

PARENTAL/CAREGIVER INFLUENCE ON SEXUAL RISK BEHAVIORS
AMONG HIV-POSITIVE YOUNG PEOPLE IN KINSHASA,
THE DEMOCRATIC REPUBLIC OF THE CONGO

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A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department of Health Behavior and Health Education

Chapel Hill
2009

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ABSTRACT

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Parental/Caregiver Influence on Sexual Risk Behaviors among HIV-Positive Young People
in Kinshasa, the Democratic Republic of the Congo
(Under the direction of Audrey Pettifor and Suzanne Maman, co-chairs)

Young people make up more than 60% of the population in the Democratic Republic of the Congo (DRC) and have an HIV prevalence of over 1%. Parents/caregivers of HIV-positive young people play an important role in helping their children understand how their decisions affect their health and the health of others. The first aim of this research was to examine the relationships between parental/caregiver monitoring, social support, and sexual risk behaviors for young people living with HIV (YPLWH) in Kinshasa, DRC. Quantitative data collected from 103 YPLWH, age 14-24 and who reported ever having sex, were analyzed. The second aim was to describe the norms and patterns of communication about sex between parents/caregivers and their HIV-positive child through 52 semi-structured interviews of caregivers. In the first aim, the majority of participants reported low parental/caregiver monitoring (68%) and low social support (68%). Among all young people, 55 (53.4%) reported no sex in the past 12 months, 29 (28.2%) reported protected sex at last intercourse, and 19 (18.4%) reported unprotected sex at last intercourse. Social support was an effect modifier in the relationship between monitoring and sexual behavior, with marginal significance (OR = 1.7, 95%CI: 0.98-2.79). This interaction effect weakened when adjusted for time-since-HIV-diagnosis (OR=1.6, 95%CI: 0.91-2.75). In the second aim, reasons for communication about sex, including HIV disclosure and child attributes and content of communication, including sexual risk, HIV status disclosure and other risk behaviors, were

identified. Reasons for communication were similar for parents/caregivers with children who knew their HIV status compared to those with children who did not know; however, most parents/caregivers waited until after puberty or until the child already started having sex to talk about sex. Parents/caregivers focused their conversations on the risks associated with sex, though males were told to be more careful compared to females, who were told to avoid sexual contact. For children who did not know their status, some parents/caregivers used scare tactics to influence their child's sexual behavior, even mentioning that they could contract HIV. These findings can inform culturally sensitive strategies for transmission risk interventions among young people living with HIV.

To the young people living with HIV and their families who participated in this research
and dedicated their time in order to help us find ways to improve their lives
and the lives of others.

ACKNOWLEDGEMENTS

I would like to thank the UNC-DRC study coordinators and team who made this research possible: Sandra Duvall, Bavon Mupenda, Mamie Lema, Mujalambo Kashosi, Nicole Kutumbakana, Angèle Mbuyi, Odette Daiku, Asha Elizabeth Yumba, Cléo Tshimanga, Erasme Kapenda, Guy Nkoba, Djoloko André, Saleh Michel, and Torro Tsukunya. I am also grateful to Frieda Behets, for the opportunity to be a part of her DRC projects, allowing me to personally experience Kinshasa, DRC and for her support in this dissertation as a committee member.

I am indebted to Audrey Pettifor, who has worked closely with me for more than 3 years and has been my mentor throughout my work as a research assistant on the DRC studies and throughout my dissertation experience as co-chair of the committee— for that, I give my deepest appreciation. To Suzanne Maman, who graciously accepted to co-chair my committee— I thank you for your guidance and commitment throughout the entire dissertation process and for pushing me to truly understand what my research means in the DRC context. To my other committee members, Mike Bowling and Carol Golin, I thank you for the insight and direction which certainly shaped my dissertation to what it became.

Many others have contributed to the completion of this dissertation through reading drafts, editing, inputting data, listening to my practice talk, and/or through mere emotional support— I cannot thank them enough: Nina Sperber, Jessica Cance, Andrea Jost, Nganga Ngugi, Raphael Kirumba, Robert Sakey, Ryan McLaughlin, friends of Ka Pu’uwai ‘O Hawai’i, and Elizabeth King. I also thank my professors and staff of the Health Behavior and

Health Education Department, who have supported me since I began the program and have helped me grow professionally—in particular, I thank Shelley Golden, who took me on as a teaching assistant for over two years, Professors Jo Ann Earp, Susan Ennett, Vangie Foshee, and Kurt Ribisl, and staff members Robin Perkins, Laura Pearson, and Linda Cook.

Finally, if not for my parents, Harley Holub and Rose Sakey, I would have never made it this far. Thank you for always believing in me.

TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION.....	1
1.1 SETTING AND HISTORICAL OVERVIEW.....	1
1.2 TODAY’S CONGO	4
1.2.1 <i>Family, Upbringing, and Gender Roles</i>	5
1.3 CONTEXTUAL SIGNIFICANCE.....	7
1.4 CONTRIBUTION OF DISSERTATION AND ORGANIZATION OF CHAPTERS	8
CHAPTER TWO: LITERATURE REVIEW.....	10
2.1 SEXUAL RISK BEHAVIORS AMONG HIV-POSITIVE YOUNG PEOPLE.....	10
2.2 POSITIVE PREVENTION STRATEGIES FOR YOUTH IN THE AFRICAN CONTEXT	11
2.2.1 <i>HIV/AIDS Epidemiology</i>	11
2.2.2 <i>Prevention Efforts</i>	12
2.3 PARENTAL/CAREGIVER INFLUENCE ON SEXUAL RISK BEHAVIORS	14
2.3.1 <i>Parental Monitoring</i>	15
2.3.2 <i>Parental Communication about Sex</i>	17
2.4 SOCIAL SUPPORT AMONG HIV-POSITIVE YOUTH.....	20
2.5 THE RELATIONSHIP BETWEEN SOCIAL SUPPORT AND PARENTAL/CAREGIVER MONITORING	22
CHAPTER THREE: SPECIFIC AIMS AND METHODS	24
3.1 SPECIFIC AIM #1	25

3.2 SPECIFIC AIM #2	25
3.3 METHODS.....	26
3.3.1 <i>Conceptual Framework and Theory</i>	26
3.3.2 <i>Sample and Eligibility for Quantitative Analysis (Aim #1)</i>	29
3.3.3 <i>Sample and Eligibility for Qualitative Analysis (Aim #2)</i>	30
3.3.4 <i>Data Collection Procedures</i>	30
3.3.5 <i>Material and Measures</i>	31
3.3.6 <i>Quantitative Measures (Aim#1)</i>	31
3.3.7 <i>Qualitative Constructs (Aim#2)</i>	33
3.3.8 <i>Analytic Strategy</i>	33
3.4 RESEARCH DESIGN STRENGTHS AND LIMITATIONS.....	37
 CHAPTER FOUR: INFLUENCE OF PARENTAL/CAREGIVER MONITORING AND SOCIAL SUPPORT AMONG HIV-POSITIVE YOUNG PEOPLE	 39
4.1 ABSTRACT.....	39
4.2 INTRODUCTION.....	40
4.3 METHODS.....	46
4.3.1 <i>Measures</i>	47
4.3.2 <i>Statistical Analysis</i>	48
4.4 RESULTS	49
4.5 DISCUSSION	53
 CHAPTER FIVE: COMMUNICATION ABOUT SEX BETWEEN PARENTS/CAREGIVERS AND HIV-POSITIVE YOUNG PEOPLE.....	 64
5.1 ABSTRACT.....	64
5.2 INTRODUCTION.....	65
5.3 METHODS.....	69

5.3.1 <i>Setting and Research Design</i>	69
5.3.2 <i>Sample</i>	70
5.3.3 <i>Data Collection</i>	70
5.3.4 <i>Data Analysis</i>	71
5.4 RESULTS	72
5.5 DISCUSSION	80
5.6 CONCLUSION	89
CHAPTER SIX: CONCLUSION.....	93
6.1 SIGNIFICANCE OF DISSERTATION	93
6.2 FINDINGS OVERVIEW	96
6.2.1 <i>Specific Aim #1</i>	96
6.2.2 <i>Specific Aim #2</i>	99
6.3 IMPLICATIONS: RESEARCH, PRACTICE, AND THEORY.....	102
6.4 STRENGTHS AND LIMITATIONS.....	107
6.5 CONCLUSION	109
APPENDIX.....	112
A.1 FIGURE OF SOCIAL SUPPORT NETWORKS AND SOCIAL SUPPORT PATHWAYS	112
A.2. FIGURE OF PARENT-BASED EXPANSION OF THE THEORY OF PLANNED BEHAVIOR.....	113
A.2 SCALES.....	114
A.2.1 <i>Parental Monitoring</i>	114
A.2.2 <i>Social Support</i>	114
A.3 SOP: PROCESS OF SEROSTATUS DISCLOSURE TO MINORS	115

REFERENCES 123

LIST OF TABLES

Table 1.1. Democratic Republic of the Congo (DRC) socio-demographic information.....	page 4
Table 4.1. Demographic characteristics of HIV+ youth by gender (n = 103).....	page 59
Table 4.2. Demographic, psychosocial, and sexual practices by parental/caregiver monitoring, social support, and sexual risk behavior among HIV+ young people in Kinshasa, DRC, n=103.....	page 60
Table 4.3. Proportional odds ratios for the interaction between parental/caregiver monitoring and social support on sexual risk (no sex, protected last sex, or unprotected last sex in last 12 months) among HIV positive young people from Kinshasa, DRC.....	page 62
Table 4.4. Effect of social support on the value of the estimated adjusted odds ratio for parental/caregiver monitoring.....	page 62
Table 5.1. Characteristics of Primary Caregiver and Child Participants.....	page 92
Table 5.2. Primary caregiver beliefs about the sexual experience of their child compared to the young person's self-report on their sexual experience.....	page 92

LIST OF FIGURES

- Figure 3.1. Conceptual model for the relationship between parental/caregiver,
monitoring social support, and sexual risk behavior..... page 28
- Figure 4.1. Sample Size Chart..... page 63
- Figure A.1. The relationship of social networks and social support to health..... page 112
- Figure A.2. Parent-Based Expansion of the Theory of Planned Behavior.....page 113

CHAPTER ONE: INTRODUCTION

1.1 Setting and Historical Overview

The Democratic Republic of the Congo (DRC)—also commonly known as Congo or the Congo—is the third largest country in Africa. As part of Central Africa, the Congo borders Republic of the Congo on the West, Central African Republic and Sudan to the North, Uganda, Rwanda, Burundi and Tanzania on the East, and to the South Zambia and Angola. Much of the Western and Eastern parts of Congo's borders are shaped by bodies of water. The Congo River, which is the second-largest river in Africa and from which Congo gets its name, largely makes up the border between Congo and Republic of the Congo. Lake Tanganyika, the world's longest lake, makes up the Eastern border with Burundi and Tanzania. Lakes Albert, Edward, and Kivu also share borders with Uganda and Rwanda. The total area of Congo is 905,563 square miles (2,345,410 sq km), which is slightly less than one-fourth of the size of the United States (Central Intelligence Agency [CIA], 2009).

Congo's landscape, largely made up of rain forest, savanna, and mountains, brings great diversity to the country. It has the greatest number of animal and plant species and the greatest natural wealth in Africa. In the early 20th century, Congo provided ivory and rubber for tires, which was especially important for the new invention, automobiles. In the 1980's, diamonds were the source of millions of dollars for Congo, as they were one of the world's leading industrial diamond suppliers. More recently, mining in Congo brings cobalt, copper, columbite-tantalite (coltan), and gold. Coltan, specifically, is used in manufacturing high-tech products (i.e., cell phones and computers).

Although Congo holds some of the greatest natural wealth, the economy is weak. Much of the reason for Congo's destitution lies in the natural resources itself, as it became an attraction for other foreign entities, or people outside the country, to take. Throughout history, Congo has suffered corruption and exploitation by people who aim to profit from Congo's natural resources. In a report by the United Nations in 2001, Uganda, Rwanda, Burundi, and rebel soldiers from these countries were recognized as players in the looting of Congo's resources. For example, Uganda has become one of the world's leading suppliers of diamonds—a country that has no diamond mines. However, such “fortune-making” can be traced as far back as the slave trade by the Portuguese in the early 1500's and, in the late 1800's, the exploitation and forced labor by King Leopold II of Belgium. To best understand Congo and Congolese people today, it is necessary to understand the history of colonization and corruption by which they suffered.

“Red rubber” is a term— still commonly used today— to reference the physical violence and brutality of King Leopold II's history in the Congo. In 1885, the Congo Free State, named by Leopold, became a colony of Belgium. Native kings and chiefs gave up their land to promises, made by Leopold, of education and medical care; but those promises were far from the truth. The Congolese people were forced into hard labor, killing elephants for ivory, tapping rubber trees for their sap, and making roads and railroads towards the Congo River to export the resources. This time in history went largely unnoticed until other nations became aware of the atrocities, which started an international uproar, particularly by the United States and Great Britain.

Congo was finally annexed and made a colony in 1908 by the Belgian parliament. Now called Belgian Congo and out of Leopold's direct control, Belgian colonist still treated the Congolese as inferior, but they were more generous and improved health care, education, and work opportunities. During World War II, there was a large movement from the rural areas to

urban areas for employment. The Congolese began to speak out about the way they were governed and eventually they were allowed to own land and participate in local politics. After several years of calling for complete independence by the Alliance of the Kongo People (ABAKO), independence was gained in 1960 and the country renamed to Republic of the Congo.

Since independence, the country continued to face political, social, and economic hardships. The economy was suffering, people were starving, and the many ethnic groups within the Congo were fighting. In 1965, Joseph-Désiré Mobutu (later changed to Mobutu Sese Seko) controlled the country for over 30 years, renaming the country Zaire in 1971. Reminiscent of Congo's long history, Mobutu gained immense personal wealth and allowed outside investors to reap Congo's resources, while the country itself fell deeper into economic destitution. Ethnic fighting and war over natural resources overwhelmed the country in the mid-1990's; but finally, after months of fighting, the Alliance for Democratic Forces for the Liberation of the Congo took control of the government in 1997 and Mobutu stepped down. The fight was led by Laurent Kabila, who declared himself President and renamed the country to its present-day name, the Democratic Republic of the Congo.

Kabila was unable to bring Congo to peace, as war continued. This conflict, often referred to as Congo's Second War (1998-2004), had the most casualties of any war since World War II, with an estimated death toll of 3.9 million (Coghlan et al., 2006). In 2001, Kabila was assassinated and replaced by his son, Joseph Kabila—who was 29 years old at that time. Though fighting continued throughout the country, Joseph Kabila demonstrated greater strength and desire to end the unrest and called for peace talks to end the war. Congo had since been in a transitional government until official elections could take place. Finally, in July of 2006, Congo held its first multi-party election since independence in 1960. Joseph Kabila held 45% of the

votes and his opponent, Jean-Pierre Bemba, 20%. The two parties fought in August 2006 in the streets of Kinshasa, the capital, until a new election was held in October 2006 with Kabila holding 70% of the votes. December 6, 2006 marked the end of the transitional government and Joseph Kabila was sworn in as President of the Democratic Republic of the Congo.

1.2 Today's Congo

According to the most recent data in a 2006 report, compared to data from other African countries gathered by the World Health Organization, social indicators of DRC (e.g., life expectancy and infant mortality rate) are relatively poor. See Table 1.1.

Table 1.1. Democratic Republic of the Congo (DRC) Basic Indicators

Demographic	Year	Estimate
Total population	2005	57,548,000
Gross national income per capita (PPP Intl \$)	2004	680
Life expectancy at birth (years)	2004	42 male, 47 female
Healthy life expectancy at birth (years)	2002	35male, 39 female
Probability of dying under five (per 1 000 live births)	2004	205
Probability of dying between 15 and 60 years (per 1,000 population)	2004	576 male, 446 female
Infant mortality rate (per 1,000 live births)	2004	129
Adult literacy rate (%)	2004	65.3
Total expenditure on health per capita (Intl \$)	2003	14
Total expenditure on health as % of GDP	2003	4.0

Source: WHO Statistics, 2006

Currently, as of July 2009, the Democratic Republic of the Congo has a population of over 68 million (CIA, 2009). The CIA World Fact Book notes, however, that “estimates for this country explicitly take into account the effects of excess mortality due to AIDS; this can result in lower life expectancy, higher infant mortality, higher death rates, lower population growth rates, and changes in the distribution of population by age and sex than would otherwise be expected.”

DRC's age structure is largely skewed towards younger ages with 46.9% between 0-14 years, 59.6% 15-64 years, and 2.5% 65 years and over; the median age for males is 16.2 years and 16.6 years for females (CIA, 2009). Most Congolese speak several languages. The main ones are French (the official language) and Lingala (the lingua franca trade language), followed by Swahili, Kikongo, and Tshiluba. The majority of popular music coming from the Congo, and heard throughout the continent, is sung in Lingala.

Thirty-four percent of the population lives in urban areas, with nearly 8 million in Kinshasa, DRC's capital, situated along the Congo River (CIA, 2009). Kinshasa has been considered the second largest francophone city in the world after Paris and it ties with Johannesburg for the second largest city in sub-Saharan Africa. Rated as one of the most dangerous cities in Africa, robberies, rape, and gang violence are not uncommon. Kinshasa is also a city of economic dichotomies—as affluent and commercial areas, as well as major universities, are situated along side some of the poorest areas and slums.

1.2.1 Family, Upbringing, and Gender Roles

Traditionally, marriage in the Congo is not only a union between two people. It is also a union between two families. The marriage alliance is often sealed with a bridewealth, a transfer of some values from the groom's family to the bride's family—a practice that is still seen today (Mukenge, 2002). It is the dream of most Congolese woman to get married and become a mother, a dream that begins in childhood. Mukenge (2002) notes that, “Her motherhood responsibilities—caring and providing for her children—typically rank higher in her heart than any other”.

The nuclear family (husband, wife, and children) is a subunit of a larger extended family and shared living space with other relatives is common practice. In an extended family

household, the upbringing of a child is not left exclusively to the biological parents, as other family members are often involved (Sudarkasa, 2004). Additionally, any woman may take on the responsibility for upbringing a child of other relatives, which is referred to as child fostering. The treatment of biological versus “adopted” children by the mother is often indistinguishable. Urban families may house children of relatives or other relatives in search of better education, employment, or health care.

Respect for elders in traditional African culture is a highly valued quality of one’s character and is a part of daily life in the Congo. Young people are considered “good” if they display utmost respect for elders and do what they are told without question (Ziemke, 2001). If a child lives with extended family, the respect a child shows their mother does not change depending on whether she is the birth mother (Sudarkasa, 2004). Asking permission before doing various tasks or leaving the household is one way to display such respect for elders-- and the type of permission given may also be based on gender; for example, males may be more likely to get permission to go out in the evening, while females are less likely to get permission to leave the household. The ability to give permission to a child or young person to do various activities allows the adults in the family to have knowledge of the child’s activities.

Many customs and practices are divided along gender lines, as in the example given above. In many relationships, men are expected to provide for the household and women are expected to manage the household activities and care for the children (Ziemke, 2001). Generally, women are regarded as lower in the social hierarchy compared to males. As children, when they are able to walk, “...they are thrust into the realm of adult responsibilities” (Ziemke, 2001), ones that make gender roles apparent even for youth. For example, young girls often have more responsibilities in assisting their mother and other adult women in daily household activities

compared to young males, who are most likely to have permission to spend more time outside the household (Warkentin, 2004).

1.3 Contextual Significance

The aim of this introductory chapter is to set the stage for contextualizing this dissertation research in the historical, socio-economic, and cultural perspectives of the Democratic Republic of the Congo. The historical account presented here is not, by far, a comprehensive review of Congo's history. There are many more details and events that have shaped the country to become what it is today. However, what we do see is a distinct pattern of civil unrest and corrupt leadership—and as a result, we see a nation that is devastated. As Congo strives to rebuild the country, conflict has continued and Congo remains under the watchful eye of human rights groups, especially in the eastern region. War has left Congo's government fragile, the economy is suffering, and the people continue to die at alarming rates, as basic health care services are disrupted. Patterns of childhood diseases have also matched the geographical areas most affected by conflict in Congo (Kandala, Emina, Nzita, & Cappuccio, 2009). For Congolese children growing up in war-affected regions of the Congo, over 95% have experienced at least one traumatic event and more than half have met criteria for posttraumatic stress disorder (Mels, Derluyn, Broekaert, & Rosseel, 2009). Children in war-torn countries are at risk for adverse physical and mental health outcomes, impacting their lives as they grow and transition into adulthood.

However, we also know that despite such adversity, high values are placed on the upbringing of youth, both in the immediate and extended family—giving us some cultural information that can provide insight into potential strategies for health promotion. Important to the core of this dissertation, is Congo's transition to a government that is striving for “increased

stability and economic revitalization,” allowing more interest to be placed on strengthening strategies for improving the health of the Congolese, especially in areas such as expanding HIV/AIDS prevention and care (UNAIDS, 2004).

1.4 Contribution of Dissertation and Organization of Chapters

This dissertation contributes to formative research on strategies in HIV/AIDS prevention, specifically to inform the development of transmission risk reduction interventions among HIV-positive young people, in the Democratic Republic of the Congo. From a historical perspective, we see that the country is still in transition, but such prevention efforts are imperative, not only to address Congo’s high rates of disease and poverty, but also to contribute to the country’s revival as a whole. The research for this dissertation aims to understand factors related to sexual risk behavior, namely parenting behaviors and social support — and these factors must be understood in the socio-cultural context of the Congo.

First, in this **Chapter 1**, an overview of the setting and historical context was provided. Second, we explored the culture and customs of the Congo, especially those related to kinship and family interaction. **Chapter 2** presents a literature review of the theoretical basis and empirical evidence (or lack thereof), which demonstrates the need for this research and the gap in literature that this dissertation fills. Additionally, a review of Congo’s HIV/AIDS epidemiology and young people’s experience in the Congo is included. **Chapter 3** outlines the specific aims and methods for the dissertation. **Chapters 4 and 5** comprise of two manuscripts based on research findings on: (1) the relationship between parental/caregiver monitoring, social support, and sexual risk behavior and (2) parent-child communication about sex. **Chapter 6** provides a summarizing discussion and conclusion for the entire dissertation experience and research,

ending with recommendations and direction for future research in intervention development for young people living with HIV.

CHAPTER TWO: LITERATURE REVIEW

2.1 Sexual Risk Behaviors among HIV-Positive Young People

The transition into adulthood is unique for young people living with HIV. It is, not only marked with new responsibilities in making decisions regarding sexual activity and other risk behaviors, but moreover, it is marked with the need for a critical understanding and appreciation for how such decisions affect their own health and the health of others. Young people, in general, are likely to underestimate their sexual risk behaviors, even among those who are at high risk (i.e., those who report inconsistent condom use, more than one partner, and/or an additional STD or partner risk) (Kershaw, Ethier, Niccolai, Lewis, & Ickovics, 2003). However, for young people living with HIV, it is critical that they overcome any misperception about their sexual risk behaviors and, in accordance, make healthy life-style decisions.

To date, little is known about the factors that *influence* sexual behaviors among young people living with HIV. However, there is some research, predominately in the United States, that provides insight into these behaviors. Research has shown that many adolescents who are aware of their HIV status delay or decrease their sexual risk behavior (Lightfoot, Rotheram-Borus & Tevendale, 2007a). On the other hand, a significant number of sexually active HIV-positive youth continue to engage in risky behavior, such as unprotected sex (Johnson & Buzducea, 2007). Research has shown that up to 47% of HIV-positive youth report unprotected sex at last intercourse (Murphy et al., 2001). The majority of pregnancies among HIV-positive adolescent females, for example, are unintended and approximately half did not know their

serostatus prior (Koenig, Espinoza, Hodge, Ruffo, 2007). One longitudinal study of HIV-positive youth in the U.S. found that youth who were infected perinatally or through transfusion had relatively low knowledge of sexual transmission risk behaviors (Wiener, Battles, & Wood, 2007). The study also found that HIV-positive youth perceive that most people their age are having sex and thus feel pressured to do so (Wiener et al. 2007).

