UNDERSTANDING THE PROCESS OF DISCLOSURE TO HIV-INFECTED CHILDREN IN KINSHASA, DEMOCRATIC REPUBLIC OF THE CONGO

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ABSTRACT

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Understanding the Process of Disclosure to HIV-Infected Children
in Kinshasa, Democratic Republic of the Congo
(Under the direction of Eugenia Eng and Suzanne Maman (co-chairs))

In 2006, 2.5 million children under age 15 were living with HIV infection, over 90 percent in developing countries. Antiretroviral treatment (ART) increases the likelihood that HIV-infected children will survive to adolescence and beyond. Children on ART are often not told their diagnosis, despite some evidence that informing them can have positive psychosocial and clinical outcomes.

This study's goal was to identify factors associated with disclosure patterns to HIV-infected children in the Democratic Republic of Congo (DRC), in order to develop appropriate, effective interventions to support families. We conducted 201 structured interviews with primary caregivers who had not informed their child, ages 5-17, of his/her diagnosis, measuring factors at individual, interpersonal, and community levels possibly associated with disclosure patterns. In-depth interviews were conducted with 8 caregiver-child dyads whose children, ages 8-17, had been told their diagnosis; these focused on experiences throughout the disclosure process, which to date have not been documented in sub-Saharan Africa.

Caregivers who had not yet told their child of her/his HIV status fell into one of three groups: nearly 50% had given their child <u>no information</u>, 15% had given <u>partial</u>

information; and 33% had provided misleading information. Multinomial logistic regression found these patterns to be associated with: (1) caregiver gender, age, and stigmatizing attitudes placing blame for infection; (2) child's age; and (3) characteristics of the caregiver-child relationship. Findings from the in-depth interviews on the moments before, during and after disclosure revealed that caregivers were influenced to disclose by concerns about treatment adherence, the eminent onset of adolescent sexual activity, and their desire to protect their child as well as others. Children experienced disclosure as a discrete event; although many had subsequent questions and concerns, most did not discuss them with others.

In sum, disclosure to HIV-infected children is a process that can take multiple paths. Providers should work closely with caregivers to understand how communication patterns evolve, assist them in communicating with their child, and support them through full disclosure. Providers should work with HIV-infected children, before, during, and after disclosure to create opportunities for children to share experiences with each other.

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LIST OF ABBREVIATIONS

Abbreviation	Definition
AAP	American Academy of Pediatrics
AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CDC	United States Centers for Disease Control & Prevention
DHHS	United States Department of Health & Human Services
DRC	Democratic Republic of the Congo
GDP	Gross Domestic Product
GNI	Gross National Income
HIV	Human Immunodeficiency Virus
KLL	Kalembe Lembe Pediatric Hospital
NIH	National Institutes of Health (US)
PLHA	Person/People living with HIV/AIDS
PNLS	Programme Nationale de la Lutte Contre le VIH/SIDA et les IST (National AIDS Control Program)

Abbreviation	**Definition**
UID	Unit of Infectious Diseases, Kalembe Lembe Pediatric Hospital
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNC-GAP	University of North Carolina Global AIDS Program Project
UNICEF	United Nations Children’s Fund
USAID	United States Agency for International Development
WHO	World Health Organization

CHAPTER 1:
INTRODUCTION

1.1 PROBLEM STATEMENT

In 2006, an estimated 39.5 million people worldwide (range 34.1 -47.1 million) were living with HIV infection (UNAIDS, 2006). Of those, 2.3 million (range 1.7-3.5 million) were children under 15 years of age. During the past year, 530,000 children under 15 years of age acquired HIV, translating roughly into 1,000 new infections every day. Of these, 460,000 occurred in Sub-Saharan Africa, representing 85% of new infections among children under 15 years of age (UNAIDS, 2006).

Treatments using multiple antiretroviral drug regimens have dramatically reduced morbidity and mortality associated with HIV infection (Hammer et al., 1997; Palella et al., 1998). Global efforts to reduce drug costs, along with additional funds becoming available to address the pandemic, mean that access to antiretroviral treatment for adults and children in Sub-Saharan Africa will continue to expand. An estimated 28 percent of those needing treatment (1.3 million of 4.7 million) in Sub-Saharan Africa currently receive it (WHO, UNAIDS, & UNICEF, 2007), representing a substantial increase from the 500,000 receiving treatment in 2005, 11 percent of those in need at that time (WHO, 2005a) . Whereas in late 2003, 25 percent of people on antiretroviral therapy in low- and middle-income countries were living in Sub-Saharan Africa, as of 2007 the region is home to 67% of low- and middle-income country recipients of antiretrovirals (WHO et al., 2007).

Infected children who, without access to antiretroviral treatment were likely to die before reaching their fifth birthday (Jones, Steketee, Black, Bhutta, & Morris, 2003), may now see their lives extended to adolescence and beyond. However, access to antiretovirals for children lags behind that of adults. Globally only 115,500 children under age 15 years in need of antiretrovirals had access to treatment, representing only 15 percent of the estimated 780,000 needing access (WHO et al., 2007). Sub-Saharan Africa has the lowest pediatric treatment coverage for any region, with only 13 percent of children needing treatment receiving it as of 2007 (WHO et al., 2007)

Our understanding of the clinical manifestations and evolution of HIV-related illness and its treatment among children has increased as a result of the last two decades of research on the subject. However, limited work has been conducted to increase our understanding of the psychosocial aspects of HIV/AIDS in infected children. One such area needing exploration is what, when, and how HIV-infected children are told about their health. HIV-infected children under medical care are seldom informed of their HIV-status, despite some evidence from industrialized countries indicating that informing children and their families can have positive psychosocial and clinical outcomes (Bachanas, Kullgren, Schwartz, McDaniel et al., 2001; L. Wiener, Theut, Steinberg, Riekert, & Pizzo, 1994). The factors associated with parental/ caregiver decision-making processes around disclosure are important to understand so that appropriate support structures can be created for parents and caregivers of HIV-infected children prior to, and following, disclosure.

While there is evidence that children with chronic illnesses are at risk of experiencing emotional and behavioral difficulties (Bachanas, Kullgren, Schwartz, Lanier et al., 2001; R. J. Thompson, Jr., Gil, Burbach, Keith, & Kinney, 1993; Wallander & Varni, 1998), there is also evidence that children benefit from an open discussion of their illness and that nondisclosure does not necessarily protect children from psychological distress (Claflin & Barbarin, 1991; Eiser, 1994; Slavin, O'Malley, Koocher, & Foster, 1982). Despite concerns about the negative social and psychological impacts of disclosure to children, some studies from industrialized countries show that HIV-infected children fare well after disclosure, and better than children unaware of their HIV infection (L. Wiener et al., 1994). For example, Bachanas and colleagues found that children in the United States who had not been told their diagnosis reported more psychological distress than children who had been told their diagnosis (Bachanas, Kullgren, Schwartz, Lanier et al., 2001). Similarly, Mellins et al noted no difference in mental health between children who had been disclosed to, versus those who had not had been so, as well as a trend towards less depression among children who knew their HIV status (C.A. Mellins et al., 2002). A intervention study providing social support during and after the disclosure process to families and adolescents in Puerto Rico found that six months after disclosure, adolescents had returned to their pre-disclosure levels of depression, and that the majority considered disclosure to be a positive event (Blasini et al., 2004).

The complexity of the interplay between stigma and fear of disclosure, and the implications it might have on adherence to antiretroviral regimens, have yet to be fully explored. However, initial data collected indicate that fear of the repercussions of disclosure are correlated with poor adherence to antiretroviral regimens. Data on adults indicates that stigma and access to social support affect adherence to antiretroviral regimens. A qualitative study of US rural patients on antiretrovirals found that many reported missed doses because of fear of identification as HIV-positive (Golin, Isasi, Bontempi, & Eng, 2002). A review of quantitative studies found that of the 20 studies reviewed, between 14-33 percent of study participants reported skipping medication because of fears of inadvertent HIV status disclosure (Ammassari et al., 2002). The review also found that among studies exploring the relationship between family or social support and adherence, a majority found lack of support to be a significant predictor of nonadherence (Altice, Mostashari, & Friedland, 2001; Ammassari et al., 2002; Gifford et al., 2000; Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999; Murri et al., 2000; Singh et al., 1999; Stone et al., 2001). Similar levels of evidence for treatment adherence among children are not available; however, some studies have found an inverse relationship between children's knowledge of HIV status and their adherence (Giacomet et al., 2003; Gibb et al., 2003), and parent/caregiver fear of disclosure was identified as a factor leading to nonadherence (Gibb et al., 2003). It is critical to the success of treatment programs that more be known and understood about disclosure of HIV status to children, as it may be implicated in their long-term survival, through its influence on antiretroviral regimen adherence as well as their psychosocial well-being.

For HIV-infected children, access to antiretrovirals can extend their lives through childhood into adolescence and even into early adulthood. It is therefore important to understand the implications of HIV status disclosure on their adaptation to long-term illness, their coping strategies, and their participation in their health care. Also, it is vital that we understand the process of disclosure in order to better address secondary prevention as well as adherence efforts.

1.2 STUDY AIMS

The goal of this study was to identify factors associated with disclosure behaviors of parents and caregivers of HIV-infected children, in order to develop more appropriate and effective interventions to support these families. To achieve this goal, the study had three aims:

Aim 1: To describe existing patterns of nondisclosure among 200 caregivers *who have not yet disclosed HIV status* to HIV-infected children, ages 5-17 years, receiving clinical services at Kalembe Lembe Pediatric Hospital, Kinshasa, Democratic Republic of the Congo.

Aim 2: To describe factors at individual, interpersonal and community levels that are significantly associated with different patterns of disclosure of HIV status, among 200 caregivers of HIV-infected children, ages 5-17 years, receiving clinical services at Kalembe Lembe Pediatric Hospital *who have not yet disclosed*.

Aim 3: To explore the full process of HIV status disclosure and its sequelae among families receiving care at Kalembe Lembe Pediatric Hospital, through qualitative interviews with up to 8 child-caregiver dyads who have already experienced full disclosure of the child's HIV status; children are between 8-17 years of age.

1.3 ORGANIZATION OF THE DISSERTATION

This dissertation is composed of two scientific papers, plus additional chapters that provide an overview of the issues and summarize the contribution of this research to the literature. Chapter Two begins with a description of the contextual setting for the research, including the status of the HIV/AIDS epidemic in the Democratic Republic of the Congo. The chapter then continues with a literature review covering the epidemiology of HIV transmission among children and the existing knowledge of disclosure patterns to children. Chapter Three describes the study's conceptual model, presents the research questions, and sets forth the hypotheses that were tested. Chapters Four and Five present the results of the study, in the format of two manuscripts. Chapter Six provides final conclusions and presents suggestions for future work.

CHAPTER 2
LITERATURE REVIEW

OVERVIEW

This chapter presents a review of the relevant literature in order to understand the context and rationale for the study. The chapter provides an overview of (a) Kinshasa, Democratic Republic of the Congo (DRC), the study setting; (b) the HIV/AIDS situation in the DRC; (c) information about children and HIV/AIDS; and (d) research on disclosure of HIV/AIDS, with an emphasis on disclosure to infected children. The conclusions drawn on the current state of knowledge are synthesized at the end of this chapter. Finally, the study's aims are presented with regard to understanding the process of disclosure to infected children in Kinshasa and its implications for psychosocial support service delivery to children and their families.

2.1 CONTEXTUAL SETTING: KINSHASA, THE DEMOCRATIC REPUBLIC OF THE CONGO (DRC)

2.1.1 Political and Economic Context of the Democratic Republic of the Congo

Since its creation in the late nineteenth century, the present-day Democratic Republic of the Congo (DRC) has been characterized by groups, both internal and external to the country, with images and meaning that not only serve to define the nation but also to symbolize its place in the understanding of Africa. In the late colonial period, as the "darkest Africa", it was the last, unexplored frontier. As the "heart of Africa", it became a symbolic stand-in for sub-Saharan Africa in the immediate post-colonial period, full of resources and hope. At the end of the twentieth century, as the "Heart of Darkness", became the symbol of the failures of a post-colonial Africa beleaguered by civil war, corrupt governments, health crises, and overwhelming poverty (Dunn, 2003).

With a geographic area of over 2.3 million square kilometers—approximately one-quarter the area of the continental United States—the DRC is the second largest country in all of Africa and the largest in Central Africa. The estimated total population in 2005 was approximately 57.5 million, of which approximately 47 percent was under the age of 15 years (UN Population Division, 2007) . Nearly one-third of the population lives in urban areas (BASICS II, 2001; World Bank, 2004), with an estimated 14 percent living in the capital, Kinshasa, alone. The country has a wealth of natural resources, including rubber, diamonds, copper, zinc, uranium, cobalt and hydropower (CIA, 2006).

Despite its vast size, rich natural resources and, therefore, its great economic potential, the DRC has seen its economic potential falter and subsequently collapse, since its independence from Belgium in 1960. Today, the DRC is among the world's poorest countries, with some of the worst development indicators. In 2006, the DRC ranked 167th out of 177 countries in the Human Development Index, a composite indicator compiled by the United Nations Development Programme[1] (UNDP, 2006). The Gross National Income

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[1] The Human Development Index measures the average achievements along three basic dimensions: a long and healthy life (life expectancy at birth), knowledge (adult literacy rate, combined gross enrollment ration for primary, secondary, and tertiary schools), and a decent standard of living (per capita gross domestic product).

(GNI) per capita in 2005 was only US$120 (World Bank, 2006). Literacy rates are estimated at 67 percent for the total adult population, and 54 percent for the female adult population (UNICEF, 2006).

The current political conflict in DRC erupted following the ousting of the government of President Mobuto Sese Seko in 1997. Seven African nations, three main rebel groups and numerous militias began fighting over a complex mix of economic, ethnic, state and factional interests. A recent report by the International Rescue Committee estimates that, since the war began in 1998, an estimated 3.8 million people have died from violence, famine and disease—approximately 31,000 every day for 6 years (Coghlan et al., 2005). More people have died as a result of the war in the DRC than in any other conflict since World War II. While a peace accord was signed by rival factions in 2002 and a transitional government established in 2003, the country remains in turmoil, particularly in the northeast. An estimated 2.4 million people are still internally displaced; an additional 300,000 refugees from Rwanda and Burundi are based in the northeastern regions (McConnell, 2003). The first national elections in 40 years took place in June and November 2006. While the democratically-elected government, led by President Joseph Kabila and his ruling party, the People's Party for Reconstruction and Democracy (PPRD) was inaugurated in December 2006, fighting with rebels continues in the eastern region of the country, which threatens to destabilize the country yet again.

The mismanagement of public funds during the years of the Mobutu regime (1965-1997), followed by the complete collapse of government infrastructure and the ensuing war has devastated the public health infrastructure for the country. Total per capita expenditures on health were only US$12 in 2001; of this, 44.4 percent were public expenditures, indicating that the majority of costs incurred for health care are private (WHO, 2004c). Government expenditures on health reflect only 10 percent of total government expenditures in 2001; the total expenditures on health represent 3.5 percent of the Gross Domestic Product (GDP) (WHO, 2004c)—all of this indicates that very limited financial resources are being invested in health. In most cases, health workers have not received salaries from the government for decades. People continue to work because there are limited other options for survival. Many doctors left the rural areas and went to the cities in search of better work, or were employed by international agencies or in some cases left the country altogether. The remaining personnel are stretched thin over an increasingly large population with a heavy disease burden. There are an estimated 44.2 nurses, 6.9 physicians, and 1.4 hospital beds per 100,000 population (WHO, 2004a). The 2000 BASICS II annual report indicates that these scarce human resources are even less available as activities such as polio eradication efforts divert them from other urgent health problems (BASICS II, 2001).

2.1.2 Sociocultural Context of the DRC

The geographic boundaries of the DRC serve as home to over 200 ethnic groups, the majority of which are classified as Bantu peoples. As is often the case in Africa, some ethnic groups' traditional boundaries cross over existing political boundaries, resulting in some fluidity in population movements and at times adding to political tensions. Throughout the DRC's prehistory, most ethnic groups were isolated from one another by the thick forests that cover vast portions of the country. For several hundred years before the arrival of Europeans in the late fifteenth century, many of the kingdoms in modern-day DRC were highly organized and efficient administrators of health, education, and trade. Today, 45 percent of the population of the DRC belong to one of four main ethnic groups: the Kongo, Luba, Mongo (Bantu) and the Mangbetu-Azande (Hamitic) (CIA, 2006).

While many languages are spoken, five predominate across the country. They are French (official), Lingala (main trade language), Swahili (predominant in the East), Kikongo, and Tshiluba (Gordon Jr., 2005). In Kinshasa, French and Lingala serve as the main languages; the Lingala spoken has incorporated elements of languages of the confluence of the different people who have migrated to the city in the last few decades.

The Congolese are predominantly Christian. Over 50 percent are Roman Catholic, 20 percent are Protestant, and 10 percent Kimbanguist (a Christian sect of Congolese origin); 10 percent of the population is Muslim and the remaining 10 percent are either of sects that have fused multiple belief systems or practice indigenous belief systems (CIA, 2006).

2.1.3 Social groups and social order

Only a few elements of the sociopolitical patterns of indigenous Congolese communities remain today, albeit altered and adapted over the colonial era and since independence. Local communities persist as the main units of society, often changed by the aggregation of smaller units into larger ones. Lineage groups maintain ties to local communities, particularly in rural areas, and kinship networks create ties between individuals. With very few exceptions, traditional communities distinguished their members on some scale of worthiness based on age and sex; such distinctions persist (Meditz & Merrill, 1994). In the traditional African model of kinship rules, there is a clear delineation of power, starting with the male head of the family. Chiefs come to rule based on their popularity within the village, their personal charisma, and their overall prestige. Respect for elders, chiefs, and ancestors is an extremely important facet of daily life in the Congo. All other things being equal, older age in general requires respect; however, seniority does not necessarily create access to the office of highest status in the descent group or local community. Males in general have higher status than females, despite the presence in many communities of matrilineal descent groups and matrilineally based succession and inheritance (Meditz & Merrill, 1994).

In general, the range of fairly important kin is wider than that in the West and has not appreciably narrowed, even in modern day urban society, in part because many urban Congolese maintain ties with the rural areas from which they come, in part because kin ties provide ways of coping with some of the difficulties of urban life. This, however, has become more and more limited over the last decade as the prolonged conflict has strained traditional systems of support to the limit.

2.1.4 Family Structure and Family Functioning

While there is a substantial literature on the economic function of households across Sub-Saharan Africa, very little has been written specifically on family structure and family functioning, including in the DRC. While many of the ethnic groups have a matrilineal kinship structure, defining their descent through their maternal ancestors, nonetheless

Congolese society is male-dominated, with men having the established authority over women and children, including control over the allocation of resources (International Women's Rights Action Watch, 2003; Meditz & Merrill, 1994).

In the past, single women in the Congo belonged to their fathers, and, upon marriage, their ownership would be transferred to the husband. The man's father would give gifts such as knives, food, or slaves to the new wife's father, in exchange for his loss of precious labor and kinship. Polygyny is illegal but still practiced. In rural areas it is common for men to have many wives. Village chiefs or headmen usually have more than one wife. The goal is to have many children who survive until adulthood, providing the household with enough hands to complete the many chores necessary for survival.

Family bonds, kinship relations and ethnic connections create personal ties that serve as social assets—these social assets create income-generating opportunities for the poor, particularly in the informal economy (MacGaffey, 1991). Those Congolese who do not have jobs survive to a great extent through the use of these social assets. Family and kinship ties also have a leveling function in the form of obligations that require the redistribution of wealth. However, as a result of the prolonged crisis, this sense of obligation has broken down to some extent, reducing the available social assets and tightening the circle of reciprocity from large webs of family and kinship ties to simple linear ones (De Herdt, 2004)

2.1.5 Children and Childhood

> “There is not one childhood, but many, formed at the intersection of different cultural, social, and economic systems, natural and man-made physical

environments. Different positions in society produce different experiences."

(Frones, 1993)

Understanding the role of children within families is important if we are to understand how communication with children and decisions about children are made—and how they may differ within the context of HIV disclosure. However, there is very little written on the experiences of children and childhood, for Sub-Saharan Africa as a whole, and the DRC in particular.

Traditionally children were seen as a source of investment for the future, and their proliferation strengthens families, lineages, and kinship systems (Aguilar Molina, 2006). A child's place within his/her home was governed by a system of family ties. This gives the child a sense of belonging, a role, a living environment and a series of expectations, on the part of the parents, as to their future. This system is also intended to shape the child's behavior towards adults; submission and docility are expected (Aguilar Molina, 2006). From the time they are able to walk, children are thrust into the realm of adult responsibilities (Ziemke, 2001). Youth learn from their parents and elders how to manage the homestead. Young girls, especially, are expected to contribute in the household chores for the family (Ziemke, 2001). Good children treat their elders with utmost respect and perform chores without complaint. In modern urban times, children are faced with other social models that sometimes clash with traditional expectations (Aguilar Molina, 2006). This is particularly true in the urban jungle of Kinshasa.

Evidence of the role of children and their function in families can be found in the newly written constitution of the DRC, finalized in November 2005 and ratified by voters in

January, 2006. The constitution defines family as “the natural group unit of society” and places it under the “protection of public authorities.” (Aguilar Molina, 2006) The care of children is defined as a natural right and obligation of parents, with help to be provided by public authorities (Aguilar Molina, 2006). The duty of children is specified as assisting their parents; parents have a duty, in turn, to care for children and to assure their protection (Aguilar Molina, 2006).

Traditionally children were seen as a source of investment for the future (Aguilar Molina, 2006; Ziemke, 2001). In alliance transactions, children represent, even more so than women, the supreme gift or the ultimate binding agents in the cycles of reciprocity and redistribution that underpin social life (de Boeck, 2004). It is especially the circulation of children that create the social architecture of kinship, alliance and residence (Lallemand 1993) Children thus appear both as medium and as actors in the creation and extension of kinship and alliance: without children, there are no gifts. Without gifts, there are no kin, no allies, or social body.

While a 1994 study found that the presence of a concerned extended family appeared to minimize any adverse health and socioeconomic effects experienced by children orphaned by HIV (Ryder, Kamenga, Nkusu, Batter, & Heyward, 1994), there is growing evidence that precarious family relations due to prolonged adversity in the Congo may limit the resources available to families with HIV-infected children. When adversity or change hits the family, it is not the family structure that is a risk factor but the dynamic of family relations. Most noticeable is the disappearance of collective support with regard to the child. The ability to mobilize the family network, enabling a child to move around the extended biological family, has suffered significant transformations in recent years; the child is now first and foremost a burden for the host family (De Herdt, 2004; Ziemke, 2001).

2.1.6 The Confluence of Political, Economic, and Sociocultural Contexts in Kinshasa

Kinshasa was founded as the Belgian colonial outpost of Leopoldville in 1881 by explorer Henry Stanley. An important trading post, the completion of the railroads turned it into an important transportation center; in 1929, it became the capital of the Belgian Congo. The city was renamed Kinshasa in 1966 by then-President Mobuto. Conflicts in other parts of the country and the concentration of wealth in the capital drew people from across the nation to Kinshasa, and it experienced an explosive growth in the post-independence years. At the country's independence in 1961, the city had 400,000 inhabitants. By 1976, it had grown to 2 million. Today, the city's exact size is not known, but if calculated as 14 percent of the total country population (World Bank, 2004), it can be estimated to be 8 million, making it the second largest city in Sub-Saharan Africa, behind Lagos. The city is divided into 24 administrative zones that also function as neighborhoods.

Kinshasa is often portrayed as a forsaken corner characterized by "calamity, chaos, confusion, and a bizarre form of social cannibalism where society is its own prey." (Trefon, 2004) The city has practically no formal economy. The remnants of its administration provide little in terms of social services or infrastructure. People are poor, sick, hungry, unschooled, underinformed and disillusioned by decades of political oppression, economic crisis and war. However, despite its problems, Kinshasa is also a fascinating and fantastic social space. It is a city of paradox, contrast and contradiction where new and remarkable patterns of stability, organization and quest for well-being have emerged.

Today, aided by an unending political and economic crisis, the city is undergoing a large scale process of informal "villagization" (de Boeck & Plissart, 2006). Local associations are emerging to help neighbors as families' strained resources fail to support its individual members (De Herdt, 2004). Reliance on individual reciprocity has replaced reliance on government. While people do depend on others, they have at the same time become experts in *la débrouille* (fending for oneself) (Trefon, 2004). Although individual interests are supplanting collective ones, social pressure to share remains strong (Nzeza Bilakila, 2004); however, few have the economic ability to do so. People help each other primarily if they can expect something in return (De Herdt, 2004). While the nuclear family household has not replaced the extended family, ties are increasingly built on vertical (parent-child-grandchild) rather than horizontal family lines (De Herdt, 2004).

The vast majority of households in Kinshasa have less than $50 per month, which is barely enough to cover the food bill. Many families have less (Trefon, 2004). A study in the Kinshasa community of Matete in 1997 found that 50 percent of individuals ate only one meal a day; 25 percent ate a meal every other day (De Herdt, 2004). Another study conducted by the University of Kinshasa in 2002 captured the ongoing food security crisis, noting that 30 percent of families reported reducing the number of meals per day, and 25 percent reported that they had reduced the number, quality and overall consumption of some foods (Okitolonda, Lapika, Kayembe, Kaba, & Malengreau, 2002).

Today, there are an estimated 30,000 children living on the streets in Kinshasa. Children living and working on the streets are a relatively new phenomenon in the DRC (Human Rights Watch, 2006). Prior to the 1970s there were few, if any, permanent street children in the DRC; vagrant children were taken before a judge and either reunited with their families or else placed in private or government institutions for children. In the last 15 years, numerous interrelated and complex socioeconomic factors have led to the explosion in the number of children on the streets in the DRC. These include, but are not limited to: 1) the civil war resulting in orphaned or abandoned children, huge numbers of displaced peoples, a sharp deterioration of essential state services, and a related increase in poverty and unemployment; 2) rapid urbanization and the breakdown of traditional support structures of the African extended family; 3) the difficulties faced by single- or child-headed households; 4) the inability of parents/guardians to pay for school fees and other related costs of public education; and 5) the impact of HIV/AIDS on society (Human Rights Watch, 2006).

2.2 HIV/AIDS IN THE DRC

The DRC was one of the first African countries to document HIV/AIDS cases, in the early 1980s. Between 1986-1989, HIV prevalence among antenatal women in urban areas was between 5.8 and 6.5 percent (Batter et al., 1994; Ryder et al., 1989). Since then, HIV prevalence among antenatal care attendees in Kinshasa has fluctuated between 3.0 percent and 7.1 percent. The HIV prevalence in the population was most recently estimated at 4.2 percent(WHO, UNAIDS, & UNICEF, 2004). The latest prevalence estimates indicate that

110,000 children under age 15 are living with HIV/AIDS in the DRC (range 42,000-280,000) (WHO/UNAIDS/UNICEF, 2004).

HIV sentinel surveillance in antenatal clinics was established in the DRC in 1985. However, sentinel surveys have not been conducted regularly and sites have not been consistently used. With the limitations in the data available, HIV-1 prevalence in the DRC appears to have remained fairly stable for many years (Buve, Bishikwabo-Nsarhaza, & Mutangadura, 2002). WHO/UNAIDS estimates, based on surveillance data, place adult prevalence in 2005 at 3.2 percent (WHO, UNAIDS, & UNICEF, 2006). In May 2003, sentinel surveillance in urban and rural areas in DRC showed an overall HIV seroprevalence of 4.1 percent for the country (PNLS, 2003). In rural areas, the HIV seroprevalence ranged from 1.8 to 2.5 percent. In Kinshasa, HIV seroprevalence was estimated at 3.8 percent. Between 1985 and 1999, the median HIV prevalence among antenatal clinic attendees in Kinshasa fluctuated between three and seven percent. Between January 2006 and June 2007, prevalence at 21 antenatal clinics, where prevention of mother-to-child transmission programs are being provided by the University of North Carolina at Chapel Hill (UNC-CH), ranged from 0.30 to 4.22 percent (UNC-GAP, 2007). Between 1985 and 1997, HIV prevalence among sex workers in Kinshasa fluctuated between 26.8 and 38 percent (WHO/UNAIDS/UNICEF, 2004).

Although DRC has not experienced an explosive HIV epidemic, the latest WHO/UNAIDS estimates postulate that there are 1 million people ages 0-49 years living with HIV infection in the country (range 560,00-2,000,000) (WHO et al., 2006), of whom 200,000 are in need of antiretroviral (ARV) therapy (range100,000-330,000) (WHO et al., 2007). The latest figures include an estimated 44,000 children aged under 15 years needing ARV therapy (range 20,000-81,000) and only 550 receiving it as of September 2006 (WHO et al., 2007). The country's National AIDS Control Program estimated in 2003 that 36,000 adults and children were eligible for ARV treatment in Kinshasa alone (Lara M. E. Vaz, 2006). Antiretroviral access in Kinshasa is made available mostly through a Médecins Sans Frontières (Doctors Without Borders) program, the Bralima beverage industry (a subsidiary of Heineken), one national non-governmental organization, the UNC-CH program, and some private providers, although the National AIDS Control Program is also receiving support to scale up treatment programs (WHO, 2005b).

The relatively low HIV prevalence in the DRC contrasts with the high HIV prevalence (30 to 40 percent) in many other African countries such as Kenya, South Africa, and Botswana. Evidence on the impact of conflicts on HIV prevalence is mixed, showing increases in HIV transmission in some studies (add references) in some circumstances, while in others showing no effect at all. A recent systematic review of HIV infection prevalence in seven sub-Saharan African countries affected by conflict included data from the DRC (Spiegel et al., 2007). The review found insufficient evidence supporting the premise that HIV transmission has increased in the presence of armed conflict. The reason that HIV prevalence has apparently not increased in the DRC remains unclear. The political unrest and social and economic problems the country has faced could have easily contributed to the spread of HIV because of the ensuing population movements. However, the collapse of essential infrastructure and the conflict may have also served to further isolate populations, reducing the mixing of high and low-risk populations essential for fuelling the epidemic.

Some have postulated that conflicts might reduce social networks exposing individuals to HIV transmission risk, because of reduced mobility caused by the destruction of transportation routes and populations going into hiding (Spiegel et al., 2007; Strand, Fernandes Dias, Bergstrom, & Andersson, 2007). The end of long-term conflict might in fact signal the increase in HIV transmission, as transportation routes reopen and population mixing increases. The first signs of an increase of HIV prevalence in DRC have been observed in Lubumbashi, the country's second largest city, where HIV seroprevalence among pregnant women more than doubled between 1989 and 1999, from 3 percent to 8.5 percent, then dropping to 7 percent in 2002 and 6.6 percent in 2005 (Denolf, Musongela, Nzila, Tahiri, & Colebunders, 2001; WHO et al., 2006).

An estimated 110,000 children under age 15 years are infected with HIV in the DRC. [UNAIDS 2004]. While no figures exist for the number of HIV-infected children in Kinshasa, the number can be estimated. Kinshasa's population is approximately 13.7 percent that of the country as a whole [2]. If we assume that HIV is proportionally distributed across the country, based on population size, approximately 15,000 children under age 15 years are infected with HIV in the city. This number is likely an underestimate--the number of infected children in Kinshasa might in fact be higher because of the large numbers of child soldiers and other children who emigrated to the city, who are themselves at higher risk of HIV infection.

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[2] Kinshasa's population is estimated at 7.5 million while that of the country as a whole is 60 million.

2.3 CHILDREN AND HIV/AIDS

2.3.1 Epidemiology of HIV Transmission Among Children

The public discourse on HIV/AIDS and children emphasizes *affected* children, defined as children living in households where at least one member is infected with the virus. At the end of 2003, an estimated 15 million children under 15 years had lost a parent to HIV/AIDS. Approximately 90% of all HIV-affected children (i.e., are HIV-infected, an AIDS orphan, or both) live in developing countries (UNAIDS, 2005).

Children's vulnerability to the devastation of HIV/AIDS stems, however, not only from the loss of one or both parents to the epidemic but also from the possibility of being themselves infected. Globally, in 2006 2.3 million children under the age of 15 (range 1.7-3.5 million) were living with HIV infection—nearly six percent of the 39.5 million total estimated (range 34.1-47.1 million); over 90 percent of these children resided in developing countries (UNAIDS, 2006). In that same year, 530,000 children under 15 years of age acquired HIV (range 410,000-660,000), translating roughly into 1,500 new infections every day and approximately 12 % of the 4.3 million total new infections worldwide; of these, 460,000 occurred in Sub-Saharan Africa, representing 85% of new pediatric infections (UNAIDS, 2006). Over the same time period, 380,000 children died of AIDS (range 290,000-500,000), one-sixth of the total estimated 2.9 million AIDS deaths (range 2.5-3.5 million); this is equivalent to over 1,000 children dying from AIDS per day (UNAIDS, 2006).

The majority of cases of pediatric infection are attributed to viral transmission from mother to child during pregnancy, labor and delivery, and breastfeeding. UNAIDS estimates that worldwide, 90% of current pediatric infections are due to mother-to-child transmission (MTCT), and that 90% of these infections take place in developing countries. Compared to industrialized nations, countries in sub-Saharan Africa experience a greater amount of transfusion-associated HIV transmission due to a higher prevalence of HIV infection in donor populations, a lack of HIV antibody screening in some areas, and a higher residual risk of contamination in blood supplies, despite antibody screening (McFarland, Mvere, Shandera, & Reingold, 1997).

While interventions now exist that can greatly reduce transmission from mother to child, prevention efforts will never completely eliminate pediatric HIV. Even with universal access to programs to prevent mother-to-child transmission (PMTCT), defined as 80 percent coverage, approximately 300,000 children will be newly infected with HIV each year [Global AIDS Alliance Advocacy Brief, 2006].

2.3.2 Disease Progression

While children represent only 6 percent of overall HIV infections, they account for 13 percent of deaths due to AIDS. Early studies of perinatally-infected children in developed countries before the era of current antiretroviral treatment regimens indicated that approximately 25 percent of children progressed very rapidly—within one year--to AIDS (Chakraborty et al., 2005). For the remaining 75 percent, the median time to AIDS was seven years; a minority of HIV-1-infected infants remained clinically asymptomatic beyond childhood and into adolescence (Chakraborty et al., 2005; Goulder, Jeena, Tudor-Williams, & Burchett, 2001). One review article reported that 10–20 percent and 35–54 percent of children without antiretroviral access die by age 2 years in developed and developing countries, respectively (Obimbo et al., 2004). The article also noted that infected, untreated children who survive beyond age two years experience slower disease progression, with a 5-year mortality rate of around 28 and 62 percent in developed and developing countries, respectively (Obimbo et al., 2004). Other reports state that today, roughly 50 percent of children with HIV/AIDS will die before their second birthday (WHO, 2004b). The mechanisms behind this difference in pediatric HIV-1 disease progression between developed and developing countries are poorly understood. Potential contributing factors include the high burden of infectious disease in developing countries, quality of immune response, malnutrition, breastfeeding, maternal factors such as advanced disease stage, viral determinants and host genetic factors (Chakraborty, 2005; Chakraborty et al., 2005; Obimbo et al., 2004).

The decades of progress made in reducing national childhood mortality rates are being undermined, and in some cases reversed, as a result of the AIDS epidemic (Jones et al., 2003; Walker, Schwartlander, & Bryce, 2002). In hard-hit countries such as Botswana and Swaziland, AIDS accounts for as many as half of all deaths among children under the age of five (Global AIDS Alliance, 2006). In addition, 80 percent of HIV-infected children are removed from school. Thus, in addition to its devastating health impacts, AIDS is undercutting future productivity and prospects for economic growth (Global AIDS Alliance, 2006).

2.3.3 Antiretroviral Access

Through strides made in medical research, treatment using multiple antiretroviral drug regimens have dramatically reduced morbidity and mortality associated with HIV infection in children (Hammer et al., 1997; Palella et al., 1998). In the absence of access to antiretroviral therapies, an estimated 80 percent of children with HIV/AIDS will die before their fifth birthday; however, 80 percent of HIV-infected children with access to antiretroviral treatment regimens are still alive on their sixth birthday (Global AIDS Alliance, 2006). However, scale-up of antiretroviral treatment programs for children lags far behind that for HIV-infected adults. Globally only 115,500 children under age 15 years in need of antiretrovirals had access to treatment, representing only 15 percent of the estimated 780,000 needing access (WHO et al., 2007). Sub-Saharan Africa has the lowest pediatric treatment coverage for any region, with only 13 percent of children needing treatment receiving it as of 2007 (WHO et al., 2007). In the DRC, only one percent of the estimated 44,000 children needing antiretroviral regimens in September 2006 were under treatment; this figure is in contrast to the estimate of 11 percent of adults with access to antiretrovirals in the same period (WHO et al., 2007).

The need for appropriate strategies to deliver ARV treatment and services to infected children is receiving growing amounts of attention. At the end of 2005, UNICEF, along with WHO and UNAIDS, launched a new campaign—Unite for Children, Unite Against AIDS—bringing the need for appropriate drug regimens, treatment protocols, and support services for infected children to the forefront of the agenda. In 2006, The Clinton Foundation joined forces with this agenda, helping to negotiate prices for pediatric formulations of antiretrovirals as well as advocating for appropriate drug regimens to become available. In late 2006, WHO released new guidelines for formulations of antiretroviral regimens specifically for pediatric patients. The momentum to improve health outcomes for children living with HIV infection is increasing.

2.4 DISCLOSURE OF HIV STATUS

While strides are being made towards increasing our understanding of the clinical manifestations and evolution of HIV-related illness and treatment among children, limited work has been conducted to increase our understanding of the psychosocial aspects associated with HIV/AIDS in infected children. One area that begs exploring is what, when, and how HIV-infected children are told about their health. Disclosure is the act of exposing something to view, to make known or public (Merriam-Webster Online, 2005-2006). As it relates to HIV, disclosure is the act of informing others of a person's HIV status. Disclosure of HIV status has been described in several alternate ways and can occur in many contexts. An in-depth examination of the conceptualization of disclosure will follow in Chapter 3. In this section, we will review the existing evidence on the prevalence of disclosure and its correlates, with particular attention paid to disclosure to children.

2.4.1 Prevalence of Disclosure and Factors Influencing Disclosure of HIV Status

Prevalence of disclosure of HIV status to infected children varies according to several factors. Studies conducted in the United States, Canada, and Europe indicate that the proportion of HIV-infected children who have not been told—or disclosed—their HIV status ranges from 25 to 70 percent in the U.S. and Canada (Cohen et al., 1997; C.A. Mellins et al., 2002; Nehring, Lashley, & Malm, 2000; L. S. Wiener, Battles, & Heilman, 1998) and is as high as 75-82 percent in Europe (Funck-Brentano et al., 1997; Lwin & Melvin, 2001; Thorne, Newell, & Peckham, 2000).

Only three studies published to date have included information on disclosure prevalence among HIV-infected children in developing countries. In an examination of factors influencing adherence to antiretroviral regimens, Bikaako-Kijura and colleagues in Uganda noted that 29 percent of their sample of 42 children had been fully disclosed their status (Bikaako-Kajura et al., 2006). In Thailand, Oberdorfer et al noted that 30.1 percent of caregivers reported having disclosed to children; however, only 53 percent of those caregivers had actually mentioned HIV and/or AIDS to their child (Oberdorfer et al., 2006). Butterworth and colleagues, also in Thailand, observed that older age groups had greater disclosure prevalence (Butterworth et al., 2007); while none of the children 6-9 years of age had been disclosed, 18.8 percent of those between the ages of 10-13 years had been disclosed, and 62.5 percent of those aged 14-17 years. Appendix 1 summarizes the levels of disclosure reported in published literature and conference abstracts.

For parents/caretakers of HIV-infected children, stigma and the resulting fear of children becoming socially isolated compounds the difficulty of deciding when and how, if at all, to disclose the diagnosis (Lwin & Melvin, 2001). In Sub-Saharan Africa, the fear of negative social repercussions, such as violence or banishment from the household, prevents people from disclosing their HIV status to spouses and family members (Maman, Campbell, Sweat, & Gielen, 2000; Maman, Mbwambo, Hogan, Kilonzo, & Sweat, 2001; Maman et al., 2002). Little has been published on the stigma associated with HIV infection among children in Sub-Saharan Africa, including the DRC.

Social support—including tangible and emotional support from family and others--is an important factor contributing to the well-being of people living with HIV/AIDS. (Ammassari et al., 2002; Morse et al., 1991; Paterson et al., 2000; Stall et al., 1996; WHO, 2003). Social support has been linked to a variety of coping skills, less depression and psychological distress, better quality of life, and better adherence to antiretroviral regimens for HIV infected individuals (Ammassari et al., 2002; Blaney et al., 2004; Yen et al., 2004) Stigma, and the secrecy and isolation it generates, reduces the social support available to individuals and families affected by HIV/AIDS (Bachanas, Kullgren, Schwartz, McDaniel et al., 2001).

Children's age and their cognitive development were most often identified as reasons for disclosure among studies conducted in the United States, Canada, and Europe (D. DeMatteo, Harrison et al., 2002; D. DeMatteo, Wells, Salter Goldie, & King, 2002; Funck-Brentano et al., 1997; Gerson et al., 2001; Ledlie, 1999). The actual age of disclosure varied across the many studies, but prevalence of disclosure generally increased with increasing age of the child (Bor, Miller, & Goldman, 1993; Cohen et al., 1997; Flanagan-Klygis, Ross, Lantos, Frader, & Yogev, 2001). Children under age 6 years were least likely to have been told their HIV status. Cohen et al, for example, found an overall prevalence of disclosure of 30 percent among children ages 5-10 years, but 95 percent for those over age 10 (Cohen et al., 1997). Flanagan-Klygis and colleagues, found a prevalence of full disclosure of 35%

among 65 US children, with a mean age of disclosure of 7.8 years (Flanagan-Klygis et al., 2001); Weiner and colleagues documented a similar mean age of disclosure, at 7.5 years. Appendix 1 summarizes the evidence on age of disclosure. Other reasons to disclose cited by parents or adult caregivers include the child's deteriorating health status (Funck-Brentano et al., 1997; Gerson et al., 2001; Grubman et al., 1995), questioning by the child (Lester, Chesney, Cooke, Weiss et al., 2002; L. S. Wiener, Battles, Heilman, Sigelman, & Pizzo, 1996), the need to maintain family trust (D. DeMatteo, Wells et al., 2002; Nehring et al., 2000), and the child's right to know (Lester, Chesney, Cooke, Whalley et al., 2002; Nehring et al., 2000)

To date, seven studies from low- and middle-income countries have published data related to disclosure of HIV status to children; (Abadia-Barrero & Larusso, 2006; Ayres et al., 2006; Bikaako-Kajura et al., 2006; Ionescu, 2006; Kouyoumdjian, Meyers, & Mtshizana, 2005; Myer, Moodley, Hendricks, & Cotton, 2006; Oberdorfer et al., 2006); another six have presented study findings at international conferences (Azondekon et al., 2005; Butterworth et al., 2007; Enzama & Mugyenyi, 2005; Nannyonga-Musoke et al., 2007), (Oberdorfer et al., 2007; Semeere Semwendero et al., 2007). Nine studies identify possible reasons for disclosure or lack of disclosure to children. Young age, the desire to protect the child from psychological harm, and the desire to protect the child and/or family from social stigma feature as main reasons for not disclosing (Ayres et al., 2006; Kouyoumdjian et al., 2005; Oberdorfer et al., 2007; Oberdorfer et al., 2006) Two studies noted starting treatment or problems adhering to treatment as reasons for disclosure (Azondekon et al., 2005; Oberdorfer et al., 2006). In South Africa, a study conducted with health providers treating infected children identified cognitive development—namely, understanding concepts of chronic illness—and the time period preceding the onset of puberty as factors influencing disclosure (Myer et al., 2006). Another South African study explored reasons for disclosure or nondisclosure among parents or caregivers (Kouyoumdjian et al., 2005). Parents/ caregivers participating in focus group discussions identified several reasons for nondisclosure to their infected children, including: fear of discrimination, social rejection and isolation for the child; fear of being judged by the child; not having enough information to explain the diagnosis or answer questions; the perception that the child is too young to understand and might tell others; and disclosure as an emotional and/or psychological challenge for the caregiver. In Benin, a pilot study for health care providers to disclose HIV status to children ages 6-14 years noted that lack of adherence to treatment was a reason to disclose for 30 percent of participants, the child's expressed will to know his/her condition for 80 percent, and the child's expressed fear of the health condition a reason to disclose for 50 percent (Azondekon et al., 2005). Ugandan national policy requires disclosure of HIV status to all children ages 7 years and older about to start antiretroviral treatment, based it appears on the belief that children under age 7 years are not developmentally capable of understanding their diagnosis (Bikaako-Kajura et al., 2006; Nannyonga-Musoke et al., 2007).

