PSYCHOSOCIAL CHARACTERISTICS OF PATIENTS IN A FAMILY-CENTERED HIV
CARE AND TREATMENT PROGRAM IN KINSHASA,
DEMOCRATIC REPUBLIC OF CONGO

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ABSTRACT
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Psychosocial Characteristics of Patients in a Family-Centered HIV Care and Treatment
Program in Kinshasa, Democratic Republic of Congo
(Under the direction of Brenda DeVellis)

Introduction. In resource-limited settings where HIV disproportionately affects women,
there is a need for family-centered HIV care that includes the provision of psychosocial
support services. This dissertation drew on baseline interviews with HIV-positive adults who
were either caregivers or first-line relatives of HIV-infected children enrolled in a family-
centered HIV care and treatment program in Kinshasa, Democratic Republic of Congo
(DRC). This study explored the relationships among social support, perceived stigma, and
quality of life (QOL) in the adult patients. I also examined associations among caregiver
education, disease stage upon enrollment, and program attrition among the pediatric patients.
Finally, I considered measurement issues in adapting scales developed elsewhere to the
context in DRC.

Methods. Data were obtained from baseline interviews with 275 HIV-positive adults and
from 780 children enrolled in a family-centered HIV care and treatment program.

Results. The adult sample was 84% female and largely mothers. There was a positive
association between social support and psychological status, one of six domains in the World
Health Organization HIV Quality of Life measure, and a negative association between
perceived stigma and psychological status. Perceived stigma moderated the relationship
between social support and psychological status but did not moderate the relationship
between social support and overall QOL. There was a negative association between

caregiver education and pediatric HIV clinical stage at enrollment. However, children of

caregivers with less education were not more likely to be deactivated from the study than

children of caregivers with more education.

Conclusions. Enhancing social support may be particularly important for those reporting

high stigma in improving psychological status, one of six QOL domains. Though a negative

association was observed between caregiver education and pediatric HIV clinical stage at

enrollment, children of caregivers with less education were not more likely to be deactivated

from the study than children of caregivers with more education. This may have been due, in

part, to the psychosocial support services provided to patients and their caregivers. Program

recommendations include examining factors associated with delayed enrollment and

documenting which patients receive support services so that dose-response relationships can

be considered when assessing program attrition.

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It was when the rigors of academic pursuit were at their greatest that I was particularly tempted to don blinders to achieve my goals. I would like to acknowledge Grant, Chris, and Eric whose early passing from this world taught me that we are not guaranteed tomorrow and the importance of stepping back at times to see the big picture.

I extend a sincere *Thank You* to my husband, Seth Murray, for the daily expression of love, support, patience, and encouragement. *Milesker!*

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CHAPTER 1: INTRODUCTION

In low-resource settings where patients are frequently malnourished and the need for improved staff training and upgraded medical facilities is high, compelling reasons are required to support funding of other needs such as psychosocial support. The main goal of this dissertation was to explore the relationship between psychosocial characteristics of patients in a family-centered HIV care and treatment program in Kinshasa, Democratic Republic of Congo (DRC). The Sustainable Antiretroviral Access (SARA) program has been providing comprehensive HIV care and treatment including free antiretroviral therapy to HIV-positive children and their first-line relatives at the public sector Kalembe Lembe Pediatric Hospital (KLL) in Kinshasa since November 2004. As of March 2009, 1055 patients were enrolled in this operational research study and 74% of those were children. Specific Aim 1 explored relationships between psychosocial characteristics of adult SARA patients at enrollment while Specific Aim 2 examined linkages between psychosocial characteristics at enrollment and study outcomes of both pediatric and adult patients.

