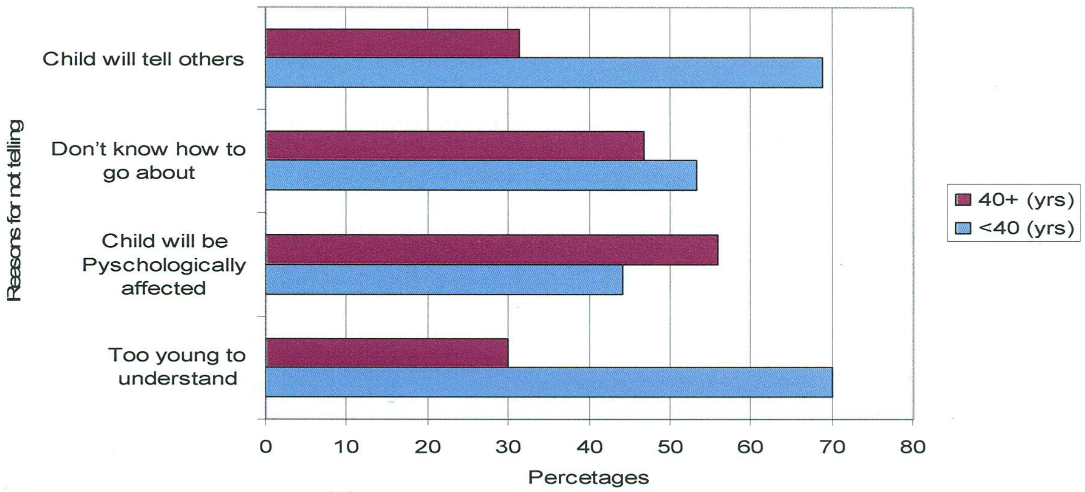


Perceived advantages of disclosure and disadvantages of non-disclosure: Advantages of disclosure mentioned by disclosing parents/caretakers included; the child benefits through being able look after him/herself better, reported by 19 (57.6%), and better adherence to medication when the child knows why they are required to take medications, reported by 14 (42.4%). One basic reported disadvantage of not disclosing, as mentioned by 25 (75.7%) of the disclosing parents/caretakers was the child becoming psychologically affected if he/she found out about their status in the future. The rest thought there were no disadvantages of not disclosing.

Measures taken to avert disclosure and reasons for non-disclosure: The parents/caretakers who had not disclosed HIV diagnosis to their infected child reported various ways they used to avoid children's requests for information about their health. The majority, 155 (64.9%), of the parents/caretakers misinformed their children about illness, attributing illness to such common illnesses as malaria, tuberculosis, heart disease, skin diseases and allergies rather than HIV. Some did not tell their children any thing at all with regard to the illness were 81 (33.9%), while three (1.3%), only explained what was required in terms of drug compliance without mentioning the exact name of the disease being treated.

The most common reason given for not disclosing by, 130 (54.4%) the non-disclosing parents/caretakers as summarised in Figure 2, was the child's lack of the maturity and ability to understand. Fifty-nine (24.4%) parents/caretakers did not disclose out of fear that the child would be psychologically affected, 35 (14.6%) feared the child would compromise family privacy by revealing to others the HIV diagnosis and 15 (6.3%) did not know how to go about disclosing. Most, 231 (96.7%) of the non-disclosing parents/caretakers, however, planned to disclose in the future; though eight (3.3%) believed the child would eventually find out by him/herself with age and did not to plan to disclose HIV diagnosis at all.

Figure 2 **Reasons for non-disclosure by age of parents/caretakers**



Children's Awareness of Illness and Treatment: Children were asked their awareness of why they had to attend frequent hospital visits. Of the 272 interviewed children, 112 (41.2%) reported that they did not know why they had to come to hospital frequently; 73 (26.8%), said they came to hospital to get medications, while 72 (26.5%), said they came to hospital because they were sick. Other reasons given for hospital visits included undergoing medical examination as reported by nine (3.3%) children and six (6.6%) children reported they came because they were told to do so by their parents/caretakers. Thirty-four (12.5%) of the interviewed children knew that they were HIV positive and 29 (85.3%) of these children's parents/caretakers had reported affirmatively to having disclosed HIV diagnosis to their children. The remaining five were children of non-disclosing parents/caretakers. Children who claimed to be unaware of their illness were reportedly disclosed to by their parents/caretakers.

All children who knew their HIV sero-status were asked to respond to a question on expectations on outcomes of their illness. In response 20 (58.8%) anticipated the disease would be cured some day in the future. Only one (2.9%) reported the disease had no cure and the remaining 13 (38.2%) did not have any particular outcome expectations.

Twenty-two (64.7%) of the children reporting awareness of their diagnosis talked about their illness mostly with their parents/caretakers. Silence was reported to be a strategy used to respond when asked about their illnesses by nine (26.5%) children. Of the remaining, two (5.9%) talked to other relatives, and one talked to friends. Reasons given by the children for limited communication about their illnesses, was feeling ashamed or having been forbidden by their parents to reveal the secret.

Reticence in talking to persons outside the home about the illness and its treatment was also evidenced in information collected from parents/caretakers as summarized in table 6 below. Responses to communication about the child's HIV diagnosis, to other persons in the household were given by both the disclosing and non-disclosing parents/caretakers. One hundred and seventy eight (65.4%) respondents reported that they had communicated with some or all-family members in the home about the child's diagnosis, while 94 (36.6%) provided no information to other household members. Knowledge about the child's diagnosis was limited to the respondent for 36 (13.2%) informants, while 88 (21.3%) had shared this information with their partner.