2.4.2 Evidence on Consequences of Disclosure

Despite concerns about the social and psychological impacts of disclosure to children (AAP, 1999) some studies in industrialized nations show that HIV-infected children fare well after disclosure (L. Wiener et al., 1994), and even better when compared to children unaware of their HIV infection (Bachanas, Kullgren, Schwartz, Lanier et al., 2001).

Some publications have focused their attention on the resulting increased involvement of the child in medical treatment(Gerson et al., 2001; Lester, Chesney, Cooke, Weiss et al., 2002), others note disclosed children have better access to social support (Lester, Chesney, Cooke, Weiss et al., 2002) and tend to be less depressed over the long-term (Hirschfeld, 2002; C.A. Mellins et al., 2002). The literature on disclosure of pediatric cancer diagnosis corroborates the evidence surround HIV disclosure, noting that despite parents' wishes to protect their children from the negative effects of knowing their disease condition, children who are not disclosed their status experience just as much emotional and psychological distress as children who are told their diagnoses (Chesler, Paris, & Barbarin, 1986; Claflin & Barbarin, 1991; Slavin et al., 1982).

A recently published review of 22 studies by Wiener and colleagues (L. Wiener, Mellins, Marhefka, & Battles, 2007) noted that the evidence of the outcomes of disclosure of HIV status to children is, to date, mixed. Some studies showed that not disclosing (nondisclosure) is associated with increased internalizing behavior problems for children, and increased psychological distress for their adult caregivers. While one study found more behavior problems among children whose status had been disclosed to them, its cross-sectional design prevented any conclusions on causality from being drawn; another study found that children who knew their status had lower depression and anxiety scores. However, the remaining studies reviewed found little or no difference between children who have been disclosed and those who have not been disclosed their status. The review's authors note that a limitation in comparing studies is that most are limited in the details of what type of information was provided to the child, the timing of disclosure in relation to the measurement of its outcomes, and the number of times the child's status was discussed (L. Wiener et al., 2007).

For children, access to antiretrovirals can extend their lives through childhood into adolescence and even early adulthood, raising concerns for secondary prevention as well as medication adherence efforts. The complexity of the interplay between stigma and fear of disclosure, and the implications it might have on adherence to antiretroviral regimens, have yet to be fully explored. However, initial data collected indicate that fear of the repercussions of disclosure is correlated with poor adherence to antiretroviral regimens. Data on adults indicated that stigma and access to social support affect adherence to antiretroviral regimens. A qualitative study of US rural patients on antiretrovirals found that many reported missed doses because of fear of identification as HIV-infected (Golin et al., 2002). A review of quantitative studies found that of the 20 studies reviewed, between 14-33 percent of study participants reported skipping medication because of fears of HIV disclosure (Ammassari et al., 2002). The review also found that the majority of studies that explored the relationship between family or social support and adherence found that the lack of support is a significant predictor of nonadherence (Altice et al., 2001; Ammassari et al., 2002; Gifford et al., 2000; Gordillo et al., 1999; Murri et al., 2000; Singh et al., 1999; Stone et al., 2001). Similar levels of evidence for adherence among children is not available; however, some studies have found an inverse relationship between children's knowledge of HIV status and their adherence (Giacomet et al., 2003; Gibb et al., 2003), and fear of disclosure was identified as a factor leading to nonadherence (Gibb et al., 2003). It is critical to the success of programs that more be known about disclosure of HIV status and its implications for long-term survival, including antiretroviral regimen adherence, among children.

Of the thirteen studies from developing countries published or presented to date on disclosure of HIV status to infected children, six mentioned outcomes of disclosure. In a qualitative study of children living in state institutions in Brazil, Abadia-Barrero and colleagues found that prolonged silence about HIV status contributed to poor adult-child communications, psychological distress, self-stigma, and adherence problems among HIV-infected versus uninfected children(Abadia-Barrero & Larusso, 2006). Another qualitative study based in Brazil looked at the implications of HIV diagnosis on well-being (Ayres et al., 2006); it found that youth's lives were unnecessarily and involuntarily restricted by caregivers, from allowed activities to investing in their futures. In Benin, a pilot study to disclose HIV status to children ages 6-14 reported that while 33 percent had suspected their HIV status and that following disclosure, 80 percent had concerns about the length of their lives and 50 percent were concerned about future fertility, nonetheless all children were pleased to learn their status and were ready to meet other infected children (Azondekon et al., 2005). A study on adherence to antiretroviral regimens in Uganda found nondisclosure of HIV status to be associated with poor adherence (Enzama & Mugyenyi, 2005); the study's cross-sectional design makes it hard to assess the direction of the relationship. A study by Oberdorfer and colleagues in Thailand (Oberdorfer et al., 2006) found that the majority of caregivers who reported having disclosed to their child noted that the child had quietly accepted the information (71 percent); the remaining expressed sadness (16 percent), anger (10 percent) or rebellion (3 percent). However, only 53 percent of caregivers reporting disclosure in this study had actually mentioned HIV and/or AIDS to their child, and the reported response of the child did not delineate between those who had been told the name of their illness versus those who had not. A second study by Oberdorfer and colleagues examined the effect of an intervention designed to disclose HIV status to infected children (Oberdorfer et al., 2007). The study found no changes in rates of depression or anxiety in children and a decrease in caregiver depression after disclosure, more positive attitudes among children about HIV-infection and hopes for the futures, a better understanding of the importance of adherence to drug regimens (Oberdorfer et al., 2007).

2.5 PRIOR STUDIES: FORMATIVE STUDY ON ASSENT & DISCLOSURE IN KINSHASA, DRC

A qualitative, descriptive study with a primary aim of developing a culturally appropriate approach for obtaining assent from children aged 8 through 17 years to participate in the Pediatric HIV Care Program was conducted during August-September 2005 using in-depth interviewing techniques. The Pediatric HIV Care Program is an operational research study designed to develop an appropriate model for providing comprehensive HIV care and management, including ARV treatment, for adults and children in Kinshasa, Democratic Republic of Congo. The project provides comprehensive HIV care services, including ARV treatment when appropriate, as well as psychosocial support services; enrollment of participants began in November 2004.

Because we recognized that fully informed consent should ideally include knowledge of HIV diagnosis, two secondary objectives were added to the formative research. They were: (1) to determine culturally appropriate approaches for disclosing an

HIV diagnosis to children in Kinshasa, and (2) to gather information to develop systems of support for families who choose to disclose the child's HIV diagnosis to the child.

The formative research was conducted over a six-week period in August-September, 2005. Participants were recruited from the Pediatric HIV Care Program as well as from two local non-governmental organizations with long histories of providing services to HIV-affected families. A total of 94 interviews were conducted with (1) parents who have disclosed the HIV diagnosis to their HIV-infected children; (2) parents who have not disclosed the HIV diagnosis to their HIV-infected children; (3) children aged 8 to 17 who have been disclosed their HIV-positive status (n=16), (4) young adults 18-21 who were disclosed their HIV status as minors (n=4); (5) parents on assent to participate in studies; and (6) health care providers who provide care to HIV-infected children and key informants who are involved with psychosocial support and medical care programs for HIV-infected children and their families.

Table 2.1: Interviews conducted for formative research, August-September 2005

Type of Interview	**Completed**
Parents who HAVE Disclosed	21
Parents who HAVE NOT Disclosed	20
Children who have been disclosed (includes 4 young adults disclosed as minors)	19
Parents on Assent	15
Key Informants	18

Research questions that were explored during the formative study included:

1. Is an HIV diagnosis normally disclosed to children in Kinshasa? If yes, what are factors that influence the decision to disclose HIV status to children? What is involved in the disclosure process? If no, what are factors that prevent disclosure?
2. How do children understand their illness (HIV)?
3. What are factors that influence family intention to disclose an HIV status to the child?
4. Under what conditions do participants believe disclosure of HIV status should be encouraged? When do they believe it should be discouraged?
5. What systems of support (as defined by the participants) should be developed to support families in their decision to disclose, including support following disclosure?

Data analysis began in October 2005. Initial findings on disclosure were shared with local stakeholders in Kinshasa in June 2007. The findings indicated that, as in other settings, age and developmental stage of the child are important factors influencing caregivers' decisions to disclose in Kinshasa; concerns about adherence to treatment regimens also feature in caregivers' decisions to disclose (L. M. E. Vaz et al., in press). Concerns about causing the child emotional distress and of others learning of the child's status through subsequent disclosure by the child were among the main reasons for nondisclosure. While youth reported negative reactions to learning their HIV status, the vast majority felt it was good to know it; only one of the minors interviewed expressed a wish to not know her HIV diagnosis. Several factors influencing family decisions to disclose were mentioned, including the age and developmental stage of the child, concerns about adherence to treatment regimens, and eminent sexual debut.

2.6 SUMMARY

The HIV/AIDS epidemic is affecting the lives of millions of children worldwide. Even with improved access to prevention programming, children will continue to be infected in years to come. To date, evidence indicates that few HIV-infected children are likely told of their HIV status. Findings from the few studies on the impetus for and consequences from disclosure suggest that children were told about their HIV status as a function of several factors including their age and health status, and, in general, did well after learning about their HIV diagnosis. The rollout of antiretroviral programs in Sub-Saharan Africa is changing the prognosis of the lives of infected children from certain and impending death to longer, more productive lives, making disclosure of HIV status to infected children a more salient issue. The complex interplay of factors influencing parental/caretaker decisions to disclose to HIV-infected children has yet to be systematically explored in Sub-Saharan Africa, in general, and Kinshasa DRC, in particular.

This study was based at the Pediatric Hospital of Kalembe Lembe in Kinshasa, Democratic Republic of Congo, where a cohort of over 500 children receives comprehensive care through UNC-CH's Pediatric HIV Care Program. The care provided by the program's efforts, funded by the US Centers for Disease Control and Prevention (CDC), include antiretroviral therapy; other children eligible for the Pediatric HIV Care Program receive basic care at the pediatric hospital while awaiting enrollment.

The findings from this study have direct implications for interventions to improve pediatric patient well-being, and given the current "roll-out" of antiretroviral drug treatment in developing nations, have implications on adherence to drug regimens as well as on secondary prevention efforts. The findings also have implications for the development of programs to support caregivers of infected children in disclosing HIV status to the child.

CHAPTER 3
THEORETICAL FRAMEWORK, CONCEPTUAL MODEL, & RESEARCH QUESTIONS

OVERVIEW

As described in the literature review, the local context, theoretical perspectives and empirical findings from the field of HIV/AIDS and pediatric disclosure informed the conceptual model for this study. In this chapter, we conceptually define each construct examined by this study and describe a conceptual model of the relationships between constructs, as well as set out this study's research questions and hypotheses.

3.1 CONCEPTUAL MODEL

3.1.1 Disclosure

Three conceptualizations of disclosure emerge from the literature. The first conceptualization views *disclosure as a single event*, the provision of the diagnosis of HIV or AIDS to an individual (Flanagan-Klygis et al., 2001; Ledlie, 1999, 2001; Ostrom, Serovich, Lim, & Mason, 2006; Thorne et al., 2000). However, some of these articles discuss factors before the actual disclosure event, such as preparation to disclose (Flanagan-Klygis et al., 2001; Ostrom et al., 2006).

Disclosure is better conceptualized not as a single event in time but as a process. A report by the National Institutes of Health in 2005 noted that more research is needed on understanding the components of the disclosure process so as to build better strategies to improve trust between providers and caregivers, to empower adolescents, and to protect the health of potential partners (National Institute Of Nursing Research, 2005). While the literature frequently refers to the *process* of disclosure, however, what the process of disclosure actually entails is generally not elucidated, nor is it necessarily the same across studies.

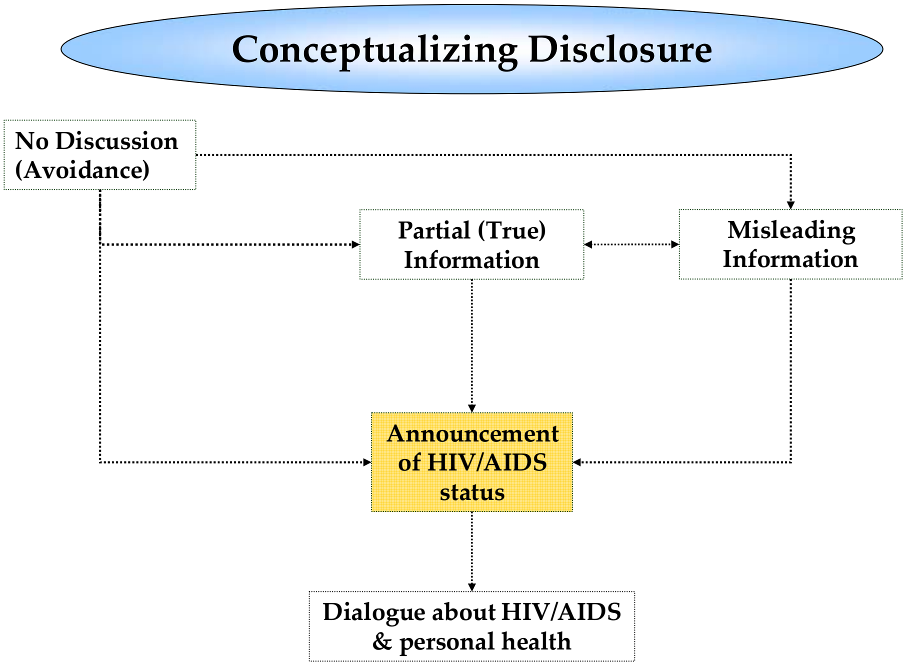
A second conceptualization of disclosure focuses on the process *undertaken by parents/caregivers in preparation to disclose* (D. DeMatteo, Harrison et al., 2002; Gerson et al., 2001; C. L. Lee & Johann-Liang, 1999; Pequegnat & NIMH Consortium on Family & HIV/AIDS Research, 2002). The process as described incorporates preparation of the parent/caregiver, preparing the child, determining the risks and benefits, finding the right time, and placing supports in place (D. DeMatteo, Harrison et al., 2002; Gerson et al., 2001). Gerson et al. go on to describe the process beyond the disclosure of the diagnosis to incorporate postdisclosure coping by the child and the family (Gerson et al., 2001). This framework is akin to the process described by Kimberly for adult decision-making to disclose own HIV status (Kimberly & Serovich, 1995) and is used as the framework for discussing the disclosure process in a WHO document on gender dimensions of HIV disclosure to sexual partners (Maman & Medley, 2003). The formative research on assent and disclosure conducted in the summer of 2005 (see Section 2.5 for more information) included questions exploring the preparation process of caregivers to disclose HIV diagnosis to their children. Although the analysis of the collected data is still underway, preliminary findings indicate that for some caregivers, the process undertaken to prepare for disclosure was hard to describe.

The third conceptualization of the disclosure process focuses on the outcome of disclosure—the *information provided to the recipient of the disclosure*. A large portion of the literature published on disclosure of HIV diagnosis to children used this characterization of the disclosure process, whether explicitly defined or else implicitly in how disclosure is described (Abadia-Barrero & Larusso, 2006; Blasini et al., 2004; Funck-Brentano et al., 1997; Kouyoumdjian et al., 2005; M. B. Lee & Rotheram-Borus, 2002; Lester, Chesney, Cooke, Weiss et al., 2002; Lester, Chesney, Cooke, Whalley et al., 2002; Lipson, 1993; Myer et al., 2006; Nehring et al., 2000; Rotheram-Borus, Draimin, Reid, & Murphy, 1997; Waugh, 2003; L. S. Wiener et al., 1996). The American Academy of Pediatrics guidelines on disclosure of illness information to children with HIV uses an information-based characterization of the disclosure process (AAP, 1999). There are two approaches taken in the discussion of disclosure as a process of information provision. In the first, more commonly used, approach, disclosure is broken down into types of information given, generally into "no information", "deceptive information", "partial information", and "full disclosure" (Funck-Brentano, 1995; Funck-Brentano et al., 1997; Kouyoumdjian et al., 2005; Lester, Chesney, Cooke, Whalley et al., 2002; Nehring et al., 2000; L. S. Wiener et al., 1996); Nehring's description emphasizes a continuum of disclosure rather than stages of disclosure, but nonetheless moves from no information to full information provided (Nehring et al., 2000). The two published studies from South Africa (Kouyoumdjian et al., 2005; Myer et al., 2006) and the preliminary analyses of the formative research conducted in Kinshasa in 2005 indicated that this conceptualization of the process of disclosure is appropriate in the context of the study.

A few studies used the information provided to the child as the basis for their definition of the disclosure process; however, they emphasized the ongoing nature of disclosure and included conversations following the disclosure of the diagnosis itself as part of the disclosure process (Abadia-Barrero & Larusso, 2006; C. L. Lee & Johann-Liang, 1999; Lipson, 1993; Myer et al., 2006; Waugh, 2003). In their work in South Africa, Myer et al. (2006) distinguished between the first disclosure moment, wherein general information about health is provided, and the initiation of discussions about HIV/AIDS (Myer et al., 2006), delineating specific ages as mentioned by the health providers interviewed appropriate for each (6 years for general health information, 10 years for discussions about HIV/AIDS.) Abadia-Barrero et al. emphasized in their findings from Brazil that understanding of one's HIV status is a gradual, lifelong process, with HIV/AIDS taking on different meanings to the child at different ages, although they do not specify what those meanings are (Abadia-Barrero & Larusso, 2006). The interviews from the formative work in Kinshasa were notable in that children rarely reported any discussions following the initial disclosure of HIV status, with some reporting confusion and unanswered questions about the meaning of their illness.

For the purpose of this study, disclosure was conceptualized as a process, with an emphasis on what is told to the child, both before full disclosure and in communication following the first mention of the diagnosis of HIV/AIDS to the child. The process of disclosure was conceptualized as patterns rather than stages, ranging from no information to misleading information and/or partial information that does not mention HIV/AIDS, to disclosure of the diagnosis of HIV or AIDS, and subsequent discussions about the meaning of the diagnosis to the child. Figure 1 shows the conceptualization of disclosure used in this study.

Figure 3.1: Study's Conceptualization of Disclosure



3.1.2 Stigma

Stigma was described first by Erving Goffman as "an attribute that is deeply discrediting" and results in the results in the diminution of a person or group from a "whole and usual" one to a tainted, discounted one (Goffman, 1963; USAID, 2005). Link and Phelan subsequently reframed stigma as a process occurring within the framework of power (Link

& Phelan, 2001). Stigma has several domains. Recent work to measure HIV stigma in the Sub-Saharan context selected four domains as key areas to measure to comprehensively capture the experiences of stigma (USAID, 2005).

3.1.1.1 Social Stigma

Social stigma is the level of stigma perceived by the respondent to exist within the community at large. Both the Theory of Reasoned Action and the Theory of Planned Behavior posit that perceived community norms have an influence on individual intentions as well as their behaviors(Azjen, 1991; Azjen & Fishbein, 1980). Several studies assessed how people living with HIV and AIDS (PLHA) perceive others, including partners, family members, and the community at large, might react to a PLHA. These studies, in general, assessed perceptions of existing attitudes or fear of response to revelation of one's HIV status to others (Berger, Ferrans, & Lashley, 2001; Clark, Lindner, Armistead, & Austin, 2003; Derlega, Winstead, Greene, Servoich, & Elwood, 2002; Preston et al., 2004; Swendeman, Rotheram-Borus, Comulada, & Weiss, 2004; USAID, 2005).

3.1.1.2 Individual-level Stigma (personal perceptions of HIV)

Individual-level stigma refers to the attitudes held by an individual about HIV and people living with HIV and AIDS. Individual level stigma can include internalized stigma, which is defined as negative self-image resulting from the incorporation of external stigma into one's own perception of self. One study measuring individual stigma found that mothers with lower scores on a Personal Stigma Scale were more likely to disclose their HIV status to their children (Bauman, Silver, & Camacho, 2000).

3.1.3 Perceived Social Support

Social support refers to the various types of assistance that people may receive from other individuals. Social support is generally classified into three major categories: emotional, instrumental and informational support. Emotional support refers to the things that people do that make one feel loved and cared for; such support frequently takes the form of non-tangible types of assistance. Instrumental support refers to the various types of tangible assistance that others may provide, such as monetary help or assistance with household tasks. Informational support refers to help offered through the provision of information, including advice on how to handle an unknown situation. The limited but growing literature available on social support and disclosure in Africa suggest that most disclosure occurs in environments perceived to be socially supportive, and results in positive social support (Grinstead, Gregorich, Choi, & Coates, 2001; Kilewo et al., 2001; Maman et al., 2003; USAID/Synergy, 2004).

3.1.4 Relationship to Child: Emotional Closeness

Emotional closeness is a construct from attachment theories. It addresses the affective quality of the relationship between two individuals. Studies have shown that the kinship relation between infected children and their caregiver is associated with disclosure of HIV status. Findings from the formative research done in Kinshasa in 2005 also noted that caregivers' concerns about the child's well-being were often cited as reasons for nondisclosure. For this study, emotional closeness will be examined, from the perspective of the caregiver, as the affective relationship between caregiver and child.

3.1.5 Sociodemographic Characteristics

Sociodemographic characteristics with possible relationships with disclosure that will be explored include the biological age of the child, the perceived developmental stage of the child, and the kinship relationship of the caregiver to the child. Several studies on pediatric disclosure have revealed that age of the child is a factor associated with disclosure of HIV status (Gerson et al., 2001; Ledlie, 1999; M. B. Lee & Rotheram-Borus, 2002; C.A. Mellins et al., 2002; L. S. Wiener et al., 1996). The kinship relation with the child has also been associated with likelihood to disclose, with non-parental caregivers more likely to disclose (Thorne et al., 2000). The initial analysis of the formative work conducted in Kinshasa revealed that parents and children both differentiate between the biological age and the developmental stage of the child, and indicate that they perceive the developmental stage of the child to be an important factor in the decision to disclose HIV status.

3.1.6 Health Status Characteristics

Health status characteristics reflect the child's current health status. Some studies have shown that deteriorating health status has been associated with disclosure of HIV diagnosis to children (Gerson et al., 2001; C.A. Mellins et al., 2002). Other studies have shown that length of time since diagnosis is associated with increased likelihood to disclose (M. B. Lee & Rotheram-Borus, 2002), although this may be confounded with increasing age of the child. Initial analyses of the formative research conducted in Kinshasa suggested that concerns about medication adherence serve as motivations to disclose. Health status can be determined by the length of time since diagnosis, whether the child has been placed on antiretroviral regimens, and the staging criteria developed by the US Centers for Disease Control and Prevention. Additionally, caregivers' knowledge of their own HIV diagnosis has been noted as being associated with caregivers' reluctance to disclose HIV diagnosis to infected children (D. DeMatteo, Harrison et al., 2002), sometimes because of concerns that disclosure will lead to questions about vertical transmission (Flanagan-Klygis et al., 2001; Gerson et al., 2001; C. L. Lee & Johann-Liang, 1999).

3.1.7 Model Description

The full conceptual model guiding this research suggests direct and indirect relationships among the explanatory and outcome variables (Figure 1). Disclosure decisions are hypothesized to predict pattern of disclosure. All explanatory variables are hypothesized to influence patterns of disclosure through influencing caregiver decisions to disclose. The model also hypothesizes that current level of disclosure influences future decisions concerning disclosure. Figure 2 shows the reduced model displaying only the variables examined in the study.

3.1.7.1 Stage versus Continuum Theory Framework

Theories of health behavior fall in large part under one of two categories. One category assumes the existence of a continuum or single equation that can predict behavior (Weinstein & Sandman, 2002). Such theories recognize that there are differences between individuals' likelihood of action and on the variables that influence them; these theories, however, assume that the barriers to adoption of behaviors or changes in behavior do not change as people move towards adopting actions. The goal of continuum theories is to maximize those variables that increase the likelihood of the outcome of interest.

Stage theories, on the other hand, do not perceive behaviors in a continuum but rather as incorporating several stages which have different variables influence them towards achieving the outcome of interest (Weinstein, Rothman, & Sutton, 1998; Weinstein & Sandman, 2002). Advocates of stage theories see the adoption of behaviors as encompassing a series of changes, with each transition between stages having a set of variables influencing it in a specific combination. The particular variables associated with each stage and the ways in which they combine may differ from stage to stage.

Based on the available literature, the process of disclosure of HIV diagnosis to infected children seems to fit more closely to a stage theory than a continuum theory. Different factors seem to be associated with different patterns of disclosure, from not having disclosed to an ongoing dialogue around HIV/AIDS. These patterns of disclosure seem to have an order, moving from no information or misleading information to partial information provided, then to revelation of the diagnosis of HIV/AIDS and subsequent discussions of the implications of having HIV for the child. The research will in part assess whether this conceptualization of disclosure as a stage process is appropriate or not.

3.1.7.2 Social Ecological Framework

The conceptual framework of the study builds upon ecological models such as Urie Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1979; Sallis & Owen, 2002). Bronfenbrenner described three levels of environmental factors that interact with variables at the individual level to influence behaviors. The levels included the microsystem, which focused on interpersonal interactions in specific settings, the mesosystem, which are interactions between settings, and the exosystem, defined as the larger social system that affects both individuals and settings (Sallis & Owen, 2002) Stokols built upon existing ecological systems and tied to them to health behavior research (Stokols, 1992). He described an ecological perspective as one that focuses on the interaction of an individual with their physical and sociocultural settings (Sallis & Owen, 2002). The conceptual model for this study adopts an ecological framework, recognizing that factors at multiple levels influence parents' disclosure intentions and patterns of disclosure. Figures 2 and 3 show the full conceptual model as well as the reduced model that was the basis for this study.

Figure 3.2: Conceptual Model (Full)

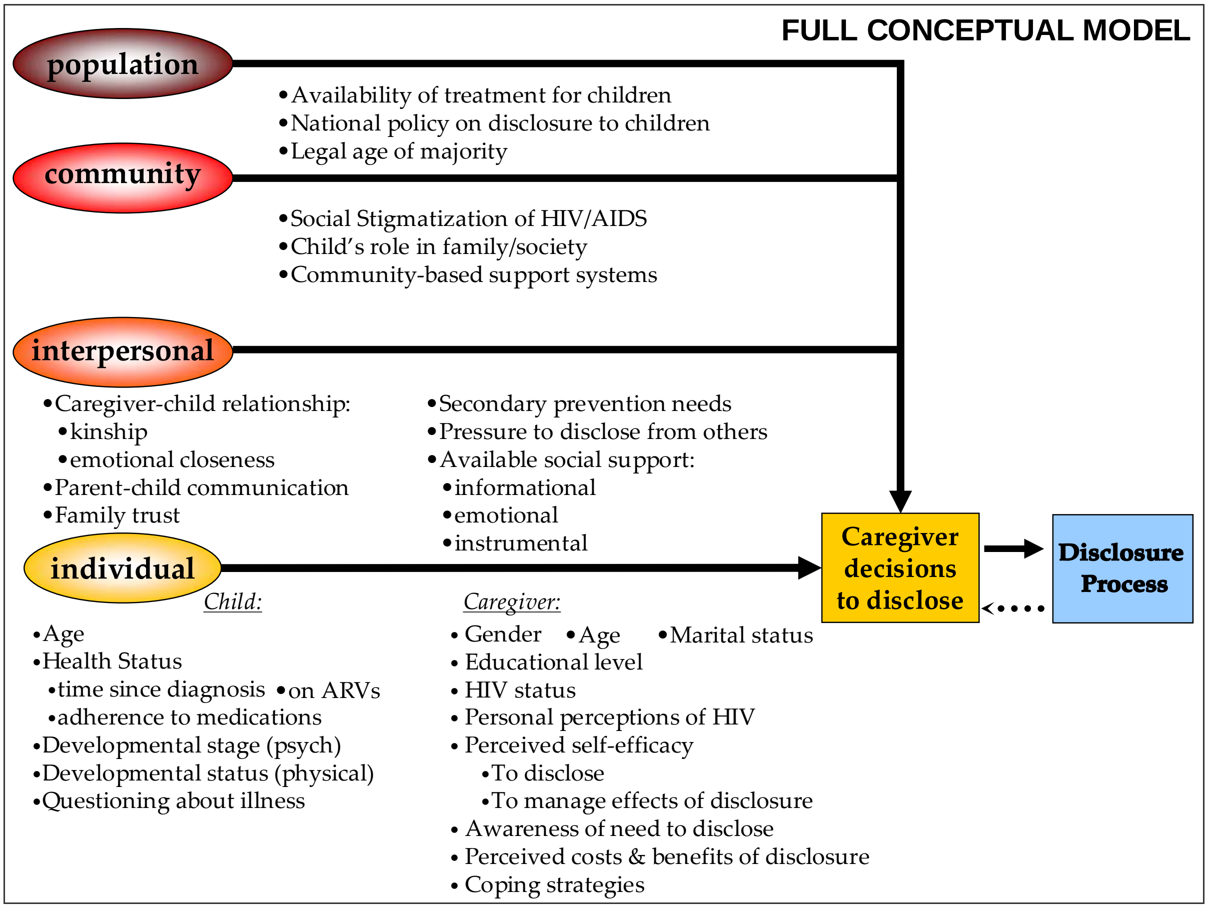
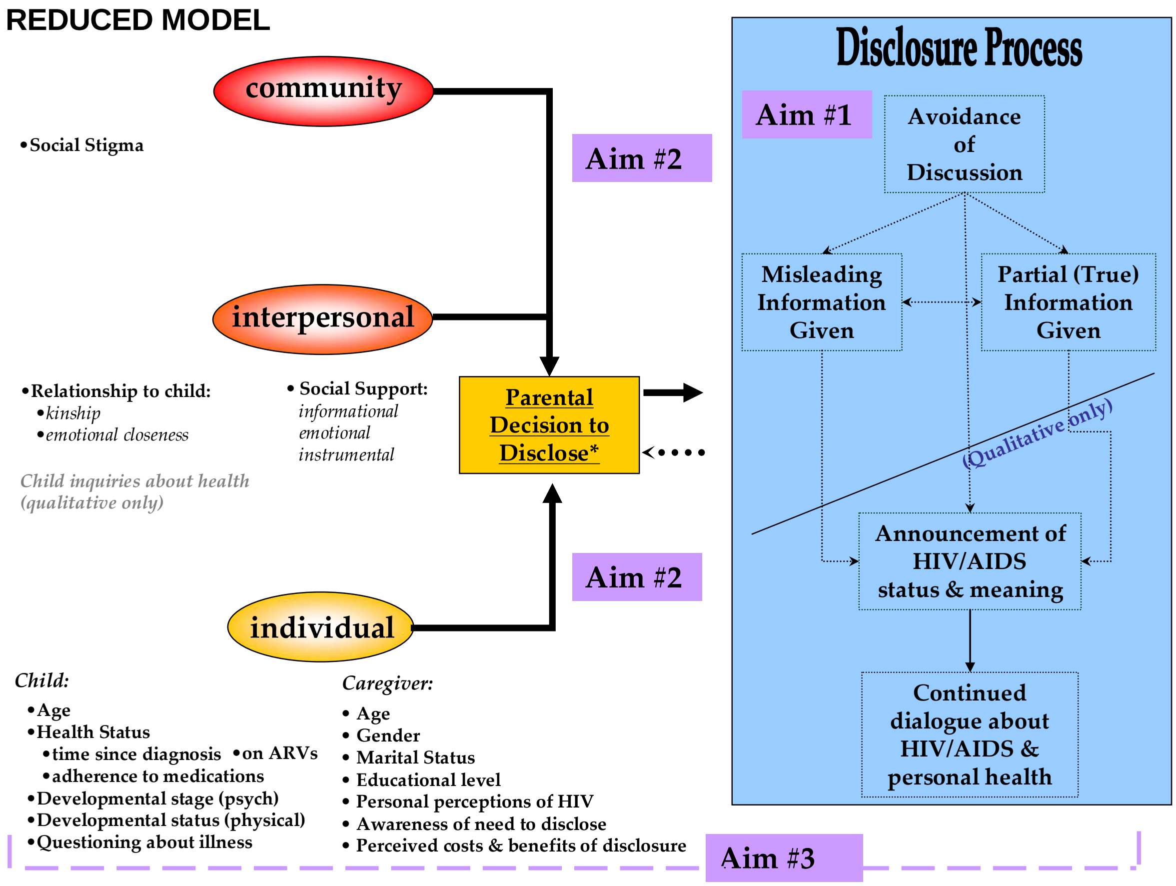


Figure 3.3: Conceptual Model, Reduced to Variables of Interest for Study



3.2 RESEARCH QUESTIONS AND HYPOTHESES

3.2.1 Aim 1

Aim 1: *To describe existing patterns of nondisclosure among 200 caregivers, who have not yet disclosed HIV diagnosis to HIV-infected children, ages 5-17 years, receiving clinical services at Kalembe Lembe Pediatric Hospital, Kinshasa, Democratic Republic of the Congo.*

As we learned in the formative study conducted in 2005, disclosure is an extremely rare event in our setting. In this study, we conducted a cross-sectional study of the factors associated with levels of nondisclosure among caregivers of HIV-infected children, in order to better understand the patterns of nondisclosure in this setting. Research questions associated with Aim 1 include:

RQ1.1 What are the patterns of pediatric disclosure in a sub-Saharan African setting?

RQ1.2 What are the demographic, health, and psychosocial characteristics of caregivers and their HIV-infected children that are associated with different levels of disclosure?

RQ1.3 What characteristics, if any, differ between the levels of disclosure of diagnosis to infected children?

As there is very little information published on the patterns of nondisclosure in resource-limited Sub-Saharan African settings such as this one, we have not generated any hypotheses related to these research questions.

3.2.2 Aim 2

Aim 2: *To describe factors at individual, interpersonal and community levels that are significantly associated with different patterns of disclosure among 200 caregivers who have not yet disclosed HIV diagnosis to HIV-infected children ages 5-17 years receiving clinical services at Kalembe Lembe Pediatric Hospital.*

The cross-sectional study examined the factors associated with the different patterns of disclosure among caregivers of HIV-infected children, in order to inform the generation of hypotheses about how caregivers make decisions about disclosure. Research questions associated with Aims 2 include:

RQ2.1 What are the demographic, health, and psychosocial characteristics of caregivers and their HIV-infected children that are associated with patterns of disclosure?

RQ2.2 What characteristics, if any, differ between the patterns of disclosure of HIV status to infected children?

RQ2.3 To what extent is social support associated with different patterns of disclosure?

RQ2.4 Is stigma associated with different patterns of disclosure of HIV status to infected children?

Based on research on disclosure for other chronic illnesses, and on the emerging literature on disclosure to HIV-infected children, I present the following hypotheses *for Aim 2:*

H1. Individual level characteristics of children such as higher age of child and development stage will be associated with increased likelihood having provided partial illness information among caregivers.

H2. Interpersonal and environmental factors such as higher social support from other individuals or groups and decreased perceived stigma will be associated with increased likelihood of having provided some truthful information versus no information to infected children. .

H3. Higher levels of perceived HIV stigma will be associated with an increased likelihood to give misleading information about health status versus providing some truthful information.

3.2.3 Aim 3

Aim 3: *To explore the process of disclosure of HIV status and its consequences among families receiving care at Kalembe Lembe Pediatric Hospital, through qualitative interviews with 8 caregivers who have ever informed their children currently aged 5-17 years of the child's HIV status, as well as interviews with the 8 children who have been informed of their HIV status.*

We explored the experiences of disclosure through case studies of child-caregiver dyads, recruited through patients receiving care through Project SARA and the Unit of Infectious Diseases at Kalembe Lembe Pediatric Hospital.

RQ3.1 Among caregivers, what were the factors that influenced the process of disclosure? What factors were barriers to disclosure, and what factors were supportive?

RQ3.2 Among caregivers, what steps were taken prior to full disclosure of the name of the illness? From where did they receive informative and/or emotional support, if any, during these steps?

RQ3.3 Among caregivers, what was the event of disclosure of the name of the illness like?

RQ3.4 Among children, what have been the experiences of children who have been through the disclosure process?

RQ3.5 Among children, what specifically, if anything, was the child aware of regarding their health prior to the disclosure of their HIV status?

RQ3.6 Among children, what were their experiences during the moment of disclosure of the name of their illness? What was their reaction?

RQ3.7 Among children, how have their lives changed, if at all, since learning about their HIV status? What are their perceived benefits and disadvantages to knowing about their HIV status?

RQ3.8 Among both adult caregivers and their children, what have been their experiences following the full disclosure moment?

CHAPTER 4
COMMUNICATION WITH HIV-POSITIVE CHILDREN PRIOR TO FULL DISCLOSURE: AN EXPLORATION OF THE PROCESS OF DISCLOSURE IN AN AFRICAN SETTING

4.1 ABSTRACT

Children living with HIV infection are often uninformed of their HIV status. Parents and other caregivers provide them with varying types of information about their health status, including full disclosure of their condition. We conducted interviews with 201 primary-caregivers of children ages 5-17 years receiving comprehensive care and treatment services. The study's aims were to (1) describe current patterns of communication to HIV-positive children by their primary caretakers, and (2) explore factors associated with different patterns of disclosure to children. Nearly 50% of children had not been given any information about their health; 15% had been given partial information about their health without disclosing HIV status, and 33% had been given misleading information. Caregiver characteristics, including gender, age, and stigmatizing attitudes placing blame on infection, were found to be associated with existing patterns of disclosure. The age of the child, along with characteristics of the interpersonal relationship between caregiver and child, were also found to be associated with existing patterns. The findings have implications for the design and delivery of services to families of HIV-infected children. Health providers must work closely with caregivers to understand how communication patterns evolve, to help them

provide appropriate information to the children, and to support them through full disclosure.

4.2 INTRODUCTION

In 2006, an estimated 2.3 million children under 15 years of age (range 1.7-3.5 million) were living with HIV infection (UNAIDS, 2006). During the past year, 530,000 children under 15 years of age acquired HIV, translating roughly into 1,000 new infections every day; 85 percent of these were born in Sub-Saharan Africa (UNAIDS, 2006). UNAIDS estimates that worldwide, 90% of current pediatric infections are due to mother-to-child transmission (MTCT), and that 90% of these infections take place in developing countries (UNAIDS, 2004). Compared to industrialized nations, countries in sub-Saharan Africa experience a greater amount of transfusion-associated HIV transmission due to a higher prevalence of HIV infection in donor populations, a lack of HIV antibody screening in some areas, and a higher residual risk of contamination in blood supplies, despite antibody screening (McFarland et al., 1997).

While children represent only 6 percent of overall HIV infections, they account for 13 percent of deaths due to AIDS. Early studies of perinatally-infected children in developed countries before the era of current antiretroviral (ARV) treatment regimens indicated that approximately 25 percent of children progressed very rapidly—within one year--to AIDS (Chakraborty et al., 2005). For the remaining 75 percent, the median time to AIDS was seven years; a minority of HIV-1-infected infants remains clinically asymptomatic beyond childhood and into adolescence (Chakraborty et al., 2005; Goulder et al., 2001). However, the once-bleak futures facing children infected with HIV is now improving as a result of increasing numbers of programs providing access to antiretroviral therapy. Perinatally-infected children who, without access to antiretroviral treatment were likely to die before reaching their fifth birthday (Jones et al., 2003), may now see their lives extended to adolescence and beyond.

The Democratic Republic of the Congo (DRC) reported some of the earliest cases of HIV/AIDS in Sub-Saharan Africa (Quinn, Mann, Curran, & Piot, 1986). While it has not experienced the high prevalence levels of its neighbors to the east and south, the latest WHO/UNAIDS estimates postulate that there are 1 million people ages 0-49 years living with HIV infection in the country (range 560,00-2,000,000) (WHO et al., 2006), approximately 4.2 percent of the total population. Of these, approximately 200,000 are in need of ARV therapy (range 100,000-330,000) (WHO et al., 2007). The latest national prevalence estimates were that 110,000 children under age 15 are living with HIV/AIDS in the DRC (range 42,000-280,000) (WHO/UNAIDS/UNICEF, 2004). The latest treatment figures include an estimated 44,000 children aged under 15 years needing ARV therapy (range 20,000-81,000) and only 550 receiving it as of September 2006 (WHO et al., 2007). Estimates from the country's National AIDS Control Program in 2003 estimated 36,000 adults and children to be eligible for ARV treatment in Kinshasa alone (Lara M. E. Vaz, 2006).

Limited work has been conducted to date to increase our understanding of the psychosocial aspects associated with HIV/AIDS in infected children, particularly in non-industrialized settings. One area that begs exploring is what, when, and how HIV-positive children are told about their health. HIV-positive children under medical care are seldom informed of their HIV-status, despite some evidence from industrialized countries indicating that informing children and their families can have positive psychosocial and clinical outcomes (Bachanas, Kullgren, Schwartz, McDaniel et al., 2001; L. Wiener et al., 1994). The factors associated with parental/ caregiver decision-making processes around disclosure are important to understand so that appropriate support structures can be created for parents and caregivers of HIV-positive children prior to, and following, disclosure.

Evidence on HIV Status Disclosure to Children

Studies in developed countries have explored factors associated with disclosure and levels of nondisclosure to HIV-positive children. Most of these have been cross-sectional in nature. A recently published review (L. Wiener et al., 2007) found that caregivers are more likely to disclose early if they have older children (C.A. Mellins et al., 2002), are HIV negative (Ledlie, 1999; C. A. Mellins, Kang, Leu, Havens, & Chesney, 2003; L. S. Wiener et al., 1996), report greater social support (L. S. Wiener et al., 1996) and family expressiveness (Lester, Chesney, Cooke, Whalley et al., 2002), have higher socioeconomic status (L. S. Wiener et al., 1996) and live in urban areas (Lester, Chesney, Cooke, Weiss et al., 2002). Caregivers who had fully informed children of their HIV status had higher scores on scales of quality of parent-child interactions and lower levels of maternal depression (Lester, Chesney, Cooke, Whalley et al., 2002; C.A. Mellins et al., 2002; L. S. Wiener et al., 1996). While the age of disclosure varied across many studies, the prevalence of disclosure generally increased with increasing age of the child (Bor et al., 1993; Cohen et al., 1997; Flanagan-Klygis et al., 2001). Children under age 6 years were least likely to have been told their HIV diagnosis. Cohen et al, for example, found an overall prevalence of disclosure of 30 percent among children ages 5-10 years, but 95 percent for those over age 10 (Cohen et al., 1997). Flanagan-Klygis and colleagues, found a prevalence of full disclosure of 35% among 65 US children, with a mean age of disclosure of 7.8 years (Flanagan-Klygis et al., 2001); Weiner and colleagues documented a similar mean age of disclosure, at 7.5 years. Children who had been told also had a greater number of major life events, were rated higher in anxiety by caregivers, and had higher IQ scores as compared to children who had not been informed of their HIV status (Lester, Chesney, Cooke, Weiss et al., 2002; Lester, Chesney, Cooke, Whalley et al., 2002).

Child's increasing age and their level of cognitive development were most often identified as reasons for disclosure among studies conducted in the United States, Canada, and Europe (D. DeMatteo, Harrison et al., 2002; D. DeMatteo, Wells et al., 2002; Funck-Brentano et al., 1997; Gerson et al., 2001; Ledlie, 1999). Other reasons provided by caregivers included not wanting to keep secrets from the child, being concerned that the child would be informed of his/her diagnosis through other sources, fearing that the child might become sexually active, and believing that informing the child will improve health care and adherence to medication regimens (Blasini et al., 2004; Waugh, 2003; L. Wiener et al., 2007). Still other reasons included the child's deteriorating health status (Funck-Brentano et al., 1997; Gerson et al., 2001; Grubman et al., 1995), questioning by the child (Lester, Chesney, Cooke, Weiss et al., 2002; L. S. Wiener et al., 1996), the need to maintain family trust (D. DeMatteo, Wells et al., 2002; Nehring et al., 2000), and the child's right to know (Lester, Chesney, Cooke, Whalley et al., 2002; Nehring et al., 2000).

