

**THE UNIVERSITY OF ZAMBIA
SCHOOL OF HUMANITIES AND SOCIAL SCIENCES
DEPARTMENT OF PSYCHOLOGY**

**CAREGIVER-CHILD ATTACHMENT AND DRUG ADHERENCE AMONG HIV
POSITIVE CHILDREN: THE EFFECT OF BEHAVIORAL AND EMOTIONAL
PROCLIVITIES ON ADHERENCE.**

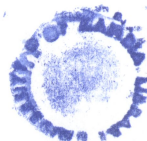
**By
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THESIS
MA
HAP
2009

A dissertation submitted to the University of Zambia in partial fulfillment of the requirement for the award of Master of Arts Degree – Child and Adolescent Psychology Programme.

**THE UNIVERSITY OF ZAMBIA
LUSAKA**

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DECLARATION

I Given Hapunda hereby declare that this dissertation was carried out by me under the supervision of Dr Imasiku, Department of Psychology at the University of Zambia in consideration of the award of Master of Arts in Child and Adolescent Psychology. I also declare that this dissertation is submitted to the University of Zambia in partial fulfillment of the requirement for the award of MA in Psychology. This research work has not been submitted to any other university or institution for any purpose. References borrowed from other sources are acknowledged.



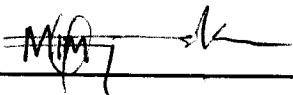
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CERTIFICATE OF APPROVAL

This dissertation by **Given Hapunda** is submitted as partial fulfillment for the award of the degree of Master of Arts in Child and Adolescent Psychology of the University of Zambia.

EXAMINERS SIGNATURE

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Date 29th July 2009

ACKNOWLEDGEMENT

I owe my deepest gratitude to Prof Marinus H. van IJzendoorn and Dr Marian J. Bakermans-Kranenburg (Leiden University, the Netherlands) for their guidance and support during the development of the study methodology. I also thank, Dr Mwiya Imasiku (University of Zambia), Haatembo Mooya and Tamara Chansa (University of Zambia) for their unweaving support, guidance and encouragements during the period of data collection and my dissertation writing.

My special thanks also go to Nicholas Banda, Mwaba Mumba and Chalwe Mumba for their assistance in data collection during the pilot programme and during the main study.

Finally, I also want to thank the Lolle Nauta Foundation for their financial support rendered during data collection for this study.

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ABBREVIATIONS AND ACRONYMS

AIDS.....	Acquired Immune Deficiency Syndrome
ARV.....	Antiretroviral
ASCT.....	Attachment Story Completion Task
ASQ.....	Ages and Stages Questionnaire
BDI.....	Beck Depression Inventory
DOT.....	Directly Observed Therapy
EDM.....	Electronic Drug Monitoring
HAART.....	Highly Active Antiretroviral Therapy (treatment)
HAD.....	HIV Associated Dementia
HIV.....	Human Immune Virus
MTCT.....	Mother-to Child Transmission
NIAID.....	National Institute of Allergy and Infectious Diseases
SPSS.....	Statistical Package for Social Sciences
SPS.....	Social Provisions Scale
UTH.....	University Teaching Hospital
VL.....	Viral Load

ABSTRACT

Purpose/Aim of study: Assessing emotional and behavioral function in children and adolescents who are HIV+ may help predict and explaining adherence in future. The aim of the study was to investigate the relationship between caregiver-child attachment classification styles and adherence to medication among HIV positive children.

Sample: The sample consisted of 22 HIV positive children aged 3 – 5 years old.

Procedure: Informed consent (caregiver) was obtained and screening for eligibility. Eligible subjects responded to the adherence questionnaire and interview, the Beck depression scale, the Self Efficacy questionnaire, Social provision Scale, Ages and Stages Questionnaire (all to caregiver). Anthropometric measurements were taken and children completed the Attachment Story Completion Task (ASCT). Observations (EAS) were made of the child-caregiver interacting during “complete a dot” task and during medication administration.

Results: The Chi-Square analysis on adherence and attachment was significant. ANOVA yielded a significant effect of depression on adherence, and a significant effect of education on adherence. There was significant positive correlation between adherence and the 5 dimensions of the EAS; parental sensitivity, parental nonhostility, parental nonintrusiveness, child responsiveness and child involving, but a low nonsignificant correlation between adherence and parental structuring. There was a negative moderate correlation between self efficacy to manage mood and adherence but low correlations between the 5 other domains (guidance, assurance of worth, social integration, opportunity to nurturance, attachment) of social support and adherence. BMI fall between 5th and 95th percentile. 59% of children had deficits in problem solving, 32% had deficits in gross motor and 41% in fine motor respectively.

Conclusions and Implications: Emotional and behavioral proclivities are important in pediatric health; particularly the nature of the bond between the caregiver and the child which seem to increase the resilience of young children to the damaging effects of illnesses and diseases. Counseling should be dedicated to parents and children’s well-being and social support. High rate of developmental delays in HIV infected children underscores the need for screening, prevention and calls for access to early interventions, nutritional and care programs for these vulnerable children.

Key words: *caregiver-child attachment; adherence; HIV; behavioral; emotional*

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CHAPTER ONE

INTRODUCTION

1.0 Background

The Human Immune Virus and the Acquired Immune Deficiency Syndrome (HIV and AIDS) are not a new pandemic in Zambia. The first case of HIV in Zambia was first diagnosed and reported in 1982 and since then the pandemic has reached astronomic proportions in Zambia. In its 2004 report on global AIDS epidemic, UNAIDS estimated that one in six Zambian adults was living with the virus and that there were over half a million orphans, aged 0-14 years, as a result of HIV/AIDS (UNAIDS,2004) and this figure has risen over the years. "According to a recent study, there are an estimated 130,000 children living with HIV in Zambia (www.children.org)". These children acquire HIV through mother to child transmission. There might be many more infected children in Zambia. UNAIDS 2006 in ZARAN (2006) stated that far less attention and resources have been devoted to Zambia's tens of thousands of children currently infected with HIV. This increase in infected children is worrisome. This is especially true because of inadequate policies and guidelines concerning treatment and care of HIV infected children. Furthermore, ZARAN (2006) alluded to the fact that the neglect of HIV - infected children in HIV and AIDS response are deeply rooted in the complexities of the epidemic and little or no comprehensive research on children's social service requirements to ensure that they are able to live relatively normal lives. The epidemiology tract on issues and problems associated with the collection of data on the population is very limited. Problems with the current HIV/AIDS surveillance systems need to be addressed, in particular, the limited value of this data for analyzing current trends in the spread of HIV infection and AIDS among a diverse population.

Most of what we know about the epidemiology of HIV and AIDS is based on data from existing surveillance systems. Although these are useful and provide the most comprehensive information on Zambian AIDS cases, there are limitations which prohibit further analyses into areas where little data is currently available. The current HIV seroprevalence studies are questioned on their accuracy and validity in providing a true picture of the rate of HIV infection among the Zambian populations.

The complexity of the epidemic is made worse by children being infected through Mother to Child Transmission (MTCT), adherence to treatment and children not being able to make independent decisions about the epidemic with regards to treatment and care. Essential to this complexity, is adherence to Antiretroviral (ARVs) medication. ARV drug adherence means remembering to take ARV drugs at the right time, taking the right dose each and every day for the rest of ones life. If, however, the patient does not adhere to medication, the body would be unable to fight the virus because the virus would become stronger (resistant), therefore the drug will no longer work effectively. As a result, adherence to medication is an act or quality to stick to medication. Musomali (2007) stated that adherence is an act of compliance, confirming and yielding to the need of taking the medication. Many factors affect adherence, among others, multiple caregivers' inconsistent administration of medication, disclosure of status, self esteem and many more. **Adherence** is a medical term that is used to indicate a patient's correct following of medical advice. The hallmark of this paper is to find out how behavioral and emotional proclivities of children and caregivers are related to drug adherence.

1.1 Statement of the Problem

Taking anti-HIV medication consistently and properly is a critical issue for patients infected with HIV. Drug regimens are complex and when not taken properly, HIV can become resistant to the drugs. On the other hand, taking anti-HIV medication properly leads to improved health. Children and adolescents infected with HIV face unique challenges of taking HIV medication properly. They are most likely to have poor adherence because of their developmental challenges and the way they perceive things. Of particular interest is the way they respond to things emotionally and socially, which is different from the way adults process and understand information, react emotionally and interact with one another.

These developmental differences between adults and children call for more cross cutting approaches to promote sound drug adherence among children. What has made drug adherence difficult and challenging among children could be that some factors have not been integrated in the mainstream of making at least 95 percent adherence possible. In particular, social, emotional and behavioral predispositions of children have not been considered much as predictors or to be associated with of drug adherence among children. Studies have shown that most emotional and behavioral predispositions are a result of the nature of caregiver – child attachment especially in the first three years of life. Weinfield, et al (1999) stated that the nature of the affective tie and the effectiveness with which the caregiver can be used as a source of comfort in the face of danger differs across infant- caregiver dyads and that these variations are individual differences in the quality of attachment relationships.

These variations known as attachment classification styles in turn affect children emotionally and behaviorally and thus affect their health development in most aspects of life. Interestingly, studies have shown that children are both physically and mentally more able to co-operate and more able to resist (Adherence Network Group, 2006) and that past experiences of pain sensitize the child to similar experiences. The emotional reactions of the child to these distressing situations may make him/her co-operate or resist.

The events which take place in a child's early life can impact upon their development over the rest of their lifespan. Ensuring that children have an opportunity for normal and healthy development in the early years has been shown to be an effective strategy for building resilience for the adolescent years and later life (Rochat & Richter, 2008). As such it is important to regularly examine children's physical and neuro-development so that early interventions can be implemented. This is especially important among children with chronic illness. Since the first reports of pediatric AIDS in the 1980s, delayed neurodevelopment has been a well-recognized complication of HIV disease. Experiences from the United States and Europe indicate that HIV in central nervous system (CNS) can occur before there is significant immunosuppression and may be the first AIDS defining illness in as many as 18% of pediatric patients (Rie, Mupaula and Dow, 2007).

Due to this gap, it has become difficult to make adherence at least 95% possible. As such a holistic approach to addressing the issue of drug adherence, to which the government

and other stakeholders have been injecting huge amounts of money, can be made possible if the caregiver – child attachment relationship is put into consideration.

1.2 The purpose of the study

The purpose of this study was to test whether there is a relationship between the caregiver-child attachment and the child's emotional and social functioning. In particular, the purpose of this study was to determine whether different caregiver-child attachments styles are associated with adherence outcomes among HIV + children. "Efforts to make HIV positive children adhere to their medication at least by 95% require a multi-factorial approach (<http://aidsetc.org/aidsetc>)". A single approach or selected factorial approach (es) would not help to make adherence to antiretroviral drugs possible. In this proposed study, both sociological and psychological factors as determinants of adherence were considered because they have rarely been considered. If adherence is related to the ability and willingness of HIV positive individuals to take complex antiretroviral regimes correctly, there is no doubt that these variables should play an important role. Thus, considering only few factors as essential make adherence difficult. There are equally other factors which must be considered important, such as the behavioral and emotional proclivities of children. According to mills et al (2006) the following are the barrier factors to adherence;

- Distance to health centres where medicines are obtained
- Lack of frequent meals which potentially make it difficult to co-ordinate giving medication with or without food
- Changes in routines due to changes in the child's or caregiver's circumstances

- Changes in the caregivers in the course of a day is more likely (e.g different caregivers at different times of a day, school attendance), hence increased likelihood of different approaches to administration of medication
- The non-disclosure of HIV status of caregivers or children; secrecy may limit when, where and who gives children medication.
- The taste and texture of medication
- Growing up and striving for independence increases the possibility that a child may be non co-operative and refuse to take medication
- Continued dependence on the caregiver to administer medication

These factors have been given much attention at the expense of behavioral and emotional factors. However, multidisciplinary treatment teams that can assess and optimize children's home environment appear warranted. As such, teams must include behavioral and early childhood specialists that can provide education and guidance regarding development and positive behavioral support to caregivers of children with HIV. This environmental assessment may be very important to make adherence possible because caregiver-child coping and attachment related strategies suggest that more active problem - focused strategies should be included in pediatric HIV/AIDS treatment. Some studies have shown how the early infant-parent attachment relationship affect the child's growth and the aforementioned problems in adhering to medication may be explained by such early dyadic relationships. For instance, Wiefield et al (1999) argue that using sensitive caregivers effectively to meet the infants' needs would lead the

children to believe, as children, that they can influence the world to meet their needs and achieve their goals.

The importance of attachment in pediatric HIV/AIDS treatment

The child - caregiver attachment will be an important factor to consider because of a number of factors which are strongly related to both predicting attachment relations and adherence to medication. These factors among others include obedience of the child to the caregiver, easy instruction of the caregiver and confidence of the child in the caregivers' intentions and goals in any given task or situation. The degree to which each of these factors can help to predict the attachment classification of the child to the caregiver have also been documented to be important in pediatric HIV/AIDS treatment especially in adherence to medication.

There is an extensive body of literature on infant – mother dyads on the sequelae of attachment security. For example Londerville & Main (1981) in Braungart-Rieker et al (2001) found that securely attached children had greater compliance to maternal request. Some bodies of literature suggest that secure and insecure attachment in infancy can shape many aspects of the developing personality including sociability, emotional predispositions, curiosity, self esteem, independence, cooperation and trust (Thompson, 1999). Similarly, pediatric settings have also suggested independence, cooperation and trust to be important variables in predicting adherence among children. Kobak & Duemmler 1994 in Kobak (1999) also argued that by age 4 and the formation of “goal – corrected partnership”, confidence in the attachment figure is likely to be reflected in open discussion of goal conflicts, negotiation of plan, and perspective - taking

communication. Goal corrected partnership refers to the relationship in which behavior is determined not only by the child's current needs and desires , but also by recognition of the need to manage certain "set goals" for the partnership (Bowlby, 1973; Kobak & Duemmler 1984). Thus, this indicates how important goal partnership is in medication taking especially if the caregiver is in charge.

Bowlby proposed that early infant experience of sensitive and insensitive care contribute to the growth of broader representations concerning caregivers' accessibility and responsiveness, as well as to beliefs about ones' deservingness of such care (Thompson, 1999). He also argues that such expectations not only enable immediate forecast of the sensitivity of caregivers' responsiveness, but also guide future relational choices and expectations, self appraisal, and behavior towards others. In addition, open parent – child communication allows a child to develop secure expectations for his or her caregiver's responsiveness. These expectations result in more open and direct signaling to the parent. Secure relationships often foster a self-sustaining virtuous cycle. For instance in relationships marked by secure working models and open communication, normal attachment disruptions often result in conversations that restore the child's confidence in the caregiver's availability (Kobak, 1999). Likewise, open caregiver-child communication involving a child infected with HIV would restore the child's confidence in the caregiver's intentions and goals during medication taking and other medical routines.

Unfortunately, more dysfunction patterns of communication among insecurely attached children may also become self sustaining. These children become detached and show

cool neutrality toward parents and an apparent apathy (Kobak, 1999), which in turn may affect medication taking and ultimately affect adherence to ARVs. Therefore, a history of poor caregiver- child communication and a child's lack of confidence in the intentions and goals of the attachment figure will exacerbate these problems in pediatric HIV/AIDS treatment.

Furthermore, attachment is important to consider because of the insight it may provide in explaining the relationship between the child's personal efficacy, ego-resilience and medication adherence. These variables have been studied in relation to attachment history. According to Weinfield et al (1999), personal efficacy is the confidence, belief that one can succeed and tolerate frustration in goal seeking. Ego-resilience is the child's ability to respond flexibly to changing requirements of the situation, particularly in the face of frustration. These dimensions of personal efficacy were explored in a longitudinal Minnesota study, a study of middle - class families. In this study, mothers and their children aged 2 years were observed in a tool use situation. Metas, Arend & Sroufe (1978) found that children with secure histories appeared more competent in the tool use task than those with anxious histories, *showing more enthusiasm, compliance with maternal directives and persistence*. When these children were in pre school Arend, Gove and Sroufe found that children with secure histories were judged to be more ego - resilient than their anxious counterparts in a teacher Q- sort (Weinfield et al, 1999).

These studies all point to the reason why attachment would be important to include in assessing medication adherence among HIV positive children. Attachment can help understand why secure versus insecure children would differ in the levels of obedience,

compliance to maternal requests, mutual cooperation, open communication, personal efficacy and ego-resilience. These dimensions are very important predictors of adherence and therefore warrant the inclusion of attachment in understanding ways of improving adherence in pediatric settings. This means that enhancing attachment strategies of the caregiver- child interaction may improve the caregiver – child relationship which can later improve their functioning. Therefore, this suggests that examination of the interaction between various coping or adoptive styles of the dyads and dosing regimens may yield more ecological valid information than just examination of demographic and medicine related factors exclusively.

Thus, factors such as the aforementioned, supported with empirical studies, show evidence enough to justify the need for this study to include attachment so that a multi – factorial approach to improving drug adherence among children can be considered. If such behavioral and emotional factors can be integrated in the mainstream advocacy and educational campaign on improving adherence, much more can be achieved than 95% which is currently sought for. This study will also alert clinicians and stakeholders of circumstances requiring enhanced interventions or education and possible need for improved and more consistent methods of adherence assessment which may have implications for practice. This study may also have long term indirect benefits to children by improving medication adherence and subsequently improve their health. Equally caregivers may find more adoptive behaviors and strategies of administering medication to children.

1.3 Objectives of the study

The general and specific objectives of the present study were;

General objective

- a) To examine the relations among attachment classification styles, caregiver emotional availability and adherence to treatment.

Specific objectives

- a) Identify attachment classification styles which are likely to generate difficulties adhering to HIV/AIDS medication
- b) Identify emotional and behavioral proclivities that contribute to poor adherence among HIV positive children.
- c) Determine cognitive, physical and Neuro – developmental delays that HIV/AIDS + children may experience as a result of the illness.
- d) Determine the importance of caregiver sensitivity and responsiveness to their children

1.4 Hypotheses:

- a) Insecure caregiver-child attachments are associated with poor drug adherence
- b) Insensitive caregivers and caregivers who are insensitively disciplining their HIV+ children find it difficult for their children to adhere to treatment.
- c) Insecurely attached children are problematic and difficult during medication taking.
- d) Non adherence will be related to high levels of depression of the caregiver, poor social support of the dyad, less perceived self-efficacy of the of the caregiver,

education levels of caregivers and insecure attachment classification style of the child.

- e) The HIV+ children will have delayed physical, mental and Neuro – development.

1.5 Operational Definitions of Variables

The key variables included the dependant variable of this study which was Drug Adherence while the independent variables included Attachment classification styles, caregiver's sensitivity and responsiveness, structuring, limit setting and discipline

Attachment - a special emotional relationship that involves an exchange of comfort, care and pleasure.

Anti – retroviral treatment (ART) – the use of antiretroviral drugs to suppress or prevent the replication of HIV in the body and its destruction of the immune system

Adherence – the degree to which the caregiver and child follow a treatment plan and the requirements for taking medication (the recommended dose, at the recommended time, in the recommended way).

Non-adherence – not following the prescribed treatment plan and includes missed or delayed doses or failing to follow guidelines (e.g taking too little or too much medication, taking it at incorrect times).

Dementia – lowering overall cognitive functioning; difficulties with attention, language, and fine motor skills; and problems with behavioral and academic functioning. AIDS dementia complex (ADC) caused by HIV infection is a complicated syndrome made up of different nervous system and mental symptoms. These symptoms are somewhat common in people with HIV disease.

Depression- caregiver's periodic episodes of sadness, discouragement, apathy and passivism and perceiving of the future with great pessimism and hopelessness.

Education – the amount of knowledge possessed by the caregiver as a result of schooling.

Self-efficacy- the caregiver's sense of ability to administer medication to the child correctly without doubt and problems

Sensitivity – the parent's (herein caregiver's) ability to perceive infant's (herein child's) signals accurately and vary his or her behavior appropriately e.g. contingent responding to appropriate levels of stimulation in which the child is neither under – nor over stimulated.

Responsiveness – the reflection of two aspects; (1) eagerness or willingness to engage and/or following a suggestion or bid for exchange; (2) display of clear signs of pleasure in interaction.

Structuring, limit setting and discipline - the degree to which the parent or caregiver appropriately structures the child's play by taking care to follow the child's lead and set limits for appropriate child behavior and /or misbehavior. The qualities may be observed in the parent's establishing rules and requesting or demanding compliance from the child.

Intrusiveness - qualities of over directiveness, over stimulation, interference, or over protectiveness. Treating the child as younger than he or she really is, is a sign of intrusiveness.

1.6 Chapter Summary

This chapter started with the introduction of the subject matter and research question. It went on to explain the general views on the subject as captured from different authors about the subject. This then makes clear why the researcher wants to study the role of caregiver- child attachment in predicting for adherence.

A brief background is given bearing in mind that the subject matter in consideration is quite wide and there are many players involved. Then the researcher makes known the aim and discusses the objectives of the study.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

In order to account for the role of attachment in medication adherence among children, other psychological factors were reviewed so as to find out the extent to which attachment related sensitivity would account for adherence to HAART among HIV positive children. As such, the empirical framework of this literature review considered three other psychological factors other than attachment sensitivity and these are depression, self efficacy and social support.

2.1 Theoretical Framework

Not many studies have been conducted to find out the effect of behavioral and emotional predisposition of caregivers and their HIV positive children on drug adherence. Simoni et al (2007) came up with a comprehensive model of factors related to adherence which could be useful when assessing the effect of behavioral and emotional predispositions on adherence. This model includes factors related to medication, patient and caregiver/family factors. According to Simoni et al (2007), the medication or treatment – related factors that are likely to complicate paediatric adherence include the indefinite duration of treatment, multiple and precise dosing time, multiple medication, high pill burden, complex dietary consideration, storage requirements, low palatability, large pills, significant short term and long term adverse effects (e.g nausea, rashes etc) and long term toxicities. To this model, Pontali in Simoni et al (2007) added other factors such as availability and cost of medication, accessibility of treatment and health care provider's experience and relationship to the patient as medication or treatment variables that are possibly associated with adherence.

For factors related to the caregiver/ family Pontali in Simoni et al (2007) “stressed the role of family disruption and the characteristics of the caregiver such as his or her relationship to the child, level of anxiety and depression, education, resources and their self-efficacy. Caregivers who are biological parents of HIV – positive children often share their diagnosis and confront challenges associated with their own illness and its comorbidities. Thus, they may be physically fatigued or debilitated”. Better caregiver knowledge of antiretroviral medication, better parent –child communication and better caregiver cognitive functioning have also been found to be related to adherence to medication (Simoni et al 2007).