Table 6. **Communication to others of the child's illness and treatment by disclosing and non-disclosing parents/caretakers of HIV infected children in Dar es Salaam**

Communication variables	Total N	Disclosing n (%)	Non-Disclosing n (%)	p
Who knows about the child's diagnosis?				
Only one/both parents/caretakers	94	7 (7.4)	87(92.6)	
Other family members	178	26 (14.6)	152 (85.4)	0.09
Did they receive the same information about treatment as was given to you at CTC?				
No	99	3 (3.0.)	96 (97.0)	
Yes	179	30 (17.3)	143 (82.7)	<0.001
How many out side the house hold members have been told about child's diagnosis				
None	209	24 (11.5)	185 (88.5)	
Some	63	9 (14.3)	54 (85.7)	0.5
Who gives the child medications				
Him/herself	55	17 (30.9)	38.(69.1)	
Others	217	16 (7.4	201 (92.6)	<0.001

When distributions of proportions of parents/caretakers that kept information on the child's illness to themselves and those that informed others are assessed by disclosure of diagnosis to the child, higher proportions of those that informed others compared to those that had not, had also disclosed to children (14.6% compared to 7.4%; p-value =0.09). This variation was however, marginally significant. Similarly, non-significant trends are noted in variations in responses to the questions on communicating with persons outside the home about the child's HIV positive sero-status by diagnosis disclosure to the child. Over two thirds (76.8%) of parents/caretakers had not shared the child's diagnosis with person's outside the home.

Parents/caretakers were asked if the information they gave to family members in the home was similar to that they had received concerning the child's diagnosis and management of HIV and AIDS. Those who had shared similar amount of information with family members were 173 (63.6%). The parents/caretakers who had disclosure were over presented, when compared to those that had provided less information to others. (17.6% compared with 4.8%; p-value 0.04); this variation was statistically significant.

There were also significant differences in parents/caretakers responses to who administered medication to the child by whether or not they had disclosed diagnosis to the child. Parents/caretakers that had disclosed diagnosis to their children were more likely to say the children took charge of administering medication themselves rather than relying on others (30.9% compared with 7.4%; p-value <0.001).

Adherence Information to the Child and Use of ART: The type of information given to children regarding the drugs they were taking varied among parents/caretakers. One hundred and one (37.1%) parents/caretakers said no information was shared with the child. Only four (2.1%) of the parents/caretakers who had disclosed HIV diagnosis to the child reported they had given no information regarding ART to the child. Information that treatment was for an illnesses other than HIV & AIDS was provided by 142 (52.2%) parents/caretakers (findings not in table.)

ART Administration Timing and Monitoring for Adherence: According to the parents/caretakers self reports, all participating parents/caretakers knew the medication timing schedules. They all mentioned morning and evening schedules and the need to administer medication within one hour of a scheduled time. Parents/caretakers were requested to inform on missed doses in the four-day period prior to assessment. Hospital pharmacy records were also inspected for refills to assess attendance adherence. These records had dates for next visits, which coincided with new refills, so missed scheduled visits meant missed ART refills for the scheduled period.

On the whole, 259 (95.2%) children had excellent drug adherence (100% of drugs taken) as reported by parents/caretakers in the four days prior to interview. Non-drug adherence was reported in 13 children (3.3%). Among these, three had omitted one dose and six had omitted two doses. Among the disclosing group, 30 (90.9) attained the 100% level of adherence. Only five (1.8%) had missed a dose once, one being a child who knew the diagnosis and eight (2.9%) had missed two doses, two of whom were children that knew their diagnosis.

Table 7. Rates of drug adherence in HIV infected children 7-14 years by parents/caretakers reports.

Dose taken (% of total taken)	n (%)	Level of drug adherence
95-100%	259(95.2)	**259 (95.2) drug Adherent**
80-94%	5 (1.8)	**13(4.7)Non-drug adherent**
Less than 80%	8 (2.9)	

Refill records from pharmacy of previous three months, were available for 263 (96.7%), while nine (3.3%) children had no records for at least once in the previous three-month period. Review of these records, showed 258 (94.5%) children never missed any refills. The remainder 5 (1.8%) missed refills once or twice. Nine (3.3%) children had no pharmacy refill records.

5.2 Findings of the individual in-depth interviews

In total, eight children aged 10 - 14 years; (two children at each clinic, one knowing and the other not knowing the HIV diagnosis) were recruited and participated in in-depth interviews. Similarly, eight parents/caretakers, aged 30-48 years (one disclosing and another non-disclosing at each of the four CTCs) participated in the in-depth interviews. Emergent themes related to child's perceptions towards the illness and medication and the parent/caretaker's perception related to child disclosure, benefits, disadvantages, barriers, enhancers of HIV diagnosis disclosure are summarised below.

On the whole, the children (disclosed to or not disclosed to) had all gone through a period of ill health. The children reported that with commencement of use of medications from the clinic, their health status improved. For example, and I quote:

> *"...when I started using the drugs, I became well and my school mates became my friends again. The drugs are good, they have helped me but the daily use is tiring. I wonder till when?"* [13-year-old girl; did not know her diagnosis]

Another child said:

> *"You know I have HIV. I am required to take my drugs every day at six in the morning and six in the evening so that I don't fall sick frequently"*. [13-year-old girl; knew her HIV sero-status].

Perceptions about the purpose of medications used varied between the two groups. There were general similarities in the accounts of children who reported that their HIV diagnosis had been disclosed to them. All the children, who reported diagnosis disclosure, knew the medication they took was for the treatment of HIV and that they had to be taken for a lifetime. This is evidenced by the following and I quote:

"...the disease has no cure, unlike some other diseases like TB and it is important to take the drugs for the rest of my life." [13-year-old boy; knew his diagnosis]

They also perceived that their good health was attributable to the drugs they used. Good health for this group of children encompassed both physical and psychosocial well being. It meant feeling better, having fewer episodes of illnesses, peers asking fewer questions about their illnesses and drug use and feeling a greater sense of acceptance by their peers. Children with knowledge about their diagnosis reported they were often tired of taking medications daily, but were prepared to continue doing so, since their well being depended on the drugs.

Finally, the children especially who had been disclosed to, reported several strategies in an effort to enhance adherence to ART. These included use of alarm clocks, mobile phone with alarms and prompts from family members. Support from family members with constant reminders about taking drugs were reportedly of help with timing dosing.