Background on the Democratic Republic of Congo (DRC)

Natural resources

The Democratic Republic of Congo (DRC), with a total area of 2,345,410 square km, is a nation the size of Western Europe and is rich in natural resources such as cobalt, copper, niobium, tantalum, petroleum, industrial and gem diamonds, gold, silver, zinc, manganese, tin, uranium, coal, hydropower, and timber (CIA, 2008). The fall in copper prices, coupled

with political instability, contributed to a decline in the economy in the 1970's and 1980s that became severe in the 1990's (Shapiro and Tambashe, 2003). Of importance to today's marketplace is columbite-tantalite, or coltan as it is colloquially referred to, a metallic ore from which niobium and tantalum are extracted. The international press has made analogies of coltan extraction from the DRC to "blood diamonds" or "conflict diamonds" due to the high demand in the international market from its widespread use coupled with harsh mining conditions (Vesperini, 2001; Hochschild, 2003). Tantalum is used in electronic consumer products such as cell phones, laptop computers, video game consoles, video cameras, and digital cameras, in automotive electronics, as well as medical products such as hearing aids and pacemakers (USGS, 2008). An estimated 80% of the world's known coltan reserves are found in the DRC, where mining is concentrated in the eastern part of the country. A 2003 United Nations Security Council report (S/2003/1027) cites coltan extraction as an example involving the exploitation of a natural resource in a fashion that can be directly linked to funding the conflict in DRC:

> In 1999 and 2000 a sharp increase in the world prices of tantalum occurred, leading to a large increase in coltan production in eastern Democratic Republic of Congo. Part of the new production involved rebel groups and unscrupulous business people forcing farmers and their families to leave their agricultural land, or chasing people off land where coltan was found and forcing them to work in artisanal mines. As a result, the widespread destruction of agriculture and devastating social effects occurred, which in a number of instances were akin to slavery (p. 5).

Coltan is not the only example of the extraction of a natural resource that has led to exploitation of DRC's inhabitants. The extraction of rubber during the colonial period resulted in gruesome human rights violations including forced labor (Hoschild, 1998). The extraction of copper during the post-colonial era profited an elite few while inhabitants of then-called Zaire suffered the harsh consequences of poverty, inflation, and a deficient public

infrastructure. Public institutions functioned under insufficient funding from the state leaving buildings in disrepair, supplies low, and staff unpaid for months (Wrong, 2001). Insufficient funding of public hospitals remains a problem today and is countered with frequent health care worker strikes that persist for months at a time.

Despite DRC's wealth of natural resources, it remains one of the poorest countries in the world. Seventy-one percent of people in DRC live on less than $1 US per day (UNPF, 2007). The United Nations Development Program's 2007-2008 Human Development Index (HDI) ranking for DRC was 168th out of 177 countries. The HDI provides a composite measure of three dimensions of human development: 1) living a long, healthy life, measured by life expectancy at birth on which DRC ranked 168th out of 177 countries, 2) education, measured by adult literacy (ages 15 and older) on which DRC ranked 110th out of 177 as well as enrolment at the primary, secondary and tertiary level on which DRC ranked 167th out of 177, and 3) standard of living, measured by purchasing power parity and gross domestic product per capita on which DRC ranked 172th out of 177 (UNDP, 2008). In 2006, the life expectancy at birth was 46 years and 38% of children less than five years of age were suffering from moderate or severe stunting which is calculated as below minus two or three standard deviations from median weight for height of the reference population (Unicef, 2008).

Conflict in DRC

A former Belgian colony, the Democratic Republic of Congo gained its independence in 1960. After a November 1965 coup d'état in which the prime minister, Patrice Lumumba, was killed, the country was named Zaire by President Mobutu on October 27, 1971. The country was renamed the Democratic Republic of Congo after the First Congo War which led

to the overthrow of President Mobutu in 1997 at which time Laurent Kabila was installed as president. The current president, Joseph Kabila, became president when his father, Laurent Kabila, was assassinated in 2001. Joseph Kabila was elected as president in October 2006 and has remained the president until today. Under the current system, the president is elected by popular vote for a five-year term and is eligible for a second term.