Caregiver/family factors are very crucial in understanding the effect of behavioral and emotional proclivities on adherence to treatment especially among children. Medication adherence is a critical issue for HIV infected children and adolescents because of drug resistance and the increased complexity of treatment regimens. The NIAID (2003) states that children with other chronic diseases are less likely to adhere to their medication regimes if they have behavioral or emotional problems; assessing emotional and behavioral function in children and adolescents with HIV may help in predicting adherence and explaining adherence failure. As such, it can be deduced that insecurely attached children may find it difficult to adhere to drug intake because of the attachment related behaviors both from the children themselves and their insecure parents/caregivers. This is made worse because of the young children’s inability to independently follow their ARV regimes, meaning an ARV treatment knowledgeable caregiver must always supervise their adherence. Thus, the caregivers’ or child’s behavioral and emotional problems may escalate the problem of adherence in the child.

Therefore, avoidant children are likely not to adhere to drug intake schedules because of their disobedient and difficult to guide behavior which put off the caregiver. Similarly, resistant children may be difficult to administer drugs to due to their tantrum and punitive behavior and habits.

Put differently, insecure dyads are prone to conflicts and bad conflict resolution styles, and insensitive caregivers may not find subtle ways to softly but firmly move children to take medication in time partly because insecure caregivers have problems with firm limit setting and structuring which are essential for regular medication schedules. Pontali in Simoni et al (2007) recognised this when he stressed the role of family disruption, caregiver characteristics such as his or her relation to the child and levels of anxiety as factors capable of influencing adherence among children.

Therefore, it suffices to state that behaviors that lead to the above mentioned problems may be due to unresponsive and insensitive caregiving that children may receive from their caregivers. As earlier alluded to, for drug adherence to be possible, compliance must be observed in the child. With regard to this, Greenberg (1999) stated that numerous empirical findings indicate that the development of a secure attachment with caregiver(s) in the first 2 years of life is related to higher sociability with other adults and children, higher compliance with parents, and more effective emotional regulations. This is mostly possible if the attachment dyad communicate positively in their daily interactions. In a study of 75 perinatally infected 3 to 13 year olds in New York, Mellins et al found that nonadherence was related to worse *parent-child communication*, higher caregiver stress, lower caregiver quality of life and worse caregiver cognitive

functioning (Simoni et al, 2007). As such secure children may find it easy to adhere to medication while insecure children may not adhere to medication easily partly because compliance and effective emotional regulation are essential during medication taking. Leah, Richard & Sroufe (1978) concluded that from infancy to early childhood, the predication is that children with secure, effective attachment relationships will later exhibit competent, more autonomous functioning of both affective involvement and problem solving styles. They also found that secure children in the tool-using task were significantly more enthusiastic, affectively positive and persistent; they exhibited less non task behavior, ignoring mothers and non compliance than insecure children displayed. While insecure attachment prior to the age of 2 has been related to lower sociability, poor peer relations, symptoms of anger and poorer behavioral self control during preschool years and beyond (Greenberg, 1999), such behavioral and emotional predispositions can make adherence to medication difficult for insecure children.

2.2 Empirical Research

Attachment related factors

It is assumed that there is coherence in personality development over time, that early assessment predicts the presence of later developmental difficulties, and that particular difficulties are linked to quality of early adaptation in a logical manner (Leah, et al, 1978). These developmental difficulties stem from early attachment ties with caregivers. These difficulties have been also found in the health settings and are believed to thwart the health development of the child. In 1995, the American Public Health Association Committee on Child health defined child health as “a state of physical, mental, and social well being, not merely in the absence of disease or infirmity (Dworkin, 2000).

Similarly, the American Academy of Pediatrics has defined the goal of child health supervision as the promotion of optimal growth and development of children (American Academy of Pediatrics, Committee on Standards of Child Health Care (1992).

The aforementioned definitions encompass and acknowledge the importance of certain emotional behavioral propensities in child health. Attachment related emotional and behavioral proclivities are not independent to this cause but are part of the major health problems that children may encounter. There is little if any literature of attachment and medication adherence. However, there are some studies that suggest attachment related behaviors and the role they play in predicting adherence to medication among HIV positive children. In their study, Reddington et al (2000) indicated that for children with HIV infection, successful adherence to medication requires the caregiver to take responsibility and the child to be cooperative. These findings could suggest that the caregiver – child interaction according to attachment theory may be a barrier or facilitator to adherence in that, the degree of caregiver responsibility and child cooperativeness would be determined by the working models of the dyads. As such, Bowlby (1988) suggested, that the pathway to change in attachment behavior depends on the reality-based characteristics of internal working models of attachment. Therefore, it is likely that attachment –based interventions will focus on the caregivers' representational level. Further, Steele & Grauer (2003) report in their review of literature that a number of predictors to antiretroviral therapy have been examined in HIV patients. Among them Chesney (2000) categorized the quality of the patient – caregiver relationship as a predictor of adherence. These findings are consistent with what Haggerty and colleagues found in their study. They identified behavioral development

and psychosocial problems as the new morbidity of pediatric practice (Haggerty, Roughman & Pless, 1975). Subsequent studies confirm the high prevalence of such problems within primary care practicing settings (Hickson, Altemeier, & O'Connor, 1983).

However, unlike their adult counterpart, children's adherence to antiretroviral medication necessarily involves the behavior and the perception of another agent, namely the parent or caregiver (Steele & Grauer, 2003). These findings suggest that if the child has internal working models that look at the caregiver as unavailable or irresponsible he or she may not cooperate. Therefore, emotional involvement of the caregiver is important to the healthy development of the child and improvement of adherence. As a result, Pediatric preventive care has increasingly focused on the behavioral and social aspects of child health. As such, Berlin, Ziv, Amaya-Jackson & Greenberg (2005) argued that supportive early child-caregiver relationships pave the way for children's subsequent development, especially in terms of the social skills and mental health. Mostashari et al 1998 in Catz (2000) observed that the presence of good emotional support was associated with antiretroviral adherence. Moreover, as earlier stated children with other chronic diseases are less likely to adhere to their medication regimens if they also have behavioral or emotional problems (NIAID 2003).

In the same line the Adherence Network Group (2006) observed that highlighting to caregivers the importance of positive relationships with children can be the basis for promoting adherence. In so doing, their child adherence counseling also explores with the caregivers ways of interacting positively with children outside of illness or

medication. This intervention approach has direct attachment interventions towards the earned secure attachment classification dimension.

Thus, in the primary care setting, child health providers offer parents guidance and support in promoting their children's development through provision of anticipatory guidance. Telzrow 1973 in (Dworkin, 2000) defined anticipatory guidance as the provision of information to parents or children with expected outcomes being change in parent attitude, knowledge, or behavior and emphasize the mutual participation of parents and health providers in discussion of ideas and opinions about parental responses to development. This means that both caregiver's sensitivity and responsiveness have been identified to be important in the child's health.

2.3 Other psychological factors

Several studies have looked at the effect of psychological factors in adherence to medication in adults and children. In their study for instance, Catz et al (2000) found that both relationships with one's health care provider and psychosocial factors including social support and depression contribute to adherence with Zidovudine (AZT). Like wise, consistent with Chesney, Ickovics et al 2000 in Steele et al(2003) and Singh et al 1999 in Steele et al (2003) and Reddington (2000) identified health beliefs and perceived social support as correlates of adherence among children. Similarly, recent reviews of pediatric HIV adherence literature suggests wide variability in adherence rates, and that these rates may be associated with a number of factors including demographics, available social support, child and parent health beliefs and caregiver and child psychosocial functioning (Steele, Nelson and Cole,2007).

Further, Steele et al (2003) in their review of literature on pediatrics discovered that parents of nonadherent children evidenced greater concern about others discovering the child's serostatus. One interpretation of these finding is that nonadherent parents had less instrumental social support particularly as it had impacted their ability to maintain adherence. Thus, disclosure of the child's status is important for one to enjoy social support network and therefore adhere to medication. Social isolation as a barrier to adherence has also been reported by Mills et al (2006). In their Meta – analysis they report ten studies indicating social isolation as a barrier to medication adherence. Furthermore, they report that positive interpersonal relationships as reported by patients were necessary for successful adherence. Mills et al (2006) also observed as Steele et al (2003) noted that openly disclosing one's HIV status to family, friends and having strong support network was influential to adherence. Steele, Nelson & Cole (2007) found that from a system perspective, caregiver copying strategies and caregiver social support may be expected to influence the copying and adjustment of children with HIV.

It is also worth noting that there is a moderating relationship between social support and depression to adherence. In a study by Gordillo et al (1999), depression was found in 148 (40.4%) of patients and 94 (25.7%) patients reported that they had no social support. Interestingly, subjects without depression and good social support had compliance which was nearly twice that of depressed subjects who lacked social support (OR 1.86; 95 CI, 0.98 – 3.53). However, when analyzed in the invariant analysis, Gordillo et al (1999) found that both depression and lack of social support were associated with worse compliance with treatment. However, in a multivariate analysis, the interaction found between depression and perceived social support suggested that social support does not

contribute further to improved adherence in the presence of depression. From this study, Gordillo et al (1999) argued that depressed individuals comply worse with treatment irrespective of social support they may have whereas in subjects who are not depressed, social support does not contribute to improved adherence to treatment. Gordillo et al (1999) suggested that this implies that efforts to provide social services to HIV – positive subjects should run parallel with adequate management of depression by multidisciplinary teams.

However, other studies have found that depression on its own is associated with poor adherence. A study by Reddington et al (2000) documented that depression and psychological distress of caregivers is associated with poor adherence to HIV medication. Similarly, Steele & Grauer (2003) found that caregiver's psychosocial adjustment or distress may impact their ability to maintain pediatric adherence to complicated antiretroviral regimens. Singh et al; 1996 in Catz et al (2000) did a longitudinal investigation on the effects of depression to medication adherence among HIV patients. This study found that patients who had lower levels of depression and more adaptive coping patterns were more adherent to their treatment than patients who had higher levels of depression and less adaptive coping patterns. This study indicates that the depressive state of the patients contribute to poor adherence to medication. Murphy et al in Steele and Grauer (2003) also examined a number of factors of adherence, but found a significant relationship only between number of depressive symptoms and self reported adherence.

It is worth noting that not only the caregiver's depressive state contributes to predicting adherence to medication but that a child's depressive state may also contribute to poor medication adherence. Bennet reviewed 60 studies of depressive symptoms among children and adolescents with chronic medical problems and concluded that chronically ill children had slightly elevated risk of depressive symptoms but not clinical depression. This finding indicates that depression even in children should be considered crucial as a barrier to adherence to medication since depression especially of caregivers has been found as a barrier to adherence. This should be considered because of emerging studies indicating that HIV positive children are susceptible to depression and somatic complaints. Heaven and colleagues found that children with HIV had elevated scores on the child behavior checklist, though these scores were not significantly different from the scores for the seroreverted control group.

Another psychological factor that has been found to contribute to poor adherence to medication is self efficacy. Reddington et al (2000) found that the biggest difference between adherent and nonadherent caregiver's attitudes was in response to a statement that addressed their perception of their own ability to successfully administer their child's medication regimens. Non adherent caregivers reported needing help at home with medication administration. Steele and Grauer (2003) hypothesized in one study that parents of adherent children had good perceptions of their ability to administer the prescribed doses as well as the efficacy of the medication. As expected, the non adherent group was significantly more likely to strongly agree with a statement regarding inefficacy ("it is almost impossible to get every dose during a week").

Similar studies have found self efficacy as a predictor of adherence. For instance, in their 1998 study, Eldred, et al (1998) found out that even in relatively easy single – drug regimens, the beliefs held by patients concerning their ability to adhere to drugs were related to their levels of treatment adherence. Reddington et al (2000) also identified caregiver perception of medication efficacy and dosing self efficacy as significant predictors of child adherence.

Psychological factors such as these reviewed above have attracted attention especially in an epoch to find intervention programmes that would significantly act as barriers and facilitators of adherence than most demographic factors. In a preliminary analysis, Catz et al (2000) examined whether there were differences between the adherent and nonadherent groups in age , education levels, gender, ethnicity, current CD4 levels, length of time since HIV diagnosis, number of medication prescribed or length of time on HAART regimens and reported that no differences were found (all ps >.10). However, there were differences in psychological characteristics. Mean comparisons across adherent groups indicated that non adherent participants had significantly higher levels of depression, lower levels of treatment adherence self efficacy and lower levels of perceived social support.

With this background, this study endeavored to find out the extent to which attachment related sensitivity may account for adherence independent of other psychological factors namely; depression, self efficacy and social support.

2.4 Chapter Summary

The chapter started with a theoretical framework of the possible factors affecting adherence among children and adolescents. Attachment theories were also described in relation to how they affect achievement of certain individual set goals. The theoretical framework was then backed by empirical research on infant-mother attachment and how it predicts an individual social competence such as compliance, obedience and trust to caregivers' caring and treatment.

The chapter end with a description of psychological factors that affect adherence among children and adults alike such as depression, caregiver or patients self efficacy and social support.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This study employed a test for significance method of research (Chi-Square test) to assess the association of attachment classification styles and adherence to treatment. Further a correlation test was employed to assess the relationship of caregiver sensitivity, structuring, limit setting, discipline and responsiveness with adherence to treatment among HIV+ children. If the above variables have any relation on medication adherence, this study may lead to an intervention programme to enhance caregiver sensitivity and responsiveness which can improve children's medication adherence.

3.1 Sample

Fourty (40) participants were recruited from health centers. This sample consisted of 20 HIV positive children aged 3 – 5 years old and their caregivers with either a positive or negative HIV/AIDS status.

Description of Sample

The subjects of this current investigation were selected from a pool of hundreds of dyads with children living with HIV and AIDS aged 3 -5 years old who were on HAART. 2(9%) of the subjects were 3 years old, 9(41 %) 4 years old and 11(50%) were 5 years old respectively. The mean age was ($M= 4.4$, $SD=0.67$). The sample size consisted of 11 females and 11 males, each gender consisting 50% of the total sample size. 7(32%) of the subjects were recruited from Kalingalinga clinic while 6(27%) from Ng'ombe clinic and 9(41%) from Chelstone clinic.

Table 1: Gender and Clinic distributions of the Child- subjects

GENDER	FREQUENCY	PERCENTAGE	CLINIC	FREQUENCY	PERCENTAGE
Male	11	50	Kalingalinga	7	32
Female	11	50	Ng'ombe	6	27.
Total	22	100	Chelstone	9	41
			Total	22	100

Table 2: Age distribution of the child – subjects

AGE	FREQUENCY	PERCENTAGE	OTHER STATISTICS	
3	2	9	Mean Age	4.4
4	9	41	Median	4.5
5	11	50	Standard Deviation	0.67
Total	22	100		

The caregivers of the children were largely female. Out of the 22 caregivers, only 1 was a male caregiver and 21 were female caregivers. The age for the caregivers ranged from 18 years to 64 years of age. The mean age was 36 years and most of the caregivers were 45 years old.

Table 3: Age distribution of caregivers

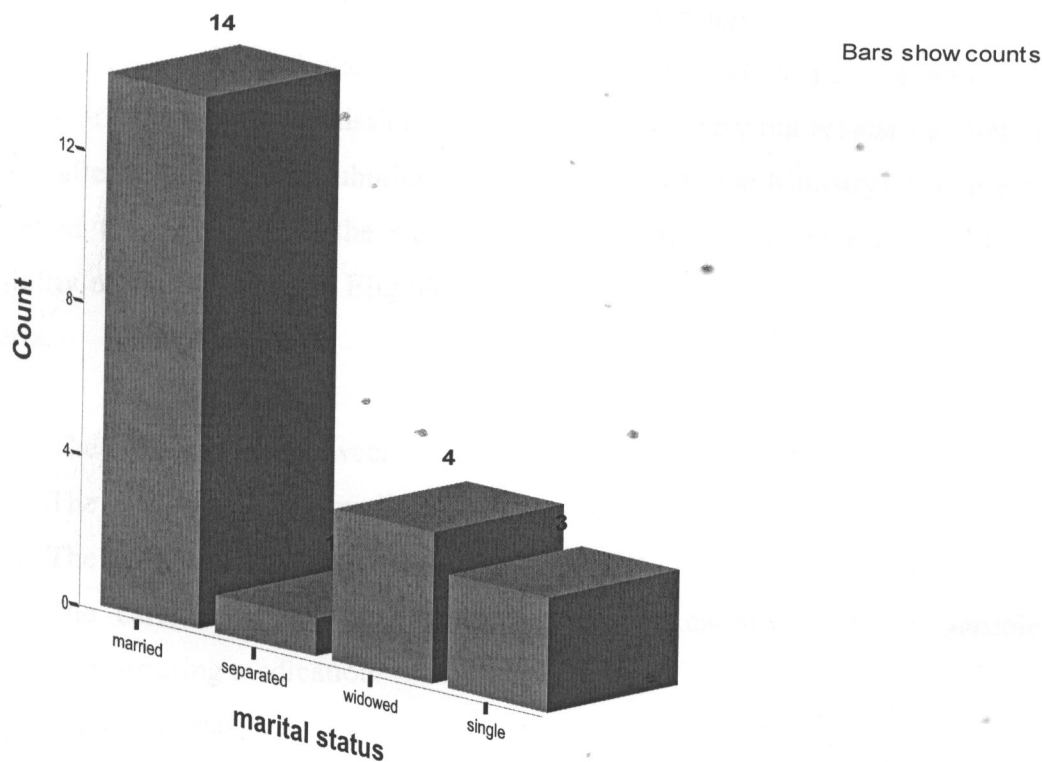
Mean Age	Mode	Age Range
36	45	18 – 64

Marital status, Education and Income of Caregivers

Marital Status

The present study examined the marital status of the caregivers. Of the 22 caregivers, 14 were married, 1 separated, 4 widowed and 3 were single.

Graph 1: Marital status of caregivers.



3.2 Sampling Procedure

A non probability method called purposive sampling was used in this study. “In this sampling method an already defined group is sought for (<http://www.socialresearchmethods.net/kb/samprnon.htm>)”. This sampling technique was ideal for the study because the sample was not compared to another group (non clinical sample) and it was selected at least from three different health centers in Lusaka. The identification and recruitment of HIV [children] participants was done through home based care organizations who in turn contacted the participant’s respective pediatrics adherence clinics. Since these are legitimate organizations dealing with HIV positive children, identification of participants were done through these organizations. The research then approached the Sister –in –Charge in each center for approval (the Ministry of Health gave permission to the researcher to carry out research in their health centers after the researcher submitted the full protocol to the Ministry). Caregivers that consented to participate in the study underwent a screening interview to determine eligibility of the participants. Eligible participants were supposed to meet the following criteria:

1. The child must be between the age of 3-5 years old
2. The child must be on medication(ARVs or Septrin)
3. The child was not supposed to be critically ill
4. The caregiver must have been the primary caregiver and responsible for administering medication.

Exclusion criteria;

1. children not on ARVs/Septrin medication
2. critically ill children
3. caregivers not responsible for administering medication
4. children from orphanages or related institutions

3.3 Study Site

The study was conducted in the urban areas of Lusaka province. Three strategic health centres were considered for the study from which participants recruited and these included Chelstone Health Center HIV/AIDS (family support group), Kalingalinga Health centre (family support group) and Ng'ombe health centre (family support group).

3.4 Research Strategy

Chi-Square test was used to assess the relationship between attachment classification styles and adherence to treatment. Further Pearson correlation was used to assess the relationship among caregiver sensitivity, structuring, limit setting, discipline and responsiveness with the effect that these variables have on HIV positive children on their medication adherence. Data will be collected using different techniques using a multiple triangulation method in which the research will combine in one investigation various observational methods, questionnaires and methodologies. Therefore, these techniques will include video recordings, self administered questionnaires and interviews. It is worth noting that the videotapes analyzed for attachment classification and emotional availability of the parent- child interactions were rated without expert training.

3.5 Instruments and Procedure

Data collection was done in a period of three months (July and September) from the inception of the research. To gather the data, the following procedures and instruments were employed;

Screening Interview - to determine participants who were eligible for the study, a structured interview was conducted by the researcher. The interview aimed at obtaining information such as (1) is the caregiver the person responsible for administering medication to the child and if he or she is a primary caregiver of the child (2) if the child is on medication and the form of medication (3) the days and times when the child takes medication (4) their details such as home address and/or phone number on which they can be contacted for home observations (5) the age and sex of the child (6) the current wellbeing of the child (7) problems if any that they face when administering medication to the child (8) the days when they come to the health centre for their regular appointments with a counsellor (9) the social economic status of the dyad and (10) any other information that they would have wanted to add about the child or medication.

The prospective participants were given all the information about the purpose of the study before the interview and if they accepted they signed a consent form. An appointment was then made with eligible participants for the home observations. The health centre observations and an attachment story completion task were conducted on their next appointment with the researcher.

Assessing Adherence

There are two methods of capturing adherence to medication and these are direct and indirect methods. However, this study will only use some of the indirect methods. "The direct method involves biological assays of an active drug, its metabolite or other markers in the bodily fluids that confirm active drug injection. Indirect method (which does not measure the presence of the drug in the individual) includes self report,

caregiver report, clinician assessment, medical chart review, clinic attendance, pill count, pharmacy refill records, electronic drug monitoring (EDM), behavioral observation in the form of directly observed therapy (DOT), resistance testing and therapeutic impact such as viral load (VL) CD4 lymphocyte count (Simoni et al 2007)".

Adherence to treatment was assessed using self reports measures answered by the children's caregivers. These included a questionnaire, an interview and a medical chart were also used to assess adherence.

Adherence Questionnaire – all caregivers were asked to complete a structured adherence questionnaire. Questionnaires were filled in at the time of the clinic visit or during home visitations. Adherence was assessed by asking questions such as, "Did the child take the morning dose of the medication mentioned? Then tracing backward to the evening and the day before followed by asking how many doses could not be given in the previous week. The activities that the child engages in were also asked about to find out if they prevented the child from taking medication as scheduled. The questionnaire took about 10 -15 minutes to be completed.

Adherence interview –All caregivers were interviewed using a structured adherence interview. The interview was administered either at the time of the clinic visit or during home visitations. Adherence was assessed by asking questions concerning predictors/correlates of adherence such as those related to medication, dosing, the environment and child behavior.

Medical Chart- this is a child friendly medical record/ chart where the child, with the help of the caregiver, marks against the day and time when he/she is supposed to take medication every time he/she takes the medication. These charts are available to the paediatrics counsellor /nurse every time the child has an appointment at the health centre. These were ideal for assessing how many doses could not be given in the previous weeks. Therefore, the research also examined medical records or charts for each child.

Scale of adherence

The scale of adherence ranged from 0 – 100% and good adherence was indexed at 90% or above. The scale considered consistency with appointments, taking medicine and nutritional advice correctly.

Social Attachment subscale of the Social Provisions Scale (SPS; Cutrona, 1989) – was used to assess perceived adequacy of and satisfaction with emotional support of caregivers who administer medication to the concerned children. Participants were rated with perceived support on 4-point scales using response anchors ranging from 1 (strongly disagree) to 4 (strongly agree). Scores on the Social Attachment Scale range from 4 -16, with high scores reflecting greater levels of perceived support. The validity of the SPS has been supported by past studies with seropositive persons.