Only a few studies from developing countries have looked at factors associated with full disclosure of HIV diagnosis to children. Two Thai studies found that older age was correlated with increased proportions of children informed of their HIV status (Butterworth et al., 2007; Oberdorfer et al., 2006). Reasons given by caregivers to not disclose included the young age of the child (Kouyoumdjian et al., 2005; Oberdorfer et al., 2006), the emotional challenge to the caregiver (Kouyoumdjian et al., 2005), not knowing how to answer children's subsequent questions(Kouyoumdjian et al., 2005), concerns that children would suffer negative psychological consequences (Nannyonga-Musoke et al., 2007; Oberdorfer et al., 2006), fears that the child will negatively judge the caregiver (Kouyoumdjian et al., 2005; Nannyonga-Musoke et al., 2007), fears of discrimination against and social rejection of the child (Kouyoumdjian et al., 2005), and concerns that the child would go on to tell others (Kouyoumdjian et al., 2005; Nannyonga-Musoke et al., 2007). One study looked at health providers' decisions to inform pediatric patients of their HIV status, and noted lack of adherence to treatment regimens and the child's desire to know about their health as reasons to inform the child (Azondekon et al., 2005)

Only three studies to date have looked at the impact of disclosure of HIV status to infected children, using longitudinal designs. All three looked at the effect of interventions designed to disclose HIV status (Azondekon et al., 2005; Blasini et al., 2004; Oberdorfer et al., 2007), but only one included both pre- and post-disclosure measures of the children. In the one study (Oberdorfer et al., 2007), Thai children who went through a 5-step intervention to inform them of their HIV status did not score higher on measures of depression or anxiety following disclosure, increased their understanding of HIV infection, preventive measures, and the importance of adherence to medication regimens.

Conceptualization of Disclosure

Three conceptualizations of disclosure emerge from the literature on HIV-positive children. The first approach conceptualizes *disclosure as a single event*, the provision of the diagnosis of HIV or AIDS to an individual (Flanagan-Klygis et al., 2001; Ledlie, 1999, 2001; Ostrom et al., 2006; Thorne et al., 2000). A second conceptualization of disclosure focuses on the *process undertaken by parents/caregivers to disclose* (D. DeMatteo, Harrison et al., 2002; Gerson et al., 2001; C. L. Lee & Johann-Liang, 1999; Pequegnat & NIMH Consortium on Family & HIV/AIDS Research, 2002). The process incorporates preparation of the parent/caregiver, preparing the child, determining the risks and benefits, finding the right time, and placing supports in place (D. DeMatteo, Harrison et al., 2002; Gerson et al., 2001). Gerson et al. go on to describe the process beyond the disclosure of the diagnosis to incorporate post-disclosure coping by the child and the family (Gerson et al., 2001). This framework is akin to the process described by Kimberly for adult's decision-making to disclose own HIV status (Kimberly & Serovich, 1995) and is used as the framework for discussing the disclosure process in a WHO document on gender dimensions of HIV disclosure to sexual partners (Maman & Medley, 2003).

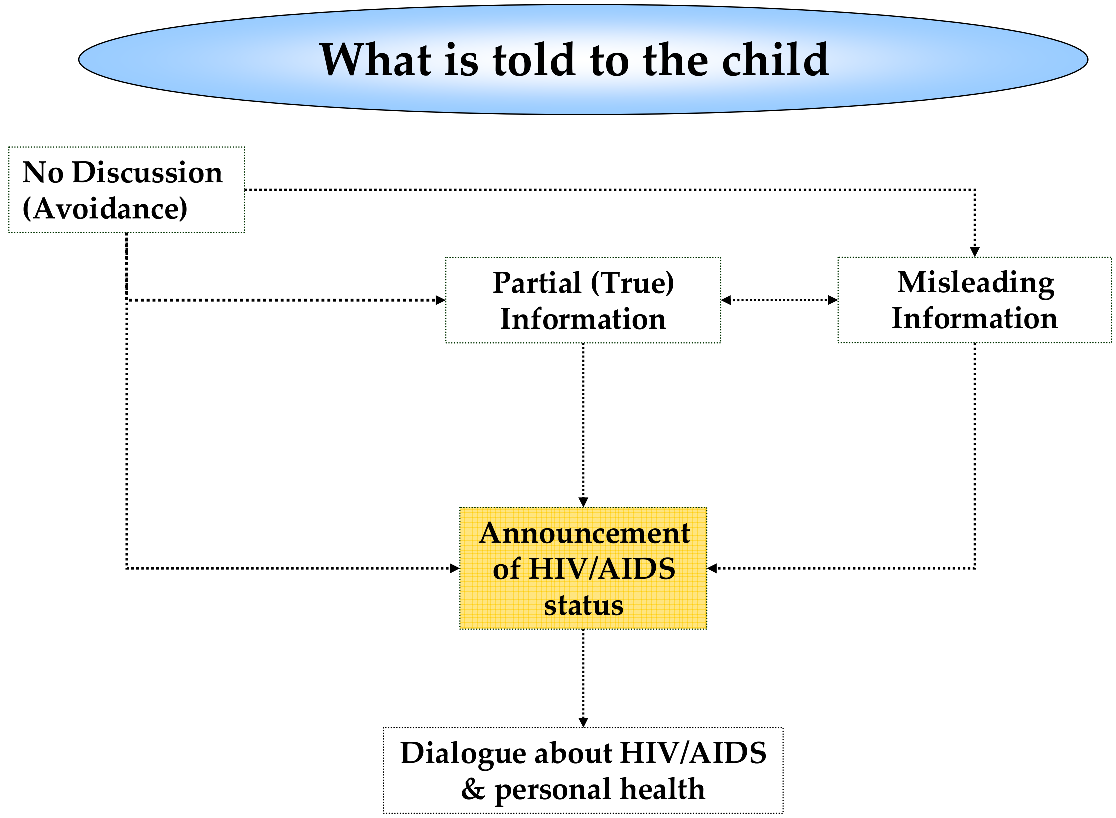
The third conceptualization of the disclosure focuses on the *process of information provision to the recipient*. A large portion of the literature published on disclosure of HIV status to children uses this characterization of the disclosure process, whether explicitly defined as such or else implicitly defined in the description of the disclosure events (Abadia-

Barrero & Larusso, 2006; Blasini et al., 2004; Funck-Brentano et al., 1997; Kouyoumdjian et al., 2005; M. B. Lee & Rotheram-Borus, 2002; Lester, Chesney, Cooke, Weiss et al., 2002; Lester, Chesney, Cooke, Whalley et al., 2002; Lipson, 1993; Myer et al., 2006; Nehring et al., 2000; Rotheram-Borus et al., 1997; Waugh, 2003; L. S. Wiener et al., 1996). The American Academy of Pediatrics guidelines on disclosure of illness information to children with HIV uses an information-based characterization of the disclosure process (AAP, 1999).

There are two approaches taken in the discussion of disclosure as a process of information provision. In the first, more commonly used, approach, disclosure is broken down into types of information given, generally into "no information", "deceptive information", "partial information", and "full disclosure" (Funck-Brentano, 1995; Funck-Brentano et al., 1997; Kouyoumdjian et al., 2005; Lester, Chesney, Cooke, Whalley et al., 2002; Nehring et al., 2000; L. S. Wiener et al., 1996); Nehring's description emphasizes a continuum rather than stages of disclosure, but nonetheless moves from no information to full information provided (Nehring et al., 2000). The second approach emphasizes the ongoing nature of disclosure, including conversations following the disclosure of the diagnosis itself as part of the process (Abadia-Barrero & Larusso, 2006; C. L. Lee & Johann-Liang, 1999; Lipson, 1993; Myer et al., 2006; Waugh, 2003).

For this study, disclosure was conceptualized as a process of information provision to an HIV-positive child that encompasses both the periods before and after the first mention of the diagnosis of HIV/AIDS. The process of disclosure is seen as composed of patterns rather than stages, because stages imply a certain linearity of events that may or may not take place. The patterns are: no information, misleading information, partial truthful information that does not mention HIV/AIDS, disclosure of the diagnosis of HIV or AIDS ("full" disclosure), and subsequent discussions about the meaning and implications of the diagnosis. Figure 1 illustrates the conceptualization; Box 1 describes how each of the patterns is defined.

Figure 4.1: Conceptualization of Process of Disclosure of HIV Status to Children



The aims of this paper are to describe current patterns of communication to HIV-positive children who have not yet been fully informed of their HIV status, and to explore what factors might be associated with different patterns of disclosure to children.

4.3 METHODS

The data presented here are part of a larger study on disclosure practices to HIV-positive children. The study on disclosure practices was embedded within the HIV Pediatric Care Program, a comprehensive, family-centered HIV care and treatment program in Kinshasa, Democratic Republic of the Congo (DRC) based at the Infectious Disease Unit of Kalembe Lembe Pediatric Hospital. Since it began in 2004, the program has provided over 500 children and over 200 of their first-line relatives with clinical and psychosocial care, including antiretroviral treatment when appropriate. Structured interviews were conducted with primary caregivers of HIV-positive children ages 5-17 years who had not yet fully disclosed HIV status to their child.

All interviews were conducted by local interviewers trained in quantitative and qualitative research for this study. Recruitment took place at the time of a child's regularly scheduled clinical visit, either to the program itself or to the Infectious Disease Unit of Kalembe Lembe Pediatric hospital. The research was approved by the Institutional Review Boards both at the University of North Carolina at Chapel Hill in the U.S. and the Kinshasa School of Public Health in DRC, and informed consent obtained prior to the interview. Interviews were conducted either in Lingala or French, depending on the preference of the participant. To overcome literacy problems, questions were read out loud to the participants and answers were recorded by the interviewers.

A *primary caregiver* was defined as an adult aged 18 years and over who is responsible for the day-to-day care of the minor, including biological parents, and identified through eligibility screening by program staff. Adolescents who appeared to a regularly scheduled visit without a caregiver were asked by program staff to come to their next appointment with their primary caregiver. Adults accompanying children who were not primary caregivers for the child or who did not know the child's HIV status were excluded, as were caregivers who were not at least 18 years of age. Caregivers of children 8-17 years who had already informed their child of their HIV status were excluded from the structured interviews but invited for in-depth interviews, along with their child.

Measures:

A structured questionnaire was developed based on prior research, reviewed and modified for cultural appropriateness by the research study team, and pilot tested prior to the start of data collection. The questionnaire explored sociodemographic characteristics of the participant and the child; health status of the child; emotional closeness between caregiver and child; developmental stage of the child; patterns of disclosure; caregivers' thoughts on disclosure; individual and community-level stigma; and social support.

Pattern of Disclosure: Pattern of disclosure was defined as our outcome of interest. Pattern of disclosure was defined based on the description of the disclosure process described earlier, with categories based on research by Funck-Brentano and colleagues (Funck-Brentano et al., 1997): "no information", "partial, truthful information", and "misleading information." Caregivers were asked an open-ended question about what had been told to the child about their health, with probes about how they respond to any questions their child asked. Answers were later categorized as no information, partial information, misleading information, and both partial information and false information. During the pilot phase, a fourth category--"partial, truthful information as well as false information"--was identified and added. The categories of full disclosure and discussions since disclosure were not used, as our interviews were with caregivers who had not yet fully disclosed HIV status to their child.

Box: Defining Patterns of Disclosure

Degrees of disclosure defined

No information provided: In this stage, no information about the illness or the health status of the child is given to the child, even if questions are asked. Questions are ignored and/or very general information is given to the child. Information was considered to be general if, from the perspective of the child being given the information, it provides no additional insight on their health. An example of general, nonspecific information that was categorized as "avoidance of discussion" is, "We go to the hospital so that the doctor can check your health." If a child was given the name of an opportunistic infection they had but no other information about their health status, they were classified in this stage of disclosure. If a child is told to take preventive measures (do not play with sharp objects) without a reason given as to why, or for a generic reason such as to avoid getting hurt, it was classified as no information. Information on how to take medications without any reasons why was classified as no information given as it does not provide any information about the child's health status. Most of these children have been brought to the clinic because they were symptomatic and so know that they have been sick; therefore, telling them that they have been sick was classified as no information given.

Misleading information provided: Information given to the child was classified as misleading if it was not true or if it would have to be retracted at a later date in order to provide other information. Misleading information was either intentionally misleading or else ambiguous in the caregiver's intent. Only cases where the caregiver denied HIV infection, said s/he lied to the child, or else gave information that, upon probing by the interviewer, was known by the caregiver to not be true were considered intentionally misleading. Examples of ambiguous, but misleading information include the child being told that they have another health condition, such as sickle cell anemia or tuberculosis, or that their medications are to cure an opportunistic infection, rather than prevent it. If a child is told to adopt preventive measures to avoid being infected with HIV, this was categorized as ambiguously misleading information because the child already has HIV.

Partial (truthful) information provided: Information that could be considered as providing some insight on their health, even though HIV was not mentioned was considered to be partially true. This included information that medications being taken help reduce the incidence of symptoms (but not that the medications are for the rash), or that the child is "sickly" or prone to falling ill. Statements encouraging children to take their medications or else they would die were classified as partially true as they provided some information—that they had a potentially fatal condition—to the child. If a child is told to adopt preventive measures to keep others from getting sick, this was categorized as partial information.

Some false & some truthful information provided: This category was not originally conceptualized during the study's design, but had to be created as data was being collected. It became evident during data collection that adult caregivers sometimes provide information that is accurate as well as misleading or inaccurate information, either simultaneously or separately, over a period of time. For example, a child could be told that her body has been ill since birth (true) and in response to a question told she does not have HIV (false).

Sociodemographic Characteristics: We documented age, gender, and educational attainment of both caregiver and child. In addition, we obtained marital status, employment status, and kinship to the child from the caregiver; where appropriate, employment status of the caregiver's spouse was also captured. Orphan status of the child was assessed by asking separate questions about the status of each of the biological parents of the child, regardless of the kinship of the caregiver to the child; if a biological parent was deceased, the age of the child at that time was documented. Child's health status was assessed using three questions. The first was the length of time since diagnosis as reported by the parent/caregiver, a continuous variable. The second was what drugs, if any, the child was currently taking. The third measure of child's health status was based on the WHO stage classification; the parents/caregivers were asked about current presence of different symptoms in the child.

Attitudes Towards Disclosure: We explored caregivers' attitudes towards disclosure in several ways. First, we asked if they believed their child should someday be told her/his HIV status. We then asked whether they had ever thought of what specifically might lead them to inform the child. Those who responded in the affirmative were then asked to provide details on what would lead them to inform the child and during what moments they think of these things; these questions were open-ended and responses were later categorized. A close-ended question then determined how frequently the parent/caregiver thought about the moment of full disclosure.

Next, a series of ten reasons other parents choose to disclose HIV status was read; after each statement, caregivers were asked how likely they would disclose for that reason;

answers were based on a 5-point Likert scale. The series was adapted from prior studies on the topic in industrialized settings (D. DeMatteo & Roberts, 2001; L. S. Wiener et al., 1996) and augmented by findings from a formative evaluation conducted in 2005 on assent to research participation and disclosure of HIV status in Kinshasa(L. M. E. Vaz et al., in press). We then asked them to list both perceived benefits and perceived harms of full disclosure to children; the total number of perceived benefits and of perceived harms were totaled and the sum value as each was treated as a count variable. Finally, we asked who they felt was the best person to inform the child of their HIV status someday.

Stigma: Both individual-level stigma and community-level stigma were assessed using a scale tested and validated in Tanzania (USAID, 2005), with 3 defined domains: fear of casual contact, shame and blame/judgment. The scale was a result of an examination of existing stigma scales as well as new questions, assessing their validity and reliability. The USAID study tested the internal reliability of the items using factor analysis; the three shame items explained 80 percent of the variance in the sample; the four blame items explained 70 percent of the variance in this domain. The fear of casual contact items were new and while they had some variation in test-retest reliability assessment (~10 percent) were considered an improvement over previous scales (USAID, 2005). We dropped two questions from the fear of casual contact domain because they were inappropriate for our participants, who already have HIV-positive children for whom they provide care. We added one additional statement on purchase of food products at the market from someone visibly sick or suspected of having HIV, which was recommended by the USAID-funded study team but not considered an essential question in the subscale.

Social Support: Perceived Social Support was measured using a scale adapted for use in Kinshasa and currently in use with adult participants of the SARA Project. The original scale was developed by O'Brien and colleagues (O'Brien, Wortman, Kessler, & Joseph, 1993) and consists of seven items mapping across three dimensions of social support: instrumental, informational, and emotional support. The scale was modified for cultural relevance with input from local staff and pre-tested in Kinshasa before the start of the SARA Project. While the modified scale has not yet been validated; the original scale had an Cronbach's alpha of 0.873 (O'Brien et al., 1993). The internal reliability of the scale in this setting was assessed using primary component analysis (PCA); the analysis revealed a Cronbach's α of 0.642, considered sub-optimal for using the questions as a scale. All of the individual questions were then incorporated into the analyses.

Developmental status of child: Most development scales focus on early childhood and are for use with children under age 5 years. We developed eight Likert items based on 2005 formative study data, where participants elaborated on developmental signs that a child was old enough to know of their HIV status. Signs included being able to distinguish right from wrong, being able to take care of basic needs for self, and is becoming sexually aware. The scale showed good reliability for this population (Cronbach's ◎ = 0.739); a sum value of all items was used in the bivariate analyses.

We also asked caregivers to compare their child on five factors to other children of the same age. These items were not incorporated into the scale but instead treated as separate variables.

Emotional closeness: We used the Quality of Parent-Child Relationship Scale (Barbarin, 2001) to assess the relationship between caregiver and child. This scale is derived from a validated scale developed by Robert Pianta to assess student-teacher relationships (Pianta & Nimetz, 1989), and was adapted for use in South Africa. The 15-item scale forms an index of the emotional (affective) quality of the parent-child relationship from the perspective of the parent—the strength of the tie or attachment between the parent and the child. The items combine into 2 subscales—Closeness and Conflict—which were derived using factor-analysis; internal consistency reliability are over 0.80 for each of the subscales (Barbarin, 2001). However, the sub-scales demonstrated low internal consistency reliability for this population (Cronbach's α of 0.452, and 0.552 respectively), and so were not used as scaled values in the remaining analyses; instead, single items were evaluated for association with the current pattern of disclosure.

4.4 ANALYSIS

We first conducted descriptive analyses on all data collected to describe the sample and to assess the distribution of variables in the sample population. Next, we ran analyses of the relationship between the explanatory variables and the dependent variable patterns of disclosure. *Multinomial logistic regression* was used for the bivariate and multivariable analyses. Multinomial logistic regression exists to handle dependent variables with more than two classes, when there is no ordering of the dependent variable categories. When the predictor variables are characteristics of the individual and his/her environment, multinomial logistic regression analysis is preferred over ordinal logistic regression and discrete-choice models(Allison, 2001). In the logistic regression, likelihoods—or odds—of being in one category of the outcome versus a referent category are calculated for each group within the explanatory variables. In order to be able to compare each of the types of disclosure to each other, therefore, two separate multinomial logistic regressions were run for each explanatory variable of interest. A Bonferroni correction is customary for multiple comparisons during the bivariate and multivariable analyses such as this. Weights of cell counts were adjusted for a few variables to account for empty cells, which cause difficulties in estimating odds ratios. We added a very small constant (0.01) to cell counts; the method has been recommended for saturated models and has a conservative effect on the estimated effects (Agresti, 2002). We first ran bivariate analyses between variables in each domain of interest and the outcome, current pattern of disclosure. For each domain, we then ran adjusted models using multivariate analyses to determine the associations between the dependent variable and the explanatory variables either found to be significant in the bivariate analyses or otherwise found significant in prior studies. A final model was developed using only those variables found to be significant in the adjusted models for each domain. Results are reported at the $\alpha=0.05$ only, and not at the corrected $\alpha=0.017$ (0.05/3) level. All analyses were conducted using the SAS System for Windows, version 9.1 (The SAS Institute Inc., 2003-2005), except for the factor analyses, which were conducted using SPSS ("SPSS for Windows," 2006)

4.5 RESULTS

Descriptive Analyses

Over a five-month period, 259 caregivers of pediatric patients aged 5-17 years were screened for eligibility. Of those, eight (3%) had already informed their child of his/her HIV status and were referred for in-depth interviews. Forty-one caregivers (16%) did not meet at least one of the criteria for inclusion into the study and were excluded. Nine caregivers (3%) refused to participate, requested to come back at another time to participate but did not keep the appointment, or were not interested in participating. In all, 201 caregivers were interviewed (78%). Nearly all of the participants were caregivers enrolled in the Pediatric HIV Care Program (95%), and most interviews were conducted in Lingala (87%).

Participant ages ranged from 18-70 years (median age, 40 years.) A large majority of those interviewed were female (162, 81%). The largest proportion interviewed were biological mothers of the child (72, 36%), followed by a maternal aunt or uncle of the child (42, 41%), reflecting Congolese matrilineal societies. Most had at least some secondary school education (153, 76%). Only three caregivers had more than one HIV-positive child over the age of 5 years under their care. Table 1 summarizes the sociodemographic characteristics of the caregivers.

Table 4.1: Characteristics of Caregivers Interviewed

Characteristic			
Age	Median (Range)	40	18-70
		N	**%**
Gender	Male	39	19%
	Female	162	81%
Education	None	3	1%
	Some primary school	26	13%
	Completed primary school	7	3%
	Completed trade/ professional school	12	6%
	Some secondary school	77	38%
	Completed secondary school	37	18%
	Any post- secondary school	39	19%
Marital Status	Single	37	18%
	Formally married	80	40%
	Living with partner	12	6%
	Has partner but not living together	3	1%
	Separated	3	1%
	Divorced	22	11%
	Widowed	44	22%
Relationship to child	Biological Mother	72	36%
	Biological Father	12	6%
	Grandparent	32	16%
	Brother or sister	13	6%
	Paternal aunt or uncle	16	8%
	Maternal aunt or uncle	42	21%
	Other	14	7%
Employment	None*	66	33%
	Big company	8	4%
	Public servant	15	7%
	Small company/home	9	4%
	Informal work	102	51%
	Other	1	0%
	*Never worked	13	6%
Length of Unemployment (Years)	Median (Range) (N=53)	3	(<1-20)

*"Never worked" is a subset of those who responded that they had no current employment.

The children represented were nearly evenly split between male and female. Median age was 8 years. Nearly all of the youth were on some form of daily medications, based on caregiver reports: approximately three-quarters were on antiretrovirals at the time of the interviews, and an additional 19 percent were taking cotrimoxazole prophylaxis. Nearly all had either no clinical symptoms (89, 44%) or few symptoms (95, 47%) as reported by caregivers at the time of interview. Slightly over half are maternal orphans (n=102, 51%) and approximately one-quarter were orphans of both parents (19%, n=53); 62 (31%) of the children had both biological parents living at the time of the interview. Table 2 summarizes characteristics of the children of caregivers interviewed.

Table 4.2: Characteristics of HIV-positive youth

Characteristic			
Age	Median (Range)	8	5-17
		N	**%**
Gender	Male	94	47%
	Female	107	53%
Orphan	Mother deceased	102	51%
	Father deceased	87	43%
	Double orphan	53	26%
Education	Ever been to school	170	85%
	Currently in school	135	67%
Current Medications	Cotrimoxazole (prophylaxis) only	39	19%
	ARVs	149	74%
	None	2	1%
	Don't know	10	5%
	Missing	1	0%
Reported Health Status	No symptoms	89	44%
	Minor symptoms	95	47%
	Frequent illness but no hospitalization	10	5%
	Frequent hospitalization, no overnight stays	2	1%
	Hospitalization, overnight stays	5	2%

Nearly half of the caregivers reported not having provided their child with any information about their health (93, 46%). A full third (67, 33%) reported having given only misleading information about this/her health, and an additional 3 percent (n=7) had given the child misleading information along with true information about their health. Of the 67 caregivers who gave misleading information, 11 (16%) gave intentionally inaccurate information; the remaining 53 (82%) gave responses that were otherwise misleading, although caregivers' intentions could not be confirmed. Only approximately one in eight caregivers interviewed (31, 15%) had given their child only truthful, partial information about their health.

While almost all caregivers said that they felt the child should be told his/her HIV status someday (188, n=94%), three-quarters reported ever thinking about what might lead them to tell their child s/he has HIV (n=151.) The open-ended responses of caregivers about what would lead them to fully inform the child about his/her health fell into two general categories: time-related factors (triggers), that fit a response of "When *x* takes place"; and outcome-related factors (reasons), that fit a pattern of "So that *y* happens". A majority of caregivers who had thought about what might lead them to fully inform their child gave both triggers and reasons (65%, n=98). Responses to the open-ended question "When do you think about these things" were classified into moments centered around the child—such as when the child asks questions, or when the child goes to school—health-care related moments, such as on the day of clinic appointments; and other types of moments. Table 3 summarizes the data on attitudes towards disclosure.

Caregivers were also asked who they thought would be the best to inform the child of her/his HIV status. A majority of caregivers felt that they were the best person to tell the child (98, 49%), while approximately one-third felt a health care provider was the best person to talk to the child (72, 36%); the remainder felt another family member might be the best person (10%), and only 4 (2%) said no one should tell the child.

Table 4.3: Current Pattern of Disclosure and Caregiver Thoughts of Full Disclosure

Characteristic		N	%
Current Pattern of Disclosure	No information provided	93	46%
	Misleading information provided	67	33%
	Some partial information provided	31	15%
	Some partial & some misleading information given	7	3%
	Other/refuse answer/missing	3	1%
Should Child Be Told Status Someday?	No	9	4%
	Yes	188	94%
	Don't know	3	1%
	Missing	1	0%
Have you thought about what types of events would lead you to tell your child s/he has HIV?	No	48	24%
	Yes	151	75%
	Refuse to answer	2	1%
What types of things? (n=151)	Triggers only ("when…")	41	27%
	Reasons only ("so that…")	12	8%
	Both reasons and triggers given	98	65%
Triggers leading to full disclosure	Child gets older	106	70%
	Child asks questions	22	15%
	Eminent sexual debut	53	35%
	Other	24	16%
Reasons leading to full disclosure	So child can remain abstinent	34	23%
	So child can know self	17	11%
	Medical care reasons	27	18%
	So child can protect self	67	44%
	So child can protect others	71	47%
	Other	6	4%
What moments/under what circumstances think about these things (n=145)	Child-centered moments	88	61%
	Health-care related activities	34	23%
	Other moments	62	43%
How often do you think about these things?(n=151)	Not very often	64	42%
	About once a month	7	5%
	About once a week	10	7%
	Several times a week	26	17%
	Every day	34	23%
	Another time	8	5%
	Refuse to answer	2	1%

Nearly one-third of caregivers felt there were no benefits to telling the child her/his HIV status. The most commonly cited benefits were that the child would be able to protect him/herself and others from possible harm (93 (46%) and 72, (36%), respectively), and that the child would be able to take better care, in general, of her/himself (66, 33%). The most commonly cited harms resulting from telling the child were psychological in nature: that the child would be worried (100, 50%), and that the child would be sad or lose the will to live (78, 39%). Figure 2 lists the benefits and harms as cited by caregivers. The percentages add up to more than 100% as caregivers could list more than one harm and/or benefit.

Figure 4.2: Perceived Harms and Benefits of Full Disclosure of HIV Status to Children (n=201)

In your opinion, what are some GOOD things that can happen if your child is told that s/he has HIV?

	#	%
Child will better protect self from possible dangers	93	46%
Child will better protect others from possible dangers	72	36%
Child will take better care, in general, of self	66	33%
Nothing	64	32%
Child will take his/her medicines as he/she should	50	25%
Child will be relieved	22	11%

In your opinion, what are some BAD things that can happen if your child is told that s/he has HIV?

	#	%
Child will be worried	100	50%
Child will become sad/depressed/lose will to live	78	39%
Child will tell others	40	20%
Child will die of worry/shock	34	17%
Child will isolate him/herself	34	17%
Nothing	29	14%
Child will commit suicide	25	12%
Child will become rebellious	14	7%
Child will blame caregiver for being sick/hate me because of her/his illness	12	6%

Factors Associated with Patterns of Disclosure

Domain: Sociodemographics and Child's Health Status

Certain caregiver characteristics were associated with the patterns of disclosure to the child. Caregivers who were male were less likely to have given misleading information, versus no information, to the child. Caregivers under age of 35 were more likely than caregivers over age 45 to have said something true than have said nothing or something misleading. Caregivers' education level was also associated with patterns of disclosure. Caregivers who had not completed secondary school were more likely than those who had completed secondary school to have given their child misleading information versus nothing; caregivers with no more than primary school showed a tendency to give misleading over truthful information. Caregivers who had been aware of the child's diagnosis for less than a year tended to be less likely to have said something true, versus nothing, than those who had known for more than two years; those who had known for 1-2 years were less likely to have said something true as well.

Certain child characteristics were associated with patterns of disclosure. Children ages 5-8 years tended to be less likely than children ages 13 years and over to have been told something true, versus nothing; children ages 9-12 years tended to be more likely to have been told something misleading than something true. Compared to children who had frequent illnesses or hospitalizations, children who currently had minor symptoms were more likely to have been told something misleading versus nothing.

A model adjusted for factors found to be significant in the bivariate analyses, and that also included the age of the child, is displayed in Table 4. Results from the bivariate analyses are not presented. While caregiver age and gender continued to have a significant influence on patterns of disclosure, caregiver education's influence was reduced. The influence of the amount of time the caregiver had been aware of the child's HIV diagnosis and the child's health status at the time of interview also remained.

Table 4.4: Adjusted Odds Ratios with 95% Confidence Intervals and P-Values for Sociodemographics & Health Domain

	Something True vs Nothing		**Something Misleading vs Nothing**		**Something True vs Something Misleading**	
	OR (95% CI)	**p-value**	**OR (95% CI)**	**p-value**	**OR (95% CI)**	**p-value**
Caregiver Gender						
Male	0.6099 (0.1903, 1.9547)	0.4053	0.3535 (0.1288, 0.9700)*	0.0435	1.7255 (0.4622, 6.4421)	0.4170
Female						
Caregiver Age						
<35 years	3.8279 (1.0571, 13.8617)*	0.0409	1.0669 (0.4314, 2.6386)	0.8885	3.5879 (0.9539, 13.4943)	0.0587
36-45 years	2.5846 (0.6987, 9.5611)	0.1548	1.6050 (0.6993, 3.6839)	0.1548	1.6103 (0.4356, 5.9526	0.2643
45+ years						
Caregiver Education						
No more than primary	1.2625 (0.2471, 6.4504)	0.7794	1.9564 (0.6924, 5.5276)	0.2054	0.6453 (0.1269, 3.2829)	0.5977
Some 2o or prof. school	1.5454 (0.5582, 4.2782)	0.4021	1.7584 (0.7937, 3.8954)	0.1643	0.8789 (0.3082, 2.5066)	0.8092
2o school or more						
Age of child						
5-8 years	0.3454 (0.0929, 1.2845)	0.1126	0.8921 (0.2472, 3.2194)	0.8615	0.3871 (0.0908, 1.6501)	0.1995
9-12 years	0.7248 (0.1888, 2.7833)	0.6392	2.0131 (0.5541, 7.3138)	0.2878	0.3601 (0.0845, 1.5335)	0.1671
13-17 years						
Time Since Caregiver Aware of Diagnosis						
<1 year	0.2812 (0.0740, 1.0684)	0.0625	0.5627 (0.2076, 1.5254)	0.2585	0.4996 (0.1270, 1.9661)	0.3208
1-2 years	0.3924 (0.1515, 1.0161)	0.0540	0.6794 (0.3164, 1.4587)	0.3214	0.5776 (0.2186, 1.5263)	0.2682
2+ years						
Current Health of child						
no symptoms	1.8698 (0.3250, 10.7592)	0.4833	3.1254 (0.7380, 13.2358)	0.1218	0.5983 (0.0809, 4.4235)	0.6148
minor symptoms	1.8610 (0.3312, 10.4561)	0.4807	3.6716 (0.8947, 15.0676)	0.0710	0.5069 (0.0711, 3.6114)	0.4976
frequent illness/ hospitalization						
Intercept (estimate)	-1.3652	0.2577	-1.6735	0.0974	0.3084	0.0974

Referent categories for each categorical independent variable are underlined.

** significant at $\alpha = 0.05$*

Domain: Child Development

The child's developmental level was significantly associated with what children had been told about their health. Children with higher scores on the development scale were more likely to have been told something misleading, versus nothing.

Table 4.5: Adjusted Odds Ratios with 95% Confidence Intervals and P-Values for Child Development Domain Variables

	Something True vs Nothing		**Something Misleading vs Nothing**		**Something True vs Something Misleading**	
	OR (95% CI)	**p-value**	**OR (95% CI)**	**p-value**	**OR (95% CI)**	**p-value**
Total Sum of Scale Items						
continuous (OR)	1.0295 (0.9685, 1.0945)	*0.3501*	1.0526 (1.0043, 1.1033)*	*0.0328*	0.9780 (0.9175, 1.0426)	*0.4968*
Intercept (estimate)	-1.8412	*0.0268*	-1.5617	*0.0159*	-0.2795	*0.7533*

** significant at* $\alpha = 0.05$

Domain: Emotional Closeness

Only two of the 18 items related to emotional closeness were associated with pattern of disclosure to the child, one from the conflict dimension of the scale and the other from the closeness dimension. The conflict question asked whether the child's feelings towards the caregiver were unpredictable, whereas the closeness question asked whether the child feely shares feelings and experiences. Caregivers who did not feel their child's feelings were unpredictable were more likely to have given misleading information than no information, and tended towards having said something true versus nothing. Caregivers who felt that their child did not openly share feelings tended to be less likely to have told the child something misleading versus nothing. The report of unpredictable feelings remained significant after including the two variables together in a model.

Table 4.6: Adjusted Odds Ratios with 95% Confidence Intervals and P-Values for Emotional Closeness Domain

	Something True vs Nothing		Something Misleading vs Nothing		Something True vs Something Misleading	
	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
Child's emotions unpredictable						
Disagree	2.3605 (1.0215, 5.4547)*	0.0444	2.6097 (1.3813, 4.9306)*	0.0031	0.9045 (0.3809, 2.1482)	0.8201
Agree						
Child openly shares feelings						
Disagree	0.4785 (0.1276, 1.7948)	0.2745	0.3909 (0.1415, 1.0798)	0.0700	1.2241 (0.2854, 5.2492)	0.7855
Agree						
Intercept (estimate)	-1.4404	<.0001	-0.6150	0.0105	-0.8254	0.0188

Referent categories for each categorical independent variable are underlined.
** significant at $\alpha = 0.05$*

Domain: Attitudes Towards Disclosure

Several attitudes towards disclosure were either significantly associated with pattern of disclosure or revealed a tendency towards a pattern of disclosure. Caregivers who had not thought about what would lead them to full disclosure some day were less likely to have said something misleading versus nothing. Caregivers who gave both triggers and reasons for disclosure were more likely than caregivers who never thought about disclosure to have said something misleading and tended to have said something true, versus nothing. Only one specific reason or trigger was associated with any increased likely of being at a particular pattern of disclosure. Caregivers who gave medical care reasons as ones that would lead them to fully inform the child tended to be more likely to have told the child something true than to have said nothing.

Frequency of thoughts around disclosure was also associated with pattern of disclosure. Caregivers who thought about disclosure weekly were more likely than those with daily thoughts to have told the child something misleading, versus nothing.

Caregivers who could name more benefits to disclosure were more likely to have said something true as well as something misleading to the child, versus nothing. Caregivers who could name more harms to informing the child of her/his HIV status tended to be more likely to have said something misleading, versus nothing.

In a model adjusted for all of the domain's variables significant in the bivariate analyses, only the frequency of thoughts around disclosing and the number of benefits to disclosure named remained significant. Table 7 shows the results from these analyses.

Table 4.7: Adjusted Odds Ratios with 95% Confidence Intervals and P-Values for Attitudes towards Disclosure Domain

	Something True vs Nothing		**Something Misleading vs Nothing**		**Something True vs Something Misleading**	
	OR (95% CI)	**p-value**	**OR (95% CI)**	**p-value**	**OR (95% CI)**	**p-value**
Type of Answer						
Reasons	0.9990 (0.2086, 4.7837)	.	0.7847 (0.2300, 2.6772)	0.6986	1.2731 (0.2317, 6.9941)	0.7812
Triggers	0.5586 (0.0491, 6.3585)	0.6389	0.7510 (0.1389, 4.0615)	0.6389	0.7438 (0.0542, 10.2065)	0.8247
Both reasons & triggers	1.4682 (0.3431, 6.2369)	0.6072	2.1999 (0.7493, 6.4592)	0.1514	0.6649 (0.1451, 3.0471)	0.5993
No reasons or triggers						
Frequency of thoughts on disclosure						
Monthly or less	1.3676 (0.4078, 4.5865)	0.6122	0.9288 (0.3623, 2.3810)	0.8778	1.4724 (0.4199, 5.1629)	0.5456
Weekly	1.9483 (0.4119, 9.2143)	0.4002	3.6157 (1.1478, 11.3895)*	0.0281	0.5388 (0.1232, 2.3575)	0.4116
Daily	1.0000	.	1.0000	.	1.0000	.
Never						
Sum of Benefits of disclosure						
continuous	1.3957 (1.0478, 1.8592)*	0.0227	1.1092 (0.8831, 1.3931)	0.3733	1.2585 (0.9453, 1.6754)	0.1155
Sum of harms of disclosure						
continuous	0.8497 (0.6247, 1.1556)	0.2990	1.0660 (0.8446, 1.3455)	0.5905	0.7970 (0.5851, 1.0857)	0.1504
Intercept (estimate)	-1.7662	0.0007	-1.0911	0.0060	-0.6751	0.2323

** significant at $\alpha = 0.05$*

Domain: Stigma

Stigma, both at the individual and the community levels, were associated with current patterns of disclosure to children in the study. As caregivers' own fear of casual contact increased among caregivers, they tended to be less likely to have said something misleading, versus nothing, to the child. As blaming attitudes increased among caregivers, they were less likely to have said something—whether true or misleading—than have said nothing. Increasing reports of fear of casual contact and blaming attitudes among community members tended to be associated with increased odds of having said something misleading to the child, versus nothing. An adjusted model for this domain found that community level blaming attitudes was no longer associated with different patterns of disclosure; while not significant, increasing community level fears of casual contact showed a tendency towards increasing the likelihood of saying something misleading, versus nothing.

Table 4.8: Adjusted Odds Ratios with 95% Confidence Intervals and P-Values for Stigma Domain

	Something True vs Nothing		**Something Misleading vs Nothing**		**Something True vs Something Misleading**	
	OR (95% CI)	**p-value**	**OR (95% CI)**	**p-value**	**OR (95% CI)**	**p-value**
Individual Fear of Casual Contact						
continuous	0.08894 (0.5632, 1.4045)	0.6153	0.6343 (0.4121, 0.9763)*	0.0385	1.4021 (0.8035, 2.4469)	0.2341
Individual Blaming Attitudes						
continuous	0.6362 (0.4589, 0.8821)*	0.0067	0.9672 (0.7636, 1.2252)	0.7822	0.6578 (0.4723, 0.9162)*	0.0132
Community Fear of Casual Contact						
continuous	1.0690 (0.7706, 1.4829)	0.6896	1.2719 (0.9676, 1.6718)	0.0848	0.8405 (0.5843, 1.2090)	0.3489
Community Blaming Attitudes						
continuous	1.4379 (0.8775, 2.3564)	0.1495	1.2401 (0.8668, 1.7741)	0.2388	1.1595 (0.6913, 1.9450)	0.5750
Intercept (estimate)	-1.6884	0.0562	-1.4683	0.0336	-0.2201	0.8209

** significant at* $\alpha = 0.05$

Social Support

Only two social support items, both related to instrumental social support, seemed to be related to patterns of disclosure to children in bivariate analyses. The instrumental support questions captured access to small amounts as well as large amounts of support measured by access to loans or favors. For both variables, caregivers with no access to instrumental support were more likely to have said something misleading to the child than to have said nothing at all. Once put into an adjusted, multivariable model, only smaller instrumental support available remained significant. Caregivers who did not have this support available were more likely to have said something misleading versus nothing to their child.

Table 4.9: Adjusted Odds Ratios with 95% Confidence Intervals and P-Values for Social Support Domain

	Something True vs Nothing		Something Misleading vs Nothing		Something True vs Something Misleading	
	OR (95% CI)	p-value	OR (95% CI)	p-value	OR (95% CI)	p-value
Have small instrumental support						
Disagree	1.1538 (0.4730, 2.8145)	0.7533	2.4892 (1.2039, 5.1467)*	0.0139	0.4635 (0.1785, 1.2033)	0.1142
Agree						
Have large instrumental support						
Disagree	2.1791 (0.6307, 7.5296)	0.2182	1.5138 (0.5924, 3.8685)	0.3864	1.4395 (0.3651, 5.6748)	0.6027
Agree						
Intercept (estimate)	-1.8077	0.0009	-1.1252	0.0050	-0.6824	0.2615

** significant at $\alpha = 0.05$*

Full Model of Influences on Patterns of Disclosure

The final model, after adjusting for all factors found to be significant within each of the domain-adjusted models, yielded interesting findings. Children in the youngest age group were less likely to have been given true information than either something misleading or no information. Gender and caregiver age remained significant influences on patterns of disclosure. Male caregivers were less likely to have given misleading information, versus no information, to their child. Younger caregivers were more likely to provide truthful rather than misleading information, and caregivers 36-45 years tended to have given more misleading information, versus no information. Individual-level blaming attitudes were strongly associated with being less likely to have provided true information to the child, versus providing either no information or misleading information.

Table 4.10: Adjusted Odds Ratios with 95% Confidence Intervals and P-Values for Full Model

	Something True vs Nothing		Something Misleading vs Nothing		Something True vs Something Misleading	
	OR (95% CI)	**p-value**	**OR (95% CI)**	**p-value**	**OR (95% CI)**	**p-value**
Caregiver Gender						
Male	0.7042 (0.3741, 1.3524)	0.2271	0.5065 (0.2854, 0.8988)*	0.0201	1.3903 (0.6830, 2.8301)	0.3636
Female						
Caregiver Age						
<35 years	1.7105 (0.8491, 3.4461)	0.1331	0.7125 (0.4012, 1.2655)	0.2475	2.4007 (1.1761, 4.9002)**	0.0161
36-45 years	1.4878 (0.6956, 3.1821)	0.3057	1.7251 (0.9821, 3.0301)*	0.0578	0.8624 (0.4126, 1.8026)	0.6940
45+ years						
Age of child						
5-8 years	0.2911 (0.1159, 0.7312)**	0.0086	0.7021 (0.3254, 1.5151)	0.3674	0.4146 (0.1604, 1.0717)*	0.0692
9-12 years	1.6112 (0.7165, 3.6233)	0.2487	2.1332 (1.0541, 4.3169)**	0.0352	0.7553 (0.3484, 1.6372)	0.4771
13-17 years						
Time Since Caregiver Aware of Diagnosis						
<1 year	0.8820 (0.3368, 2.3099)	0.7983	0.9653 (0.4660, 1.9996)	0.9243	0.9137 (0.3499, 2.3861)	0.8538
1-2 years	0.6312 (0.3096, 1.2867)	0.2054	0.7231 (0.4133, 1.2650)	0.2559	0.8729 (0.4215, 1.8075)	0.7143
2+ years						
C_SUM						
continuous	0.9886 (0.9000, 1.0859)	0.8104	1.5073 (0.9851, 1.1348)	0.1221	0.9350 (0.8487, 1.0301)	0.1734
Child's Emotions Unpredictable						
Disagree	1.6356 (0.9769, 2.7385)**	0.0614	1.7712 (1.1709, 2.6794)**	0.0068	0.9234 (0.5466, 1.5601)	0.7659
Agree						
Child openly shares feelings						
Disagree	0.3993 (0.1577, 1.0110)*	0.0528	0.5473 (0.2928, 1.0231)*	0.0590	0.7297 (0.2804, 1.8990)	0.5184
Agree						
Frequency of thoughts on disclosure						
Monthly or less	0.8868 (0.4017, 1.9573)	0.7661	0.8685 (0.4657, 1.6197)	0.6575	1.0210 (0.4721, 2.2081)	0.9578
Weekly	1.4198 (0.4523, 4.4567)	0.5482	2.8145 (1.2033, 6.5829)**	0.0170	0.5044 ((0.1826, 1.3939)	0.1870
Daily	1.0711 (0.3820, 3.0032)	0.8961	0.7364 (0.3343, 1.6222)	0.4477	1.4544 (0.5391, 3.9239)	0.4594
Never						
Sum of Benefits of disclosure						
continuous	1.4253 (1.0283, 1.9757)**	0.0334	1.2207 (0.9325, 1.5979)	0.1468	1.1677 (0.8562, 1.5924)	0.3274
Individual Fear of Casual Contact						
continuous	0.9255 (0.5475, 1.5647)	0.7726	0.6629 (0.3898, 1.1273	0.1291	1.9361 (0.7329, 2.6595)	0.3101
Individual Blaming Attitudes						
continuous	0.5823 (0.3896, 0.8705)**	0.0084	0.9341 (0.6840, 1.2756)	0.6679	0.6234 (0.4243, 0.9160)**	0.0161
Community Fear of Casual Contact						
continuous	1.0176 (0.6928, 1.4944)	0.9292	1.1891 (0.8450, 1.6734)	0.3202	0.8557 (0.5703, 1.2839)	0.4516
Have small instrumental support						
Disagree	1.3460 (0.8056, 2.2490)	0.2566	1.8977 (1.2405, 2.9031)**	0.0031	0.7093 (0.4212, 1.1945)	0.1965
Agree						
Intercept (estimate)	-1.2152	0.4541	-3.3168	0.0123	2.1016	0.2368

*** significant at $\alpha = 0.05$, *significant at $\alpha = 0.10$*

4.6 DISCUSSION

This is the first study within a Sub-Saharan African context to explore what caregivers have communicated to their HIV-positive children about their health *prior to* full disclosure of their HIV status. The proportion of children who have been told something misleading about their HIV status (33%) is higher than what was reported in Funck-Brentano's European sample (21%) (Funck-Brentano et al., 1997). In a Thai study, 70.8% of caregivers had given the child inaccurate information about their health, such as a diagnosis other than HIV (Oberdorfer et al., 2006); however, the study categorized caregivers providing partial information to their child as caregivers who had disclosed, and so as a proportion of all caregivers, those who had said something inaccurate is in fact smaller than reported.