Conflict since 1998, also referred to as the Second Congo War, has resulted in violence, famine and disease and has contributed to the deaths of more then 3.5 million people according to U.S. government estimates (CIA, 2008). However, according to an International Rescue Committee (IRC) mortality survey, 5.4 million people have died since 1998 from war-related causes in DRC, most of which include preventable and treatable conditions such as malaria, diarrhea, pneumonia, and malnutrition (IRC, 2008). This is the world's deadliest conflict since World War II and it has contributed greatly to the lack of public infrastructure, overall economy, and lack of availability of health care services. DRC has a population of more than 66 million and 48 % are under the age of 15 years old (EDS-RDC, 2007).

HIV in DRC

An estimated one million people were living with HIV/AIDS in the DRC in 2005 (UNAIDS & WHO, 2006). The HIV epidemic in DRC is generalized with an estimated 87% of infections occurring through heterosexual contact (USAID, 2008). Only 8.6% of people living with HIV/AIDS in DRC were receiving antiretroviral therapy in 2006 (USAID). According to the 2007 Democratic Republic of the Congo Demographic and Health Survey (EDS-RDC), 1.3% of the population age 15 to 49 years is HIV-positive. The HIV prevalence is 1.6% for women and 0.9% for men; both men and women in urban areas are at higher risk

of HIV infection than those living in rural areas (EDS-RDC). The highest HIV prevalence is between the ages of 40-44 years for women (4.4%) and between the ages of 35 to 39 years for men (1.8%).

HIV in Kinshasa

Kinshasa, the capital city, is densely populated, has high unemployment, and has among the highest HIV prevalence in the country. HIV disproportionately affects women in Kinshasa where the prevalence for women is estimated to be 2.3% and the prevalence for men is 1.3% (EDS-RDC, 2007). When HIV prevalence is evaluated in terms of four regions, Kinshasa is at 1.9%; the East region is at 1.9% which includes the Orientale, Nord-Kivu, Sud-Kivu, and Manlema provinces; the Central-South region is at 1.2% which includes the Katanga, Kasaï Oriental, and Kasaï Occidental provinces; and the West region is at 0.7% which includes the Bas-Congo, Bandundu, and Equateur provinces (EDS-RDC). The HIV prevention, care, and treatment needs remain largely unmet in Kinshasa as in the country overall. The sprawling geography of Kinshasa, poor road conditions, and public sector health care worker strikes present additional barriers for patients seeking HIV care are treatment. Though French is the official language, Lingala is commonly spoken in Kinshasa where the SARA program is being implemented.

Background on the Sustainable Antiretroviral Access (SARA) Program

The University of North Carolina at Chapel Hill (UNC) started collaborating with the Congolese Ministry of Health in 2003 with funding from the Centers for Disease Control and Prevention (CDC) Global AIDS Program (GAP) to improve HIV prevention and care in DRC through the University Technical Assistance Program (UTAP). This program is now

supported through Providing AIDS Care and Treatment (PACT) under the President's

Emergency Plan for AIDS Relief (PEPFAR). This U.S. Government (USG)-funded program

works in partnership with the Kinshasa School of Public Health and is designed to support

HIV prevention and treatment programs for children and adults. The Sustainable

Antiretroviral Access (SARA) program is one of four projects under the PACT umbrella in

Kinshasa and also receives support from the Elizabeth Glaser Pediatric AIDS Foundation

(EGPAF). The SARA program seeks to provide comprehensive medical care, including free

antiretroviral therapy, and psychosocial support to HIV-positive children and their first-line

relatives. Pediatric participants, as well as their HIV-positive parents and guardians, are

enrolled at Kalembe Lembe Pediatric Hospital (KLL) which is centrally located in Kinshasa.