There is little information about sexual activity among young people living in the DRC, especially for HIV-positive young people. However, in one formative study of HIV-positive adolescents in Uganda, focus group discussions revealed that many abstained from sex or, if sexually active, they used condoms; however, many also mentioned that peer pressure, HIV-related stigma, and poverty were barriers for adopting protective behaviors (Bakeera-Kitaka, Nabukeera-Barungi, Nöstlinger, Addy, & Colebunders, 2008). In DRC, there is some evidence that young people are becoming sexually active at a young age, engaging in behavior that puts them at high risk of getting HIV, and lacking clear information in matters related to HIV prevention (UNAIDS, 2006; Kalambayi, Pirpiri, Nawej, & Remes, 1998; Ecole de Sante Publique de Kinshasa, 2006). In one HIV prevention intervention among adolescents age 14-19 based in Kinshasa, DRC, over 51% of females and 77% of males reported sexual intercourse before the age of 15 years; in addition, while less than 26% of adolescents felt well-informed about HIV risk behaviors, 33% reported more than one sex partner and 88% reported inconsistent condom use in the last 6 months (Pettifor et al., under review).

2.2 Positive Prevention strategies for Youth in the African Context

2.2.1 HIV/AIDS Epidemiology

The Democratic Republic of the Congo (DRC), similar to many other African countries, has an increasing number of people living with HIV/AIDS with a prevalence of 1.3%, according

to the Demographic Health Survey [DHS] (2008). This prevalence is relatively low compared to surrounding countries such as Kenya (6.7%) and Tanzania (7.0%), for example. HIV prevalence is highest for both women and men living in Kinshasa, DRC's capital, (2.3 percent for women and 1.3 percent for men) compared to the western region of DRC (1.0 percent for women and 0.5 percent for men). Prevalence of HIV among youth by age and sex category (women and men) include: 15-17 years, 0.4% and 2.4%; 18-19 years, 1.2% and 0.5%; 20-24 years, 0.4% and 0.3% (DHS, 2008). As HIV prevalence is twice as high in urban areas compared to rural areas, estimates are likely higher among young people living in Kinshasa.

Studies have shown that young people in DRC are engaging in sexually risky behaviors (UNAIDS, 2006; Kalambayi et al., 1998; Ecole de Sante Publique de Kinshasa, 2006). An average of 28% (23% female/31% male) of young people age 15-24 reported sexual intercourse before the age of 15 years, which was higher than surrounding countries (e.g., Kenya-average 21% [14% female/29% male] and Uganda-average 15% [16% female/12% male]). In addition, the percentage of young people in DRC, age 15-24, who can correctly identify ways of preventing the sexual transmission of HIV is poor, 29% for males and 22% for females (DHS, 2008). Over 60% of the DRC's population is under 20 years old, and the high HIV prevalence of young people points to the need for interventions focused on transmission risk reduction.

2.2.2 Prevention Efforts

Most recently, DRC continues to recover from 5 years of war and conflict. As the DRC government transitions to "increased stability and economic revitalization," more interest has been placed on expanding HIV/AIDS prevention and care (UNAIDS, 2004).

Efforts in transmission risk reduction or "positive prevention" refers to preventive interventions targeted toward HIV infected individuals (Bunnell, Mermin, & De Cock, 2006).

Several studies, including randomized controlled trials, using various positive prevention strategies have proven to be efficacious in transmission risk reduction (Crepaz et al., 2006; Kalichman et al., 2001; Patterson, Shaw, & Semple, 2003; Richardson et al., 2004; Rotheram-Borus et al., 2001; Wingwood et al., 2004; Wolitski, Parson, & Gomez, 2004). However, few of these studies have been conducted among HIV-positive young people. Interventions that specifically recruit from HIV clinics have also proven successful. From less intensive strategies (e.g., delivery of brief intervention messages at HIV clinics) to more intensive strategies (e.g., multiple weekly intervention sessions), both have demonstrated their ability to reduce HIV transmission risk behaviors among HIV-positive people (Crepaz & Marks, 2002; Richardson et al., 2004; Wingwood et al., 2004). The success of these interventions suggests that strategies aimed at young people who are living with HIV can play an integral role in efforts to prevent the spread of HIV/AIDS.

While such intervention strategies have proven successful in the U.S. context, there is limited information on culturally adapted positive prevention interventions in the African context, especially ones that focus on transmission risk reduction among young people. One HIV intervention in Uganda targeting HIV-positive youth has shown strong support for culturally adapting existing interventions (Lightfoot et al., 2007b). This intervention was adapted from a U.S.-based intervention by Rotheram and colleagues (2004), which consisted of 18 sessions on physical health and nutrition, mental health, and reducing HIV transmission and, in addition, included two measurement time points (baseline and 3 months following the intervention). Focus groups, individual interviews, and observations of youth and staff guided the adaptation process. At follow-up, youth in this intervention demonstrated increased consistent condom use and

decreased number of sexual partners compared to the usual care condition (Lightfoot, Kasirye, Comulada, & Rotheram-Borus, 2007b).

To achieve effective interventions among vulnerable populations, such as HIV-positive young people, formative research is needed to identify culturally relevant strategies and program components. When formative research is conducted before an intervention or program begins, it serves to inform program development and implementation, specifically to meet the needs of the population (AIDS Partnership in California, 2003). When the formative stage of information gathering, before implementing an intervention, is insufficient or even overlooked, the efficacy of an intervention may be at risk. Based on the literature and empirical evidence supporting the influence of parents on sexual risk behaviors for young people in general, formative research is important for understanding parent/caregiver influence on sexual risk behaviors, specifically among young people already living with HIV.

2.3 Parental/Caregiver Influence on Sexual Risk Behaviors

Parents and primary caregivers strongly influence the lives of their children and they can play a critical role, particularly in the transition from childhood to young adulthood. Research on parenting has long established a relationship between parental influence and their child's emotional and behavioral health, including sexual risk behaviors (Ackard, Neumark-Sztainer, Story, & Perry, 2006; Babalola, Tambashe, & Vondrasek, 2005; Yang et al., 2006; Yang et al., 2007). There are innumerable ways parents/caregivers can influence their children. One type of influence is parental monitoring, which provides a way for parents to be aware of their child's whereabouts and activities. Another form of influencing children is by directly communicating with the child about specific issues, beliefs, and/or values. Each of these types of parental influence can have profound effects on a child's behavior (Yang et al., 2007). Additionally, when

used together, the combination of high parental monitoring and open communication can have protective effects on risk behaviors, such as sexual abstinence, secondary abstinence, and reduced number of sex partners among adolescents (Babalola et al, 2005; Yang et al., 2006; Yang et al., 2007).

2.3.1 Parental Monitoring

Parenting practices that include maintaining knowledge of a child's activities and use of free time, in other words, parental monitoring, have been shown to influence many different risk behaviors (DiClemente et al., 2001; Stanton et al., 2004). Research from the U.S. has found that adolescents who perceive higher parental monitoring are more likely to report using a condom at last sexual intercourse, have fewer sexual partners, and are less likely to test positive for a sexually transmitted disease (DiClemente et al., 2006). The effects of parental monitoring have further been supported using a randomized controlled study in the U.S. which showed sustained adolescent behavior change after intervention (Stanton et al., 2004). In this intervention, youth who were randomized to receive an extra parent-focused session, which emphasized parental monitoring, communication, and interactive role-playing with the parent, reported a reduction in several risk behaviors including school suspension, smoking cigarettes, and using marijuana. Increased communication with a sexual partner about condom use was also observed among participants receiving the extra parent session compared to those youth who received the usual 8-session, small group risk-reduction intervention only (Stanton et al., 2004). While parental influence and sexual behavior research is readily available among youth in the U.S., information on parental or caregiver monitoring in other parts of the world, especially among HIV-positive youth, is scarce.

There is some research in the African context, however, that offers evidence supporting findings from the U.S. on the role of parental influence on youth sexual-risk behavior. A report from the World Health Organization on adolescent reproductive behavior showed that research in developing countries (including in the African context) has demonstrated that living with both parents and having a positive parent-child relationship can influence later sexual debut (Blum & Mmari, 2005). In Côte d'Ivoire, Babalola and colleagues (2005) found that parental factors (i.e., living with a father, parental pregnancy disapproval, and parent-child communication about abstinence) was associated with later sexual debut among female youth age 15-24 years. The only parental factor associated with sexual debut among male youth was parent-child communication, however in an unexpected direction, indicating that communication with male youth may have been initiated after signs of sexual activity (Babalola et al., 2005). In addition, researchers in Ghana found that, for both males and females, parental monitoring (i.e., knowing where kids are at night and who their friends are) was negatively associated with recent sexual activity in the last twelve months among youth age 12-19 years (Kumi-Kyereme, Awusabo-Asare, Biddlecom, & Tanle, 2007).

In ethnographic studies of the DRC, inferences can be made regarding parental influence on adolescent sexual behavior. Traditional gender roles in the DRC have been found to transcend to youth, as young girls are often found assisting their mother and other adult women in daily household activities (Warkentin, 2004). A major benefit that comes from adolescent girls working closely with the mother is the ability to monitor the child's whereabouts. This type of parental monitoring can indirectly influence the delay of sexual debut. In Kinshasa, the offering of a bridewealth is still commonly practiced and may provide incentives for Congolese families to monitor their daughter's whereabouts, thereby influencing her sexual behavior since more

bridewealth is expected if the daughter has not yet become sexually active (Mupenda, 2008a). While more research is needed in the African context, the findings thus far support those from the U.S., demonstrating that parents can have an influence on the sexual risk behaviors of their children.

2.3.2 Parental Communication about Sex

Research about the association between parent-child communication and risky sexual practices of youth has found comparable effects to that of parental monitoring among adolescents. Specifically, communication about sexual risk with adolescents is associated with more conservative sexual attitudes and beliefs and greater confidence in sexual communication with partners (Hutchinson & Montgomery, 2007). Particularly, mother-daughter communication has been shown to decrease sexual risk behaviors and pregnancies among females (Hutchinson & Montgomery, 2007). Research on parent-child communication from the U.S. is abundant, demonstrating a strong association of communication with overall emotional and behavioral health of children (Ackard et al., 2006; Mathew, Shugaba, & Ogala, 2006; Miller, Forehand, & Kotchick, 1999). Results from studies in the African context are consistent with what has been found in U.S.-based studies.

However, due to limited research on parent-child communication about sex in the African context, the majority of studies in Africa have been designed to document the occurrence (Kiragu, Obwaka, Odallo, & Van Hulzen, 1997; Mathew, Shugaba, & Ogala, 2006), rather than explore the content (Izugbara, 2007), of such communication. In traditional African society, parents did not talk about sex with their children, as the topic was taboo. Communication on sexual matters was often left to other relatives, such as aunts or uncles, to speak about the subject (Izugbara, 2007; Kumi-Kyereme, Awusabo-Asare, Biddlecom, & Tanle, 2007). However, rising

modernization in many African countries has shaped these approaches and parents are taking a more active role in discussions about sexuality with their children (Izugbara, 2008). Additionally, the HIV epidemic has sparked a number of media campaigns encouraging communication about sex and HIV, such as the “Love Life” campaign in South Africa, which encourages parents to talk with their children (see www.lovelife.org.za/parents), and MTV’s “Staying Alive” global campaign, which promotes young peoples’ interpersonal communication with friends, parents, and other family members about HIV prevention (Geary et al., 2007).

In Ghana, one study found that communication about sex did not solely occur with parents, but also with other adults outside the immediate family (i.e., aunt, grandparents, and other community members). This study also found that when communication did occur between a child and their parent, it was not an interactive one, as little was left for discussion (Kumi-Kyereme et al., 2007). The message was different for females than for males, where females were instructed to avoid sexual contact and males told to be careful (Kumi-Kyereme et al., 2007).

Low levels of communication about sexual matters and, particularly, about HIV/AIDS were documented in Kenya and Nigeria among youth ranging 10-19 years old (Kiragu et al., 1997; Mathew et al., 2006). Religion could be a factor that influences parent-child communication about sex in the African context, particularly in the DRC where approximately 50% are Roman Catholic, and possibly more in urban areas such as Kinshasa. An HIV intervention study among adolescents in Kinshasa revealed that about 74% identified as Catholic or attending Church of Revelation, which has practices based in Catholicism (Behets, unpublished). Roman Catholics compared to other religions have reported low levels of ease and frequency in communication about sex with their adolescent children (Regnerus, 2005). Findings in the U.S. also show that mothers of African American inner-city youth have reservations about

talking about sex for fears of encouraging sexual behavior (Jaccard, Dittus, & Gordan, 2000).

Similarly, Nigerian parents also expressed fears that if a child was too young, talking about sex might influence sexual debut (Izugbara, 2008).

A survey of Kenyan parents found that many do not have adequate information to talk to their child and give correct information; and, in addition, studies in Nigeria found that adolescents themselves perceived that their parents did not know enough to talk about sex (Kiragu et al., 1997; Mathew et al., 2006). Other studies in the African context have documented caregivers or parents mentioning the use of fear tactics in matters related to sex communication with youth in order to influence their behavior (Izugbara, 2008). In part, because of such barriers, youth often report feeling more comfortable talking about sex with other people besides their parents (i.e., friends and health care workers). However, as parents have the opportunity to be an early source of information surrounding sexual health and HIV/AIDS, recommendations in the African context have included interventions and programs that enhance information and encourage parents to talk with their children about sexual matters (Kiragu et al., 1997; Mathew et al., 2006).

Specifically, there are little data about communication about sex between parents and HIV-positive young people. However, communication in the area of status disclosure is available. Evidence from the U.S. has shown that open communication about HIV diagnosis (disclosure) with children infected with HIV was associated with increased social support, increased self-competence, and decreased problem behaviors (Battles & Wiener, 2002). In addition, poor parent-child communication can influence the medical needs of HIV-positive children and youth, such as poor adherence to antiretroviral treatment (Mellin, Brackis-Cott, Dolezal, & Abrams, 2004). In the Democratic Republic of the Congo, Vaz and colleagues (2008b) found that, while

disclosure of HIV status was not always clearly communicated to the child and over a third received misleading information, children felt it was best to know their status.

In sum, the research on parental influence involving both HIV negative and positive youth points towards the potential benefits of targeting parents and caregivers in efforts that promote responsible sexual behaviors. In the case of HIV-positive young people, such efforts additionally translate to a reduction in risk for HIV transmission.

2.4 Social Support among HIV-Positive Youth

The association between psychosocial health and sexual risk behavior in the general adolescent population is well-established in the U.S. (DiClemente et al., 2008; Buhi & Goodson, 2007). These relationships have also been studied and confirmed among adults living with HIV/AIDS (Crepaz & Marks, 2002). However, there are few studies linking psychosocial factors, such as social support, and sexual risk behaviors for young people living with HIV, particularly in the African context. Social support can be defined in terms of types of relationship behaviors or acts, such as emotional (e.g., love, trust, & caring), instrumental (i.e., providing tangible aid), informational (e.g., advise & suggestions), and appraisal support, namely information useful for self-evaluation (Heaney & Israel, 2002). In many studies, however, such as in this dissertation research, the measure of “social support” is general, encompassing all sub-types, and is perceived by the individual.

Social support may be particularly important for HIV-positive young people since they are prone to experiencing the loss of their parents due to ill health or HIV/AIDS, and experiencing general stigma associated with their status. Preliminary analyses from the current study’s sample indicate that over 20% of the HIV-positive young people reported experiencing HIV stigma (Mupenda, 2008b). Perceived stigma was found to be negatively correlated with

social support, such that less perceived social support was correlated with higher perceived stigma. In 2001, UNAIDS (2004) reported an estimated 927,000 Congolese children who had lost one or both parents to HIV/AIDS, of which many of the children themselves were HIV positive. Other adult family members, along with older siblings, are often involved with bringing up children in households that have experienced a parental death (Warkentin, 2004). The important role of extended family suggests that other older adults living with youth have the opportunity to provide different types of support.

Studies in the U.S. have found that less social support was associated with unprotected sex among HIV-positive adults (Clement, 1992; Heckman, Kelley, & Somlai, 1998). These studies are largely among men who have sex with men (MSM) and women injection drug users (IDU). In one study targeting HIV-positive youth among four U.S. cities, compared to the control group, youth who received a health behavior change intervention increased their strategies for seeking social support and decreased transmission risk behaviors (e.g., number of unprotected sex acts and number of partners). Modules in the intervention included how to deal with learning one's serostatus, disclosure issues, and healthy lifestyle changes (Rotheram-Borus et al., 2001). Still, little is known on how social support influences sexual risk behaviors among HIV-positive young people, especially in Africa.

While there is some information linking social support to sexual risk behaviors for HIV-positive adults (Clement, 1992; Gore-Felton et al., 2002; Heckman et al., 1998), much of the information on social support among HIV-positive young people comes from studies examining ARV medication adherence. In one study, social support was correlated with self-efficacy to take medication, which in turn was associated with medication adherence (Naar-King et al., 2006). In

addition, among HIV-positive women with depression, social support was found to influence coping strategies, resulting in improved medication adherence (Vyavaharkar et al., 2007).

The available studies linking social support to transmission risk and medication adherence demonstrate that HIV-positive young people perceiving more social support can improve their wellbeing; and therefore, points in the right direction for further research examining social support to sexual risk behaviors. In light of the little research done in this area to date among HIV-positive young people, particularly in Africa, more research examining how sexual risk behaviors may be influenced by social support is needed.

2.5 The Relationship between Social Support and Parental/Caregiver Monitoring

There is little information on the nature of the relationship between parental/caregiver monitoring and perceived social support. However, there is some knowledge of how supportive families influence the behaviors of young people. In one study in the U.S., parental support and parental monitoring were associated with each other and were reported highest amongst adolescents who perceive their families to be well balanced (i.e., adaptable and close) (Henry, Robinson, & Neal, 2006). Another study found that, among African American female adolescents who were sexually active, living with a mother in a supportive family decreased the likelihood of reporting HIV risk behaviors (i.e., not using a condom, lack of communication with a sexual partner, and sex with a non-steady partner) (Crosby, DiClemente, & Wingood, 2001). While there is strong evidence to support that parenting practices are associated with positive developmental outcomes and healthy behaviors (Steinberg, Lamborn, Darling, Mounts, & Dornbusch, 1994), there is little documenting parenting practices for parents/caregivers with children who are already living with HIV and how it might relate to social support.

Given that many HIV-positive young people are orphaned due to HIV/AIDS (UNAIDS 2004) and often times are living with and cared for by other family members, understanding social support related to parental/caregiver influence may provide important clues into their well-being, particularly sexual health. The evidence of associations between parenting practices, social support, and sexual risk behaviors is promising and warrants further investigation for transmission risk reduction interventions.

CHAPTER THREE: SPECIFIC AIMS AND METHODS

The transition into adulthood is unique for young people living with HIV. It is, not only marked with new responsibilities in making decisions regarding sexual activity and other risk behaviors, but moreover, it is marked with the need for a critical understanding and appreciation for how their decisions affect their own health and the health of others.

It is estimated that 50% of HIV infections worldwide are acquired in adolescence and individuals with HIV are surviving much longer than they were earlier in the epidemic (UNAIDS, 1998), potentially allowing more opportunities to transmit the HIV virus. As with many other African countries, the population of the Democratic Republic of the Congo (DRC) is largely under the age of 20 (UNAIDS, 2006). The need for the development of new and innovative interventions to prevent new infections is unmistakable. In order to develop effective prevention interventions that are culturally and developmentally appropriate, research is needed to inform and identify potential strategies and program components.

This dissertation research uses data from both HIV-positive young people and their primary caregivers (including biological parent or relative caring for the child) to examine the relationship between parental/caregiver influence and sexual risk behaviors, and to describe communication about sex between parent/caregivers and their HIV-positive children. Based on previous research on the protective effects of parental/caregiver monitoring and open communication on adolescent risk behaviors both in the U.S. and in the African context (Babalola et al, 2005; Kumi-Kyereme et al., 2007; Yang et al., 2006; Yang et al., 2007), an overarching goal of this dissertation is to inform potential strategies for parent/caregiver-related

intervention components within HIV transmission risk reduction interventions for young people living with HIV in Kinshasa, DRC.

3.1 Specific Aim #1

To examine the relationships between perceived parental/caregiver monitoring, perceived social support, and sexual risk behaviors among young people living with HIV.

Research Questions:

1. What is the relationship between perceived parental/caregiver monitoring and sexual risk behaviors among young people living with HIV (YPLWH)?
2. What is the relationship between social support and sexual risk behaviors among YPLWH?
3. Is social support an effect modifier in the relationship between parent/caregiver monitoring and sexual risk behaviors among YPLWH?

3.2 Specific Aim #2

To describe, from the perspective of the parents/caregivers, the norms and patterns of communication about sex with their HIV-positive child.

Research Questions:

1. How do parents/primary caregivers *decide* to talk to their child about sex?
2. How do parents/primary caregivers determine *when* to talk to their child about sex?

3. What types of information about sex do parents/ caregivers of YPLWH discuss with their child?

3.3 Methods

To address the specific aims of this research, secondary data analysis was conducted from a larger study, “Formative Research to Develop Effective Prevention Interventions for HIV-positive Youth in Kinshasa”, which was based in DRC with technical support and oversight from the University of North Carolina at Chapel Hill, School of Public Health, Department of Epidemiology (Principal Investigator: Frieda Behets, PhD). The data did not contain any identifying information, protecting the participants’ confidentiality.

The larger study consisted of three parts: 1) Young people living with HIV/AIDS (YPLWH) took part in an interviewer-administered questionnaire on sexual behavior and psychosocial wellbeing (n=189), 2) A selected number of YPLWH who took part in the quantitative questionnaire were selected to take part in an in-depth interview (n=30), and 3) Parents/caregivers of the YPLWH were asked to take part in an interviewer-administered semi-structured interview (n=52). This study was funded by the National Institute of Child Health and Human Development (NICHD) and approval for the research was obtained from the Institutional Review Board (IRB) at the University of North Carolina, Chapel Hill and from the Ethics Committee of the Kinshasa School of Public Health.

3.3.1 Conceptual Framework and Theory

The conceptual framework of this research stems from theory as well as empirical evidence and serves as the basis for exploring parental/caregiver influence on sexual risk behaviors among HIV-positive young people. Based on evidence supporting the link between

parental influence and adolescent risk behaviors (DiClemente et al., 2001), this research, first, *quantitatively* examined the relationships between parental/caregiver monitoring, social support, and sexual risk behavior among HIV-positive young people. Secondly, based on the associations between parental/caregiver communication and adolescent risk behaviors (Hutchinson & Montgomery, 2007), we *qualitatively* explored parents' patterns and content of communication about sexual behavior with their HIV-positive child, including some descriptive quantitative analyses (mixed methods). Together, these objectives work to inform the design and content of parent/caregiver-related intervention components for positive prevention interventions among young people in DRC.

Quantitative analyses (specific aim #1) was based, in part, from the empirical evidence surrounding parental monitoring and, in addition, on conceptual models proposed by Heaney and Israel (2002) which delineate different pathways for the relationship between social support and social network (i.e., those that provide social support) to health. Social support and social networks can influence health, for example, through influencing the frequency and duration of stressors and/or enhancing coping resources. However, the pathway of interest for this study is one linking social support to health through influencing health behaviors (i.e., behavioral risk factors and preventive health practices). This is labeled pathway 5 in Figure A.1 of the Appendix. Based on this theoretical pathway, it is suggested that, in the case of HIV-positive youth, those who perceive more social support are less likely to engage in maladaptive behaviors, namely sexually risky behaviors. Likewise, those who do not perceive having social support are more likely to engage in maladaptive behaviors.

Empirical evidence for the relationship between parental monitoring and sexual risk behavior suggests that those who perceive more parental/caregiver monitoring are less likely to

engage in sexually risky behaviors and, likewise, those who do not perceive more parental/caregiver monitoring are more likely to engage in sexually risky behaviors. However, because many HIV-positive young people are orphaned due to HIV/AIDS and often times living with and cared for by other family members, understanding social support related to parental/caregiver influence may provide important clues into their well-being. Especially in the lives of HIV-positive young people, a parent or caregiver plays an important role in providing support, and may be considered a part of the young person's social network. As such, we also explored social support as a moderator in the relationship between parental/caregiver monitoring and sexual risk behaviors to better understand these potential links. Integrating empirical findings surrounding parental monitoring with Heaney and Israel's model of social support and social networks (2002), the figure below depicts the conceptual model for this study's quantitative analysis.