The study is also among the first studies in Sub-Saharan Africa to explore what caregivers' thoughts are around full disclosure of HIV status to children. An overwhelming majority of caregivers felt that the child should be told some day, and approximately three-quarters had already thought about what might lead them to fully inform the child of her/his status. Reasons to disclose among this sample are not so different from what have been mentioned by caregivers in other settings (D. DeMatteo, Harrison et al., 2002; D. DeMatteo, Wells et al., 2002; Funck-Brentano et al., 1997; Gerson et al., 2001; Ledlie, 1999). Older age and eminent onset of sexual activity were main reasons or triggers to inform the child, similar to prior studies in developed countries (L. Wiener et al., 2007), and medical care reasons, including improving adherence to treatment regimens as well as attending health care visits by themselves (Blasini et al., 2004; Waugh, 2003), were also mentioned by caregivers. Most commonly cited harms to the child upon full disclosure, including negative psychological reactions and subsequent disclosure to others, are also among the more frequently identified barriers to disclosure in other studies (L. Wiener et al., 2007).

Most of the factors associated with patterns of disclosure in this study were caregiver characteristics, along with those reflecting the interpersonal relationships between caregivers and children. While most of the literature on pediatric disclosure, which highlights characteristics of children associated with patterns of disclosure (Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001; Azondekon et al., 2005; Cohen et al., 1997; L. Wiener et al., 2007) some prior studies have highlighted certain caregiver characteristics that appear to influence disclosure patterns, such as coping strategies (D. DeMatteo, Wells et al., 2002; Funck-Brentano et al., 1997), emotional readiness (Flanagan-Klygis et al., 2001), parenting style (D. DeMatteo, Harrison et al., 2002) , and caregiver HIV status(D. DeMatteo, Harrison et al., 2002). Lester, in particular, focused on caregiver characteristics associated with disclosure, including age, gender, relationship to the child, and HIV status (Lester, Chesney, Cooke, Weiss et al., 2002; Lester, Chesney, Cooke, Whalley et al., 2002).

The findings, however, should not be taken to mean that other factors are not important in patterns of disclosure. Caregiver and interpersonal characteristics might be influenced by other individual level and community level factors. For example, there is evidence that different coping styles influence children's reactions to learning diagnosis information and undergoing surgical procedures (Bachanas, Kullgren, Schwartz, Lanier et al., 2001; Carson, Council, & Gravley, 1991; Phipps, Fairclough, & Mulhern, 1995; Suls & Fletcher, 1985; R. H. Thompson & Vernon, 1993). Caregivers may therefore communicate with their child based upon their experiences with how their child copes with stressful information. Caregivers' own coping styles and parenting skills might also influence their communication patterns (Bachanas, Kullgren, Schwartz, McDaniel et al., 2001; D. DeMatteo, Wells et al., 2002; Mullins et al., 1991; R. J. Thompson, Jr. et al., 1993; R. J. Thompson, Jr., Gustafson, Hamlett, & Spock, 1992).

The role of community level factors in the final model bears further examination, in particular the absence of effect from community-level stigma variables. A lack of effect seen in this study does not necessarily mean that there is no effect. The small sample size of the study coupled with limited variability in the community-level stigma variables could have affected the findings of their association with patterns of disclosure. Additional analyses were conducted to determine whether any of the three community level stigma variables were associated with any of the other variables in the model. There were small but significant correlations present between community level fear of casual contact and what would lead caregivers to disclose (triggers and reasons), frequency of thoughts on disclosure, and community level feelings of shame; a small but significant correlation was also present between community level blaming attitudes and caregiver blaming attitudes. These correlations, coupled with limited power of the study, may partly explain why the community level stigma variables did not remain significant in the final model.

Limitations and Future Directions for Research:

The study has several limitations. First, cross-sectional nature of study allows for identification of possible associations of factors with different patterns of disclosure, but does not allow us to draw conclusions on causality. Further studies could look at the evolution of communication with children about their health, over time, which would give us more information about the causal relationships that may exist between the dimensions explored in this study.

The cross-sectional nature of the study also does not allow us to fully explore the process of disclosure, but only see it at a particular moment in time. Our current conceptualizations of disclosure do not distinguish between different paths taken towards full disclosure, only that there is a process. We cannot determine whether it is better to say nothing to the child until the moment of full disclosure as compared to providing misleading information. It would be important to see how the different patterns of disclosure play out over time, and to see whether children who experience different paths to full disclosure have different outcomes. Future longitudinal studies should also incorporate measures of psychological and emotional well-being and distress for children, to better assess the impact of experiencing different paths towards full disclosure on children.

The study's small sample size also limited our ability to test multivariable models incorporating more than one domain of interest at a time. Larger studies could explore more elaborate models, involving multiple factors across multiple domains of interest. Despite their validation in similar settings, several of the scales used in this study were, in the end, not reliable. Further studies should also conduct more in-depth pilot testing of scales, and adapt them to each local context.

The study population represents a very unique group of children within Sub-Saharan Africa, to date. Findings from this study are generalizable to a very specific population. The children were all accessing medical care for their HIV infection, and were mostly enrolled in a program providing antiretroviral treatment for those requiring it. Only 13 percent of children in Sub-Saharan Africa requiring antiretrovirals currently have access to them (WHO et al., 2007). The impact of access to medications, beyond extending their lives and creating hope for futures, on what caregivers tell children about their health can only be determined by comparing children with access to these life-prolonging regimens to those with no access.

We found that male caregivers were less likely to have said something true or something misleading, versus nothing, but are unable to explain why. It is possible that male caregivers communicate less to children under their care, whether or not the communication is misleading or not. Further studies need to explore the impact of traditional family roles and gender on information given to children. Qualitative work exploring the traditional roles of family members, particularly around communication to children, would not only help us understand why communication occurs as it does, but also help to design stronger programs to help families with this communication.

Implications for interventions

Misleading information figures strongly in communication between caregivers and children. For this study, misleading information was defined as information given to the child that was (1) intentionally misleading and (2) ambiguous in its intention. Understanding what factors are associated with caregivers giving children misleading information may help treatment programs assess families' support needs around communicating with HIV-positive children about their health. For example, if the youngest children are most likely to have been told nothing, while children within the middle age category (9-12 years) more likely to have been told something misleading than nothing, messages reinforcing the possible negative consequences of telling children misleading information could be targeted to those caregivers with children in the appropriate age range. It is also possible that caregivers are themselves misinformed or misunderstand the child's health status, or else unsure of how to respond to children's inquiries. Service providers could assist caregivers in developing appropriate responses to questions from children, as well as providing children with age appropriate information about their health as they get older.

Awareness of reasons to disclose for caregivers also helps providers with possible entry points for discussions about informing children and determining best moment to tell them of their HIV diagnosis. It is apparent from this study's results that many caregivers see themselves playing a main role at the moment of full disclosure of HIV status to the child. A third of the caregivers named providers as the best persons to eventually inform their child of her/his HIV diagnosis. Providers can therefore work with caregivers to identify the best moment and approach to tell the child, and in cases where caregivers wish to inform the child on their own, help the caregiver to prepare for that conversation and the ones that may follow.

Children live within social contexts. Working with the factors influencing communication patterns with them—their caregivers' own circumstances and the interpersonal relationships existing between children and their caregivers—is critical if we want disclosure to lead to positive outcomes with minimal negative consequences.

The interplay between caregiver characteristics, child characteristics, and the interpersonal relationships between the two should be incorporated into disclosure preparation by care, treatment, and support programs. Awareness that the caregivers' characteristics, as well as those of the child, are associated with disclosure should lead programs to assess caregivers more closely, and to assist them, rather than solely focusing on the needs of the children, in order to improve disclosure practices and outcomes.

The fragile socioeconomic context may have contributed to making the availability of the smallest amounts of instrumental social support the most strongly associated factor in patterns of communication with infected children. Also, inaccurate knowledge about HIV and blaming attitudes towards people living with HIV/AIDS, whether internalized by caregivers or seen to exist in the larger community, are associated with the types of information given to children about their health. While treatment programs could address these issues at the individual level, with caregivers, the findings seem to point to broader social factors that impact caregiver behaviors.

CHAPTER 5
INFORMING CHILDREN OF THEIR HIV STATUS IN KINSHASA, DEMOCRATIC REPUBLIC OF THE CONGO: CHILDREN'S EXPERIENCES AND IMPLICATIONS FOR INTERVENTIONS

5.1 ABSTRACT

Understanding the disclosure experience from the perspective of HIV positive children is critical to developing appropriate interventions to support families through the disclosure process. Through the children's experiences we can learn about what works well, what needs to be strengthened, and what is missing in current disclosure practices. We conducted in-depth interviews with eight caregiver-child dyads in Kinshasa, Democratic Republic of the Congo. The children were in a comprehensive HIV pediatric care and treatment program and had previously experienced disclosure of their HIV status. For the analysis we placed particular emphasis on the communication, as experienced by the children, throughout the disclosure process. Patterns emerged of limited communication between children and their caregivers, as well as with their providers, before, during, and after disclosure. The experiences of the children in this study were similar to those reported in other settings. From their perspective of children in this study, however, disclosure was by and large viewed as a discrete event rather than a process.

5.2 INTRODUCTION

Globally, in 2006 2.3 million children under the age of 15 (range 1.7-3.5 million) were living with HIV infection—nearly six percent of the 39.5 million total estimated (range 34.1-47.1 million); over 90 percent of these children resided in developing countries (UNAIDS, 2006). At the end of 2006, only 115,500 children under age 15 years in need of antiretrovirals worldwide had access to treatment, representing only 15 percent of the estimated 780,000 needing access (WHO et al., 2007). Sub-Saharan Africa has the lowest pediatric treatment coverage for any region, with only 13 percent of children needing treatment receiving it as of 2007 (WHO et al., 2007). With increasing access to these treatment regiments, infected children will increasingly be surviving into adolescence and adulthood.

Our understanding of the clinical manifestations and evolution of HIV-related illness and its treatment among children has increased as a result of the last two decades of research on the subject. However, limited work has been conducted to increase our understanding of the psychosocial aspects of HIV/AIDS in infected children. One such area needing exploration is what, when, and how HIV-infected children are told about their health. HIV-infected children under medical care are often not informed of their illness, despite some evidence from industrialized countries indicating that informing children can have positive psychosocial and clinical outcomes (Bachanas, Kullgren, Schwartz, McDaniel et al., 2001; L. Wiener et al., 1994).

Evidence on Disclosure of HIV Status to Children

Disclosure of HIV status to infected children varies across geographic regions. Studies conducted in the United States, Canada, and Europe indicated that the proportion of HIV-infected children who had not been told—or disclosed—their HIV status ranged from 25 to 70 percent in the U.S. and Canada (Cohen et al., 1997; C.A. Mellins et al., 2002; Nehring et al., 2000; L. S. Wiener et al., 1998) and was as high as 75-82 percent in Europe (Funck-Brentano et al., 1997; Lwin & Melvin, 2001; Thorne et al., 2000).

Only four studies published to date have included information on disclosure levels among HIV-infected children in developing countries. In an examination of factors influencing adherence to antiretroviral regimens, Bikaako-Kijura and colleagues in Uganda noted that 29 percent of their sample of 42 children had been fully disclosed their status (Bikaako-Kajura et al., 2006). A Zambian study, looking at mental health status of HIV-infected adolescents ages 11-15 years, found that only 37.8 percent of the sample had been told of their HIV infection; the study found that those informed of their status were, after controlling for age, gender, and medication, significantly less likely to have a score in the abnormal range of a scale assessing emotional difficulties (Menon, Glazebrook, Campain, & Ngoma, 2007). In Thailand, Oberdorfer et al noted that 30.1 percent of caregivers reported having disclosed to children; however, only 53 percent of those caregivers had actually mentioned HIV and/or AIDS to their child, or 16 percent of the total sample (Oberdorfer et al., 2006). Butterworth and colleagues, also in Thailand, observed that older age groups had greater levels of full disclosure (Butterworth et al., 2007); while none of the children 6-9 years of age had been informed of their HIV status, 18.8 percent of those between the ages of 10-13 years had been told, and 62.5 percent of those aged 14-17 years.

Children's age and their cognitive development were most often identified as reasons for disclosure among studies conducted in the United States, Canada, and Europe

(D. DeMatteo, Harrison et al., 2002; D. DeMatteo, Wells et al., 2002; Funck-Brentano et al., 1997; Gerson et al., 2001; Ledlie, 1999). The actual age of disclosure varied across the many studies, but in general disclosure was more common as the age of children increased (Bor et al., 1993; Cohen et al., 1997; Flanagan-Klygis et al., 2001). Children under age 6 years were least likely to have been told their HIV status. Cohen et al, for example, found an overall prevalence of disclosure of 30 percent among US children aged 5-10 years, but 95 percent for those over age 10 (Cohen et al., 1997). Flanagan-Klygis and colleagues, found that 35 percent of 65 US children had been fully informed of their HIV status, with a mean age of disclosure of 7.8 years (Flanagan-Klygis et al., 2001); Weiner and colleagues documented a similar mean age of disclosure of 7.5 years among US children (L. S. Wiener et al., 1996). Other reasons to disclose cited by parents or adult caregivers included the child's deteriorating health status (Funck-Brentano et al., 1997; Gerson et al., 2001; Grubman et al., 1995), questioning by the child (Lester, Chesney, Cooke, Weiss et al., 2002; L. S. Wiener et al., 1996), the need to maintain family trust (D. DeMatteo, Wells et al., 2002; Nehring et al., 2000), and the child's right to know (Lester, Chesney, Cooke, Whalley et al., 2002; Nehring et al., 2000)

The nine studies to date from low- and middle-income countries identified similar factors that influence telling children of their HIV status. Young age, the desire to protect the child from psychological harm, and the desire to protect the child and/or family from social stigma feature as main reasons for not disclosing (Ayres et al., 2006; Kouyoumdjian et al., 2005; Oberdorfer et al., 2007; Oberdorfer et al., 2006) Two studies noted starting treatment or problems adhering to treatment as reasons for disclosure (Azondekon et al., 2005; Oberdorfer et al., 2006). In Benin, a pilot study for health care providers to disclose HIV status to children ages 6-14 years noted that lack of adherence to treatment was a reason to disclose for 30 percent of participants, the child's expressed will to know his/her condition for 80 percent, and the child's expressed fear of the health condition a reason to disclose for 50 percent (Azondekon et al., 2005). In two studies, the decision to inform the child was made by health providers, with caregiver approval, and tied to medication regimens (Azondekon et al., 2005; Nannyonga-Musoke et al., 2007). In South Africa, a study conducted with health providers treating infected children identified cognitive development—namely, understanding concepts of chronic illness—and the time period preceding the onset of puberty as factors influencing disclosure (Myer et al., 2006).

While there is evidence that children with chronic illnesses are at risk of emotional and behavioral difficulties resulting from their health status (Bachanas, Kullgren, Schwartz, Lanier et al., 2001; R. J. Thompson, Jr. et al., 1993; Wallander & Varni, 1998), there is also evidence that children benefit from an open discussion of their illness and that nondisclosure does not necessarily protect children from psychological distress (Claflin & Barbarin, 1991; Eiser, 1994; Slavin et al., 1982). Despite concerns about the negative social and psychological impacts of disclosure to children, a few studies from industrialized countries found that HIV-infected children fared well after disclosure, and better than children unaware of their HIV infection (L. Wiener et al., 1994). For example, Bachanas and colleagues found that children in the United States who had not been told their diagnosis reported more psychological distress than children who had been told their diagnosis (Bachanas, Kullgren, Schwartz, Lanier et al., 2001). Similarly, Mellins et al noted no difference in mental health between children who had been told their HIV status, versus those who had not had been so, as well as a trend towards less depression among children who knew their HIV status (C.A. Mellins et al., 2002). An intervention study providing social support during and after the disclosure process to families and adolescents in Puerto Rico found that six months after disclosure, adolescents had returned to their pre-disclosure levels of depression, and that the majority considered disclosure to be a positive event (Blasini et al., 2004).

Conceptualization of Disclosure to Children

The literature on disclosure of HIV status to children conceptualizes disclosure in one of three ways. One way envisions disclosure as a one-time event when information about the diagnosis of HIV or AIDS is provided to the person (Flanagan-Klygis et al., 2001; Ledlie, 1999, 2001; Ostrom et al., 2006; Thorne et al., 2000). Some of these articles discuss factors before the actual disclosure event, such as preparation to disclose (Flanagan-Klygis et al., 2001; Ostrom et al., 2006). The second conceptualization sees disclosure from the perspective of caregivers/parents and focuses on the process undertaken by them (D. DeMatteo, Harrison et al., 2002; Gerson et al., 2001; C. L. Lee & Johann-Liang, 1999; Pequegnat & NIMH Consortium on Family & HIV/AIDS Research, 2002). This conceptualization incorporates the parent/caregiver's preparation of self as well of the child, the assessement of risks and benefits, the identification of the right moment, and the establishment of proper support (D. DeMatteo, Harrison et al., 2002; Gerson et al., 2001).

The third conceptualization of disclosure is also process-oriented, but focuses on the recipient of the information rather than its provider. A large portion of the literature published on disclosure of HIV status to children uses this characterization of the disclosure process (Abadia-Barrero & Larusso, 2006; Blasini et al., 2004; Funck-Brentano et al., 1997; Kouyoumdjian et al., 2005; M. B. Lee & Rotheram-Borus, 2002; Lester, Chesney, Cooke, Weiss et al., 2002; Lester, Chesney, Cooke, Whalley et al., 2002; Lipson, 1993; Myer et al., 2006; Nehring et al., 2000; Rotheram-Borus et al., 1997; Waugh, 2003; L. S. Wiener et al., 1996). Two approaches are taken in this definition of disclosure. The more commonly used approach breaks down the information received into categories, such as "no information", "deceptive information", "partial information", and "full disclosure" (Funck-Brentano, 1995; Funck-Brentano et al., 1997; Kouyoumdjian et al., 2005; Lester, Chesney, Cooke, Whalley et al., 2002; Nehring et al., 2000; L. S. Wiener et al., 1996). The second approach focuses less on stages and instead emphasizes the ongoing nature of disclosure, incorporating conversations following the disclosure of the diagnosis as part of the overall process (Abadia-Barrero & Larusso, 2006; C. L. Lee & Johann-Liang, 1999; Lipson, 1993; Myer et al., 2006; Waugh, 2003).

Little has been published that pays particular attention to the process of disclosure to HIV-infected children in developing countries. This article focuses on the process of information provision throughout the disclosure process to children in a comprehensive HIV pediatric care and treatment program in Kinshasa, Democratic Republic of the Congo. The lessons drawn from their experiences can give us some practical ideas of how to create interventions to support families through the process of disclosure of HIV status to their infected children in this setting.

The Study Setting

The Democratic Republic of the Congo (DRC) was one of the first sub-Saharan African countries to document HIV/AIDS cases in the early 1980s. The latest national figures estimate an HIV prevalence of 4.2 percent, translating roughly to one million people ages 0-49 years living with HIV infection in the country (range 560,00-2,000,000), including 110,000 children under age 15 (range 42,000-280,000) (WHO et al., 2006). The latest treatment figures include an estimated 44,000 children aged under 15 years needing ARV therapy (range 20,000-81,000) and only 550 receiving it as of September 2006 (WHO et al., 2007).

Although no figures exist for the number of HIV-infected children in Kinshasa, the number can be estimated using existing data. Kinshasa's population is approximately 13.7 percent that of the country as a whole[3]. If we assume that HIV is proportionally distributed across the country, based on population size, approximately 15,000 children under age 15 years are infected with HIV in the city. This number is likely an underestimate--the number of infected children in Kinshasa might in fact be higher because of the large numbers of child soldiers and street children found in the city, who are themselves at higher risk of HIV infection as a result of their social marginalization and high risk behaviors (Human Rights Watch, 2006; Lockhart, 2002; Wutoh et al., 2006).

5.3 METHODS

The data presented here are part of a larger study on disclosure practices to HIV-infected children. This disclosure study was embedded within the Pediatric HIV Care Program, a comprehensive, family-centered HIV care and treatment program in Kinshasa,

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[3] Kinshasa's population is estimated at 7.5 million while that of the country as a whole is 60 million.

Democratic Republic of the Congo (DRC) based at the Infectious Disease Unit of Kalembe Lembe Pediatric Hospital. Funded by the US Centers for Disease Control and Prevention (CDC), the program has enrolled over 500 children and over 200 of their first-line relatives, since its inception in 2004, and provided them with clinical and psychosocial care, including antiretroviral treatment when appropriate.

Recruitment

We used two strategies for identifying families who had already fully disclosed HIV status who were potentially eligible for participation. First, based on their knowledge of the disclosure status of children in the project, program staff identified and contacted potentially eligible participants ahead of time,; the primary caregiver was informed about the study and invited to come with the child to the hospital at a time most convenient to them. Second, the program's team and the Infectious Disease Unit nursing staff also screened all caregivers of infected children ages 8-17 years when they presented for a regularly-scheduled clinic visit to identify families who had disclosed to their HIV-infected but not informed the clinical team. Those meeting eligibility criteria were told of the study and if they agreed to participate, an appointment made for them to return for the interviews.

Eligibility was reassessed by program staff on the day of the interview, prior to obtaining informed consent. For the purposes of this study, a youth was considered to have been fully informed of his or her status if the terms HIV, AIDS, or any other local term specifically associated with HIV/AIDS were used in a discussion with the youth specific to the youth's health status. Children who were unable or unwilling to state that they had

HIV, AIDS, or other local terms used for HIV/AIDS when screened for eligibility were not interviewed, even if the caregiver had said that the child had been disclosed their HIV status, in order to avoid causing emotional distress to the child; in such circumstances, only the caregiver was interviewed.

If both the parent/caregiver and the child consented to have the child's interview conducted without the parent/caregiver present, the two interviews were conducted separately and simultaneously, each by a different interviewer. If the caregiver preferred to be present during the child's interview, the adult interview was conducted first, in the absence of the child; after the caregiver interview was completed, the child's interview was done with the same interviewer because the caregiver would have become familiar with the interviewer and developed a level of trust during the first interview.

Data Collection

In-depth interviews were conducted with children ages 8-17 years who had undergone full HIV disclosure, as well as with their primary caregivers. The research was approved by the Institutional Review Boards both at the University of North Carolina at Chapel Hill in the U.S. and the Kinshasa School of Public Health in the DRC. Informed consent, parental consent, and informed assent were obtained as appropriate.

Semi-structured interview guides for parents/caregivers and for children were used for all interviews. These guides outlined the topics for discussion and suggested probes for the interviewers. The adult interviews began with a series of structured questions about individual level characteristics such as: demographics, time since diagnosis, educational levels of both caregiver and child; and family characteristics such as: relationship of caregiver to child, marital status, whether the child's biological parents were still alive. The remaining questions were open-ended in order to best capture the disclosure experience of these dyads; open-ended questions and qualitative methods are appropriate strategies when attempting to gain insights on little-understood processes rather than capturing frequencies or associations between factors (Patton, 2002). The open-ended questions explored preparation activities, anticipated reactions of children, the moment of disclosure, and what has taken place since the initial disclosure moment. The children's interviews did not include the structured questions from the adult interviews. Instead, the children's interviews began with an exploration of their understanding of their health prior to disclosure, moving into a description of the disclosure event and the child's reaction, and then into events since the full disclosure moment; the child's opinion on disclosure and his/her understanding of HIV before and after disclosure were also examined. Questions were adapted from the interview guides used in previous studies (D. DeMatteo, Harrison et al., 2002; C. A. Mellins & Ehrhardt, 1994; L. S. Wiener et al., 1998); additional questions were developed from themes emerging from the analysis of the formative work done the previous year (L. M. E. Vaz et al., in press).

The interviews were held in a private room at the site of the Pediatric HIV Care Program. Participants had a choice of being interviewed in either French or Lingala, the local language; all but one of the children and one of the adult caregivers chose to be interviewed in Lingala. Local Congolese interviewers trained in research methods conducted the interviews, which were audiotaped with participant permission. Adult interviews lasted approximately 90 minutes each, while interviews with the children lasted between 60-90 minutes each. All interviews were transcribed directly into French by the interviewer who conducted the interview. All transcripts were then verified by a second interviewer, both for completion of the transcript as well as accuracy of the translation from Lingala to French. Analysis was conducted in French.

Data were analyzed using qualitative content analysis to identify themes and patterns related to research questions (Miles & Huberman, 1994). Deductive and inductive codes were developed and applied to the data using Atlas-TI v. 5.2. We ensured inter-coder reliability by coding selected transcripts separately by two analysts, then comparing codes and resolving discrepancies when necessary. Data display and reduction tables were developed with feedback from a multidisciplinary team.

5.4 RESULTS

Of the 259 children ages 5-17 years screened from the Pediatric and the hospital's Infectious Disease Unit, only eight (3%) between the ages of 8 and17 years were identified as having been informed of their HIV status. We conducted in-depth interviews with seven of these children and nine of their caregivers. One child did not state she had HIV during the screening process, and thus was not interviewed; her caregiver, however, was included in the study. Both biological parents requested to be interviewed in the case of another child. Although most pediatric HIV infections in this setting are thought to be a result of perinatal transmission, other modes of acquisition do exist for children, although not well-documented, such as blood transfusions. In only one of the dyads interviewed was there a suggestion that the youth might have been infected sexually; among the rest, where parent HIV status was either negative or presumed to be negative, transmission might have occurred through infected blood products. Mode of HIV acquisition can only rarely be confirmed in this setting. All of the youth interviewed were on antiretroviral regimens at the time of the interview. Table 1 provides basic demographic information about the eight dyads interviewed.

Table 5.1: Basic Demographic and Clinical Characteristics of Dyads Interviewed

Family	A	B	C	D	E	F	G	H
Adult ID(s)	**PD01**	**PD02, PD03**	**PD04**	**PD05**	**PD06**	**PD07**	**PD08**	**PD09**
Age:	34	38, 45	30	46	41	53	44	48
Gender:	F	F, M	F	F	F	M	F	F
Relationship to child	Biological mother	Biological mother, father	Biological mother	Biological mother	Biological mother	Biological father	Biological mother	Biological mother
Biological parents (of child) alive	Yes, both	Mother yes, Father yes	Mother yes, Father no	Mother yes, Father yes	Mother yes, Father no	Mother unclear, Father yes	Mother yes, Father yes	Mother yes, Father yes
Caregiver HIV status	Mother HIV+	Mother HIV+	Mother HIV+	Mother HIV-	Mother HIV+	Unknown, father presumed negative	Unknown (presumed negative)	Mother HIV-
	Father's status unknown	Father HIV-	Father's status unknown (likely HIV+)	Father HIV-	Father HIV+			Father's status unknown
Minor ID	**M01**	**M02**	**No minor interview**	**M03**	**M04**	**M05**	**M06**	**M07**
Child gender	F	M	F	F	F	M	F	F
Child age at interview	11	8	9	15	15	14	17	17
Child age at diagnosis	10	8	8	12-13	<1 year	11-12	16.5	15
Parent present during child's interview	YES	YES (mother)	No minor interview	Last section only	NO	Yes	NO	NO

The data presented here is organized linearly, summarizing events before, during and after disclosure to present a narrative of the process as experienced by the children. Although findings from caregivers as well as youth will be presented, particular emphasis is placed on the process as experiences by the youth. Special attention is paid to the communication between the caregiver-child dyad as well as that between the health providers and the children. This approach towards the data provides a very detailed understanding of the children's experiences with their health and their interaction with the health care system.

Before full disclosure

Youth were asked what they knew of their health prior to being told the name of their illness. Almost all youth interviewed said they had been told nothing about their illness prior to full disclosure of HIV status. However, during the interviews, a different story emerged. Most had been given limited partial information about their health. They believed that they were sickly and suffered from multiple illnesses and symptoms that they believed would be cured one day. Two had been given misleading information about their health and thought they had another illness. One thought he had tuberculosis, based on his symptoms and a prior diagnosis (M05). The mother of another child (PD09) reported that the child had been told that she had a problem with her spleen that was inoperable.

Children and their health providers rarely communicated with each other before disclosure.

Almost all youth reported having no direct conversations about their health with the health providers with whom they were in contact before being told of their HIV status. Several commented that the providers would speak to a parent, but not to them. Some were told of diagnoses of other illnesses by providers, but not of HIV. Two of the children expressed concerns about their health to their providers and said they received some information in return. This ranged from general information on chronic illness to actions to prevent others from contamination. Youth also noted that providers simply told them not to worry and that their health would improve. Only one spoke of an in-depth conversation with health providers about her health, which preceded the disclosure of her HIV status. The youngest children interviewed made no mention at all of providers during the time before disclosure. The mother of one of these children, however, reported that the child was shown a film during a support group meeting at a health center; the child also mentions this film as part of his retelling of the moment of disclosure.

> *He [the doctor] put it [the film] on the television. It was a sick child, who could not make it to school, who was not in a condition to play, who was not able to play ball…now, he had friends : Jerry… now, he became strong, he had gone to the hospital [where] they gave his some medicines, he began to play ball, to play as well, he began to sing…*
>
> *(8-year old boy, M02)*

Communication between children and caregivers before full disclosure revolved around children's questions about their health

Most youth reported having prior conversations with their caregivers about their health prior to being told of their HIV status. The conversations revolved around youth's questions about what sickness they had, why they were constantly ill, or why they had to continually take medications. Of the five who reported asking questions, most were given either vague responses or else no responses at all. Some youth also reported receiving advice from parents that they should avoid worrying or place their faith in God. One reported having no prior conversations at all with his parents before he was disclosed his HIV status.

When asked, all of the youth reported having some questions and/or concerns about their health prior to being told their HIV status. Most of the youth wondered why they were always sick and/or what illness they had. A few wondered why they were the only ones in their families who were constantly sick; three had concerns about their symptoms. Only one reported having specific questions about having to take medications all the time. One child, the youngest interviewed (age 8 years) said that he wondered whether he had AIDS; however, throughout his interview he had difficulties distinguishing the time before disclosure and the time since disclosure. Although they had questions and concerns, two also reported that they saw their illnesses as "normal" because they had always been that way. The youth most often turned to their parents, most frequently to their mothers, with their health concerns and were given vague responses that it was an illness and would pass. Some, however, reported that they had questions but that they kept them to themselves.

> *There are times when I cried, why only me and not my sisters… when I said that, only me, sometimes they would say to me… it's nothing, it's just the way it is… it will change. (15-year old female, M03)*
>
> *…I would worry inside me, mother suffers, I suffer also, but who will help whom ? When they did not make things clear for me, I found that normal, mother told me nothing. Perhaps it is an illness that disturbs her and bothers me as well. (15-year old female, M04)*

Based on caregiver reports, communication with children about the child's health before full disclosure were in large part initiated by the child's emerging questions. Two reported that their conversations stemmed from questions about taking medications; this line of questioning served as an impetus to inform their child of their HIV status. Others reported that children wondered why they were always sick; parents had different responses, ranging from not knowing to naming another illness to saying it was God's will.

Two parents, both of adolescent girls, reported their daughters' concern about not developing physically like their peers. Other parents stated their child never asked them questions. Some parents reported health-related conversations that did not stem from their child's questions; these conversations focused largely on the importance of taking medications, although one caregiver used the conversations as preparation to inform the child of her HIV status.

Parents thought about informing their children before telling them about their HIV diagnosis, but rarely prepared the child to receive the information.

Parents were asked about the circumstances that lead them to tell their child about their HIV status. Medications featured strongly in parents' decisions to inform their children, either because children were increasingly difficult in taking them, or because they were starting antiretroviral regimens. The majority of parents also mentioned the importance for the child to know him/herself, as well as the reason for their prolonged ill-health, as impetus informing the child as. Informing children so that they could take precautionary measures to prevent infection of siblings and others was also a common response from participants. Three parents specifically mentioned the increasing age of their daughters and concern about infecting others through sexual transmission.

Although the caregivers' interviews suggest that several thought why and how to inform their child about their HIV status, only one of the youth (M03) interviewed specifically referred to being prepared for disclosure. In her narrative, the youth says she was well-prepared by her mother, who spoke to her of her health, showed her love and affection, and provided her with advice to seek strength in God. The mother explained that she strove to ensure that the child did not feel as though she were being treated differently from the rest of her siblings, and to demonstrate that people often misunderstand what they do not experience themselves. The child also referred to preparation activities by the program team, who had her look up information on the internet about various chronic illnesses, including HIV, in the weeks before the moment of full disclosure.

Nearly half of parents reported not preparing the child at all for full disclosure; of those, two had disclosed during moments of frustration with their children's medication taking. For the rest, preparation of the child was done on the day of full disclosure, often in the moments immediately preceding the conversation. Preparation activities included preparing favorite foods, offering gifts and making sure the child felt loved.

All of the parents interviewed anticipated that their child would react negatively in some way to learning his/her HIV status. Most thought that the child would be worried, and some that their child would be sad or cry. A few thought the child could possibly try to harm herself afterwards. A couple thought their child might ask some questions. In contrast to the other parents, one spoke about measures she took to try to avoid or minimize the negative reactions she thought her daughter might have to learning her status. None of the other parents mentioned taking steps to offset the anticipated reaction.

> *…it is necessary to take time to talk a lot to the child and attest to him a lot of love, so when the parent is aware that nothing changes in your relationships, on the contrary, it must be multiplied so that the home… so that she sees that matters have not changed the arrangements [of the home] towards her…*
> *(Biological mother of a 15-year-old female, PD05)*

The moment of disclosure

The stories of disclosure in this study took place between 3 months and 2 years before the interviews. In all but one of the cases, parents learned of their children's HIV diagnoses when the child was beyond age 2 years of age. In all but one case, parents were aware of their child's diagnosis for several months, if not several years, before the child was informed. Although only two of the youth were on antiretroviral regimens at the time of disclosure, all but one was already taking medications on a daily basis, and two were about to start antiretroviral treatment.

In most of the families interviewed, a parent informed the child of his/her HIV status. However, there were some discrepancies between reports of children and reports of adults on who disclosed—in two cases, the child indicated that they were informed by a doctor, with a caregiver present, while the parents' reports stated that the child was informed by the parent at the home, rather than by the doctor, although mention of discussions with doctors were made in their interviews. Table 2 summarizes some characteristics of the moments of full disclosure of HIV status.

Table 5.2: Basic characteristics of moment of full disclosure

Family	A	B	C	D	E	F	G	H
Child age at disclosure	11	8	9	13	14	13	16.5	16
Time between diagnosis & disclosure	5 months	3 months	9 months	6 months	14 years	1 year	Same moment	~1 year
Time since disclosure	6 months	4 months	3-4 months	1.5 years	1 year	1.5-2 years	5-6 months	7 months
Location of disclosure	home	P: home Y: hospital	home	P: home Y: hospital	home	home	hospital	home
Who disclosed	mother	P: mother Y: doctor	mother	P: mother Y: doctor	mother	father	nurse/ counselor	mother
Who Else Present	no one	P: no one Y: mother	aunt	P: alone Y: mother & another doctor	no one	no one	P: no one Y: nurse trainee	P: no one Y: older sister
Disclosure planned	yes	yes	no	yes	yes	no	no*	yes

*P=parent report, Y=child report; *disclosure was done at the moment of diagnosis*
Note 1: *information from both interviews is included in the table where discrepancies exist between the parent and the child reports of the disclosure moment*
Note 2: *All children were reportedly in good health at the time of disclosure.*

Disclosure, from youth reports, included minimal information about the illness itself.

Two of the three youth who were told by health providers mention some information provided to them in addition to being told of their status—one over several visits, the other through a video screening in a support group. The information provided clinical context to the illness, by discussing chronic illnesses or by demonstrating how medications can keep a person healthy. Only one of the youth interviewed—one who was told her HIV status by a health provider—said that she was given information about how HIV works and how the drugs work to keep the infection at bay. A few noted that medications featured in the disclosure conversation, whether as a starting point for discussion or as advice on being healthy. Others specifically noted they were told not to worry as it will cause them to become sicker or die; this message featured in conversations with caregivers as well as with providers. Several youth who had been told by caregivers reported discussing the source of infection with a parent; none of the youth who had been informed by providers mentioned discussions about HIV acquisition during the conversations.

Interviewer.: What else did mother do or say ?
Participant: She said that I should not worry. If not I will die from them.
(11-year-old female, M01)

I was told to properly follow the treatment so that I may be cured.
(14-year old HIV-positive male, informed by biological father, M05)

She said to me : the way I am, I am sick ; I asked her what was the illness. She answered me that she had the illness that they call AIDS.
(15-year-old female, M04)

They explained to me how that (the drug) works in the body and what it will do when I will stop. They explained how it's given…with the ARV [antiretroviral medications], one will lead it [to a cure]…it[the cure] is not yet there by regular means.
(15-year old female, M03)

Medications feature prominently in disclosure discussions as reported by parents. All conversations touched upon medications, whether as an entry point for full disclosure, as part of the description of the illness, or as part of the advice given to the child on how to act. A few parents stated they gave some description of how HIV/AIDS works in the body as part of the rationale for having to take medications. Several talked about avoiding contaminating others by not sharing sharp objects.

Some of the HIV-positive parents revealed their own status whilst informing their child of their own HIV status, as a way to comfort and reduce the possible distress of the child. In the one case the mother did not inform the child, but the father reports telling the child in a later subsequent conversation. The one caregiver who did not share her own HIV status with the child had informed her child of her HIV status in a moment of anger. However, only one child mentioned learning of her parent's HIV status at the same time as she learned about her own status.

Youth Reported Negative Reactions But Also Relief Upon Learning of Their HIV Status

Approximately half of the youth described feeling hurt or bad ("mal au coeur") immediately upon learning their HIV status; in addition some felt saddened upon hearing the news. Three youth specifically mentioned stigmatizing perceptions of HIV as reasons why they had negative reactions upon first learning their HIV status. In contrast, two of the youth described feeling relief, joy and happiness in learning what was causing their illness so that they could now take care of themselves. One claimed not have felt anything, claiming that she did not believe the news. One youth felt hurt but then felt reassured once her sister told her it was a disease like any other.

> *That hurt me a lot. Because this illness, it is for the debauchers, but me, at this age, I cannot have this illness.*
> *(11-year-old female, M01)*
>
> *I felt…well, I did not feel uneasy, I was well… really, as for worries, I did not have any, I did not have any worries… I was happy that they told me this news, I love my mother a lot up to today because she told me the truth beforehand.*
> *(15-year-old female, M04)*

After expressing their reactions upon first learning of their HIV status, youth were given a series of emotions other children had felt upon learning their HIV status for the first time, and asked whether or not they too felt that way. Most were worried upon hearing their diagnosis, but only few could explain the reasons they were worried, citing either fears that they would get sicker or disbelief that they could have this illness. The majority also expressed being relieved upon disclosure of their HIV status, mainly because they now had a name to put to their suffering. Many felt sad upon learning their HIV status, because of their young age, and because of the stigma associated with the illness. Most also said that they were not calm when they learned the name of their illness; however, two said that they quickly regained their calm. Those who felt calm at the moment of the full disclosure stated that learning their HIV status brought them peace after not knowing from what they were suffering.

> *There was like a hard ball in me, I was uneasy… I only wanted to know my illness… as I heard the name of my illness, I was relieved, I found my inner peace….*
> *(15-year-old female, M03)*
>
> *Well, when I left [the hospital], I implored God, told him to give me peace because I did not know… I risk dying like that [she says it with a affirmative head gesture]. I felt a calm fill my heart, I began to play.*
> *(15-year-old female, M04)*

__Caregivers Perceptions of Their Child's Reactions Differed from Children's Reports__

In contrast to the youth, more than half of the parents reported that their child had no reaction upon being told their HIV status; one of these parents felt it was because the child did not understand what had been told (PD04). Three parents reported that their child cried upon being told their HIV status, but only one reported that it lasted beyond a short period of time. A few parents also reported that the child asked questions. Also in contrast to the youth reports, parents were more evenly split between those that reported their children being surprised at the moment of full disclosure and those reporting they were not surprised. Those who felt their child was not surprised mostly felt it was because of the methods used to disclose, although one felt that the child did not understand what she was told. Those who felt their child was surprised felt that it was because they did not understand how they could get it or did not expect it.

After full disclosure

Youth were told things by their caregivers following disclosure, but did not engage in discussions about their health.

It appears that youth distinguished between being provided with information by parents and engaging in dialogues with them. Almost all of the youth interviewed said they have had no conversations with their parents since the disclosure of their HIV status; however, all but one reported being told something by a parent. Youth reported receiving advice from caregivers ranging from medication adherence and appointment reminders to avoiding worries, how to protect siblings from infection, and spiritual guidance. In one family (D), conversations did take place, but only between the youth and her mother, and not her father.

> *He told me to take my medicines correctly.*
> *(15-year-old male, M05, about conversation with biological father, PD07)*
>
> *She only said to have hope, even if it is what, even if it is AIDS, God, he, atoned for this illness on the cross, he will heal me.*
> *(15-year-old female, M03, about conversation with biological mother, PD05)*

Most caregivers reported talking to their child about their health after full disclosure of their HIV status. Conversations include reminders about taking medications (5/7), actions to be taken to protect others from infection as well as to protect one's own health, and questions or thoughts about the future). Several reinforced the importance of trusting God and in praying for a cure. A few parents had told their child to keep her/his HIV status a secret between them, citing concerns about rejection by others as reasons for doing so. Of note, three of the four HIV-positive parents mentioned that their own status is incorporated into conversations with their child, within the context of the importance of taking medications. Two parents, both mothers, noted that they have not spoken to their child about their health status since disclosure, and one other noted that she feels uncomfortable talking about HIV and prefers to only give her child advice.

> *I, your mother, I am there. I take my medications, I am well.*
> *PD01, biological mother of 11-year-old female, M01*
>
> *…show me or talk to me about this or that, no, no. I do not know if she is*
> *aware that I am not happy with this kind of chatter.*
> *PD08, Biological mother of 17-year-old female, M06*

Caregivers were unaware of youth's questions and concerns following disclosure

Most of the youth reported having at least one question or concern following disclosure. The most common questions and concerns revolved around understanding the source of their illness, confirming their diagnosis, getting better or cured, and knowing that AIDS is fatal. As with the questions and concerns before full disclosure, youth most frequently turned to their parents—in particular, their mothers—for answers or solutions.

In two instances, mothers worked in tandem with health professionals to address the youths' concerns. A few of the youth were told to stop worrying or else they would relapse or get sicker. One child spoke to the health provider and not to a parent; another stated that his parents ignored his questions, which made him feel bad, and two kept their concerns to themselves. Of note, most of the youth had questions or concerns that they either did not voice to anyone or else felt were left unanswered.