Children's narratives revealed challenges relating to constant use of drugs: While some of the challenges varied by whether or not a child knew the diagnosis, others were similar across both groups. An example below illustrates the challenge of needing to maintain secrecy about the illness:

> *"I share the bed room with the house boy who is always inquisitive about my drugs and what they are for. I don't like it."* [12-year-old boy, knew HIV diagnosis]

This burden of keeping the illness secret is also carried by non-disclosing parents/caretakers as evidenced in the quantitative findings and parent/caretaker narratives that will be described later. Children belonging to the non-disclosed group attributed their illness to some other disease. Reportedly, this was the information that had been provided to them by their parents/caretakers. One child provides an illustrative example and I quote:

> *..."my grand mother tells me I have a long standing chest infection and I think she is right"* [11-year-old boy, not aware of diagnosis]

Non-disclosed to children complained about having to continue taking drugs even when they did not feel sick. They narrated that despite this concern, they took their drugs out of fear of falling sick again or because they were told to do so by their parents/caretaker. From the narratives of these children, resentment regarding illness and drug taking was evident. One child's resentment was evident in the following quotation:

> *"I cannot understand why my grandmother denies me permission to engage in vigorous games. She often punishes me if she finds out that I have taken part in games at school.*" [11 –year-boy not knowing his HIV diagnosis]

Yet another child informant demonstrated resentment due to interference caused by drug taking, and I quote:

"...when I am with friends or watching TV at the neighbours, I am called and forced to take the drugs. I don't like it."[12-year-old boy, not knowing HIV diagnosis]

Contrary to the children who knew their HIV sero-status, for most of the children that were not aware of their illness diagnosis, what was required of them did not appear to have a purpose, that is; why they had to take drugs daily or why they had to visit the clinic frequently.

Common concerns to both groups of children (i.e. disclosed to and non-disclosed to) was the excessive weakness that they attributed to adverse effects of the drugs or the illness itself. This also reportedly raised concerns and question from their peers for example when they were not more active in games.

Narratives suggesting discrimination in the school setting and amongst peers were evident from the interviews. Constant questioning about illness episodes from peers was reported to be distressing. Children also reported that this was particularly the case when they had certain symptoms such as skin lesions and certain schedules relating to illness such as regular hospital visits and daily use of drugs. Most children felt that this illness and treatment features were what raised suspicion among peers that they may have HIV disease. Some peers were reportedly ready to voice their suspicions to the children or to tell others. Such encounters were reported as unpleasant and non-disclosed to children reported they turned to their parents/caretakers for reassurances that their peers were being untruthful in saying they had HIV or AIDS. Some child informants also reported being talked about, being laughed at and ridiculed or segregated by peers. From the account of a thirteen-year-old girl I quote;

> *..."one child who came to know that I am taking drugs daily, and coming to hospital many times, told my friends that I am suffering from HIV. She had heard from her mother that those who have HIV take drugs daily. My friends laughed at me and I cried but when I told my aunt, she said it was a lie"* [Girl, 13years old, not aware of HIV diagnosis]

One nine-year-old boy reported that, he was provided with an identification red tag at school so that teachers would not allocate him heavy duties. He was not aware of his illness diagnosis and found the experience of being singled out very distressing.

Views on sharing information about use of medication were obtained from the participating children. Children who reported that members of the family knew about the drug treatments, narrated that family members, in unison helped especially in the timing and taking of the drugs. In contrast, such support was not reported by children who said that knowledge about the drugs they used was limited to parent/caretakers who gave the child medications. One child who knew about his HIV diagnosis narrated collusion between his mother and himself to keep, his illness a secret from other family members. He narrated that his mother and himself hid the medications and that he could only take drugs in the bedroom. In this example, the mother was the only one in the family that knew about the drugs and she was the only person that provided them for him to take.

5.1.2 Parents/caretakers experiences in caring for a child living with HIV

Attitude towards child disclosure*:* All parents/caretakers who took part in the in-depth interview realised the importance of a child knowing the HIV diagnosis. All parents/caretakers recognised the importance of disclosure for proper management of HIV. One caretaker, narrated and I quote:

> *"...it helps to prepare the child to look after himself, prepare for boarding school and the child will protect himself and others when he matures sexually and becomes sexually active. The child will be taught what is required of him especially concerning drugs for HIV and diet. He can come by himself to hospital and tell the doctor his problem. I don't have unnecessary worries*". [Male, aged 36 years old; disclosing uncle]

Disclosure experiences and communication about child's illness*:* Parents/caretakers expressed the view, that carrying out the process of disclosure is made easier if it is planned together with the healthcare provider. One caretaker said, before disclosure, he had spent time talking about HIV/AIDS openly and positively in presence of the child. For this caretaker, a number of reasons were mentioned that prompted disclosure. These included advice from the health care providers, the child being unhappy with taking the drugs and constant questions from the child about why he/she was taking drugs all the time as illustrated by the quotation below:

> *"I told my son about his HIV diagnosis following his constant questioning about his being sick all the time. When I told him, by then he was 10 years, he cried a lot. But since then, his attitude is okay and he is careful about taking his drugs. He understands the problem and tries to keep well".* [Female, 38 years old, disclosing aunt]

Non-disclosing parents/caretakers often narrated fears regarding being unable to maintain some privacy related to the diagnosis. They were concerned about negative emotional responses from the child after disclosure. These included mainly the child's anger, and the child's inability to keep a secret. These fears are illustrated in the following quotes:

> "*I don't want people to know. First, they are rumourmongers, and hypocrites. They can laugh behind my back and talk about me in front of their children who may later*

> *tease my child."* [Female, 43 years old, non-disclosing mother]

Another said the following:

> " *..we Africans can be bad at times. Therefore, there is no need to let others know. What do they help any way, apart from talking about us and spreading the information to others?"* [34-year-old mother, non- disclosing]

In contrast to these sentiments from parents/caretakers that had not disclosed diagnosis to the child, one who had disclosed said that their life had not changed much despite a number of people, including, neighbours knowing their HIV diagnosis. One said her husband, their child and herself felt peace within themselves and with others, following disclosure. Other non-disclosing parents/caretakers in exploration of children's anger expressed fears that if informed of diagnosis, their child may turn against them and hate them or they may feel bad, become depressed or commit suicide.