KLL is a public hospital that provides services to about 1,400 children per month (Belgian

Red Cross, 2006). Enrollment in the SARA program began in late November 2004; however

due to concerns over ARV supplies, additional enrollments were suspended in June 2006 and

resumed on April 24, 2007. The overview of patient enrollment is presented in Figure 1.1

below.

Figure 1.1: Overview of SARA program enrollment, November 2004 to March 2009

1055 patients enrolled from Nov 2004 to March 2009

780 children

275 adults

530 active

250 inactive

225 active

50 inactive
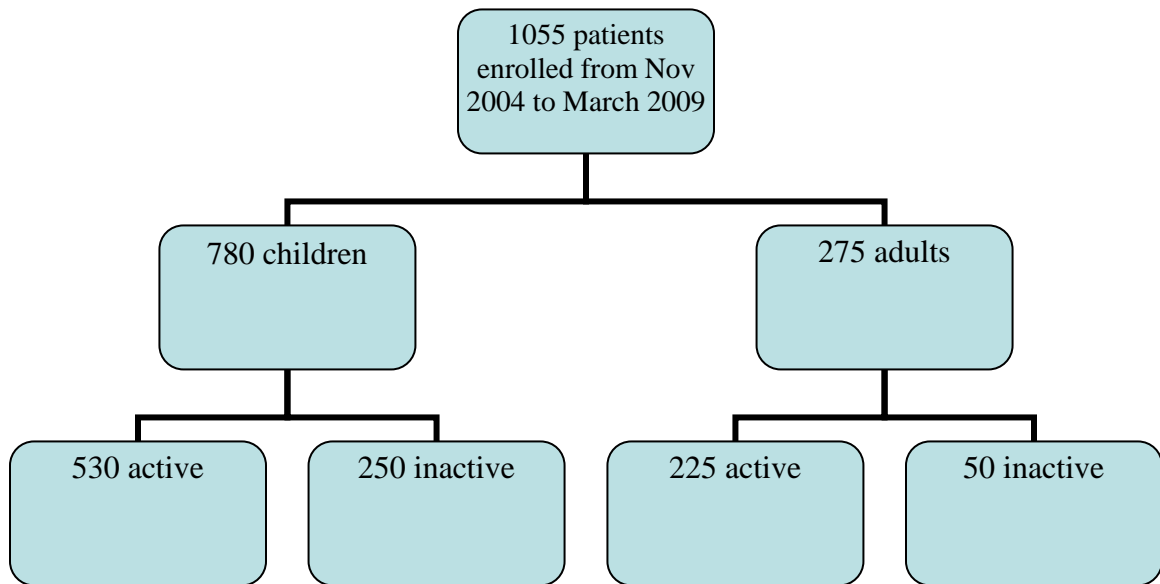
The most common clinical diagnoses of patients enrolled in the SARA program were TB, oral candidiasis, fever, and diarrhea. Malnutrition and oral candidiasis were found to be predictors for mortality in children initiating ART in this program (Callens et al., 2009). Plans for the continuation of the SARA program include the continued recruitment and follow-up of eligible HIV-positive children and their first-line relatives as well as the increasing development of the SARA program at KLL as a training and reference center for other care providers in DRC. The results of this dissertation research examining psychosocial characteristics of patients in this program will be shared with staff from KLL to inform the implementation and evaluation of ongoing psychosocial support activities.

Psychosocial support services provided by the SARA program

Psychosocial support services provided by the SARA program include home visits to patients with missed clinic appointments, support groups, and counseling for SARA patients and their caregivers. Because these services are provided after patients are enrolled into the

SARA program, they are most pertinent in considering contextual factors underlying Specific Aim 2, which examines linkages between psychosocial characteristics at enrollment and study outcomes. However, a better understanding psychosocial characteristics at enrollment (Specific Aim 1), can inform psychosocial support activities to optimize improvements during the course of patient involvement in this program.