In contrast to youth reports, most caregivers interviewed reported that the child did not have any questions or concerns following the moment of full disclosure; one of these adults admits that she is uncomfortable discussing HIV status with her child, and that the child knows this. Only one caregiver reported that her child wondered whether a cure would be found; another reported that her child wondered if she had to take the drugs for life. Two caregivers reported that youth needed clarification on how a child could be infected. Only one parent reported that the child had concerns about her future and being able to finish school.

Conversations between youth and health providers remained nonspecific and clinically-focused after youth knew their HIV diagnosis

All but one of the youth interviewed described conversations with health providers in the time since full disclosure of their HIV status. Conversations largely focused around ensuring that medications were being taken as they should, with advice that must be taken on time to avoid becoming ill again. Youth also reported receiving other advice from providers, including ways of protecting themselves and others and the importance of not worrying. Providers also assured youth that there will be an improvement in their health, if they follow their drug regimens and do not worry. Questions to youth focused on the physical well-being of the youth, such as whether the youth is feeling well, have there been any symptoms, and whether drugs are being taken as prescribed. One youth, the youngest interviewed, reported that a provider told his parents in his presence that AIDS is bad; this child repeatedly returns to this message, that AIDS is bad, throughout his interview. One youth specifically mentioned that a provider contacted her at home, and alluded to communication between her parent and the provider to convince her to stick to her treatment plan. No other youth alluded to receiving support beyond clinical care from providers, after learning of her/his HIV status.

The scissors… if someone cuts with them… hmm, if the scissors hurt someone
and you take them, it is not good.
8-year-old male, M02, recounting words of health provider

They give me advice for me to not worry, like other children who are worried…
you start to isolate yourself, to stay alone saying that AIDS is there to kill me,
the way I am, I will die, I am going to die—me, I do not act that way.
15-year-old female, M04

Youth Felt That Knowing Their HIV Status Was Important and Necessary

The youth were asked to identify the good things as well as the bad things about being informed of their HIV status. Overall, the majority of youth interviewed said that it was good to know one's HIV status. All but one youth named at least one positive aspect of knowing their HIV status. Often, youth talked of the importance of knowing themselves or knowing their bodies as one of the benefits. Some also mentioned that knowing their status means that they no longer worry; one stated that she does not worry specifically because she was told that worrying would make her sick. Being able to protect others from infection, either by not sharing sharp objects of through avoiding sexual relations, was mentioned by a couple of participants. One youth said it was bad to know because AIDS is bad, while another felt that negative consequences would arise if proper preparation steps were not taken so that the youth is not shocked or troubled. Interestingly, despite the negative emotions experienced at the time of disclosure, youth for the most part could not state any negative consequences of knowing their HIV status.

Participant :   So I myself, I no longer worry that I am sick. I take the drugs. Sometimes I even forget.
Interviewer: What do you forget?
Participant : I forget that I am sick, that I take drugs. It comes back to me only at the time to take the drugs, I take them and then…
(15-year-old female, M03)

It was necessary that they tell me…so that I don't touch other people's things.
(8-year-old male, M02)

I no longer think about the illnesses that used to bother me… oh… this.. do I think of it? No ! I am at ease ; I know that I take my drugs….I know that I will be cured.
(17-year-old female, M06)

I was very happy that they told me this news. To this day I love my mother because she told me the truth before. If she had told me when I was an adult… ay! When I had grown up… that would not have been good.
(15-year-old female, M04)

5.5 DISCUSSION

The experiences of disclosure among children in Kinshasa captured here are comparable to those described in other settings. Adult caregivers' decisions to disclose are influenced by their concerns around treatment adherence, the eminent onset of sexual activity of adolescents, and their desire to protect their children and to protect others from becoming infected (Blasini et al., 2004; Oberdorfer et al., 2006; Waugh, 2003; L. Wiener et al., 2007).

Disclosure is often viewed as a process, particularly as experienced by caregivers who contemplate disclosure and prepare for the moment, sometimes providing children with partial or inaccurate information. While some children had gleaned partial information about their health, and a couple had been given misleading information, many had been given no information by either caregivers or health providers prior to being told the name of their illness. The experiences of the children interviewed in this study, however, show that, from their perspective, disclosure is by and large a discrete event rather than a process. Only one of the youth interviewed described activities that prepared her for receiving her diagnosis. While a few mentioned follow-up discussions with caregivers or providers, most do not have subsequent conversations, although many have questions and concerns.

The experiences of the children in this study are similar to those reported in other settings. Youth reported negative reactions upon learning of their HIV status, ranging from sadness to hurt and worried; this is comparable to experiences of youth with HIV disclosure in other settings (Blasini et al., 2004; D. DeMatteo, Harrison et al., 2002; L. S. Wiener et al., 1996). However, similar to DeMatteo and colleagues work in Canada, relief in finally knowing the source of their suffering was also common reaction (D. DeMatteo, Harrison et al., 2002). Similar to work by Instone (Instone, 2000), children had a sense of social isolation and emotional distress, noted in questions and concerns not expressed, perhaps as a result of the message given to them that worrying will make them sicker, but also possibly a result of cultural norms of communication with parents. Youth experiences after being informed of their HIV status, however, are not well documented in the literature (Gerson et al., 2001).

The reports of youth in this study that support being told their HIV status are also similar to what has been reported elsewhere. Blasini and colleagues tested an intervention to support families and youth through the disclosure process in Puerto Rico, with 85% of the youth (ages 9-13 years) afterwards reporting disclosure as a positive event for them and their families, and 90% supporting disclosure in general (Blasini et al., 2004). Researchers in Thailand found that youth who had participated in an intervention to be informed of their HIV status had more positive attitudes about HIV-infection and hope for future following the intervention (Oberdorfer et al., 2007)

Access to medication regimens clearly plays a role in disclosure to youth in this context. Increased access to treatment within the last few years has meant that more youth are now on daily medication regimens, which challenges their prior understanding of medication-taking as short-term, in order to cure illness rather than prevent or control it. Difficulties in getting youth to adhere to long-term regimens, whether experienced or anticipated, in turn influence parents' decisions to disclose. Youth, in turn, cite being more conscious of the importance of properly taking medications following disclosure. The findings here reflect findings seen in Benin and Thailand (Azondekon et al., 2005; Oberdorfer et al., 2006), and point to the need to consider the complexities of informing children of their HIV status as programs scaling-up access to AIDS care and treatment expand.

The experiences of the youth in this study must be understood within the cultural context of Kinshasa. Parental obligations to protect both their infected child as well as the other children in their household influence their decisions to disclosure. The child's sense of belonging within the home and relationship with family members is affected by new rules of how s/he can interact with other members of the family, as a result of HIV infection. The culture of respect and submission towards elders is reflected in youth's apparent acceptance of adult advice on how to behave with infection. A better understanding of caregiver-child communications in this context is needed in order to design better programs to assist families in communicating illness information to children; in the meanwhile, interventions should consider how communication takes place within families.

Understanding the role of children within families is important if we are to understand communication with children and how decisions involving children are made—and how they may differ within the context of HIV disclosure. Understanding how communication between caregivers and youth is particularly important if programs are to be developed to assist caregivers communicate health information to the youth under their care. Vygotsky theorized that interpersonal processes gradually become intrapersonal ones, and that interaction between individuals structures cognition (Vygotsky, 1962, 1978). Within this context, how caregivers and providers interact with youth and communicate—either verbally or nonverbally—information about health status could theoretically have a strong influence on youth's understanding of their health and well-being. Cultural contexts no doubt influence parental roles and communication styles with children; however, little has been studied about what these roles and styles are, and how culture influences them, particularly in sub-Saharan Africa. One study looked at distinguishing universal features of parental input from culturally specific ones, focusing on maternal-infant interactions. The study found that verbal communication between parents and infants was given an educational function among European cultures, while among African mothers was functionally meant to involve the child as a "genuine social partner" (Rabain-Jamin, 1989; Yingling, 1995). Another study looked at maternal responsiveness to infant attention-getting behavior, noting that behaviors of Kenyan mothers were associated with a perceived role of protectiveness and calming, as compared to mothers from Mexico and the United States, who saw their role as more educational. Although there is rich documentation on how parenting attitudes and behaviors influence behaviors and development of children, most of the parent-child literature on communication and parenting focuses on preventing or reducing risky behaviors in adolescents, with a focus on the United States and other industrialized countries, and espouses the creation of supportive environments for youth (Dittus, Miller, Kotchick, & Forehand, 2004; Kotchick & Forehand, 2002) A greater emphasis needs to be placed on understanding the role and function of communication between caregivers and youth in developing country contexts as programs targeting parent-child communications are developed.

The study results have implications for future interventions to support families in their experiences informing youth of their HIV status. Interventions could look at supporting caregivers as they prepare to tell youth, sharing experiences when possible. Silence as a response by youth should not be assumed to be evidence that youth are not experiencing distress, and given the cultural context it may be more appropriate for key adults to solicit responses from youth rather than wait for the child to initiate it.

Strong messages to children about not worrying may need to be moderated by opportunities for children to express their thoughts and gain additional information about their illness and their health. While ruminating about one's poor health might be detrimental to a child's mental and physical well-being, suppressing questions or not voicing concerns might isolate the child and promote poor coping skills. A Brazilian study found that prolonged silence, poor adult-child communications, and self-discovery resulted in psychosocial distress, self-stigma and adherence problems among HIV-positive youth (Abadia-Barrero & Larusso, 2006).

We must be conscious that disclosure at any particular point in time might not be beneficial to children. Some studies, including this one, have documented immediate negative reactions from children upon learning their HIV status (Azondekon et al., 2005; Blasini et al., 2004; D. DeMatteo, Harrison et al., 2002). However, most studies have shown that in the longer term disclosed children are neither more distressed nor do they display more behavioral problems than children who have not been informed of their HIV status. Only one of the participants in this study could not think of any positive things about knowing her HIV status at the time of her interview. Children with inadequate coping skills or insufficient support systems in place might fare poorly when inadequately prepared and follow-up is not provided. The potential benefits of disclosure must therefore be weighed against possible negative consequences, before a decision is made to go ahead and fully inform the child of his/her diagnosis.

Health services can provide support to caregivers in several ways. First, they can modify the messages given to youth, from saying to not worry to encouraging them to talk about their concerns, in order to create a space for youth to ask questions and obtain more information as their understanding of HIV and their own health evolves. Second, they can help caregivers address youth concerns by discussing with caregivers the questions and concerns brought up by youth and helping the caregivers respond to them. Third, they can engage in conversations with youth about their health, both before and after they are told of their HIV status, providing them with accurate information that will ultimately prepare them to learn of their diagnosis. Finally, they can provide more psychosocial support, creating opportunities for youth to express themselves during regular clinic visits and developing support group sessions especially for youth, in order to help them adjust to their HIV status.

The study has several limitations. We only interviewed children whose caregivers knew that they had been told their HIV status. The experiences of youth who are told their HIV status without family knowledge, and the implications this has for their well-being as well as for health services for youth, need to be explored in further detail. We recruited from one health care facility, which provides medical treatment including access to antiretrovirals in a resource-constrained environment.. The experiences of families with youth who have been diagnosed but do not have the same level of access to medical care might be quite different and should be further explored.

We did not collect clinical information about the children's health status, despite recruiting them at a clinic. However, we do have information on medication taking by youth at the time of disclosure as well as at the time of the interview, and caregiver reports of health status at the time of disclosure. We felt that caregiver's perceptions of the child's health might be more important in understanding disclosure experiences within families. Also, while we have information about the age of the child at diagnosis, we do not have information about the probable mode of transmission to the child. We do, however, know that half of the families interviewed had an HIV-infected parent. Only one of the youth in this study appears to have been sexually active prior to diagnosis. While the majority of children in this setting are perinatally-infected, non-parenteral transmission is a factor, particularly in sub-Saharan Africa where blood supplies may not be fully secure and blood transfusions for malaria-induced anemia not uncommon. Furthermore, up until recently, when treatment became more accessible, children could be sick for many years before finally being diagnosed with HIV in this setting.

Parental presence in some of the interviews had an impact on child participation in interview. While interviewing children in the absence of their caregivers might have resulted in more candid responses, we could not in this setting deny caregivers from sitting in on the interview, as it would affect their trust of the researchers and was within their rights as parents. In one case, child mentioned, in absence of parent, that s/he would prefer not to have father to be present because s/he felt ashamed, but father was insistent on sitting in the interview—the child was not very forthcoming in answers during the interview. Unexpectedly, all of the adults interviewed were the biological parents of children. The caregiver's relationship to the child might influence when, where, why, and how a child is informed of their HIV status. Also, caregivers' own HIV status might be a strong influence on the disclosure process.

Despite these limitations, this study is an important step towards better understanding how youth experience disclosure of their own HIV status. This information is vital in an era of expanding access to antiretroviral regimens. The findings from this study point to the need for creating comprehensive care and treatment programs for HIV-infected children that address not only their clinical needs but also their overall well-being. Further examination of the needs and experiences of children living with HIV infection and their caregivers will help to further define the roles of health system staff as well as psychosocial programs throughout the disclosure process.

CHAPTER 6
DISCUSSION

The goal of this dissertation study was to identify factors associated with disclosure patterns of parents and caregivers of HIV-infected children in the Democratic Republic of the Congo, in order to develop more appropriate and effective interventions to support these families. The study had three specific aims in order to achieve this goal. In this discussion, we synthesize the findings from the two components of the study reported earlier, revisit the conceptualization of disclosure as a process, in general, and examine the pattern of behavior we call "providing misleading information," in particular. The section ends with some reflections on methodological limitations and implications for future research and practice.

6.1 STUDY AIMS

> **Aim 1:** To describe existing patterns of nondisclosure among 200 caregivers *who have not yet disclosed HIV status* to HIV-infected children, ages 5-17 years, receiving clinical services at Kalembe Lembe Pediatric Hospital, Kinshasa, Democratic Republic of the Congo.

This study was successfully able to describe current patterns of communication among 201 caregivers who had not yet informed their child, aged 5-17 years, of her/his HIV status. As described in detail in Chapter 4, nearly half of children have not been given any information about their health status, while 15% have been given some truthful information; one-third of the caregivers reported that their children had been given some misleading information, whether intentionally misleading or not, about their health. While 95 percent felt that the child should be informed some day of their HIV status, 75 percent had already thought of what would lead them to inform the child. The study was also able to describe caregiver attitudes surrounding disclosure, from what they perceived to be benefits and harms of disclosure, to who they felt was the best person to inform the child.

> **Aim 2:** To describe factors at individual, interpersonal and community levels that are significantly associated with different patterns of disclosure of HIV status, among 200 caregivers of HIV-infected children, ages 5-17 years, receiving clinical services at Kalembe Lembe Pediatric Hospital. *who have not yet disclosed*

The study was also successful in describing factors at the individual, interpersonal, and community levels that were associated with different patterns of disclosure to children. Caregiver characteristics featured strongly among the individual characteristics associated with patterns. The caregivers' age, gender, and blaming attitudes towards HIV, as well as their frequency of thoughts on disclosure, were associated with an increased likelihood of having one pattern of disclosure versus another. Of the individual characteristics of children, only age remained significant in an adjusted full model. . Two interpersonal characteristics describing the emotional closeness between caregiver and child, as well as the availability of small amounts of instrumental support were characteristics found to be associated with patterns of disclosure. No community-level factors were found to be associated with patterns of disclosure in adjusted models. The results paint a complex picture of how patterns of disclosure are associated with various factors at different levels of socioecological influence.

> **<u>Aim 3:</u>** To explore the full process of HIV status disclosure and its sequelae among families receiving care at Kalembe Lembe Pediatric Hospital, through qualitative interviews with up to 8 child-caregiver dyads who have already experienced full disclosure of the child's HIV status; children are between 8-17 years of age.

Aim 3 of the study was also successfully met. We were able to explore the full process of disclosure through interviews with caregivers of 8 children who had been told their HIV status. As described in Chapter 5, the qualitative component of the study provided us with insight on children's experiences with disclosure, which to date have not been documented in sub-Saharan Africa. A small proportion of children in this study—three percent—had been informed of their HIV status, much smaller than has been reported elsewhere (L. Wiener et al., 2007). The reasons for this are not well understood. However, similar to other studies, this research showed that children are provided with varied patterns of information prior to being told of their HIV status (D. DeMatteo, Harrison et al., 2002; Funck-Brentano et al., 1997; Lipson, 1994). Some of the children in our study had been given no information about their health before they were told of their HIV status. Others were given incremental information leading to their diagnosis. Others were given information about other conditions besides HIV. Despite the various paths taken, and their initial reactions, both positive and negative, upon learning of their HIV status, the children were by and large of the opinion that it was important that they be aware of their HIV status. Following disclosure, children have been given advice by both caregivers and health providers but reported not having many conversations specifically about their health, or opportunities to fully explore their questions and concerns.

In sum, the two components of the study are complementary pieces of a puzzle and together present a complex picture of the issue of disclosure of HIV status to infected children. Both pieces provide information on factors influencing caregivers' decisions on when, how, and why children should be told their HIV status. The quantitative component focused more on elucidating what happens before the child is informed of her/his HIV status, while the qualitative component takes us through the moment of disclosure and afterwards, with a focus on the experiences of children, rather than the caregivers. We revealed several factors that influence the paths of disclosure taken by caregivers, and from the experiences of the children see how the paths of disclosure continue into full information about their HIV status and beyond. Both components of the study note that a child's age influences caregivers' decisions on disclosure, and that interpersonal interactions between caregiver and child also influence how disclosure patterns are manifested.

6.2 IS DISCLOSURE A PROCESS?

Revisiting the Conceptualization of Disclosure

Disclosure has been conceptualized as a process by most researchers (Lesch et al., 2007; Pequegnat & NIMH Consortium on Family & HIV/AIDS Research, 2002; L. Wiener et al., 2007). The two components of this study reveal that disclosure can take several forms and move along several different paths in the process of informing children of HIV status to children. This study supports prior research that shows that there is no single approach taken to disclose HIV status to children (Funck-Brentano et al., 1997; L. Wiener et al., 2007).

While caregivers in this study appear to move through a process in their decision-making and then their actions to disclose, there were variations. Some caregivers informed the child without much planning or forethought. Others prepared themselves and thought of how the child might respond. A few thought of how to prepare the child for the announcement. Among caregivers who have not yet informed their child, some have thought about what would lead them to inform the child one day, whereas others have not. There was also variation in how frequently they had thought about these issues.

We had theorized that the process of disclosure of HIV status to infected children fit a stage theory framework, rather than a continuum. While our results show that different factors seem to be associated with different patterns of disclosure, these patterns of disclosure do not seem to have an order, as previously suggested. Disclosure as experienced by children is a process; however, the process may take very different paths and occur over varying time periods. In this study, some youth were prepared to be told their HIV status in the minutes immediately before their HIV status was announced. Others were given information over a period of days or weeks. Some were given no information before being told of their HIV status. Others had been given some information about their health, whether it was about the importance of taking their medications or advice on how to act to reduce the risk of infecting others. Still others had been given misleading information.

6.3 PROVIDING MISLEADING INFORMATION TO CHILDREN

The provision of misleading information to children, whether intentionally misleading or otherwise, bears further examination. Funck-Brentano and colleagues documented “deceptive” information provided to HIV-positive children in France as information that intentionally confused the child’s HIV status with another medical condition totally unrelated to HIV infection (Funck-Brentano et al., 1997). Oberdorfer and colleagues noted in their Thai study that over 80 percent of caregivers who said that their child did not know of her/his diagnosis had told the child they had another illness (Oberdorfer et al., 2006). We saw similar practices among caregivers in our study, although we are unable, in most circumstances, to determine the intent of caregivers in providing this information. Among caregivers who had not fully disclosed, a third had provided some information to the child that could be misleading. Among the caregivers who had informed their children of their HIV status, one-quarter had previously provided misleading information. In the qualitative component, the two youth who had been given another diagnosis—tuberculosis and spleen disease—prior to being told of their HIV status reported being surprised upon learning their status, and also reported not having additional conversations about their health with their caregivers. In one case, the caregiver was uncomfortable discussing the child's health with her. All of the caregivers in this study were aware of the child's HIV status, but their full comprehension of the diagnosis and the progression of illness were not assessed; the misleading information could have been therefore reflective of the caregiver's comprehension of the illness status rather than intent to deceive the child. One caregiver in the qualitative piece of the study, however, noted that the child had been told she had another health problem rather than HIV because the caregivers and providers were not prepared to tell her that she was infected with HIV.

Funck-Brentano showed that children who had been given partial or full information about their health a had better understanding of their condition and were coping better with their health than children who had been given deceptive information or else not told anything about their health (Funck-Brentano et al., 1997). This, coupled with evidence that children with serious health diagnoses, including HIV, do not fare worse in psychosocial or health outcomes if they are told of their diagnoses (Claflin & Barbarin, 1991; Lipson, 1994; Slavin et al., 1982; L. Wiener et al., 2007), provides some impetus to promote accurate information to children. It is possible that providing misleading or deceptive information can erode the trust between children and their caregivers, which could lead to anxieties, emotional distress, and maladjustment (Funck-Brentano et al., 1997).

6.4 STUDY LIMITATIONS

As mentioned earlier, one of the study's limitations is that its study population represents, to date, a very unique group of children within Sub-Saharan Africa. These children all had access to regular medical care and had a primary caregiver aware of their health status caring for them at home. Only 13 percent of children in Sub-Saharan Africa requiring antiretrovirals currently have access to them (WHO et al., 2007). The impact of access to medications, beyond extending their lives and creating hope for futures, on what caregivers tell children about their health can only be determined by comparing children with access to these life-prolonging regimens to those with no access.

The cross-sectional study design allowed us to identify factors associated with different patterns of disclosure but not identify causal relationships. The retrospective nature of the qualitative component is subject to recall bias, with details of the events prior to and during disclosure possibly remembered inaccurately or not in much detail.

Another limitation of the study is its focus on what has been told to the child, rather than what the child has discerned about their health, whether from information provided by others or gleaned on their own. While this was not seen in the interviews of this study, youth may learn of their HIV status on their own, by piecing together clues, or overhearing conversations, or even directly from providers, without caregiver knowledge. While we can draw upon the experiences from other chronic illnesses, as well as limited data available on nondisclosure and secrecy as it relates to HIV (Abadia-Barrero & Larusso, 2006; Claflin & Barbarin, 1991; Slavin et al., 1982), we must remember that disclosure by others is only one way children learn of their HIV status, and that these different ways of learning may also impact the child's adherence to medications as well as their psychosocial well-being. A Ugandan study on adherence noted that youth who suspected their diagnosis but had not been fully informed were less adherent to antiretroviral regimens.

This study did not systematically collect clinical data on the children of interest, nor did it collect information about the caregivers' HIV status; however, caregiver HIV status was given in most of the in-depth interviews. Other studies have shown that caregivers' own HIV status can play a role in decisions regarding communication with infected children (D. DeMatteo, Harrison et al., 2002; Gerson et al., 2001; Lesch et al., 2007; L. Wiener et al., 2007).

6.5 IMPLICATIONS FOR RESEARCH

What is clear from the study is that there are multiple paths taken in the process of disclosure. What is not clear is whether some paths are better than others in psychosocial and adherence outcomes for the children. It is also not clear what factors influence path choices. Further studies should follow children through their experiences of disclosure, assessing the impact of different factors as well as the different paths taken towards informing children. The information acquired from these studies would help refine programs designed to help caregivers and children through disclosure by knowing what paths ought to be avoided and what paths ought to be promoted, and under what situations. Also, it would be important to see how the different patterns of disclosure play out over time, and to see whether children who experience different paths to full disclosure have different outcomes. Future studies should also incorporate measures of psychological and emotional well-being and distress for children, to better assess the impact of experiencing different paths towards full disclosure on children.

As mentioned in Chapter 4, the study found that male caregivers were less likely to have said something true or something misleading, versus nothing, but is unable to explain why. Qualitative work exploring the traditional roles of family members, particularly around communication to children, would not only help us understand why communication occurs as it does, but also help to design stronger programs to help families with this communication.

6.6 IMPLICATIONS FOR PRACTICE

The goal of this study was to identify factors associated with disclosure behaviors of parents and caregivers of HIV-infected children, in order to develop more appropriate and effective interventions to support these families. The study results provide us with several findings that will help health-care based programs create appropriate systems to support families through disclosure.

As seen, misleading information figures strongly in communication between caregivers and children. Understanding what factors are associated with caregivers giving children misleading information may help treatment programs assess families' support needs around communicating with HIV-positive children about their health. It is possible that caregivers are themselves misinformed or misunderstand the child's health status, or else unsure of how to respond to children's inquiries. This, coupled with the limited direct communication between health providers and children, points to a clear role for health staff to provide concise, accurate information to caregivers as well as children, and to consistently assess what has been told to children and why.

Awareness of reasons caregivers might disclose helps providers with possible entry points for discussions about informing children and determining best moment to tell them of their HIV diagnosis. Providers can work with caregivers to identify the best moment and approach to tell the child, and in cases where caregivers wish to inform the child on their own, help the caregiver to prepare for that conversation and the ones that should follow.

The children's interviews highlight a need for health service providers to work not only with caregivers but also directly with the children. Silence as a response by youth should not be assumed to be evidence that youth are not experiencing distress, and given the cultural context it may be more appropriate for key adults, such as health providers, to engage in dialogue with children rather than wait for them to initiate it. The children's experiences also point to a need to create opportunities for the youth to share experiences with one another, through support groups that serve not as educational sessions but rather as opportunities to express their concerns and together find solutions.

In conclusion, the study was successful in its goal of identifying factors associated with disclosure patterns of caregivers of HIV-positive children that are important to address in developing effective, appropriate interventions to support families through the disclosure process. The study highlights caregiver characteristics associated with different patterns of disclosure, and points to the importance of not just working with caregivers as they prepare to disclose, but also to work with the children to help them make sense of their health and adapt to their diagnoses. While there are similarities between disclosure patterns seen in industrialized countries and what has been documented here, there are also noted differences. The study showcases the need to better understand the implications of providing children with misleading information about their health, which to date has only been minimally explored. Findings will be used to design intervention programs and improve current psychosocial support to families of HIV-infected children of the Pediatric HIV Care Program in Kinshasa. As more and more HIV-infected children see their lives extended and their health improved with the expansion of HIV care programs in sub-Saharan Africa, providers must assess initial practices before moving ahead with improving services.

APPENDIX 1:
LEVELS OF DISCLOSURE BY AGE: SUMMARY OF REVIEWED LITERATURE

Article (First Author only)	**Country**	**n, Age range (if available)**	**Levels of disclosure (by age if available)**	**Other info on disclosure**
INDUSTRIALIZED COUNTRIES				
Bacha et al 1998 *Conference abstract*	US	9-12, n=13	NA	• Children who know their HIV status were less depressed
Blasini 2004	PR	n=40, 9-15	100%	• disclosure intervention • following intervention, reported improved medication adherence & healthy psychological adjustment
Bor 1993	UK	n=503, <=16	<10 37% 10-15 48% 16 100% (n=1)	• review
Cohen 1997	US	n=92, 5-17	5-10 30% >10 95%	59% family alone 24% family with provider there 16% provider alone
DeMatteo (a) 2002	Canada	n=54, 5-30		• median age at disclosure 10 • 44% had partial disclosure before full disclosure
Flanagan-Klygis et al, 2001	US	n=65	35% overall by age: <4 20%* 4-8 15% 9-12 74% 12+ 100% (n=1)	• mean age 7.8 at disclosure *parents of <4 children said they disclosed when child was infant, result is questionable
Funck-Brentano 1997	Europe	n=35, 5-10	41% partial 17% full disclosure 21% deception 24% no disclosure	Patterns of disclosure discussed
Gerson 2001	US	n=70, 5-15	76% among children >8	
Grubman 1995	US	n=12, 9-16	57%	
Hammami et al, 2004	Belgium	n=11, 0.25-18.75	NA	• opposition to taking meds serves as trigger to disclosure
Instone, 2000	US	n=12, 6-12	67%	• typical time between diagnosis and disclosure: 4 years (2-8 range)
Ledlie 1999	US	n=20, >=6	50%	Concealing the diagnosis, telling something, disclosing the diagnosis as conditions/stages

Article (First Author only)	Country	n, Age range (if available)	Levels of disclosure (by age if available)	Other info on disclosure
Lee et al 1999	US	n=73, >=6	41% complete 19% partial	
Lester 2002b	US	n=51, >=4	43.1% 46% 6-10	
Lewis 1994	US	n=42, 9-16	57%	
Lipson 1993	US	n=30, 6+	10%	
Marhefka et al, 2006	US	n=54, 1-13	Not reported	• children who knew status were more likely to be older • children who were not disclosed more likely to be adherent (confounded by age)
Mawn 1999	US	n=12, 3-7	25% over five years	• ages at baseline (5 yr f/up) • 2 of 4 did not understand status
Mellins, 2002	US	n=77, 3-13	30% overall 76% 6-13	• 59% told another health problem • 11% told just routine care
Mellins et al, 2004	US	n=75, 3-13	Not reported	• Children who knew status more likely to be nonadherent, but age correlated with disclosure and also with nonadherence
Mialky et al, 2001	US	n=54, 5-18	43% <10 18% (5/28) 10+ 69% (18/26)	• Mean age at disclosure 9 yrs • All aged 12+ were disclosed
Nehring 2000	US	n=6, >=6	33% full 33% partial 33% nothing	
Nicholson et al, 2006	US	n=77, 3-13	23%	
Nöstlinger et al, 2006	Europe	n=93	55%	• Median age of disclosure 10 years
Nöstlinger et al, 2004	Belgium	n=279	10%	• Study interviewed African parents living in Belgium
Salter et al, 2007	Canada	NA	NA	• Discussion of disclosure intervention
Thorne 2000	UK	n=140	18% overall 60% of children aged 11+	
Thorne et al, 2002	US	n=34, 10+	76% 3% partial (1)	• Median age at disclosure 10, range 7-11
Waugh 2003	UK	n=15, 5-9	11%	• All parents said they wanted to wait until "child was ready" before disclosing

Article (First Author only)	**Country**	**n, Age range (if available)**	**Levels of disclosure (by age if available)**	**Other info on disclosure**
Wiener et al, 1996	US	n=99	75%	• mean age 7.5, 2 yrs between dx & disclosure
Wiener et al, 1998	US	n=10	NA	• qualitative study on nondisclosure
Wiener et al, 1998	US	n=17, 5-18	41%	•
Developing Countries				
Azondekon 2005 (abstract only)	Benin	n=24, 6-14	NA	• Nonadherence associated with lack of disclosure
Abadia-Barrero et al, 2006	Brazil		na	• NA
Ayres et al, 2006	Brazil	n=22, 10-20	100% (Criteria for eligibility in study)	• Delayed disclosure as a way to protect adolescents • Most disclosure took place between ages of 11-14 years • Typical disclosure scenario for perinatally infected youth was receipt of information already foreseen by youth, disclosure done by caregiver and health professional together
Ionescu, 2006	Romania	N=6000, <16	80%	
Kouyoumdjian et al, 2005	South Africa	NA	NA	• Focus groups of caregivers on barriers to disclosure
Myer 2006	South Africa	NA	NA	• 96% of providers would like support in disclosure process
Butterworth et al, 2007 (abstract only)	Thailand	n=87, 6-17	6-9 0% 10-13 18.8% 14-17 62.5%	• Older age appears to be correlated with increased ratio of disclosure • No significant correlation between disclosure & CDC class, CD4% or count, viral load • No difference in adherence between disclosed/not disclosed
Oberdorfer et al, 2006	Thailand	n=103, 6-16	30.1%	• 53% of n=17 who said they had disclosed had mentioned HIV or AIDS
Oberdorfer et al, 2007 (abstract only)	Thailand	n=75, 6-16	100% (intervention)	• No change in child depression or anxiety rates post intervention

Article (First Author only)	Country	n, Age range (if available)	Levels of disclosure (by age if available)	Other info on disclosure
Bikaako-Kajura et al, 2006	Uganda	n=42, 5-17	Full 29% Partial 38%	• Partial disclosure includes lies • Caregivers of children who had not been told status but suspected it reported poor adherence • Fully disclosed children never reported missed doses
Enzama 2005 (abstract only)	Uganda		NA	• Nondisclosure of child's status to others listed as barrier to adherence
Nannyonga-Musoke et al 2007 (abstract only)	Uganda	n=210, 1-18	Not reported	Ugandan national policy required disclosure to all children 7+ before starting ARVs
Semwendero et al, 2007 (abstract only)	Uganda	n=134	Not reported	• Disclosure problems contributed 8% to missed medications

APPENDIX 2:
TIMELINE OF STUDY ACTIVITIES

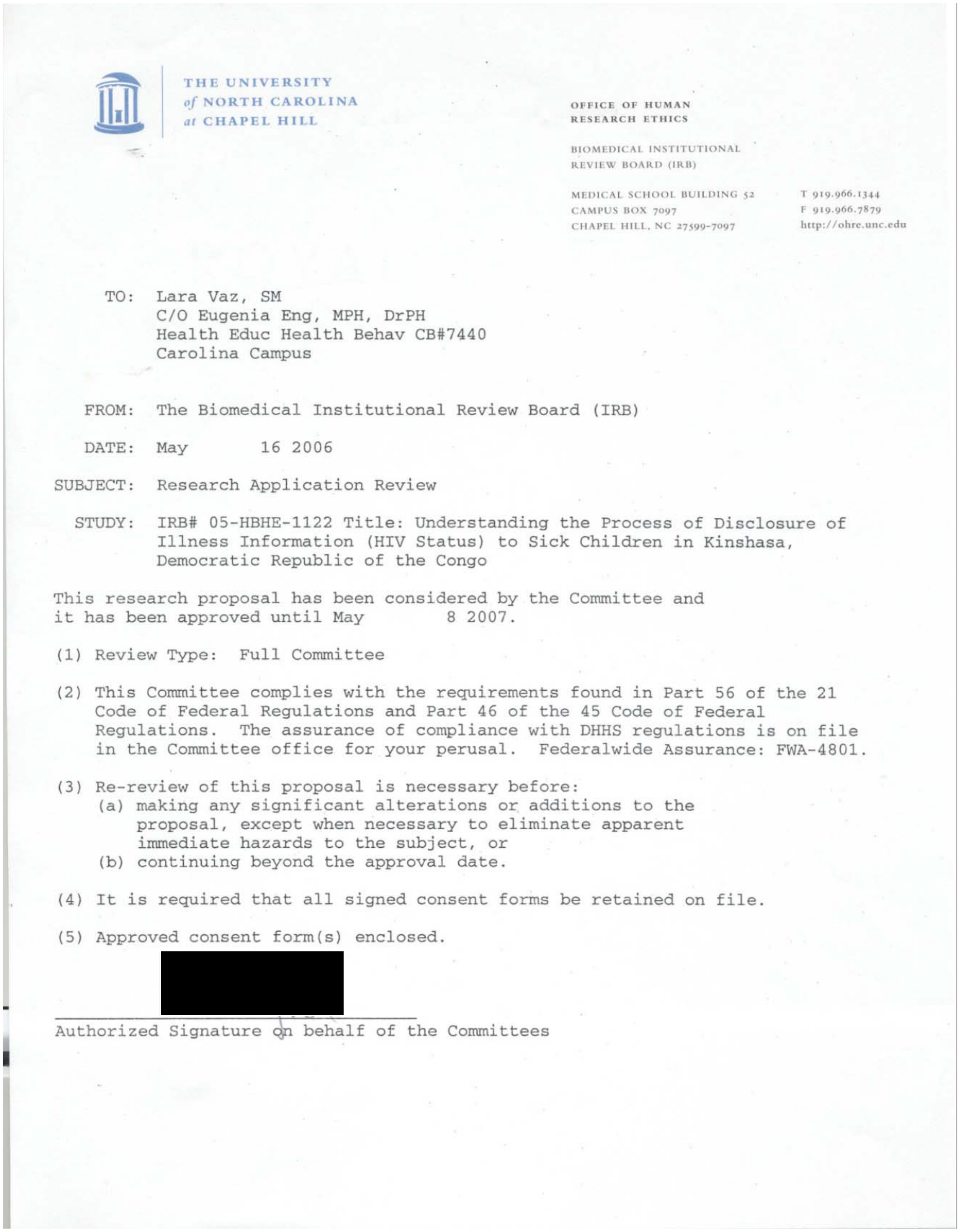
April 2006	May	Jun	July	September	December	Jan-April 2007	May-June	July-September
Proposal to defense committee Submission to UNC IRB	Proposal Defense 3 May Proposal to Kin IRB Basic Training May 15-30	Continued Training Instrument & Consent Form Modifications Field Testing & Revisions	Data Collection begins Data verification and initial reading begins	Qualitative data collection ends Data cleaning begins	Quantitative data collection ends Dec 7 Begin data analysis	Data analysis	Break (Assent-Disclosure meeting)	Finalize data analysis Prepare manuscripts

APPENDIX 3
BUDGET FOR STUDY ACTIVITIES

PERSONNEL							
Type	**No**	**Rate/ day**	**FTE**	**Weeks**	**Other**	**CDC/GAP**	**Total US$**
Interviewers	4	25	100%	13		6,500	6,500
Typists	1	12	60%	13		468	468
LV per diem (30/day)	1	30	100%	15	3,150		3,150
subtotal Personnel					**$3,150**	**$6,968**	**$10,118**
NON-PERSONNEL	**Unit**	**No.**	**Price/Unit**		**Other**	**CDC/GAP**	**Total US$**
<u>Travel Expenses</u>							
Airfare					4,000		4,000
Visa					400		400
subtotal Travel					**$4,400**	**$0**	**$4,400**
<u>Equipment</u>							
Filing Cabinet (4-drawer)--shared with other short-term studies	ea					400	400
Filing Cabinet (2-drawer)--shared with other short-term studies						-	-
Chairs	ea	4	10			40	40
Tables	ea	4	25			100	100
subtotal Equipment					**$0**	**$540**	**$540**
<u>Supplies</u>							
Clipboards	ea	4			20		20
Misc office supplies (paper clips, markers, post-its, tape, staples,…)					200		200
Stapler (heavy duty)					30		30
Stapler (regular)					10		10
Batteries	2/pk	8	3		24		24
Paper	ream	15	5			75	75
Note Pads	ea	20	2			40	40
Pens	ea	20	0.2			4	4
Interviewer bags	ea	4			40		40
General office supplies						201	201
Laser Printer Cartridges	ea	2	120			240	240
subtotal Supplies					**$324**	**$560**	**$884**

NON-PERSONNEL COSTS *(cont)*		**Unit**	**No.**	**Price/ Unit**	**Other**	**CDC/GAP**	**Total US$**
<u>Other Costs</u>							
Telephone	4/wk	60	$5.00			300	300
Participant incentives							
-Transportation advance for participants		325	$1.00			325	325
-Transportation reimbursement for participants		325	$2.00			650	650
-Incentives for child participants		12	$3.00		36		36
-Food Incentives for Participants	soda/bun	325	$1.50			488	488
-Food Incentives for Children	soda/bun	325	$1.50			488	488
Training							
Per diem: $17/day, 10 days of training		person	4	17		680	680
Space rental: $30/day		day	10	30		300	300
Lunch $8.50/person		person	5	8.5		425	425
Breaks $2.50/person		person	5	2.5		125	125
Supplies					100		100
Materials		page	400	70		56	56
notepads		ea	4	2		8	8
pens		ea	5	0.2		1	1
markers		set	1	5	5		5
additional expenses						1,405	1,405
Copies		ea	2500	0.05		125	125
Translation of forms, procedures, training materials		day	10	40	400		400
subtotal Other Costs					**$541**	**$5,375**	**$5,391**
Subtotal Direct Costs					**$8,415**	**$13,443**	**$21,333**
Subtotal Direct Costs - Equipment						**$12,903**	**$20,793**
Indirect Costs (based on direct minus equipment costs)		**0.08**				**$1,032**	**$1,032**
GRAND TOTAL					**$8,415**	**$14,475**	**$22,365**

APPENDIX 4
INSTITUTIONAL REVIEW BOARD APPROVALS



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

OFFICE OF HUMAN
RESEARCH ETHICS

BIOMEDICAL INSTITUTIONAL
REVIEW BOARD (IRB)

MEDICAL SCHOOL BUILDING 52
CAMPUS BOX 7097
CHAPEL HILL, NC 27599-7097

T 919.966.1344
F 919.966.7879
http://ohre.unc.edu

TO: Lara Vaz, SM
C/O Eugenia Eng, MPH, DrPH
Health Educ Health Behav CB#7440
Carolina Campus

FROM: The Biomedical Institutional Review Board (IRB)

DATE: May 16 2006

SUBJECT: Research Application Review

STUDY: IRB# 05-HBHE-1122 Title: Understanding the Process of Disclosure of Illness Information (HIV Status) to Sick Children in Kinshasa, Democratic Republic of the Congo

This research proposal has been considered by the Committee and it has been approved until May 8 2007.

(1) Review Type: Full Committee

(2) This Committee complies with the requirements found in Part 56 of the 21 Code of Federal Regulations and Part 46 of the 45 Code of Federal Regulations. The assurance of compliance with DHHS regulations is on file in the Committee office for your perusal. Federalwide Assurance: FWA-4801.

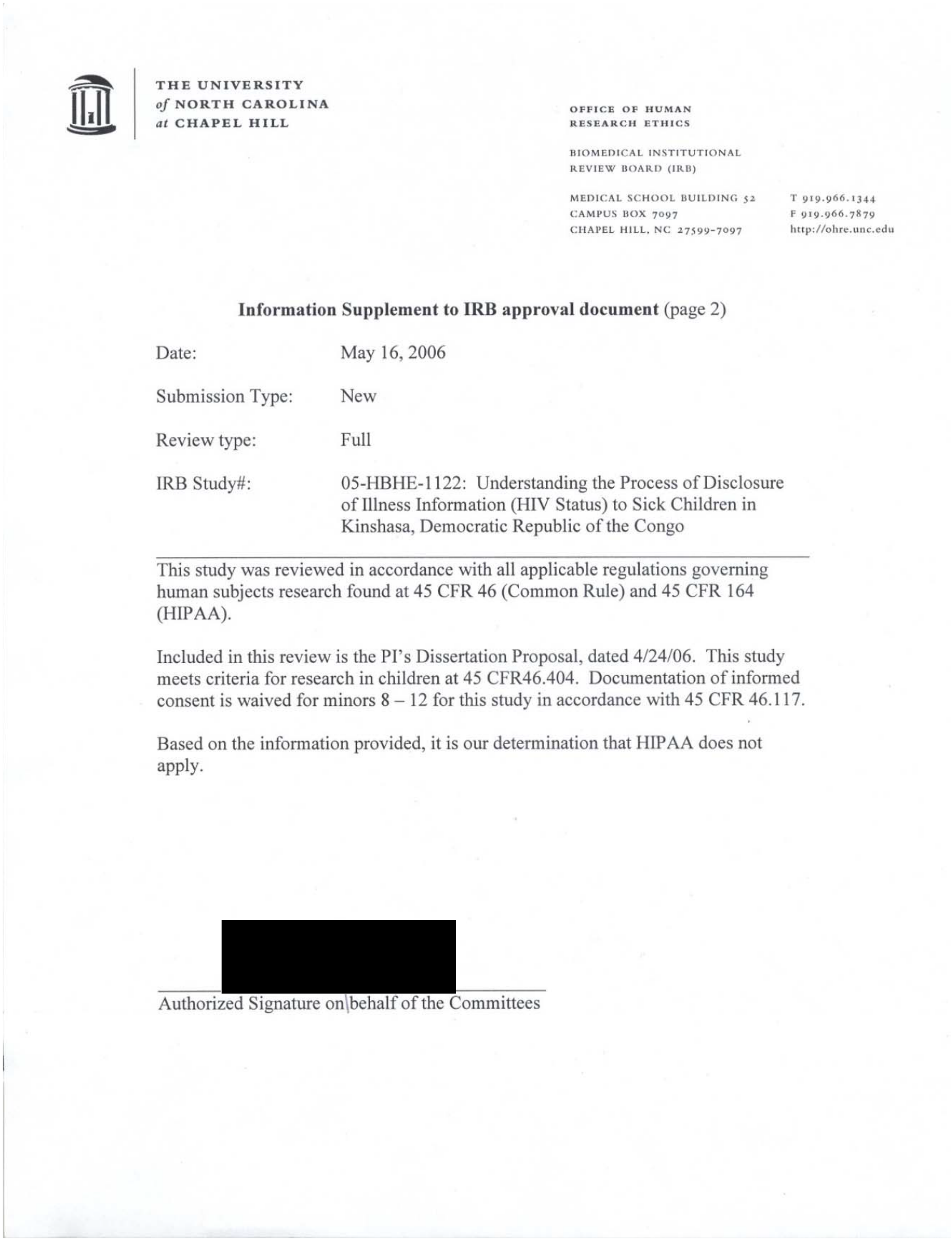
(3) Re-review of this proposal is necessary before:
  (a) making any significant alterations or additions to the proposal, except when necessary to eliminate apparent immediate hazards to the subject, or
  (b) continuing beyond the approval date.