Beck Depression Inventory (BDI) – was used to examine depression among caregivers because children rely on caregivers for medication administration and the depressive state of the caregiver would impact the correct administration of medication among

children. The BDI was successfully used to assess the depression levels in HIV – infected patients in previous studies (Gordillo et al, 1999).

Adherence self-efficacy – Perceived ability to adhere to a prescribed treatment plan was assessed using the adherence self efficacy measure which has been used in past HIV research. This measure was used to assess the caregivers’ and not the patients’ (herein children) confidence in their ability to help their children to manage adherence barriers and to tailor medication regimens to daily life. Response anchors range from 1 (you think you can not do it at all) to 10 (you are certain you can do it).

Video Recordings (Emotional Availability Scale)

Using the Emotional Availability Scale (EAS) as a tool of assessing caregivers’ sensitivity, responsiveness, restructuring and hostility, videos were recorded during physical measurements (herein health centre observation) and medication taking of the child (herein home observation). Equally, the Attachment Story Completion Task was video recorded to assess the quality of the children’s attachment relationship with the caregiver. Acknowledging the nature of the sample and how crucial confidentiality and anonymity is for this sample, the researcher took the following actions;

1. The videos were securely kept in a lockable place
2. Only the researcher had access to the videos
3. After successful data analysis the videos will be deleted or destroyed

Anonymity of the respondents in this study could only be reduced by the aforementioned action because the study could not disguise their faces since overt expressions were very crucial in assessing the caregiver’s sensitivity and responsiveness.

Health Centre Observations

Emotional Availability Scale (3rd Ed) – This scale was developed by Zeynep Biringen in the 1980s and she continued to perfect it. Using the scale, observations were done at the health centres when the dyad came for their regular appointments with the counsellor and family support programmes at their respective health centres. The Emotional Availability Scale was used in these observations. The Emotional Availability Scales was designed to examine and measure the quality of the emotional interaction between parents (herein caregivers) and their children. The scales include: parental sensitivity, parental structuring, parental nonintrusiveness, parental nonhostility, child responsiveness and child involvement (<http://www.emotionalavailability.com/eas.htm>). Because of different activities that surround such visitations, standard activities were designed in which caregiver's sensitivity and responsiveness can be observed and assessed. Maternal sensitivity and responsiveness is defined as the mother's ability to perceive her child's signals accurately, and to respond to them promptly and appropriately (Ainsworth, Bell, & Stayton, 1971, 1974). "The scale has been validated and has become the first system based on attachment theory and research that provides a comprehensive and scientific understanding of not only parental behavior towards a child, but also the child's side of the experience (<http://www.emotionalavailability.com/eas.htm>)".

Thus, each child was taken through 4 different physical measurements. A video recording was done during the physical measurement of the child. The video shooting involved the caregiver helping the child undergo the physical measurements. These measurements included weight, height, head circumference and chest circumference

measurements. *The purpose of the video recording was to capture and assess the degree of the caregiver's sensitivity expressed overtly.* The NICHD criteria and measurement procedures were followed (see NICHD study of early child care and youth development, 2006). In all these activities the caregiver took an active role such that the researcher only came in when the caregiver did not know how to read the measurements. Studies have shown that it is not easy to manage young children during medical examinations and procedures. It is difficult to explain to them or prepare them for procedures that may be uncomfortable, painful or frightening. Past experience of pain sensitizes the children to the possibility of further similar experiences. Thus, caregiver sensitivity and responsiveness in such situations may help calm the child and make the routines, examinations and procedures much easier. Adherence Network Group (2006) observed that the emotional reactions of the caregiver to a child's distress may compound the difficulties and that some children tend to be less anxious if they are talked through a procedure, allowed to watch what is happening and encouraged to participate as much as possible.

These measurements will be recorded as accurate as possible because failure to thrive is a common problem amongst HIV- infected children and their physical growth may be stunted. The stress of the child's HIV – positive status is made worse if the child is diagnosed as developmentally delayed or disabled and these may present a further set of challenges related to bringing up a child with special needs (Adherence Network Group, 2006). For caregivers who take over the care of such children after the death of parents, the double challenge may be seen as overwhelming, especially if the child's status as both HIV + and developmentally delayed are evident. In such situations, caregivers'

sensitivity and responsiveness are required even more for the child. Thus, how sensitive and responsive the caregiver is, was to be elicited from such interactions with his/her child. The measurements were preceded by a connect-a-dot task in which the caregiver was scaffolding the task before the child completes it on his/her own. Scaffolding is an instructional technique in which the caregiver models the desired learning strategy or task, and then gradually shifts responsibility to the child. Therefore, a single dyad was observed at a time for about 20 - 30 minutes for all these activities. All these activities were video recorded. However, the proposed video recordings will be recorded only if the primary care giver consents.

Home Observations

Emotional Availability Scale (3rd Ed) by Zeynep Biringen (1980, 1998) - observation was done in the participants' homes. Appointments were made on the day and time when the child would be taking medication. The researchers arrived earlier to start the observation and filming the interactions during drug administration. The shooting was done during the time the caregiver was administering medication to the child. The dyad was recorded during this process of medication taking. Similar with the health center observations, a connect-a-dot task preceded the medication taking observation. The difference between the two was on the number of tasks that the dyad did. The health center observation included 2 different connect-a-dot tasks while the home observation included 3 different connect-a-dot tasks. As with the health center observations, researchers were observing for parental sensitivity, parental structuring, parental nonintrusiveness, parental hostility, child responsiveness and child involvement. This observation is crucial to assess how parental sensitivity, non-intrusiveness,

responsiveness and structuring may predict medication adherence among children. Recent studies suggest that these may give insight on why some children are ambivalent, avoidant and aggressive when taking medication, and why some caregivers find it difficult to administer medication to children. Such caregivers' behaviors are marred with hostility and spillage of medication. "The emotional availability will also give insight on the child's pattern of attachment since it assess if children are emotionally secure or not (www.emotionalavailability.com)".

Thus, in both the home observation (during medication taking) and physical measurement observation, the researcher captured by *video* and assessed the caregiver's sensitivity, structuring and nonintrusiveness. This scale (EAS) emphasizes behavioral styles rather than discrete behaviors. As such a highly sensitive caregiver would display much genuine, authentic and congruent interest, pleasure and amusement with the child. On the other hand an insensitive caregiver would typically display active/harsh styles that involve harsh volatile facial expressions, signs of disgust, anger, abusive condescending tone of voice, disinterested and unenthusiastic behaviors.

For optimal structuring, a caregiver would let the child lead while providing a supportive frame, that is, the caregiver offers the child the chance to explore and to do things while providing a frame from which the child can build. In the context of limit setting and discipline, the parent is firm (not harsh) and includes preventive measures whenever possible. A caregiver with non optimal structuring sets no limits and provides no structure for the child. The caregiver appears passive, indulgent and does not provide adequate scaffolding.

A caregiver who is optimal in structuring tends to also be optimally non-intrusive. Thus, nonintrusive behaviors include caregivers' non-powering and directive behaviors in the interaction. The interaction is non-intrusive if it is smooth and spacious while intrusive behaviors include over-stimulating or controlling sometimes even physically, pushing and manhandling.

Criteria for assessing emotional availability

Emotional availability of the caregivers was examined during physical measurements which was preceded by "complete a dot task" in the health centers and during medication taking preceded by "complete a dot task" at the subjects' home.

The criteria for scoring the degree of emotional availability of the caregiver were adopted from the Biringen, Robinson & Emde's (2000) emotional availability scale (3rd ed.; an abridged infant/early childhood version). A caregiver was scored *highly sensitive* if emotional communication between a parent and child was for the most part positive, appropriate and creative. The caregiver was highly sensitive if he/she displayed much genuine, authentic and congruent interest, pleasure and amusement with the child as demonstrated by warm smiles and giggles, interested eye contact and comforting and playful physical contact. A caregiver was *generally sensitive* if she/he was similar to highly sensitive except that there was less spectacular quality to caregiver-child exchanges. A caregiver was scored *inconsistently sensitive* if the caregiver was sensitive in some ways but the observer found it difficult to give this relationship a clean bill of health. *Somewhat insensitive* caregivers were those in which insensitivity was typically displayed in one of the two general ways, one being an active/harsh style (overly active and over bearing) and the other being a passive/depressed flat style. A caregiver was

highly insensitive if the caregiver could not engage in an interactional style that was one sided (Biringen et al, 2000).

On the scale of parental structuring, a caregiver was *optimally structuring* if he/she showed appropriate degree of structuring. The caregiver's bids were successful in structuring instruction if he/she could let the child lead while providing a supportive frame, that is, the caregiver offered the child the chance to explore and play while providing a frame on which the child can build on. In the context of limit-setting and discipline, the caregiver was firm (not harsh). A caregiver was *inconsistent in structuring* if there was overall inconsistency in the caregivers' ability to structure and set limits. This caregiver could also show unvarying or repetitive attempts to structure that were not successful. *Non-optimal structuring* was scored if the caregiver set no limits and provided no structure for the child (Biringen et al, 2000).

For parental non-intrusiveness, a caregiver was *non-intrusive* if the caregiver did not overpower the interactions. That is if he or she let the child lead and based play interactions on the child's lead. The interaction was non intrusive, smooth, and spacious. The caregiver was available to the child without being intrusive and had quality of emotionally being there or being emotionally available without necessarily doing something to the child. *Some what Intrusive* was scored to a caregiver who too frequently set the pace of the interaction, asking questions, directing the course of the play, making suggestions, and creating frequent theme changes, as opposed to following the child's directions. Parental intrusiveness was not striking however. Such behavior appeared more directive and slightly overprotective rather than truly intrusive. The

quality of being “at” the child or doing something to the child was there as well, even if the child was unresponsive to the parent’s behaviors. *Intrusive* was scored to a caregiver who was highly stimulating and did not leave enough space in the interaction for the child to explore and lead. The caregiver controlled the interaction, sometimes even physically, punishing, or manhandling, and jumped in to do much for the child, showing a lack of respect and space for not only the child’s wishes but also the child’s abilities. This parent was consistently “at the child” or doing something to the child. This appeared to elicit certain behaviors from the child (Biringen et al, 2000).

For parental nonhostility, a caregiver was scored *nonhostile* if there was no expressions of overt or covert hostility toward the child as could be discerned by the observer. The general emotional climate appeared nonhostile. A caregiver was *covertly hostile* if he/she showed pervasive low-level negative affect, in the form of impatience, discontent, resentment, discomfort, boredom, huffing and puffing, rolling eyes, teasing, raising the voice, or adopting a long –suffering attitude. *Markedly and overtly hostile* was scored if the caregiver was overly harsh, abrasive, and demeaning-facially and/or vocally. And if a caregiver behavior was threatening and or frightening. Threats of separation or threats of abuse were viewed as very hostile even if the caregiver was joking about it (Biringen et al, 2000).

Child’s Part

A child was scored as *optimal in responsiveness* if this child showed an optimal balance between responsiveness to the caregiver and autonomous activities; such behavior was combined with an affectively positive stance. He/she responded often to the caregiver’s bids, but without any sense of urgency or necessity. The child generally showed pleasure

and eagerness in attending to the caregiver's comments, suggestions, questions, and demonstrations. *Moderately optimal in responsiveness* if the child was still affectively positive and responsive overall but was less so or there was slightly more blasé or just OK quality. The child had a generally responsive quality but again it was OK, rather than the beautiful, spectacular sort seen in optimal responsiveness (Biringen et al, 2000). *Somewhat nonoptimal in responsiveness* was a rating given whenever there were serious concerns about the child's emotional and behavioral responsiveness toward the parent. Somewhat nonoptimal in responsiveness referred to emotional and behavioral responsiveness indicative of nonoptimal interactions in the dyadic relationship. Not only did the child not show a good balance between autonomous pursuits and responsive behavior toward the parent, but he or she was less happy, content and/or emotionally robust. *Clearly nonoptimal in responsiveness* was given if the child rarely showed emotional and behavioral responsiveness when engaged with the caregiver and rarely responds to the parental initiative. The balance of the autonomous pursuits and responsive behavior is clearly not optimal; further, there are serious concerns about the child's emotional health (Biringen et al, 2000).

Optimal in involving behaviors was given if the child showed a balanced pattern between autonomous play and drawing the caregiver into interaction. He/she tried to engage the parent in the interaction and appeared eager to do so in a non anxious way. The child seemed interested in engaging the parent in interaction without compromising autonomous pursuits. *Moderately optimal in involving behavior* was given if the child showed more interest in the task at hand than in involving behaviors. The child was much more oriented toward being alone or playing alone than in engaging in interaction

with the caregiver. There was a periodic request of the caregiver's attention and interest. Somewhat nonoptimal in involving behaviors was given if the child did not show a style of optimally drawing the caregiver into play or interaction, that is, by showing a balance between involving and pursuits. *Clearly nonoptimal in involving behaviors* on the other hand was given if the child did not optimally orient toward the caregiver. He/she did not show a good balance between involving behaviors and autonomous pursuits at all (Biringen et al, 2000).

Attachment Story Completion Task - The quality of the children's attachment relationship with their mothers was measured using the Attachment Story Completion Task (ASCT; Verschueren & Marcoen, 1994; based on Bretterton, Ridgeway, & Cassidy, 1990, and Cassidy, 1988). These stories were designed to elicit individual differences in the children's enactment of a variety of attachment related issues (Bretterton, Ridgeway, & Cassidy, 1990). Using child and mother dolls, children will be asked to complete five attachment-related stories (see Verschueren, Marcoen, & Schoefs, 1996, for a complete description of the stories). An additional story concerning medication taking with the help of the caregiver will be completed.

Each story was coded as "secure", "insecure-avoidant", "insecure-bizarre/ambivalent", or if the child did not tell a clear secure or insecure story- "secure/insecure". Stories classified as "secure" contain descriptions of positive feelings and harmonious interactions between the child and her/his mother, without any negative, unclear or bizarre subjects or issues. Stories which show negative, hostile, or bizarre interactions with the mother figure were classified as "insecure-bizarre/ambivalent". Stories with

minimal interaction between mother and child, avoiding the topic, or reluctance to complete the story were classified as “insecure-avoidant”. Three independent coders, who were unaware of the physiological and temperament data, rated the verbal transcripts of the children’s stories.

Criteria for assessing attachment

Criteria for security: separate criteria for security were established for each story. In the “spilled juice” story, responses were classified as secure if the juice was cleaned up, and parental discipline or anger (if mentioned) was not violent or extreme. In the “hurt knee” story, responses were classified as secure, if one of the parents or the older sibling responded to the hurt child’s pain by hugging or administering a band-aid. In the “monster” story, responses were categorized as secure if the parents dealt with the child’s fear of the monster or the child approached the parents for comfort, allowing the child to eventually go to sleep. In the “departure” story, responses were regarded as secure if the children displayed coping behavior in response to the parents’ absence (looking for the parents, playing with grandma, going to sleep). Finally, in the “reunion” story, responses were judged secure if the family figures faced each other, sometimes hugged each other, engaged in reunion conversations and/or undertook a joint family activity (Bretherton et al, 1987).

Criteria for Insecurity: two types of criteria for scoring insecure responses were used (1) avoidance of the story issue, and (2) incoherent or odd story responses were coded as avoidant if the subject responded only after several “I don’t know’s and prompts, or gave no response other than “I don’t know” or “I want another story”. Where a subject

requested another story after giving a minimal though appropriate response, this was coded as a very mild form of avoidance only if it occurred repeatedly across several stories (Bretherton et al, 1987).

Odd and disorganized responses (e.g., violent throwing the child figure on the floor; a car wreck after father rejoined mother and children who left on a second trip; giving answers that did not make sense within the story such as “we ate nshima” when asked “what did they do about the monster?”) were regarded as indicative of a different type of insecurity. Subjects who displayed strong defensive responses (“I don’t know”, or responded with complete avoidance of the issues) over three or more stories were classified as avoidant-insecure even if they also showed some disorganized responses while subjects with odd or disorganized responses over three or more stories were classified as insecure-disorganized even if they also displayed some avoidant responses (Bretherton et al, 1987).

The Ages and Stages Questionnaires (ASQ) – ASQ is a parent-completed child monitoring system. The ASQ screening system is composed of 19 questions designed to be completed by parents or primary caregivers. Questionnaire intervals include 3,6,8,10,12,14,16,18,20,22,24,27,30,33,36,42,48,54, and 60 months of age. Each questionnaire contains 30 developmental items that are written in simple, straightforward language. The items are divided into five areas: communication, gross motor, fine motor, problem solving and personal/social. Overall sections address parental concerns. For the 30 developmental items, parents check “yes” to indicate that their child performs the behaviors specified in the item, sometimes to indicate an occasional

or emerging response from the child, or “not yet” to indicate that their child does not yet perform the behavior.

This instrument was used to assess cognitive and neural impairment other wise known as Dementia in the study sample. The ASQ questionnaire can be used to monitor the development of children who are at risk of developmental disabilities or delays resulting from medical factors and is thus appropriate for dementia related purposes. Both test-retest and interrater reliability exceeds 90 %(introduction to ASQ 2nd Ed p, 1).

The administration of the questionnaire was done in the participants` respective homes during home visitations. Administering of the ASQ can be completed within 15-20 minutes. Scoring was be done by a competent scorer and scoring can take as little as 1 minute but not more than 5 minutes (introduction to ASQ 2nd Ed, p2).

Table 3: Instruments and Tools (Constructs and Measurements)

Domain	Construct	Measure	Source of data	Comments
Caregivers	Sensitivity	Emotional availability scale	Naturalistic observations	10 -20 min observation
	Parental predictions of the child development	Age and stage questionnaire	Questionnaire	15 -20 min admin
		Social attachment	Scale	

	Social support	subscale of the social provisions scale		
	Depression	Beck Depression Inventory(BDI)	Inventory	
	Self efficacy	Adherence self – efficacy measure	Questionnaire	
	Adherence	Assessing adherence of the child to medication	Adherence to medication questionnaire	10 – 15 min
	Adherence	Assessing adherence of the child to medication	Interview	20 – 35 min
Children	Physical characteristics	Height	Examination of the child	
		Weight		
		Head circumference		

	Attachment completion story task	Assessing the child's attachment style	Observation of the child's play with doll under a theme of story	20 min
Family	Characteristics of the family	Socio-economic data , child, health status and other relevant information	Assessing of records and through the screening interview	10 – 15 min
	Adherence	Assessing the child's adherence	The medical chart	10 to 15 minutes interview

3.6 Pilot Study

Before the main study was conducted a pilot study preceded it. The inclusion criteria used in the selection of tools in this study was that tests and tools should be standardized. However the objective of the pilot study was to test the measuring and assessment tools in the following ways;

- Reactions of respondents to the use of assessment tools (whether with interest or difficult).
- Use of simple language.

- Their relevance to the objectives of the study.

3.7 Training of Research Assistants

Training was provided to all research assistants who were undergraduate psychology students. The training involved general education about reflective listening, probing and creating rapport with participants during the recruitment of participants, administration of the screening interview and the ASQ. Further, three trained coders for the Emotional Availability Scale and for the attachment story completion task were used. Coding of the Emotional Availability Scale and the attachment story completion task were independently done among the three coders. This reduced observer biases and expectations during coding. The interrater reliability of the three coders was calculated.

3.8 Ethical Consideration

Before data collection, this research proposal was submitted to the University Ethical Committee for review and approval. All participants were informed about the purpose of the research and informed consent was obtained from those who agreed to participate in the study. Therefore, all necessary ethical guidelines were considered in this research. See appendix for the informed consent form.

3.9 Time Frame

This data collection for this research was conducted in three months. The research time collected data from July to September 2008.



3.10 Chapter Summary

This chapter started with an introduction of the research strategy employed in the study and how it fits into the subject of the study.

The methods of collecting data, sampling method, sample size, study site and ethical considerations are also highlighted. Further, procedures and methods of data collection were described.

CHAPETER FOUR

RESULTS

4.0 Introduction

The data collected during the study was subjected to statistical analysis to examine the relationship between attachment classification style and adherence to treatment. The analysis also sought to verify the hypotheses stated. The protocol were all hand scored. Raw scores were determined for the attachment classification style, emotional availability, depression, self-efficacy and social support dimensions based on the manuals were subjected to various statistical analyses to arrive at a meaningful interpretation. The research data was analyzed both quantitatively and qualitatively. A computer programme, Statistical Package for Social Sciences (SPSS Version 14.0) was used to analyze the data. The data was analyzed using Chi-Square test, Pearson correlation, Analysis for Variance (ANOVA) and measures of central tendency.

Results are presented under the following headings;

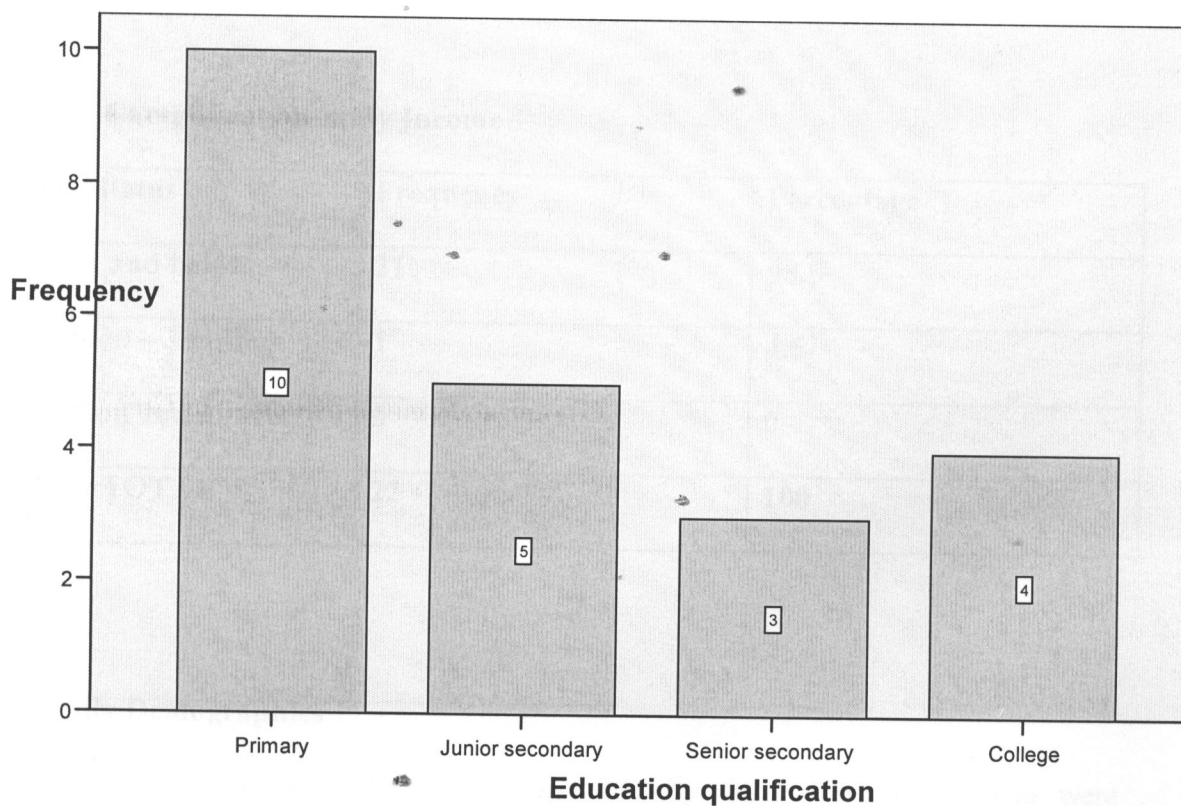
1. Participants demographical data
2. Physical and neural development of the subjects
3. Adherence to treatment and caregiver-child attachment
4. Dyadic emotional availability and adherence to treatment
5. Caregiver depression, social support, self-efficacy , education and adherence to treatment

4.1. Participants demographical data

Education Qualification

Education has been reported in literature to correlate with performance in different areas. As such, the present study examined the education levels of caregivers. 10 caregivers had attained primary education, 5 junior secondary education, 3 senior secondary education and 4 had attained tertiary education.