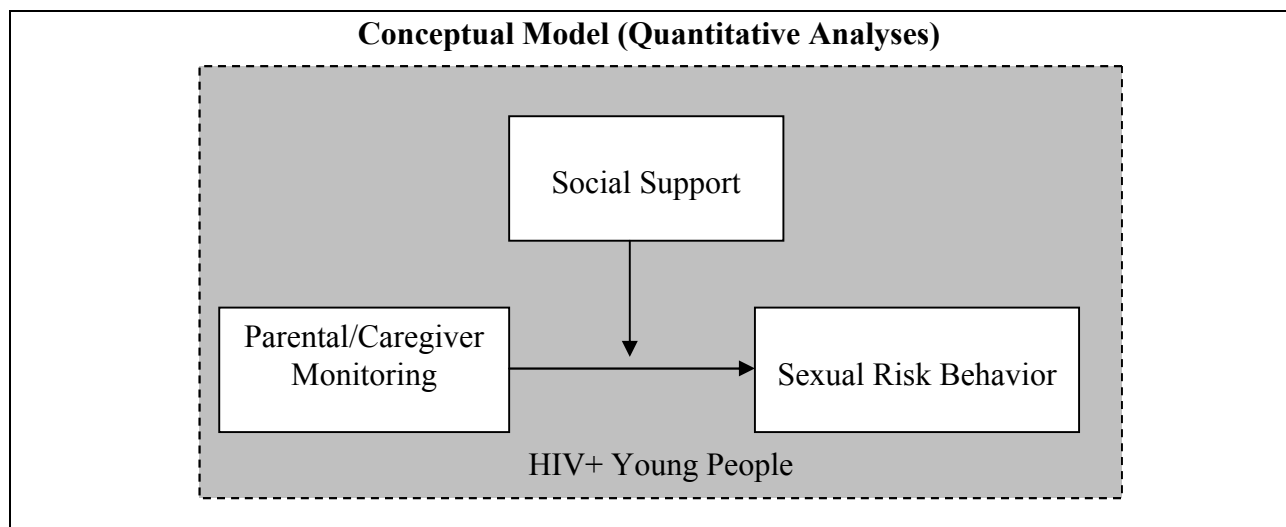


Figure 3.1 Conceptual model for relationship between parental/caregiver monitoring, social support, and sexual risk behavior.

Qualitative research questions (for specific aim#2) were exploratory in nature, but could be framed within the concepts of a parent-based expansion of the theory of planned behavior

(Hutchinson & Wood, 2007). See Figure A.2 in Appendix for the full expanded model. Of interest to this current study within the theoretical framework is the understanding of a parent's intention to influence an adolescent's behavior and the parent's reported behavior. Specifically, this study aimed to understand a parent/caregiver's intention to influence their child's sexual behavior through talking about sex and the parent/caregiver's reported communication behavior. In this case, parents/caregivers of HIV-positive children responded to open-ended questions which provided information on: 1) "intention" (i.e., whether/how they *decided* to talk about sex with their child, whether/how they determine *when* to talk about it, and if they have not, do they *plan* to) and 2) among those who did talk to their children, what types of information were discussed. Hutchinson and Woods (2007), stress the importance of understanding parenting processes and behaviors which are unique in a specific culture in order to inform the design of culture-specific parent-based HIV interventions, thus inspiring the use of this theory to understand this study's qualitative exploration on sex communication with HIV-positive young people in DRC.

3.3.2 Sample and Eligibility for Quantitative Analysis (Aim #1)

Between June and September 2007, 189 young people (age 14-24) completed quantitative interviews. All participants were HIV positive and were recruited, using purposive sampling methods based on eligibility criteria, by HIV counselors among four HIV treatment centers in Kinshasa, Democratic Republic of the Congo. Inclusion criteria for the study included: (1) HIV positive diagnosis, including participants who did and did not know their HIV status, (2) 14 to 24 years of age, (3) Kinshasa resident, (4) registered and receiving assistance from one of four predetermined HIV clinics (5) willingness to participate. To be included in the analysis for the first aim, participants had to report the following: living with a parent or primary caregiver and

sexual activity in the last twelve months (n=103). See Figure 4.1 for Sample Size Flow Chart on page 63.

3.3.3 Sample and Eligibility for Qualitative Analysis (Aim #2)

A total of 52 interviews were completed with the parents/caregivers of an HIV-positive young person. Twenty-six parents/caregivers were selected who had a child participant that was not aware of their HIV status. Another 26 parents/caregivers, who had a child that was aware of their HIV status, were randomly selected and matched on sex and age of the child.

Parents/caregivers were recruited through the counselors of the YPLWH and therefore had to be the caregiver of a young person who participated in the larger study.

All participants provided informed consent/assent prior to interviews and parental/caregiver consent was obtained for youth under 18.

3.3.4 Data Collection Procedures

Data from the youth quantitative questionnaire and parent semi-structured questionnaire were collected by interviewers who have been previously trained in both quantitative and qualitative data collection by UNC. All interviews were conducted face-to-face, in Lingala, where the participant received HIV services and care. After participant consent/assent was obtained, along with necessary parental/caregiver consent, interviewers read the questionnaire to the participants and filled in responses. Interviewers were trained in privacy and confidentiality procedures, especially related to HIV patients. In addition, training module topics included probing techniques for the parent interview open-ended responses and sensitivity in conducting interviews with youth whose HIV status had not been disclosed to them.

3.3.5 *Material and Measures*

The youth behavioral questionnaire consisted of both established scales and developed questions, for which existing scales are not available or reliability is unknown. The questionnaire was designed to take no more than 2 hours to complete and covered the following topics: sexual behavior (condom use, partner number, age of sexual debut, frequency and type of sexual activity, concurrency, age of partners); drug and alcohol use; pregnancy history; STI symptoms; health seeking behaviors; information about sexual partners; HIV knowledge; HIV testing and knowledge of status; socio-demographics.

The parent interview used a semi-structured questionnaire to gather information, with many of the items containing follow-up, open-ended questions. Topics in this questionnaire included parental perceptions regarding disclosure of HIV status, communication, their child's sexuality, HIV prevention needs, and other potential interventions. Questions in the parent interview, which are of interests to the current study (specific aim #2), were presented as open-ended responses. As such, answers were coded and interpreted using qualitative data analysis methods.

3.3.6 *Quantitative Measures (Aim#1)*

Parental/caregiver monitoring was measured using an adapted 5-item likert scale (Li, Feigelman, & Stanton, 2000). Participants rating from 1 (never) to 5 (always) on items that assessed the young person's perception of whether their *family* knew where they were at all times and whether the child felt obligated to communicate their whereabouts to their family. Given that many young people had lost their biological parents, may be living with another primary caregiver, and given that in the African context child rearing is often undertaken by different family members (Mukenge, 2002), we chose to use the word "family" rather than

“parent” in each scale item. Sample items included: “My family knows where I am before/after school or work” and “I tell my family who I am going to be with before I go out”. Preliminary analyses have shown good reliability of the adapted scale among the participants in this study (Cronbach’s alpha = 0.72).

Social Support was assessed by agreement to eight statements, adapted from the Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991). Responses ranged from 1 (none of the time) to 5 (all of the time) to statements which indicated whether a person felt they had someone who could support them in various ways. Statements include: having, “someone you can count on to listen to you when you need to talk” and “someone to give you money/provide you with financial support if you were in need.” Preliminary analyses have shown good reliability of the scale among the participants in this study (Cronbach’s alpha = 0.78). See Appendix for full scales.

Sexual Risk Behavior among HIV-positive young people is defined as the reported sexual activity and condom use with the most recent sexual partner in the past 12 months. This variable combines two questions: “Have you had sex with anyone in the past 12 months?” and “Did you use a condom the last time you had sex with this partner?” Condom use at last sex serves as a general indicator of condom use prevalence in the last 12 months (HIV/AIDS Survey Indicator Database, 2008). Responses were combined and categorized into three levels:

- 1) No sex
- 2) Protected Sex (used condom at last sex)
- 3) Unprotected Sex (did not use condom at last sex)

This variable is ordinal, indicating level of effective transmission risk reduction behavior, where not having sex is considered the most effective transmission risk reduction behavior, followed by

having protected sex, and lastly, having unprotected sex in the past 12 months is considered the least effective behavior in transmission risk reduction.

3.3.7 Qualitative Constructs (Aim#2)

Parental/Caregiver Communication about Sex was assessed using a semi-structured interview. The main question for this measure is “Have you talked to your child about sex?” with a dichotomized response yes/no option. Sub-questions/probes, which required open-ended responses, were: “If no, why not?”, “If yes, when did you start talking to them about this?”, “What made you decide to talk to them?”, and “What have you told them?”

3.3.8 Analytic Strategy

Data Analysis for Specific Aim #1

Analyses for research questions 1-3 identified the relationship between parental/caregiver monitoring, social support, and sexual risk behaviors using a proportional odds model. A proportional odds model was appropriate for the outcome because the response categories for sex were ordinal. Responses were ordered from most effective transmission risk reduction behavior to least effective transmission risk reduction behavior (i.e., no sex, protected sex, and unprotected sex in the last 12 months). To account for the complex survey design of four recruitment sites, a stratum variable “clinic” was included in the analyses.

With three response levels, we computed 2 logits (3 response levels[k] – 1):

Logit(θ_1)= [probability of no sex/ probability of (all else)]

Logit(θ_2)= [probability of no sex + protected sex/ probability of unprotected sex]

The equation for the model that applies to all logits simultaneously, allowing different intercept parameters (α_k) and regression parameters (β_k) for each logit was:

$$\text{Logit}(\theta_k) = \alpha_k + x (\beta_k)$$

The proportional odds assumption is that $\beta_k = \beta$ for all k. That is, there is a common parameter β instead of distinct β_k . In the analyses, a test for proportional odds was conducted, where an insignificant p-value is good, which indicated that the null hypothesis ($\beta_k = \beta$ for all k) cannot be rejected. An interaction variable was added into the model by creating a product term, parental/caregiver monitoring x social support.

Results from the proportional odds model produced parameter estimates with the following interpretation:

<u>Parameter</u>	<u>DF</u>	<u>Estimate</u>	<u>SE</u>	<u>Chi-sq</u>	<u>p-value</u>
Intercept2 (α_1)					
Intercept2 (α_2)					
Parental/caregiver monitoring (β_1)					
Social support (β_2)					
Parental/caregiver monitoring x Social Support (β_3)					

α_1 = log odds of no sex vs. all else

α_2 = log odds of no sex or protected sex vs. unprotected sex

β_1 = increment for all types of log odds due to parental/caregiver monitoring

β_2 = increment for all types of log odds due to social support

β_3 = increment for all types of log odds due to parental/caregiver monitoring x social support

e^{β_1} = odds ratio estimate for parental/caregiver monitoring

e^{β_2} = odds ratio estimate for social support

e^{β_3} = odds ratio estimate for parental/caregiver monitoring x social support

Interpretation of the proportional odds ratio: for every 1 unit increase in the independent variable, the odds of changing levels towards more beneficial risk reduction responses (i.e., no sex or protected sex) is (the given value).

Age, gender, and time-since-diagnosis were individually examined as potential confounders using a change-in-estimate criterion (Mickey & Greenland, 1989). For confounders to be included in an adjusted model, it must change the estimate of interest by 10% or more.

We examined social support as a potential effect modifier in the relationship between parental/caregiver monitoring and sexual risk behavior to further understand whether parental/caregiver monitoring and social support work completely independent of each other or whether another mechanism is involved. Pearson's correlation was also calculated to describe the association between parental/caregiver monitoring and social support.

Power Calculation

Based on literature assessing parental monitoring and adolescent sexual risk behaviors, it was estimated that approximately 8-35% of those reporting sexual risk will report less parental/monitoring and about 3-25% will report more parental/caregiver monitoring. Using SAS, the first estimation made below was based on the highest proportion of less parental/caregiver monitoring reported in the literature and the "needed" second proportion to make 80% power with $\alpha=0.05$. The second estimation for power was based on approximations using the study's actual data. For both power estimations, the Fisher's exact method was used since it works well with small sample sizes and is usually more conservative. These calculations suggest that with at least 49 individuals per group, to detect a difference in the outcome based on parental/caregiver monitoring, the effect must be large due to the small sample size.

	Proportion 1	Proportion 2	n per group	actual power
#1	.35	.12	49	80.5%
#2	.32	.14	49	60.2%

Data Analysis for Specific Aim #2

From the parent semi-structured interview, summary statistics were used to describe the characteristics of parents/caregivers, whether they reported communicating with their child about sex, and if not, whether they plan to. In addition, responses from parents/caregivers on whether they think their child was sexually experienced were matched to the actual responses of the young person from their previous interview. The agreement between primary caregiver and child responses regarding sexual activity experience were presented descriptively. In addition, bivariate analysis (i.e., chi-square) was conducted to examine the association between parent-child agreement and the child's awareness of their HIV status.

Open-ended responses about parent-child communication about sex were analyzed using *qualitative methods*, such as reading for content, coding, and interpretation. Analyses were performed using ATLAS.ti, version 5.2 (Muhr & Friese, 2004). A combination of deductive and inductive coding methods and memo writing (i.e., recording ideas for potential codes) were used. Once codes were created they were recorded in a code book. When new codes arose, previously coded responses were reviewed again. The overall strategy for coding the qualitative data was to: 1) write memos for the first 5 interviews, 2) develop an initial code list, 3) code half the interviews (n = 26) while adding new codes as needed, 4) review code list, 5) refine coding and make any adjustment, 6) code next 26 interviews. Once coding was complete, themes and central ideas were extracted and interpreted. Where appropriate, tables and/or figures were created which visually represents the interpretation of the data. Any translations needed for open-ended

answers, were back translated and verified by the Kinshasa study coordinator who is fluent in English, French, and Lingala.

3.4 Research Design Strengths and Limitations

Though this research is exploratory in nature, sample size and power were limitations of the quantitative analyses of the first specific aim. As such, findings from this study were suggestive, not conclusive. Additionally, limitations of the study include recalling sexual behavior for the last 12 month, which is more difficult than recalling the last 30 days for example, and social desirability. Participants were likely to have received sexual education counseling at their HIV treatment or care clinic and may feel pressured to answer in ways consistent with the education they have received. Specifically, for participants who received counseling, and thereby social support, they may have been more likely to answer that they did not have sex or that they used condoms.

Regarding the second specific aim, another limitation involved the responses by parents/caregivers in the semi-structured interview used for gaining qualitative insight. As the parent survey was not designed to elicit other responses beyond the question prompt, the length of responses (and thus information) was limited. Traditional qualitative interviews, which would allow the participant to speak more freely and openly, would have likely brought out additional insights into the particular topic. However, since questions were more focused, the amount of information was not as rich.

This study has several strengths. The dissertation research is distinctive because it expands on findings of the relationship between parental/caregiver monitoring, social support, communication, and sexual risk behavior to young people living with HIV in Kinshasa, DRC. A major strength is that it examined theoretically- and empirical-based research questions about

sexual behavior using data from both young people and parents/caregivers. This provided information which is culturally specific to HIV-positive young people living in Kinshasa. Lastly, this research contributes to the need for formative studies that push forward efforts in developing HIV transmission risk reduction interventions among young people.

CHAPTER FOUR: INFLUENCE OF PARENTAL/CAREGIVER MONITORING AND SOCIAL SUPPORT AMONG HIV-POSITIVE YOUNG PEOPLE

4.1 Abstract

Young people make up more than 60% of the population in the Democratic Republic of the Congo (DRC) and have a prevalence of HIV over 1%. Information on factors that influence sexual activity among young people living with HIV in DRC is sparse. There is some evidence in the African context, which supports data from the U.S., that monitoring and social support can influence sexual risk behaviors. However, to our knowledge, no studies have explored these factors in the African context. One hundred and three sexually active young people living with HIV (age 14-24), who completed quantitative interviews from June-September 2007, were included in this study. All participants were recruited among four HIV treatment centers in Kinshasa, DRC. A proportional odds model was used to examine the effect of monitoring and social support on sexual risk behaviors. The majority of participants reported low monitoring by a parent/caregiver (68%) and low social support (68%). The average age at first intercourse among participants was 15.6 years (SD = 2.7) with an average lifetime number of partners of 3.5 (SD=5.1). Among all young people, 55 (53.4%) reported no sex in the past 12 months, 29 (28.2%) reported protected sex at their last intercourse, and 19 (18.4%) reported unprotected sex at last intercourse. Parental/caregiver monitoring and social support worked together as an interaction, rather than independently, to influence sexual risk behavior. Specifically, for every one unit increase in social support, the impact of monitoring on sexual risk behaviors increased by a factor of 1.7 (unadjusted OR = 1.7, 95%CI: 0.98-2.79). The interaction further weakened

when adjusted for time-since-HIV diagnosis (OR=1.6, 95%CI: 0.91-2.75). Further understanding of parental/caregiver monitoring and social support in the context of child fostering, HIV caregiver burden, and gender roles is recommended to inform new approaches for including parents/caregivers in HIV transmission risk reduction interventions for young people in Kinshasa, DRC.

4.2 Introduction

The Democratic Republic of the Congo (DRC), similar to many other African countries, has an increasing number of people living with HIV/AIDS with a prevalence of 1.3%, according to the Demographic Health Survey (2008). HIV prevalence is highest for both women and men living in Kinshasa, DRC's capital, (2.3 percent for women and 1.3 percent for men) compared to the western region of DRC (1.0 percent for women and 0.5 percent for men). Prevalence of HIV among youth by age and sex category (women and men) include: 15-17 years, 0.4% and 2.4%; 18-19 years, 1.2% and 0.5%; 20-24 years, 0.4% and 0.3% (DHS, 2008). As HIV prevalence is twice as high in urban areas compared to rural areas, estimates are likely higher among young people living in Kinshasa. Over 60% of the DRC's population is under 20 years old, and the high HIV prevalence among young people points to the need for interventions focusing on reducing new infections.

The transition into adulthood is unique for young people living with HIV. It is, not only marked with new responsibilities in making decisions on sexual activity and other risk behaviors, but moreover, it is marked with the need for a critical understanding and appreciation for how their decisions affect their own health, as well as the health of others. That is, for HIV-positive young people, understanding how to reduce the risk of HIV transmission to others and reduce secondary HIV infection is imperative. In general, young people are likely to believe that their

sexual behaviors are not risky, even among those who are at high risk for contracting a sexually transmitted disease (STD) (i.e., those who report inconsistent condom use, more than one partner, and/or an additional STD or partner risk) (Kershaw et al., 2003). On the other hand, one study conducted among Nigerian young people, age 15-24, found that those who perceived themselves as “at-risk” for HIV were less likely to use a condom (Adedimeji, Heard, Odutolu, & Omololu, 2008). Nevertheless, it is especially critical for young people living with HIV to overcome any misperception about their sexual risk behaviors and, in accordance, make healthy life-style decisions.

Studies in the U.S. have shown that many youth who are aware of their HIV status delay or decrease their sexual risk behavior (Lightfoot, Rotheram-Borus & Tevendale, 2007a). Nevertheless, in the U.S., a significant number of sexually active HIV-positive youth continue to engage in risky behavior, such as unprotected sex (Johnson & Buzducea, 2007). Up to 47% of HIV-positive youths report unprotected sex at last intercourse (Murphy et al., 2001). Information on factors that influence sexual activity among young people living with HIV is sparse, both in the U.S. and African context. However, in one formative study in Uganda, focus group discussion revealed that many HIV-positive adolescents reported abstaining from sex or, if sexually active, using condoms; they also reported that peer pressure, HIV-related stigma, and poverty were barriers for adopting protective behaviors (Bakeera-Kitaka, Nabukeera-Barungi, Nöstlinger, Addy, & Colebunders, 2008). Specifically in the DRC, we know that youth are becoming sexually active at a young age (16.2 years for males and 17.6 years for females) and are engaging in risky sexual behaviors (Kalambayi et al., 1998; Kayembe et al., 2008; Ecole de Sante Publique de Kinshasa, 2006). The percentage of youth in DRC, age 15-24, who can correctly identify ways of preventing the sexual transmission of HIV is poor, 29% for males and

22% for females (UNAIDS, 2008). Similar information from DRC on sexual behaviors of HIV-positive young people is lacking.

Parental influence has been found to influence the sexual behaviors of young people (Babalola et al., 2005; DiClemente et al., 2006; Kumi-Kyereme et al., 2007). In the U.S., DiClemente and colleagues (2006) found that youth who perceive higher parental monitoring are more likely to report using a condom at last sexual intercourse, have fewer sexual partners, and are less likely to test positive for a sexually transmitted disease. Another U.S. study found a protective effect of perceived parental monitoring on abstinence among urban, African-American females, age 13-16 years (Yang et al., 2007). In the African context, there is some research that supports findings from the U.S. on the role of parental influence on youth sexual risk behavior. In Côte d'Ivoire, Babalola and colleagues (2005) found that parental factors (i.e., living with a father, parental pregnancy disapproval, and parent-child communication about abstinence) was negatively associated with sexual debut among female youth age 15-24 years. In addition, researchers in Ghana found that, for both males and females, parental monitoring (i.e., knowing where kids are at night and who their friends are) was negatively associated with recent sexual activity in the last twelve months among youth age 12-19 years (Kumi-Kyereme et al., 2007). To our knowledge, no studies have examined parental monitoring among HIV-positive young people living with a parent or caregiver.

Parental monitoring, as perceived by young people in the U.S., is likely very different than that in the African context. In ethnographic studies of the DRC, traditional gender roles appear to play an indirect part in what Westerners would consider parental monitoring. For example, young girls may have more responsibilities in assisting their mother and other adult women in daily household activities compared to males children (Warkentin, 2004). A major

benefit that comes from adolescent girls working closely with the mother is the ability of the parent to be aware of the child's whereabouts, which can indirectly influence the delay of sexual debut. It may be that the role and responsibilities in a household that is given to a young girl is more relevant to influencing sexual behavior, than the girl's perception of the family knowing her whereabouts. Males are less likely to have responsibilities in the household, so there may not be the same opportunity for monitoring their activities. In this way, direct or indirect parental monitoring for males may also be less relevant to their sexual risk behaviors. Additionally, as male children may be more likely to get permission to leave the house, cultural norms surrounding gender roles likely play an important role in the influence of opportunities to engage in sexual risk behaviors.

Social support is another factor that can influence the sexual behavior of young people living with HIV. Social support may be particularly important for HIV-positive young people since they are prone to experiencing the loss of their parents due to ill health or HIV/AIDS, and experiencing general stigma associated with their status. Studies in the U.S. have found that less social support was associated with unprotected sex among HIV-positive adults (Clement, 1992; Heckman, Kelley, Somlai, 1998). These studies are largely among men who have sex with men (MSM) and women injection drug users (IDU). One intervention study in the U.S. among HIV-positive young people, however, demonstrated an increase in strategies for seeking social support and decrease transmission risk behaviors, namely number of unprotected sex acts and number of partners (Rotheram-Borus et al., 2001). Social support and social networks can influence health, for example, through influencing the frequency and duration of stressors and/or enhancing coping resources (Heaney and Israel, 2002). In addition, social support can work by directly influencing health behaviors (i.e., behavioral risk factors and preventive health practices). Based

on the latter theoretical pathway, it is suggested that, in the case of HIV-positive young people, those who perceive more social support are less likely to engage in maladaptive behaviors, namely sexually risky behaviors. Given that many HIV-positive young people are orphaned due to HIV/AIDS and often times living with and cared for by other family members, understanding social support related to parental/caregiver influence may provide important clues into their well-being, particularly sexual health. Still, little is known on how social support influences HIV-positive young people, especially in Africa.

More than one person or family member may share the responsibility in monitoring a child's behavior and in providing other types of support in the African context. Shared living space with other relatives is a common practice in DRC (Mukenge, 2002). Any woman may take on the responsibility for upbringing a child of other relatives, referred to as child fostering. In an extended family household, the upbringing of a child is not left exclusively for the biological parents, as other family members are often involved (Sudarkasa, 2004). The difference or treatment of biological versus "adopted" children by the mother is often indistinguishable, just as the respect a child shows their mother does not change depending on whether she is the birth mother (Sudarkasa, 2004). Respect for elders in traditional African culture is a highly-valued quality of one's character and is a part of one's daily life in the Congo. For young people, they are considered "good" if they display utmost respect for elders and do what they are told without question (Ziemke, 2001). This type of relationship, where power is clearly defined, makes monitoring the child or young person manageable and, in addition, may be supportive of the favorable functionality of child fostering.