(4) It is required that all signed consent forms be retained on file.

(5) Approved consent form(s) enclosed.

[redacted]

Authorized Signature on behalf of the Committees



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

OFFICE OF HUMAN
RESEARCH ETHICS

BIOMEDICAL INSTITUTIONAL
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http://ohre.unc.edu

Information Supplement to IRB approval document (page 2)

Date:	May 16, 2006
Submission Type:	New
Review type:	Full
IRB Study#:	05-HBHE-1122: Understanding the Process of Disclosure of Illness Information (HIV Status) to Sick Children in Kinshasa, Democratic Republic of the Congo

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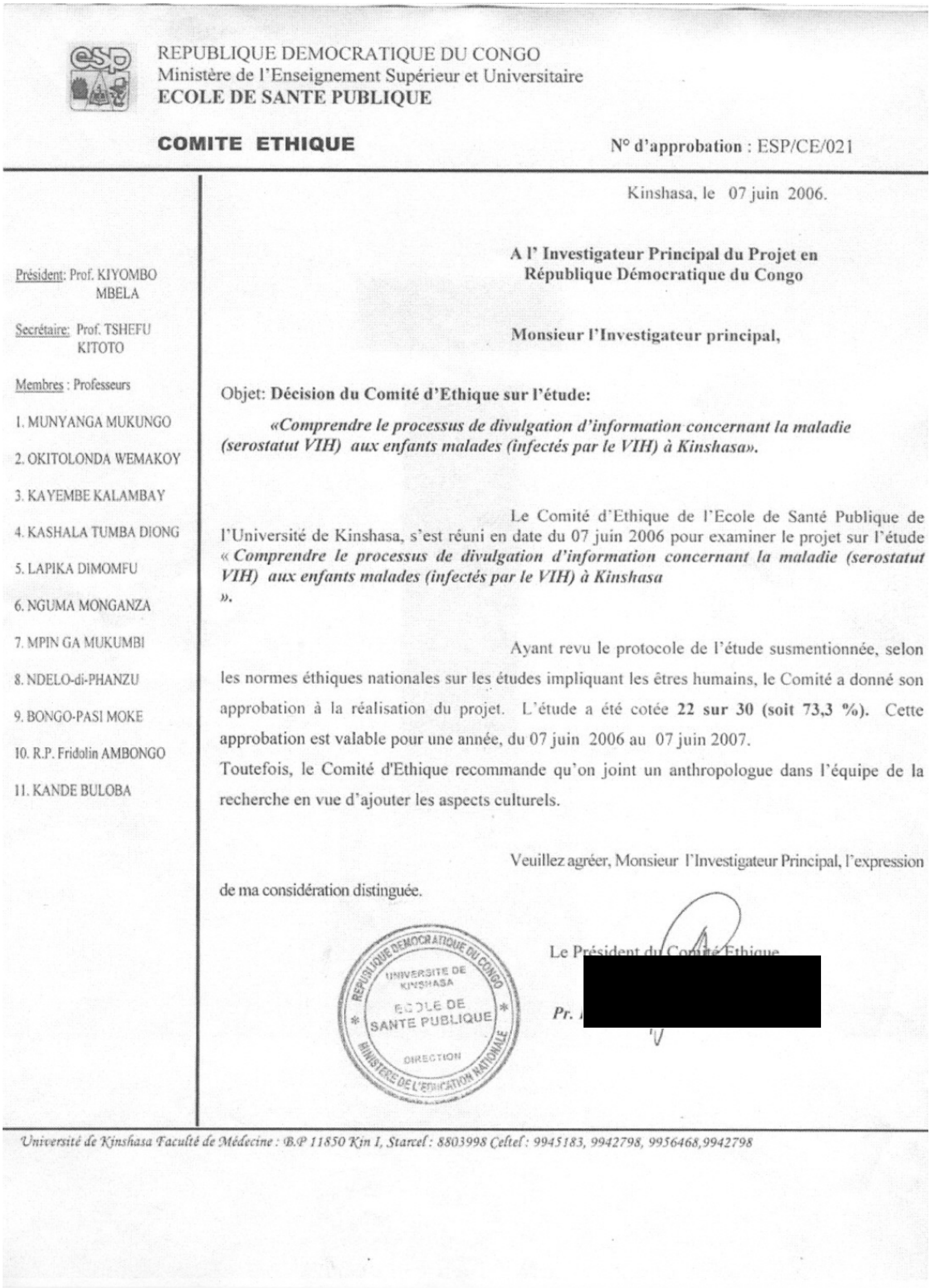
This study was reviewed in accordance with all applicable regulations governing human subjects research found at 45 CFR 46 (Common Rule) and 45 CFR 164 (HIPAA).

Included in this review is the PI's Dissertation Proposal, dated 4/24/06. This study meets criteria for research in children at 45 CFR46.404. Documentation of informed consent is waived for minors 8 – 12 for this study in accordance with 45 CFR 46.117.

Based on the information provided, it is our determination that HIPAA does not apply.

[redacted]

Authorized Signature on behalf of the Committees



REPUBLIQUE DEMOCRATIQUE DU CONGO
Ministère de l'Enseignement Supérieur et Universitaire
ECOLE DE SANTE PUBLIQUE

COMITE ETHIQUE

N° d'approbation : ESP/CE/021

Président: Prof. KIYOMBO MBELA

Secrétaire: Prof. TSHEFU KITOTO

Membres : Professeurs

1. MUNYANGA MUKUNGO
2. OKITOLONDA WEMAKOY
3. KAYEMBE KALAMBAY
4. KASHALA TUMBA DIONG
5. LAPIKA DIMOMFU
6. NGUMA MONGANZA
7. MPIN GA MUKUMBI
8. NDELO-di-PHANZU
9. BONGO-PASI MOKE
10. R.P. Fridolin AMBONGO
11. KANDE BULOBA

Kinshasa, le 07 juin 2006.

A l' Investigateur Principal du Projet en
République Démocratique du Congo

Monsieur l'Investigateur principal,

Objet: **Décision du Comité d'Ethique sur l'étude:**

«Comprendre le processus de divulgation d'information concernant la maladie (serostatut VIH) aux enfants malades (infectés par le VIH) à Kinshasa».

Le Comité d'Ethique de l'Ecole de Santé Publique de l'Université de Kinshasa, s'est réuni en date du 07 juin 2006 pour examiner le projet sur l'étude « ***Comprendre le processus de divulgation d'information concernant la maladie (serostatut VIH) aux enfants malades (infectés par le VIH) à Kinshasa*** ».

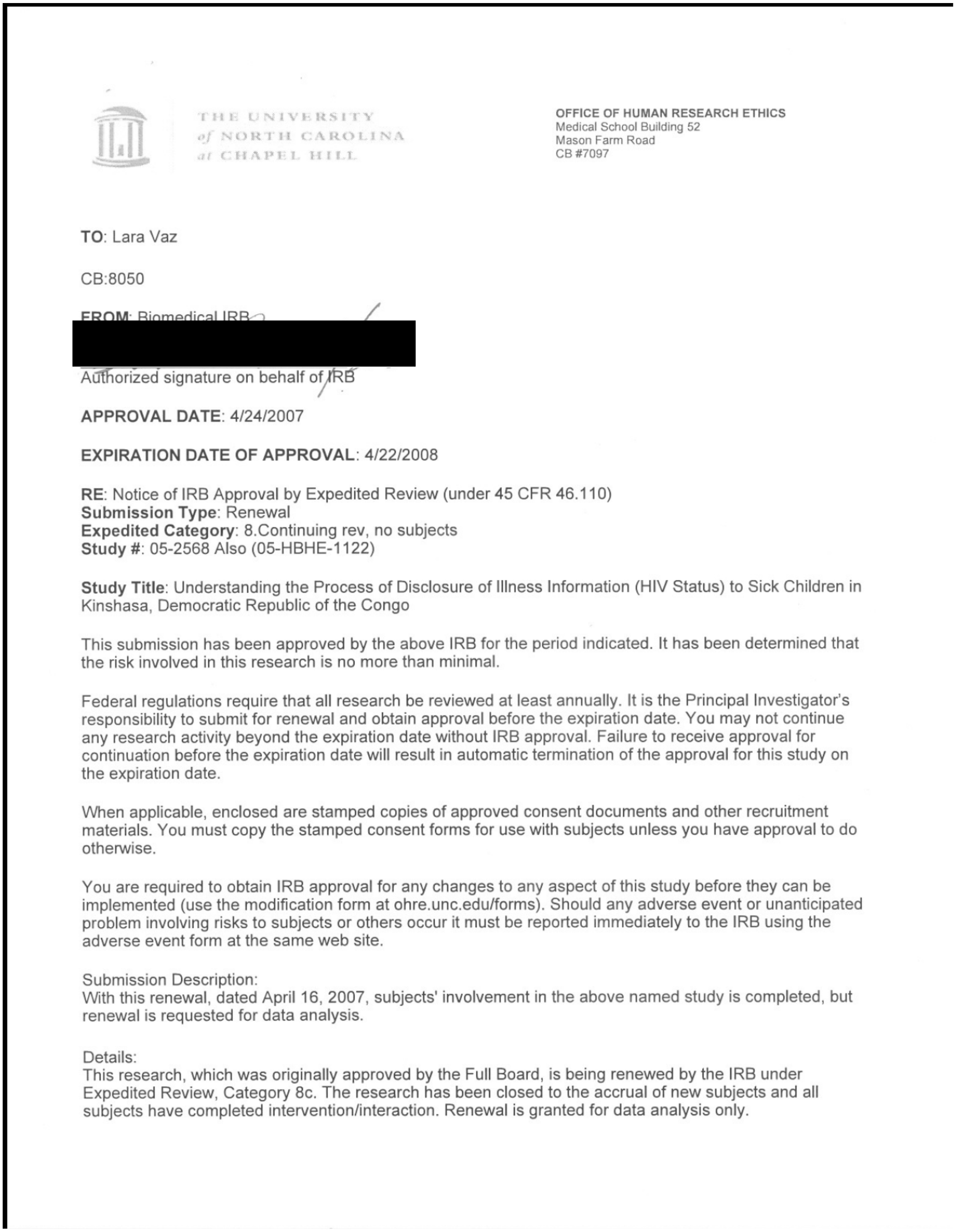
Ayant revu le protocole de l'étude susmentionnée, selon les normes éthiques nationales sur les études impliquant les êtres humains, le Comité a donné son approbation à la réalisation du projet. L'étude a été cotée **22 sur 30 (soit 73,3 %).** Cette approbation est valable pour une année, du 07 juin 2006 au 07 juin 2007.
Toutefois, le Comité d'Ethique recommande qu'on joint un anthropologue dans l'équipe de la recherche en vue d'ajouter les aspects culturels.

Veuillez agréer, Monsieur l'Investigateur Principal, l'expression de ma considération distinguée.

Le Président du Comité Ethique

Pr. [redacted]

Université de Kinshasa Faculté de Médecine : B.P 11850 Kin I, Starcel : 8803998 Celtel : 9945183, 9942798, 9956468,9942798



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

OFFICE OF HUMAN RESEARCH ETHICS
Medical School Building 52
Mason Farm Road
CB #7097

TO: Lara Vaz

CB:8050

FROM: Biomedical IRB

[redacted]

Authorized signature on behalf of IRB

APPROVAL DATE: 4/24/2007

EXPIRATION DATE OF APPROVAL: 4/22/2008

RE: Notice of IRB Approval by Expedited Review (under 45 CFR 46.110)
Submission Type: Renewal
Expedited Category: 8.Continuing rev, no subjects
Study #: 05-2568 Also (05-HBHE-1122)

Study Title: Understanding the Process of Disclosure of Illness Information (HIV Status) to Sick Children in Kinshasa, Democratic Republic of the Congo

This submission has been approved by the above IRB for the period indicated. It has been determined that the risk involved in this research is no more than minimal.

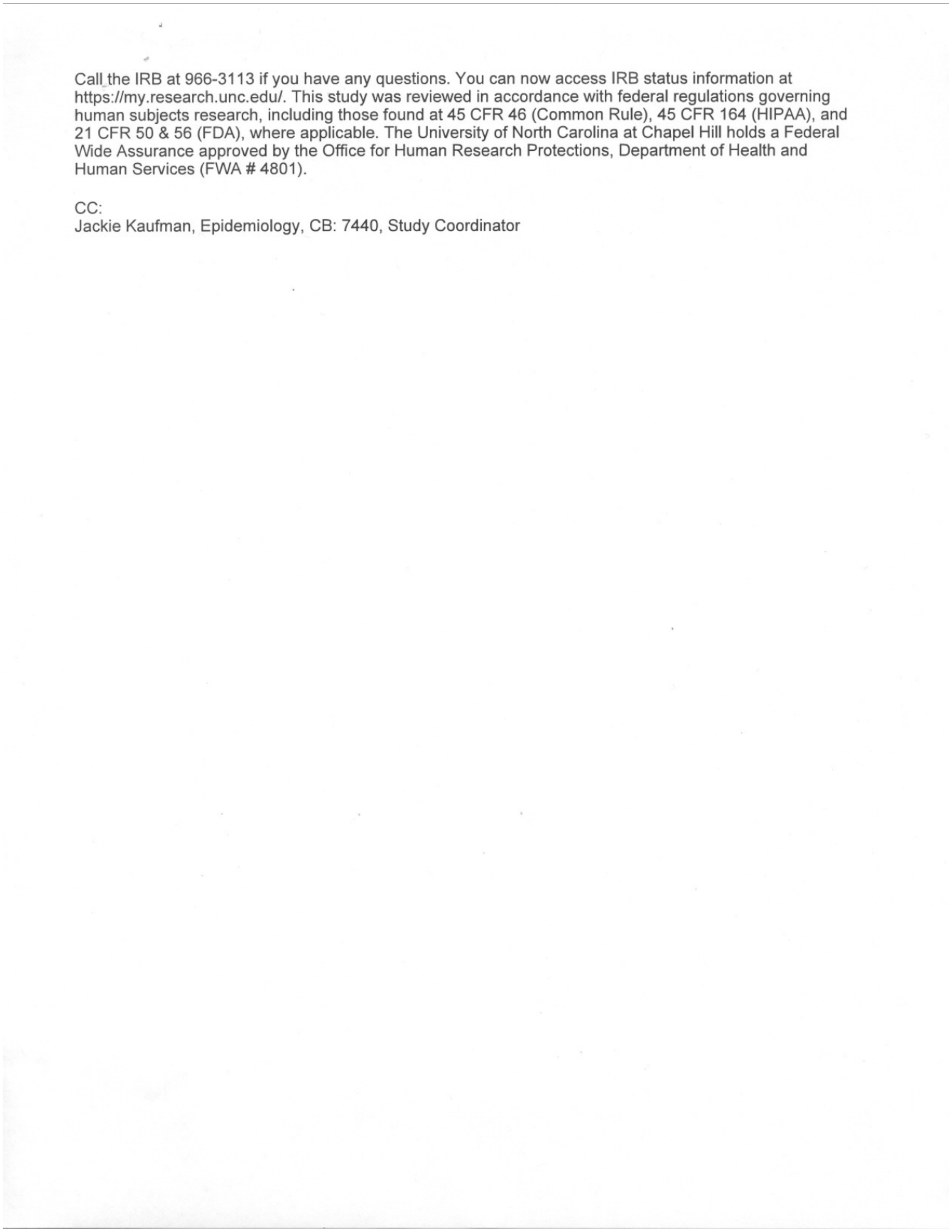
Federal regulations require that all research be reviewed at least annually. It is the Principal Investigator's responsibility to submit for renewal and obtain approval before the expiration date. You may not continue any research activity beyond the expiration date without IRB approval. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.

When applicable, enclosed are stamped copies of approved consent documents and other recruitment materials. You must copy the stamped consent forms for use with subjects unless you have approval to do otherwise.

You are required to obtain IRB approval for any changes to any aspect of this study before they can be implemented (use the modification form at ohre.unc.edu/forms). Should any adverse event or unanticipated problem involving risks to subjects or others occur it must be reported immediately to the IRB using the adverse event form at the same web site.

Submission Description:
With this renewal, dated April 16, 2007, subjects' involvement in the above named study is completed, but renewal is requested for data analysis.

Details:
This research, which was originally approved by the Full Board, is being renewed by the IRB under Expedited Review, Category 8c. The research has been closed to the accrual of new subjects and all subjects have completed intervention/interaction. Renewal is granted for data analysis only.



Call the IRB at 966-3113 if you have any questions. You can now access IRB status information at https://my.research.unc.edu/. This study was reviewed in accordance with federal regulations governing human subjects research, including those found at 45 CFR 46 (Common Rule), 45 CFR 164 (HIPAA), and 21 CFR 50 & 56 (FDA), where applicable. The University of North Carolina at Chapel Hill holds a Federal Wide Assurance approved by the Office for Human Research Protections, Department of Health and Human Services (FWA # 4801).

CC:
Jackie Kaufman, Epidemiology, CB: 7440, Study Coordinator

APPENDIX 5
ELIGIBILITY SCREENING TOOLS

Projet SARA : Étude sur la Divulgation de Sérostatut Texte et Critères d'Eligibilité

Manuscrit et questions de sélection pour le recrutement de tous les parents/tuteurs, à utiliser par l'infirmier ou conseiller recruteur:

Le projet SARA de l'Université de Caroline du Nord conduit une petite étude avec les parents ou tuteurs d'enfants recevant des services dans ce centre. Je voudrais vous parler pour quelques instants maintenant pour voir si vous souhaiteriez faire partie de cette recherche. Êtes-vous d'accord? (*Si oui, procéder avec le paragraphe suivant. Si non, remercier le parent/tuteur pour son temps et remplissez le Formulaire de Refus et d'Inéligibilité pour Parents/Tuteurs.*)

Questions de Sélection	**Action**
1. Avant que je vous parle de l'étude, s'il vous plait pouvez-vous me dire si vous avez 18 ans ou plus ?	Si oui, procéder à la question suivante. Si non, arrêter et dire au parent/tuteur que vous ne devez parler qu'avec les individus qui ont 18 ans ou plus.
2. Est-ce que vous êtes le parent biologique ou un des principaux tuteurs de cet enfant? (*Note à l'infirmier/l'assistante sociale : un tuteur principal peut être tout adulte ayant la principale responsabilité de s'occuper d'un enfant à l'absence des parents biologiques. Cela inclue la provision de soins et supervision à la place (1) des parents biologiques décédés de l'enfant, (2) des parents trop malades pour s'occuper de leur enfant, ou (3)qui ont laissé la responsabilité de l'enfant à quelqu'un d'autre..*)	Si oui, procéder à la question suivante. Si non, arrêter et dire au parent/tuteur que vous ne devez parler qu'avec le parent biologique ou à l'un des principaux tuteurs.
3. En tant que parent/principal tuteur, êtes-vous responsable des soins quotidiens et de la supervision de l'enfant?	Si oui, procéder à la question suivante. Si non, dire à la personne que vous devez parler à la personne responsable des soins quotidiens de l'enfant

Questions de Sélection	Action
4. Quel est le nom de la maladie de votre enfant?	Si le parent/tuteur indique que son enfant a le VIH ou le SIDA, ou un autre terme local qui indique le VIH ou SIDA, procéder avec la question suivant. (*Note à l'infirmier/l'assistante sociale: Explorer avec sensibilité, en cas de besoin. Par exemple, un parent peut dire que l'enfant a la diarrhée. Demander alors, si l'enfant a d'autres maladies ou s'il y a des causes initiales à la condition que le parent vient de vous expliquer?*) Si le parent/tuteur n'indique pas que son enfant a le VIH ou le SIDA, ne pas procéder et remercier le parent/tuteur pour son temps.
5. Quel est l'âge de l'enfant actuellement?	Si 5+ ans, noter dans la fiche de suivi. Si <5 ans, noter dans la fiche de suivi. Expliquer le parent/tuteur que les ênqueteurs ne peuvent parler qu'avec les parents/tuteurs des enfants âgés de 5 à 17 ans. Remercier le parent/tuteur pour son temps. Ne pas procéder à la question suivante.
6. Avez-vous dit, ou avez-vous demandé à quelqu'un d'autre de dire à votre enfant qu'il avait le VIH ou le SIDA?	Si l'enfant a été divulgué (annoncé) son sérostatut ET l'enfant a 8-17 ans, confirmer que le tuteur a utilisé les mots VIH ou SIDA, ou un autre terme local qui indique le VIH ou SIDA, pour informer l'enfant de sa maladie. Noter dans la fiche de suivi et expliquer au parent/tuteur que l'assistante sociale lui donnera des autres détailles concernant l'étude. Remplir la fiche d'introduction pour l'assistante sociale et noter dans la fiche de suivi. Ne pas procéder avec le paragraphe suivant. Si l'enfant a qui a été divulgué (annoncé) son sérostatut, ET l'enfant a 5-8 ans, noter dans la fiche de suivi. Expliquer au parent/tuteur qui vous devez parler seulement avec les parents/tuteurs dont l'âge d'enfant qui connait son sérostatut est entre 8-17 ans. Remercier le parent/tuteur pour son temps. Ne pas procéder avec le paragraphe suivant. Si l'enfant N'A PAS été divulgué (annoncé) son sérostatut ET l'enfant a 5-17ans, noter dans la fiche de suivi. Continuer avec la question suivante.

Questions de Sélection	Action
7. Avez-vous participé dans une interview concernant votre enfant pour une étude de recherche par l'UNC ici à KLL, au cours des trois derniers mois ?	Si OUI, expliquer au parent/tuteur qui vous devez parler seulement avec les parents/tuteurs qui n'ont pas encore participé dans cet étude. Remercier le parent/tuteur pour son temps. Ne pas procéder avec le paragraphe suivant. Si NON, procéder avec le paragraphe suivant.

<u>Texte d'Introduction :</u>

Les chercheurs faisant l'étude veulent découvrir les opinions des parents et tuteurs ayant un enfant VIH positif pour savoir si les enfants VIH+ devraient être informés de leur statut séropositif. En tant que parent ou tuteur d'un enfant séropositif, ils aimeraient entendre vos idées sur ces questions. L'enquêteur vous posera des questions sur la révélation aux enfants à propos de leur statut de VIH. Votre participation est volontaire, et elle permettra d'améliorer les services dispensés par les programmes de recherche et de traitement du VIH pour les enfants VIH+ et leurs familles à Kinshasa. Si vous consentez à participer, un membre de l'équipe de l'étude vous posera des questions dans un endroit privé, et ceci prendra environ une heure ou une heure trente. Vous recevrez 1500 Francs Congolais pour vous rembourser les frais de transport et pour votre temps.

Avez-vous le temps de parler avec un membre de l'étude maintenant ? (*Si oui, remplir la fiche d'introduction et introduire le parent/tuteur à l'enquêteur*). (*Si non*) Voudriez-vous fixer un rendez-vous pour revenir au centre en vue d'un entretien? (*Si oui, déterminer la date/heure. Si non, dire au parent/tuteur de vous faire savoir à la prochaine visite clinique s'il/elle est disponible pour parler avec un membre de l'équipe. Remplissez le Formulaire de Refus et d'Inéligibilité pour Parents/Tuteurs*)

Enregistrer ces informations sur le Formulaire d'Introduction pour le parent/tuteur.

Pour Les Parents/Tuteurs Qui ONT Divulgué le Sérostatut : Interviews en Profondeur

Manuscrit et questions de sélection pour le recrutement de tous les parents/tuteurs qui ont divulgué, à utiliser par l'assistante sociale:

Vérifier l'information sur la fiche d'introduction, qui a été rempli avec les questions ci-dessous.

Questions de Sélection	Action
1. Avant que je vous parle de l'étude, s'il vous plait pouvez-vous me dire si vous avez 18 ans ou plus ?	<u>Si oui</u>, procéder à la question suivante. <u>Si non</u>, arrêter et dire au parent/tuteur que vous ne devez parler qu'avec les individus qui ont 18 ans ou plus.
2. Est-ce que vous êtes le parent biologique ou un des principaux tuteurs de cet enfant? (*Note à l'infirmier/l'assistante sociale : un tuteur principal peut être tout adulte ayant la principale responsabilité de s'occuper d'un enfant à l'absence des parents biologiques. Cela inclut la provision de soins et supervision à la place (1) des parents biologiques décédés de l'enfant, (2) des parents trop malades pour s'occuper de leur enfant, ou (3)qui ont laissé la responsabilité de l'enfant à quelqu'un d'autre..*)	<u>Si oui</u>, procéder à la question suivante. <u>Si non</u>, arrêter et dire au parent/tuteur que vous ne devez parler qu'avec le parent biologique ou à l'un des principaux tuteurs.
3. En tant que parent/principal tuteur, êtes-vous responsable des soins quotidiens et de la supervision de l'enfant?	<u>Si oui</u>, procéder à la question suivante. <u>Si non</u>, dire à la personne que vous devez parler à la personne responsable des soins quotidiens de l'enfant
4. Quel est le nom de la maladie de votre enfant?	Si le parent/tuteur indique que son enfant a le VIH ou le SIDA, ou un autre terme local qui indique le VIH ou SIDA, procéder avec la question suivant. (*<u>Note à l'infirmier/l'assistant social</u>: Explorer avec sensibilité, en cas de besoin. Par exemple, un parent peut dire que l'enfant a la diarrhée. Demander alors, si l'enfant a d'autres maladies ou s'il y a des causes initiales à la condition que le parent vient de vous expliquer?*) Si le parent/tuteur n'indique pas que son enfant a le VIH, ne pas procéder et remercier le parent/tuteur pour son temps.

Questions de Sélection	Action
5. Avez-vous dit, ou avez-vous demandez à quelqu'un d'autre de dire à votre enfant qu'il avait le VIH ou le SIDA?	Si oui, confirmer que le tuteur a utilisé les mots VIH ou SIDA, ou un autre terme local qui indique le VIH ou SIDA, pour informer l'enfant de sa maladie. . Procéder avec la question suivante. Si non, le parent/tuteur n'est pas éligible pour l'étape qualitative mais pourra être éligible pour l'étape quantitative. Continuez avec les critères d'éligibilité pour les questionnaires (Annexe A). Ne pas procéder avec la question suivante.
6. Quel est l'âge de l'enfant actuellement?	Si 8+ ans, noter dans la fiche de suivi. Si <8 ans, noter dans la fiche de suivi. Expliquer le parent/tuteur que les enquêteurs ne peuvent parler qu'avec les parents/tuteurs des enfants âgés de 8 à 17 ans. Remercier le parent/tuteur pour son temps. Ne pas procéder avec la question suivante.
7. Avez-vous participez dans une interview concernant votre enfant pour une étude de recherche par l'UNC ici à KLL, au cours des trois derniers mois ?	Si OUI, expliquer au parent/tuteur que vous devez parler seulement avec les parents/tuteurs qui n'ont pas encore participé dans l'étude. Remercier le parent/tuteur pour son temps. Ne pas procéder avec le paragraphe suivant. Si NON, vérifiez l'information sur sa carte de visite. Procéder avec le paragraphe suivant.

Texte d'Introduction :

Les chercheurs faisant l'étude veulent découvrir les opinions des parents et tuteurs ayant un enfant VIH positif pour savoir si les enfants VIH+ devraient être informés de leur statut séropositif, aussi que leurs expériences d'informer l'enfant son sérostatut. En tant que parent ou tuteur d'un enfant VIH+, ils aimeraient entendre vos idées sur ces questions. Ils s'intéressent aussi de l'expérience des enfants qui ont été informé de leur sérostatut VIH+. L'enquêteur vous posera des questions sur la révélation aux enfants à propos de leur statut de VIH. Votre participation est volontaire, et elle permettra d'améliorer les services dispensés par les programmes de recherche et de traitement du VIH pour les enfants VIH+ et leurs familles à Kinshasa. Si vous consentez à participer, un membre de l'équipe de l'étude vous posera des questions dans un endroit privé, et ceci prendra environ une heure et demie. Si votre enfant connaît son statut de VIH, nous pouvons également lui questionner, mais seulement si cela convient à vous et à votre enfant. Vous recevrez 1500

Francs Congolais pour vous rembourser les frais de transport et pour votre temps. Votre enfant recevra un petit cadeau s'il participe.

Voudriez-vous fixer un rendez-vous pour revenir au centre en vue d'un entretien? (*Si oui, déterminer la date/heure. Si non, dire au parent/tuteur de vous faire savoir à la prochaine visite clinique s'il/elle est disponible pour parler avec un membre de l'équipe.*)

(*Si le parent/tuteur a dit qu'on a annoncé à l'enfant son statut sérologique)* Est-ce que vous permettez que votre enfant soit interviewé ? (*Si oui*) Est-ce que vous voulez rester dans la même salle avec votre enfant pendant qu'il/elle est interviewé ? (*Expliquer que l'enquête du parent/tuteur et celui de l'enfant peuvent avoir lieu au même moment, mais dans les différentes salles. Expliquer que cela réduira la durée au centre par le parent/tuteur. Cependant, le parent/tuteur peut être présent pendant l'enquête de son enfant si il/elle et l'enfant le préfère. Si un parent/tuteur est présent pendant une enquête, veuillez le noter sur la fiche d'introduction du parent/tuteur.)*

Pour les Enfants À Qui A Été Divulgué Leur Statut Sérologique

Nous sommes en train de mener une petite étude avec des enfants et adolescents recevant des services dans ce centre. Les enfants et adolescents qui participent dans cette étude seront interrogés sur les circonstances et le moment où ils ont découvert le nom de leur maladie. Tous les enfants et adolescents seront également interrogés sur leur perception quant à leur maladie. Ils seront interrogés dans un endroit privé du centre. Nous parlerons également avec les parents de ces questions.

Votre parent ou tuteur m'a dit que je pourrais vous demander si vous aimeriez participer à cette étude.

Cela vous va-t-il si je vous pose quelques questions pour savoir si vous voulez participer à l'étude? (*Si oui, procéder avec le paragraphe suivant. Si non, remercier l'enfant pour son temps. Remplissez le Formulaire de Refus et d'Inéligibilité pour Parents/Tuteurs*)

Questions de sélection	**Action**
1. Quel âge avez-vous?	Si l'enfant a moins de 8 ans, ne pas lui poser le reste des questions de sélection. Dire à l'enfant que vous ne pouvez parler qu'aux enfants âgés de 8 ans ou plus. Si l'enfant est âgé de 8 ans ou plus, procéder à la question suivante.
2. Quel est le nom de la maladie que vous avez?	Si l'enfant/l'adolescent ne dit pas qu'il/elle a le VIH ou SIDA immédiatement, ou si l'enfant parle des autres maladies, demander à l'enfant/l'adolescent s'il/elle a d'autres maladies. Si l'enfant/l'adolescent ne dit pas qu'il/elle a le VIH ou SIDA, ou un autre terme local qui indique le VIH ou SIDA, ne pas lui poser le reste des questions de sélection. Remercier l'enfant/l'adolescent d'avoir parlé avec vous et lui dire que vous n'avez pas besoin de lui poser d'autres questions. Si l'enfant/ l'adolescent dit qu'il/elle a le VIH ou SIDA, ou un autre terme local qui indique le VIH ou SIDA, procéder à la question suivante.
3. Est-ce que votre parent ou tuteur vous avez déjà parlé de votre état de VIH [utiliser le terme de VIH employé par l'enfant dans la question 2]?	Si oui, accompagner l'enfant/l'adolescent vers un membre du personnel de l'étude. Si non, poser la question de sélection suivante.

Questions de sélection	Action
4. Est-ce qu'un médecin ou un infirmier ou un conseiller vous avez déjà parlé de votre état de VIH [utiliser le terme de VIH employé par l'enfant dans la question 2]?	Si oui, accompagner l'enfant vers un membre du personnel de l'étude. Si non, Remercier l'enfant d'avoir parlé avec vous et lui dire que vous n'avez pas besoin de lui poser d'autres questions.

APPENDIX 6 :
QUESTIONNAIRE FOR CAREGIVERS, AIMS 1 & 2

UNDERSTANDING THE PROCESS OF ILLNESS-INFORMATION DISCLOSURE TO CHILDREN IN KINSHASA, DEMOCRATIC REPUBLIC OF THE CONGO (SARA DISCLOSURE STUDY)

QUESTIONNAIRE FOR PARENTS/CAREGIVERS WHO HAVE NOT DISCLOSED
VERSION 28 JUNE 2006--FINAL

Section A. INFORMATION ABOUT THE INTERVIEW

(to be completed by Interviewer)

A1. Date of Interview [DD/MM/YYYY]:____

A2. Location of Interview: ____

A3. Name of Interviewer: ____

A4. Respondent ID# of the parent/caregiver interviewed: ________________.

Section B. DEMOGRAPHIC QUESTIONS

__Interviewer script__: I would like to begin by asking you a few questions about you and your family.

#	Question	Response categories	Skip to
B1.	***(Do not read aloud)*** Sex of respondent:	☐ (1) Male ☐ (2) Female	
B2.	How old are you?	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B3.	What is the highest grade in school that you completed?	☐ (0) None ☐ (1) Some primary school ☐ (2) Completed primary school ☐ (3) Some trade or professional school ☐ (4) Completed trade or professional school ☐ (5) Some secondary school ☐ (6) Completed secondary school ☐ (7) Any post-secondary school ☐ (98) ***Refuse to answer***	

#	**Question**	**Response categories**	**Skip to**
B4.	What do you primarily do to earn a living? ***(Do not read responses out loud)***	☐ (1) Work for a big company ☐ (2) Work as a public servant [4] ☐ (3) Work for a small company[b] or for a private person in their home[c] ☐ (4) Informal work ☐ (5) Other B5a. Specify: ________________________	B6
		☐ (0) Does not work	B5
		☐ (98) ***Refuse to answer***	B6
B5.	For how long have you not been working? ***(Check one box)***	☐ (1) (B5a.)__________ weeks ☐ (2) (B5b.)__________ months ☐ (3) (B5c.)__________ years ☐ (4) Never worked ☐ (98) ***Refuse to answer***	
B6.	Are you married? ***(Do not read responses out loud)*** ***(If response is "yes", ask whether "formally married", "living with a partner", or "relationship where supports/supported by another"***	☐ (1) Single	B9
		☐ (2) Formally married	B7
		☐ (3) Living with a partner	B7
		☐ (4) Concubinage	B7
		☐ (5) Separated	B7
		☐ (6) Divorced	B8
		☐ (7) Widow/widower	B8
		☐ (98) ***Refuse to answer***	B8
B7.	What does your partner/spouse primarily do to earn a living? ***(Do not read responses out loud)***	☐ (1) Work for a big company ☐ (2) Work as a public servant [a] ☐ (3) Work for a small company [b] or for a private person in their home [c] ☐ (4) Informal work ☐ (5) Other B7a. Specify: ________________________	B9
		☐ (0) Does not work	B8
		☐ (98) ***Refuse to answer***	B9
B8.	For how long has your partner not been working? ***(Check one box)***	☐ (1) (B5a.)__________ weeks ☐ (2) (B5b.)__________ months ☐ (3) (B5c.)__________ years ☐ (4) Never worked ☐ (98) ***Refuse to answer***	
B9.	Is the biological father of the child alive?	☐ (1) Yes	B11
		☐ (0) No	B10
		☐ (97) I do not know	B11
		☐ (98) ***Refuse to answer***	B11

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[4] For example : Soldiers, police officers, medical doctors, nurses.

[b] This includes working for small, privately owned business. For example, a business that only employs 5 people.

[c] For example : Housekeepers, gardeners, or drivers.

#	Question	Response categories	Skip to
B10.	How old was the child when the father died? ***(If <1 year, record as a fraction of a year)***	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	B11
B11.	Is the biological mother of the child alive?	☐ (1) Yes	B13
		☐ (0) No	B12
		☐ (97) I do not know	B13
		☐ (98) ***Refuse to answer***	B13
B12.	How old was the child when the mother died? ***(If <1 year, record as a fraction of a year)***	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B13.	What is your relationship to the child who receives medical care or services at this center? ***(Do not read responses out loud)***	☐ (1) Biological Mother ☐ (2) Biological Father ☐ (3) Grandparent ☐ (4) Brother or sister ☐ (5) Father's sister ☐ (6) Mother's younger sister ☐ (7) Mother's older sister ☐ (8) Father's young brother ☐ (9) Father's older brother ☐ (10) Mother's brother ☐ (96) Other (B13a. Specify): ____________________ ☐ (98) ***Refuse to answer***	
<u>Interviewer script</u>: We will finish this section by asking you a few more questions about your child.			
B14.	Currently how old is the child?	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B15.	Is your child a boy or a girl?	☐ (1) Boy ☐ (2) Girl ☐ (98) ***Refuse to answer***	
B16.	Has the child ever gone to school?	☐ (1) Yes	B17
		☐ (0) No	**Next Section**
		☐ (98) ***Refuse to answer***	
B17.	Does the child currently go to school?	☐ (1) Yes	B18
		☐ (0) No	B19
		☐ (98) ***Refuse to answer***	B19
B18.	What grade is the child in school?		**Next Section**

#	Question	Response categories	Skip to
B19.	How long has it been since the child last went to school?	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B20.	What is the highest grade that the child completed?	☐ (1) Some primary school ☐ (2) Completed primary school ☐ (3) Some trade or professional school ☐ (4) Completed trade or professional school ☐ (5) Some secondary school ☐ (6) Completed secondary school ☐ (7) Any post-secondary school ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B21.	For what reasons does the child not go to school?	☐ (1) Health reason ☐ (2) Lack of financial resources ☐ (3) Health reason & lack of financial resources ☐ (96): Other: (B21a. Specify:__________________) ☐ (98) ***Refuse to answer***	

Interviewer script: ***Thank you for answering these questions about you and your family***

Section C. ASSESSMENT OF CHILD'S COGNITIVE DEVELOPMENT STAGE

Interviewer script: ***Next I am going to read to you some statements that might describe a child's level of cognitive development. Tell me how much that statement applies to your child. The choices are: does not apply at all, does not really apply, applies a little, definitely applies and not sure or don't know.***

C1. The child can tell the difference between right and wrong. Does this apply or does it not apply?

- ☐ (1) Does not apply
  - (a) Does it not really apply or does it not apply at all ?
    - ☐ (1) Does not apply at all
    - ☐ (2) Does not really apply
- ☐ (2) Applies
  - (b) Does is apply a little or does it definitely apply ?
    - ☐ (1) Definitely applies
    - ☐ (2) Applies a little
- ☐ (3) Not sure or don't know
- ☐ (98) ***Refuse to answer***

C2. The child can take on certain basic responsibilities in the house. Does this apply or does it not apply?

- ☐ (1) Does not apply
  - (a) Does it not really apply or does it not apply at all ?
    - ☐ (1) Does not apply at all
    - ☐ (2) Does not really apply
- ☐ (2) Applies
  - (b) Does is apply a little or does it definitely apply ?
    - ☐ (1) Definitely applies
    - ☐ (2) Applies a little
- ☐ (3) Not sure or don't know
- ☐ (98) ***Refuse to answer***

C3. The child knows how to take care of his/her daily basic needs, such as getting dressed, getting ready for school, or doing his/her chores without being asked. Does this apply or does it not apply?

☐ (1) Does not apply
  - (a) Does it not really apply or does it not apply at all ?
    - ☐ (1) Does not apply at all
    - ☐ (2) Does not really apply

☐ (2) Applies
  - (b) Does is apply a little or does it definitely apply ?
    - ☐ (1) Definitely applies
    - ☐ (2) Applies a little

☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

C4. If asked, the child will keep a secret. Does this apply or does it not apply?

☐ (1) Does not apply
  - (a) Does it not really apply or does it not apply at all ?
    - ☐ (1) Does not apply at all
    - ☐ (2) Does not really apply

☐ (2) Applies
  - (b) Does is apply a little or does it definitely apply ?
    - ☐ (1) Definitely applies
    - ☐ (2) Applies a little

☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

C5. The child knows how to follow directions. Does this apply or does it not apply?

☐ (1) Does not apply
  - (a) Does it not really apply or does it not apply at all ?
    - ☐ (1) Does not apply at all
    - ☐ (2) Does not really apply

☐ (2) Applies
  - (b) Does is apply a little or does it definitely apply ?
    - ☐ (1) Definitely applies
    - ☐ (2) Applies a little

☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

C6. The child is becoming aware of the opposite sex. Does this apply or does it not apply?

☐ (1) Does not apply
  - (a) Does it not really apply or does it not apply at all ?
    - ☐ (1) Does not apply at all
    - ☐ (2) Does not really apply

☐ (2) Applies
  - (b) Does is apply a little or does it definitely apply ?
    - ☐ (1) Definitely applies
    - ☐ (2) Applies a little

☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

C7. The child can understand the idea of death. Does this apply or does it not apply?

☐ (1) Does not apply
  (a) Does it not really apply or does it not apply at all ?
    ☐ (1) Does not apply at all
    ☐ (2) Does not really apply

☐ (2) Applies
  (b) Does is apply a little or does it definitely apply ?
    ☐ (1) Definitely applies
    ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

C8. The child is aware that others may judge him/her by his/her actions. Does this apply or does it not apply?

☐ (1) Does not apply
  (a) Does it not really apply or does it not apply at all ?
    ☐ (1) Does not apply at all
    ☐ (2) Does not really apply

☐ (2) Applies
  (b) Does is apply a little or does it definitely apply ?
    ☐ (1) Definitely applies
    ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

<u>Interviewer script:</u> In these next few questions, I would like for you to think of your child in comparison with other children who are the same age.

C9. Compared to other children of his/her age, the child's general understanding of things is:

☐ (1) Less than other children his/her age.
☐ (2) The same as other children his/her age.
☐ (3) Better than other children his/her age.
☐ (98) ***Refuse to answer***

C10. Compared to other children of his/her age, the child's ability to learn things, such as lessons in school, is:

☐ (1) Less than other children his/her age.
☐ (2) The same as other children his/her age.
☐ (3) Better than other children his/her age.
☐ (98) ***Refuse to answer***

C11. Compared to other children of his/her age, the child's way of playing with others is:

☐ (1) Less than other children his/her age.
☐ (2) The same as other children his/her age.
☐ (3) Better than other children his/her age.
☐ (98) ***Refuse to answer***

C12. Compared to other children of his/her age, the child's level of awareness is:

☐ (1) Less than other children his/her age.
☐ (2) The same as other children his/her age.
☐ (3) Better than other children his/her age.

☐ (98) ***Refuse to answer***

C13. Compared to other children of his/her age, the children's level of maturity is:
☐ (1) Less than other children his/her age.
☐ (2) The same as other children his/her age.
☐ (3) Better than other children his/her age.
☐ (98) ***Refuse to answer***

Section D. EMOTIONAL CLOSENESS

<u>Interviewer script</u>: Next I am going to read to you some statements that might describe a parent's relationship with his or her child. Tell me how much that statement applies to the relationship between you and this child. The choices are: does not apply at all, not really, applies a little, definitely applies, and not sure or you don't know.

D1. You and the child share an affectionate, warm relationship. Does this apply or does it not apply?
☐ (1) Does not apply
    (a) Does it not really apply or does it not apply at all ?
        ☐ (1) Does not apply at all
        ☐ (2) Does not really apply

☐ (2) Applies
    (b) Does is apply a little or does it definitely apply ?
        ☐ (1) Definitely applies
        ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D2. You and the child always seem to be struggling with each other. Does this apply or does it not apply?
☐ (1) Does not apply
    (a) Does it not really apply or does it not apply at all ?
        ☐ (1) Does not apply at all
        ☐ (2) Does not really apply

☐ (2) Applies
    (b) Does is apply a little or does it definitely apply ?
        ☐ (1) Definitely applies
        ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D3. If upset, the child will seek comfort from you. Does this apply or does it not apply?
☐ (1) Does not apply
    (a) Does it not really apply or does it not apply at all ?
        ☐ (1) Does not apply at all
        ☐ (2) Does not really apply

☐ (2) Applies
    (b) Does is apply a little or does it definitely apply ?
        ☐ (1) Definitely applies
        ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D4. The child is uncomfortable with physical affection or touch from you. . Does this apply or does it not apply?