Home visits. Patients who have previously agreed to such are visited by a member of the psychosocial support team who are more than one week late for a scheduled clinic visit. Originally consisting of the psychosocial coordinator and a psychosocial assistant, the psychosocial team making home visits now consists of a group of trained volunteers who were recruited from the SARA program support groups. Home visits are made to determine why the patient has not returned to the SARA clinic and to address barriers to keeping scheduled appointments.

Support groups. There are currently seven support groups provided through the SARA program: 1) children age 5-10 years old that do not know their HIV-positive serostatus, 2) children age 10 and older that know their HIV-positive serostatus, 3) children age 10 and older that do not know their HIV-positive serostatus, 4) parents/guardians of HIV-positive children, 5) HIV-positive parents/guardians, 6) adult couples, and 7) pregnant women and their partners. The first support group topic is HIV basics and the topic for subsequent support groups are agreed upon by the group members.

Patient and caregiver counseling. Counseling for SARA patients and their caregivers is provided during clinic visits by the psychosocial coordinator who has a degree in sociology and performed similar work for *MSF Belgique*, Doctors without Borders-Belgium, before joining the SARA program in 2005. Topics covered during counseling include disclosing an

HIV-positive serostatus to a partner (for adult patients), working with parents to disclose an HIV-positive serostatus to pediatric patients, the importance of adhering to medications and clinic appointments, as well as discussing financial and social problems encountered by the patient or caregiver.

Previous findings from the SARA program that inform the current study

As was described by Newman et al. (2008) monitoring involuntary HIV disclosure (i.e., when an individual's HIV status is revealed without approval or consent) is informative for understanding social support as well as stigma experienced by patients enrolled in this care and treatment program. At enrollment and during follow-up visits, adult SARA patients were asked if anyone had learned of their HIV status against their wishes and if so, who learned of their HIV status and what happened. As of May 2008, 29 out of 237 (12%) of adult patients reported involuntary HIV disclosure at enrollment into the SARA program. Thirteen patients provided a positive account of what happened centering around support and advice. For example, one 33-year-old women referring to her mother, father and aunt indicated, "They supported me with their advice then they took steps for setting up my medical care." A 24-year-old woman referring to her sister-in-law indicated, "She prayed for me and since then she supports me a lot." Seven patients provided a neutral response such as, "Nothing in particular." Five patients provided negative accounts such as estrangement and arguments. For example, a 31-year-old woman referring to the family of her sister-in-law indicated, "They no longer want to shake my hand or eat what I prepare. They no longer touch my child and they no longer allow me to ride in the family car." Two accounts were missing and two patients reported both negative and positive responses such as, "It was my

own family that had somewhat rejected me in the beginning. But, now we are on good terms. They accept me."

During follow-up visits, nine patients reported 12 involuntary HIV disclosure incidents. Four accounts were positive mainly centering around encouragement, with one patient's friend seeking HIV testing after learning the patient's HIV status. Three accounts were neutral and five accounts were negative revealing rejection and stigmatization. A 51-year-old woman indicated that her pastor's wife avoided shaking hands when saying hello and during a subsequent visit that the pastor's wife no longer said hello. Another 51-year-old woman referring to her in-laws indicated, "I was a victim of rejection and discrimination from my own family and my in-laws."

Student's involvement in the SARA program

From September 2007 to July 2009 I served as the Chapel Hill-based SARA Program Coordinator through a graduate research assistantship. As a French-speaker I facilitated communication between Kinshasa-based staff and Chapel Hill-based staff on a variety of topics ranging from patient care to database maintenance. I routinely consolidated information from discussions with personnel from Kinshasa as well as the project database to write quarterly and annual reports for CDC as well as activity updates for the Elizabeth Glaser Pediatric AIDS Foundation. I located supporting materials for volunteer training and assisted project staff in preparing materials for professional meetings and conferences. Finally, I received adverse event reports from the field, translated them from French to English for the IRB, and was the liaison between the UNC-based medical reviewer and the physicians providing care.