On the other hand, the nature of family relationships and whether a child receives support or parental/caregiver monitoring could change in the face of adversity. For the case of HIV-

positive young people who are hosted by other relatives, the child could be seen as a burden rather than a normal part of the family unit (Vaz, 2008a; De Herdt, 2004, Ziemke, 2001). The burden of caregivers (e.g., high stress and unhappiness) has been documented in Kinshasa, DRC, mainly among women who care for their HIV-positive spouses (Kipp, Nkosi, Laing, & Jhangri, 2006). If the fostered young person is seen as a burden-- for example, due to the stigmatizing nature of their serostatus, fear, or resentment of taking care of an ill child-- caregivers may not prioritize or be motivated to interact with the fostered young person. This may occur to the extent of being neglected and isolated from the family, neither being monitored nor supported in any way. This can also result from misconceptions about HIV and its transmission, such as beliefs that HIV transmission can occur though using the same dishes or that a sick child is associated with witchcraft (Sabuni, 2007; Simbaya et al., 2005). In this light and in the context of extended families, the “parent-child” relationship may be more ambiguous and complex in the lives young people in DRC, especially among those who are HIV-positive, making measurement a challenge.

The specific aim for this study is to examine the relationship between perceived parental/caregiver monitoring and social support on sexual risk behavior among HIV-positive young people living in Kinshasa, DRC. There is support for the potential benefit of parental/caregiver monitoring and social support among HIV-positive young people, since other studies have shown that parents can have a positive influence on sexually risky behavior, both in the U.S. and in the African context (Babalola et al, 2005; DiClemente et al., 2001; Kumi-Kyereme et al., 2007; Rotheram-Borus et al., 2001). In the larger picture, this work aims to inform the development of parent/caregiver-related intervention components within HIV transmission risk reduction interventions for young people living with HIV in Kinshasa, DRC.

4.3 Methods

Data for this paper came from the formative study, “Formative Research to Develop Effective Prevention Interventions for HIV+ Youth in Kinshasa” at the University of North Carolina at Chapel Hill. This study, funded by the National Institute of Child Health and Human Development (NICHD), was cross-sectional and used a mixed methods approach for acquiring information, including a behavioral questionnaire with HIV-positive young people, semi-structured interviews with parents of the HIV-positive young people, and qualitative interviews with a subset of HIV-positive young people. This paper presents results from the behavioral questionnaire with young people to understand parental/caregiver influence on sexual risk behaviors.

Between June and September 2007, 189 young people (age 14-24) completed quantitative interviews. All youth were HIV positive and recruited, using purposive sampling methods based on eligibility criteria, by HIV counselors among four HIV care or treatment centers in Kinshasa, Democratic Republic of the Congo. Inclusion criteria for the study included: (1) HIV positive diagnosis, including participants who did and did not know their HIV status, (2) 14 to 24 years of age, (3) Kinshasa resident, (4) registered and receiving assistance from one of four predetermined HIV clinics (5) willingness to participate. All participants provided informed consent/assent prior to interviews and parental/caregiver consent was obtained for youth under 18. Quantitative questionnaire were administered by interviewers who had been previously trained. All interviews were conducted face-to-face, in Lingala. Interviewers were trained in privacy and confidentiality procedures, especially related to HIV+ patients. To be included in the analysis for this paper, participants had to report the following: sexual activity in the last 12 months and living with a primary caregiver (n=103). See Figure 1 for Sample Size Flow Chart.

Approval for the research was obtained from the Institutional Review Board (IRB) at the University of North Carolina, Chapel Hill and from the Comité d’Ethique of the Ecole de Santé Publique Université de Kinshasa (Ethics Committee of the Kinshasa School of Public Health).

4.3.1 Measures

Parental/caregiver monitoring was measured using an adapted 5-item likert scale (Li, Feigelman, & Stanton, 2000). Participants rating from 1 (never) to 5 (always) on items that assessed the young person’s perception of whether their *family* knew where they were at all times and whether the child felt obligated to communicate their whereabouts to their family. Given that many young people had lost parents, were living with another primary caregiver, and given that in the African context child rearing is often undertaken by different family members (Mukenge, 2002), we chose to use the word “family” rather than “parent” in each scale item. Questions included, for example: “My family knows where I am before/after school or work” and “I tell my family who I am going to be with before I go out”. Preliminary analyses have shown good reliability of the adapted scale among the participants in this study (Cronbach’s alpha = 0.72).

Social Support was assessed by agreement to eight statements, adapted from the Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1991). Responses ranged from 1 (none of the time) to 5 (all of the time) to statements which indicated whether a person felt they had someone who could support them various ways. Statements include: having, “someone you can count on to listen to you when you need to talk” and “someone to give you money/provide you with financial support if you were in need.” Preliminary analyses have shown good reliability of the scale among the participants in this study (Cronbach’s alpha = 0.78). See Appendix for full scales.

Sexual Risk Behavior among HIV-positive young people is defined as the reported sexual activity and condom use with the most recent sexual partner in the past 12 months. This variable combines two questions: “Have you had sex with anyone in the past 12 months?” and “Did you use a condom the last time you had sex with this partner?” Condom use at last sex serves as a general indicator of condom use prevalence in the last 12 months (HIV/AIDS Survey Indicator Database, 2008). Responses were combined and categorized into three levels:

- 1) No sex
- 2) Protected Sex (used condom at last sex)
- 3) Unprotected Sex (did not use condom at last sex)

This variable is ordinal, indicating level of “effective transmission risk reduction behavior”, where not having sex is considered the most effective transmission risk reduction behavior, followed by having protected sex, and lastly, having unprotected sex in the past 12 months is considered the least effective behavior in transmission risk reduction.

4.3.2 Statistical Analysis

Descriptive analyses of the sample were conducted using univariate and bivariate statistics (i.e., chi-square for categorical data), including comparisons stratified by gender (male versus female) and age (14-19 years versus 20-24 years old). In descriptive analyses, the parental/caregiver monitoring and social support scales were dichotomized, where average scores of 3 (“sometimes”) and above indicated high parental/caregiver monitoring or high social support versus low (average scale scores < 3). In statistical modeling procedures, scales are kept continuous and were mean-centered.

To examine the effect of parental/caregiver monitoring and social support on sexual risk behaviors, proportional odds modeling was used as the response categories for sexual risk

behavior were ordinal in nature. A test for proportional odds was conducted to check if a proportional odds model was appropriate for this outcome. PROC SURVEYLOGISTIC in SAS 9.1 (2009) was used to run the analyses. Since the HIV clinics (recruitment sites) were chosen purposively and not by random selection, to account for the complex survey design a stratum variable “clinic” was included in the analyses. Proportional odds models assume that when moving between outcome response levels, the estimate of effect (i.e., odds ratio) is the same. That is, there is a common parameter β (the regression estimate) instead of distinct β_k for each level, where k represents the number of levels in the response minus one. Age, gender, and time-since-diagnosis were individually examined as potential cofounders using a change-in-estimate criterion (Mickey & Greenland, 1989). For cofounders to be included in an adjusted model, it must change the estimate of interest by 10% or more. Unadjusted and adjusted odds ratio estimates with 95% confidence intervals were calculated for parental/caregiver monitoring, social support, and the interaction between parental/caregiver monitoring and social support. The interaction variable was added into the model by creating a product term, parental/caregiver monitoring x social support.

4.4 Results

Demographics

A total of 103 HIV-positive young people (age 14-24) were included in this study. The majority were 18 years or older (90.3%), female (83.5%), aware of their HIV status (94.2%), reported not having sufficient daily food (75.7%), and reported a lot of religious guidance (79.6%). Seven out of ten participants, age 14-19, were still in school and among those 18 and over, most (69%) had not finished more than high school equivalent. Many of participants had one deceased parent (36%) or two (21%). Among those who lost both parents, over 82%

reported a grandparent, older sibling, or other (e.g., aunt of their mother) as their primary caregiver compared to those who reported losing one parent (18%) or no parents (11%).

All participants, age 20-24 years, were aware of their HIV status ($n=83$) compared to 70.0% of younger participants (age 14-19, $n=14/20$). The majority of younger participants were currently attending school. Younger versus older participants did not differ on reported sex in the last 12 months, receiving money for sex, number of parents lost, sufficient daily food, and religious influence. Demographic characteristics by gender are found in Table 4.1.

Parental/Caregiver Monitoring

Overall, most participants (68%) reported low parental/caregiver monitoring. In bivariate analyses males were more likely to report low parental/caregiver monitoring compared to females, $p<0.05$. Low parental/caregiver monitoring was reported by 74% of those who reported unprotected sex at last intercourse, compared to 62% and 69% among those reporting protected sex or no sex, respectively (Table 4.2). Parental/caregiver monitoring was positively correlated with social support when both were considered as continuous variables ($r =0.32$, $p<0.01$). In other bivariate analyses, parental/caregiver monitoring was not found to be associated with any other examined variables (Table 4.2). Notably, parental/caregiver monitoring was not associated with age, awareness of HIV status, number of parents lost, nor number of sexual partners.

Social Support

The majority of participants reported low social support (68%, $n=103$). Age and gender were not found to be associated with social support. However, the number of parents lost (due to death) was associated with social support, $p<0.05$. Among those reporting both, one, and no

parents lost/deceased, low social support was reported by 48%, 81%, and 66% of participants, respectively. Similar to parental/caregiver monitoring, while not statistically different, low social support was reported by 74% of those who reported unprotected sex at last intercourse, compared to 69% and 66% among those reporting protected sex or no sex, respectively. No other examined variables were found to be significantly related to social support in bivariate analyses (Table 4.2).

Sexual Behavior

Among participants who reported ever having sex, 45% of females and 65% of males reported first sexual intercourse at or before 15 years old. Having more than one sexual partner in the last 12 months was reported by 9% of females and 0% of males. Fifty five youth (53.4%) reported no sex in the past 12 months, 29 (28.2%) reported protected sex at their last intercourse, and 19 (18.4%) reported unprotected sex at last intercourse. Sexual risk behavior was significantly associated with time-since-diagnosis, where 21.0% of participants who were diagnosed with HIV within one year reported unprotected condom use at last sex compared to 10.0% of participants who were diagnosed two years or more from the time of the interview, $\chi^2=7.02$ (2), $p<0.05$. The average time since HIV diagnosis is 1.9 years (SD=2.0). Two out of six participants (33.3%) who were not aware of their status reported unprotected sex.

Table 4.2 outlines additional demographic and sexual behavior information by parental/caregiver monitoring, social support, and sexual risk behavior.

Effects of Parental/Caregiver Monitoring and Social Support on Sexual Risk Behavior

Perceived parental/caregiver monitoring and social support worked together in combination, rather than independently, to influence sexual risk behaviors (unadjusted OR = 1.7, 95% CI 0.98-2.79, $p=0.06$). That is, the influence of parental/caregiver monitoring on sexual risk behaviors varied by the amount of social support perceived by the participant. Statistically, for every one unit increase in social support, the impact of parental/caregiver monitoring on changing levels towards more effective transmission risk behaviors increases by a factor of 1.7. When age, gender, and time since HIV diagnosis were examined as potential confounders, only time-since-diagnosis met the change-in-estimate criterion. In the adjusted estimate, the combined effect of parental/caregiver monitoring and social support on sexual risk behavior remained but weakened (OR=1.6, 95% CI 0.91-2.75 $p=0.11$), see Table 4.3.

To further illustrate that social support is an effect modifier of the relationship between parental/caregiver monitoring and sexual risk behavior, Table 4.4 shows computed values for the adjusted odds ratio for various social support scores. Based on this interaction model, the adjusted odds ratio for parental/caregiver monitoring varies from values below the null value of 1.0 when an average social support score is 1.5 to values increasingly above 1.0 when an average social support score is above 2. This suggests, for example, that a participant who reports, on average, receiving social support between “none of the time” and “some of the time” (score=1.5) is 0.82 times more likely to move towards more effective transmission risk behaviors (condom use or no sex) with higher parental/caregiver monitoring. For a participant who reports, on average, receiving social support “most of the time” (score=4), they are 2.6 times more likely to move towards more effective transmission risk behaviors with higher parental/caregiver monitoring.

4.5 Discussion

In this study, the majority of HIV-positive young people reported low parental/caregiver monitoring and low social support. In addition, regarding risky sexual practices, almost one out of five participants reported not using a condom during their last sexual intercourse. The relationship between parental/caregiver monitoring and social support on sexual risk behavior was in the expected direction, showing that the majority who reported unprotected sex also reported low parental/caregiver monitoring and low social support, more so than those reporting protected sex or no sex. In multivariable models, the relationship between parental/caregiver monitoring and sexual risk behavior varied by the amount of social support perceived by the young person. That is, as social support increased, the influence of parental/caregiver monitoring on sexual risk behaviors increased more than one and a half times. In an adjusted model accounting for time-since-diagnosis, the influence that parental/caregiver monitoring and social support had on sexual risk behavior, as a combined effect, was similar although the effect weakened. These effects were suggestive of social support as an effect modifier, but not conclusive. Sample size was likely an issue that affected the power to detect a stronger relationship.

As a formative study, critical information emerged that should influence future work in understanding factors associated with sexual risk behaviors among HIV+ young people in DRC and issues of contextual measurement. First, the percentage of young people reporting sex before age 15 is much higher than statistics for Congo's young people in general (45% female/65% male in this study versus 23% female/31% male for DRC), which is already higher than surrounding countries. Further exploration of this discrepancy could provide useful information for understanding factors specifically related to HIV-positive young people in DRC and their

sexual behavior. Second, the majority of studies linking parental/caregiver influence to youth risk behaviors have been conducted in the U.S. In addition, the development of parental monitoring scales has also taken place in a western context (DiClemente et al., 2001; Li et al., 2000; Stanton et al., 2004). As such, based on prior knowledge of child rearing practices within the extended family in Africa, the scale was revised in an attempt to adapt questions to the cultural context. However, adaptation of parental monitoring questions may still have not truly captured the unique situation of HIV-positive young people living in Kinshasa, DRC. Lastly, there was also a challenge in using a social support scale developed in the U.S., which was also not developed targeting HIV-positive young people. In addition to possible power issues, other culturally specific factors (e.g., child fostering and gender roles) may provide some insight into what the parental monitoring and social support scales may not have fully captured, implying that developing new scales may be more appropriate.

The findings of this study suggest, consistent with literature from the U.S., that parental/caregiver monitoring and perceived social support can work together in combination to influence sexual risk behaviors. Based on the importance of the extended family unit in the African context, family members play important roles in both parental/caregiver monitoring and in providing social support to young people, inherently linking these two factors that could influence health behaviors. Studies have shown that parental support and parental monitoring were associated with each other (Henry et al., 2006), which is consistent with this study's finding that perceived social support and parental/caregiver monitoring are positively correlated. Another U.S. study, among African American female youth, found that living with a mother in a supportive family decreased the likelihood of reporting HIV risk behaviors (i.e., not using a condom, lack of communication with a sexual partner, and sex with a non-steady partner)

(Crosby et al., 2001). While there is some knowledge of how supportive families influence the behaviors of young people, primarily in the U.S., there is little information on the interactive nature of the relationship between parental/caregiver monitoring and perceived social support in the African context.

Studies in the African context do show that, individually, parental monitoring and social support can influence sexual behavior. No known studies have examined the combined effects of parental monitoring and social support on sexual behavior, especially among HIV-positive young people. Researchers in Ghana found that, for both males and females, more parental monitoring was associated with less recent sexual activity in the last twelve months among youth aged 12-19 years (Kumi-Kyereme et al., 2007). Additionally, research has shown that there is an association between social support and condom use among women living with HIV in South Africa (Gaede et al., 2006). Though our study's findings were in the right direction, the link between parental/caregiver monitoring, social support, and sexual behavior was not conclusive. Our study was consistent, however, with Kumi-Kyereme and colleagues (2007) in the finding that females reported more parental monitoring compared to males. One reason may be that young girls often have more responsibilities in assisting their mother and other adult women in daily household activities, and are thus under the watch of adults more often (Warkentin, 2004). Males may also be more likely to get permission to go out in the evening, while females are less likely to get permission to leave the household. This points to the importance of considering overarching norms about gender roles as a structural or higher level influence that should be incorporated into the conceptualization of parental/caregiver monitoring related to sexual behaviors of young people in the African context, rather than considering individual influences of parental/caregiver behaviors alone.

Living in an extended family household and child fostering may be particularly important for young people living with HIV, since they are prone to experiencing the loss of their parents due to ill health or HIV/AIDS, and experiencing general stigma associated with their status. More than half of participants in this study had lost one or both parents; and for those who had lost both parents, the vast majority considered a grandparent, older sibling, or aunts of their mother as the primary caregiver. In the current study, there was no information that could ascertain where and from whom participants perceived parental/caregiver monitoring or social support-- and possibilities are broad, potentially including parents, extended family, and, for other support, outside resources, such as teachers at school or health professionals from their clinic. On the other hand, social interaction may be limited for HIV-positive young people, if the young person is too ill to leave the household or if there are fears of stigmatization from others. Little is known about perceived social support among HIV-positive young people in DRC, but in another study with this sample, Mupenda (2008b) found that the majority of HIV-positive young people reported high perceived stigma and that higher perceived stigma was associated with less social support. The important role of extended family suggests that other older adults living with young people have the opportunity to provide different types of support. There is evidence linking high social support to less sexual risk behaviors, mainly among HIV-positive adults in the U.S. (Clement, 1992; Heckman et al., 1998); however, the findings from this study also point to the need for better understanding the concept of social support as it related to influencing behavior in the African context, especially among HIV-positive young people.

A strength of this study is that it is part of the formative process of behavioral intervention research. Conducting formative research provides an excellent opportunity to explore factors that influence sexual behaviors in young people living with HIV. For example, of

clinical importance, was the finding that two people who were *not aware* of their status reported unprotected sex. Time-since-diagnosis also appears to account for whether a participant reported unprotected sex, possibly more so than our measurement of parental/caregiver monitoring and social support. As such, being aware of one's status and time-since-diagnosis emerged as important factors to consider in understanding sexually risky behavior. Since HIV prevention strategies have largely focused on HIV-negative persons and information is lacking specifically in the DRC context, formative research is useful in contributing information to better understand the characteristics, norms, and needs of this population surrounding sexual behavior and potential intervention strategies.

Parent-child relationships in the African context, especially for parents/caregivers and their HIV-positive child, may not be captured best by Western-developed scales. To further understand sexual risk behaviors and capture the meaning of monitoring by parents/caregivers and perceived social support, future research should consider other contextual aspects which contribute to the complexity of relationships within the family and in the general unique experience of HIV-positive young people. Recommendations include incorporating the following into research: (1) understanding familial relationships in a child fostering situation, (2) HIV caregiver burden, (3) gender roles related to parent-child relationships, (4) HIV-related stigma, (5) awareness of HIV status, and (6) time since diagnosis.

Overall, the influence of parental/caregiver monitoring and social support on sexual risk behavior was in the right hypothesized direction, but was not conclusive, suggesting the need for measurement improvement or that altogether new scale development may be more appropriate. Sample size and power limited the analyses. Two additional limitations of the study include recalling sexual behavior for the last 12 months and social desirability, as participants likely

received sexual education counseling at their HIV treatment or care clinic. For future formative work in this area, scale development that is both culturally and contextually specific is recommended to push forth efforts in gathering scientifically sound information to inform intervention design and development. Such research that aims to inform HIV prevention interventions which target HIV-positive persons, particularly young people, will contribute to efforts in controlling and preventing the spread of HIV.

Table 4.1. Demographic characteristics of HIV+ youth by gender (n = 103)[†].

Characteristic	Overall	Male n (%)	Female n (%)	<i>chi-sq</i> <i>p</i>
Age				
14-19 years	20 (19.4)	8 (47.1)	12 (14.0)	<0.01*
20-24 years	83 (80.6)	9 (52.9)	74 (86.0)	
Aware of HIV status				
Yes	97 (94.2)	15 (88.2)	82 (95.3)	0.26
No	6 (5.8)	2 (11.8)	4 (4.7)	
Time since HIV diagnosis				
One year or less	67 (69.1)	10 (66.7)	57 (69.5)	1.0
More than one year	30 (30.9)	5 (33.3)	25(30.5)	
Had sex in last 12 months				
Yes	48 (46.6)	4 (23.5)	44 (51.2)	0.06
No	55 (53.4)	13 (76.5)	42 (48.8)	
Ever received money for sex				
Yes	23 (22.3)	3 (17.6)	20 (23.3)	0.76
No	80 (77.7)	14 (82.4)	66 (76.7)	
Number of parents lost				
None	44 (43.1)	6 (35.3)	38 (44.7)	0.77
One	37 (36.3)	7 (41.2)	30 (35.3)	
Both	21 (20.6)	4 (23.5)	17 (20.0)	
Sufficient daily food				
Yes	25 (24.3)	5 (29.4)	20 (23.3)	0.55
No	78 (75.7)	12 (70.6)	66 (76.7)	
Religious guidance				
None or Some	21 (20.4)	2 (11.8)	19 (22.1)	0.51
A lot	82 (79.6)	15 (88.2)	67 (77.9)	
Currently in school				
Yes	33 (32.4)	11 (64.7)	22 (25.9)	<0.01
No	69 (67.6)	6 (35.3)	63 (74.1)	

[†] Totals may not add up to 103 due to missing values.

* Indicates significance for chi-square statistic (Fisher's Exact for 2x2 with counts <5).

Table 4.2. Demographic, psychosocial, and sexual practices by parental/caregiver monitoring, social support, and sexual risk behavior among HIV+ young people in Kinshasa, DRC, n=103.

Characteristic	P/C Monitoring		<i>p</i> *	Social Support		<i>p</i> *	Sexual Risk Behavior			<i>p</i> *
	High	Low		High	Low		Unprotected	Protected	No Sex	
Age										
14-19 years old	9 (45.0)	11 (55.0)	0.17	7 (35.0)	13 (65.0)	0.75	4 (20.0)	4 (20.0)	12 (60.0)	0.66
20-24 years old	24 (28.9)	59 (71.24)		26 (31.3)	57 (68.7)		15 (18.1)	25 (30.1)	43 (51.8)	
Gender										
Males	2 (11.8)	15 (88.2)	0.08	8 (47.1)	9 (52.9)	0.15	2 (11.8)	2 (11.8)	13 (76.4)	0.11
Females	31 (36.0)	55 (64.0)		25 (29.1)	61 (70.9)		17 (19.8)	27 (31.4)	42 (48.8)	
Aware of HIV status										
Yes	31 (32.0)	66 (68.0)	1.0	33 (34.0)	64 (66.0)	0.17	17 (17.5)	28 (28.9)	52 (53.6)	0.58
No	2 (33.3)	4 (66.7)		0 (0.0)	6 (100.0)		2 (33.3)	1 (16.7)	3 (50.0)	
Time since HIV diagnosis										
One year or less	25 (37.3)	42 (62.7)	0.09	25 (37.3)	42 (62.7)	0.31	14 (20.9)	14 (20.9)	39 (58.2)	0.03
More than one year	6 (20.0)	24 (80.0)		8 (26.7)	22 (73.3)		3 (10.0)	14 (46.7)	13 (43.3)	
Number of parents lost										
None	16 (36.4)	28 (63.6)	0.66	15 (34.1)	29 (65.9)	0.03	11 (25.0)	9 (20.4)	24 (54.6)	0.21
One	10 (27.0)	27 (73.0)		7 (18.9)	30 (81.1)		4 (10.8)	11 (29.7)	22 (59.5)	
Both	7 (33.3)	14 (66.7)		11 (52.4)	10 (47.6)		4 (19.0)	9 (42.9)	8 (38.1)	
Religious guidance										
None or Some	7 (33.3)	14 (66.7)	0.89	4 (19.0)	17 (81.0)	0.19	2 (9.5)	6 (28.6)	13 (61.9)	0.47
A lot	26 (31.7)	56 (68.3)		29 (35.4)	53 (64.6)		17 (20.7)	23 (28.1)	42 (51.2)	
Currently in school										
Yes	11 (33.3)	22 (66.7)	0.77	11 (33.3)	22 (66.7)	0.88	4 (12.1)	9 (27.3)	20 (60.6)	0.47
No	21 (30.4)	48 (69.6)		22 (31.9)	47 (68.1)		15 (21.8)	19 (27.5)	35 (50.7)	
Had sex in last 12 months										
Yes	16 (33.3)	32 (66.7)	0.79	14 (29.2)	34 (70.8)	0.56	19 (39.6)	29 (60.4)	--	--
No	17 (30.9)	38 (69.1)		19 (34.5)	36 (65.5)		--	--	55(100.0)	

Number of sexual partners										
Mean (SD)	0.74 (.94)	0.82 (.97)	0.83	0.79 (1)	0.80 (.95)	0.70	1.1 (.23)	1.1 (.34)	n/a	0.41
Received money for sex										
Yes	8 (34.8)	15 (65.2)	0.75	5 (21.7)	18 (78.3)	0.23	4 (17.4)	9 (39.1)	10 (43.5)	0.40
No	25 (31.2)	55 (68.8)		28 (35.0)	52 (65.0)		15 (18.8)	20 (25.0)	45 (56.2)	
Parental/caregiver Monitoring										
High	--	--	n/a	13 (39.4)	20 (60.6)	0.27	5 (15.2)	11 (33.3)	17 (51.5)	0.68
Low	--	--		20 (28.6)	50 (71.4)		14 (20.0)	18 (25.7)	38 (54.3)	
Social Support										
High	13 (39.4)	20 (60.6)	0.27	--	--	n/a	5 (15.1)	9 (27.3)	19 (57.6)	0.80
Low	20 (28.6)	50 (71.4)		--	--		14 (20.0)	20 (28.6)	36 (51.4)	

*Chi-square statistic was calculated for categorical variables (Fisher's Exact for 2x2 with counts <5) and the t-test statistic was used for continuous variables.