One mother in particular narrated her experiences in disclosing HIV diagnosis to her 12-year-old son. The child was told his HIV diagnosis by the healthcare provider in the absence of his parent following refusal to take drugs. The disclosure session had been agreed upon by the counsellor and mother. The mother's guilt and sense of failure as a result of her son's response is noted as follows:

> "*He just said "I forgive you".... I felt very guilty. Since then I have been unable to bring myself to face him on any issue related to his illness.*" [39-year-old mother, disclosing]

It would appear that non-disclosing diagnosis to a child served the function of decreasing the threat of being exposed to others as a person affected by HIV and AIDS. For many of the non-disclosing parents/caretakers, it is also very likely that HIV related stigma both felt and enacted may have a significant influence on a parent's/caretaker's ability to disclose HIV diagnosis to an infected child.

The last quotation above may illustrate the importance of the need to give some consideration to planning and timing of HIV diagnosis disclosure to children. More perspectives that are positive on HIV diagnosis disclosure to children were obtained from parents/caretakers who had disclosed to their children than those who had not. It was narrated by disclosing parents/caretakers that disclosure should be done properly at an early age and through gradual preparation of the child for disclosure in an appropriate setting by the doctor and parent/caretaker. When to disclose, was reported to be governed by the age of the child. Appropriate age of 11-12 years was reported to be the best age for full disclosure. At this age, it was perceived by informants that the child can under stand better:

> *"... just as much as we expect the child to have some responsibilities at home and at school, the child should also have some responsibilities to his/her illness from an early age."* [Disclosing uncle 36 years old]

Future planning: A major issue of concern raised by parents/caretakers related to planning for schooling for the affected child, particularly on completion of primary education. The parents/caretakers narrated difficulties in planning for future education and especially decisions related to whether schooling should occur away from home (boarding school). Particular difficulty was expressed when boarding school was the option preferred by the child. Several issues and questions were by parent/caretaker informants and a few are extracted from the narratives as illustrations:

> *"How can the child be able to continue with his/her medications when is at boarding school?"... "Where would he/she get the medication? ... "What would happen if he/she falls sick?" ... "How about their diet?" ... "Would the school authorities have to be told?"*

Both parents/caretakers who had and had not disclosed HIV diagnosis to the child had similar concerns. In addition, parents/caretakers that had not disclosed were worried that their child would find it difficult to understand why he/she could not be enrolled at a boarding secondary school.

6.0 DISCUSSION

The HIV/AIDS Care and Treatment program has a target to enrol all HIV infected individuals for treatment in its programme. Currently, of the total patients enrolled, only 10% are children. The cornerstone of improving survival of children through care and treatment of HIV is to adhere to the appropriate drugs, along with proper nutrition, prevention and treatment of opportunistic infections. In order to optimize the effects of ART one needs to achieve a high level of adherence and cooperation and this is best facilitated by a good understanding of the disease by the affected individual through information, education and communication. This understanding entails that an infected child is formally informed of her/his HIV sero status upon reaching an appropriate age.

In adults, knowing ones' HIV status is part and parcel of HIV pre- and post-counselling and it is possible to achieve this with considerable success in adults. However, among children the issue of informing one's HIV sero-status is surrounded by a lot of constraints and barriers. To begin with, children are considered labile and vulnerable, and traditionally are not often given the opportunity to participate in decision-making process even if the child is the principal subject. Nonetheless, in the context of HIV and AIDS, quality care and treatment as well as adherence to ART, it is of paramount importance that the individual patient plays a central role. This poses a challenge of how to go about informing the affected child about his/her condition in a professional manner, gain their trust, and full informed participation in care and treatment.

The results of the study showed a very low rate of HIV diagnosis disclosure, 12.1%, to children of mean age 9.8 years using parent/caretaker reports. Only 12.5% of the interviewed children knew that they were HIV positive, among whom, 85% were children of parents/caretakers who reported they had disclosed to their children. The remaining 15% were children of non-disclosing parents/caretakers that found out about their diagnosis from other sources. This implies that children can find out about their HIV diagnosis from sources other than their parents/caretakers.

This finding is similar to other studies carried out elsewhere that also reported a large majority of children living with HIV did not know their HIV diagnosis. Funck-Brentano et al, in their study in France, of HIV diagnosis disclosure to children of mean age 7.5 years, found that parents had only disclosed HIV diagnosis to 17%.[30] Likewise, diagnosis disclosure in Thai children, of mean age 7 and 8.6 years infected with HIV, was reported to range between 2% and 19.8% respectively.[31, 32] In Uganda, which shares similar socio-cultural values to those in Tanzania, a diagnosis disclosure rate of 29% has been reported in HIV affected children of mean age 12 years.[38] The rates of HIV diagnosis disclosure to children varied across studies. This variation could reflect the different age groups of children sampled across studies, as well as differing perspectives of when to disclose HIV diagnosis.

Despite these variations, the findings of this study suggest lower diagnosis disclosure rates compared to those in other developing countries.[32, 38] As noted earlier, higher stigma towards HIV/AIDS and lower experience with use of ART, may explain the lower disclosure rates in this study, compared to the USA, Thailand and Uganda.[45, 32 38] While community-based interventions to reduce HIV related stigma are in their infancy in many African countries, more efforts in this regard may have occurred in Western settings, hence facilitating openness in HIV diagnosis disclosure. We have had reasonable access to ART for the last four years in Tanzania and the concept of HIV disclosing diagnosis to others even amongst adults is a challenge, particularly when the larger proportion of the population screened (as a result of PMTCT programmes) has the least decision making power at family level. Hence, is most vulnerable to the effects of HIV related stigma. Non-disclosure of HIV diagnosis to partners possibly influences disclosure to children, when the mother is the first to know of her HIV sero-status. There is evidence in particularly PMTCT settings, that partner disclosure rates are low and range from 16.7% to 40% [24, 25] There appears to be a need to improve diagnosis disclosure rates in children infected with HIV, in the Dar es Salaam context.