Graph 2: education qualifications of caregivers



Caregiver's Monthly Income

The socio- economic status of people has been reported in literature to influence the performance of an individual in different situations. The present study examined the monthly incomes of caregivers.

Caregivers with a monthly income of ZMK1million and below Zambian Kwacha were classified under low socio-economic status (SES); those with a monthly income above ZMK1million kwacha to 3 million kwacha were classified under medium SES and those getting above 3million kwacha were classified under upper SES. 21 (95.5%) of the caregivers were under low SES and 1(4.5%) were classed under medium SES.

Table 4: Caregivers' Monthly Income

Income Status	Frequency	Percentage
1 million and below	21	95.5
1.01million – 3 million	1	4.5
3.01million and above	0	0
GRAND TOTAL	22	100

4.2 Family Demographics

Caregivers in this present study were operationally defined as adults who were responsible to administer anti-retroviral drugs to the children. Of the 22 caregivers, 20 had biological children who were not necessarily HIV positive. 8 of these had 1 or 2

biological children, 11 had 3, 4 or 5 biological children. Only one caregiver had more than 6 biological children and two of the 22 caregivers had no biological children. Other than their biological children, most caregivers had dependants they looked after. Some of these dependants were the subjects of this study because they were diagnosed HIV positive and were on medication. Twelve (12) caregivers had 1 or 2 dependants; 4 caregivers had 2, 4 or 5 dependants and 3 caregivers had 6 or more dependants. Three (3) of these 22 caregivers had no dependants they looked after.

The relationship that the caregivers had with the dependants varied. Four (4) of the caregivers indicating keeping a niece, 1 a nephew, 7 grandchildren and 4 of the caregivers looked after their own siblings. Further, 9 of the caregivers indicated that the client in question was their daughter, 4 their son, 2 their niece, 1 their nephew, 6 their grand child.

Table 5: Relationships of the dyads (caregivers and the children)

DESCRIPTION	DESCRIPTION DETAILS	FREQUENCY	PERCENTAGES
Biological Children	1-2 children	8	36.4
	3-5 children	11	50
	More than 6 children	1	4.5
	No children	2	9.1
Dependents	1-2 children	12	54.5
	3-5 children	4	18.2
	More than 6 children	3	13.6

	No children	3	13.6
Relationship to dependants	Niece	4	18.2
	Nephew	1	4.5
	Grandchildren	7	31.8
	Siblings	4	18.2
	No dependants	6	27.2
Relationship to client	Daughter	9	40.9
	Son	4	18.2
	Niece	2	9.1
	Nephew	1	4.5
	Grandchildren	6	27.3

Family type

The subjects were from different family types. 5 (22.7%) came from a nuclear Families, 1 came from a joint family and 16(72.7%) came from extended families. These findings are consistent with the literature which suggests that most African families are extended families.

Table 6: Family Types of the Subjects

FAMILY TYPE	FREQUENCY	PERCENTAGE
Nuclear family	5	22.7
Joint family	1	4.5
Extended family	16	72.7

Parental life status

The high incidence of HIV/AIDS in Zambia and the subsequent orphans (either single or double) has led to many children living without their family members (networks) to support, protect and provide for them. This situation is even exacerbated if the children themselves are also infected with the HIV virus. The high death rates of caregivers to HIV/AIDS have also seen an increase in child and grandparent headed households.

The present study examined the life status of the biological parents of the children. 12(54.5%) of the children had both parents alive, 8(36.4%) of the children had lost one parent through death (either the father or the mother) and only 2(9.1%) of the children had lost both parents through death.

Table 7: Caregiver's Life Status

	FREQUENCY	PERCENTAGE
Both parents alive	12	54.5
Only one parent	8	36.4
Both parents deceased	2	9.1

4.3 Medications and Caregivers' concerns

Antiretroviral therapy has proven to be highly effective in children, including those in resource-poor settings. Rapid initiation of treatment restores and preserves immune functions, promotes normal growth and development, and prolongs life. The antiretroviral (ARVs) drugs that the children reported taking in this study included

Lamivudine, Zidovudine Abacavir, Tenofovir, Stavudine, Efavirenz, Nevirapine, Ritonavir and Septrin. These ARVs were in two different forms, either as tablets or as syrup. Sometimes a combination of these two forms was reported being administered to children. In the present study, 6(27.3%) administered ARVs in syrup form, 11(50%) administered ARVs in tablet form and 5(22.7%) of caregivers administered a combination of syrup and tablet ARVs to their children.

Table 8: Form of medication taken by the children

FORM OF MEDICINE	FREQUENCY	PERCENTAGE
Syrup	6	27.3
Tablets	11	50
Combination	5	22.7

Some studies have reported that the number of ARV a patient takes is associated with adherence to medication. The more ARVs one takes the more complicated it may be to follow the dose instructions carefully. Of the 22 children enrolled, 1 took only one type of the above mentioned ARVs, and another child took two different ARVs. 11(50%) of the children indicated taking three different types of ARVs. 8 other children indicated taking four different types of ARVs while only 1 child indicated taking five ARVs. However, there was no correlation between adherence and the number of ARVs a child took($r = .12$, $n=22$, $p=.59$, 2-tailed).

Table 9: Number of ARVs the Children took.

NO. TYPES OF DRUGS TAKEN	FREQUENCY	PERCENATGE
One	1	4.5
Two	1	4.5
Three	11	50
Four	8	36.4
Five	1	4.5

Medicine management practices

Caregivers’ responses to medicine management practices were also examined. Two significant questions from the adherence questionnaire and interview were examined and the responses were summed into three categories. Each caregiver’s response(s) were matched with their levels of depression.

Table 10: Caregiver response to medicine management practices

<u>symptoms</u>	N	<u>Depressive</u>	
		High	low
How does your child remember to take his/her medication?			
• Reminds her/him self when its time	14	12	2
• I remind her when its time	3	1	2
• Alarm reminder	5	4	1
What makes you to always administer medication?			
• Because it's about life or death	9	4	5
• A family member help me	11	8	3
• Health worker visits help me	2	2	-

From table 10, the results indicate that of the 14 caregivers who responded that their child reminds him/her self when it was time to take medication, 12 of these caregivers were diagnosed highly depressed and 2 of them were not depressed. Three caregivers responded that they remind the child when its time for medication and 1 of the caregiver was diagnosed depressed while 2 were not depressed. Five caregivers mentioned the alarm as the reminder to the child to take medication. Of these five caregivers, 4 were diagnosed as depressed while 1 was not diagnosed depressed.

Responses on what motivates the caregivers' to continue administering medication showed that 9 of the caregivers were motivated because it was a life threatening illness. Of the 9 caregivers, 4 were diagnosed depressed and 5 as not depressed. Eleven other caregivers mentioned help/support from family members as what kept them going and the majority (8) of these caregivers were diagnosed depressed and 3 caregivers were ok. Two other caregivers mentioned the visits and support of health workers as a motivating factor and all the two caregivers were diagnosed highly depressed.

4.4 Physical and neural development of the subjects

The subject's anthropometric measures were also taken according to the American weight standards. The present study considered anthropometric measures of the subjects because changes in life styles, nutrition, chronic and acute illness and ethnic composition of populations can lead to changes in the distribution of body dimensions (e.g., the obesity, epidemic, HIV/AIDS), and require regular updating of anthropometric

data collections. Therefore, anthropometric data collection was important for initiating best intervention methods in future.

Table 11: Summary Table of Children's Anthropometric Measures

SEX	AGE	WEIGHT KGs	HEIGHT CMs	HEAD CIRC.	CHEST CIRC	BMI	PERCENTILE
M	3.3	11	81	50	49.5	16.8kg/m ²	57 th
M	5.2	19	109.5	52	59.5	15.8	50 th
M	5.7	14	99	50	54	14.3	9 th
F	4.1	15	94	48	51	17	80 th
F	4.3	14	94	52.5	50.5	15.8	48 th
M	5.8	20	110	52	58	16.5	66 th
F	5.11	19	114	53	54	14.6	22 nd
F	5	15	103.5	51	52.5	14	6 th
F	4.8	17	104	52	51	15.7	48 th
M	5.5	15	93	49	51.5	17.3	90 th
M	4.6	15	101	50	51	14.7	18 th
F	5.1	14	100	49	51	14	5 th
M	4.10	19	105	51	53.5	17.2	82 nd
F	4.8	15	93.5	49	52	17.2	82 nd
M	4.8	12	92	48	49.5	14.2	7 th
F	5	19	110	53.5	59	15.7	49 th
M	5	24	114	53	55	18.5	88 th
F	5	16	103	53	54	15.1	31 st
F	4	12	97.5	50	51	12.6	2 nd
M	4.7	17	101	25.5	58	16.7	75 th
F	3.2	15	91.5	52	50.5	17.9	93 rd
F	5.4	19	101	52.5	53	18.6	92 nd

If the subjects were at 50th percentile they were close to the average weight. At 90th percentile then the subject's weight was greater than 90% of others. At 20th percentile, then 80% of others weigh more than a particular subject.

The mean weight for the subjects was (M=14.6 kg, SD=3.19). When computed for height the results were as follows (M=100.5cm, SD=8.19). For head circumference the mean was (M=49.8cm, SD=5.69) and chest circumference (M=55.4cm, SD=3.05) respectively. The mean for Body Mass Index (BMI) was (M=15.9kg/m², SD=1.60).

Table 12: Table of Mean Distribution of Anthropometric Data

DOMAIN	SCORES	
Weight	Mean	16kg
	Mode	15
	Standard deviation	3.19
Height	Mean	100.5cm
	Mode	101
	Standard deviation	8.19
Head circumference	Mean	49.8cm
	Mode	50 , 52
	Standard deviation	5.69
Chest circumference	Mean	55.4cm
	Mode	51
	Standard deviation	3.05
Body max index	Mean	15.9kg/m ² .
	Mode	14, 17.2, 15.7, 15.8
	Standard deviation	1.60

In the table above all the children indicate that they had*normal growth according to their age. All measure above negative (-) 2 standard deviation indicates that the children had normal development. These calculations were based on the World Health Organisation (WHO) norms for children.

Children’s Development

In order to assess the development of the children in this sample each caregiver completed the ages and stages questionnaire. As a result of the HIV/AIDS illness many children tend to have developmental delays and this study endeavored to assess any developmental delays that children might have experienced in the following areas: communication, gross motor, fine motor, problems solving and personal social.

Table 13: Children's Developmental Domains

Developmental Domain	Developmental description	Frequency	Percentage
Communication	Good	18	82
	Not good	4	18
Gross – Motor	Good	15	68
	Not good	7	32
Fine – Motor	Good	13	59
	Not good	9	41
Problem Solving	Good	9	41
	Not good	13	59
Personal Social	Good	19	86
	Not good	2	9
	Miss data on personal social	1	5

Although most subjects did well in most developmental domains, a significant number subjects did not do well on problem solving tasks. Subjects were described “good” or “not good” if they met a certain cutoff unique to each developmental domain. The subjects who scored at the cuff-off or above were described as “good” on a particular developmental domain and those who scored below the cuff-off were described as “not good”. The cuff-offs were as follows according to the ASQ scoring manual:

communication 33.3, gross motor 40.1, fine motor 27.1, problem solving 35.0 and personal social 33.0.

Table 14: Mean and Standard Deviation for the ASQ domains

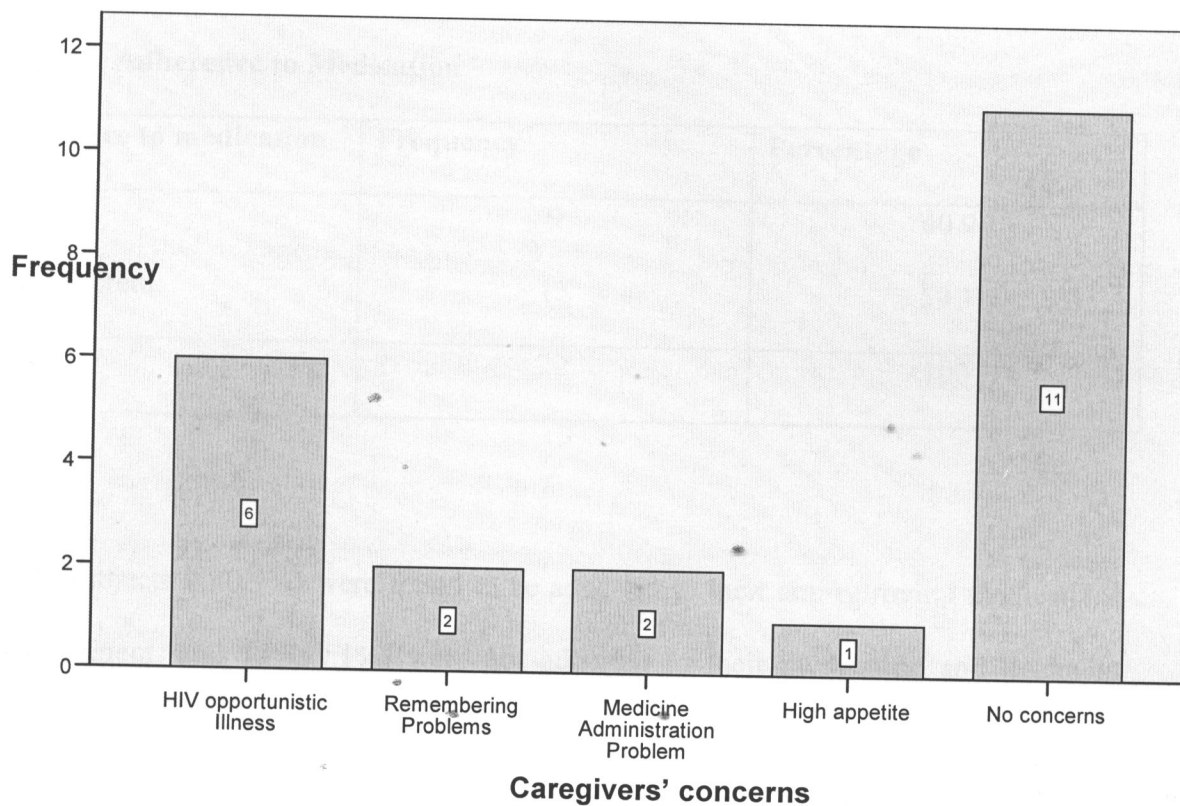
	communication	Gross-motor	Fine-motor	Problem solving	Personal social
Number	22	22	22	22	21
Mean	0	0	0	0	1
Median	1.18	1.32	1.41	1.59	1.19
Std. Deviation	1.00	1.00	1.00	2.00	1.00
Range	.40	.48	.50	.50	.30
	1.00	1.00	1.00	1.00	1.00

A big proportion of children did well in communication accounting for 18(82%) as compared to their counterparts described as “not good” who accounted for 4(18%), M=1.18, SD=.40. For gross-motor 15(68%) were above the cuff-off and were described as good while 7(41%) were below the cuff-off and they were described as “not good”(M=1.32,SD=.48). For fine- motor 13(59%) were above the cuff-off and 9(41%) were below the cuff (M=1.41, SD=.50). The analysis of problem solving indicated that a large proportion of the children accounting for 13(59%) were below the cuff-off and therefore, described as “not good” while only 9(41%) of the children were good in problem solving (M=1.59,SD=.50).19(86%) of the children were good in personal social while 2(9%) were below the cuff-off in personal social (M=1.19,SD=.30, n=21).

Caregivers' Concerns on the Children

Caregivers had different concerns about their children as obtained from the ASQ. These concerns were the most worrying things that each caregiver reported having on their children. These concerns among others included opportunistic infections or illnesses such as diarrhoea, skin rash, poor eye sight etc. Others included, difficulties administering medication as prescribed and cognitive problems such as poor memory. Caregivers who reported having concerns with HIV opportunistic infection or illness affecting the child were 6(27.3%) while 2(9%) caregivers reported difficulties remembering things. Caregivers who reported that they had difficulties administering medication as prescribed either because they could not follow instruction properly or because the child was problematic during medication taking were 2(9%). One (1) caregiver reported high concerns for his/her child's high appetite and 11(50%) of caregivers reported no concerns at all.

Graph 3: caregivers' concerns for the children



Quantitative Findings on Adherence, Attachment, Emotional availability, Depression, HIV-Self Efficacy, Social Support and Education

4.3 Adherence to treatment and caregiver-child attachment

The adherence questionnaire, interview and record chart requested information on the subjects' missed doses and average amount of missed dosages in the past three days, one week, three weeks and one month at the time these instruments were administered. The

record charts also examined the clients' consistency to appointments with the health service provider(s) and following correctly, nutritional advice to arrive at the adherence score. Good adherence was indexed at 90%.

Table15: Adherence to Medication

Adherence to medication	Frequency	Percentage
Adherent	9	40.9
Non-adherent	13	59.1
Total	22	100

Of 22 subjects 9(40.9%) were found to be adherent to their anti-retroviral medications and treatment, and 13 (59.1%) were not adherent to their medication and treatment generally.

Caregiver- Child Attachment

Detailed verbal and behavioral transcriptions were made out of the videotaped stories. Verbatim records were made out of the subject's verbal narratives and tester's prompts. Emotional responses during the story enactment (e.g., smiling, pouting, frowning) were also recorded. Three researchers worked on each transcript. Where there were disagreements, the judgment of the principle coder was accepted. A Criterion for scoring was adopted from Bretherton, Ridgeway and Cassidy's manual for assessing internal working models of attachment relationship.

Story Completion Task Findings

The content analysis performed on the transcripts of the story completion task showed that, as a group, the children understood the major issues presented in each story and that they were able to enact appropriate and differentiated story resolutions.

The spilled juice story

Detailed responses are listed in tables below. The most common response was that the subject him/herself cleaned up the mess and that nothing happened in terms of discipline.

Table 1: Response to the spilled juice story

Description/ action	no.	Total no.
Dealing with the mess:		
<i>Wiping or cleaning juice</i>		
Mother		
Father	1	
Sibling		
Subject	17	
Unspecified	2	20
<i>Picking up the cup</i>		
Mother		
Father		
Sibling		
Subject		
Discipline:		
<i>Get no more juice (water)</i>		
Child		
Father/mother	2	
Child cry at reproach		
Mother is angry	9	
Nothing happened	11	20
<i>Child or children sent out</i>		
Mother	1	
Father		
<i>Child spanked</i>		
Mother	3	
Father		
Get more juice:		
Mother		
Father		
Child	16	
Unspecified	4	20
No resolution attempted		

The hurt knee story

As may be seen in table 2, the majority of the subjects enacted having been taken to hospital or that the child got well by him/her self.

Table 2: Response to the hurt knee story

Description/ action	no.	Total no.
Empathetic responses:		
<i>Someone helps hurt child with band-aid</i>		
Mother	5	
Father	1	
Sibling		
Subject		
Unspecified	1	
<i>Child taken to hospital</i>	13	
<i>Child is taken home or bed</i>		
<i>Hurt child is picked, kissed or hugged;</i>		20
By Mother		
By Father		
Concerns about carefulness:		
<i>Parent issue warning to be careful</i>	3	3
<i>Subject she/he will not do it again</i>		
Non-empathetic responses:		
<i>Parent leaves child in the park</i>		
<i>Parent spans child</i>	3	
<i>Parent tears/ reprimand/ etc</i>	4	
<i>Subjects smiles at hurt</i>	1	8
Ignoring of hurt:		
Child gets better by self	7	7
Reenactments:		
<i>Subject reenacts fall and hurt</i>		
With Mother		
With Father		
With sibling		
<i>Subject reenacts rock/tree climbing without fall</i>		
With Mother		
With Father		
With sibling		
No resolution attempted.		

The monster story

Findings are displayed in table 3 , 1 child mentioned the father having fought or killed the monster, 14 did not specify and 3 subjects mentioned or enacted having killed the monster themselves.

Table 3: Responses to the monster story

Description/ action	no.	Total no.
Disposal of monster:		
<i>Parent/child hits beats gets out/rid of fights or kill monster or hides</i>		
Mother	1	

Father		
Sibling		
Subject	3	
Unspecified	14	18
<i>States explicitly that monster is out of action</i>		
Monster gone		
Monster dead		
<i>Parent tell child they don't see any monster</i>		
<i>Children leave room to go to parent</i>	4	
<i>Child goes to play</i>	7	
<i>Child goes to eat</i>	4	
No resolution of monster problem:	5	20

The Departure story

In response to the departure story (see table 4) 11 of the subjects were reluctant to allow the caregiver leave, 4 had no problem the caregiver leaving, 3 included themselves on the trip and 2 took the parent out of the care

Table 4: Responses to the departure story

Description/ action	no.	Total no.
Departure:		
<i>Subject makes parent leave without problem</i>	4	
<i>Subject reluctant in allowing parents leave</i>	11	
<i>Tries to include children in the trip</i>	3	
<i>Takes parents out of the car</i>	2	20
Leave taking behavior during separation:		
Children sleep while parents are gone		
Children stay with grandma	11	
Cook and eat nshima /or drink tea	6	
Children play		
Children have got to clean the house	3	20
Subject enacts separation anxiety or reunion:		
<i>Children search, call or cry for parents</i>	9	
<i>Subjects try talk about making parents back</i>	9	
<i>A subject follows parents in another car</i>	2	20
Child does not know what to do in parents' absence		

The reunion story

Most of the subjects ran to the caregiver once the tester mentioned that the parents are back and brought the car on the table. Most of them also placed the parent near the children.