Table 4.3. Proportional odds ratios for the interaction between parental/caregiver monitoring and social support on sexual risk (no sex, protected last sex, or unprotected last sex in last 12 months) among HIV positive young people from Kinshasa, DRC.

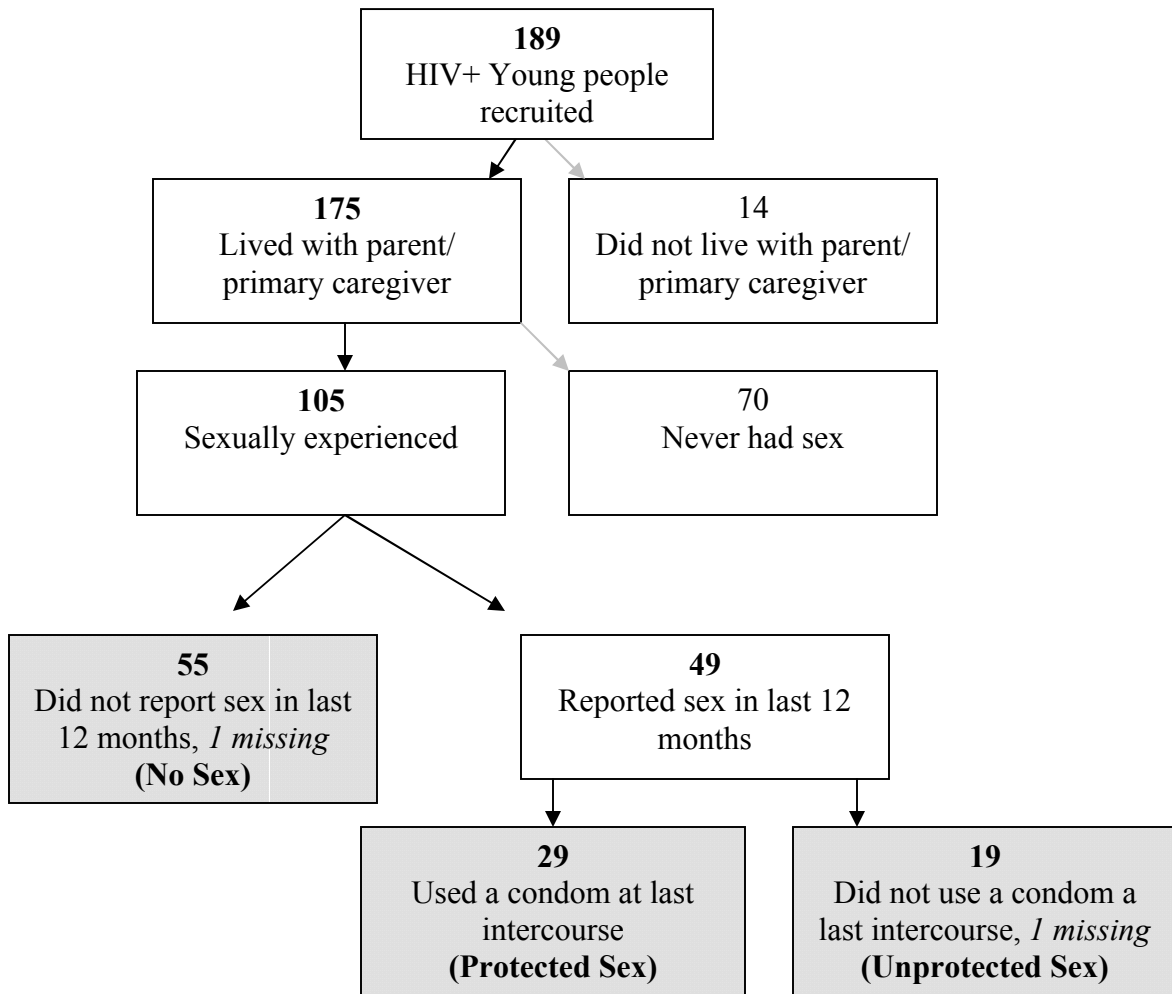
Parameter	<i>Unadjusted Estimates</i>			<i>Adjusted Estimates[±]</i>		
	Estimate	OR (95% CI)	<i>p</i>	Estimate	OR (95% CI)	<i>p</i>
Parental/caregiver Monitoring* Social Support	0.503	1.65 (0.98-2.79)	0.06	0.456	1.57 (0.91-2.75)	0.11

[±] Adjusted for time-since-diagnosis.

Table 4.4. Effect of social support on the value of the estimated adjusted odds ratio for parental/caregiver monitoring.

Social Support Average Score	OR_(Parental/caregiver Monitoring)
Receives social support:	
“None of the time” 1.0	0.65
1.5	0.82
“A little of the time” 2.0	1.03
2.5	1.30
“Some of the time” 3.0	1.63
3.5	2.05
“Most of the time” 4.0	2.58
4.5	3.24
“All of the time” 5.0	4.06

Figure 4.1. Sample Size Chart.



= Sample size per level of outcome variable, sexual risk behavior (n=103).

CHAPTER FIVE: COMMUNICATION ABOUT SEX BETWEEN PARENTS/CAREGIVERS AND HIV-POSITIVE YOUNG PEOPLE

5.1 Abstract

Communication about sex with young people is often intended to prevent sexually risky behaviors and, consequently, reduce the risk of pregnancy and contracting sexually transmitted diseases, such as HIV/AIDS; the benefits of talking about sex with young people are well established. Little is known about how parents and caregivers communicate with an HIV-positive young person regarding sexual matters. This study aims to describe, from the perspective of the parents/caregivers, the norms and patterns of communication about sex with their HIV-positive child. Fifty-two semi-structured interviews with parents/caregivers were conducted in Kinshasa, the Democratic Republic of Congo. Reasons for communication about sex, including HIV disclosure and child attributes and content of communication, including sexual risk, HIV status disclosure and other risk behaviors, were identified. We found that reasons for communication were similar for parents/caregivers who had children who were aware of their HIV status compared to those with children who were not aware of their status; however, most parents/caregivers waited until after puberty or until the child already started having sex to communicate with them about sexual matters. Content of communication differed by awareness of HIV status. For parents/caregivers with children who knew their status, they believed that it was important to communicate about sex in the context of the child's HIV status so that the child can take precautions and avoid HIV transmission to others, as well as secondary infections to the child themselves. For children who did not know their status, some

parents/caregivers used scare tactics to influence their child's sexual behavior, even mentioning that they could get HIV. In general, parents/caregivers focused their conversations on the risks of sex, though male children were told to be more careful compared to female children, who were told to avoid sexual contact. These findings can inform culturally sensitive approaches for transmission risk interventions among young people living with HIV.

5.2 Introduction

Parents are often encouraged to communicate about sex with their child or adolescent—and an abundant amount of research has confirmed that such communication is effective in influencing sexual behaviors and attitudes (Adu-Mireku, 2003; Halpern-Felsher, Kropp, Boyer, Tschann, & Ellen, 2004; Hutchinson, 2002; Hutchinson & Montgomery, 2007; McBride et al., 2005; Miller et al., 1999). Communication about sexual matters has been associated with more conservative sexual beliefs about delaying sexual debut and premarital sex and greater confidence in sexual communication with partners; and in particular, mother-daughter communication has been associated with less unprotected sex and reduced risk for pregnancy (Hutchinson & Montgomery, 2007). While the research on parent-child communication comes primarily from Western societies, showing strong links to overall emotional and behavioral health of children, research on parent-child communication about sex in the African context is also available—though limited (Ackard et al., 2006; Mathew et al., 2006; Miller et al., 1999; Kiragu et al., 1997).

Parents have the opportunity to be an early source of information surrounding sexual health and HIV/AIDS and recommendations in the African context have included interventions and programs which enhance information and encouragement to parents in talking with their children about sexual matters (Kiragu et al., 1997; Mathew et al., 2006). However, in the face of

an HIV/AIDS epidemic, with Sub-Saharan Africa representing more than two-third (68%) of all people living with HIV globally (UNAIDS, 2007), communication about sex *especially* with HIV-positive young people is needed to help push forth efforts in transmission risk reduction.

In traditional African society, parents did not talk about sex with their children, as the topic was taboo. Communication on sexual matters was often left to other relatives, such as aunts or uncles, to speak about the subject (Izugbara, 2008; Kumi-Kyereme et al., 2007). However, rising modernization in many African countries has shaped these approaches and parents are taking a more active role in discussions about sexuality with their children (Izugbara, 2008). Additionally, the HIV epidemic has sparked a number of media campaigns encouraging communication about sex and HIV, such as the “Love Life” campaign in South Africa, which encourages parents to talk with their children (see www.lovelife.org.za/parents) and MTV’s “Staying Alive” global campaign, which promotes young peoples’ interpersonal communication with friends, parents, and other family members about HIV prevention (Geary et al., 2007). In the African context, due to limited research on parent-child communication about sex, the majority of studies in Africa have been designed to document the occurrence (Adu-Mireku, 2003; Kiragu et al., 1997; Mathew et al., 2006), rather than explore the content, of such communication (Izugbara, 2008).

Levels of communication about sexual matters and HIV/AIDS have been documented in Kenya and Nigeria between parents and youth ranging 10-19 years old, with both countries reporting levels of communication under 40% (Kiragu et al., 1997; Mathew et al., 2006). A survey of Kenyan parents found that many do not have adequate information to talk with their child and give correct information and, in addition, studies in Nigeria found that adolescents themselves perceived that their parents did not know enough to talk about sex (Kiragu et al.,

1997; Mathew et al., 2006). In part, because of such barriers, youth often report feeling more comfortable talking about sex with other people besides their parents (i.e., friends and health care workers). When communication does occur between parent and child, the ideal communication is an interactive one. However, studies in Ghana and Nigeria have found that communication on sexual matters was more didactic in nature, as little was left for discussion; the message was also different for females than for males, where females were instructed to avoid sexual contact and males told to be careful (Kumi-Kyereme et al., 2007; Izugbara, 2008). One study in Ghana provided evidence for a positive influence of parent-child communication on youth sexual behavior. Among secondary school students, those who reported having ever talked about HIV/AIDS with their parents or other adults in the family, were over two times more likely to report condom use at last sexual intercourse (Adu-Mireku, 2003).

Only one study in the African context, explored how and why parents communicated with their children about sexual matters (Izugbara, 2008). This study found that 39% of Nigerian parents talked about sex with their children (age range 10-21 years old). Some of the main reasons for communicating with their child were to delay sexual debut and pregnancies, though for many parents initiating the conversation was mistimed, often waiting until puberty or after the child already started having sex. The content of communication among Nigerian parents and their children was largely framed around the “dangers of sex”, including pregnancy and the risk of contracting diseases. Some parents even mentioned that they provided misleading information to their child in order to discourage their interest in sex (Izugbara, 2008).

Little information is available on talking about sex with young people who are already HIV positive, since the focus of communication with a young person has, most often, been used for primary prevention purposes (i.e., avoiding pregnancy and infections). The need for family

support has been identified as an important factor in the well-being of HIV-positive young people and tools have been developed to measure family support among positive youth (Davey, Foster, Milton, & Duncan, 2009). Still, there is little research on parenting behaviors among parents/caregivers with HIV-positive children. In the area of parent-child communication, research has largely focused on the process and outcomes of disclosing the child's HIV status to the child. Specifically, there is evidence from the U.S. that open communication about HIV diagnosis with children infected with HIV has been associated with increased social support, increased self-competence, and decreased problem behaviors (Battles & Wiener, 2002). In addition, poor parent-child communication can influence the medical needs of HIV-positive children, such as poor adherence to antiretroviral treatment (Mellin et al., 2004). The research thus far, showing a positive influence of parent-child communication for HIV-positive young people, points toward the potential benefits of targeting parents and caregivers in efforts that promote responsible sexual behaviors. However, research is needed to understand parent-child communication, specifically in the area of sexual matters, with HIV-positive young people.

The specific aim for this paper is to describe, from the perspective of the parents/caregivers of young people living with HIV/AIDS, the norms and patterns of communication about sex with their HIV-positive child. Culturally sensitive transmission risk intervention approaches are needed. This study aims to contribute to better understanding of the reasons and content of communication about sex among parents/caregivers and their HIV-positive young person in the African context.

5.3 Methods

5.3.1 Setting and Research Design

This study was conducted in Kinshasa, the Democratic Republic of the Congo (DRC), where the HIV prevalence is highest for both women and men (2.3 percent for women and 1.3 percent for men; DHS, 2008). Compared to other African countries, social indicators of DRC (e.g., life expectancy and infant mortality rate) are relatively poor (WHO, 2006); and DRC continues to recover from the last 5 years of war and conflict. Despite such adversity, the family unit remains an important aspect of Congolese life.

Data for this research comes from the primary study, “Formative Research to Develop Effective Prevention Interventions for HIV+ Youth in Kinshasa”, a cross-sectional study aimed at examining the need for and type of appropriate interventions for youth living with HIV. HIV-positive young people were recruited by counselors from four HIV care and treatment centers between June and September 2007.

The larger study consisted of three parts: 1) Young people living with HIV/AIDS (YPLWH) took part in an interviewer-administered questionnaire on sexual behavior and psychosocial wellbeing (n=189), 2) A selected number of YPLWH who took part in the quantitative questionnaire were selected to take part in an in-depth interview (n=30), and 3) Parents/caregivers of the YPLWH were asked to take part in an interviewer-administered semi-structured interview (n=52). Parents/caregivers were asked how they decided to talk to their child about sex and how they determined when to talk. Participants were also asked about the content of their conversations. This study used information from the semi-structured interview with the primary caregiver and information gathered from the quantitative questionnaire with the

YPLWH to explore communication about sex among parents/caregivers and their HIV-positive child.

Approval for the research was obtained from the Institutional Review Board (IRB) at the University of North Carolina, Chapel Hill and from the Comité d’Ethique of the Ecole de Santé Publique Université de Kinshasa (Ethics Committee of the Kinshasa School of Public Health).

5.3.2 Sample

Inclusion criteria for the YPLWH who participated in the quantitative questionnaire included: (1) HIV positive diagnosis, including participants who did and did not know their HIV status, (2) 14 to 24 years of age, (3) Kinshasa resident, (4) registered and receiving assistance from one of four predetermined HIV clinics, and (5) willingness to participate.

Parents/caregivers were recruited through the counselors of the YPLWH and therefore had to be the caregiver of a young person who participated in the primary study. All participants provided informed consent/assent prior to interviews and parental/caregiver consent was obtained for youth under 18.

A total of 52 interviews were completed with the parents/caregivers of an HIV-positive young person. Twenty-six parents/caregivers were selected who had a child participant that was not aware of their HIV status. Another 26 parents/caregivers, who had a child that was aware of their HIV status, were randomly selected and matched on sex and age of the child.

5.3.3 Data Collection

All caregiver participants completed a semi-structured interview, including both closed- and opened-ended questions. The interview guide included questions, such as “Have you talked to your child about sex?” with a dichotomize response yes/no. Sub-questions, which required

open-ended responses, include: “If no, why not?”, “If yes, when did you start talking to them about this?”, “What made you decide to talk to them?”, and “What have you told them?”

Data from the caregiver semi-structured questionnaire was collected by interviewers who have been previously trained in both quantitative and qualitative data collection by UNC. All interviews were conducted face-to-face in Lingala, the local language. Interviewers were trained in privacy and confidentiality procedures, especially related to HIV patients. Open-ended responses were first transcribed by the interviewer and then translated into English.

5.3.4 Data Analysis

Summary statistics were used to describe the characteristics of parents/caregivers, whether they reported communicating with their child about sex, and if not, whether they plan to. In addition, responses from parents/caregivers on whether they thought their child was sexually experienced were matched to the actual self-reported responses of the young person from their previous interview. The agreement between parent/caregiver and child responses regarding sexual activity experience was presented descriptively. The association between parent/caregiver-child agreement and the child’s awareness of HIV status was also examined using bivariate analyses (i.e., chi-square).

Transcripts from the open-ended responses for each primary caregiver interview were studied and analyzed using a qualitative analytic approach. The strategy for coding the open-ended responses was to: 1) write memos for the first 5 interviews, 2) develop an initial code list, 3) code first half of interviews by interview order ($n = 26$), while continuing to write memos for potential new codes, 4) review and refine code list, 5) review coded interviews and make adjustments, and 6) code last 26 interviews. Once coding was completed, themes and central ideas were extracted and interpreted. Major themes directly related to communication about sex

include: Reasons for communication and content of communication. Subthemes for reasons for communication (i.e., HIV disclosure and child attributes) and content of communication (i.e., sexual risk, status disclosure, and other risk behaviors) were also identified. Analysis of the transcripts was performed using ATLAS.ti, version 5.2 (Muhr & Friese, 2004).

5.4 Results

Approximately 43% of participants were either the biological mother (31.4%, n=16) or the biological father (11.8%, n=6). Other types of relationship to the child included the mother's older or younger sister (18.8%, n=9), grandparent (9.8%, n=5), or other relative (28.2%, including siblings, paternal aunts, and cousins, n=13). Among the children of the parents/caregivers, 25% were orphans (lost both parents), 42% had lost one parent (largely the father, n=13/20), and 33% had not lost any parents. The mean age was 46.2 years (range 22-77 years) for parents/caregivers and 15.9 years old (range 14-19 years) for their children. See Table 5.1 for primary caregiver and child demographics.

Among 52 parents/caregivers of HIV-positive young people, 29 (56%) reported talking with their child about sex. Among those who reported not talking with their child about sex (n=23), 13 (59%) reported that they plan to talk with their child. Approximately half of those who reported talking with their child about sex, had a child who did not know their HIV status (n=14, 48%). Similarly, approximately half of those who reported that they had not talked with their child about sex, had a child who did not know their status (n=12, 52%). The average age of the child among those who had talked about sex was greater than for those who had not talked about sex (16.4 versus 15.3 years) and the average age of children who knew their status was also greater than those who did not know their status (16.7 versus 15.2 years).

Parents/caregivers of children who lost one or both parents had a higher proportion of children who knew their status compared to children who had not lost any parents (53% versus 38%).

The relationship of the primary caregiver to the child appears to be associated with whether they had reported talking about sex. Fathers, grandparents, and paternal aunts had lower proportions of communication about sex with the child (17%, 20%, and 33%, respectively) compared to mothers, maternal aunts, and other relatives (69%, 77%, and 75%, respectively). Among children who had lost one or both parents, 60% of their caregivers had reported talking about sex and, among those who had both parents alive, 44% had reported talking about sex.

Primary Caregiver Knowledge of their Child's Sexual Activity

Regardless of whether parents/caregivers thought their child was sexually active or not, the majority reported speaking to their children about sex. Among those who believed their child was sexually active, 67% (n=2/3) had reported talking about sex. Among those who did not believe the child had sexual experience, 53% (18/34) had reported talking about sex and, for those who reported that they did not know the child's sexual experience, 57% (8/14) still reported talking to them about sex.

Table 5.2 compares primary caregiver's beliefs about their child's sexual experience with the information on self-reported sexual experience provided by the child in another interview. The majority of parents/caregivers correctly identified their child's sexual experience (n = 30/47, 64%). Thirty-six percent (n = 17/47) were not aware or didn't know their child's sexual experience (five children did not report their sexual activity). Sixty percent of mothers (9/15), 75% of maternal aunts (6/8), 80% of fathers (4/5), and 100% grandparents (5/5) were correct in identifying whether their child was sexually active. Other relatives (i.e., sibling, cousin, father's

sister, or mother's brother) averaged about 46% in correctly identifying the child's sexual experience.

There was a clear association between a parent/caregiver's accuracy in their knowledge about the child's sexual activity and the child knowing their HIV status. Among parents/caregivers of children who knew their status, 80% (20/25) were aware of their child's sexual experience. Among parents/caregivers of children who did not know their status, only 45% (10/22) of the parents/caregivers were aware of their child's sexual experience. This difference was statistically significant, $\chi^2=6.05, 1, p<0.05$.

Reasons and Content for Communication about Sex

In open-ended responses from the interviews, reasons and content of communication about sex were major themes. Subthemes for reasons for communication about sex were classified as being related to the "child's attributes" or "HIV disclosure". Subthemes within content of communication were also identified, including "sexual risk", "status disclosure", and "other risk behaviors".

Reasons for Communication

The motivation for communication about sex appeared to be the same for parents/caregivers of children who knew their status and for those of children who did not know their status. Additionally, reasons for communication were similar for male and female children. Familial relationship to the child did appear to present a difference in which reasons were most emphasized. Mothers and maternal aunts were motivated by the child's attributes (i.e., age of the child and current behavior), followed by disclosure of the child's HIV status to the child as

reasons for talking about sex. For other primary caregivers (i.e., father's sister or a cousin), HIV disclosure to the child was mentioned most often as a reason for having initiated the conversation.

Child Attributes. Most parents/caregivers mentioned the child's age or onset of puberty for as the primary factor that prompted (or had not yet prompted) communication about sex. Many participants associated age ("getting older") and puberty with a natural desire to start having sex. In some cases, the start of menstruation for girls also provided a good opportunity to start a discussion on sexuality.

When I noticed that she has started seeing her period, I already started telling her [about sex].
(Biological mother of 18-year-old female, child not aware of HIV status)

He was 15 years old, when we realized that he is growing up and has friends, he can need to have sex. At his age, he's growing up, we realized that if he sees his friend with a girlfriend, he can also look for a girlfriend. *(Sibling of 16-year-old male, child not aware of HIV status)*

The perception of a child being too young or not developed physically was also mentioned as a reason for not starting a conversation about sex with their child. In some instances, parents/caregivers believed that initiating the conversation could influence the child to start thinking about having sex.

This is because she is a young child and sometimes if you start talking to a child about those things, you might end up putting them in her head when she did not yet have that idea of having sex. *(Paternal aunt of 15-year-old female, child not aware of HIV status)*

Approximately half of the parents/caregivers were prompted to talk about sex with their child because of the child's behavior. Though very few participants said that their child was sexually active (n=3, 6%) and over a third replied that they did not know or didn't answer the question (n = 17, 33%), many parents/caregivers reported talking about sex when the child's behavior

seemed to indicate that they may start becoming sexually active soon. Some of the behaviors that cued parents/caregivers into initiating the conversation include spending more time with the opposite sex, going out at night, and paying more attention to their looks.