In older children, communication about the child's health problems with significant adults may be important in determining future health promoting actions. These analyses indicate from parent/caregiver narratives, that planning for and providing clear communication on HIV diagnosis is feasible. Furthermore, children disclosed to indicate a better understanding of what they are required to do for sustaining health and have greater willingness to follow medical recommendations despite challenges reported. The few parents/caretakers, who tell their children that they have been infected by HIV, prefer to do so (full disclosure) when the child is aged between 11-14 years. More than half of the non-disclosing parents/caretakers cited the child being "too young to understand" as the main reason for not disclosing. Accordingly, for non-disclosing parents/caretakers, a higher mean age (13.7 years) was perceived to be appropriate for disclosing diagnosis. However, narratives from the disclosed to children and quantitative findings from the same group indicate that children do understand the meaning of an HIV infection diagnosis and are able to cope emotionally with this knowledge.

Psychological impact of diagnosis disclosure on children was one of the main reasons cited for not disclosing HIV diagnosis to a child. The findings of these analyses also indicate a discrepancy in recognition of children's distress when children's accounts of their distress in response to diagnosis disclosure are compared to what was recognised by disclosing parent/caretakers. About two thirds of children who had been disclosed to, reported distress in response to being informed of diagnosis, however all of the children reported no impact on their social functioning (relationships at home and school) as a result of knowledge of the HIV status. In general, these findings suggest psychological resilience in children that are disclosed to that needs to be understood further. In addition, a better understanding of what children mean when they say they become distressed as well as how they respond to this distress could provide information to develop strategies that increase parent/caretakers recognition of distress and appropriate supportive responses. This was not systemically assessed in the reported study.

Other concerns raised by non-disclosing parents/caretakers in narratives included, the child's low maturity, the child's inability to maintain confidentiality and subsequent fears of increased family vulnerability to discrimination and stigmatization and finally not knowing how to go about disclosing. Quantitative survey findings support this perception of how maturity of children influencing diagnosis disclosure decisions, if age is taken as a proxy measure of maturity. Disclosed to children were significantly older than non-disclosed to children.[29, 45] However, it is likely that factors other than perceived maturity are influencing parent/caretaker's decision to disclose the diagnosis to children. This argument is made because despite diagnosis disclosure being related to the child's age, amongst older children, three quarters had not been informed of their HIV diagnosis in this study. Mellins et al. in the USA also noted that 10 of 77 children aged between 10-13 years did not know their HIV diagnosis.[28] Furthermore, in an analysis of children of mean age 8.6 years (range 5-15 years); Boon-Yasidhi et al.[32] reported that the child's age was not an independent predictor of HIV diagnosis disclosure.

More in-depth studies to determine other factors that influence parental/caretaker decisions to disclose HIV diagnosis are warranted. Such knowledge would be useful in informing strategies to increase diagnosis disclosure to affected children by parents/caretakers. There is a need for future research to explore in greater depth parental/caretaker perceptions of children's understanding of health matters and their views on engaging children with chronic illnesses such as HIV/AIDS in health promoting actions.

The observation of low diagnosis disclosure rates in the current study raises concerns about the possibilities for developing future personal responsibility in matters related to illness in children with chronic diseases, such as HIV/AIDS as they grow into adult hood. There is a possibility that not knowing one's status in early adolescents has implications for HIV/AIDS prevention given the reported rates of early initiation of unprotected sexual behaviours amongst school based adolescents in sub-Saharan Africa.[13, 14]

Despite low diagnosis disclosure rates and parental/caretaker concerns regarding disclosing, a positive finding amongst most parents/caretakers was their perception that children should be more actively involved in the HIV and AIDS care and treatment process. Furthermore, a third of the parents/caretakers that disclosed did so in order to get children to know their health problem so they could take better care of themselves, including administering the medication. Being able to trust children to engage in their own care was rewarded by evidence that children who had been told their HIV diagnosis, were more likely to self administer their ART as compared to the children who did not know (p value <0.001).

In the analysis of communication to others of the child's illness and treatment and comparing the disclosing and non-disclosing parents/caretakers, the former were more willing than the latter to share this information with other family members, (p value = 0.04). Communication about the child's illness and treatment to other adults in the home helps break the silence about HIV and in so doing can reduce stigma as exampled in the qualitative analysis where one parent said the family has peace within themselves and others after sharing information about their illness with friends and relations. While fear of discrimination on knowledge of child's diagnosis, being widely known was raised, perceived and enacted HIV related stigma in parents/caretakers was not systematically assessed in this study, but is an important probable barrier that should be investigated.

Study findings indicate that parent/caretakers being of older age, being employed or having tested for HIV were all factors that were independently associated with HIV diagnosis disclosure to children. There are several possible explanations for these associations. This could be possibly explained by older parents/caretakers could perhaps have a greater sense of responsibility and confidence in talking to children on sensitive issues given their greater maturity. Being in employment may result in greater financial security and this may have an impact on health promotion actions including greater involvement of children in their own care. HIV testing is always accompanied by counselling that may expose one to information and techniques that may be useful in disclosing HIV diagnosis and reducing stigma related actions/behaviours although in this study it was HIV testing or status was not an influencing factor.

One study identified level of education being an independent factor in HIV diagnosis disclosure, this being in contrast to our study. This could be explained by the relatively low level of education in this sample not allowing adequate differences to show effects. Additionally exposure to CTCs and the implications of ART may have influenced parents/caregivers perceptions about active involvement of affected children in their own care and treatment.