Table 5: Responses to the reunion story

Description/ action	no.	Total no.
During reunion:		
<i>Takes parents out of the car and places near children</i>	2	
<i>Enacts greeting, welcoming or running to parents</i>	14	
<i>Denies parent return</i>		
<i>Removes grandma from scene</i>	2	

<i>Child continues plying ignores parents</i>		
<i>Does not know what happens</i>	2	20
After reunion:		
Child continue to play	3	
Engages family	14	
Does not know what happens after reunion	3	20

Adherence and Caregiver-Child Attachment

Seven of the eight securely attached children were adherent to treatment. One of the securely attached children was non-adherent to treatment and two of the insecurely attached children were adherent to treatment.

Table 16: Distribution of attachment classification styles

Attachment classification	Number /frequency	Percentage
1. secure	8	40%
2. insecure-avoidant	2	10%
3. insecure-ambivalent	10	50%

Table 17: Attachment classifications and adherence to treatment frequencies

Attachment –style	N	<u>Adherence to treatment</u>	
		Good	Poor
Secure	8	7	1
Insecure-ambivalent	10	2	8
Insecure-avoidant	2	0	2
Insecure-disorganized	0	0	0

The results on adherence and attachment indicated that there was a significant relationship between adherence to treatment and caregiver-child attachment: χ^2 (2, N = 20) = 10.00, $P = < .05$. Within the securely attached children, the majority (77.8%) were adherent to treatment whereas insecurely attached children, the minority (22.2%) scored low on adherence to treatment.

Table 18 a: Chi-Square- adherence and attachment cross tabulation
Attachment style

Adherence status		Attachment style		
Total		Secure	Ambivalent	Avoidant
Adherent	Count	7	2	0
	Expected count	3.6	4.5	.9
	%within adherence	77.8%	22.2%	.0%
	%within att-style	87.5%	20.0%	.0%
	% of Total	35.0%	10.0%	.0%
Non-adherent	Count	1	8	2
	Expected count	4.4	5.5	1.1
	%within adherence	9.1%	72.2%	18.2%
	%within att-style	12.5%	80.0%	100.0%
	% of Total	5.0%	40.0%	10.0%

Chi-Square test

	Value	df	Asymp.sig 2-sided
Pearson Chi-Square	10.000(a)	2	.007
Likelihood ratio	11.489	2	.003
Linear-by-linear	8.655	1	.003
N of cases	20		

a 5 cells (98.3%) have expected counts less than 5

Further the estimate of the proportion of variation that was common to the two variables was calculated by squaring the phi. So 59.9 % of the variation in the levels of adherence to treatment score among the children is accounted for by the type of attachment style the child has with the caregiver.

Chi –Square symmetric measures

	Values	approx sig	exact sig
Phi	.707	.007	.008
Cramer's V	.707	.007	.008
Contingency coefficient	.577	.007	.008
N of cases	20		

4.5 Dyadic Emotional Availability and adherence to treatment

The emotional availability scale consisted of six dimensions of the parent (herein caregiver) toward the child and of the child towards the caregiver. The caregiver dimensions are sensitivity, structuring, nonintrusiveness and nonhostility. And the child dimensions are the child's responsiveness to the caregiver and the child's involvement to the caregiver. Detailed verbal and behavioral transcriptions were made out of the videotaped stories. Emotional availability responses during each activity (e.g., complete a dot task) were also recorded.

For parental sensitivity, 2 caregivers were highly sensitive, 8 generally sensitive, 4 inconsistently sensitive, 4 somewhat insensitive and 4 highly insensitive respectively ($M = 5.00$, $SD = 2.62$). On the dimension of parental structuring, 4 caregivers were optimal in structuring, 4 inconsistently structuring and 14 nonoptimal in structuring ($M = 2.09$, $SD = 1.60$). For parental non intrusiveness, 11 caregiver were non-intrusive, 2 some what intrusive and 9 intrusive $M = 3.18$, $SD = 1.94$). On parental nonhostility, 10 caregivers were non hostile, 3 covertly hostile and 9 markedly-covertly- hostile ($M = 3.09$, $SD = 1.90$). On the other hand, for child responsiveness, 7 children were optimal in

responsiveness to the caregiver, 7 somewhat nonoptimal and 8 clearly nonoptimal in responsiveness to the caregiver (M=3.55, SD= 3.45). For child-involvement, 7 were optimal in involving the caregiver, 1 moderately optimal in involving, 4 somewhat nonoptimal in involving and 10 clearly nonoptimal in involving (M=2.56, SD = 2.69).

Table 19: Emotional availability of the caregiver

Dimension	Scale	Frequency	Mean	Std.deviation
Parental sensitivity	Highly sensitive	2	5.00	2.62
	Generally sensitive	8		
	Inconsistently sensitive	4		
	Somewhat insensitive	4		
	Highly sensitive	4		
Parental structuring	Optimal structuring	4	2.09	1.60
	Inconsistently structuring	4		
	Non-optimal structuring	14		
Parental nonintrusiveness	Non-intrusiveness	11	3.18	1.94
	Somewhat intrusive	2		
	Intrusive	9		
Parental nonhostility	Non-hostile	10	3.09	1.90
	Covertly hostile	3		
	Markedly –covertly-hostile	9		
Child-responsive	Optimal in involving	7	3.55	3.45
	Somewhat nonoptimal	7		
	Clearly nonoptimal	8		
Child-involvement	Optimal in involving	7	2.56	2.69
	Moderately optimal in			

	involving	1		
	Somewhat nonoptimal in			
	involving	4		
	Clearly nonoptimal in			
	involving	10		

The correlation analyses were performed between adherence and the six dimension of the emotional availability scale. There was a significant positive correlation between adherence and parental sensitivity ($r = .49$, $n = 22$, $p = .01$, one tailed). There was also a significant positive correlation between adherence and parental non intrusiveness ($r = .52$, $n = 22$, $p = .01$, one tailed), between adherence and parental nonhostility ($r = .61$, $n = 22$, $p = .00$, one tailed), between adherence and child responsiveness ($r = .58$, $n = 22$, $p = .01$, one tailed) and a moderate correlation between adherence and child involvement ($r = .56$, $n = 22$, $p = .05$, One tailed). However, there was low correlation between adherence and parental structuring ($r = .06$, $n = 22$, $p = .40$, One tailed).

Table 20: Correlation matrix-adherence, Attachment and emotional availability

	1	2	3	4	5	6	7	8
1. adherence	1							
2. attachment classification	.68**							
3. parental sensitivity	.49**	.37						
4. parental structuring	.06	.26	-.09					
5. parental nonhostility	.61**	.45	.14	.10				
6. child responsiveness	.58**	.49*	.22	-.25	.39*			
7. child involving	.36	.35	-.01	.10	.19	.11		
8. parental nonintrusiveness	.52**	.57**	.35	-.24	.13	.60**	.09	
M	1.59	1.70	3.09	2.18	2.59	2.82	3.18	2.27
SD	.50	.65	1.30	1.00	1.30	1.37	1.51	.98

** Correlation is significant at the 0.01 level (1-tailed)*

* Correlation is significant at the 0.05 level (1-tailed)

Inter-coder reliability was assessed by the same method of consultation with two research colleagues, but was not firmly established because the coders did not undergo specialized training for coding videotapes. This is similar to the videotapes for the assessing attachment quality and the ratings for emotional availability.

4.6 Caregiver depression, social support, self-efficacy, education and adherence to treatment.

Depression

The subjects' levels of depression were measured with the Beck's Depression Inventory and the following results were obtained; 3(14%) of the subjects scored as clinically depressed (severe and extreme depression), 11(50%) of the subjects scored in the moderate range (borderline clinical and moderate depression) and 8 (36%) of the subjects were considered as normal (normal ups and downs and mood disturbances).

Table 21: Distribution of the depression state of caregivers

Depression	Frequency	Percentage
Clinically Depressed	3	14
Moderately Depressed	11	50
Considered Normal	8	36
Total	22	100

This analysis was important since substantial evidence in the literature indicate a relationship between maternal depression and negative outcomes across development

stages of childhood and adolescence which otherwise might exacerbate poor adherence to medication among children.

Adherence and Depression

In order to assess the effect of maternal depression on adherence, analysis of variance (ANOVA) was performed. There was a significant effect of depression on adherence, ($F(2, 19) = 4.22, p = <.05$, partial $\eta^2 = .31$). These findings indicate that 31% of the total variance on adherence to treatment among children was as a result of the state of depression levels of the caregivers.

Table 22a: Descriptive on adherence and depression

95% confidence interval for mean

Depression status	N	Mean	SD	Std Error	lower	Upper
Normal	8	1.2500	.46291	.16366	.8630	1.6370
Moderately depressed	11	1.7273*	.46710	.14084	1.4134	2.0411
Clinically depressed	3	2.0000	.00000	.00000	2.0000	2.0000
Total	22	1.5909	.50324	.10729	1.3678	1.8140

Table 22b: Statistics for ANOVA’s on adherence and depression

Informant	depression	ANOVA	df	F	sig.
Caregiver	depression score	between group	2	4.222	.030
		Within group	19		
		Total	21		

HIV- Self Efficacy

The purpose of the HIV Self-Efficacy (HIV-SE) questionnaire in this study was to measure self efficacy for specific disease management behaviors in caregivers with children living with HIV. The HIV-SE has 34 items conceptual domains: managing

mood, managing medications, managing symptoms, communicating with health provider, getting support and managing fatigue. The psychometric properties are reported by Shively, et al (2002).

Table 23: HIV-Self Efficacy of Caregivers

Conceptual Domains	HIV-Self-Efficacy	Frequency	Percentage
Managing Mood	High SE	10	45.5
	Moderate SE	9	40.9
	Low SE	3	13.6
Managing Medication	High SE	21	95.5
	Moderate SE	0	0
	Low SE	1	4.5
Managing symptoms	High SE	14	63.6
	Moderate SE	7	31.8
	Low SE	1	4.5
Communicate with health care provider	High SE	20	91
	Moderate SE	1	4.5
	Low SE	1	4.5
Get support/health	High SE	14	63.6
	Moderate SE	4	18.2
	Low SE	4	18.2

Manage fatigue	High SE	9	40.9
	Moderate SE	9	40.9
	Low SE	4	18.2

Those who scored high on HIV-SE and those who scored moderate on the HIV-SE were categorized as having self efficacy. The table indicates that most 19 (86.4%) of caregivers had self efficacy to manage mood, 21 (95.5%) had self efficacy to manage medication, 21(95.5%) had self efficacy to manage symptoms, 21 (95.5%) had self efficacy to communicate with health care providers, 18 (81.8%) had self efficacy to get support/help and 18 (81.8%) indicated they had self efficacy to manage fatigue.

Adherence and Self efficacy

Overall, an analysis of the relation between adherence and the six self efficacy domains indicated rather surprising results. Only the relationship between adherence and self efficacy (SE) to managing mood indicated a non significant moderate negative correlation ($r^2 = -.31$, $n=22$, $p=.14$, two- tailed). Caregiver's mood swings can affect adherence to medication. In this case, low self efficacy to manage mood among caregivers showed higher frequencies of their children to be nonadherent to treatment. Although, there was relationship between managing mood and adherence, other self-efficacy domain showed no correlation with adherence. A low correlation was found between adherence and SE-getting support ($r^2 = -.15$, $n=22$, $p=.50$, one-tailed), adherence and SE-managing fatigue ($r^2 = -.21$, $n=22$, $p=.34$, one-tailed), adherence and SE-managing medication ($r^2 = -.18$, $n=22$, $p=.42$, one-tailed), adherence and SE-

managing symptoms ($r^2 = -.18$, $n=22$, $p=.42$, one-tailed) and between adherence and SE-communicating to a health care provider ($r^2 = -.18$, $n=22$, $p=.42$, one-tailed).

However, there was a significant positive relationship between managing mood and getting support/help ($r^2 = .54$, $n=22$, $p=.01$, 1-tailed), a significant positive relationship between managing fatigue and getting support/help ($r^2 = .63$, $n=22$, $p= .01$, 1-tailed).

Table 24: Correlation matrix of adherence and self efficacy

	1	2	3	4	5	6	7
1. Adherence	1						
2. Getting support	-.15	1					
3. Manage mood	-.33	.54**	1				
4. Manage fatigue	-.21	.63**	.42	1			
5. Manage med	-.18	.00	.41	.07	1		
6. Manage symp	-.18	.00	.41	.07	* 1.00**	1	
7. Manage health	-.18	.00	.41	.07	1.00**	1.00***	1
\bar{M}	1.5909	2.0000	2.2727	2.2273	2.9091	2.9091	2.9091
SD	.50324	.61721	.70250	.75162	.42640	.42640	.42640

** Correlation is significant at the 0.01 level (1-tailed)

* Correlation is significant at the 0.05 level (1-tailed)

Social Provision Scale (Social Support)

The social provision scale examined the social support and social networks of the study sample. The subjects were supposed to think of their current relationships with friends, family members, co-workers, community members and so on before answering the questionnaire.

Overall the majority of the study sample indicated that they had social support and good social network. 17(77.3%) agreed to having attachment (emotional closeness from

which one derives a sense of security) while 5 (22.8%) disagreed having any attachment ($M=2.9$, $SD=.750$). 16(72.7%) agreed to social integration (a sense of belonging to a group that shares similar interests, concerns and recreational activities), while 6 (27.3%) disagreed having social integration with others ($M=2.8$, $SD=.59$). Similarly, 16 (72.7%) agreed to having opportunity for nurturance (a sense that others rely upon one for their well-being), while 6(27.3%) disagreed having an opportunity for nurturance ($M=2.7$, $SD=.46$). 17 (77.3%) of the subjects agreed to reassurance of worth (recognition of one's competence, skills and value by others), while 5(22.7%) disagreed having reassurance of worth ($M=2.9$, $SD=.65$). Further, 14 (63.7%) of the subjects agreed to having received guidance (advice or information) and 8(36.3%) disagreed to receiving guidance ($M=2.6$, $SD=.72$). For reliable alliances only 7(31.8%) agreed having reliable alliance (assurance that others can be counted upon for tangible assistance) while the majority 15(63.7%) disagreed to having reliable alliances ($M=2.2$, $SD=.75$).

Table 25: Social Support of Caregivers

Domain	Response	Frequency	Percentage	Mean	Standard Deviation
Attachment	Agrees	17	77.3	2.90	.75
	Disagrees	5	22.7		
Social Integration	Agrees	16	72.7	2.82	.59
	Disagrees	6	27.3		
Opportunity	Agrees	16	72.7		

for nurturance	Disagrees	6	27.3	2.73	.46
Reassurance of worth	Agrees	17	77.3	2.95	.65
	Disagrees	5	22.7		
Reliable alliance	Agrees	7	31.8	2.22	.75
	Disagrees	15	67.2		
Guidance	Agrees	14	63.7	2.68	.72
	Disagrees	8	36.3		

Adherence and Social Support

Only one analysis of the six domains of the Social Provision Scale (SPS) and adherence reviewed correlation with adherence. There was a moderate positive correlation between adherence of the child and SPS-attachment (emotional closeness from which one derives a sense of security) of the caregiver ($r^2 = .45$, $n=22$, $p=.04$, 1-tailed). Thus, children with caregiver who reported having social support in terms of emotional closeness adhered better to treatment than their counterparts. No correlation was found between adherence and social support (SPS) to guidance ($r^2 = -.25$, $n=22$, $p=.27$, 1-tailed), adherence and SPS-assurance to worth ($r^2 = -.01$, $n=22$, $p=.97$, 1-tailed), adherence and SPS-opportunity to nurturance ($r^2 = -.09$, $n=22$, $p=.68$, 1-tailed), adherence and SPS- social integration ($r^2 = -.09$, $n=22$, $p=.68$, 1-tailed) and a relationship between adherence and SPS-reliable alliance ($r^2 = -.23$, $n=22$, $p=.31$, 1-tailed).

Table 26: Correlation matrix of adherence and social support

	1	2	3	4	5	6	7
1. Adherence	1						
2. SS care	-.09	1					
3. SS worth	-.01	.16	1				
4. SS alliance	-.22	-.02	-.10	1			
5. SS integration	-.09	.31	.16	-.24	1		
6. SS attachment	-.45*	.16	-.03	-.10	.40	1	
7. SS guidance	-.25	-.04	-.18	-.52*	-.04	.04	1
<hr/>							
M	1.5909	1.7273	1.7727	1.3182	1.7273	1.7727	1.6364
SD	.50324	.45584	.42893	.47673	.45584	.42893	.49257

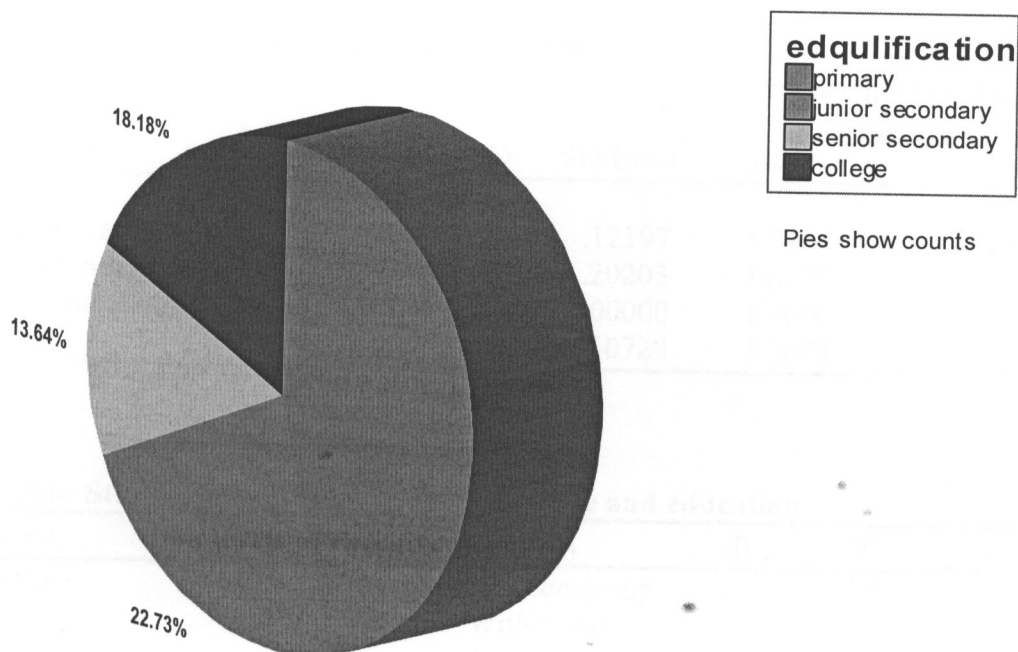
** Correlation is significant at the 0.01 level (1-tailed)

* Correlation is significant at the 0.05 level (1-tailed)

Education

The education level of the caregivers was also examined. The education levels of these caregivers ranged from no education to tertiary education. The pie chart below shows the education levels of caregivers.

Graph 4: Education levels of caregivers



The majority of the caregivers, 10(45.5%) attained primary education, 5(22.7%) had attained junior secondary school level, 3(13.6%) had attained senior secondary school level and 4 (18.2) had attained college (tertiary) education.

Adherence and education

The analysis of ANOVA adherence and education showed that there was a significant effect of education levels of caregivers on adherence to treatment on the children; ($F(2, 19) = 5.58, p < .05, \text{partial } \eta^2 = .37$). These results indicate that of the total variance of

adherence to treatment, 37% of this variance was as a result of the education levels of the caregivers.

Table 27a: Descriptive on adherence and education
95% confidence interval for mean

Education levels	N	Mean	SD	Std Error	lower	Upper
No edu-primary edu	11	1.8182	.40452	.12197	1.5464	2.0899
Junior-secondary edu	7	1.5714	.53462	.20203	1.0771	2.0658
Tertiary education	4	1.0000	.00000	.00000	1.0000	1.0000
Total	22	1.5909	.50324	.10729	1.3678	1.8140

Table 28b: Statistics for ANOVA's on adherence and education

Informant	education	ANOVA	df	F	sig.
Caregiver	education levels	between group	2	5.578	.012
		Within group	19		
		Total	21		

Adherence, number and form of medication

The analysis of the relationship between adherence and a child’s participation in family support programmes indicated that there was a low correlation ($r^2 = .02$, $N = 22$, $p=.47$,two tailed). A low negative non-significant correlation between adherence and the form of medication a child was talking was also obtained ($r^2 = -.06$, $N= 22$, $p =.43$, two-tailed) Further a low negative non-significant correlation was obtained between adherence and the number of drugs (ARVs) a child was taking ($r^2 = -.16$, $N = 22$, $p =.24$, two tailed).

Table 29: Correlations matrix –adherence, family support prog. and medication

	1	2	3	4	5
1. Adherence	1				
2. Family support prog	.02	.02			
3. Form of medication	-.05	-.20	.06		
4. No. of ARVs (drugs)	.12	-.02	.16	.11	
M	1.68	1.45	1.95	1.81	
SD	.78	.51	.72	1.05	

** Correlation is significant at the 0.01 level (1-tailed)

* Correlation is significant at the 0.05 level (1-tailed)

4.7 Chapter summery

The chapter started with a description of demographical data of the study participants. The study also found that there was a relationship between adherence and attachment, and between adherence and emotional availability. However, whether insecurely attached children would be difficulty and problematic during medication taking was not established because only one caregiver reported the child giving problems during administering medication. Overall physical development was normal but some children indicated problems with problems solving.

CHAPTER FIVE

DISCUSION

5.0 Introduction

Through out this study, caregiver-child attachment was defined as a close emotional bond between a child and a caregiver. On the other hand adherence to treatment was defined as the degree to which the caregiver and child follow a treatment and nutritional plan and the requirements for taking medication (the recommended dose, at the recommended time, in the recommended way). The analysis of the association between attachment and adherence was significant partly because different attachment classification styles have been reported to be associated with performance in different situation (Sroufe, 1983). This chapter discusses the findings that have been presented in chapter four (results section) under the following headlines;

1. The association between attachment and adherence.
2. The relationship between caregiver sensitivity and adherence to treatment.
3. Insecurely attached children and medication taking problems.
4. The relationship between psycho-social factors and adherence to treatment.
5. Delayed physical, mental and Neuro – development among HIV+ children.

5.1 The association between attachment and adherence

This section sought to examine whether there was a relationship between attachment classification styles and adherence to medication among HIV positive children. These results suggest that some variance in the scores on adherence can be accounted for by the nature of caregiver-child attachment. The findings also indicate that the majority still find it difficult to adhere to medication partly due to the complexity of the regimen and by the fact that children rely on adults to take their medication. This finding is consistent

with the literature which indicates that due to the challenging nature of anti-retroviral drugs and the fact that children rely on adults to take their medication, many children are at risk of immunological failure (Steele & Grauer, 2003). Considerable evidence suggests that various aspects of personal relationships and psychological status have significant implications for physical health. As such, human development and health perspective should endorse a wider range of adaptive alternatives and options. Subsequently, with the growing awareness and confidence channeled to the outside world, it may be possible to identify a sufficient number of certain personal characteristics which make children flexible enough to tolerate inconveniences and dislikes of medication, general treatment and improve adherence to treatment.