When I noticed that she has started having sex. [Interviewer. How did you notice that?] When she started buying stuffs for herself without being given money by me or by any other relative, and her body started being developed. (*Biological mother of 17-year-old female, child not aware of HIV status*)

I just started talking to her recently when she reached 15 years. If I go out, I find her talking to a young boy. The boy comes and sits in our house. She never talk to girls but only boys. I did so because I found that the young boy is now getting closer to her. I feared hearing that they can come up with telling us that there is a pregnancy. (*Biological mother of 15-year-old female, child aware of HIV status*)

Since one year, because he has started going out, and being disheveled in the evenings, he does the beauty care/treatment for his body, going out, staying out with friends. ...and he does not tell us where he has gone. (*Step-mother of 16-year-old male, child aware of HIV status*)

On the other hand, participants also mentioned that if they believed their child was not having sex or did not see any signs that they might start soon, there was no incentive to begin talking about sex.

Considering his age and the way he is living, I don't think that he can have started that these days. [Interviewer: What makes you think like that?] Because he does not really go out [for walks], what he does with his friends-- he is just playing marbles. (*Biological mother of 16-year-old male, child not aware of HIV status*)

A few participants mentioned that communication was prompted by the child themselves. While some questions posed by a child about sex were more direct, others asked indirectly, out of curiosity or misunderstanding, as illustrated below:

[Interviewer: When did you start talking to them about this (sex)?] When she had her period, she asked me if she could share the same bed with her brother. I asked her why not? She answered, because I hear people saying that if someone has their period, she can not sleep with boys. I explained to her what sleeping with boys means. *(Other, non-specified, relative of 16-year-old female, child not aware of HIV status)*

Just now at the age of 19, 2 months after he has started the treatment, when he got strong, when he was recovered, he asked me if in his life he can get married when he will get old. Considering the question he asked me, it was necessary that I, his confidant, orient him to the life of being HIV-positive. *(Maternal aunt of 19-year-old male, child aware of HIV status)*

HIV Disclosure. Among the 15 parents/caregivers who had a child that was aware of their HIV status and reported talking to them about sex, 10 mentioned that their child's status was the primary reason for starting the communication. Parents/caregivers believed that it was important to communicate about sex in the context of the child's HIV status so that the child can take precautions and avoid HIV transmission to others, as well as secondary infections to the child themselves. Among parents/caregivers who had a child that was not aware of their HIV status, only one caregiver explicitly mentioned not wanting the child to infect others as a reason for communication about sex—though it is noted that the majority (69%, n=18/26) mentioned having fears that the child would infect others in general (not related to talking about sex).

After a few days, after disclosing to him his illness. I started telling him [about sex] so that he knows how to behave. It makes me scared because if he started having that, he will contaminate other people who can kill themselves. He can also have other illnesses that will make him very weak and take him to death. *(Cousin of 19-year-old male, child aware of HIV status)*

I spoke with her many times [about sex] just from the moment she was diagnosed with the illness. Because she is dealing with a sexual disorder thinking that I do not know [she is sexually active]- I am old enough and I understand. *(Paternal aunt of 18-year-old female, child aware of HIV status)*

Content of Communication

What parents/caregivers reported talking about when they communicated about sex differed both for: 1) parents/caregivers of children who knew their HIV status compared with parents/caregivers of children who did not know their status, as well as 2) male and female children. Most parents/caregivers emphasized the risk of having sex and provided advice on how to protect oneself, especially among parents/caregivers of children who knew their status. However, the message was often quite different for children who did not know their status. As illustrated among the different themes and quotes below, many of the parents/caregivers with children who did not know their status used scare tactics in order to influence the child's behavior; namely they told their children they could contract illnesses from sex, like HIV/AIDS, and several mentioned that they could die from sex. Additionally, the content of communication for male children was more focused on taking precautions to protect oneself, while the content for females was more negative, emphasizing abstinence, becoming more prudent, and the consequences of becoming pregnant.

Sexual Risk. Among all parents/caregivers who reported talking to their child about sex, the vast majority emphasized the risks of pregnancy and HIV transmission (86%, n = 25/29). Often, this discussion took place in the context of the child's HIV status, for those who were aware of their HIV status. On the other hand, for children who were not aware of their status, parents/caregivers focused on the risks of pregnancy and contracting diseases, many times in a deceiving manner.

I told her: "as you have already had a monthly period, if you have sex with a boy, you will get pregnant. As you are receiving treatment, you will die if you have sex with a boy" . I said she will

die just in order to scare her. (*Maternal aunt of 14-year-old female, child not aware of HIV status*)

As she has started having her periods, it means that if she has sex, she will get pregnant. The same, if she has sex, she can get AIDS or any other disease. (*Biological mother of 15-year-old female, child not aware of HIV status*)

I told him: as you have this disease, if you have sex with a woman, you will contaminate her. If you decide to have sex with a person who has the same condition, you can get contaminated; if her virus is stronger than yours, you will fall again. (*Biological mother of 16-year-old male, child aware of HIV status*)

Approximately half of participants offered advice to the child on risk reduction for pregnancy or HIV transmission, including condom use, avoiding multiple partners, and abstinence. In some cases, for children who knew their status, the child was told they simply cannot have sex or that it was forbidden. Some talked about abstinence in the context of waiting for marriage. For children who did not know their status, parents/caregivers often emphasized condom use.

I told her that many illnesses are transmitted through sexual intercourses, mostly having sex with many partners is not good. She should pay attention with boys, using condom when having sexual intercourses with men. (*Biological mother of 17-year-old female, child not aware of HIV status*)

She has a contagious illness she can not have sex with someone. It is forbidden. (*Maternal uncle of 14-year-old female, child aware of HIV status*)

Status Disclosure. The other content area of communication between parents/caregivers and their child was disclosure of HIV status to others. A few parents/caregivers mentioned that the child should disclose their HIV status to a sexual partner. This also included indirectly eliciting disclosure to a partner by advising a child, who did not know their HIV status, to get tested before starting to have sex.

Because she has grown up... a man who she can marry can find out [her HIV status], I will oblige both of them to get tested of HIV so that he knows that. (*Biological mother of 18-year-old female, child not aware of HIV status*)

You should tell your serostatus to every man who you will love so that you have sex, it is good that you use condom if it arrives that you have sex in order to protect yourself and to protect men. (*Biological mother of 14-year-old female, child aware of HIV status*)

Other Risk Behaviors. Another largely mentioned risk behavior for HIV transmission is the use of certain household objects. Parents/caregivers suggested to their child to be careful in using sharp objects that might cut them and put others at risk for having contact. This suggestion only occurred for children who knew their status. Some objects and activities mentioned to the child that they should avoid include: razor blades, hair braid needles, nail files, and sharing toothbrushes, wash gloves, and food.

I told her so that she becomes very prudent, she takes precautions in order to live for a long time, she avoids contaminating her friends through sharp/cutting objects and sexual intercourses. (*Cousin of 18-year-old female, child aware of HIV status*)

When she was having her hair braided she got some wounds at her head. Her friend, the one who was braiding her hair, could be contaminated if she has wounds in her fingers. (*Biological mother of 18-year-old female, child aware of HIV status*)

5.5 Discussion

Little attention has been placed on communication about sexual matters with a child or young person who is already HIV-positive, especially in the African context. In this study, more than half of all parents/caregivers of HIV-positive young people reported having talked about sex with their child. For those who had not talked about sex with their child, the majority had intentions to do so. In our sample, half of the young people knew their HIV status and half did not know. This proportion did not differ among parents/caregivers who had reported talking

about sex compared to those who had not. Biological mothers, maternal aunts, and other relatives were most likely to report talking with their child about sex. Parents/caregivers who were most likely to be aware of their child's sexual experience, based on the child's self report, included biological mothers, maternal aunts, fathers, and grandparents. Research has shown that parent-child congruency on sexual behavior reports are generally low (Jaccard, Dittus, Gordan, 1998). This study found that most parents/caregivers were highly aware of their child's sexual behavior, likely because most children were not yet sexually active. Parental awareness of a child's sexual experience has been shown to influence less sexual risk involvement (Yang et al., 2006). Additionally, parents/caregivers who were aware of their child's sexual experience were more likely to have children who knew their status—thus it appears that openness about the child's status is related to openness in other areas of communication. As we found in this study, other studies in the African context also reported that communication about sex did not solely occur with parents, but additionally with other adults outside the immediate family, namely aunts, grandparents, teachers, and other community members (Kawai et al., 2008; Kumi-Kyereme et al., 2007). Major reasons for communication were related to attributes of the child (i.e., age and behavior) and disclosure of HIV status to the child. Content of communication about sex primarily focused on the risks or dangers of sex, as other studies have found.

These results must be understood in the context of the experiences faced by HIV-positive young people in Kinshasa, the Democratic Republic of the Congo. First, the young person's HIV status, in and of itself, likely served as a cue-to-action for parents/caregivers to think about talking about sex. Due to the nature of the young person's illness, parents/caregivers are faced with a particular motivation to talk about sex—HIV transmission prevention. Whether the child is aware of their HIV status or not, this motivation can be an important factor for

parents/caregivers in deciding when and how to communicate about sexual matters. In fact, parents/caregivers of children who knew their status largely mentioned transmission risk as a reason for talking about sex. While few parents/caregivers of children who did not know their status explicitly mentioned transmission risk as a reason for talking about sex, most mentioned general fears of the child infecting others. This difference may be due to the caregiver not being able to talk about transmission risk directly to a child who was not aware of their status in order to avoid revealing their HIV status. The child's health status may also play a role in whether communication about sex occurs. If the child is perceived to be weak or ill, the caregiver may not think the child is able to interact with others, including engaging in sexual activity. On the other hand, if the child is on antiretroviral treatment (ARVs), as many were in this study, and perceived to be healthy, parents/caregivers may be more motivated to prevent sexually risky behaviors by making sure their child is aware of the consequences of unsafe sexual practices.

Secondly, considering the cultural context, only recently has more interest been placed on expanding HIV/AIDS prevention and care, as the DRC government transitions to “increased stability and economic revitalization” (UNAIDS, 2004). After gaining independence in 1960 from Belgium, the history of DRC has been one of political and social turmoil. However, family still remains central to Congolese life, as living in an extended family household is a common practice in DRC (Mukenge, 2002). In the African context, the upbringing of a child often involves other family members and is not left exclusively to the biological parents (Sudarkasa, 2004). Child fostering, or taking responsibility of a relative's child in one's own home, is common in DRC—though in some cases, a sick child could be seen as a burden rather than a normal part of the family unit (Vaz, 2008a; De Herdt, 2004, Ziemke, 2001). The burden of caregivers (e.g., high stress and unhappiness) has been documented in Kinshasa, DRC, mainly

among women who care for their HIV-positive spouses (Kipp et al., 2007). If the fostered young person is seen as a burden-- for example, due to the stigmatizing nature of their serostatus, fear, or resentment of taking care of an ill child-- primary caregivers may not prioritize or be motivated to interact with the young person. Some caregivers may even have misconceptions about HIV and its transmission, which are not uncommon in DRC, such as beliefs that HIV transmission can occur through using the same dishes or that a sick child is associated with witchcraft (Sabuni, 2007; Simbaya et al., 2005). Child fostering is likely more common for HIV-positive young people who had lost one or both of their biological parents; and the relationship between caregiver and child could have implications for how they interact and communicate.

While about half of parents/caregivers reported talking about sex with their child—likely influenced by the child’s HIV status—it was still not a vast majority. This means that many parents/caregivers have not begun the discussion about sex and some do not have the intentions to do so. Other studies in the African context (i.e., Nigeria and Kenya) have reported low levels of communication among parents and their children, ranging 27-39% (Kawai et al., 2008; Kiragu et al., 1997; Mathew et al., 2006). Communication prevalence in the lower range could be explained by studies conducted in rural settings, where sexual matters largely remain taboo compared to more modern, urban settings such as Kinshasa. The current climate regarding parent-child communication about sex, including HIV/AIDS, in the African context has changed greatly in the last decade and especially in the face of an HIV epidemic. While many parents and caregivers are still coming around to the idea that communication can influence their child’s sexual behaviors, it is important to understand how parents and caregivers, who do talk to their HIV-positive children, decide to do so and what they say.

Disclosure of the child's HIV status to the child had a noticeable impact on the content of communication about sex. When a child was not aware of their HIV status, information provided by parents/caregivers for reasons not to have sex was, at times, misleading. Some parents/caregivers warned their children that they could contract HIV if they had sex. This was used as a scare tactic or deterrent in order to influence the child's sexual behavior without having to tell the child he or she was already HIV positive. While, in this study, misleading information appears to be related to a child not knowing their HIV status, other studies in the African context have also documented general "fear-arousing" tactics in matters related to sex communication with youth (Izugbara, 2008). This could be that, for children who know their HIV status, fear tactics are simply not useful and knowledge of their status alone can influence behavior. Since we found that parents/caregivers with children who do not know their status were more likely to give misleading information about sexual matters, understanding some of the broader barriers related to communication and disclosure of HIV status to children is useful. Vaz and colleagues (2008b) conducted a study regarding status disclosure to children in Kinshasa, DRC among youth age 10-21 and their caregivers. They found that information about HIV status was not always clearly communicated to the child, as nearly 50% had no information about their health, 15% had partial information without disclosing their status, and 33% had misleading information (Vaz, et al., 2008b). Based on our findings, it appears that when parents/caregivers are not open about the HIV status of the child with the child, it also compromises the openness they are able to have in matters related to communication about sex.

When parents/caregivers did report talking about sex, they often waited (or planned to wait) until puberty or until the child showed signs of starting to have sex. Most parents/caregivers had an idea of what age they wanted to start talking to their child, mainly

around the age of puberty; and for females, the onset of menstruation often provided the opportunity to talk about sex. Another study in Kinshasa also found that age was one of the primary reasons for disclosure of HIV status to the child (Vaz et al., 2008b), showing again that status disclosure and communication about sex may have similar process and timing characteristics. In other cases, being too young influenced the parent/caregiver not to approach the subject of sex for fears that it might encourage the child to start having sex. Similar findings have been documented among Nigerian parents, as many began talking about sex according to the child's age and physical development; and Nigerian parents also expressed similar fears that if a child was too young, talking about sex might influence sexual debut (Izugbara, 2008). Findings in the U.S. also show that mothers of African American inner-city youth have reservations about talking about sex for fears of encouraging sexual behavior (Jaccard, Dittus, & Gordan, 2002). The timing of talking about sex and how to protect oneself should occur at younger ages, before the child becomes sexually active. National campaigns in the U.S., for example, suggest that talking with children about sex should be a continuous flow that starts as early as possible. Information should fit with the child's age and developmental stage and talks about pregnancy and how they can protect themselves should start by 11- or 12-years old (Talkingwithkids.org, 2008). There are no known guidelines for parents on talking about sex with children who are already living with HIV. However, if parents or caregivers wait to talk until after the child has become sexually active, especially for those who are unaware of their HIV status, transmission of the virus becomes a very real danger.

The content of communication on sexual matters primarily emphasized the dangers of having sex. The risk of pregnancy or getting a female pregnant and HIV transmission risk (for children who were aware of their status) constituted the primary themes for what

parents/caregivers reported talking about when discussing sex with their child. Parents/caregivers were also apt to offer advice to the child on how to protect themselves. These findings were consistent with those of U.S. and Nigerian parents who also talked about sexual matters in terms of risk and emphasize abstinence and waiting until marriage (Sneed, 2008; Izugbara, 2008). One difference is that in our study, participants offered some advice beyond abstinence (i.e., condom use and no multiple partners), while Nigerian parents avoided these subjects (Izugbara, 2008). One explanation for the difference is that our participants/caregivers were recruited from HIV care and treatment clinics, where education is likely available to parents/caregivers; and secondly, due to the nature of their child's illness, communication about sex beyond abstinence is more likely if a caregiver is concerned about transmission risk.

In our study, the content of communication about sex differed by gender. Male children were told more often to take precautions and be careful, while the discussion with females was more negative in nature, emphasizing the importance becoming more prudent and, in some cases, females were told they would die if they became pregnant or would not be supported. Gender differences in the communication about sex are consistent with other findings in the African context, namely Ghana (Kumi-Kyereme et al., 2007). Information about sex given by parents/caregiver should be equally available and truthful for both male and female children. Women, age 15-49, in Kinshasa, DRC have almost twice the prevalence of HIV compared to men (2.3% versus 1.3%; DHS, 2008). If female children do not have accurate knowledge on how to protect themselves when they do become sexually active, they would not have the tools or information needed in order to make healthy decisions about their sexual life.

In summary, while there are similarities in the U.S. and African context for reasons for communication about sex (e.g., age, puberty, and child's behavior) and content of discussion

(e.g., abstinence until marriage and misinformation about sexual matters), there are several differences in communication that are unique to HIV-positive young people living in Kinshasa. First, though communication across many African countries is low, the higher percentage of parents/caregivers reporting communication about sex is likely due to the nature of having a child that is HIV positive, with sexual intercourse as a primary risk for transmission. Second, while abstinence was a large theme in discussions on how to protect oneself, parents/caregivers also provided advice on reducing number of partners and condom use. Avoiding sharp objects was also emphasized. It is important to note that these differences in reported discussions with an HIV-positive young person could also be influenced by social desirability. Parent/caregivers may have received sexual health education at their child's HIV treatment and care clinic and may have felt obligated to answer in ways that were consistent with the education they received. Or, even more generally, parents/caregivers could have answered in ways they thought the interviewer was expecting. Third, for those who were aware of their status, parents/caregivers mentioned disclosure of the child's status as a primary reason for communication about sex. Among parents/caregivers with children who did not know their HIV status, communication about sexual matters suffered most from misleading information and the use of fear tactics. Overall, the HIV status of young people in our study influenced motivation for communication about sex, as well as the type of additional content discussed with an HIV-positive young person.

The primary strength of this paper is the novel identification of reasons and content of communication about sex with an HIV-positive young person by parents/caregivers, for which there is little information and no known studies in the African context; however, this study is not without limitations. First, and foremost, the larger study from where the data were drawn was not specifically designed to look solely at communication about sex between parents/caregivers and

their children. The depth of information is limited to interview questions which were focused and direct in nature without extra probing as compared to more traditional qualitative interviews, which would allow the participant to speak more freely with probing from the interviewer to help guide the participant through a reflective process. Second, we did not explore the frequency of communication about sex. Martino, Elliot, Corona, Kanouse, & Schuster (2008) found that adolescents whose sexual communication with their parents occurred more often felt closer to their parents and perceived that discussions with their parents about sex occurred with greater openness compared to adolescents who talked about sex less often with their parents. Third, there is evidence that a parent's own HIV status influences whether they communicate child's status to the child (DeMatteo et al., 2002) and, thus, it could influence whether they talk about sex with the child as well. However, information on the caregiver's status was not collected. Fourth, the mode of HIV acquisition of the child and cognitive development were not assessed. Delays in development are more likely for perinatally-infected children (Smith et al., 2006). Taken together, and even separately, mode of acquisition and/or cognitive development could have influenced whether a parent/caregiver felt the child was ready for discussions on sexually-related matters, although this was not raised independently as an issue. Potential differences in parenting behavior, for example, between parents of children who were perinatally infected versus through sexual contact could provide more insight into tailoring intervention strategies and practical implications.

Lastly, this study was exploratory in nature aiming to provide further research questions for intervention development. To increase the depth of knowledge of communication about sex, a more traditional *qualitative study* that verifies our findings and continues to explore talking about sex would greatly benefit this area of research. In addition, a subsequent larger *quantitative*

study would contribute to increasing generalizability to all HIV-positive young people in Kinshasa. Over 90% (n=47/52) of participants in this study reported that they would participate in a program for parents/caregivers with HIV-positive children. As such, future research should include an assessment of how best, its acceptability, and in what setting to deliver education for how to talk about sex to parents/caregivers of HIV-positive young people.

5.6 Conclusion

Communication about sexual matters has long been established as an important influence on the attitudes, beliefs, and sexual risk behaviors of young people. Further research is needed in the area of communication about sex with HIV-positive young people to expand on our findings and, secondly, apply them to the development of research questions for HIV transmission risk reduction studies, such as questions regarding acceptability by parents/caregivers or providers. The following recommendations are offered for consideration of future intervention development studies and as guidelines for talking about sex with HIV-positive young people, should future studies be consistent with our findings:

- *Communication in the context of the HIV disclosure process.* Primary reasons for disclosure of status to a child were similar to the reasons given by parents/caregivers for communication about sex (i.e., age and need to protect oneself). Additionally, in both situations, some parents/caregivers provided partial or even misleading information. It is highly recommended that HIV care providers give additional information, support, and skill training to parents/caregivers on communication about sex during the process of HIV disclosure to the child. If the child or young person is already aware of their status, communication about sex could be framed in the context of their status. Following the research on HIV disclosure to children in Kinshasa by Vaz et al. (2008b), awareness of

the importance of disclosure and support have increased among HIV clinics and guidelines have been established for parents (see Appendix, “Processus de Divulgation de Serostatut aux Mineurs”). As such, this creates an opportunity to include support for parents/caregivers on how to communicate about sex with a child/young person in the context of HIV status disclosure; and future research could assess whether parents/caregivers would accept support on talking about sex with their child and whether providers would also accept this as part of the disclosure process guidelines.

- *Timing of discussion.* Initiating talks about sex were mistimed by many parents/caregivers, as they often waited until after puberty or until the child showed signs of already having sex. Beginning the discussion at younger ages is recommended in order to influence the delay of sexual debut or other methods of sexual risk reduction (i.e., condom use and number of partners).
- *Content of communication about sex.* Parents/caregivers should be knowledgeable in the manners in which a young person can protect themselves and others against transmission of HIV. Some parents/caregivers gave advice on abstinence, condom use, and reducing number of partners; however, other parents/caregivers were inaccurate in their beliefs about household activities or objects that the child should avoid (i.e., tooth brush, washing gloves, food sharing). Accurate knowledge on the part of the parent/caregiver will assist in improved content for communication about sex with the child. To ensure this occurs, providers and others who deliver sexual health education should also be knowledgeable on sexual matters. Lastly, the discussion should be equally available and accurate for both male and female children, giving both the same chance to make informed decisions about their sexual life.

This research contributes to formative research on strategies in HIV/AIDS prevention, specifically for transmission risk reduction interventions in the Democratic Republic of the Congo. Reasons and content of communication about sex among parents/caregivers and their HIV-positive young person were identified and recommendations for future direction in research were provided. As HIV-positive young people become aware of their status and have more open communication about sex with their parents/caregivers, this provides them the opportunity to develop a critical understanding and appreciation for how their decisions affect their own health as well as the health of others. In thinking about the broader context, while we continue to increase our knowledge on parent/caregiver influence on HIV-positive young people's sexual health, we should also think about strategies at more macro levels of influence (e.g., societal, community, etc.), for example media campaigns addressing the importance of parent/caregiver and child communication, that would compliment strategies at the individual and interpersonal levels. Addressing the acquisition and transmission of HIV at multiple levels of influence is likely to have the greatest impact on the battle against HIV/AIDS.

Table 5.1. Characteristics of Primary Caregiver and Child Participants, n = 52 pairs

Primary Caregiver Characteristics	
Sex of Respondent	40 female, 12 males
Age	Range 22-77, average = 46.2
Relationship to child	Biological Mother, n = 16 (32%) Biological Father, n = 6 (12%) Grandparent, n = 5 (10%) Sibling, n = 2 (4%) Father's sister, n = 3 (6%) Mother's younger sister, n = 3 (6%) Mother's older sister, n = 6 (12%) Mother's brother, n = 1 (2%) Other, n = 8 (16%)
Child Characteristics	
Sex	26 females, 26 males
Age	Range 14-19, average = 15.9
Aware of HIV status	50% (n = 26)
Number of parents lost	Both parents lost = 25% One parent lost = 42% No parents lost = 33%
Time since HIV diagnosis	Range 0-4 years, average = 1.4

Table 5.2. Primary caregiver beliefs about the sexual experience of their child compared to the young person's self-report on their sexual experience.