About 61% of the disclosing parents/caretakers revealed the HIV status to the child, after the child had been initiated on ART. Among disclosing parents/caretakers, 42% did so with assistance of health care providers. Patterns of disclosure have been reported by Funck-Brentano et al and these include non-disclosure, partial disclosure (with no misinformation) and complete disclosure.[30] In the current study, two categories of process of disclosure were evident; complete/full disclosure and non- disclosure. It would be important to assess the role of health care providers in HIV diagnosis disclosure to children in order to assist parents/caretakers in providing at least partial disclosure to younger children.

Parents/caregivers may have difficulties in disclosing HIV infection to children they provide care for and a significant proportion misinform children as a coping strategy to the challenges of persistent questions from children about their health. Among non-disclosing parents/caretakers, misinforming children was the most common strategy followed by not telling anything at all about the illness. Misinformation was mostly in the form of attributing children's illness to common diseases. This study looked at children of an age group, who under normal circumstances are expected to be in school. Thus, it can be deduced from the study, children were receiving information that was contradictory to what they may receive at school about general health issues. The parents/caretakers, risk laying a foundation for future mistrust between themselves and their children, when the children find out about their HIV sero-status in the future. This can have implications for health promoting behaviour in this sub population of children with HIV/AIDS.[45]

The use of ART has resulted in significant improvements in the health and longevity of HIV-infected children. Parents/caretaker self reports indicated that ART timing drugs adherence was over 95% for both disclosed to and non-disclosed to children. In this study, I would attribute the good level of drug adherence to the attitude of parents/caretakers in shouldering adherence and sheltering children from this responsibility. Over fifty percent of the children who knew their HIV diagnosis (n=33) administered the drugs themselves as compared to 18.9% of the children who were not informed of their HIV diagnosis (n=209) and depended on the parents/caretakers for drug administration.

As evidenced by this study, most children had experienced severe critical health conditions before starting ART. When the parent/caretaker has disclosed diagnosis, both the child and the parent/caretaker view drug administration as a joint responsibility. Children who were forced to comply with treatment did so out of parental/caretaker coercion. However, ART services provide additional challenges in terms of strategies in health systems for increased involvement of children in the care and treatment. For HIV-infected children, the fear of stigma and discrimination may complicate adherence to medications, although this study did not systemically assess stigma and its effects on adherence.

CONCLUSION

1. The study showed HIV disclosure rates are lower compared to other developing countries and parents/caretakers tend to under-estimate the ability of children in middle childhood to understand and respond adaptively to the implications of an HIV diagnosis the diagnosis.
2. Within parents/caretakers, by being older, having tested for HIV, being employed were independently associated with HIV diagnosis disclose to their children.
3. Among the constraints/barriers that were identified from narratives and quantitative information of non-disclosing parents/caretakers, were related to the notion that the children may have low maturity, inability to maintain confidentiality and subsequent fears of increased family vulnerability to discrimination and stigmatization and finally not knowing how to go about disclosing. Further more, because of the associated stigma to HIV infection; parents/caretakers were unwilling to share information about the child's illness and treatment with other adult family members.
4. The findings identify challenges faced by children and indicate a discrepancy in recognition of children's distress in response to diagnosis disclosure when compared to what was recognised by disclosing parent/caretakers. Unlike the disclosed to group of children, the unknowing children depended on parents/caretakers for drug administration.

RECOMMENDATIONS

1. To strengthen and make more comprehensive national policy and guidelines on paediatric, care and treatment, to include HIV diagnosis disclosure to children. Such guidelines and polices should guide development of healthcare provider training inputs interventions that support parents/caregivers, children and adolescents in addressing the difficult disclosure process.

2. Paediatric HIV/AIDS Care and Treatment guidelines need to provide guidance on the age best suited for HIV diagnosis disclosure. Evidence from this study indicates a

mean age 11.8 years amongst children disclosed to and absence of great adverse emotional consequences. Children's opinion with regard to when and why they should be informed of the diagnosis should be assessed in future studies.

3. Future exploration and development with key stakeholders of evaluated interventions that normalize the experience of parents/caretakers of providing care for infected children, and the ART experience for infected children are warranted. These include, for example, parents/caretakers as well as children's support groups; and training of healthcare providers to recognize and address stigma (both enacted and felt).

4. There is a need for future research to explore in greater depth parental/caretaker perceptions of children's understanding of health matters and their views on engaging children with chronic illnesses such as HIV/AIDS in health promoting actions. Such knowledge would be useful in informing strategies to increase diagnosis disclosure by parents/caretakers to affected children.

LIMITATIONS OF THE STUDY

HIV is a disease that carries a lot of stigma, which is a challenge for the child and parent/caretaker. It is therefore possible that in the process of collecting sensitive information, both children and parents/caretakers may have been reluctant to express what they actually felt about their situations during interviews. However, the design of the data collection process ensured that those willing to discuss issues with the research team were reached through an informed consent process. Furthermore, conducting individual in-depth interviews, rather than focused group discussions has greater ability to access individual perspectives on issues rather than social norms. Lastly, the triangulation of the results of qualitative and quantitative data collection revealed similarities in concerns raised by both children and parents/caretakers, hence, increasing the validity of the findings.

There was possibility of recall bias in the self-reporting interview for the drug adherence. This was minimized by using different recall periods- 24 hours and four days recall.

In spite of these limitations in the study, the findings point to other possible areas of intervention research that could combine both quantitative and qualitative studies. Furthermore, with this information, we shall be able to develop interventions to enhance disclosure of HIV diagnosis to children and maintain good ARV drug adherence among children infected with HIV.