☐ (1) Does not apply
	(a) Does it not really apply or does it not apply at all ?
		☐ (1) Does not apply at all
		☐ (2) Does not really apply

☐ (2) Applies
	(b) Does is apply a little or does it definitely apply ?
		☐ (1) Definitely applies
		☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D5. The child values his/her relationship with me. Does this apply or does it not apply?

☐ (1) Does not apply
	(a) Does it not really apply or does it not apply at all ?
		☐ (1) Does not apply at all
		☐ (2) Does not really apply

☐ (2) Applies
	(b) Does is apply a little or does it definitely apply ?
		☐ (1) Definitely applies
		☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D6. When you praise the child, he/she beams with pride. Does this apply or does it not apply?

☐ (1) Does not apply
	(a) Does it not really apply or does it not apply at all ?
		☐ (1) Does not apply at all
		☐ (2) Does not really apply

☐ (2) Applies
	(b) Does is apply a little or does it definitely apply ?
		☐ (1) Definitely applies
		☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D7. The child spontaneously shares information about himself/herself. Does this apply or does it not apply?

☐ (1) Does not apply
	(a) Does it not really apply or does it not apply at all ?
		☐ (1) Does not apply at all
		☐ (2) Does not really apply

☐ (2) Applies
	(b) Does is apply a little or does it definitely apply ?
		☐ (1) Definitely applies
		☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D8. The child easily becomes angry at you. Does this apply or does it not apply?

☐ (1) Does not apply
  (a) Does it not really apply or does it not apply at all ?
    ☐ (1) Does not apply at all
    ☐ (2) Does not really apply

☐ (2) Applies
  (b) Does is apply a little or does it definitely apply ?
    ☐ (1) Definitely applies
    ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D9. It is easy to be in tune with what the child is feeling. Does this apply or does it not apply?

☐ (1) Does not apply
  (a) Does it not really apply or does it not apply at all ?
    ☐ (1) Does not apply at all
    ☐ (2) Does not really apply

☐ (2) Applies
  (b) Does is apply a little or does it definitely apply ?
    ☐ (1) Definitely applies
    ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D10. The child stays angry or is resistant after you discipline him/her. Does this apply or does it not apply?

☐ (1) Does not apply
  (a) Does it not really apply or does it not apply at all ?
    ☐ (1) Does not apply at all
    ☐ (2) Does not really apply

☐ (2) Applies
  (b) Does is apply a little or does it definitely apply ?
    ☐ (1) Definitely applies
    ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D11. Dealing with the child drains your energy. Does this apply or does it not apply?

☐ (1) Does not apply
  (a) Does it not really apply or does it not apply at all ?
    ☐ (1) Does not apply at all
    ☐ (2) Does not really apply

☐ (2) Applies
  (b) Does is apply a little or does it definitely apply ?
    ☐ (1) Definitely applies
    ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D12. When the child is in a bad mood, you know you both are in for a long and difficult day. Does this apply or does it not apply?

☐ (1) Does not apply
  (a) Does it not really apply or does it not apply at all ?
    ☐ (1) Does not apply at all
    ☐ (2) Does not really apply

☐ (2) Applies
  (b) Does is apply a little or does it definitely apply ?
    ☐ (1) Definitely applies
    ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D13. The child's feelings toward you can be unpredictable or can change suddenly. Does this apply or does it not apply?

☐ (1) Does not apply
  (a) Does it not really apply or does it not apply at all ?
    ☐ (1) Does not apply at all
    ☐ (2) Does not really apply

☐ (2) Applies
  (b) Does is apply a little or does it definitely apply ?
    ☐ (1) Definitely applies
    ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D14. The child is sneaky or manipulative with you. Does this apply or does it not apply?

☐ (1) Does not apply
  (a) Does it not really apply or does it not apply at all ?
    ☐ (1) Does not apply at all
    ☐ (2) Does not really apply

☐ (2) Applies
  (b) Does is apply a little or does it definitely apply ?
    ☐ (1) Definitely applies
    ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D15. The child openly shares his/her feelings and experience with you. Does this apply or does it not apply?

☐ (1) Does not apply
  (a) Does it not really apply or does it not apply at all ?
    ☐ (1) Does not apply at all
    ☐ (2) Does not really apply

☐ (2) Applies
  (b) Does is apply a little or does it definitely apply ?
    ☐ (1) Definitely applies
    ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D16. The child is very obedient to you. . Does this apply or does it not apply?
☐ (1) Does not apply
    (a) Does it not really apply or does it not apply at all ?
        ☐ (1) Does not apply at all
        ☐ (2) Does not really apply

☐ (2) Applies
    (b) Does is apply a little or does it definitely apply ?
        ☐ (1) Definitely applies
        ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D17. You feel sad for the child that she/he has to live with this condition. Does this apply or does it not apply?
☐ (1) Does not apply
    (a) Does it not really apply or does it not apply at all ?
        ☐ (1) Does not apply at all
        ☐ (2) Does not really apply

☐ (2) Applies
    (b) Does is apply a little or does it definitely apply ?
        ☐ (1) Definitely applies
        ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

D18. You try to do whatever possible to avoid harming or hurting the child. Does this apply or does it not apply?
☐ (1) Does not apply
    (a) Does it not really apply or does it not apply at all ?
        ☐ (1) Does not apply at all
        ☐ (2) Does not really apply

☐ (2) Applies
    (b) Does is apply a little or does it definitely apply ?
        ☐ (1) Definitely applies
        ☐ (2) Applies a little
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

Section E. CURRENT LEVEL OF DISCLOSURE

Interviewer script: ***Now I would like to ask you some short questions about your child's illness.***

#	Question	Response categories	Skip to
E1.	How old was the child when he was diagnosed with HIV? ***(Check one box)***	☐ (1) (E1a.)__________ years ☐ (2) (E1b.)__________ months ☐ (97) I do not know ☐ (98) ***Refuse to answer***	

#	Question	Response categories	Skip to
E2.	How long has it been since the child was first diagnosed with HIV?	☐ (1) (E2a.)__________ years ☐ (2) (E2b.)__________ months ☐ (97) I do not know/cannot remember ☐ (98) ***Refuse to answer***	
E3.	How long has it been since you have known the child's diagnosis? ***(Check one box)***	☐ (1) (E3a.)__________ years ☐ (2) (E3b.)__________ months ☐ (97) I do not know/cannot remember ☐ (98) ***Refuse to answer***	
E4.	How would you describe your child's health now? ***(Read each response and check off one box)***	☐ (1) No symptoms ☐ (2) Minor symptoms ☐ (3) Frequent illness but no hospitalization ☐ (4) Frequent hospitalization, no overnight stays ☐ (5) Gravely ill/hospitalization, overnight stays ☐ (98) ***Refuse to answer***	
E5.	Is your child taking medications for AIDS? ***(if "yes", ask for the name of the drug")***	☐ (0) No (0) ☐ (1) Yes- cotrimoxazole/Bactrim only ☐ (2) Yes-ARVs(antiretrovirals) ☐ (3) Yes-do not know what medication ☐ (98) ***Refuse to answer***	
E6.	Does anyone in your family besides yourself know that the child has HIV?	☐ (1) Yes	E7.
		☐ (0) No	E8.
		☐ (98) ***Refuse to answer***	E8
E7.	Who? **(1--*Read each response, and 2—check each one that applies in relation to the child*)**	☐ (1) Biological mother ☐ (2) Biological father (☐ (3) Grandparent ☐ (4) Brother or sister ☐ (5) Father's sister ☐ (6) Mother's younger sister ☐ (7) Mother's older sister ☐ (8) Father's young brother ☐ (9) Father's older brother ☐ (10) Mother's brother ☐ (96) Other member of the family (E7a. Specify): ____________________ ☐ (98) ***Refuse to answer***	
E8.	Does anyone outside of your family and medical personnel know that the child has HIV?	☐ (1) Yes	E9
		☐ (0) No	E10
		☐ (98) ***Refuse to answer***	

#	Question	Response categories	Skip to
E9.	Who? ***(1 -- Read each response and 2 -- Check all that apply.)***	☐ (1) Neighbor ☐ (2) Child's Teacher ☐ (3) Village/Community Leader ☐ (4) Religious Leader ☐ (5) Friends of yours (the parent/caregiver) ☐ (6) Friends of the child ☐ (7) Medical staff other than who takes care of child ☐ (96) Other/Anyone else (E9a. Specify): ______________________ (E9b. Specify):______________________ (E9c. Specify): ______________________ ☐ (98) ***Refuse to answer***	
E10.	What, if anything, has been told to your child (the child under your care) up to today about his/her health status—by you as well as others? ***<u>(Do not read out loud responses. Write down response of participant and then classify the response):</u>***	____ ____ ____ ☐ (1) Nothing ☐ (2) Something false about his/her health ☐ (3) Something about her/his health, but not that he/she has HIV or AIDS ☐ (4) Something true as well as something false about his/her health ☐ (98) ***Refuse to answer***	
E11.	Do you believe your child should be told one day he/she has HIV or AIDS?	☐ (1) Yes ☐ (0) No ☐ (97) I do not know ☐ (98) ***Refuse to answer***	

<u>Interviewer script</u>: Thank you for your answers to these questions.

Section F. INTENTIONS TO DISCLOSE

<u>Interviewer script</u>: I will now ask you some questions about your plans, if you have any, to inform your child about her/his HIV status.

F1. Have you thought about what types of events might take place that would result in telling your child she/he has HIV?

☐ (1) Yes
☐ (2) No →**F5**
☐ (98) ***Refuse to answer*** →**F5**

F2. Could you please tell me all the types of things that would lead you to tell your child that she has HIV/AIDS? ***(list the responses given)***

____

____

____

____

F3. At what moments or under what circumstances do you think about these things? ***(list the responses given)***

____

____

____

____

F4. How much have you thought about these events?
☐ (1) Not very often
☐ (2) About once a month
☐ (3) About once a week
☐ (4) Several times a week
☐ (5) Every day
☐ (96) Another time
  (a) (Specify) ____________

***<u>Interviewer script:</u>* Now, I am going to read you a list of reasons other parents/caregivers have told their child about their HIV infection status After I read each reason, please tell me how likely it is that you would tell your child for this reason.**

F5. Some parents/caregivers have spoken to their children about their HIV status because the health status of the parent/caregiver becomes worse. Is this a reason to tell for you or is not a reason for you to tell?
☐ (1) Not a reason to tell
  (a) Is this not really a reason to tell or is it not at all a reason to tell?
    ☐ (1) Not at all a reason to tell
    ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
  (b) Is this a likely reason to tell or is it definitely a reason to tell?
    ☐ (1) Definitely a reason to tell
    ☐ (2) A likely reason to tell

☐ (3) Not sure or don't know
☐ (98) Refuse to answer

F6. Some parents/caregivers have spoken to their children about their HIV status because the child's health status gets worse. Is this a reason to tell for you or is not a reason for you to tell?
☐ (1) Not a reason to tell
  (a) Is this not really a reason to tell or is it not at all a reason to tell?
    ☐ (1) Not at all a reason to tell
    ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
  (b) Is this a likely reason to tell or is it definitely a reason to tell?
    ☐ (1) Definitely a reason to tell
    ☐ (2) A likely reason to tell

☐ (3) Not sure or don't know
☐ (98) Refuse to answer

F7. Some parents/caregivers have spoken to their children about their HIV status because the child reaches an age in which he or she should know. Is this a reason to tell for you or is not a reason for you to tell?

☐ (1) Not a reason to tell
  (a) Is this not really a reason to tell or is it not at all a reason to tell?
    ☐ (1) Not at all a reason to tell
    ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
  (b) Is this a likely reason to tell or is it definitely a reason to tell?
    ☐ (1) Definitely a reason to tell
    ☐ (2) A likely reason to tell

☐ (3) Not sure or don't know
☐ (98) Refuse to answer

F8. Some parents/caregivers have spoken to their children about their HIV status because the child asks questions about his or her illness. Is this a reason to tell for you or is not a reason for you to tell?

☐ (1) Not a reason to tell
  (a) Is this not really a reason to tell or is it not at all a reason to tell?
    ☐ (1) Not at all a reason to tell
    ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
  (b) Is this a likely reason to tell or is it definitely a reason to tell?
    ☐ (1) Definitely a reason to tell
    ☐ (2) A likely reason to tell

☐ (3) Not sure or don't know
☐ (98) Refuse to answer

F9. Some parents/caregivers have spoken to their children about their HIV status because access to treatment becomes available for the people. Is this a reason to tell for you or is not a reason for you to tell?

☐ (1) Not a reason to tell
  (a) Is this not really a reason to tell or is it not at all a reason to tell?
    ☐ (1) Not at all a reason to tell
    ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
  (b) Is this a likely reason to tell or is it definitely a reason to tell?
    ☐ (1) Definitely a reason to tell
    ☐ (2) A likely reason to tell

☐ (3) Not sure or don't know
☐ (98) Refuse to answer

F10. Some parents/caregivers have spoken to their children about their HIV status because the child is about to start antiretroviral treatment. Is this a reason to tell for you or is not a reason for you to tell?

☐ (1) Not a reason to tell
  (a) Is this not really a reason to tell or is it not at all a reason to tell?
    ☐ (1) Not at all a reason to tell
    ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
  (b) Is this a likely reason to tell or is it definitely a reason to tell?
    ☐ (1) Definitely a reason to tell
    ☐ (2) A likely reason to tell

☐ (3) Not sure or don’t know
☐ (98) Refuse to answer

F11. The child does not want to take his/her medications as they should. Is this a reason to tell for you or is not a reason for you to tell?

☐ (1) Not a reason to tell
  (a) Is this not really a reason to tell or is it not at all a reason to tell?
    ☐ (1) Not at all a reason to tell
    ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
  (b) Is this a likely reason to tell or is it definitely a reason to tell?
    ☐ (1) Definitely a reason to tell
    ☐ (2) A likely reason to tell

☐ (3) Not sure or don’t know
☐ (98) Refuse to answer

F12. Other family members become sick. Is this a reason to tell for you or is not a reason for you to tell?

☐ (1) Not a reason to tell
  (a) Is this not really a reason to tell or is it not at all a reason to tell?
    ☐ (1) Not at all a reason to tell
    ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
  (b) Is this a likely reason to tell or is it definitely a reason to tell?
    ☐ (1) Definitely a reason to tell
    ☐ (2) A likely reason to tell

☐ (3) Not sure or don’t know
☐ (98) Refuse to answer

F13. Parents/caregivers feel pressure to disclose by doctors or nurses. Is this a reason to tell for you or is not a reason for you to tell?

☐ (1) Not a reason to tell
    (a) Is this not really a reason to tell or is it not at all a reason to tell?
        ☐ (1) Not at all a reason to tell
        ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
    (b) Is this a likely reason to tell or is it definitely a reason to tell?
        ☐ (1) Definitely a reason to tell
        ☐ (2) A likely reason to tell

☐ (3) Not sure or don't know
☐ (98) Refuse to answer

F14. Parents feel pressured to disclose by others. Is this a reason to tell for you or is not a reason for you to tell?

☐ (1) Not a reason to tell
    (a) Is this not really a reason to tell or is it not at all a reason to tell?
        ☐ (1) Not at all a reason to tell
        ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
    (b) Is this a likely reason to tell or is it definitely a reason to tell?
        ☐ (1) Definitely a reason to tell
        ☐ (2) A likely reason to tell

☐ (3) Not sure or don't know
☐ (98) Refuse to answer

F15. The child is about to become sexually active. Is this a reason to tell for you or is not a reason for you to tell?

☐ (1) Not a reason to tell
    (a) Is this not really a reason to tell or is it not at all a reason to tell?
        ☐ (1) Not at all a reason to tell
        ☐ (2) Not really a reason to tell

☐ (2) A reason to tell
    (b) Is this a likely reason to tell or is it definitely a reason to tell?
        ☐ (1) Definitely a reason to tell
        ☐ (2) A likely reason to tell

☐ (3) Not sure or don't know
☐ (98) Refuse to answer

Section G. PERCEIVED RISKS AND BENEFITS OF DISCLOSURE

***Interviewer script*: Now I would like to ask you some short questions about your opinions about telling a child that they have HIV or AIDS.**

G1. In your opinion, what are some GOOD things that can happen if your child is told that they have HIV? ***[probe: for other reasons] (do not read responses aloud, check all responses given)***

☐ (0) Nothing
☐ (1)Child will be relieved
☐ (2) Child will take better care, in general, of self
☐ (3) Child will better protect self from possible dangers

☐ (4) Child will better protect others from possible dangers
☐ (5) Child will take his/her medicines as he/she should
☐ (96)Other
(G1a. Specify:________________________________)
(G1b. Specify:________________________________)
(G1c. Specify:________________________________)
☐ (97) Don't know
☐ (98) ***Refuse to answer***

G2. In your opinion, what are some BAD things that can happen if your child is told that they have HIV? ***[probe: for other reasons] (do not read responses aloud, check all responses given)***

☐ (0) Nothing
☐ (1) Child will become rebellious
☐ (2) Child will be worried
☐ (3) Child will become sad/depressed/lose will to live
☐ (4) Child will die of worry/shock
☐ (5) Child will tell others
☐ (6) Child will isolate him/herself
☐ (7) Child will commit suicide
☐ (8) Child will blame me for being sick/hate me because of her/his illness)
☐ (96) Other:
(a) (Specify:________________________________)
(b) (Specify:________________________________)
(c) (Specify:________________________________)
☐ (97) Don't know
☐ (98) ***Refuse to answer***

G3. Who do you think should tell your child that he/she has HIV or AIDS?

☐ (0) No one
☐ (1) Myself alone
☐ (2) My child's doctor alone
☐ (3) A project nurse or counselor alone
☐ (4) Another family member, alone
☐ (5) Myself, with the doctor present
☐ (6) Myself with the nurse or counselor present
☐ (7) Myself, with another family member present
☐ (8) The doctor, with me present
☐ (9)The nurse or counselor, with me present
☐ (10) Another family member, with me present
☐ (96) Other:
(a) (E12a. Specify:____________________________)
(b) (E12a. Specify:____________________________)
(c) (E12a. Specify:____________________________)
☐ (97) Don't know
☐ (98) ***Refuse to answer***

Section H. STIGMA: INDIVIDUAL

<u>Interviewer Script:</u> For the next questions, please tell me if you have fear, do not have fear, or do not know in response to the following statements:

H1. You are fearful/afraid that you could become infected with HIV if you are exposed to the saliva of a person with HIV or AIDS. Are you afraid or are you not afraid?

☐ (1) Afraid
☐ (2) Not afraid
☐ (97) Don't know
☐ (98) ***Refuse to answer***

H2. You are fearful/afraid that you could become infected with HIV if you are exposed to the sweat of a person with HIV or AIDS. Are you afraid or are you not afraid?

☐ (1) Afraid
☐ (2) Not afraid
☐ (97) Don't know
☐ (98) ***Refuse to answer***

H3. You are fearful/afraid that you could become infected with HIV if you are exposed to the excrement, urine, or vomit of someone with HIV or AIDS. Are you afraid or are you not afraid?

☐ (1) Afraid
☐ (2) Not afraid
☐ (97) Don't know
☐ (98) ***Refuse to answer***

H4. In a market of several food vendors, you are fearful/afraid of buying food from a PLHA or person suspected of HIV/AIDS. Are you afraid or are you not afraid?

☐ (1) Afraid
☐ (2) Not afraid
☐ (97) Don't know
☐ (98) ***Refuse to answer***

<u>Interviewer Script:</u> Now, please tell me whether you agree or disagree with the following statements

H5. You would feel ashamed if you were infected with HIV/AIDS. Do you agree or disagree?

☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

H6. You would be ashamed if someone in your family had HIV/AIDS. Do you agree or disagree?

☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

H7. People with HIV/AIDS should be ashamed of themselves. Do you agree or disagree?

☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

H8. People with HIV are promiscuous. Do you agree or disagree?

☐ (1) Agree

☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

H9. It is women prostitutes who spread HIV/AIDS in the community. Do you agree or disagree?
☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

H10. HIV/AIDS is a punishment from God. Do you agree or disagree?
☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

H11. HIV/AIDS is a punishment for bad behavior. Do you agree or disagree?
☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

Section I. COMMUNITY LEVEL STIGMA

Interviewer Script: ***Now, we are going to look at people in your community, not yourself. How do you think most people in your community would answer the following questions?***

I1. Most people in your community are fearful/afraid that they could become infected with HIV if they are exposed to the saliva of a person with HIV or AIDS. According to you, are most people in your community afraid or are they not afraid?
☐ (1) Afraid
☐ (2) Not afraid
☐ (97) Don't know
☐ (98) ***Refuse to answer***

I2. Most people in your community are fearful/afraid that you could become infected with HIV if you are exposed to the sweat of a person with HIV or AIDS. According to you, are most people in your community afraid or are they not afraid?
☐ (1) Afraid
☐ (2) Not afraid
☐ (97) Don't know
☐ (98) ***Refuse to answer***

I3. Most people in your community are fearful/afraid that you could become infected with HIV if you are exposed to the excrement, urine, or vomit of someone with HIV or AIDS. According to you, are most people in your community afraid or are they not afraid?
☐ (1) Afraid
☐ (2) Not afraid
☐ (97) Don't know
☐ (98) ***Refuse to answer***

I4. In a market of several food vendors, most people in your community are fearful/afraid of buying food from a PLHA or person suspected of HIV/AIDS. According to you, are most people in your community afraid or are they not afraid?

☐ (1) Afraid
☐ (2) Not afraid
☐ (97) Don't know
☐ (98) ***Refuse to answer***

***<u>Interviewer Script:</u>* Still thinking about <u>most people in your community</u>, how do you think they would respond to these questions?**

I5. Most people in your community would feel ashamed if they were infected with HIV/AIDS. Do you agree or do you disagree?

☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

I6. Most people in your community would be ashamed if someone in their family had HIV/AIDS. Do you agree or do you disagree?

☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

I7. People with HIV/AIDS should be ashamed of themselves. According to you, would most people in your community agree or would they disagree?

☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

I8. People with HIV are promiscuous. According to you, would most people in your community agree or would they disagree?

☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

It is women prostitutes who spread HIV/AIDS in the community. According to you, would most people in your community agree or would they disagree?

☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

HIV/AIDS is a punishment from God. According to you, would most people in your community agree or would they disagree?

☐ (1) Agree

☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

I9. HIV/AIDS is a punishment for bad behavior. According to you, would most people in your community agree or would they disagree?

☐ (1) Agree
☐ (2) Do not agree
☐ (97) Don't know
☐ (98) ***Refuse to answer***

Section J. SOCIAL SUPPORT

<u>Interviewer Script:</u> Finally, I am going to read to you some statements about the types of support you have. For each statement, please tell me whether you completely agree, agree, completely disagree, or don't know if you agree or disagree with it.

J1. There is someone you can talk to if you are upset, nervous, or depressed. Do you agree or do you disagree?

☐ (1) Disagree
  (a) Do you disagree or do you completely disagree?
    ☐ (1) Completely disagree
    ☐ (2) Disagree

☐ (2) Agree
  (b) Do you agree or completely agree?
    ☐ (1) Completely agree
    ☐ (2) Agree
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

J2. There is someone you can contact if you want to talk about an important personal problem you are having. Do you agree or do you disagree?

☐ (1) Disagree
  (a) Do you disagree or do you completely disagree?
    ☐ (1) Completely disagree
    ☐ (2) Disagree

☐ (2) Agree
  (b) Do you agree or completely agree?
    ☐ (1) Completely agree
    ☐ (2) Agree
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

J3. There is someone who can help take care of you if you were confined to your bed for several weeks. Do you agree or do you disagree?

☐ (1) Disagree
  (a) Do you disagree or do you completely disagree?
    ☐ (1) Completely disagree
    ☐ (2) Disagree

☐ (2) Agree
  (b) Do you agree or completely agree?
    ☐ (1) Completely agree
    ☐ (2) Agree
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

J4. There is someone you can turn to if you need to borrow a small amount of money, a ride to the doctor, or some other small immediate need. Do you agree or do you disagree?

☐ (1) Disagree
  (a) Do you disagree or do you completely disagree?
    ☐ (1) Completely disagree
    ☐ (2) Disagree

☐ (2) Agree
  (b) Do you agree or completely agree?
    ☐ (1) Completely agree
    ☐ (2) Agree
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

J5. There is someone you can turn to if you need to borrow a larger amount of money for a medical emergency. Do you agree or do you disagree?

☐ (1) Disagree
  (a) Do you disagree or do you completely disagree?
    ☐ (1) Completely disagree
    ☐ (2) Disagree

☐ (2) Agree
  (b) Do you agree or completely agree?
    ☐ (1) Completely agree
    ☐ (2) Agree
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

J6. There is someone in your personal life that can give you information, suggestions, or guidance if you need it. Do you agree or do you disagree?

☐ (1) Disagree
  (a) Do you disagree or do you completely disagree?
    ☐ (1) Completely disagree
    ☐ (2) Disagree

☐ (2) Agree
  (b) Do you agree or completely agree?
    ☐ (1) Completely agree
    ☐ (2) Agree
☐ (3) Not sure or don't know
☐ (98) ***Refuse to answer***

J7. There is someone you can turn to if you need advice to help make a decision. . Do you agree or do you disagree?

- ☐ (1) Disagree
  - (a) Do you disagree or do you completely disagree?
    - ☐ (1) Completely disagree
    - ☐ (2) Disagree
- ☐ (2) Agree
  - (b) Do you agree or completely agree?
    - ☐ (1) Completely agree
    - ☐ (2) Agree
- ☐ (3) Not sure or don't know
- ☐ (98) ***Refuse to answer***

Section K. ADDITIONAL COMMENTS

Interviewer script: ***We have reached the end of our questions. Do you have any questions or comments that you wish to share?***

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____

____

____

Thank you very much for your time.

APPENDIX 7
INTERVIEW GUIDE FOR CAREGIVERS, AIM 3

UNDERSTANDING THE PROCESS OF ILLNESS-INFORMATION DISCLOSURE TO CHILDREN IN KINSHASA, DEMOCRATIC REPUBLIC OF THE CONGO (SARA DISCLOSURE STUDY)

INTERVIEW GUIDE FOR PARENTS/CAREGIVERS WHO HAVE DISCLOSED
VERSION 28 JUNE 2006

Section A. INTRODUCTORY QUESTIONS

A1. Date of Interview: ______________________________

A2. Location of Interview: ______________________________

A3. Name of Interviewer: ______________________________

A4. Respondent ID# of the parent/caregiver interviewed: P______________.

A5. Respondent ID# of the minor of the parent/caregiver, if also interviewed: M________.

Section B. DEMOGRAPHIC QUESTIONS

Interviewer script: *I would like to begin by asking you questions about you and your family.*

#	**Question**	**Response categories**	**Skip to**
B1.	***(Do not read aloud)*** Sex of respondent:	☐ (1) Male ☐ (2) Female	
B2.	How old are you?	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B3.	What is the highest grade in school that you completed?	☐ (0) None ☐ (1) Some primary school ☐ (2) Completed primary school ☐ (3) Some trade or professional school ☐ (4) Completed trade or professional school ☐ (5) Some secondary school ☐ (6) Completed secondary school ☐ (7) Any post-secondary school ☐ (98) ***Refuse to answer***	

#	Question	Response categories	Skip to
B4.	What do you primarily do to earn a living? ***(Do not read responses out loud)***	☐ (1) Work for a big company ☐ (2) Work as a public servant [5] ☐ (3) Work for a small company[b] or for a private person in their home[c] ☐ (4) Informal work ☐ (5) Other B5a. Specify: __________________________	B6
		☐ (0) Does not work	B5
		☐ (98) ***Refuse to answer***	B6
B5.	For how long have you not been working? ***(Check one box)***	☐ (1) (B5a.)__________ weeks ☐ (2) (B5b.)__________ months ☐ (3) (B5c.)__________ years ☐ (4) Never worked ☐ (98) ***Refuse to answer***	
B6.	Are you married? ***(Do not read responses out loud)*** ***(If response is "yes", ask whether "formally married", "living with a partner", or "relationship where supports/supported by another"***	☐ (1) Single	B9
		☐ (2) Formally married	B7
		☐ (3) Living with a partner	B7
		☐ (4) Concubinage	B7
		☐ (5) Separated	B7
		☐ (6) Divorced	B8
		☐ (7) Widow/widower	B8
		☐ (98) ***Refuse to answer***	B8
B7.	What does your partner/spouse primarily do to earn a living? ***(Do not read responses out loud)***	☐ (1) Work for a big company ☐ (2) Work as a public servant [a] ☐ (3) Work for a small company [b] or for a private person in their home [c] ☐ (4) Informal work ☐ (5) Other B7a. Specify: __________________________	B9
		☐ (0) Does not work	B8
		☐ (98) ***Refuse to answer***	B9
B8.	For how long has your partner not been working? ***(Check one box)***	☐ (1) (B5a.)__________ weeks ☐ (2) (B5b.)__________ months ☐ (3) (B5c.)__________ years ☐ (4) Never worked ☐ (98) ***Refuse to answer***	
B9.	Is the biological father of the child alive?	☐ (1) Yes	B11
		☐ (0) No	B10
		☐ (97) I do not know	B11
		☐ (98) ***Refuse to answer***	B11

---

[5] For example : Soldiers, police officers, medical doctors, nurses.

[b] This includes working for small, privately owned business. For example, a business that only employs 5 people.

[c] For example : Housekeepers, gardeners, or drivers.

#	Question	Response categories	Skip to
B10.	How old was the child when the father died? ***(If <1 year, record as a fraction of a year)***	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	B11
B11.	Is the biological mother of the child alive?	☐ (1) Yes	B13
		☐ (0) No	B12
		☐ (97) I do not know	B13
		☐ (98) ***Refuse to answer***	B13
B12.	How old was the child when the mother died? ***(If <1 year, record as a fraction of a year)***	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B13.	What is your relationship to the child who receives medical care or services at this center? ***(Do not read responses out loud)***	☐ (1) Biological Mother ☐ (2) Biological Father ☐ (3) Grandparent ☐ (4) Brother or sister ☐ (5) Father's sister ☐ (6) Mother's younger sister ☐ (7) Mother's older sister ☐ (8) Father's young brother ☐ (9) Father's older brother ☐ (10) Mother's brother ☐ (96) Other (B13a. Specify): ____________________ ☐ (98) ***Refuse to answer***	
<u>Interviewer script</u>: We will finish this section by asking you a few more questions about your child.			
B14.	Currently how old is the child?	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B15.	Is your child a boy or a girl?	☐ (1) Boy ☐ (2) Girl ☐ (98) ***Refuse to answer***	
B16.	Has the child ever gone to school?	☐ (1) Yes	B17
		☐ (0) No	**Next Section**
		☐ (98) ***Refuse to answer***	
B17.	Does the child currently go to school?	☐ (1) Yes	B18
		☐ (0) No	B19
		☐ (98) ***Refuse to answer***	B19
B18.	What grade is the child in school?		**Next Section**

#	Question	Response categories	Skip to
B19.	How long has it been since the child last went to school?	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B20.	What is the highest grade that the child completed?	☐ (1) Some primary school ☐ (2) Completed primary school ☐ (3) Some trade or professional school ☐ (4) Completed trade or professional school ☐ (5) Some secondary school ☐ (6) Completed secondary school ☐ (7) Any post-secondary school ☐ (96) Other (B20a. Specify:_______________) ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B21.	For what reasons does the child not go to school?	☐ (1) Health reason ☐ (2) Lack of financial resources ☐ (3) Health reason & Lack of financial resources ☐ (96): Other: (B21a. Specify:__________________) ☐ (98) ***Refuse to answer***	

<u>Interviewer script</u>*: *Thank you for answering the questions about you and your family.

<u>TURN ON TAPERECORDER HERE</u>

Section C. CIRCUMSTANCES LEADING TO DISCLOSURE

<u>Interviewer script</u>:

- ***I would now like to ask you questions about when child was told he has HIV.***
- ***For the questions I will ask you now, you do not have to give me short answers like before. Instead, I would like to hear about your experience, and you can talk as much as you like about each question.***
- ***We are trying to learn as much as we can about the reasons parents and caregivers decide to tell their children that they have HIV.***
- ***There are reasons for and against telling children they have HIV, and we would like to know more about your experience with this very difficult issue. Anything you can tell us will be very helpful.***

C1. How old was the child when he was diagnosed with HIV?

____

____

____

C2. Does anyone in your family besides yourself know that the child has HIV? *(Probe for who and reason they know)*

____

____

____

C3. Does anyone outside of your family and medical personnel know that the child has HIV? (*Probe for who and reason they know)*

____

____

____

C4. When did you first begin thinking about telling your child the name of his illness? *(Probe for 1—age of child at the time, 2—how long before actual disclosure, 3—health status of child at time thinking began)*

____

____

____

C4a. What were the reasons that you began to think about this?

____

____

____

C5. I am now going to tell you a list of reasons why other parents have decided to tell their children that they have HIV. After I list each reason, please tell me if this was also a reason for you. (If participant gives a reason that was mentioned in C5a, acknowledge that it was mentioned earlier and then ask "what makes this a reason for you?")

Reason	***(If YES)*** **What makes this a reason for you?**
☐ The parent's health status was getting worse	

Reason	*(If YES)* What makes this a reason for you?
☐ The child's health status was getting worse	
☐ The child reached an age in which he should know	
☐ The child asked questions about his illness	
☐ Access to treatment became available	
☐ Other family members were getting sick	
☐ Parents were feeling pressured to disclose by doctors or nurses	
☐ Parents were feeling pressured to disclose by others	*(Probe about whom.)*

C6. What, if anything, concerned you about telling your child that he has HIV? (*For parents who were not concerned, probe for reasons why.*)

____

____

____

C7. What, if anything, did you do to prepare yourself to tell your child that he has HIV? (*Probe about how long before child was told did preparation begin.)*

____

____

____

C8. I am now going to read to you several things that other parents have done to prepare themselves to tell their children that they have HIV. After I read to you each item, please tell me if you did this or did not do this.

☐ Turned to prayer
☐ Read information
☐ Planned answers for questions that the child might ask
☐ Talked with spouse/partner
☐ Talked with other family member.
☐ Talked with doctor or nurse
☐ Talked to community leader
☐ Talked to religious leader

C8a. *(For each person mentioned above)* For what reasons did you talk with this people? *(Probe for each person mentioned above. Also probe for specific family member the participant wanted to speak with.)*

____

____

____

C9. What else, if anything, did you do to prepare yourself?

____

____

C10. What, if anything, did you do to prepare *your child* to learn that he has HIV?

____

____

____

C11. Before you told your child of his seropositive status, what had been told to the child, if anything had been told, by you and anyone else, about his health status? (*probe for age, circumstances, what was said and by whom)*

____

____

____

Section D. THE MOMENT OF DISCLOSURE OF HIV STATUS

***Interviewer script:* Now I would like to ask you questions about things you did to prepare to tell your child that he has HIV.**

D1. How old was the child when he was first told that he has HIV?

D1a. What were the reasons you decided to tell him at that time ? (*probe for age, developmental stage, health status, questions being asked by child.)*

D2. How would you describe your child's health at the time he was informed of his HIV status?

D3. Was your child taking any HIV medications at the time he was told that he has HIV? (***Probe for whether on Bactrim or antiretrovirals)***

D4. Where did this discussion take place?

D5. Who told the child that he has HIV?

D5a. What is the reason this person was the one who told the child?

D6. Was anyone else present when your child was told? (*If no, skip to C14)*

D6a. Who?

D6b. What reason was this person present?

D7. If you can remember, what were the exact words used to explain to your child that he has HIV? *(If the parent/caregiver does not remember the exact words, tell him that it is okay. Ask him to describe what was discussed the best that he can. Ask why these words were the ones chosen.)*

Section E. REACTION TO DISCLOSURE

***Interviewer script*: Now I would like to talk about how you and your child were feeling after the child was told he has HIV. I will also ask you about any changes in your home life.**

E1. How did you think your child would react when was told he has HIV?

E2. How did your child react immediately after he was told he has HIV? *(Probe about emotions, questions asked and comments made by the child).*

E3. In your opinion, was your child surprised to learn that he had HIV?

E3a. What makes you feel that way?

E4. How did *<u>you</u>* feel after your child was told that he has HIV?

<u>Interviewer Text:</u> Now I would like for you to think about what has taken place from the time since the first time you told the child that he is seropositive to the present. .

E5. How long has it been since the child was first told he has HIV?

E6. How have *you* felt since telling your child he has HIV, up until now?

E7. How has your child been since learning he has HIV? (*Probe about 1 -- interaction with family members, 2 -- interaction with friends, 3 -- interest in daily activities, 4 -- school performance if in school, 5 -- overall mood, and 6—changes in these over time*)

E8. What, if anything, has changed in your family's life since telling your child that he has HIV? *(Probe about 1 -- changes in parent's relationship with their child, 2-- the child's relationship with his siblings, 3 -- the child's relationship with other family members, and 4—parent's relationship with other family members)*

E9. Since your child first learned he has HIV, has your child's HIV status come up in conversations between you and your child? (*If yes, probe for 1 -- under what circumstances, 2 – what topics are discussed, and 3 -- initiated by whom*).

E10. What questions or concerns, if any, has your child had since the moment of he/she was first told he/she has HIV up until now?

E11. Since being told his/her HIV status, with whom else has the child spoken about his illness? ***(Probe about what, what circumstances or reasons, what responses received, has he spoken with other seropositive children)***

____

____

____

E12. Since telling your child his HIV status, who else, if there is anyone else, has been informed of his HIV status? (probe for 1—who else was informed, 2—by whom they were informed, 3—for what reasons or under what circumstances they were told, and 4—what reactions. If child not mentioned as person informing, ask if child has informed anyone else.),

____

____

____

____

E13. Could you tell me about the conversations within your family about your child’s serostatus, if there have been any, since having told the child his HIV status ?

____

____

____

____

E14. How do you feel about having told your child that he/she has HIV? (probes on what have been good things, what have been bad things? What have been the advantages and the disadvantages?)

____

____

____

E15. Do you have anything else you would like to share with me on this subject?

____

____

____

Thank you for your time.

APPENDIX 8:
INTERVIEW GUIDE FOR CHILDREN, AIM 3

UNDERSTANDING THE PROCESS OF ILLNESS-INFORMATION DISCLOSURE TO CHILDREN IN KINSHASA, DEMOCRATIC REPUBLIC OF THE CONGO (SARA DISCLOSURE STUDY)

INTERVIEW GUIDE FOR CHILDREN WHO HAVE BEEN DISCLOSED
VERSION 28 JUNE 2006

Section A. Introductory Questions

A1. Date of Interview:____

A2. Location of Interview: ____

A3. Name of Interviewer: ____

A4. Respondent ID# of the minor of the parent/caregiver: M_______.

A5. Respondent ID# of the parent/caregiver interviewed, if also interviewed: PD______.

Section B. Demographic Questions

Instructions for this section:

1. *If the parent/caregiver of the child is also interviewed, skip Section B and start the interview with Section C.*
2. *If the parent/caregiver is NOT being interviewed **separately,** ask questions B1-B21 to the parent/caregiver of the child.*
3. *If the parent/caregiver is **NOT INTERVIEWED AT ALL**, ask questions B22 – B29 to the child*

Interviewer script for parents/caregivers: I would like to begin by asking you questions about you and your family.

#	**Question**	**Response categories**	**Skip to**

#	Question	Response categories	Skip to
B1.	***(Do not read aloud)*** Sex of respondent:	☐ (1) Male ☐ (2) Female	
B2.	How old are you?	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B3.	What is the highest grade in school that you completed?	☐ (0) None ☐ (1) Some primary school ☐ (2) Completed primary school ☐ (3) Some trade or professional school ☐ (4) Completed trade or professional school ☐ (5) Some secondary school ☐ (6) Completed secondary school ☐ (7) Any post-secondary school ☐ (98) ***Refuse to answer***	
B4.	What do you primarily do to earn a living? ***(Do not read responses out loud)***	☐ (1) Work for a big company ☐ (2) Work as a public servant[6] ☐ (3) Work for a small company[b] or for a private person in their home[c] ☐ (4) Informal work ☐ (5) Other B4a. Specify: ____________________	B6
		☐ (0) Does not work	B5
		☐ (98) ***Refuse to answer***	B6
B5.	For how long have you not been working? ***(Check one box)***	☐ (1) (B5a.)__________ weeks ☐ (2) (B5b.)__________ months ☐ (3) (B5c.)__________ years ☐ (4) Never worked ☐ (98) ***Refuse to answer***	
B6.	Are you married? ***(Do not read responses out loud)*** ***(If response is "yes", ask whether "formally married", "living with a partner", or "relationship where supports/supported by another"***	☐ (1) Single	B9
		☐ (2) Formally married	B7
		☐ (3) Living with a partner	B7
		☐ (4) Concubinage	B7
		☐ (5) Separated	B7
		☐ (6) Divorced	B8

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[6] For example : Soldiers, police officers, medical doctors, nurses.

[b] This includes working for small, privately owned business. For example, a business that only employs 5 people.

[c] For example : Housekeepers, gardeners, or drivers.

#	**Question**	**Response categories**	**Skip to**
		☐ (7) Widow/widower	B8
		☐ (98) ***Refuse to answer***	B8
B7.	What does your partner/spouse primarily do to earn a living? ***(Do not read responses out loud)***	☐ (1) Work for a big company ☐ (2) Work as a public servant [a] ☐ (3) Work for a small company [b] or for a private person in their home [c] ☐ (4) Informal work ☐ (5) Other B7a. Specify: ____________________	B9
		☐ (0) Does not work	B8
		☐ (98) ***Refuse to answer***	B9
B8.	For how long has your partner not been working? ***(Check one box)***	☐ (1) (B5a.)__________ weeks ☐ (2) (B5b.)__________ months ☐ (3) (B5c.)__________ years ☐ (4) Never worked ☐ (98) ***Refuse to answer***	
B9.	Is the biological father of the child alive?	☐ (1) Yes	B11
		☐ (0) No	B10
		☐ (97) I do not know	B11
		☐ (98) ***Refuse to answer***	B11
B10.	How old was the child when the father died? ***(If <1 year, record as a fraction of a year)***	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	B11
B11.	Is the biological mother of the child alive?	☐ (1) Yes	B13
		☐ (0) No	B12
		☐ (97) I do not know	B13
		☐ (98) ***Refuse to answer***	B13
B12.	How old was the child when the mother died? ***(If <1 year, record as a fraction of a year)***	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	

#	Question	Response categories	Skip to
B13.	What is your relationship to the child who receives medical care or services at this center? ***(Do not read responses out loud)***	☐ (1) Biological Mother ☐ (2) Biological Father ☐ (3) Grandparent ☐ (4) Brother or sister ☐ (5) Father's sister ☐ (6) Mother's younger sister ☐ (7) Mother's older sister ☐ (8) Father's young brother ☐ (9) Father's older brother ☐ (10) Mother's brother ☐ (96) Other (B13a. Specify): __________________ ☐ (98) ***Refuse to answer***	
<u>Interviewer script</u>: We will finish this section by asking you a few more questions about your child.			
B14.	Currently how old is the child?	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B15.	Is your child a boy or a girl?	☐ (1) Boy ☐ (2) Girl ☐ (98) ***Refuse to answer***	
B16.	Has the child ever gone to school?	☐ (1) Yes	B17
		☐ (0) No	**Next Section**
		☐ (98) ***Refuse to answer***	
B17.	Does the child currently go to school?	☐ (1) Yes	B18
		☐ (0) No	B19
		☐ (98) ***Refuse to answer***	B19
B18.	What grade is the child in school?		**Next Section**
B19.	How long has it been since the child last went to school?	☐ __________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	

#	Question	Response categories	Skip to
B20.	What is the highest grade that the child completed?	☐ (1) Some primary school ☐ (2) Completed primary school ☐ (3) Some trade or professional school ☐ (4) Completed trade or professional school ☐ (5) Some secondary school ☐ (6) Completed secondary school ☐ (7) Any post-secondary school ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B21.	For what reasons does the child not go to school?	☐ (1) Health reason ☐ (2) Lack of financial resources ☐ (3) Health reason & Lack of financial resources ☐ (96): Other: (B21a. Specify:________________) ☐ (98) ***Refuse to answer***	

Note: Conclude the interview with the parent/caregiver
and begin Section C with the child/adolescent.

Interviewer script for interviews with MINORS**: **I would like to begin by asking you a few questions about yourself. (NOTE: Only ask these questions if the minor's parent/caregiver is NOT interviewed.)