Primary Caregiver Belief about Child	Self-Reported Sexual Experience from Youth Interview		Total*
	Never Had Sex	Has Had Sex	
Never Had Sex	28	4	32
Has Had Sex	1	2	3
Don't Know	10	2	12

* 5 children did not report sexual activity

CHAPTER SIX: CONCLUSION

6.1 Significance of Dissertation

Traditionally in Africa, and until recently in the U.S., HIV prevention efforts have focused on the primary prevention of HIV infection—that is, preventions targeted at uninfected people in general and uninfected people at high risk (e.g., sex workers, men who have sex with men, and intravenous drug users). Sexual transmission of HIV, however, involves interactions between an HIV-uninfected individual and an HIV-infected individual; thus prevention programs for both groups are warranted. As HIV-positive people live longer and healthier lives with the increased availability of antiretroviral treatment (ARVs) (UNAIDS, 1998), prevention programs that target people living with HIV are vital.

Efforts in transmission risk reduction, or “positive prevention,” using various strategies have proven to be efficacious in transmission risk reduction (Crepaz et al., 2006; Kalichman et al., 2001; Patterson, Shaw, & Semple, 2003; Richardson et al., 2004; Rotheram-Borus et al., 2001; Wingwood et al., 2004; Wolitski, Parson, & Gomez, 2004). Interventions that specifically recruit from HIV clinics have also proven successful. Both less intensive strategies (e.g., delivery of brief intervention messages at HIV clinics) and more intensive strategies (e.g., multiple weekly intervention sessions) have demonstrated their ability to reduce HIV transmission risk behaviors among HIV-positive individuals (Crepaz & Marks, 2002; Richardson et al., 2004; Wingwood et al., 2004). Crepaz and colleagues (2006) conducted a review of prevention interventions targeting people living with HIV and identified several characteristics of

interventions that were successful in reducing HIV risk behaviors. Namely, the most efficacious interventions included: the use of behavioral theory, strategy designs that addressed specific behaviors, delivery of intervention by health care providers or counselors to individuals and in an intensive manner, delivery of intervention where the person received medical services, skills building, and other issues related to medical adherence, mental health, and HIV risk behaviors (Crepaz et al., 2006). While few of these studies were conducted among young people, the identification of successful strategies to reduce HIV risk behaviors can assist in designing interventions that target young people living with HIV.

It is also important to consider the context in which the HIV-positive young person lives in targeting positive prevention efforts. Specifically in Africa, for interventions aimed at HIV-positive persons, Bunnell, Mermin, & De Cock (2006) propose 10 approaches, which prioritize strategies with the largest potential impact on transmission reduction. Some of these strategies include: ensuring individuals with HIV learn their status to facilitate early entry into care and treatment, supporting HIV status disclosure by HIV-positive individuals to involve partner in prevention, care and support, and behavioral interventions for individuals with HIV to reduce HIV transmission risk. While these recommendations are not particularly focused on HIV-positive young people, in combination with evidence from the U.S. on successful positive prevention interventions, we can use previous recommendations and strategies to guide the formative process in gathering information that would help develop interventions aimed at other specific populations and sub-groups.

Specifically in DRC, studies have shown that young people are engaging in sexually risky behaviors (UNAIDS, 2006; Kalambayi et al., 1998; Ecole de Sante Publique de Kinshasa, 2006). With an average that is higher than in surrounding countries, 28% of young people in

DRC, age 15-24, report sexual intercourse before the age of 15 years, compared to Kenya (21%) and Uganda (15%), for example. In addition, the percentage of young people, age 15-24, who can correctly identify ways of preventing the sexual transmission of HIV is poor, 29% for males and 22% for females (DHS, 2008). There is no known information regarding the sexual risk behaviors of HIV-positive young people in Kinshasa, DRC. However, while research from the U.S. has shown that many HIV-positive youth who are aware of their HIV status delay or decrease their sexual risk behavior (Lightfoot, Rotheram-Borus & Tevendale, 2007), a significant number of sexually active HIV-positive youth continue to engage in risky behavior (Johnson & Buzducea, 2007). Up to 47% of HIV-positive youth report unprotected sex at last intercourse (Murphy et al., 2001) and this presents a major public health concern in the efforts to control HIV/AIDS.

To facilitate and inform the development of culturally sensitive strategies and interventions aimed at HIV transmission risk reduction, formative research is imperative. This type of research, focused on the collection and analysis of data on the demographic and behavioral characteristics of a specific population, can inform the development of interventions, in this case, among HIV-positive young people in Kinshasa, the Democratic Republic of the Congo.

This dissertation contributes to formative research on strategies in HIV/AIDS prevention, specifically to inform the development of transmission risk reduction interventions involving parents or caregivers of HIV-positive young people. Effective interventions to help HIV-positive young people practice safer sex are needed. These transmission risk reduction interventions will need to be culturally sensitive to be most effective.

6.2 Findings Overview

6.2.1 Specific Aim #1

The first aim of this dissertation was to examine the relationships between perceived parental/caregiver monitoring, perceived social support, and sexual risk behaviors among young people living with HIV. We found that the majority of participants reported low parental/caregiver monitoring and low social support. Participants were relatively young at first intercourse (average=15.6 years) and many had more than 3 lifetime number of sexual partners (average=3.5). While approximately 80% reported no sex or protected sex at their last intercourse in the past 12 months, almost 20% reported unprotected sex at last intercourse. The influence of monitoring by a caregiver on sexual risk behaviors varied by the amount of social support the youth perceived, such that more social support strengthened the relationship between parental monitoring and sexual risk behavior; however, the interaction between monitoring and social support weakened when adjusted for time-since-HIV-diagnosis.

In this study, we used an adapted parental monitoring scale and social support scale, both from the U.S. It is likely that these scales did not truly capture the unique experience of HIV-positive young people living in Kinshasa. Culturally specific factors (e.g., child fostering, gender roles and HIV-related stigma) may provide insight into what the scales may not have fully captured, implying that developing new scales and measures may help capture the larger picture. Specific recommendations are provided in section 6.3, which could contribute to a better understanding of the relationships between parental monitoring, social support, and sexual risk behavior.

Still, the findings of this study were consistent with literature, primarily from the U.S., showing that parental/caregiver influence and social support can work together in combination to

influence general family well-being and, more specifically, sexual risk behaviors (Crosby et al., 2001; Henry et al., 2006). In particular, parental support and parental monitoring were associated with a balanced overall family functioning according to Henry and colleagues (2006) in a study of ninth and tenth grade students. Another U.S. study among African American female youth found that living with a mother in a supportive family decreased the likelihood of reporting HIV risk behaviors (i.e., not using a condom, lack of communication with a sexual partner, and sex with a non-steady partner) (Crosby et al., 2001). While there is evidence of how supportive families can influence the behaviors of young people, primarily in the U.S., there is little information on the interactive nature of the relationship between parental/caregiver monitoring and perceived social support in the African context. However, because extended families play a significant role in the lives and in supporting young people in DRC, especially among HIV-positive young people who may be orphaned due to HIV/AIDS and cared for by relatives, it was important to understand the links between social support and parental/caregiver influence.

Individually, however, there is support for the influence of parental monitoring on sexual behavior and, second, there is evidence for the influence of social support on sexual behavior in the African context. No known studies have examined the combined effects of parental monitoring and social support on sexual behavior, especially among HIV-positive young people. Researchers in Ghana found that, for both males and females, more parental monitoring was associated with less recent sexual activity in the last twelve months among youth aged 12-19 years (Kumi-Kyereme, Awusabo-Asare, Biddlecom, & Tanle, 2007). Additionally, research has shown that there is an association between social support and condom use among women living with HIV in South Africa (Gaede et al., 2006). While these findings do not speak to an interactive nature of parenting and social support, it gives us some confidence that such a

relationship is possible, especially given the findings of this dissertation. The extended family unit is a large part of the daily lives of young people in the African context and, as a result, family members play important roles in both parental/caregiver monitoring and in providing social support to young people.

This dissertation adds to the current literature and knowledge in the area of parental monitoring and social support by demonstrating that, for HIV positive young people in DRC, social support can impact the relationship between parental/caregiver monitoring and sexual risk behaviors. That is, more perceived social support can strengthen the relationship between a parent/caregiver who monitors their child's whereabouts and whether the child practices safer HIV transmission risk reduction behaviors, such as avoiding sexual contact or using a condom. We also suggest that parent-child relationships in the African context, especially for parents/caregivers and their HIV-positive child, may not be captured best by Western-developed scales. To further understand sexual risk behaviors and capture the meaning of monitoring by parents/caregivers and perceived social support, future research should consider other contextual aspects which contribute to the complexity of relationships within the family and in the general unique experience of HIV-positive young people (e.g., child fostering, HIV caregiver burden, gender norms, and HIV-related stigma; see Section 6.3). For future formative work in this area, scale development that is both culturally and contextually specific is recommended to push forth efforts in gathering scientifically sound information to inform intervention design and development. Such research that aims to inform HIV prevention interventions which target HIV-positive persons, particularly young people, will contribute to efforts in controlling and preventing the spread of HIV.

6.2.2 Specific Aim #2

The second dissertation aim was to describe, from the perspective of the parents/caregivers, the norms and patterns of communication about sex with their HIV-positive child. Unlike other published studies from Africa on parent-child communication about sex, more than 50% of caregivers reported talking to their child about sex and another 25% intended to do so. Due to the nature of the young person's illness, parents and caregivers are faced with a particular motivation to talk about sex—HIV transmission prevention. Hence, the young person's HIV status, in and of itself, may have served as a cue-to-action for parents and caregivers to think about and initiate conversations about sex. Additionally, as many of the young people in the study were taking antiretroviral treatment, parents/caregivers could perceive them to be healthy (rather than sick and unable to socialize), giving them even more motivation to prevent sexually risky behaviors by making sure their child is aware of the consequences of unsafe sexual practices.

Most parents and caregivers mentioned that they talked about sex with their HIV-positive child (or planned to) because the child was getting older. The reasons given by parents/caregivers for communication about sex were similar for those who had children who were aware of their HIV status compared to those with children who were not aware of their status; however, most waited until after puberty or until the child already started having sex to communicate with them about sexual matters. When it came to having the conversation about sex, most emphasized the dangers of having sex. However, male children were told to be more careful compared to female children, who were told to avoid sexual contact. For children who did not know their status, some parents/caregivers providing misleading information or used

scare tactics to influence their child's sexual behavior, even mentioning that they could contract HIV.

The findings from this dissertation address a gap in the current literature about parental communication, as very little attention has been placed on communication concerning sexual matters with a child or young person who is already HIV-positive, especially in the African context. While no known studies have reported on parental communication with an HIV-positive child, other studies in the African context (in which HIV status is not reported) have also shown low levels of communication about sex among parents and their children, ranging 27-39% in Nigeria and Kenya (Kawai et al., 2008; Kiragu, Obwaka, Odallo, & Van Hulzen, 1997; Mathew, Shugaba, & Ogala, 2006).

Research among Nigerian parents is also consistent with the findings of this dissertation, demonstrating that many parents began talking about sex according to the child's age and physical development; and Nigerian parents also expressed similar fears that if a child were too young, talking about sex might influence sexual debut (Izugbara, 2007). Among those who did communicate about sex, the content of communication and gender differences were consistent with other literature in U.S. and African contexts, showing that many parents talked about sexual matters in terms of risk, emphasizing abstinence and waiting until marriage; and the conversation was different for male children compared to females (Sneed, 2008; Izugbara, 2007; Kumi-Kyereme, Awusabo-Asare, Biddlecom, & Tanle, 2007).

Studies in the African context have also documented general "fear-arousing" tactics in matters related to sex communication with youth (Izugbara, 2007), as we revealed that some parents/caregivers provided misleading information, largely to children who did not know their HIV status. Specifically in the DRC context, Vaz and colleagues (2008) also found that health

information was not always clearly communicated to the child. Particularly regarding communication about a child's HIV status, the vast majority of children either received no information about their health, partial information without disclosing their status, or misleading information (Vaz, et al., 2008). This dissertation expands on the research in the DRC by showing that children who knew their status were more likely to have parents/caregivers who were also aware of their child's sexual experience. As such, it appears that when parents/caregivers are not open about the HIV status of the child with the child, it also compromises the openness they are able to have in matters related to communication about sex.

In both specific aims of this dissertation, the findings were consistent with literature in the U.S. and African context. Together, they demonstrate that parental behaviors, whether by a biological parent or a caregiver, can influence the sexual risk behavior of their HIV-positive child. Specifically, parental/caregiver monitoring and communication about sex are important parenting behaviors to consider in positive prevention efforts aimed at young people living with HIV in the African context. Additionally, the findings were able to fill in gaps where information was not available, especially related to young people living with HIV. Particularly, in the lives of HIV-positive young people, social support may strengthen the relationship between parental monitoring and sexual risk behavior. Additionally, while communication about sex was more prevalent in our study compared to other findings, communication to children often included misleading information among those who did not know their HIV status. This new information not only contributes and expands on the existing literature, it also provides an opportunity to offer guidance and recommendations for research and practice aimed at young people living with HIV in Kinshasa, DRC.

6.3 Implications: Research, Practice, and Theory

Parents and primary caregivers have a strong influence on the lives of their children and they play a critical role, particularly in the transition from childhood to young adulthood.

Especially for parents/caregivers of HIV-positive children, the impact they can have on their child's behavior has both individual and public health implications.

Research and Practice Implications

In this dissertation, we saw that the influence of parental/caregiver monitoring and social support on sexual risk behavior was in the right hypothesized direction, though not conclusive.

Family relationships among HIV-positive young people can be complex and future research should consider other contextual aspects in the experience of HIV-positive young people. To help further capture the nature of parental/caregiver monitoring, social support and sexual risk behaviors, recommendations provided in Chapter 4 included, understanding:

(1) Familial relationships in a child fostering situation: Living in an extended family household and child fostering may be particularly important for young people living with HIV, since they are prone to experiencing the loss of their parents due to ill health or HIV/AIDS. To better understand the type of monitoring and support a fostered child receives from the host family, survey questions should ask specifically whether the child is cared for by a specific adult or whether several adults play a role in the child's care. In addition, to better understand social support, questions should probe from whom the child is receiving different types of support. Teasing out from whom the child receives care and from whom they receive support will likely paint a better picture of the family relationships in the extended family and child fostering situation.

(2) HIV caregiver burden: The nature of family relationships and whether a child receives support or parental/caregiver monitoring could change in the face of adversity. For the case of HIV-positive young people who are hosted by other relatives, the child could be seen as a burden rather than a normal part of the family unit (Vaz, 2008; De Herdt, 2004, Ziemke, 2001). If the child is seen as a burden-- for example, due to the stigmatizing nature of their serostatus, fear, or resentment of taking care of an ill child-- caregivers may not prioritize or be motivated to interact with the fostered child. This may occur to the extent of being neglected and isolated from the family, neither being monitored nor supported in any way. Future surveys should include a measure of HIV caregiver burden.

(3) Gender roles related to parent-child relationships: Many Congolese customs and practices are divided along gender lines. For example, young girls often have more responsibilities in assisting their mother and other adult women in daily household activities compared to young males, who are most likely to have permission to spend more time outside the household (Warkentin, 2004). Parenting practices related to child gender roles may be an important factor in understanding the type of parental/caregiver monitoring, direct or passive, which occurs within the Congolese family. Future survey questions related to parental monitoring in the Congolese context should include questions to parents about their thoughts about monitoring male versus female children. Although our findings did show that males were more likely to report low parental/caregiver monitoring, gathering qualitative information on parent/caregiver beliefs on gender roles will help to better understand the relationship between gender and parental/caregiver monitoring.

(4) HIV-related stigma: Perceived social support may be greatly impacted by whether a person perceived experiencing HIV-related stigma. In another study with this sample, Mupenda

et. al., (2008) found that the majority of HIV-positive young people reported high perceived stigma and that higher perceived stigma was associated with less social support. As such, future studies should continue to consider the relationship between HIV-related stigma and social support.

(5) Awareness of HIV status and (6) Time since diagnosis: Of clinical importance was the finding that two people who were *not aware* of their status reported unprotected sex. Time-since-diagnosis also appears to account for whether a participant reported unprotected sex. As such, being aware of one's status and time-since-diagnosis emerged as important factors to consider in understanding sexually risky behavior and these measures should continue to be assessed in future studies.

We also found that many parents/caregivers reported talking about sex with their child. While a more traditional qualitative study, coupled with a larger quantitative study, would greatly benefit this area of research, the following recommendations were offered in Chapter 5 as consideration for future intervention development studies and as potential guidelines for talking about sex with an HIV-positive young person:

(1) Communication in the context of HIV disclosure process: As guidelines have been recently established regarding parental support in the disclosure process, the opportunity exists to additionally include support for parents/caregivers on how to communicate about sex with a child/young person—and future research should assess the possibility and acceptance for both parents/caregivers and providers.

(2) Timing of talking about sex: Beginning the discussion at younger ages is recommended in order to influence the delay of sexual debut or other methods of sexual risk

reduction (i.e., condom use and number of partners). As the child gets older, information should fit the child's age and developmental stage.

(3) Content of communication about sex: While some parents/caregivers gave advice on abstinence, condom use, and reducing number of partners, others were inaccurate in their advice or provided misleading information. Accurate knowledge on the part of the parent/caregiver will assist in improved content for communication about sex with the child. Parent/caregivers should also learn how discussions about sex should be equally available and accurate for male and female children, giving both the same chance to make informed decisions about their sexual life. To ensure this occurs, health care providers and others who deliver sexual health education should also be knowledgeable on sexual matters and communication skills.

All together, findings from this dissertation and the recommendations provided, give context to a larger picture of how parenting/caregiver behaviors can influence the sexual risk behaviors of their HIV-positive child. If future qualitative and quantitative research continues to support the findings of the dissertation, implications for practice can have a profound effect on how parents/caregivers are involved in transmission risk reduction strategies. This dissertation is very timely, as it follows several important studies on HIV disclosure to children and other important work and practices among HIV-positive children and young people in Kinshasa.

Primarily, following the research on HIV disclosure to children in Kinshasa by Vaz et al. (2008), awareness of the importance of disclosure and support have increased among HIV care and treatment clinics, and guidelines have been established for parents/caregivers (see Appendix, A.3). These guidelines outline definitions, key players, and even options for parents/caregivers for ways to disclose the child's HIV status to the child. As we observe an increase in disclosure support and recognition of the important role of parents/caregivers in the lives of their HIV-

positive children, this creates an opportunity to include additional support for parents/caregivers on how to influence sexual risk behaviors through monitoring, social support, and communication about sex (as developmentally appropriate). Additional guidelines and education to parents/caregivers in matters related to influencing sexual risk behaviors can be provided in the context of HIV disclosure support that is already taking shape; and research which assesses this possibility and acceptance by both parents/caregivers and health care providers would be valuable in informing future practices in HIV-related care.

Theoretical Implications

From a theoretical perspective, the dissertation was based both in empirical evidence surrounding parental influence and, in addition, was framed within theoretical models proposed by Heaney and Israel (2002) addressing social support and a parent-based expansion of the theory of planned behavior (Hutchinson & Wood, 2007) to understand parental communication (see Appendix for model figures). Based on the findings of this dissertation and recommendations offered, the use of the fully expanded model of the theory of planned behavior, which was created in the context of a parent-based HIV intervention, is recommended for future research and intervention development. Many of the ideas and constructs from this dissertation fall into the theoretical concepts that make up the expanded model. For example, factors related to parents/caregivers include beliefs about sex communication timing or beliefs about parental monitoring (behavior beliefs), norms regarding differences in parenting behaviors towards male children compared to female child (subjective norms), and the actual parental influence reported by parents/caregivers (the external influences on the child or young person). Given this framework, parental factors would influence those of the child or young person including, for example, attitudes about condom use or talking with parents about sex (behavioral beliefs),

beliefs about whether others are using condoms or talking about sex (subjective norms), and the reported sexual risk behavior (the HIV-related risk behavior outcome). Future research should also include concepts related to behavioral control (or beliefs about factors that deter or facilitate behavior) and intentions to perform a specific behavior.

The application of this theoretical framework can further benefit the understanding of factors associated with parenting behaviors as they directly relate or link to factors that influence a young person's sexual behavior. Hutchinson and Woods (2007) stress the importance of understanding parental/caregiver processes and behaviors which are unique in a specific culture in order to inform the design of culture-specific parent-based HIV interventions; and it is the hope that this dissertation will inspire the application of this model in future research and intervention development aimed at HIV-positive young people in DRC and across other countries, backgrounds, and cultures.

6.4 Strengths and Limitations

A major strength of this dissertation was the focus on the formative process of behavioral intervention research. Conducting formative research provides an excellent opportunity to explore factors that influence sexual behaviors in young people living with HIV. As the research was conducted in Kinshasa, the Democratic Republic of the Congo, culturally sensitive information can help to best inform strategies in this specific region and sub-group. This dissertation identified important relationships for parental/caregiver factors that could influence sexual risk behavior and it identified reasons and content of communication about sex with an HIV-positive young person by parents/caregivers. There is little research examining these factors among HIV-positive young people and no known intervention studies in the African context; however, this dissertation research is not without limitations.

While the formative and exploratory nature of this research was emphasized throughout, sample size and power were limitations in the quantitative analyses. In the first dissertation aim, an additional limitation included recalling sexual behavior for the last 12 months, as opposed to the last 30 days, for example, which would likely be more accurate. In addition, the parental monitoring and social support scales may not have truly captured the unique situation and experience of HIV-positive young people living in Kinshasa, DRC. For future formative work in this area, scale development that is both culturally and contextually specific is recommended to push forth efforts in gathering scientifically sound information to inform intervention design and development.

In the second dissertation aim, the larger study from where the data was drawn was not specifically designed to look solely at communication about sex between parents/caregivers and their children. The depth of information is limited to interview questions which were focused and direct in nature without extra probing, as compared to more traditional qualitative interviews, which allows the interviewer to guide the participant in a reflective process. Findings based on the second aim also did not explore the frequency of communication about sex, though there is evidence that frequency of communication is associated with greater openness about sexual matters with parents/caregivers. Additionally, while there is evidence that a parent's own HIV status can influence communication, information on the parent/caregiver's status was not collected. Information was also not collected on mode of HIV acquisition of the child and cognitive development, though there is evidence that delays in development are more likely for perinatally-infected children (Smith et al., 2006), which may influence parenting behaviors, such as communication about sex, if the child is perceived to be cognitively delayed. Parenting behaviors may also be different towards children who acquired HIV through their own sexual

behavior; and understanding that difference in parenting behavior between parents of children who were perinatally infected versus through sexual contact could provide more insight into tailoring intervention strategies and practical implications.

It is important to note that social desirability is a potential limitation in both specific aims of this dissertation research. Parents/caregivers and their HIV-positive child may have received sexual health education at the child's HIV treatment and care clinic and, although interviewers were independent of the service provider and clinic, participants may have felt obligated to answer in ways that were consistent with the education they received. Or, even more generally, participants could have answered in ways they thought the interviewer was expecting (e.g., young people may be more likely to report protected sex and parents/caregivers may be more likely to report talking about sex with their HIV-positive child).

6.5 Conclusion

As a whole, exploring parental/caregiver monitoring, social support, and parent-child communication about sex has provided a better understanding of parent/caregiver behaviors for those with an HIV-positive child in Kinshasa, DRC. We realize that not all caregivers are biological parents and many HIV-positive young people are under the care of other family members. We found that, for young people living with HIV, more social support was suggestive of a stronger relationship between parental/caregiver monitoring and the likelihood of not having sex or having protected sex. We also show that, likely due to the nature of the child having HIV, the majority of parents or caregivers reported having talked with their child about sex. Together, combining efforts and applying various parenting strategies, such as monitoring a child, providing social support, and having discussions about sex, is likely to be more effective in influencing a child's sexual risk behavior than each strategy alone. No known studies have

explored these relationships among HIV-positive young people, especially in the African context—and the implications are great. HIV prevention efforts, which enlist the help of parents, have most often come from the perspective of avoiding pregnancy and new infections for seronegative children. This dissertation suggests that the behaviors of parents and caregivers with HIV-positive children were associated with their child's sexually risky behavior, which has implications for health outcomes for the HIV-positive child and, additionally, translates into reducing the risk of HIV transmission to others. With over 90% of parents/caregivers (who completed semi-structured interviews) reporting that they would participate in an HIV program, this suggests great potential for reaching out to parents/caregivers with HIV-positive children to participate in such interventions.