7.0 REFERENCES

1 UNAIDS. AIDS epidemic update AIDS epidemic update December 2007. Publication Dec.2007 UNAIDS /07/027E JC1322E. (English original Dec 2007). http://data.unaids.org/pub/EPISlides/2007/2007_epiupdate_en.pdf (accessed January 2008).

er

2 World's AIDS HIV statistics including deaths. http://www.avert.org/worldstats html (accessed January 2008)

er

3 Tanzania Commission of AIDS 2005 report. Global health reporting, http://www.global health reporting.org/control/Tanzania (accessed March 2008)

er

4 UNAIDS unite the world against AIDS. http:www unaids.org/en/country responses/countries/Tanzania. Asp (March October 2008)

er

5 Kawo G, Karlson K, Lyamuya E, Kalokola F, Fataki M, Kazimoto T, et al. Prevalence of HIV type 1 infection associated clinical features and mortality among hospitalized children in, Dar es salaam Tanzania. *Scandinavia Journal of Infectious Disease. 2000;* ***32****:357-363.*

ej

6 The WHO Reproductive Health Library-Vaginal disinfection preventing mother -to -child transmission of HIV infection. (last revised: 8 September 2003) Available from *http*://www.who.int/rhl/hiv_aids/mtcom/en/index.html.

er

7 Tanzania Commission For AIDS-UNGASS-Country Progressive report Tanzania Mainland, 2005-2006

er

8 Kuhn L, Thomas PA, SinghT, Tsai WY. Centre for Disease Control and Prevention on HIV/AIDS Surveillance report: Long term survival of children with human immunodeficiency virus infection in N.Y city.1997, *AMJ epid.1998 May1;* ***147(9)****:146-85.* http://www.ncbi.nlm.nih.gov/pubmed/9583715 (accessed August 2007)

ej

er

9 American Academy of Paediatrics February 5, 1999. Complex Issues of HIV Disclosure of Diagnosis to Children and Adolescents in the Forefront. A Summary of the Recommendations on Disclosure of Diagnosis to Children and Adolescents Living with HIV Infection. http://www.the body.com/nphrc/disclosure.html.(accessed June 2007).

eg

10 Maurizio de Martino, Tovo, Balducci, et al. Reduction in Mortality with Availability of Antiretroviral Therapy for Children with Perinatal HIV-1 Infection. *JAMA. 2000;**284**:190-197*

eg

11 Blasini, Cruz,Salabarria I, Scalley. Disclosure model for paediatric patients living in Puerto Rico *J. Dev. Behav. Paedtr. 2004;**25**:181-189*

eg

12 Kaaya SF, Flisher AJ, Mbwambo JK, Schaalma H, Aaro LE, Klepp K-I, et al. Review of studies of sexual behaviour of school students in sub-Saharan Africa. *Scand. J Public Health. 2002; **30**: 148-160*

eg

13 Todd J, Changalucha J, Ross DA, Mosha F, Obasi AIN, Plummer M, et al. The sexual health of pupils in years 4 to 6 of primary schools in rural Tanzania. Sex Transm Infect. 2004; **80**:35-42. Available from: www.stijournal.com

b

14 Sylvia F. Kaaya, Melkizedeck T Leshebari, Van den Gerh GI, Klepp K. Social change and health in Tanzania: Contextual aspects in relation to reproductive health information among school youths in Rombo district, Tanzania. *Heggenhougen KH.ede.University Dare salaam Press 2003: p47-68*

eb

15 Heleen Piwoz. Academy for Educational Development Global Health, Population and Nutrition Group. Nutrition and HIV/AIDS: Evidence, Gaps and Priority Actions. (CD_ROM) April 2004

eb

16 The Africa Network for the Care Children Affected by AIDS: in Africa: Early nutritional supplements. Handbook on Paediatric AIDS in Africa. July 2006 ed.Kampala, Uganda; 2004: p 223.

eg

17 Experiences of Prevention of Mother to Child Transmission of HIV in Rural Tanzania: Claire MN, Anna CK, David MK, David O'C *BMJ,2004,**349**,1147-1150*

er 18 Global Progress 2003-2005 a Report on 3 by 5 and beyond. March 2006 http://www.who.int/hiv/full_report_en_highres.pdf

eb 19 MDH internal monitoring documents; Cumulative program coverage reports of June 30th 2006 and September 30th 2007)

ej 20 Elise A, France A M,, Louise WM, Bata D, Francois R, Rogers S, et al. Assessment of adherence to highly active antiretroviral therapy in a cohort of African HIV infected children in Abidjan, Cote d'Ivoire. *Journal of Acquired Immune Deficiency Syndrome, 2005;* ***40****: 498-500.*

ej 21 Fassonou P, Elenga N, Rouet F, Laugide R, Kouakoussui KA, Timite M, et al. Highly active antiretroviral therapies among HIV-1 infected children in Abidjan, Cote d'Ivoire; *AIDS. 2004;18(14):1905-13.*

ej 22 Martha B. Lee, Mary Jane Rotheram-Borus. Parents' Disclosure of HIV to Their Children. *AIDS* 2002, ***16***: 2201-2207

er 23 Medley A, Garcia-Moreno C, McGill.S, Maman S. Rates, barriers, and outcomes of HIV sero status disclosure among women in developing countries: Implications for prevention of mother to child transmission programmes. *Bulletin of the World Health Organization*.82 (4):299-307.

ej 24 Kilewo C, Massawe A, Lyamuya E et al, HIV Counselling And Testing of Pregnant Women In sub-Saharan Africa: Experiences from a study on prevention of mother-to-child HIV-1 transmission in Dar es Salaam, Tanzania**.** J Acquir Immune Defic Syndr. 2001 Dec 15;28(5):458-62

ej 25 Antelma G, Mary C, Fawzia S, Kaaya S, Mwambo J, Msomaga IG, et al. Predictors of HIV-1 sero-status disclosure: A prospective study among HIV infected pregnant women in Dar es Salaam, Tanzania. *AIDS 2001;* ***15:****1865-1874*

ej 26 Grubman S, Gross E, Lerner-Weiss N. Older children and adolescents living with perinatally acquired human immunodeficiency. *Paediatrics. 1995;* ***95****:657-663* eb 27 Lori SW: Disclosure In Steven L. Zeichner, Jennifer S. Read: Textbook of Pediatric HIV Care. Chapter 46 pg 661

ej 28 Mellins CA, Brackis-Cott E, Dolezal C. Patterns of HIV disclosure to Perinatally HIV-Infected Children and Subsequent Mental Outcomes Clinical Child Psychology and Psychiatry : *Clinical Child Psychology and Psychiatry,* ***7***, 101-114.