In addition to the various environmental systems or layers, intra-individual characteristics – which consist of built-in biological components, maturational processes, regulatory mechanisms, and developmental trajectories also, exert influence on the environment which in a circular way may operate back on the child (Sagi, 2002) and foster adherence to treatment. This is not the only study that has established the relationship between adherence and attachment. For instance, Leonard (2007) established that all seven of the subjects who were adherent had, at minimum, one secure attachment. Six out of the seven adherent subjects had a secure attachment to at least one caregiver and four subjects had secure attachment to both caregiver. As such attachment should be taken seriously in pediatric settings and should be integrated into mainstream health provision.

This relationship between adherence and attachment raises a question as to what may be the explanation to this relationship. In infancy, a child instinctually attracts his/her caregiver through a number of cues; eye contact, cooing, crying, and grasping. If the caregiver is consistently attuned, and responsive to the infant's negatively aroused states, the infant internalizes this experience of being soothed and becomes able to manage greater amounts of tension and arousal (Sroufe, 1979). Gradually, through this continued experience with the caregiver, the infant develops and maintains internal security. This internal security transforms into an internal working model, which mediates the child's experience of interpersonal relationships and the feelings that go along with this relationship (Bowlby, 1980) and allows the child to put up with inconveniences and discomforts associated with every day challenges and hassles such as taking medication. In a way, this explains why secure children develop psychological resilience, or why they thrive in adverse circumstances.

However, when the child does not develop trust and confidence in the caregivers because they have been neglected, dismissed and left for a very long time in negatively aroused states, they do not trust that their mother will come to comfort them. They do not believe themselves to be safe in the world and many aspects of their development are arrested (Cicchetti & Toth, 1998). Children left in this prolonged state of negative affective arousal develop psychological defenses in order to survive these unbearable states (Bradley, 2000). These children perceived their caregivers as unavailable and rejecting, while simultaneously regarding themselves as unloved. Their capacity to regulate their own affect was stunted (Bradley, 2000; Cicchetti and Toth, 1998). In the worst cases, they withdrew from the world around them because they perceived it as an

unsafe world in which nobody is trustworthy, as such, they may not put up with any inconveniences and discomforts that securely attached children may put up with this includes taking bitter ARVs every day for the rest of their lives.

Recently, researchers (Feeney, 2000; Hunter & Maunder, 2001) suggested that attachment theory provides a useful model of understanding illness behavior and /or outcomes, primarily because the theory explains individual differences in emotional regulation, stress reactions and interpersonal behaviors. In the context of caregiver-child attachment, children develop internal working models of self and others, which are carried forward to influence ongoing development and mental health (Thompson, 1991).

In non-clinical populations, preoccupied and fearful attachment styles are associated with depression (e.g. Carnelley et al., 1994), and preoccupied attachment also appears to be closely associated with anxiety symptoms. A diagnosis of life-threatening disease is a major source of stress that is likely to activate the attachment system and can affect both physical and emotional well-being. As such assessing attachment of patients depending on others (caregivers in case of children) to administer medication is important to improving adherence. For instance, the Adherence Network Group (2006), alluded to the fact that if the relationship between the caregiver and child is warm and respectful and the child looks up to the caregiver, it is more likely that the child will be prepared to put up with inconveniences and discomforts to please the caregiver. This is especially true since ARVs are bitter and children dislike them. Consequently, parental sensitivity and responsiveness would prepare these children to co-operate and please the caregiver. It has become common knowledge that physical, mental cooperation and compliance are

very vital for adherence to treatment especially among children. This finding dispels the argument that children do not necessarily need to adhere to taking drugs; after all, they simply obey what they are told to do by their caregivers. On the contrary, children are active participants to treatment who do not just respond at the receiving end to the wish and wants of a caregiver. Their overt and covert behaviors and actions attest to this.

5.2 The association between caregiver sensitivity and adherence to treatment

The association was established between adherence and the 5 scales of EA namely; parental sensitivity, parental nonintrusiveness, parental nonhostility, child responsiveness and child involvement but not with parental structuring. The present study findings indicating the association with most dimensions of the EA scale and adherence to medication, and attachment are not novel to this study. Several literatures have reported on the nature of the child-caregiver relationship and the effect it has on the psychological and physical health of the child. Take for instance; the review by Zeitlin, Ghassemi & Mansour (1990), concluded that the psychological adjustment of caregivers and a positive attitude to the child are important variables influencing child growth, especially in low income families living in deprived conditions. Close and affectionate interactions between caregivers and children may promote growth. They encourage the caregiver's responsiveness to the child's cues and the child's positive affect, which in turn directly stimulates growth, immune function, and exploratory behavior.

Why would the dimensions of the Emotional Availability Scale significantly correlate with adherence to medication one may ask? What this literature and the study findings suggest is that improved caregiver child interactions promote the health and

development of vulnerable children. They also increase the resilience of young children to the damaging effects of deprivation, inconvenience, discomfort and perceived difficulties in their very day health life and therefore, cooperate with the caregiver in such circumstances.

An unstable or inadequately nurturant caregiver-child relationship affects the child's health and development. In addition, the poor health of a child presents a challenge to the caregiver and threatens the establishment of warm and responsive interactions. Parents are less likely to provide stimulating and responsive caregiving if they do not realize that their interactions are important for their child's development, or if they are not aware of the need to support their child's emerging capacities. As such, sensitive and responsive nurturant caregiver child-relationship interventions should be encouraged in the health system and centers. It should be noted that young children who do not have a relationship with at least one emotionally invested, predictably available caregiver, even in the presence of adequate physical care and cognitive stimulation, display an array of development deficits that endure over time. Some children develop intense emotional ties to parents and other caregivers who are unresponsive, rejecting, highly erratic or frankly abusive, and these relationships can also be a source of serious childhood impairment (Shonkoff & Phillips, 2000, p.389).

There is an enormous body of literature that indicates that the quality of the infant caregiver relationship is a major determinant of psychological adjustment in the health life of the child. Writing on the basis of his experience in Peru, Lanata (2001) argued that recurrent infections, poor growth and increased mortality amongst young children

cluster in families where the child is not wanted and where the child experiences neglect and even abuse (Das Gupta, 1990; Schellenberg et al., 2002).

Cohn and Tronick (1989) also argued that negative or disruptive interactions force the infant to self-regulate their own negative emotional states in an attempt to reduce the effects of their caregiver's inappropriate behavior. "It is expected that the accumulation of such interactive experience has a structuring effect on infants such that a self-directed regulatory style comes to dominate all interpersonal exchanges". Take for instance *Internal working models* or mental representations of the self and other people which determine subsequent behavior. These can have a knock-on effect because the child may avoid experiences that have the potential to alter negative representations (Bretherton, 1987b; Main, Kaplan & Cassidy, 1985; Zeanah & Anders, 1987). For example, if a child expects adults to be uncaring, he/she may stop seeking assistance and comfort from adults, even though some adults in her environment would respond warmly if he/she approached them.

Repetitive or enduring interactional failures may become another part of a cycle of determinants that are linked to poor outcomes. In themselves, "they may seemingly be of little clinical significance and yet cause major problems because they may function as starting points for chains of reciprocal consequences, becoming vicious circles that hinder development" (Papoušek & Papoušek, 1983, p.35). In addition, enduring conditions of impoverished or neglectful interactions with caregivers often reduce the likelihood of positive interactions with other adults in the child's environment. This minimizes the exposure of the child to compensatory experiences.

5.3 Insecurely attached children and medication taking problems.

The relationship between insecure attachment and the tendency to be problematic during medication taking among the subjects was considered. However, of the 22 caregivers who participated in this study only one caregiver reported having problems administering medication to the child. As such the relationship between these two variables was not further explored.

During interviews, a good number of caregivers reported that their children were initially problematic, difficult and refused to take the medicine when they were just put on HAART. However, gradually they got used to taking medicines as part of their every day routine; these children were now reported used to their situations and take these drugs without any problems. The analysis of the videos of these children during medication taking proved that the children where not difficult and problematic when taking their medicine. Therefore, no further analysis of this relationship was examined. As such, the hypothesis that insecurely attached children are problematic and difficult during medication taking was rejected.

5.4 The relationship between psycho-social factors and adherence to treatment.

An attempt was made to explore the variance that levels of depression and education levels of caregivers account for on adherence. Further the relationship between adherence and social support of the dyad was explored and that of perceived self-efficacy of the caregivers of caregivers and adherence.

A significant variance of maternal depression was found to account for adherence among children. While the proportion that each group accounted for was not established, there was no doubt that maternal depression affected adherence among the children. The association between maternal depression and poor child outcomes is one of the most robust findings in psychological research (Gross, Shaw, & Moilanen, 2007). Consistent with adherence findings involving HAART and other diseases, depression in clinical samples significantly contribute to the variance that account for adherence to treatment. For instance, (Greenberg, Cicchetti & Cummings, 1990) argued that distress especially maternal depression is associated with chronic illnesses compounded by specific circumstances related to HIV/AIDS. Both maternal clinical depression and sub-clinical (sic), elevated levels of depressive symptoms have been found to be related to child maladjustment (Cummings, Keller, & Davies, 2005; Farmer, McGuffin, & Williams, 2002). This relationship also suggests that depression may affect the caregiver's ability to be attentive, engaging and responsive to their children's physical and socio-emotional need.

While depression may arise from the illness, especially in those with predisposition to mood disorders, it can also influence treatment and the health outcome (Kyrios et al, 2006). With regard to the current study depression was found to account for adherence partly because depression in and of itself is a distressing and interfering condition, and, in addition, the primary and associated symptoms of depression can dramatically affect the self-care behaviors you need to maintain a medical treatment regimen. Moreover, Ciechanowski, Katon and Russo (2000) found that depression was associated with poor adherence to medication regimens. Because Depression is a distressing, disabling, and

interfering condition that can negatively impact quality of life. Improving depression can improve functioning and well-being. In the context of chronic illness, improving depression may have additional important benefits. Specific symptoms of depression (e.g., poor concentration, loss of interest) or associated symptoms (e.g., low motivation, poor problem solving) can certainly interfere with a person's ability to adhere to a regimen of treatment for a chronic illness (<http://www.us.oup.com>). With HIV, for example, adherence to medications is critical for treatment success.

In some cases, the relationship between depression and chronic illness may even be a cycle. Living with a chronic illness can be stressful and can limit your involvement in things that you previously liked to do. Not having enough enjoyable activities can lead to or maintain symptoms of depression. In HIV, depression can lead to worse immune functioning, both through worse treatment adherence and possibly through biochemical changes associated with depression (<http://www.us.oup.com>). Having worse immune functioning leaves one at risk for various infections, causing symptoms and impairment and consequently leading back to increased depression. Successful treatment may require both decreasing depression and improving self-care.

With regard to this sample other than the illness itself, contributing and resilience factors could not be established. Further, the sample came from clinics supported by the Center for Infection and Disease Research in Zambia (CIDRZ), as such, an examination of their activities and programmes might help explain these results in future. For, example they

have pediatric support teams who regularly visits the subjects in their respective home. However, these results and suggestions can not be generalized.

When the relationship between adherence and social support was analyzed, most domains of social support indicated that there was low correlation. However, one domain of the social provisional scale (SPS-attachment -emotional closeness from which one derives a sense of security) was found to be moderately correlated with adherence. This relationship has been supported by the social support theory which emphasizes the quality of a person's relationship rather than the quantity of the person's relationship. Brehm & Kassin (1996) noted that intimacy predicts that having a close confiding relationship with significant others will be associated with better health.

Although there was this relationship with adherence, other domains of social support finding were in contrast with numerous literatures on correlates and facilitators of adherence. For instance Murphy et al (2001) examined a number of factors of adherence, but found significant relationship only between a number of predictors of depressive symptoms and self reported adherence. Surprisingly, neither structural social support (i.e. number of people in one social network) nor satisfaction with social support was associated with adherence. Equally, Gordillo et al (1999) found that compliance was poorer in depressed people irrespective of their social support and subjects who were not depressed but lacked social support.

This finding also suggests that we must avoid exaggerating the value of social support, especially when an individual is facing severe stressors. For example Bolger et al (1996)

found that higher levels of social support for patients suffering from breast cancer did not reduce their distress or the progression of the disease. This finding by Bolger and others suggests that methodological issues in studying social support may be important and one of the methodological issues is the failure to distinguish between positive effects of the presence of social support and the negative effects of its absence. As such, perceived social support does not simply reflect received support; the two are weakly related (Lakey & Cassidy). Instead perceived support may be located in the “eyes of the beholder” than the social environment.

What seems very apparent in these findings is that, social support operates through multiple mechanisms to influence the likelihood that a caregiver will lead the child to adhere to medication. It seems that the distinction among informational, emotional and instrumental support may be an important one. Family, friends and institutions may provide one and not the other. This study did not distinguish informational, emotional and instrumental support. It's clear from these findings and others that, social support is a product rather than a structure. Social support represents assistance a person can count on as a buffer or aid in problem solving. As many as four types have been conceptualized: emotional, informal, appraisal and instrumental, it is clear that support in one of these tends to overshadow others. For example, the problem with the low and sometimes middle class definition of social support when applied to disadvantaged populations, such as low income households and extremely poor mothers, is that it minimizes the importance of emotional and informational support. If a low income household (especially woman's) basic needs are not met, no amount of emotional support will improve her circumstances and those of her family. Providing instrumental

support is often the key to establishing a true helping relationship with low income households and their families as it indicates a genuine understanding of their current circumstances.

Therefore, it is possible that conceptually, participants were considering instrumental support as falling under a general “total support” category. The two main types of social support namely; informational and emotional were available for some of the participants through family support programs (home based care), Yes = 12, No = 10 ($M=1.45$, $SD = .51$). It could have been that family support program, help/ support which they get once in a week was not perceived as a support. For this sample which was entirely from low income households, emotional and informational support might not have been considered as support which indicated genuine understanding of their situations. Instrumental support is very important for this sample more so, that 99% of caregivers were female and Brehm & Kassin (1996) stated that because of women’s traditional responsibility for taking care of others and household chores, women incur high costs with regards to the cost-benefit relationship of social support. For example, Katopodi (19...) found no association between mammography and emotional, and informational support in a population of Latina, Africa-American and White women.

There was low correlation between the self-efficacy of caregivers and adherence to treatment among children. Only the relationship between adherence and self efficacy (SE) to managing mood indicated a moderate negative relationship. This finding is consistent with the findings on depression and attachment in this present study. The reasons for this would be the same as those argued on depression and attachment.

Though consistent with those found on depression and attachment, this finding is not consistency with other findings in literature. For instance, Belsky (1984) noted that mood and/ or depression compromise a parent's ability to be responsive to their children's social and emotional needs. However, self efficacy in getting support/ help correlated positively with self efficacy to manage fatigue.

Getting support/help also correlated positively with self efficacy to manage mood and self efficacy to communicate with a health provider was also correlated positively with self efficacy to manage medication. While these correlations were expected, it was surprising that there was no correlation between self efficacy of caregivers and adherence to treatment among their children. However, a review of pediatric HIV literature by Simoni et al (2007) indicates that pediatric antiretroviral adherence was not related to self efficacy. The reason for this finding can be as a result of what Sarason and his colleagues asserted. "The person who perceives high levels of available social support is a social optimist", Sarason et al, 1994 in (Brehm & Kassin, 1996). They further stated that such individuals possess a strong sense of self efficacy, positive evaluation of self, low anxiety and positive expectations about social interactions (Sarason et al, 1983).

Consequently, it could be the reason why there was low relationship between self efficacy and adherence. Since there was a possibility that participants conceptually considered instrumental support as falling under a general total support category, hence one possibility why self efficacy did not correlated with adherence. Although, social support and perceived self efficacy predicted nonadherence, we can not generalize these relationships. For instance, it is possible that participants based current self efficacy on

their adherence behavior and not their children's adherence behavior especially that caregivers who were biological parents to these children were also on HAART themselves.

Education of caregivers was found to significantly contribute to adherence to medication among the children. A robust body of literature indicates the significance of education on adherence. For instance, Gordillo et al (1999) found that subjects with low education had the worst adherence, where as individuals with university degrees had the best. However, few studies have also found that there is no difference between adherent and nonadherent groups in education (Cartz et al, 2000).

Adherence was measured according to appointments attended, doses missed and following nutritional advice. Failure to meet any one of these was associated with poor adherence to treatment. One reason why there was a significant variance of caregiver education accounting for the total variance on adherence was because educated caregivers easily understood prescriptions and instruction as while as followed appointments and schedules. Moreover, education could have made caregivers to have keen interest to read and find out more about the illness and medication for their children. Further, most of the study participants also participated in family support programmes and home based care which enhances adherence to treatment.

Participants of family support programmes and home based care have privileges such as, informational support (on HIV/AIDS and medication) and emotional support from other infected and affected families. Home visits by pediatric counselors and family support

teams were also more accessible to the subjects irrespective of their education status. Accordingly, these subjects benefited a lot and were more likely to have children who adhered to medication.

5.5 Delayed physical, mental and Neuro – development among HIV+ children

Literature on HIV/ AIDS indicates the susceptibility of infected individuals to physical, developmental delays, impaired cognitions and Neuro development otherwise known as HIV/AIDS dementia. This study examined physical, mental and neuro-development in the children. It was hypothesized that HIV positive children will have delayed physical, mental and neuro development.

Any child whose height, weight and/or head circumference was above the 95th percentile or below the 5th percentile was considered at risk. From the findings of this study only one child was below 5th percentile and the other children were considered normal because they fall within the range of 5th to 95th percentile with regards to height, weight head circumference and BMI. A child who was low in weight-for-age (below 5th percentile) could have been experiencing growth retardation and indicated need for referral for assessment to determine growth and nutritional status. However, measures of physical growth are interpreted in relation to other expected values considered normal or usual for a child of the age, sex and genetic potential of the one being measured. The most fruitful interpretations of children's growth are made from several observations made over a period of time rather than measures at a single point in time. However, this study did not have several observations over a period of time.

The personal social and communication development of these children was globally good. This can partly be attributed to the rich communication environment that these children were exposed to when they met every week for their family support programme which included learning (much about HIV/AIDS) and playing with their mates. Developmentalists know that children whose environment's are language stimulating such as talking, reading and use of a wide range of words in their speech develop large vocabulary and use more complex sentences, learn to read more readily than their counterparts (Bee & Boyd, 2004).

Most of the children had developmental delays especially in problem solving but also in fine motor and gross motor. 13(59%) out of 22 children were assessed as having difficulties in problem solving skills. According to Eysenck (2004), problem solving is a cognitive processing directed at transforming a given situation into a goal situation when no obvious method of solution is available to the problem. Childhood illnesses and diseases can have marked effects on brain development and cognitive functioning. Children at this age are especially vulnerable to infections that can disrupt brain development (Blanchette, 2000; Potterton 2001, 2006a, 2006b; Brown & Lourie, 2000). Although HIV is a systemic infection, it particularly affects those parts of the brain that govern executive functions, including higher aspects of attention and task-dependent changes in behavior (Ellis et al, 2007). This suggests that HIV impairs cognition which also affects problem solving in these children. In HIV, although synaptodendritic injury is distributed widely throughout the brain, some regions of the forebrain show selective vulnerability to injury or insult to the dendritic arbor is also seen as retraction of dendritic spines, dendritic beading and aberrant sprouting, all of which can occur

without neuronal death (Ellis et al, 2007). The result of these pathological processes is disruption or loss of normal synaptodendritic communication and axoplasmic flow. Higher cognitive functions depend on a highly complex synaptodendritic network, and damage to this network results in abnormal output, measured as deficiencies in cognitive skills and behavior (Ellis et al 2007).

Similarly, the children's environments may have contributed to poor problem solving skills. Most of these children came from low income households meaning that their environments were not cognitively stimulating. Developmentalists argue that the environment plays a very significant role in stimulating children cognitively. Environments with giggles puzzles; brick building tools help children develop problem solving skills. However, such environments seemed to have been lacking in this sample. Rie, Mupuala & Dow (2008) observed that the high prevalence of delays in cognitive development may in part be attributable to differences in child-rearing practices and lack of exposure to educational toys and multimedia by African children. More so, that the developing brain at this age is more sensitive to their nutrition and stimulation than at any other time over their life course. Nevertheless, these findings should not be generalized especially that the children were not assessed on several intervals to monitor their development.

However, problem solving and creativity should be understood within a social context because the magnitude of influence of cultural factors on the development and expression of good problem solving skills and creativity are to some extent cultural

determined. This study did not take into consideration the cultural aspect of problem solving skills and creativity. Future studies should consider this aspect.

Infected children are also at increased risk of motor impairments. Studies have found the impact of HIV and AIDS on children's neurological development including gross and fine motor deficits. A considerable number of children {7(32%)} indicated having deficits in gross motor and {9 (41%)} indicated having fine motor deficits. Previous studies have found a similar pattern and percentages of motor deficits in children (Rie, Mupuala & Dow, 2008). Severe delay in motor development was observed in 28.6% of HIV-infected and 14.3% of HIV-affected children, and moderate delay was present in 40% of HIV-infected and 14.3% of HIV-affected children (Rie, Mupuala & Dow, 2008). Like this study, they also observed that mental and not motor delay was most severely affected in HIV infection children.

The observed motor results could be as a result of the illness which might have not enabled the caregivers to engage in caregiver-infant activities that facilitate developmental milestones and progress in motor development. Snell, R. (1997) argued that when an infant is developmentally delayed or neurologically impaired, motor skills are often delayed, and do not develop easily. Gross motor skills occur in a typical sequence. However, these skills can only occur as the infant develops the balance, coordination and postural control needed to move his body about in space and each of these activities would allow the infant to experience normal movement to increase the likelihood that typical movement patterns would develop. As a result of the HIV/AIDS illness, the infants are put to handling and stimulating vulnerability. Snell's (1997)

stimulating and handling activities which enhance motor development progress such as head control, rolling, sitting pulling, cruising and walking might not have been actively engaged in these children. As such, an environment which stimulates body movements is very important in developing sound motor coordination not only in HIV positive children but in all children.