#	Question	Response categories	Skip to
B22.	(*Do not read aloud*) Sex of respondent:	☐ (1) Male ☐ (2) Female	
B23.	How old are you?	☐ _____________ years ☐ (97) I do not know ☐ (98) ***Refuse to answer***	
B24.	Have you ever gone to school?	☐ (1) Yes	B25
		☐ (0) No	B27
B25.	Do you currently go to school?	☐ (1) Yes	B26
		☐ (0) No	B27
B26.	What grade are you in school?		Section C
B27.	How long has it been since you last went to school?	__________ years	B36

#	Question	Response categories	Skip to
B28.	What is the highest grade that you completed?	☐ (0) None ☐ (1) Some primary school ☐ (2) Completed primary school ☐ (3) Some trade or professional school ☐ (4) Completed trade or professional school ☐ (5) Some secondary school ☐ (6) Completed secondary school ☐ (7) Any post-secondary school ☐ (98) ***Refuse to answer***	
B29.	For what reasons do you not go to school? ***(do not read responses out loud)***	☐ (1) Health reason ☐ (2) Lack of financial resources ☐ (3) Health reason & Lack of financial resources ☐ (96): Other: (B21a. Specify:________________)	

TURN ON TAPERECORDER HERE

Section C. QUESTIONS ABOUT INITIAL UNDERSTANDING, BEFORE ILLNESS WAS NAMED

***Interviewer script*: First, I would like to ask you some questions about how you what you understood about your health before you were told the name of your illness. There are no right or wrong answers to the questions I will ask you. Learning about your life is important to me so I am interested in hearing anything that you would like to tell me.**

C1. What, if anything, did you know about your health before you were told the name of your illness? *(Probe about 1—what told, 2—sources of information, 3—suspicions about their illness)*

____

____

____

C2. What, if any, kinds of questions or concerns did you have about your health before you were told the name of your illness?

____

____

____

C2a. (*For each questions or concern mentioned)* Where did you go, if anywhere to answer your questions or discuss your concerns about your health?

____

____

____

Section D. QUESTIONS ABOUT DISCLOSURE PROCESS

***Interviewer script*: Now I would like to talk to you about when you were first told that you were sick with your illness.**

D1. Please think back to the time when you first told something about your illness. Tell me everything you can remember about that time. **(***Probe about 1 – Age, 2 – Health status at time of discussions , 3 – Location of discussion, 4 – Who initiated conversation, 5– Who else participated in the discussion, and 6—Exact words used)*

____

____

____

D2. ***(If child was not told name of illness at first discussion)*** Can you please tell me about the time when you were first told the name of your illness? (*Probe about 1 – Age, 2 – Health status at time of discussion, 3 – Length of time between first discussion about illness and naming of illness, 4 – Location of discussion, 5 – Who told child, 6 -- Who else took part in the discussion, 7--and Exact words used.)*

____

____

____

D3. How did you feel after immediately after you were told?

____

____

____

D3a. What about being told that you have this illness made you feel this way? (*Probe for each feeling mentioned.*)

____

____

____

D4. Were you surprised to learn that you have this illness?

____

____

____

D4a. What made you surprised/not surprised? (P*robe about child's understanding of their health prior to disclosure of name of illness*)

____

____

____

D5. I am now going to read you a list of feelings that other children have had when they were told they had this illness. After I read each one to you, please tell me if you also felt this way. Did you also feel…? (*For each emotion, probe for reasons why they felt that way, when appropriate.)*

D5a. ☐ Calm
D5b. ☐ Relieved
D5c. ☐ Sad
D5d. ☐ Worried
D5e. ☐ Angry
D5f. ☐ Confused
D5g. ☐ Hopeless

D6. What questions or worries, if any, did you have at the moment you were first told the name of your illness?

____

____

D6a. What did you do with these questions/worries? (F*or each of the questions or concerns s/he had, probe for 1—person approached, 2--other information sources sought or 3—other ways of coping with concerns. If did not try to resolve questions/concern, probe for reasons did not do so.)*

D6b. How did you feel about the answers/advice you got?

Section E. UNDERSTANDING OF ILLNESS

Interviewer: Now I would like to ask you some questions about what you understood by the name of your illness. As I said earlier, one of the things we are trying to understand is how best to tell a child about the name of your illness. The best way we can do that is to learn about your experiences and your opinions about what should be done or not done.

E1. Before you were told the name of your illness, what, if anything, did you know about this illness?

E2. Since you were first told the name of your illness, what, if anything, has changed in what you understand about this illness? *(probe for reasons why they have changed)*

E2a. What has remained the same?

Section F. LIFE FOLLOWING DISCLOSURE OF ILLNESS NAME

F1. What questions or worries, if any, have you had since you were first told the name of your illness?

F1a. What did you do with these questions/worries? (F*or each of the questions or concerns s/he had, probe for 1—person approached, 2--other information sources sought or 3—other ways of coping with concerns. If did not try to resolve questions/concern, probe for reasons did not do so.)*

F1b. How do you feel about the answers/advice you got?

F2. What, if anything, has been said about your health since the first time you were told the name of your illness? *(Probe for 1-additional information, 2—advice given, 3—person(s) to whom spoken, 4—who initiated conversations)*

____

____

F3. In your opinion, what have been the good things about knowing the name of your illness?

____

____

____

F4. In your opinion, what have been the bad things about knowing the name of your illness?

____

____

____

F5. How has your life changed, if at all, since learning the name of your illness *(Probe for how relationships with people, emotions, activities taken up or given up.)*

____

____

____

F6. Have you told anyone about your illness? *(Probes : 1—who, 2—reasons for speaking to the person, 3—what specifically was mentioned ; if no, probe for reasons not talking to others.)*

____

____

____

<u>Interviewer script</u>: Thank you for telling me about what it was like for you to find out you had this illness. It was very helpful to find out these things from you.

F7. Do you have anything else you would like to share with me on this subject?

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Thank you for your time.

REFERENCES

AAP. (1999). Disclosure of illness status to children and adolescents with HIV infection. American Academy of Pediatrics Committee on Pediatrics AIDS. *Pediatrics, 103*(1), 164-166.

Abadia-Barrero, C. E., & Larusso, M. D. (2006). The disclosure model versus a developmental illness experience model for children and adolescents living with HIV/AIDS in Sao Paulo, Brazil. *AIDS Patient Care STDS, 20*(1), 36-43.

Agresti, A. (2002). Building and Extending Loglinear/Logit Models. In *Categorical Data Analysis* (2nd ed., pp. 397). Hoboken, New Jersey: J Wiley & Sons, Inc.

Aguilar Molina, J. (2006). *The Invention of Child Witches in the Democratic Republic of Congo*. London, UK: Save the Children UK.

Allison, P. D. (2001). Multinomial Logit Analysis. In *Logistic Regression Using the SAS System: Theory and Application* (pp. 111-131). Cary, NC: SAS Institute Inc.

Altice, F. L., Mostashari, F., & Friedland, G. H. (2001). Trust and the acceptance of and adherence to antiretroviral therapy. *J Acquir Immune Defic Syndr, 28*(1), 47-58.

Ammassari, A., Trotta, M. P., Murri, R., Castelli, F., Narciso, P., Noto, P., et al. (2002). Correlates and predictors of adherence to highly active antiretroviral therapy: overview of published literature. *J Acquir Immune Defic Syndr, 31 Suppl 3*, S123-127.

Armistead, L., Tannenbaum, L., Forehand, R., Morse, E., & Morse, P. (2001). Disclosing HIV status: are mothers telling their children? *J Pediatr Psychol, 26*(1), 11-20.

Ayres, J. R., Paiva, V., Franca, I., Jr., Gravato, N., Lacerda, R., Della Negra, M., et al. (2006). Vulnerability, human rights, and comprehensive health care needs of young people living with HIV/AIDS. *Am J Public Health, 96*(6), 1001-1006.

Azjen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes, 50*, 179–211.

Azjen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior.* Englewood Cliffs, NJ: Prentice Hall.

Azondekon, A., Hinson, F., Mignanhouande, D., Keitchion, A., Sagui, A., Houedjissin, L., et al. (2005, 24-27 July 2005). *Disclosure of HIV status to Children in African context: outcomes and challenges, Abstract no. TuPe11.9C13.* Paper presented at the 3rd IAS Conference on HIV Pathogenesis and Treatment, Rio de Janeiro, Brazil.

Bachanas, P. J., Kullgren, K. A., Schwartz, K. S., Lanier, B., McDaniel, J. S., Smith, J., et al. (2001). Predictors of psychological adjustment in school-age children infected with HIV. *J Pediatr Psychol, 26*(6), 343-352.

Bachanas, P. J., Kullgren, K. A., Schwartz, K. S., McDaniel, J. S., Smith, J., & Nesheim, S. (2001). Psychological adjustment in caregivers of school-age children infected with HIV: stress, coping, and family factors. *J Pediatr Psychol, 26*(6), 331-342.

Barbarin, O. A. (2001). Parent-Child Relationship Scale: NCEDL.

BASICS II. (2001). *BASICS II Annual Report: Project Startup Through December 31, 2000. The Democratic Republic of Congo Country Report.*: USAID, BASICS II.

Batter, V., Matela, B., Nsuami, M., Manzila, T., Kamenga, M., Behets, F., et al. (1994). High HIV-1 incidence in young women masked by stable overall seroprevalence among childbearing women in Kinshasa, Zaire: estimating incidence from serial seroprevalence data. *Aids, 8*(6), 811-817.

Bauman, L., Silver, E., & Camacho, S. (2000). *Stigma among mothers with HIV/AIDS. (abstract no. MoPeD2578).* Paper presented at the International Conference on AIDS Conference 13, Barcelona, Spain.

Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV Stigma Scale. *Research in Nursing and Health, 24*(6), 518-529.

Bikaako-Kajura, W., Luyirika, E., Purcell, D. W., Downing, J., Kaharuza, F., Mermin, J., et al. (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS Behav, 10*(4 Suppl), S85-93.

Blaney, N. T., Fernandez, M. I., Ethier, K. A., Wilson, T. E., Walter, E., & Koenig, L. J. (2004). Psychosocial and behavioral correlates of depression among HIV-infected pregnant women. *AIDS Patient Care STDS, 18*(7), 405-415.

Blasini, I., Chantry, C., Cruz, C., Ortiz, L., Salabarria, I., Scalley, N., et al. (2004). Disclosure model for pediatric patients living with HIV in Puerto Rico: design, implementation, and evaluation. *J Dev Behav Pediatr, 25*(3), 181-189.

Bor, R., Miller, R., & Goldman, E. (1993). Hiv Aids and the Family - a Review of Research in the 1st Decade. *Journal of Family Therapy, 15*(2), 187-204.

Bronfenbrenner, U. (1979). *The Ecology of Human Development*. Cambridge, MA: Harvard University Press.

Butterworth, O., Bunupuradah, T., Mengthaisong, T., Sakornjun, W., Ananworanich, J., Pancharoen, C., et al. (2007). *HIV disclosure in HIV positive Thai children, Abstract No. TUPEB142*. Paper presented at the 4th IAS Conference on HIV Pathogenesis and Treatment.

Buve, A., Bishikwabo-Nsarhaza, K., & Mutangadura, G. (2002). The spread and effect of HIV-1 infection in sub-Saharan Africa. *Lancet, 359*(9322), 2011-2017.

Carson, D. K., Council, J. R., & Gravley, J. E. (1991). Temperament and family characteristics as predictors of children's reactions to hospitalization. *J Dev Behav Pediatr, 12*(3), 141-147.

Chakraborty, R. (2005). HIV-1 infection in children: a clinical and immunologic overview. *Curr HIV Res, 3*(1), 31-41.

Chakraborty, R., Morel, A. S., Sutton, J. K., Appay, V., Ripley, R. M., Dong, T., et al. (2005). Correlates of delayed disease progression in HIV-1-infected Kenyan children. *J Immunol, 174*(12), 8191-8199.

Chesler, M. A., Paris, J., & Barbarin, O. A. (1986). "Telling" the child with cancer: parental choices to share information with ill children. *J Pediatr Psychol, 11*(4), 497-516.

CIA. (2006, 29 March 2006). The World Factbook 2006: Democratic Republic of the Congo. 2006. Retrieved 6 April, 2006, from http://www.cia.gov/cia/publications/factbook/index.html

Claflin, C. J., & Barbarin, O. A. (1991). Does "telling" less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *J Pediatr Psychol, 16*(2), 169-191.

Clark, H. J., Lindner, G., Armistead, L., & Austin, B. J. (2003). Stigma, disclosure, and psychological functioning among HIV-infected and non-infected African-American women. *Women Health, 38*(4), 57-71.

Coghlan, B., Brennan, R., Ngoy, P., Dofara, D., Otto, B., & Stewart, T. (2005). *Mortality in the Democratic Republic of Congo: Results from a Nationwide Survey Conducted April - December 2004*: International Rescue Committee
Burnet Institute.

Cohen, J., Reddington, C., Jacobs, D., Meade, R., Picard, D., Singleton, K., et al. (1997). School-related issues among HIV-infected children. *Pediatrics, 100*(1), E8.

de Boeck, F. (2004). On Being Shege in Kinshasa: Children, the Occult, and the Street. In T. Trefon (Ed.), *Reinventing Order in the Congo: How People Respond to State Failure in Kinshasa* (pp. 155-173). London, UK: Zed Books.

de Boeck, F., & Plissart, M.-F. (2006). *Kinshasa: Tales of the Invisible City*. Ghent, Belgium: Ludion.

De Herdt, T. (2004). Hidden Families, Single Mothers and Cibalabala: Economic Regress and Changing Household Composition in Kinshasa. In T. Trefon (Ed.), *Reinventing Order in the Congo: How People Respond to State Failure in Kinshasa* (pp. 116-136). London, UK: Zed Books.

DeMatteo, D., Harrison, C., Arneson, C., Salter Goldie, R., A., L., Read, S. E., et al. (2002). Disclosing HIV/AIDS to children: the path families take to truthtelling. *Psychology, Health and Medicine, 7*(3), 339-356.

DeMatteo, D., & Roberts, J. (2001). *Disclosing HIV/AIDS to Chldren: The Paths We Take*. Calgary, AB: Detselig Enterprises Ltd.

DeMatteo, D., Wells, L. M., Salter Goldie, R., & King, S. M. (2002). The 'family' context of HIV: a need for comprehensive health and social policies. *AIDS Care, 14*(2), 261-278.

Denolf, D., Musongela, J. P., Nzila, N., Tahiri, M., & Colebunders, R. (2001). The HIV epidemic in Kinshasa, Democratic Republic of Congo. *Int J STD AIDS, 12*(12), 832.

Derlega, V., Winstead, B., Greene, K., Servoich, J., & Elwood, W. (2002). Perceived HIV-related stigma and HIV disclosure to relationship partners after finding out about the seropositive diagnosis. *Journal of Health Psychology, 7*(4), 415-432.

Dittus, P., Miller, K. S., Kotchick, B. A., & Forehand, R. (2004). Why parents matter!: The conceptual basis for a community-based HIV prevention program for the parents of African American youth. *Journal of Child and Family Studies, 13*(1), 5-20.

Dunn, K. C. (2003). *Imagining the Congo: The International Relations of Identity*. New York, NY: Palgrave Macmillan.

Eiser, C. (1994). Making sense of chronic disease. The eleventh Jack Tizard Memorial Lecture. *J Child Psychol Psychiatry, 35*(8), 1373-1389.

Enzama, R., & Mugyenyi, P. (2005, 24-27 July, 2005). *Determining Barriers And Predictors To Adherence In Children Accessing HIV/AIDS Treatment In Uganda, Abstract no. WePe12.7C03.* Paper presented at the 3rd IAS Conference on HIV Pathogenesis and Treatment, Rio de Janeiro, Brazil.

Flanagan-Klygis, E., Ross, L. F., Lantos, J., Frader, J., & Yogev, R. (2001). Disclosing the diagnosis of HIV in pediatrics. *J Clin Ethics, 12*(2), 150-157.

Frones, I. (1993). Changing Childhood in Childhood, Revue. *presentation slides from Université de Fribourg, Switzerland* Retrieved 16 April, 2006, from http://www.unifr.ch/socsem/cours/compte_rendu/Pr%E9sentation1_2.ppt.

Funck-Brentano, I. (1995). [Informing a child about his illness in HIV infection: words and meaning]. *Psychiatr Enfant, 38*(1), 109-139.

Funck-Brentano, I., Costagliola, D., Seibel, N., Straub, E., Tardieu, M., & Blanche, S. (1997). Patterns of disclosure and perceptions of the human immunodeficiency virus in infected elementary school-age children. *Arch Pediatr Adolesc Med, 151*(10), 978-985.

Gerson, A. C., Joyner, M., Fosarelli, P., Butz, A., Wissow, L., Lee, S., et al. (2001). Disclosure of HIV diagnosis to children: when, where, why, and how. *J Pediatr Health Care, 15*(4), 161-167.

Giacomet, V., Albano, F., Starace, F., de Franciscis, A., Giaquinto, C., Gattinara, G. C., et al. (2003). Adherence to antiretroviral therapy and its determinants in children with human immunodeficiency virus infection: a multicentre, national study. *Acta Paediatr, 92*(12), 1398-1402.

Gibb, D. M., Goodall, R. L., Giacomet, V., McGee, L., Compagnucci, A., & Lyall, H. (2003). Adherence to prescribed antiretroviral therapy in human immunodeficiency virus-infected children in the PENTA 5 trial. *Pediatric Infectious Disease Journal, 22*(1), 56-62.

Gifford, A. L., Bormann, J. E., Shively, M. J., Wright, B. C., Richman, D. D., & Bozzette, S. A. (2000). Predictors of self-reported adherence and plasma HIV concentrations in patients on multidrug antiretroviral regimens. *J Acquir Immune Defic Syndr, 23*(5), 386-395.

Global AIDS Alliance. (2006). Advocacy Brief: Children Left Behind: Global Stakeholders Failing to Adequately Prevent of Treat Pediatric HIV/AIDS (pp. 24). Washington DC: Global AIDS Alliance.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall.

Golin, C., Isasi, F., Bontempi, J. B., & Eng, E. (2002). Secret pills: HIV-positive patients' experiences taking antiretroviral therapy in North Carolina. *AIDS Educ Prev, 14*(4), 318-329.

Gordillo, V., del Amo, J., Soriano, V., & Gonzalez-Lahoz, J. (1999). Sociodemographic and psychological variables influencing adherence to antiretroviral therapy. *AIDS, 13*(13), 1763-1769.

Gordon Jr., R. G. (2005). Ethnologue: Languages of the World, Online version. Fifteenth edition. Retrieved 15 March, 2006, from http://www.ethnologue.com/.

Goulder, P. J., Jeena, P., Tudor-Williams, G., & Burchett, S. (2001). Paediatric HIV infection: correlates of protective immunity and global perspectives in prevention and management. *Br Med Bull, 58*, 89-108.

Grinstead, O. A., Gregorich, S. E., Choi, K. H., & Coates, T. (2001). Positive and negative life events after counselling and testing: the Voluntary HIV-1 Counselling and Testing Efficacy Study. *AIDS, 15*(8), 1045-1052.

Grubman, S., Gross, E., Lerner-Weiss, N., Hernandez, M., McSherry, G. D., Hoyt, L. G., et al. (1995). Older children and adolescents living with perinatally acquired human immunodeficiency virus infection. *Pediatrics, 95*(5), 657-663.

Hammer, S. M., Squires, K. E., Hughes, M. D., Grimes, J. M., Demeter, L. M., Currier, J. S., et al. (1997). A controlled trial of two nucleoside analogues plus indinavir in persons with human immunodeficiency virus infection and CD4 cell counts of 200 per cubic millimeter or less. AIDS Clinical Trials Group 320 Study Team. *N Engl J Med, 337*(11), 725-733.

Hirschfeld, S. (2002). Comment: Disclosing a diagnosis of HIV in pediatrics: Providing the best possible care. *AIDS & Public Policy Journal, 17*(1), 13-16.

Human Rights Watch. (2006). *What Future? Street Children in the Democratic Republic of the Congo, Volume 18* (No. 2(A)): Human Rights Watch.

Instone, S. L. (2000). Perceptions of children with HIV infection when not told for so long: implications for diagnosis disclosure. *J Pediatr Health Care, 14*(5), 235-243.

International Women's Rights Action Watch. (2003, 2003). Country Report: Democratic Republic of the Congo. combined 1994, 1996 and 1998 reports. Retrieved 10 March, 2006, from http://iwraw.igc.org/publications/countries/congo.htm#_edn19

Ionescu, C. (2006). Romanian parents keep HIV a secret from infected children. *Lancet, 367*(9522), 1566.

Jones, G., Steketee, R. W., Black, R. E., Bhutta, Z. A., & Morris, S. S. (2003). How many child deaths can we prevent this year? *Lancet, 362*(9377), 65-71.

Kilewo, C., Massawe, A., Lyamuya, E., Semali, I., Kalokola, F., Urassa, E., et al. (2001). HIV counseling and testing of pregnant women in sub-Saharan Africa: experiences from a study on prevention of mother-to-child HIV-1 transmission in Dar es Salaam, Tanzania. *J Acquir Immune Defic Syndr, 28*(5), 458-462.

Kimberly, J. A., & Serovich, J. M. (1995). Disclosure of HIV-positive status: five women's stories. *Family Relations, 44*, 316-323.

Kotchick, B. A., & Forehand, R. (2002). Putting parenting in perspective: A discussion of the contextual factors that shape parenting practices. *Journal of Child and Family Studies, 11*(3), 255-269.

Kouyoumdjian, F. G., Meyers, T., & Mtshizana, S. (2005). Barriers to Disclosure to Children with HIV. *J Trop Pediatr, 51*(5), 285-287.

Ledlie, S. W. (1999). Diagnosis disclosure by family caregivers to children who have perinatally acquired HIV disease: when the time comes. *Nurs Res, 48*(3), 141-149.

Ledlie, S. W. (2001). The psychosocial issues of children with perinatally acquired HIV disease becoming adolescents: a growing challenge for providers. *AIDS Patient Care STDS, 15*(5), 231-236.

Lee, C. L., & Johann-Liang, R. (1999). Disclosure of the diagnosis of HIV/AIDS to children born of HIV-infected mothers. *AIDS Patient Care and Stds, 13*(1), 41-45.

Lee, M. B., & Rotheram-Borus, M. J. (2002). Parents' disclosure of HIV to their children. *Aids, 16*(16), 2201-2207.

Lesch, A., Swartz, L., Kagee, A., Moodley, K., Kafaar, Z., Myer, L., et al. (2007). Paediatric HIV/AIDS disclosure: towards a developmental and process-oriented approach. *AIDS Care, 19*(6), 811-816.

Lester, P., Chesney, M., Cooke, M., Weiss, R., Whalley, P., Perez, B., et al. (2002). When the time comes to talk about HIV: factors associated with diagnostic disclosure and emotional distress in HIV-infected children. *J Acquir Immune Defic Syndr, 31*(3), 309-317.

Lester, P., Chesney, M., Cooke, M., Whalley, P., Perez, B., Petru, A., et al. (2002). Diagnostic disclosure to HIV-infected children: How parents decide when and what to tell. *Clinical Child Psychology and Psychiatry, 7*(1), 85-99.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363-385.

Lipson, M. (1993). What do you say to a child with AIDS? *Hastings Cent Rep, 23*(2), 6-12.

Lipson, M. (1994). Disclosure of diagnosis to children with human immunodeficiency virus or acquired immunodeficiency syndrome. *J Dev Behav Pediatr, 15*(3), S61-65.

Lockhart, C. (2002). Kunyenga, "real sex," and survival: Assessing the risk of HIV infection among urban street boys in Tanzania. *Medical Anthropology Quarterly, 16*(3), 294-311.

Lwin, R., & Melvin, D. (2001). Annotation: Paediatric HIV infection. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 42*(4), 427-438.

MacGaffey, J. (1991). *The Real Economy of Zaire: an anthropological study*. Philadelphia, PA: University of Pennsylvania Press.

Maman, S., Campbell, J., Sweat, M. D., & Gielen, A. C. (2000). The intersections of HIV and violence: Directions for future research and interventions. *Social Science and Medicine, 50*(4), 459-478.

Maman, S., Mbwambo, J., Hogan, N. M., Kilonzo, G. P., & Sweat, M. (2001). Women's barriers to HIV-1 testing and disclosure: Challenges for HIV-1 voluntary counselling and testing. *AIDS Care, 13*(5), 595-603.

Maman, S., Mbwambo, J. K., Hogan, N. M., Kilonzo, G. P., Campbell, J. C., Weiss, E., et al. (2002). HIV-positive women report more lifetime partner violence: findings from a voluntary counseling and testing clinic in Dar es Salaam, Tanzania. *Am J Public Health, 92*(8), 1331-1337.

Maman, S., Mbwambo, J. K., Hogan, N. M., Weiss, E., Kilonzo, G. P., & Sweat, M. D. (2003). High rates and positive outcomes of HIV-serostatus disclosure to sexual partners: reasons for cautious optimism from a voluntary counseling and testing clinic in Dar es Salaam, Tanzania. *AIDS Behav, 7*(4), 373-382.

Maman, S., & Medley, A. (2003). *Gender Dimensions of HIV Status Disclosure to Sexual Partners: Rates, Barriers and Outcomes. A Review Paper*. Geneva, Switzerland: WHO.

McConnell, B. (2003). *Demographic Republic of the Congo--Complex Emergency* (Situation Report No. Situation Report #1, FY 2004). Washington DC: US Agency for International Development, Bureau for Democracy, Conflict, and Humanitarian Assistance, Office of US Foreign Disaster Assistance.

McFarland, W., Mvere, D., Shandera, W., & Reingold, A. (1997). The epidemiology and prevention of transfusion associated HIV infection in sub-Saharan Africa. *Vox Sang., 72*(2), 85-92.

Meditz, S. W., & Merrill, T. (1994). *Zaire : a country study* (Vol. 4th ed.). Washington DC: Federal Research Division, Library of Congress.

Mellins, C. A., Brackis-Cott, E., Dolezal, C., Richards, A., Nicholas, S., & Abrams, E. J. (2002). Patterns of HIV Status Disclosure to Perinatally HIV-Infected Children and Subsequent Mental Health Outcomes. *Clinical Child Psychology and Psychiatry, 7*(1), 101-114.

Mellins, C. A., & Ehrhardt, A. A. (1994). Families affected by pediatric acquired immunodeficiency syndrome: sources of stress and coping. *J Dev Behav Pediatr, 15*(3), S54-60.

Mellins, C. A., Kang, E., Leu, C. S., Havens, J. F., & Chesney, M. A. (2003). Longitudinal study of mental health and psychosocial predictors of medical treatment adherence in mothers living with HIV disease. *AIDS Patient Care and Stds, 17*(8), 407-416.

Menon, A., Glazebrook, C., Campain, N., & Ngoma, M. (2007). Mental Health and Disclosure of HIV Status in Zambian Adolescents With HIV Infection: Implications for Peer-Support Programs. *J Acquir Immune Defic Syndr*.

Merriam-Webster Online. (2005-2006). Merriam-Webster Online Dictionary. Retrieved 1 April, 2006, from http://www.m-w.com/dictionary/disclosure

Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis : an expanded sourcebook.* Thousand Oaks, CA: Sage Publications.

Morse, E. V., Simon, P. M., Coburn, M., Hyslop, N., Greenspan, D., & Balson, P. M. (1991). Determinants of subject compliance within an experimental anti-HIV drug protocol. *Soc Sci Med, 32*(10), 1161-1167.

Mullins, L. L., Olson, R. A., Reyes, S., Bernardy, N., Huszti, H. C., & Volk, R. J. (1991). Risk and resistance factors in the adaptation of mothers of children with cystic fibrosis. *J Pediatr Psychol, 16*(6), 701-715.

Murri, R., Ammassari, A., Gallicano, K., De Luca, A., Cingolani, A., Jacobson, D., et al. (2000). Patient-reported nonadherence to HAART is related to protease inhibitor levels. *J Acquir Immune Defic Syndr, 24*(2), 123-128.

Myer, L., Moodley, K., Hendricks, F., & Cotton, M. (2006). Healthcare Providers' Perspectives on Discussing HIV Status with Infected Children. *J Trop Pediatr*.

Nannyonga-Musoke, M., Penazzato, M., Morell, i. E., Mayanja, S. P., Ingabire, R., Mazza, A., et al. (2007). *The challenge of disclosure in resource-limited setting: experience in Ugandan HIV-infected children, Abstract No. TUPEB143*. Paper presented at the 4th IAS Conference on HIV Pathogenesis and Treatment.

National Institute Of Nursing Research. (2005). *Report Workshop--Cultural Dynamics in HIV/AIDS Biobehavioral Research Among Young People.* Bethesda, Maryland: National Institutes Of Health.

Nehring, W. M., Lashley, F. R., & Malm, K. (2000). Disclosing the diagnosis of pediatric HIV infection: mothers' views. *J Soc Pediatr Nurs, 5*(1), 5-14.

Nzeza Bilakila, A. (2004). The Kinshasa Bargain. In T. Trefon (Ed.), *Reinventing Order in the Congo: How People Respond to State Failure in Kinshasa* (pp. 20-32). London, UK: Zed Books.

O'Brien, K., Wortman, C. B., Kessler, R. C., & Joseph, J. G. (1993). Social relationships of men at risk for AIDS. *Soc Sci Med, 36*(9), 1161-1167.

Oberdorfer, P., Phuthanakit, T., Louthrenoo, O., Charnsil, C., Sirisanthana, V., & Sirisanthana, T. (2007). *Effectiveness of a ´5-step intervention technique´ for disclosure of HIV status to HIV-infected children, Abstract No. WEPDB05*. Paper presented at the 4th IAS Conference on HIV Pathogenesis and Treatment.

Oberdorfer, P., Puthanakit, T., Louthrenoo, O., Charnsil, C., Sirisanthana, V., & Sirisanthana, T. (2006). Disclosure of HIV/AIDS diagnosis to HIV-infected children in Thailand. *J Paediatr Child Health, 42*(5), 283-288.

Obimbo, E. M., Mbori-Ngacha, D. A., Ochieng, J. O., Richardson, B. A., Otieno, P. A., Bosire, R., et al. (2004). Predictors of early mortality in a cohort of human immunodeficiency virus type 1-infected african children. *Pediatr Infect Dis J, 23*(6), 536-543.

Okitolonda, W., Lapika, D., Kayembe, K., Kaba, K., & Malengreau, M. (2002). *Perception de la Crise Alimentaire, Ses Causes et Mecanismes d'Adaptation dans les Zones de Santé de Masina et Kisenso*. Kinshasa, DRC: Ecole de Santé Publique, Université de Kinshasa, RDC.

Ostrom, R. A., Serovich, J. M., Lim, J. Y., & Mason, T. L. (2006). The role of stigma in reasons for HIV disclosure and non-disclosure to children. *AIDS Care, 18*(1), 60-65.

Palella, F. J., Jr., Delaney, K. M., Moorman, A. C., Loveless, M. O., Fuhrer, J., Satten, G. A., et al. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. *N Engl J Med, 338*(13), 853-860.

Paterson, D. L., Swindells, S., Mohr, J., Brester, M., Vergis, E. N., Squier, C., et al. (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Ann Intern Med, 133*(1), 21-30.

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3 ed.). Thousand Oaks, CA: Sage Publications.

Pequegnat, W., & NIMH Consortium on Family & HIV/AIDS Research. (2002). Research issues with children infected and affected with HIV and their families. *Clinical Child Psychology and Psychiatry, 7*(1), 7-15.

Phipps, S., Fairclough, D., & Mulhern, R. K. (1995). Avoidant coping in children with cancer. *J Pediatr Psychol, 20*(2), 217-232.

Pianta, R. C., & Nimetz, S. L. (1989). *The Student-Teacher Relationship Scale: Results of a Pilot Study.*: Elementary and Early Childhood Education (PS018146).

PNLS. (2003). *Surveillance de seconde generation 2003. Phase I. Rapport du passage des activités.* Kinshasa, DRC: Programme National de lutte Contre le VIH/SIDA et las IST.

Preston, D. B., D'Augelli, A. R., Kassab, C. D., Cain, R. E., Schulze, F. W., & Starks, M. T. (2004). The influence of stigma on the sexual risk behavior of rural men who have sex with men. *AIDS Educ Prev, 16*(4), 291-303.

Quinn, T. C., Mann, J. M., Curran, J. W., & Piot, P. (1986). AIDS in Africa: an epidemiologic paradigm. *Science, 234*(4779), 955-963.

Rabain-Jamin, J. (1989). Culture and early social interactions: The example of mother-infant object play in African and native French families. *European Journal of Psychology of Education, 4*(2), 295-306.

Rotheram-Borus, M. J., Draimin, B. H., Reid, H. M., & Murphy, D. A. (1997). The impact of illness disclosure and custody plans on adolescents whose parents live with AIDS. *Aids, 11*(9), 1159-1164.

Ryder, R. W., Kamenga, M., Nkusu, M., Batter, V., & Heyward, W. L. (1994). AIDS orphans in Kinshasa, Zaire: incidence and socioeconomic consequences. *Aids, 8*(5), 673-679.

Ryder, R. W., Nsa, W., Hassig, S. E., Behets, F., Rayfield, M., Ekungola, B., et al. (1989). Perinatal transmission of the human immunodeficiency virus type 1 to infants of seropositive women in Zaire. *N Engl J Med, 320*(25), 1637-1642.

Sallis, J. F., & Owen, N. (2002). Ecological Models of Health Behavior. In K. Glanz, B. Rimer & F. Lewis (Eds.), *Health Behavior and Health Education* (3rd ed., pp. 462-484). San Francisco, CA: Jossey-Bass.

Semeere Semwendero, A., Kiyingi, S. H., Okech, B., Byaruhanga, R., Egwang, T. G., Nanyonga, M., et al. (2007). *Adherence to antiretroviral therapy in HIV positive children at Nsambya Home Care, Abstract No. WEPEB092* Paper presented at the 4th IAS Conference on HIV Pathogenesis and Treatment.

Singh, N., Berman, S. M., Swindells, S., Justis, J. C., Mohr, J. A., Squier, C., et al. (1999). Adherence of human immunodeficiency virus-infected patients to antiretroviral therapy. *Clin Infect Dis, 29*(4), 824-830.

Slavin, L. A., O'Malley, J. E., Koocher, G. P., & Foster, D. J. (1982). Communication of the cancer diagnosis to pediatric patients: impact on long-term adjustment. *Am J Psychiatry, 139*(2), 179-183.

Spiegel, P. B., Bennedsen, A. R., Claass, J., Bruns, L., Patterson, N., Yiweza, D., et al. (2007). Prevalence of HIV infection in conflict-affected and displaced people in seven sub-Saharan African countries: a systematic review. *Lancet, 369*(9580), 2187-2195.

SPSS for Windows. (2006). Chicago: SPSS Inc.

Stall, R., Hoff, C., Coates, T. J., Paul, J., Phillips, K. A., Ekstrand, M., et al. (1996). Decisions to get HIV tested and to accept antiretroviral therapies among gay/bisexual men: implications for secondary prevention efforts. *J Acquir Immune Defic Syndr Hum Retrovirol, 11*(2), 151-160.

Stokols, D. (1992). Establishing and maintaining healthy environments. Toward a social ecology of health promotion. *Am Psychol, 47*(1), 6-22.

Stone, V. E., Hogan, J. W., Schuman, P., Rompalo, A. M., Howard, A. A., Korkontzelou, C., et al. (2001). Antiretroviral regimen complexity, self-reported adherence, and HIV patients' understanding of their regimens: survey of women in the her study. *J Acquir Immune Defic Syndr, 28*(2), 124-131.

Strand, R. T., Fernandes Dias, L., Bergstrom, S., & Andersson, S. (2007). Unexpected low prevalence of HIV among fertile women in Luanda, Angola. Does war prevent the spread of HIV? *Int J STD AIDS, 18*(7), 467-471.

Suls, J., & Fletcher, B. (1985). The relative efficacy of avoidant and nonavoidant coping strategies: a meta-analysis. *Health Psychol, 4*(3), 249-288.

Swendeman, D., Rotheram-Borus, M., Comulada, S., & Weiss, R. (2004). *Experienced and perceived HIV-related stigma among young people living with HIV: Implications for preventative and supportive interventions. [Abstract #92208].* Paper presented at the American Public Health Association Annual Meeting, Washington, DC.

The SAS Institute Inc. (2003-2005). The SAS System for Windows (Version 9.0). Cary, NC: The SAS Institute, Inc.

Thompson, R. H., & Vernon, D. T. (1993). Research on children's behavior after hospitalization: a review and synthesis. *J Dev Behav Pediatr, 14*(1), 28-35.

Thompson, R. J., Jr., Gil, K. M., Burbach, D. J., Keith, B. R., & Kinney, T. R. (1993). Role of child and maternal processes in the psychological adjustment of children with sickle cell disease. *J Consult Clin Psychol, 61*(3), 468-474.

Thompson, R. J., Jr., Gustafson, K. E., Hamlett, K. W., & Spock, A. (1992). Stress, coping, and family functioning in the psychological adjustment of mothers of children and adolescents with cystic fibrosis. *J Pediatr Psychol, 17*(5), 573-585.

Thorne, C., Newell, M. L., & Peckham, C. S. (2000). Disclosure of diagnosis and planning for the future in HIV-affected families in Europe. *Child Care Health Dev, 26*(1), 29-40.

Trefon, T. (2004). Introduction: Reinventing Order. In T. Trefon (Ed.), *Reinventing Order in the Congo: How People Respond to State Failure in Kinshasa* (pp. 1-19). London, UK: Zed Books.

UN Population Division. (2007). World Population Prospects: The 2006 Revision Population Database (Publication. Retrieved 14 August 2007, from Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat,: http://esa.un.org/unpp, UNAIDS. (2004). *2004 Report on the Global HIV/AIDS Epidemic: 4th global report*: UNAIDS.

UNAIDS. (2005). *AIDS epidemic update: December 2005*. Geneva, Switzerland: UNAIDS.

UNAIDS. (2006). *2006 Report on the Global HIV/AIDS Epidemic: A UNAIDS 10th anniversary special edition*. Geneva, Switzerland: UNAIDS.

UNC-GAP. (2007). unpublished data from PMTCT antenatal sites.

UNDP. (2006). Human Development Report Country Profile: Democratic Republic of the Congo. 2006. Retrieved 14 August, 2007, from http://hdr.undp.org/hdr2006/statistics/countries/country_fact_sheets/cty_fs_COD.html

UNICEF. (2006). At a Glance, Congo, Democratic Republic of the (Publication. Retrieved 14 August 2007: http://www.unicef.org/infobycountry/drcongo_statistics.html

USAID. (2005). *Working Report Measuring HIV Stigma: Results of a Field Test in Tanzania*. Washington, DC: US Agency for International Development (USAID).

USAID/Synergy. (2004). *Women's Experiences with HIV Serodisclosure in Africa: Implications for VCT and PMTCT*. Washington, DC: USAID.

Vaz, L. M. E. (2006). Personal communication with Dr Steven Callens, Project Director SARA.

Vaz, L. M. E., Corneli, A. L., Dulyx, J., Rennie, S., Omba, S., Kitetele, F., et al. (in press). The process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of the Congo. *AIDS Care*.

Vygotsky, L. S. (1962). *Thought and Language* (E. H. a. G. Vakar, Trans.). Cambridge, MA: MIT Press.

Vygotsky, L. S. (1978). *Mind in society: The development of higher mental processes*. Cambridge, MA: Harvard University Press.

Walker, N., Schwartlander, B., & Bryce, J. (2002). Meeting international goals in child survival and HIV/AIDS. *Lancet, 360*(9329), 284-289.

Wallander, J. L., & Varni, J. W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *J Child Psychol Psychiatry, 39*(1), 29-46.

Waugh, S. (2003). Parental views on disclosure of diagnosis to their HIV-positive children. *AIDS Care, 15*(2), 169-176.

Weinstein, N. D., Rothman, A. J., & Sutton, S. R. (1998). Stage theories of health behavior: Conceptual and methodological issues. *Health Psychology, 17*(3), 290-299.

Weinstein, N. D., & Sandman, P. M. (2002). The Precaution Adoption Process Model. In K. Glanz, B. Rimer & F. Lewis (Eds.), *Health Behavior and Health Education* (3rd ed., pp. 121-143). San Francisco, CA: Jossey-Bass.

WHO. (2003). *Adherence to Long-Term Therapies: Evidence for Action*. Geneva, Switzerland: World Health Organization.

WHO. (2004a, July 27 2004). Democratic Republic of the Congo. Retrieved November 20, 2004, from http://www.who.int/disasters/repo/15104.pdf

WHO. (2004b). *Improving Access to Appropriate Paediatric ARV Formulations*. Geneva, Switzerland: World Health Organization.

WHO. (2004c). *World Health Report 2004: Changing history*. Geneva, Switzerland: World Health Organization.

WHO. (2005a). *Progress on Global Access to HIV Antiretroviral Therapy: An update on "3 by 5"*. Geneva, Switzerland: World Health Organization.

WHO. (2005b, June 2005). Summary Country Profile for HIV/AIDS Treatment Scale-up: Democratic Republic of the Congo. Retrieved 1 April, 2006, from http://www.who.int/3by5/support/june2005_cod.pdf

WHO, UNAIDS, & UNICEF. (2004). *Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections: Democratic Republic of the Congo, 2004 Update*. Geneva, Switzerland: WHO/UNAIDS/UNICEF.

WHO, UNAIDS, & UNICEF. (2006). *Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections: Democratic Republic of the Congo, 2006 Update*. Geneva, Switzerland: WHO/UNAIDS/UNICEF.

WHO, UNAIDS, & UNICEF. (2007). *Towards universal access : scaling up priority HIV/AIDS interventions in the health sector : progress report, April 2007*. Geneva, Switzerland: World Health Organization.

WHO/UNAIDS/UNICEF. (2004). *Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections: Democratic Republic of the Congo, 2004 Update*. Geneva, Switzerland: WHO/UNAIDS/UNICEF.

Wiener, L., Mellins, C. A., Marhefka, S., & Battles, H. B. (2007). Disclosure of an HIV Diagnosis to Children: History, Current Research, and Future Directions. *J Dev Behav Pediatr, 28*(2), 155-166.

Wiener, L., Theut, S., Steinberg, S. M., Riekert, K. A., & Pizzo, P. A. (1994). The HIV-infected child: parental responses and psychosocial implications. *Am J Orthopsychiatry, 64*(3), 485-492.

Wiener, L. S., Battles, H. B., Heilman, N., Sigelman, C. K., & Pizzo, P. A. (1996). Factors associated with disclosure of diagnosis to children with HIV/AIDS. *Pediatr AIDS HIV Infect, 7*(5), 310-324.

Wiener, L. S., Battles, H. B., & Heilman, N. E. (1998). Factors associated with parents' decision to disclose their HIV diagnosis to their children. *Child Welfare, 77*(2), 115-135.

World Bank. (2004). Congo, Democratic Republic Data Profile. Retrieved May 23, 2005, from http://devdata.worldbank.org/external/CPProfile.asp?SelectedCountry=ZAR&CCODE=ZAR&CNAME=Congo%2C+Dem.+Rep.&PTYPE=CP

World Bank. (2006). Congo, Democratic Republic Data Profile (Publication., from The World Bank Group: http://devdata.worldbank.org/external/CPProfile.asp?PTYPE=CP&CCODE=ZAR

Wutoh, A. K., Kumoji, E. K., Xue, Z. Y., Campusano, G., Wutoh, R. D., & Ofosu, J. R. (2006). HIV knowledge and sexual risk behaviors of street children in Takoradi, Ghana. *Aids and Behavior, 10*(2), 209-215.

Yen, C. F., Tsai, J. J., Lu, P. L., Chen, Y. H., Chen, T. C., Chen, P. P., et al. (2004). Quality of life and its correlates in HIV/AIDS male outpatients receiving highly active antiretroviral therapy in Taiwan. *Psychiatry Clin Neurosci, 58*(5), 501-506.

Yingling, J. (1995). The First Relationship: Infant-Parent Communications. In T. J. Socha & G. H. Stamp (Eds.), *Parents, children, and communication* (pp. 23-42). Mahwah, NJ: Lawrence Erlbaum Associates, Publishers.

Ziemke, J. J. (2001). Democratic Republic of Congo. Retrieved 27 February, 2006, from http://www.everyculture.com/Bo-Co/Democratic-Republic-of-the-Congo.html