ej 29 Lester P, Chesney M, Cooke M, Whalley P, Perez B, Petru, A et al. Diagnostic disclosure to HIV-infected children: How parents decide when and what to tell. *Clinical Child Psychology and Psychiatry, 7, 85-99 2002*

ej 30 Fuck-Brentano I, Costagliola D, Seibel N, Straub E, Tardieu M, Blanche S, et al: Patterns of Disclosure and Perceptions of the Human Immunodeficiency Virus in Infected Elementary School-age Children. *Arch Pediatr Adolesc Med.1997;**151**: 978-985*

ej 31 Apateerapong W, Pancharoen C, Eggermont L, Koekkoek S, Chuamchaitrekool A,Cheunyam T, et al. HIV disclosure in children. *Int Conf AIDS. 2004 Jul 11-16; 15*

ej 32 Vitharon Boon-yasidhi, Uraporn Kottapat, Yuitiang Durier et al. Diagnosis Disclosure in HIV-Infected Thai Children Med , *J.Med Assoc. Thai* 88 Suppl 8:*2005 S1005*

er 33 Azondekon K. Disclosure of HIV status to children in African context: Outcomes and challenges. Proceedings of the 3rd International AIDS Conf on HIV Pathog Treat. *2005 Jul 24-27; Rio de Janeiro. Scientists and Healthcare workers Committed to HIV/AIDS*

ej 34 Kouyoumdjian FG, Meyers T, Mtshizana T Barriers to disclose to children with HIV. *Trop Pediatr.*2005; 51: 285-287

ej 35 Myer L, Moodley K, Hendricks F, Cotton M. Healthcare providers' perspectives on discussing HIV status with infected children**.** *J Trop Paediatric. 2006 Aug;**52(4)**:293-295*

er 36 The Africa Network for the Care Children Affected by AIDS: in Africa At what age should counselling start? Handbook on Paediatric *AIDS in Africa. July 2006 ed.Kampala, Uganda; 2004: p 209.*

ej 37 Winnie B-K, Emmanuel L, David WP .Julia D, Frank K, Jonathan M, et. al. Disclosure of HIV Status and Adherence to Daily Drug Regimens Among HIV- infected Children in Uganda. *AIDS Behav. 2006;* ***10:****585-593.*

ej 38 Wanyenya LJ. An experience at 'The Mildmay Centre: Issues and challenges around disclosure of sero status in adolescents. *Int Conf AIDS; 2002: Jul 7-12; Kampala, Uganda: Mildmay Internationa.14.*

er 39 The Africa Network for the Care Children Affected by AIDS: in Africa. Adherence Monitoring. Handbook on Paediatric AIDS in Africa. July 2006 ed.Kampala, Uganda; 2004: p 148.

ej 40 Van Dyke RB, Lee S, et al. Reported adherence as a determinant of response to HAART in children who have immuno deficiency virus infection. *Paediatrics 2002;****109****;-116*

ej 41 Watson Dc, et al. Efficacy of and adherence to ARV therapy in children infected with human immuno-deficiency virus type 1. *Paedtr Infec Dis J. 1999;* ***18****:682-689*

er 42 Valeria E. Stone. Strategies for Optimizing Adherence to Highly Active Antiretroviral Therapy: Lessons from Research and Clinical Practice. *Clinical Infectious Diseases 20001;33:865-72*

er 43 USAID Working report measuring HIV stigma: Results of a field test in Tanzania. June 2005

er 44 Stella Alamo-Talisuna. Talking HIV/AIDS With Children Perspective The Monitor (Kampala) OPINION 29th July 2005

ej 45 American Academy of Paediatrics Disclosure of Illness Status to Children and Adolescents With HIV Infection Pediatrics. **103** 1999, 164-166 Available at http://www.pediatrics.org/cgi/content/full/103/1/164(as of February 12, 2007).

ej 46 Farley J, Hines S, Musk A, et al. Assessment of adherence to ART in HIV infected children using Medication Event Monitoring System, pharmacy refill, provider assessment, care giver self report and appointment keeping. *J aids 2003;* ***33.****211-218.*

ej 47 Paige LW, Deborah S, Grace M, Sharon N, Betsy K. Predictors of Adherence to Retroviral Medications in Children and Adolescents with HIV Infection*: Paed. 2006 December; Vol.* ***118*** *No. 6, pp. e1745-e1757.*

48 Magic UN Convention in the Rights of a child http://www.unicef/org/brifing/unorc.html

eb 49 HIV infection. Diagnostic and treatment strategies for Health workers: Paediatric problems.2nd ed. Kampala. STI/AIDS Control Programme; 2000: **14** p.95.

er 50 United Republic of Tanzania. 2002 Population and Housing Census. General Report

er 51 Jean Piagets theory of cognitive development. *http://mi.essortment.com/jean piagettheo.rnrn.ht*

er 52 MTCT Plus Lecture Series, 2005. Paediatric Disclosure: Talking to children about HIV. Kids Count: Children's ART Adherence Resource Pack 2006

ej 53 Chelsney MA, Ickovic JR, Chambers DB, Gifford AL, et al. Self-reporting adherence to antiretroviral medications among participants in HIV clinical trials: the AACTG adherence instruments. Patient Care Committee & Adherence Working Group of the Outcomes Committee of the Adult AIDS Clinical Trials Group (AACTG). AIDS Care 2000; 12.255-266.

er 54 STATISTICAL package for social science programme version 10.0 spss Inc version 10.0. The statistical Package for Soc Sci Chicago, 11:SPSSInc,2004

ej 55 Wiener LS, Battles HB, Heilman N, Sigelman CK, Pizzo PA. Factors associated with disclosure of diagnosis to children with HIV/AIDS. *Paediatric AIDS HIV Infect. 1996;7:310-24*