Number of ARVs (pills) and Adherence to treatment

The relationship between adherence to treatment and the number of Anti-retroviral drugs a subject was taking was considered and to the researcher's surprise there was no correlation between these two variables. The reason could be that caregivers with children on multiple ARVs feel that the severity of their disease is significant and hence become more cautious with their treatment, compared to those on mono-therapy, who may take treatment lightly. Conversely caregivers with children on mono-therapy found it easy and less strenuous to administer medication to their children than their counterparts on multiple ARVs. Another reason may perhaps be that when patients have to take multiple medications, they are less likely to forget to take them, compared to having to take only one pill. On the other hand when a caregiver of a patient is to administer only one pill, they are more motivated and less agitated than if they are to administer multiple pills. However, other studies have found different results. For instance, Hashmi et al (2007), observed an inverse relationship between adherence and number of pills prescribed. Patients on mono-therapy had a mean adherence of 79% compared to 90% for those on three drugs or more (OR; 95% CI, 0.3; 0.1–0.6). This is in contrast to what has been frequently reported so far. A recent meta-analysis of eight studies reports that the average adherence for once-daily dosing was significantly higher

than for multiple daily dosing (91.4% vs. 83.2%, respectively, $P<0.001$) (Hashmi et al, 2007). Some latest studies, however, have identified no relation between increasing number of drugs and poor adherence, including one such study in an Asian population.

5.6 Chapter Summery

Securely attached children adhered better to medication than the insecurely attached probably because they are able to put up with the inconveniences and discomfort to please their caregivers. In the same vein, caregiver sensitivity communicates to the children that the world is safe and that their caregivers are a safe haven such that bitter ARVs pills or syrups are not considered as deliberately induced harm/pain on them. Social support and self efficacy on its own does not enhance adherence. The children were also lagging in some areas of physical and neural development probably as a result of the illness.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.0 Conclusion

In conclusion, current evidence supports suggestions that attachment constructs can be usefully applied in models of psychological and physical health. Though a relationship between attachment and adherence to treatment was found, these findings can not be generalized because the sample size was very small and came from health centers sponsored by CIDRZ alone. As such the sample was too homogenous to be generalized to other settings. Further, findings from this sample do not represent HIV+ children whose caregivers earn sufficient income for private pay care. Additionally, data was derived exclusively from self reports, which can contribute to common method variance and was subject to bias related to social desirability responses or the defensive style of participants. Although the direction of effects is supported by theory because the data were gathered at one time point, it is impossible to determine whether psychological distress develops before or after, or occur in tandem with attachment style.

Similarly, it is unclear whether caregiver-child attachment styles change in response to a diagnosis of HIV or whether attachment insecurity preceded the diagnosis and characterizes a group of individuals who are more at risk for contracting HIV/AIDS. In addition to examining internalized adherence among HIV+ clients, counselors may find it useful to explore the potential impact of caregiver-child attachment style on physical and mental health. Psychosocial interventions addressing interpersonal functioning in the context of caregiver-child attachments may be particularly helpful to HIV+ persons. Future studies should examine the possibility of insecurely attached children being problematic and difficult in taking medication when they are just put on HAART. This would make the analysis of the relationship between the variables feasible.

Otherwise, it could be that the children were not problematic or difficult to take these medications because they had become resilient to these bitter and non-palatable drugs.

One of the limitations of this study was that other socio-economic factors were not considered as possible causes of the nature of the child-caregiver relationship. Poor social and economic circumstances beyond the caregiver's control have been reported to disrupt the caregiver-child relationship. As such future studies should control for social economic factors or consider them as possible factors contributing to the poor outcome in children's performance. Equally, this study was unable to determine the children's genetically influenced temperament as the cause of the nature of the child-caregiver relationship.

6.1 Recommendations

Caregiver-child attachment

The researcher recommends that in future, sensitivity interventions should be incorporated in the mainstream pediatrics programmes and activities. Messages conveyed to mothers (caregivers) encouraging them to hold, hug, play with, talk to, and kiss their babies frequently are important. Such advice may seem to some policy makers to be too obvious or simplistic or to insult the natural mothering abilities of their constituents. Zeitlin, Ghassemi & Mansour (1990, p.52), observed that since the nature of caregiver child relationship has direct effects on the health well-being of the children, health centers can come up with deliberate programmes in which caregivers can sensitively and responsively practice these behaviors for 10-15 minutes every time they come to the health centers.

Emotional Availability

Why should the clinician and physician be concerned with emotional development? There are many reasons which Emde (1998) has immaculately suggested. The first reason is that emotions help define one's individuality. From the standpoint of an individual's experience, emotions define a sense of consistency and set parameters for one's sensitivity and responsiveness to events wherein one comes to "feel right" or otherwise about the relation of oneself with the world. Clinicians and physicians who are in treatment relationships with their patients make use of the connections between emotions and individuality. When the clinician or physician gets in touch with the complexity of another's emotional life, whether parent or child, that person is likely to feel understood; helping and healing then becomes possible. Moreover, getting in touch with another's emotional life can engage a clinical skill some have referred to as "systems sensitivity," wherein a particular felt problem area can be worked on while appreciating its connection with other areas. It is also the case that when the clinician or physician helps a parent to appreciate her infant's temperament or emotional individuality, caregiving attitudes may improve (Emde, 1998).

A second reason concerns the fact that emotions during early development, as well as later, have two central adaptive functions that help define the meaning of experience. These consist of *motivation* and *communication*. Emotions motivate an infant, for example, to either approach or withdraw from a situation, to either maintain or terminate stimulation. Infant emotions are also tied to need states and may indicate suffering, thereby motivating caregiving actions by others (Emde, 1998).

For inter coder reliability all coders did not get the required expert training to compute reliability for the study observations and therefore, it is recommended that for future studies an expert coder reviews the video tapes and gives ratings based on standardized coding of the observations. The aforementioned observation applies for coding of the dyadic emotional availability and attachment quality.

Adherence and Depression

The effect of maternal depression on adherence suggests incorporating the home environment factors as possible variances facilitating the relationship between the variable. Future investigations of children's adherence should include caregiver behaviors and cognitions as well as child pharmacological and environmental variables as possible contributors to adherence. The network of secondary responsible caregivers may help ameliorate the effect of a depressed primary caregiver on the child's adherence to treatment. Further, because these children develop mental models and representation of time and routines of taking their medicine, they themselves became resourceful when taking the medicine. In other words, they reminded the caregiver consistently when it was time to take the medicine.

These findings also suggest introduction of eclectic versions of HIV and AIDS counseling programs for young children with components dedicated to parental well being and social support (Baydar, Reid, & Webster-Stratton, 2003; Olds, 2002); and continued focus on modifying caregiving practices. For example, cognitive-behavioral therapy is a directive, skills-based treatment that focuses on strategies that are designed to directly improve the symptoms of depression. As such, future studies should assess

depression in children themselves and the consequences that it may have on their adherence to treatment rather than on assessing it on caregivers alone.

Social support and Self efficacy

Social support and Self efficacy should be examined in the context of other instrumental variables such social and economic strains. For low income households emotional and informational support may not have much change on their lives if they have astronomic economic strains. These also raise questions on cultural differences in perceiving and appreciating social support and self efficacy. The researcher suggests that models of adherence should incorporate multiple domains (i.e., environmental, individual, medical) as possible correlates of adherence. These would help explain correlates and predictors of adherence to treatment. Equally they would improve children's adherence to antiretroviral therapy and ultimately their quality of life. For example, examination of the interaction between various coping or adaptive styles and dosing regimens may yield more ecologically valid information than examination of either variable alone. For example, Murphy et al's (2001) findings that neither social network/support nor perceived quality of social support predicted adherence is in contrast with numerous studies that report such relationships. Murphy et al's (2001) findings may reflect the impact of development on correlates of adherence, and suggest the need for participant age to be more effectively incorporated into future models of adherence.

Physical and Neuro-development

In future, when examining physical development among HIV + children, a comparative sample of non-infected children would yield more plausible results which can be attributed completely to the effect of HIV/AIDS and therefore be generalized. These results may indicate a possible picture of physical development among the children but we can not be totally sure whether this picture was completely as a result of HIV and AIDS. Whether these results were HIV related or not, the high rate of developmental delay reported in HIV-infected and HIV-affected children as compared with control children underscores the need for screening for and prevention of neuro-developmental delay at an early age and calls for access to early interventions and nutritional and care programs for these vulnerable children.

One of the limitations of this study was that the subjects were only measured at one point. As such, it was difficult to attribute the measures to HIV and AIDS alone. In future, when determining what normal growth for a child is, the following factors should be taken into account:

1. Previous weight and length/stature measurements, such as low birth weight.
2. Account for small size (length/stature or weight or both) up to age 7;
3. History of illness;
4. Parental body build and physical stature;
5. Genetic disorders.

This also means that developing a multidisciplinary team which should include Pediatric Occupational, Physical, Behavior, Nutritional, Music, Vision and Developmental Therapies is important in physical development programmes and interventions.

Similarly, noted cognitive and neuro-cognitive problems may not completely be attributed to HIV and AIDS. Longitudinal studies on dementia and other neurological problems should be undertaken especially that neurological imaging and standardized classification of neurological examination were not available in this study. Consequently, frequent neurocognitive and Neuro-developmental testing remains important for tracking children's functioning overtime and should be integrated into routine primary care whenever possible. Accordingly, I recommend that the children's environments, family support programme and pediatric clinics should create an environment that is stimulating with facilities such as educational toys and media to help the children catch up in the neurological development. Further, multidisciplinary treatment teams that assess and optimize children's home environments appear warranted. Such teams might include behavioral and early childhood specialists that can provide education and guidance regarding appropriate developmental milestones, early learning opportunities and positive behavioral supports to caregivers of children with HIV.

Failure to thrive is a diagnosis given to children with developmental delays for unclear reasons. There are many causes. Most causes involve environmental and social factors that interact to keep the child from getting the nutrition the child needs. Occasionally, medical disorders prevent a child from growing normally. However, this study considered the later only. As such in future there is need for a broader frame of reference to interpret appropriate developmental delays three alternatives to achieve this would include a comparison or control group, locally appropriate standardized norms and longitudinal data to track changes over time.

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APPENDIX

APPENDIX A

INFORMED CONSENT FORM ON TAKING ANTIRETROVIRAL MEDICATION

STUDY TITLE
Caregiver-child attachment and drug adherence among HIV positive children: The effect of behavioral and emotional proclivities on adherence.

INFORMED CONSENT FORM FOR PARENTS

INFORMATION

This research is being carried out by student researchers in the Department of Psychology at the University of Zambia.

Why have you been chosen?

You have been randomly chosen to participate in this study not because you are unique or that you have any special qualities and your child.

What will happen if I take part?

The study will require you to participate in 2 observations of about 20 minutes of your interaction with your child and one observation of your child playing with dolls/toys for about 15 minutes. It will also require you to answer a number of questionnaires and 2 interviews. We will also examine your child's medical record for adherence.

Do you have to take part?

It is up to you whether you take part or not in this study. If you do not take part it will not affect the medical care or any other benefit. If you do take part you can withdraw from the study at any time, again with no penalty and without having to give a reason. However, the indirect benefit of participating fully to this study is that the results of this study may be used in improving Highly Active Antiretroviral Therapy/Treatment (HAART) for children living with HIV/AIDS.

What will happen to the information I give?

The information is confidential. The research will not identify you individually and no one other than the researcher will know what you have said. The questionnaires will only use numbers and not names. Observation recordings will also be confidential and

only the researcher will have access to them. We will also remove any information that you give that can identify you personally.

Who can I ask if I have any questions?

If you would like to ask any questions about the research then you can ring Given Hapunda on +26097 7630871 or Dr Mwiya Imasiku on 097 396176.

Thank you for reading this.

INFORMED CONSENT

The participant should complete the whole of this sheet himself/herself
Cross out as necessary

- Have you read & understood the information sheet? YES/NO
- Have you had opportunity to ask questions & discuss the study? YES/NO
- Have all the questions been answered satisfactorily? YES/NO
- Have you received enough information about the study? YES/NO
- Who have you spoken to Dr/Mr/Mrs/Ms
- Do you agree to take part in the study? YES/NO

If yes sign here _____

For the researcher

Signature _____ Name (In block capitals) _____ Date _____
I have explained the study to the above participant and he/she has indicated his/her willingness to participate.

SCREENING INTERVIEW ON TAKING ANTIRETROVIRAL MEDICATION

STUDY TITLE
Caregiver-child attachment and drug adherence among HIV positive children: The effect of behavioral and emotional proclivities on adherence.

DIRECTIVES FOR ANSWERING THE SCREENING INTERVIEW

We would like to find out some information about you and your child. All your responses will be kept confidential. All the information gathered will be purely used for academic purposes only. It is thus important for you to make an effort to give your answers as precise as possible.

Demographical Data

1. How old are you?
2. What is your Marital Status?
 - Married
 - Divorced
 - Separated
 - Widowed
 - Single
 - Not married but living together
3. What educational standard have you attained?
 - Primary
 - Junior secondary
 - Senior secondary
 - College
 - University
 - Others
4. How many biological children do you have?
.....
5. How many other children do you look after?

6. How are you related to them?.....
7. Are you the primary caregiver of the patient?.....
8. If No, who is the primary caregiver.....
9. If not biological caregiver, are the biological parents still alive.....
10. How are you related to the patient.....
11. How would you classify your family type? Nuclear____ Joint____ or Extended____
12. Whats the age and sex of your child?.....
13. How would you describe the current wellbeing of your child's health?.....
-
14. What is your occupation/ what do you do to earn a living?.....
-
15. What is the occupation of your spouse/partner? What does your spouse/partner do to earn a living?.....
16. What is your family's monthly income?
 - ZMK 1,500,000 and below
 - ZMK 1,600,001 – 5,000,000
 - ZMK 5,000,001 and above

Medicine and Administration Related Data

17. Is the child on medication? If **yes** what is the form of the medication your child takes?.....
18. When was the last time your child took these
medications.....
19. What are the days and times when the child takes his or her
medications?.....
.....
...
20. What are the days and times that you and you child are required to go to your
respective health centre or counselor?.....
.....
...
21. Do you face any problems administering medication to your child? I f yes what
some of these problems or challenges?.....
.....
.....
.....
.....
.....
.....
22. We would like to visit you at home. What is your home address and how can we
get your house.....
.....
.....
23. What is your on phone number on which we can contact you to make an
appointment for the home
visit.....
24. Do you have any information that you would like to add and/ or say about the
child and medication that your child takes?.....
.....

.....

Thank you for your participation

APPENDIX B2

INTERVIEW ON TAKING ANTIRETROVIRAL MEDICATION

TITLE

Caregiver-child attachment and drug adherence among HIV positive children: The effect of behavioral and emotional proclivities on adherence.

DIRECTIVES FOR ANSWERING THE INTERVIEW
--

INTERVIEWER: Now I'm going to ask some questions about your Child's HIV medications. Most people including children with HIV have many pills or other medications to take at different times during the day. As such many children and especially their caregivers find it hard to always remember to administer pills or medicines to their children. For example:

- Some caregivers get busy and forget to carry and/or give pills and other medicines to their children.
- Some caregivers find it hard to administer pills or other medicines to their children according to all the instructions, such as "with food" or "on an empty stomach," "every 8 hours," or "with plenty of fluids."
- Some caregivers decide to skip giving their children pills or other medicines to avoid adverse effects they have on their children or to just not give pills that day.

We need to understand what children with HIV with the help of their caregivers are really doing with their pills or medicines. Please tell us what you are actually doing. Don't worry about telling us you don't give all your pills or medicines to your child. We need to know what is really happening, not what you think we "want to hear."

1. What HIV medication does your child take and what is their dosage?

2. When does your child take these?
3. How does your child remember to take his/her medications?
4. "Thinking of the medications PRESCRIBED to you by your doctor(s), please answer the following questions." *Response options: never = 0; rarely = 1; sometimes = 2; often = 3; always = 4*
5. Do you ever forget to give your child medications?
6. Are you careless at times when giving/ administering to your child medications?
7. When your child feels better, do you sometimes stop giving your child medications?
8. Sometimes, if your child feels worse when giving her/him medications, do you stop giving them?
9. How many doses of HIV medication has your child missed in the last 72 hours, last week, last 2 weeks, and last month?

Scales to Assess Adherence to HIV Medication Regimens

INTERVIEWER: LIST CODES FOR ALL ANTIRETROVIRALS THAT SUBJECT'S CHILD WAS PRESCRIBED TO TAKE IN LAST 30 DAYS. IDENTIFY UP TO 4 DRUGS.

DRUG A:	DRUG C:
DRUG B:	DRUG D:

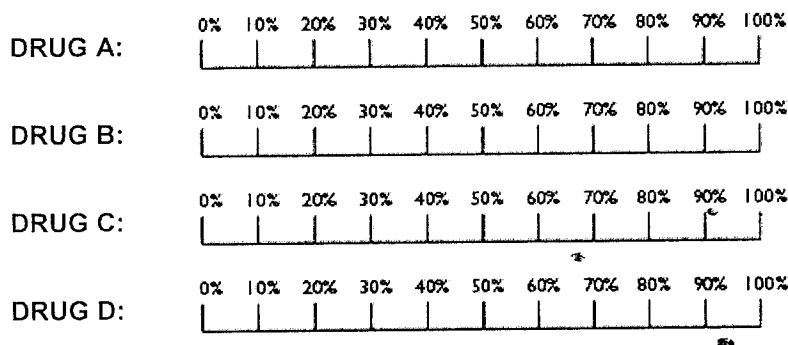
Interviewer Now, I am going to ask you some questions about these drugs. Please put an "X" on the line below at the point showing your best guess about how much (DRUGS A-D) your child has taken in the last 3-4 weeks. We would be surprised if this were 100% for most children or even adults.

HAND INSTRUMENT AND PEN TO RESPONDENT

Interviewer 0% means you have taken no (DRUG A)
50% means you have taken half your (DRUG A)
100% means you have taken every single dose of (DRUG A)

Adherence Self Assessment Instrument

Instructions for Patient: Put an "X" on the line below at the point showing your best guess about how much of each drug you have given to your child in the last 3 to 4 weeks.
0% means you have given none of the drug
50% means you have given half of the drug
100% means you have given every single dose of the drug



Adapted but modified from Morisky DE, Green LW, Levine DM. *Concurrent and predictive validity of a self-reported measure of medication adherence*. Med Care 1986; 24: 67-74.

APPENDIX B3

QUESTIONNAIRE ON TAKING ANTIRETROVIRAL MEDICATION

TITLE

Caregiver-child attachment and drug adherence among HIV positive children: The effect of behavioral and emotional proclivities on adherence.

DIRECTIVES FOR ANSWERING THE QUESTIONNAIRE

Like most adults, it is likely that your child missed taking one or several pills or syrups at some point in time. In fact, even the most disciplined parents to HIV+ children many not always administer medication to their children as they may wish because of forgetfulness, unexpected situations etc. The most difficult thing will no doubt be for your child or you as the caregiver to remember the times that your child missed taking one or several pills or syrups. It is thus important for you to make an effort to remember so that your answers are as precise as possible. Take the time you need to answer.

We ask you to answer the questionnaire with only the **ANTIRETROVIRAL** medication that your child takes in mind.

The word **PILL** is used to mean tablet, caplets and capsules. **Syrups** include liquid antiretroviral medicines.

The expression **MISS** one or several pills or syrups mean **NOT** taking antiretroviral pills or other medicines at a certain time as required or prescribed.

Answer **ALL** the questions by entering a number or by checking one of the suggested answers.

Q 1.Indicate the name of the antiretroviral medication that your child takes. Next enter the number of pills or syrup that your child has to take each day for each of these medications (*please refer to the prescription or labels on the medication containers/ plastic bags*).

Name of Antiretroviral Medication*	Number of antiretroviral pills/syrups		
	Wake up, breakfast, morning	Lunch, afternoon	Supper, evening, bedtime
Example: lamiduvine(3TC,Epvir	1		1
1.			
2.			
3.			
4.			
5.			

*indicate one of the names of the medication.

Q2. Many patients taking these medications find it difficult from time to time. Does the child ever have troubles taking the pills or syrups?

(Mark × or tick on the response best suited for your child)

___ Never ___ Rarely ___ Sometimes ___ often ___ Very often.

Q3. How many antiretroviral pills or syrups has your child missed during the last three (3) days?

(If your child has not missed any, write down the number "0")

	Number of antiretroviral pills or syrups that your child has missed...		
	Wake-up, breakfast, morning	Lunch, afternoon	Supper, evening , bed time
Example:	0	0	1
Yesterday			
The day before yesterday			
3 days ago			

Q4. During the last 7 days did your child...

	YES	NO
• Go out for leisure activity?	___	___
• (Play park, show, physical activity etc)		
• Sleep away from home?	___	___
• Visit friend(s) or family member?	___	___
• Go to a party?	___	___
• Any other activity		
• (Indicate the activity).....	___	___

Q5. During the last 7 days did one of the situations listed in Q 4 prevent your child from taking his/her antiretroviral pills or syrups?
YES _____ NO _____

Q6a. During the last 7 days, how many times, in total did your child miss taking one or more of his/her antiretroviral pills or syrups?
(If your child has not missed any, write down the number "0")
_____ TIMES

Q6b. In total, this represents how many antiretroviral pills or syrups?
_____ PILLS _____ SYRUPS

Q7. Is the child enrolled in home based care?
_____ YES _____ NO

PHYSICAL MEASUREMENT FORM FOR CHILDREN

STUDY TITLE
Caregiver-child attachment and drug adherence among HIV positive children: The effect of behavioral and emotional proclivities on adherence.

DIRECTIVES FOR FILLING IN THE PHYSICAL MEASUREMENT FORM
--

This form should only be filled in during or after the health centre observations of the dyad. Therefore, the dyad will actively be involved in the physical measurement of the child. To be filled by the caregiver but with the help of a nurse or researcher if necessarily

Details of the child

Name / label of the child _____

Age of the child _____

Sex of the child _____

Measurement Domains

Height _____

Weight _____

Head circumference _____

Chest circumference _____

Thank you for your participation

APPENDIX D

Beck's Depression Inventory

STUDY TITLE

Caregiver-child attachment and drug adherence among HIV positive children: The effect of behavioral and emotional proclivities on adherence.

DIRECTIVES FOR ANSWERING THE QUESTIONNAIRE

We would like to find out some information about you as the caregiver. All your responses will be kept confidential. All the information gathered will be purely used for academic purposes only. It is thus important for you to make an effort to give your answers as precise as possible.

Clients Name/ Identification _____

1.
0 I do not feel sad.
1 I feel sad
2 I am sad all the time and I can't snap out of it.
3 I am so sad and unhappy that I can't stand it.
2.
0 I am not particularly discouraged about the future.
1 I feel discouraged about the future.
2 I feel I have nothing to look forward to.
3 I feel the future is hopeless and that things cannot improve.
3.
0 I do not feel like a failure.
1 I feel I have failed more than the average person.
2 As I look back on my life, all I can see is a lot of failures.
3 I feel I am a complete failure as a person.

4.

- 0 I get as much satisfaction out of things as I used to.
- 1 I don't enjoy things the way I used to.
- 2 I don't get real satisfaction out of anything anymore.
- 3 I am dissatisfied or bored with everything.

5.