In thinking about the broader context, as we continue to increase our knowledge about parent/caregiver influence on HIV-positive young people's sexual health, we should also think about strategies at more macro levels of influence (e.g., societal, community, etc.), for example media campaigns addressing the importance of parent/caregiver and child communication, that would compliment strategies at the individual and interpersonal levels. Addressing both the acquisition and transmission of HIV at multiple levels of influence is likely to have the greatest impact on the battle against HIV/AIDS.

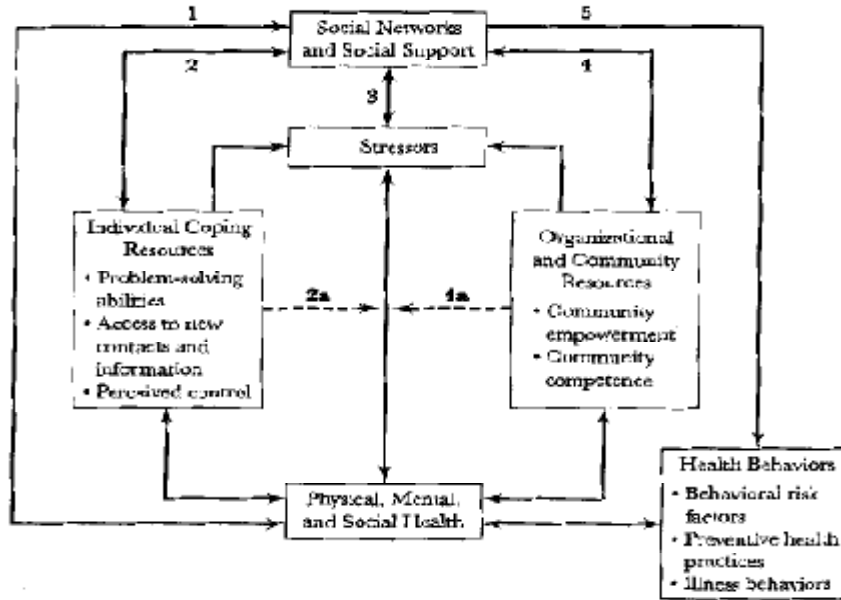
Especially in Sub-Saharan Africa, where countries are severely affected with the largest number of persons living with HIV worldwide (UNAIDS, 2007), the development of culturally sensitive strategies and interventions aimed at HIV transmission risk reduction among young people is imperative. As young people become aware of their HIV status and parents/caregivers become confident in influencing behaviors and communicating with their child about sex, HIV-

positive young people have the opportunity to develop a critical understanding and appreciation for how their decisions affect their own health, as well as the health of others.

APPENDIX

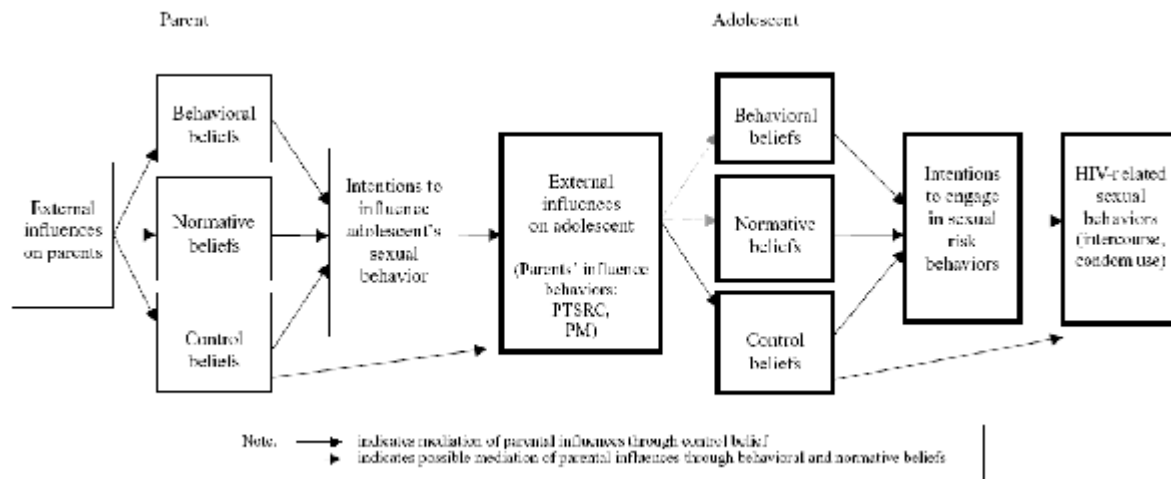
A.1 Figure of Social Support Networks and Social Support Pathways

(Heaney & Israel, 2002)



A.2. Figure of Parent-Based Expansion of the Theory of Planned Behavior

(Hutchison & Wood, 2007)



A.2 Scales

A.2.1 Parental Monitoring

1. Where is your main place of living?

Read answers to participant

1 = With parents/guardian/other family members at home.

2 = I live on my own or with my spouse.

IF 2, SKIP TO SECTION "C" # 1.

1 = Never

2 = Rarely

3 = Sometimes

4 = Most of the time

5 = Always

Q #	Question/Statement
2	My family knows where I am before/after school or work.
3	If I am going to be home late, I am expected to let my family know.
4	I tell my family who I am going to be with before I go out
5	When I go out at night, my family knows where I am.
6	I talk with my family about the plans I have with my friends
7	When I go out, my family asks me where I am going

A.2.2 Social Support

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

1 = None of the time 2 = A little of the time 3 = Some of the time 4 = Most of the time 5 = All of the time

Q #	Question/Statement
1	Someone you can count on to listen to you when you need to talk
2	Someone to turn to for suggestions about how to deal with a personal problem
3	Someone to share your most private worries and fears with
4	Someone to confide in or talk to about yourself or your problems
5	Someone who shows you love and affection
6	Someone to have a good time with
7	Someone to help you if you were confined to bed

A.3 SOP: Process of Serostatus Disclosure to Minors

Processus de Divulgence de Serostatut aux Mineurs

Vue d'ensemble

Ce SOP décrit la procédure à suivre pour divulguer le sérostatut aux enfants infectés du VIH enrôlé au projet SARA.

Définitions

- Divulgence: c'est un processus qui consiste à présenter quelque chose, à le faire connaître au public (Merriam-Webster Online, 2005-2006).
Dans le cadre du VIH, la divulgation est un processus qui donne l'information du statut VIH d'une personne à d'autres, soit l'information donnée à la personne infectée, soit par la personne infectée à quelqu'un d'autre ou l'information donnée au public.
- FPD = Fiche de Processus de Divulgence, c'est une feuille de suivi du processus de divulgation -la préparation, la divulgation proprement dite et les aspects importants post divulgationnels-. Elle présente en grandes lignes les étapes du processus. [*Voir Annexe 1 pour modèle de fiche*]

Considérations générales

- Le processus de divulgation existe comme une relation d'échange et de soutien entre le prestataire et l'enfant via le parent/tuteur afin d'annoncer à l'enfant son statut sérologique.
- Le but de la divulgation est de permettre à l'enfant de participer à ses soins en prenant connaissance du nom de sa maladie.
Pour y parvenir, il importe de créer une atmosphère de confiance entre l'enfant, son parent/tuteur, et l'équipe de soins.
- La divulgation est un processus graduel qui donne des informations appropriées à la situation de chaque mineur.
Le processus peut prendre plusieurs jours, semaines, mois ou années ; Il faudrait considérer l'âge approprié pour telle ou telle autre information à transmettre.
L'information donnée dépend de l'âge de l'enfant au début du processus, du climat familial, des questions posées par l'enfant et de son développement cognitif.
- Avec le consentement du parent/tuteur de l'enfant, la préparation à la divulgation commence à l'enrôlement de l'enfant au projet; lors de ces entretiens de préparation, nous évaluerons le degré de maturité psychologique de l'enfant et sa capacité cognitive à comprendre les choses.
- Le respect de la confidentialité du patient doit être toujours maintenu et respecté.
- Aussi longtemps l'enfant est légalement mineur, la décision finale de la divulgation revient au parent/tuteur de l'enfant.
- Les discussions avec l'enfant doivent évaluer la compréhension actuelle de l'enfant concernant sa santé et le VIH/SIDA, et sa capacité à comprendre, en corrigeant les inexactitudes.
- Il n'y a pas de délais prédéfini pour la durée du processus de divulgation.
- La situation de chaque patient est unique. Le meilleur moment de la divulgation dépend de la situation de chaque enfant, des avantages en attirés ou des risques en courus ;

- Le moment de la divulgation devrait être l'aboutissement des entretiens constants avec le parent / tuteur pour un bon suivi des renseignements donnés à l'enfant.
- Plusieurs facteurs peuvent influencer d'une manière ou d'une autre le moment de la divulgation :
 1. milieu familial,
 2. milieu scolaire,
 3. la communauté de base (l'église, le quartier,...)
 4. L'encadrement psychosocial et médical de l'enfant
 5. L'âge mental (niveau de développement)
 6. L'âge biologique de l'enfant, surtout lorsqu'il/elle arrive à l'adolescence ou s'approche à l'âge de 18 ans.
 7. Les types de questions posées par l'enfant concernant son état de santé, et la fréquence de ces questions.
 8. S'il y a des fortes suggestions que l'enfant soupçonne son statut sérologique. Par exemple : L'enfant commence à poser des problèmes par rapport aux rendez-vous ou la prise des médicaments.
- Dans le processus de divulgation, les fausses informations doivent être évitées car elles peuvent endommager la confiance entre l'enfant et l'adulte ;
 - Une fausse information est quelque chose qui n'est pas vrai ; Dire à l'enfant qu'il a une maladie autre que ce qu'il a.
 - Le personnel soignant est tenu de ne pas donner les fausses informations à l'enfant
 - Le personnel soignant est tenu également de conseiller aux parents d'éviter de donner des fausses informations.
 - Que faire en cas des fausses informations données et le personnel soignant devient au courant de ce fait ?
 - Parler avec le parent/tuteur des raisons qu'il a amené à donner ces fausses informations, les raisons pour lesquels il faut éviter les informations trompeuses, et de trouver un plan pour remédier la situation actuelle. L'essentiel est de trouver les voies de sortie. (Confère les étapes à la divulgation).
- Toutes les notes en rapport avec le processus de la divulgation seront prises sur la FPD (voir plus loin) et ladite fiche sera insérée dans le dossier médical du patient.

Étapes à suivre

Le processus de divulgation est assuré principalement par le prestataire en charge de la divulgation.

Ce processus se déroule en 3 étapes :

- 1) La préparation
- 2) L'annonce (la divulgation ppdte)
- 3) La période post divulgationnelle

1. LA PREPARATION

- La préparation est assurée principalement par la personne en charge de la divulgation et subsidiairement par l'ensemble du staff du projet.
- Pendant la préparation, s'assurer selon l'âge et le niveau de maturité de l'enfant, que les notions suivantes ont été abordées :

- La confidentialité et l'adhérence
- Les maladies aiguës et chroniques
- Les IST et moyens de prévention
- Le système immunitaire
- La relation entre le traitement et le système immunitaire
- S'assurer de la bonne compréhension de ces notions par l'enfant
- S'accorder avec le parent/tuteur sur le plan de la divulgation (Qui doit annoncer à l'enfant ; il sera assisté par Qui ; Où aura-t-il lieu ? ; Quand [lors de son anniversaire, après cet événement, pendant la consultation médicale de routine, lors d'une réunion de groupe de support,...] ; Comment cela doit-il se faire ;...)

Du consentement,

- Le prestataire va se présenter et expliquer son rôle au parent/tuteur
- Expliquer la fiche de consentement pour l'enrôlement au projet (Cfr procédure SARA d'enrôlement des participants) et relever l'aspect de la divulgation du sérostatut de l'enfant qui se fera en commun en accord avec lui.
- Expliquer le bénéfice de la divulgation du sérostatut à l'enfant.
- Répondre aux questions du parent/tuteur à ce sujet et dissiper les inquiétudes
- Expliquer au parent/tuteur la démarche à suivre (la préparation, la divulgation et la période post divulgationnelle)

Des responsabilités,

□ Rôles des prestataires

- Le prestataire assure les entretiens avec le parent/tuteur pour la divulgation du sérostatut à l'enfant dès l'enrôlement au projet.
- Le staff assiste le parent/tuteur à décider sur les informations appropriées et correctes à donner à l'enfant, même si elles ne sont pas complètes.
- Si le parent/tuteur ne veut pas divulguer à l'enfant à un certain moment, le prestataire devra
 - Noter la discussion et la décision prise sur la FPD
 - Revenir au sujet régulièrement, surtout au moment où l'enfant commence à poser beaucoup de questions au sujet de sa maladie ou lorsqu'il s'approche de l'adolescence.
- Le staff (le prestataire indiqué) organise des réunions de groupe de support des parents d'une part et des enfants d'autre part afin de renforcer la préparation à la divulgation (outils : questions d'ordre général, vidéos, BD,...)
- Le rôle du staff (le prestataire indiqué) auprès des parents/tuteurs change en fonction de l'âge du jeune patient :

Aux plus jeunes (5 ans à 12ans),
Le staff devra :

 - a) **Dire au parent/tuteur que cette tranche d'âge n'est pas le meilleur moment de divulguer.**

- b) Préparer le parent/tuteur à la divulgation par des conseils et des informations concises et précises au sujet du VIH et le suivi à domicile.
- c) Présenter au parent/tuteur le bienfait de la divulgation du sérostatut à l'enfant et l'importance de ne pas lui donner de fausses informations. Les inconvénients d'une mauvaise divulgation et les réactions potentielles de l'enfant (voir le point 4)
- d) Répondre aux questions des parents/tuteurs, en leur prodiguant des conseils et suggestions en rapport avec la santé de l'enfant pendant la vie quotidienne.
Le staff pourra aussi clarifier les renseignements de l'enfant et/ou du parent/tuteur afin d'assurer une compréhension correcte de la maladie.

Enfants de 12 ans et plus (12ans à 17ans),

- a) Le rôle du staff à ce niveau est principalement de **négocier** avec le parent/tuteur du meilleur moment et la meilleure manière de divulguer.
- b) Le staff continue à donner des conseils et des informations concernant le VIH, la divulgation aux enfants, selon les besoins.
- c) Le staff confirme le rôle du parent/tuteur dans le processus tel que consenti dans le plan de divulgation.
- d) Toutes les normes notées pour les plus jeunes enfants sont applicables mutatis mutandis.

Enfants à l'approche de 18 ans (à partir de 17 ans révolus),

Le rôle du prestataire devient principalement de **convaincre** le parent/tuteur d'entamer la divulgation en insistant non seulement sur son bienfait par rapport à l'enfant mais envers les autres.

□

Rôles du parent / tuteur

- Créer une atmosphère de confiance et d'amour avec l'enfant
- Donner des informations pertinentes à l'enfant concernant sa santé
- Choisir le moment et le lieu pour la divulgation
- Déterminer, de commun accord avec le prestataire la personne qui va divulguer
- Communiquer avec l'équipe SARA sur les échanges avec l'enfant à propos des personnes qui pourront influencer le moment de la divulgation ;
- Informer le prestataire sur les préoccupations et/ou les questions posées par l'enfant sur la divulgation.
- Assurer que l'enfant est préparé pour être annoncé de son statut sérologique

2. L'ANNONCE (DIVULGATION ppte)

L'annonce du statut sérologique à l'enfant se fait suivant le plan mis en œuvre par le parent/tuteur et le prestataire en charge de la divulgation.

1) **Si la divulgation est faite par le prestataire :**

- Rappeler à l'enfant certaines informations importantes évoquées lors de la préparation

- Faire découvrir à l'enfant son état sérologique par des questions et astuces le permettant à découvrir seul le nom de sa maladie
 - Laisser l'enfant réagir
 - Demander à l'enfant qu'est-ce qu'il en comprend
 - Demander à l'enfant s'il n'a pas de questions à poser
 - Lui rappeler la différence entre une PVV et un malade du SIDA
 - Assurer à l'enfant la confidentialité, le soutien moral et psychologique
 - Démontrer à l'enfant l'importance de ne pas le partager avec quelqu'un d'autre (rappel de la notion de confidentialité)
 - Encourager l'enfant à vivre positivement
 - Lui donner rendez-vous dans 48 heures
- 2) **Si la divulgation est faite par les parents/tuteurs**
- ***Divulgation en présence du prestataire:***
Après l'annonce du nom de la maladie de l'enfant par le parent/tuteur, le prestataire devra :
 - Soutenir les parents et l'enfant moralement
 - Circonscrire les propos du parent/tuteur et/ou le compléter le cas échéant par d'autres informations supplémentaires sur l'infection à VIH de l'enfant
 - Insister sur les notions d'adhésion au traitement et de la confidentialité
 - Répondre aux questions et /ou préoccupations de l'enfant s'il y en a ; les susciter au besoin.

 - ***Divulgation en absence du prestataire:***
Le prestataire devra :
 - Demander aux parents d'envoyer l'enfant après leur entretien auprès de lui pour un autre entretien.
 - S'assurer auprès de l'enfant du moment, de l'endroit, de circonstance et des mots utilisés par le parent/tuteur pour l'annonce du statut sérologique à l'enfant
 - Demander à l'enfant ce qu'il en a compris
 - Circonscrire les propos du parent/tuteur et/ou le compléter le cas échéant par d'autres informations supplémentaires sur l'infection à VIH de l'enfant
 - Insister sur les notions d'adhésion au traitement et de la confidentialité
 - Répondre aux questions et /ou préoccupations de l'enfant s'il y en a.

Quelques exemples de comment le staff pourra aider le parent/tuteur à divulguer :
(De *Counseling Guideline on Disclosure of HIV Status*, Southern Africa AIDS Training Programme. June 2000):

- Aider le parent/tuteur à penser de toutes les conséquences—bonnes aussi que mauvaises—de la divulgation à l'enfant avant le moment de la divulgation.
- Assister le parent/tuteur à créer un plan pour la divulgation. Ça pourra inclure : penser du moment approprié, les mots ou phrases à utiliser, les réponses aux questions que l'enfant pourra poser, le comportement du parent/tuteur par rapport aux réactions de l'enfant. Le staff pourra utiliser des jeux de rôles ou

des autres techniques pour aider le parent à se préparer pour la divulgation du sérostatut.

- Les plans devront rendre compte à ce qui a été déjà dit à l'enfant avant la divulgation du sérostatut. La divulgation est un moment pour analyser la compréhension de l'enfant de sa maladie et de corriger des renseignements, si nécessaire.
- Il faut assurer que le parent/tuteur aura des informations correctes et précises concernant la santé et le VIH/SIDA. Si l'enfant est déjà adolescent, il sera important de discuter de la sexualité et l'importance de protéger ses partenaires de l'infection. A ce sujet, toutes les méthodes de prévention seront présentées à l'enfant (jeune adolescent) afin de permettre à celui-ci de faire un choix éclairé et conséquent.

3. PERIODE POST DIVULGATIONNELLE

- La divulgation ne se termine pas lorsque l'enfant aura été annoncé de son statut sérologique. La divulgation est un processus continu qui donne des informations, clarifications, conseils et suggestions selon les besoins qui se présentent.
- La période post divulgationnelle est assurée par l'équipe psychosociale et subsidiairement par l'ensemble du Staff du projet.
- Il faut s'assurer des points suivants :
 - L'enfant a compris l'information donnée
 - Ses préoccupations sont satisfaites,
 - L'enfant s'adapte aux renseignements reçus.
 - L'enfant s'accepte et vit positivement.
 - Que des opportunités sont accordées à l'enfant afin qu'il puisse exprimer ses préoccupations et poser ses questions.
Ne pas supposer qu'un enfant qui ne pose pas de questions n'a pas des questions ni des préoccupations.
Ex. D'opportunité : Groupes de support des enfants divulgués.
 - L'adhérence de l'enfant au traitement
- Si la divulgation est faite par un membre de la famille, sans qu'un prestataire soit présent, une visite à domicile doit être faite par l'équipe psychosociale dans les 48 heures après qu'ils sont informés de l'évènement, avec l'approbation du parent/tuteur. Le but de la visite est de s'assurer que l'enfant a compris l'information donnée, que ses questions sont satisfaites, et que l'enfant s'adapte aux renseignements reçus. Une visite à domicile pourra être substituée par une visite au projet par l'enfant, selon le choix du parent/tuteur.
- Il faut noter dans le dossier clinique une fois que l'enfant a été divulgué son sérostatut (Noter dans le dossier à la date du jour et sur la couverture extérieure la lettre 'D'= Divulgué)

4. SITUATIONS PARTICULIERES DE DIVULGATION

Sous cette rubrique, nous citons entre autre :

- Les enfants à qui on a divulgué sans préparation
- Les enfants divulgués fortuitement par une personne tierce

- Les enfants qui ont vu la description de leur état à la télé (un spot publicitaire par exemple)
- Les inconvénients d'une mauvaise divulgation et les réactions potentielles de l'enfant
-

Dans ces cas, le prestataire en charge de la divulgation devra :

- Demander à l'enfant ce qu'il a réellement appris et/ou entendu
- Demander à l'enfant ce qu'il a compris de cela
- Evaluer le niveau de maturité de l'enfant

Si l'enfant n'est pas mature :

- Rassurer l'enfant de ne pas s'inquiéter
- Fixer un RDV pour continuer à en parler
- Inviter le parent/tuteur de l'enfant et planifier ensemble le plan de la divulgation
- Accélérer le processus de la divulgation (Cfr les étapes sus développées)

Si l'enfant est jugé mature :

- l'enfant est prêt à être divulgué

Le prestataire devra :

- ✓ annoncer à l'enfant son statut sérologique et/ou le nom de la maladie.
- ✓ Apporter à l'enfant des notions pertinentes et concises sur l'infection à VIH et autres maladies (La confidentialité et l'adhérence, Les maladies aiguës et chroniques, Les IST et moyens de prévention, Le système immunitaire, La relation entre le traitement et le système immunitaire, Les généralités sur le VIH)
- ✓ Répondre aux questions de l'enfant
- ✓ Fixer un DRV à l'enfant dès possible (voir son DRV clinique)
- ✓ Inviter le parent/tuteur de l'enfant et planifier ensemble le plan de suivi psychologique (à domicile)

- L'enfant n'est pas prêt à être divulgué

Le prestataire devra :

- ✓ Accélérer le processus de divulgation pour l'annonce du statut sérologique à l'enfant, le plus tôt possible.
- ✓ Inviter le parent/tuteur de l'enfant et planifier ensemble du plan de l'annonce
- ✓ L'enfant jugé prêt à être divulgué, annoncer le son statut sérologique (cfr le cas ci haut présenté)

Les inconvénients d'une mauvaise divulgation et les réactions potentielles de l'enfant,

Lorsque l'annonce du statut sérologique de l'enfant est faite dans les conditions non requises, l'enfant pourra :

- Ne pas accepter son état sérologique
- Se révolter
- Ne pas adhérer à son traitement
- Se déséquilibrer psychologique (Choc, Délire, ...)
- Se suicider (dans le pire de cas)

5. CIRCUIT DU PATIENT

1. Au consentement, le prestataire insiste auprès du parent/tuteur sur la divulgation du statut sérologique à l'enfant au temps opportun de commun accord avec lui.
2. Le prestataire inscrit sur la *carte de rendez vous du patient la lettre D*, signe que le patient est dans le processus de divulgation.
3. Au vue de la carte de RDV « D », à la réception, le prestataire constitue **le dossier PD** du patient (farde + FPD)
4. De la réception, le patient est orienté vers **CD** (Conseil de divulgation composé des prestataires en charge de la divulgation) pour counsling de divulgation – suivant l'étape en cours dans le processus de divulgation-.
5. Du CD, le patient est orienté pour la consultation médicale ; son dossier PD est reclassé sous clé dans les armoires à la réception ;
6. Le prestataire de la réception note sur la couverture extérieure du *dossier médicale du patient la lettre D*, signe que le patient est dans le processus de la divulgation.
7. Le médecin consultant, durant la consultation médicale, pourra, le cas échéant, rappeler au patient, certaines notions en rapport avec la divulgation.

Note : La prise de note sur la fiche FPD doit tenir compte des éléments clés inhérents à l'étape en cours dans le processus de la divulgation.

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