- 0 I don't feel particularly guilty
- 1 I feel guilty a good part of the time.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

6.

- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

7.

- 0 I don't feel disappointed in myself.
- 1 I am disappointed in myself.
- 2 I am disgusted with myself.
- 3 I hate myself.

8.

- 0 I don't feel I am any worse than anybody else.
- 1 I am critical of myself for my weaknesses or mistakes.
- 2 I blame myself all the time for my faults.
- 3 I blame myself for everything bad that happens.

9.

- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

10.

- 0 I don't cry any more than usual.
- 1 I cry more now than I used to.
- 2 I cry all the time now.
- 3 I used to be able to cry, but now I can't cry even though I want to.

11.

- 0 I am no more irritated by things than I ever was.
- 1 I am slightly more irritated now than usual.
- 2 I am quite annoyed or irritated a good deal of the time.
- 3 I feel irritated all the time.

12.

0 I have not lost interest in other people.

1 I am less interested in other people than I used to be.

2 I have lost most of my interest in other people.

3 I have lost all of my interest in other people.

13.

0 I make decisions about as well as I ever could.

1 I put off making decisions more than I used to.

2 I have greater difficulty in making decisions more than I used to.

3 I can't make decisions at all anymore.

14.

0 I don't feel that I look any worse than I used to.

1 I am worried that I am looking old or unattractive.

2 I feel that there are permanent changes in my appearance that make me look unattractive.

3 I believe that I look ugly.

15.

0 I can work about as well as before.

1 It takes an extra effort to get started at doing something.

2 I have to push myself very hard to do anything.

3 I can't do any work at all.

16.

0 I can sleep as well as usual.

1 I don't sleep as well as I used to.

2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.

3 I wake up several hours earlier than I used to and cannot get back to sleep.

17.

0 I don't get more tired than usual.

1 I get tired more easily than I used to.

2 I get tired from doing almost anything.

3 I am too tired to do anything.

18.

0 My appetite is no worse than usual.

1 My appetite is not as good as it used to be.

2 My appetite is much worse now.

3 I have no appetite at all anymore.

19.

0 I haven't lost much weight, if any, lately.

1 I have lost more than five pounds.

- 2 I have lost more than ten pounds.
- 3 I have lost more than fifteen pounds.

20.

- 0 I am no more worried about my health than usual.
- 1 I am worried about physical problems such as aches and pains, or upset stomach, or constipation.
- 2 I am very worried about physical problems and it's hard to think of much else.
- 3 I am so worried about my physical problems that I cannot think about anything else.

21.

- 0 I have not noticed any recent change in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I have almost no interest in sex.
- 3 I have lost interest in sex completely.

Thank you for your participation

APPENDIX E

Social Provisions Scale

* TITLE *	
Caregiver-child attachment and drug adherence among HIV positive children: The effect of behavioral and emotional proclivities on adherence.	

Instructions: In answering the following questions, think about your current relationships with friends, family members, co-workers, community members, and so on. Please indicate to what extent each statement describes your current relationships with other people. Use the following scale to indicate your opinion:

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

So, for example, if you feel a statement is very true of your current relationships, you would respond with a 4 (strongly agree). If you feel a statement clearly does not describe your relationships, you would respond with a 1 (strongly disagree).

1. There are people I can depend on to help me if I really need it. _____
2. I feel that I do not have close personal relationships with other people.* _____
3. There is no one I can turn to for guidance in times of stress.* _____
4. There are people who depend on me for help. _____
5. There are people who enjoy the same social activities I do. _____
6. Other people do not view me as competent.* _____
7. I feel personally responsible for the well-being of another person. _____
8. I feel part of a group of people who share my attitudes and beliefs. _____
9. I do not think other people respect my skills and abilities.* _____
10. If something went wrong, no one would come to my assistance.* _____
11. I have close relationships that provide me with a sense of emotional security and well-being. _____
12. There is someone I could talk to about important decisions in my life. _____
13. I have relationships where my competence and skill are recognized. _____
14. There is no one who shares my interests and concerns.* _____
15. There is no one who really relies on me for their well-being.* _____
16. There is a trustworthy person I could turn to for advice if I were having problems. _____
17. I feel a strong emotional bond with at least one other person. _____
18. There is no one I can depend on for aid if I really need it.* _____
19. There is no one I feel comfortable talking about problems with.* _____
20. There are people who admire my talents and abilities. _____
21. I lack a feeling of intimacy with another person.* _____
22. There is no one who likes to do the things I do.* _____

23. There are people I can count on in an emergency._____

24. No one needs me to care for them.* _____

Adopted from Cutrona, C. E., & Russell, D. W. (1987). The provisions of social relationships and adaptation to stress. *Advances in Personal Relationships*, 1, 37-67.

Thank you for your participation

APPENDIX F

The HIV-SE Questionnaire

STUDY TITLE
Caregiver-child attachment and drug adherence among HIV positive children: The effect of behavioral and emotional proclivities on adherence.

INSTRUCTIONS

Please **CIRCLE** the number that corresponds to how sure or confident you are that you can do the tasks regularly at the present time.

How sure are you that you can . . .

1. Keep from getting discouraged when nothing you do seems to make a difference?

1 2 3 4 5 6 7 8 9 10

Not at all sure

* Totally Sure

2. Do something to make yourself feel better when you are feeling discouraged?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

3. Keep from feeling sad or down in the dumps?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

4. Do something to make yourself feel better when you feel sad or down in the dumps?

1 2 3 4 5 6 7* 8 9 10

Not at all sure

Totally Sure

5. Keep yourself from feeling lonely?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

6. Do something to make yourself feel better when you are feeling lonely?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

7. Keep your sadness or depression from interfering with what you want to do?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

8. Do something to make yourself feel better when your sadness or depression interferes with what you want to do?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

9. Reduce the emotional distress caused by your child's health condition so that it does not affect your everyday life?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

10. Follow the instructions correctly for a large number and variety of prescription medications for your child?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

11. Administering your child's prescription medications at the appropriate timing?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

12. Administer the medications to treat or prevent HIV or HIV-related diseases as directed?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

13. Thinking about the side effects, numbers, and timing of these medications, how sure are you that you can administer most or all of your child's Protease Inhibitor and/or NNRTI medications as directed?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

14. Now suppose there were NO SIDE EFFECTS. Thinking about the number and timing of these medications, how sure are you that you can administer most or all of your child's Protease Inhibitor and/or NNRTI medications as directed?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

15. Administer your child's medications everyday as they are prescribed?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

16. Work with your child's doctor/nurse practitioner to reach agreement on the best medication for your child's overall?

1	2	3	4	5	6	7	8	9	10
Not at all sure					Totally Sure				

17. Reduce your child's symptoms in general?

1	2	3	4	5	6	7	8	9	10
Not at all sure					Totally Sure				

18. Help keep the sleep problems caused by your child's disease from interfering with the things you want to do?

1	2	3	4	5	6	7	8	9	10
Not at all sure					Totally Sure				

19. Keep the physical discomfort or pain of your child's disease from interfering with the things you want to do?

1	2	3	4	5	6	7	8	9	10
Not at all sure					Totally Sure				

20. Keep any other symptoms or health problems your child may have from interfering with the things you want to do?

1	2	3	4	5	6	7	8	9	10
Not at all sure					Totally Sure				

21. Control any symptoms or health problems your child may have so that they don't interfere with the things you want to do?

1	2	3	4	5	6	7	8	9	10
Not at all sure					Totally Sure				

22. Ask your child's doctor/nurse practitioner things about your child's illness that concerns you?

1	2	3	4	5	6	7	8	9	10
Not at all sure					Totally Sure				

23. Discuss openly with your child's doctor/nurse practitioner any problems that may be related to your child's medications?

1	2	3	4	5	6	7	8	9	10
Not at all sure					Totally Sure				

24. Work out differences with your child's doctor/nurse practitioner when they arise?

1	2	3	4	5	6	7	8	9	10
Not at all sure					Totally Sure				

25. Ask your doctor/nurse practitioner things about your medications and treatments that concern you?

1	2	3	4	5	6	7	8	9	10
Not at all sure					Totally Sure				

26. Get information about your child's illness and its treatments from community resources?

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

Not at all sure

Totally Sure

27. Get family and friends to help you with the things you need (such as household chores like shopping, cooking, or transportation)?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

28. Get community resources to help you with the things you need (such as household chores like shopping, cooking, or transportation)?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

29. Get emotional support (such as listening or talking over your child's problems) from friends and family?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

30. Get emotional support (such as listening or talking over your problems) from community resources other than friends or family?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

31. Decrease your fatigue?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

32. Keep the fatigue caused by your child's disease from interfering with the things you want to do?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

33. As compared with other people with your child's condition, how sure are you that you can manage fatigue during your daily activities?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

34. How sure are you that you can deal with the frustration caused by your fatigue?

1 2 3 4 5 6 7 8 9 10

Not at all sure

Totally Sure

Thank you for participating

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APPENDIX:

STORY COMPLETION TASKS TO ASSESS YOUNG CHILDREN'S INTERNAL WORKING MODELS OF CHILD AND PARENTS IN THE ATTACHMENT RELATIONSHIP

Inge Bretherton and Doreen Ridgeway

This assessment consists of five story beginnings that are to be acted out with small family figures and other simple props. Each story is designed to elicit responses regarding a particular attachment issue. The idea for these stories came from a prior study, designed in collaboration with Marjorie Beechly, in which we assessed children's understanding of emotions and roles. The issues addressed in the story beginnings are (1) the attachment figure in an authority role (the spilled juice story), (2) fear as an elicitor of attachment and protective behavior (the hurt knee story), (3) separation anxiety and coping (the departure story), and (4) responses to parental return (the reunion story).

ATTACHMENT STORY COMPLETION PROTOCOL

Materials

Family Figures. Two "realistic, bendable" (catalog description) doll families each comprising a father, mother, girl, and boy. The two families can be combined so as to yield a father (F), mother (M), grandmother (GM), and two children (2 Cs), a smaller and larger boy, or smaller and larger girl. To create the grandmother, the hair of one of the mother dolls is painted grayish-white. The dolls can be obtained from several national school supply firms. To prevent the dolls from falling over, they are mounted on plastic stands (those used for Barbie dolls are suitable if you can obtain them).

Other Props. A small wooden box to represent a table; a birthday cake (about the size of a piece of tinkertoy); a set of very small dishes and silverware in suitcase or box; a table cloth (optional); a piece of green felt to represent grass (9x9 inches); a piece of gray or beige artificial sponge, cut to look like a rock; a bed and small felt blanket; a wooden box (4x6 inches) painted like a car.

Administration

The task is administered at a child's table, with the child and tester sitting opposite one another. Bring out the props as needed, naming each one (except for the dolls that are identified at the beginning). After each story, ask the subject to put the figures over to one side, saying, "Can you get them ready for the next story?" To lead into the next story, the tester may say something like, "Now I have an idea for a different story," or "Are you ready for something different now?"

The stories contained in this protocol are part of a larger set developed in collaboration with Helen Buchsbaum and Robert Emde. The remaining stories can be obtained from them. The monster in the bedroom story was developed by Helen Buchsbaum; the remainder were developed by Inge Bretherton and Doreen Ridgeway.

ATTACHMENT STORY COMPLETIONS

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Before beginning presentation of the stories that are part of the assessment, it is a good idea for the tester (T) to present a warm-up story to get the subject to feel comfortable with handling the figures. We have chosen a birthday-party story for this purpose. It is not important to stick precisely to the script for the warm-up story, but it is important to follow standard procedure for the stories that form part of the assessment: "spilled juice," "hurt knee," "monster in the bedroom," "departure," "reunion." The latter is true whether the stories are used as written or whether they are somewhat altered. For example, they could be administered with one parent only, or with a babysitter instead of the grandmother. One change that we are considering for further studies is to present the five stories as events of one day in the family's life (a suggestion we owe to Ned Mueller).

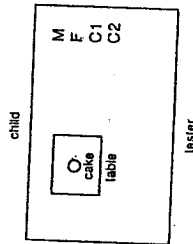
STORIES

Introduction of Figures

T: "Look who we have here." (Bring out family.) "Here's our family. Look. This is the grandma, this is the daddy, this is the mommy, and these are the girls, Jane and Susan (and these are the boys, Bob and George)." (Show them to the subject as you name them.)

T: "Who've we got?" (Point to family figures.) "You know what? I've got an idea. Let's pretend to make up some stories about them. Tell you what, how about if I start a story about our family and you finish it."

Warm-up: Birthday Story. (M, F, GM, 2Cs, table dishes, cake.)
Put out the figures like this:



T: "Here's their table and what's this?" (Show cake to subject and wait for subject to name it.) "... What kind of cake?" "... Yes, it's a birthday cake. You listen carefully to the story. The mommy has baked this beautiful birthday cake and she calls out:"

M: "Come on grandma, come on Dad, come on boys (girls), let's have a birthday party."

T: "Show me what happens now." (Inviting tone of voice; let the subject play with the figures or tell a story yourself if the subject does not.)

T: (Shake the box with the silverware.) "Can you help me set the table for dinner? (Give box to subject, wait till subject has set the table, help if necessary.)"

T: "Now put the family around the dinner table so they're ready to eat." (Wait till subject has placed the figures.)

T resumes: "Here is our family eating dinner and Bob (Jane) gets up and reaches and spills his juice." (Make child figure knock cup off toy table so cup is visible to subject.)

M: "Bob (Jane) you spilled your juice!" (Reproachful tone of voice, but don't overdo; turn M toward Bob or Jane, and move her up and down while she is talking.)

T: "Show me what happens now."

Prompting Procedure

T prompt (if subject does not spontaneously mention: "What do they do about the spilled juice?") T prompt if subject gives only one response: "Anything else?" "What else?" or "Then what?" If subject performs ambiguous actions with figures, ask "What are they doing?" and if the subject uses an ambiguous pronoun when talking about the figures, ask "Who was doing it?" T can also repeat the subject's statement in question form, to verify what the subject said ("The mommy wiped the juice? And then what?"). If the subject asks for the GM, say "She's not in the story, we'll get her out again later."

Note that these prompts are designed not to suggest precise ideas to the subject. The only exception is the prompt that focuses the subject's attention on the issue (spilled juice) if it has not been addressed.

Hurt Knee Story. (2 Cs, M, F, felt for guns, sponge for rock.)

T: "O.K. I have an idea for another story. You put our family there and get them ready for the next one while I put these away." (T points to the side of the table, see below. It is important that the rest of the family be about 30 cm away from the rock the story child will climb.)

C: "Look, mommy and daddy. Watch me climb this high, high rock." (Make child figure climb rock, then fall off.) "Boo-hoo (or ouch), I've hurt my knee (crying voice)."

T: "Show me what happens now."

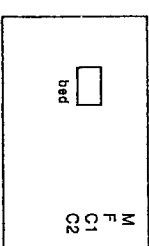
T prompt (if subject does not spontaneously mention): "What do they do about the hurt knee?" For other prompts, see "spilled juice" story, i.e., ask what the figures are doing if it's not accompanied by speech, ask the subjects to show you what they say the figures are doing, and prompt for elaboration by saying things like "Anything else?" "And then what?" etc.

If the subject seems to have finished, or becomes repetitive, say:

T: "All done? Shall we try another? Let's put these away."

Monster in the Bedroom Story. (2 Cs, M, F, bed with felt blanket.)

T: "Can you get the family ready for the next one?" (Set out the props as below, if subject does not do it. Again, it is important to have the rest of the family at least 30 cm from the bed in the "bedroom.")

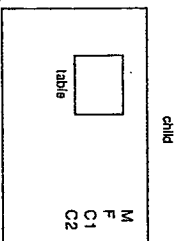


T: "Look what happens now. Listen carefully."

M: (Face M toward story child and move her slightly as she speaks.) "It's bedtime. Go up to your room and go to bed."

Spilled Juice Story. (2Cs, M, F, table, dishes.)

- T: "O.K., I think I have an idea for a new story." (Put away the grandmother and set out the figures as below, away from the table.)



- T: (Shake the box with the silverware.) "Can you help me set the table for dinner. (Give box to subject, wait till subject has set the table, help if necessary.)

- T: "Now put the family around the dinner table so they're ready to eat." (Wait till subject has placed the figures.)

- T resumes: "Here is our family eating dinner and Bob (Jane) gets up and reaches and spills his juice." (Make child figure knock cup off toy table so cup is visible to subject.)

- M: "Bob (Jane) you spilled your juice!" (Reproachful tone of voice, but don't overdo; turn M toward Bob or Jane, and move her up and down while she is talking.)

- T: "Show me what happens now."

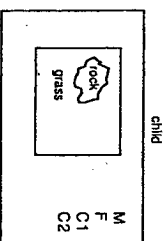
Prompting Procedure

T prompt (if subject does not spontaneously mention: "What do they do about the spilled juice?" T prompt if subject gives only one response: "Anything else?" "What else?" or "Then what?" If subject performs ambiguous actions with figures, ask "What are they doing?" and if the subject uses an ambiguous pronoun when talking about the figures, ask "Who was doing it?" T can also repeat the subject's statement in question form, to verify what the subject said ("The mommy wiped the juice? And then what?"). If the subject asks for the CM, say "She's not in the story, we'll get her out again later."

Note that these prompts are designed not to suggest precise ideas to the subject. The only exception is the prompt that focuses the subject's attention on the issue (spilled juice) if it has not been addressed.

Hurt Knee Story. (2Cs, M, F, felt for grass, sponge for rock.)

- T: "O.K. I have an idea for another story. You put our family there and get them ready for the next one while I put these away." (T points to the side of the table, see below. It is important that the rest of the family be about 30 cm away from the rock the story child will climb.)



- T: "O.K. Look what I've got." (Set out piece of green felt and sponge rock.) "This is the park. Do you sometimes go to the park with your mom and dad?" "Here is our family and they're out walking in the park, and at this park there is this high, high rock."

- C: "Look, mommy and daddy. Watch me climb this high, high rock." (Make child figure climb rock, then fall off.) "Bee-hoo (or ouch), I've hurt my knee (crying voice)."

- T: "Show me what happens now."

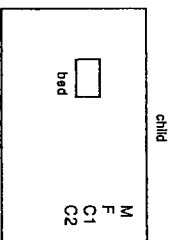
- T prompt (if subject does not spontaneously mention): "What do they do about the hurt knee?" For other prompts, see "spilled juice" story, i.e., ask what the figures are doing if it's not accompanied by speech, ask the subjects to show you what they say the figures are doing, and prompt for elaboration by saying things like "Anything else?" "And then what?" etc.

- If the subject seems to have finished, or becomes repetitive, say:

- T: "All done? Shall we try another? Let's put these away."

Monster in the Bedroom Story. (2Cs, M, F, bed with felt blanket.)

- T: "Can you get the family ready for the next one?" (Set out the props as below, if subject does not do it. Again, it is important to have the rest of the family at least 30 cm from the bed in the "bedroom.")



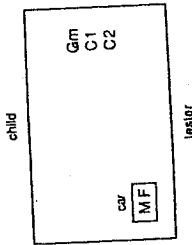
- T: "Look what happens now. Listen carefully."

- M: (Face M toward story child and move her slightly as she speaks.) "It's bedtime. Go up to your room and go to bed."

T prompt: if subject does not spontaneously mention, "What do the children do while the mom and dad are gone?" and use other prompts to clarify actions, or actors, or to ask subject to act out what is being described.

Departure Story. (Same Props as departure story.)

Bring the car with the two parents back out from under the table and set it on table a distance from the family (i.e., keep it near T, so the subject has to reach for it and make it drive "home"). If the subject has put the child and grandmother figures in the middle of the table during the previous story, put them back close to the subject to make distance between the returning car and the child figures).



T: "O.K. And you know what? It's the next day and the grandma looks out of the window (make grandma look toward car, move her as she speaks) and she goes":
GM: "Look boys (girls), here come your mommy and daddy. They're home from their trip."
T: "Show me what happens now." (Let subject drive car toward "home," intervene only if the subject does not do so.)

Prompt: if subject does not spontaneously take the figures out of the car. "What do we do now that the mom and dad are home?" Also use other prompts given in "spilled juice" story where appropriate.

If the subject asks for other props, like a bed, etc., bring it out. However, do not bring out the grandmother during the earlier stories. Just say, "She'll come back later" or "We'll use her in another story later." It is very important to adhere to the spatial arrangements suggested in each story, especially the distance between parent and child figures in the hurt knee, monster, and reunion stories.

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- Ainsworth, M. D. S., & Bell, S. M. (1974). Mother-infant interaction and the development of competencies. In K. J. Connolly & J. Bruner (eds.), *The growth of competence*. New York: Academic Press.
- Ainsworth, M. D. S.; Bell, S. M.; & Stayton, D. (1974). Infant-mother attachment and social development: "Socialization" as a product of reciprocal responsiveness to signals. In M. P. M. Richards (ed.), *The integration of the child into a social world*. London: Cambridge University Press.

F: "Go up to bed now." (Same action as with M, deep voice.)

C: "O.K. mommy and daddy, I'm going." (Make child figure walk to bed.)

T comment: "Bob goes upstairs to his room, and he goes!"

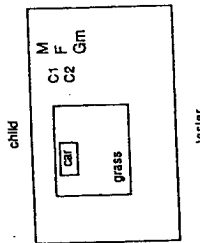
C: "Mommy! Daddy! There's a monster in my room! There's a monster in my room!" (Alarmed tone of voice.)

T: "Show me what happens now."

T prompt: if subject does not mention spontaneously, "What do they do about the monster in the room?" If necessary, use other prompts given in "spilled juice" story, i.e., ask for clarification of ambiguous action, ask subjects to show you actions they simply described, and for elaboration by saying "Now what?" "Anything else?" etc. If the subject stops playing, or becomes overtly repetitive, move on by saying:
T: "Are you ready for the next one?"

Departure Story. (2Cs, M, F, GM, felt grass, box as car.)

T: "Let's use the grandmother this time." (Set out family and grandmother at side of table, with green felt and car as below; it is important to have the car in front of the subject, and the two parents facing the grandmother and two children.)



T: "Here we have their front lawn, and here we have their car, this is the family car." (Make mom and dad face the children and grandma, with car in front of subject.)

T: "You know what it looks like to me, (subject's name). It looks like the mommy and the daddy are going on a trip."

M: "O.K. boys (girls). Your dad and I are going on a trip. We are leaving on our trip now." (Move M slightly as she speaks to the children.)

F: "See you tomorrow. Grandma will stay with you." (Move F slightly like M.)

T: "Show me what happens now."

Important: T should let the subject put the figures in the car and make the car drive off. Only intervene if the subject seems unable to make the car drive off. If the subject puts the children in the car say, "No, only the mom and dad are going." After the subject (or if necessary, the tester) makes the car drive off, T puts the car under the table, out of sight. If the subject wants to retrieve the car, T replies, "No, they're not coming back yet."

T: "And away they go." (As the car is moved under the table.)