Processing the adverse event reports required me to obtain additional information from SARA program physicians as well as the project database and provided me with insight on the events leading up to patient deaths, which is an outcome of interest in Specific Aim 2. Details from home visits were often included in adverse event reports shedding light on the patient's support network, experienced stigma, as well as beliefs held by those closest to the patient. For example, a 39-year-old woman committed suicide who had previously experienced stigmatization due to her weight loss. She had not disclosed her serostatus for fear of her husband's anger and her family's rejection. The patient did not reveal her intention to commit suicide to the SARA team. However, the volunteer who learned of the patient's death during a home visit spoke with her aunt who revealed that the day prior to her death, the patient had voiced her intentions due to the way she was being treated by her husband and her family. Another example was a 14-year-old boy who died following untreated fever and vomiting. The family brought the child to their church in accordance with their religious beliefs rather than to the SARA program clinic as a volunteer had advised during a home visit. The family practiced the Kimbanguiste religion and the child's HIV treatment had temporarily been suspended several months prior to his death because the patient was reportedly having visions and prophesizing. The child's grandmother, his primary caregiver and the only one who knew his serostatus, thought her grandson possessed the spirit of God and the act of prophesizing would result in a cure.

Routine interactions with project physicians, nurses, the psychosocial coordinator, and the database manager provided me with insight on the challenges that the staff experienced in providing HIV care and treatment as well as barriers that patients experienced in accessing that care. For example, during public sector health care worker strikes, patients

could not be referred to public hospitals for admission in response to acute episodes and lab results were delayed or not available. Frequent electricity cuts made it difficult for physicians to consult online resources and electronic patient records. Options for HIV care and treatment were scant in the sprawling city which made poor road conditions and limited transportation options barriers for patients, particularly in the rainy season when heavy rains further hindered transportation.

I traveled to Kinshasa in November 2007 which provided me with the opportunity to meet the SARA program staff, familiarize myself with the SARA clinic and KLL Hospital, and learn more about Kinshasa in general. Though the main focus of my trip was the SARA program psychosocial activities, I also spent time with Prevention of Mother to Child Transmission of HIV (PMTCT) program and the tuberculosis-HIV program to learn more about the psychosocial support activities provided through these programs. Objectives of my visit were to: 1) Conduct interviews with program staff to gain a better understanding of psychosocial needs of SARA patients and HIV-positive pregnant women attending PMTCT maternities, 2) Identify what psychosocial services were being provided through the SARA program and PMTCT maternities, 3) Determine what additional services staff would like to provide if additional funds were available, 4) Attend SARA program as well as PMTCT support group meetings to gain a better understanding of group functioning and issues raised by attendees, and 5) Attend a group pre-test counseling session at a PMTCT maternity and attend a monthly meeting of PMTCT nurse counselors to better understand experiences of HIV-positive pregnant women in Kinshasa. Meeting the objectives of this site visit improved my overall understanding of HIV prevention, care, and treatment in this context and provided the foundation on which the specific aims of this dissertation were developed.

Organization of the Dissertation

   This dissertation is comprised of two stand-alone manuscripts plus additional chapters that elaborate details that cannot be included in the journal-length manuscripts due to page limitations. Chapter 1 provides an introduction to the research context and provides an overview of the SARA program, along with the student's involvement in the program. Chapter 2 presents the specific aims, conceptual model, research questions, and hypotheses. A comprehensive literature review is presented in Chapter 3 and Chapter 4 details the methods of this dissertation research. Chapters 5 and 6 present the results of this dissertation research in the format of two stand-alone manuscripts. Implications for practice and research as well as final conclusions are discussed in Chapter 7.

CHAPTER 2: SPECIFIC AIMS

This dissertation addressed the following specific aims.

I. To explore relationships between psychosocial characteristics of adult SARA patients at enrollment.

II. To examine linkages between psychosocial characteristics at enrollment and study outcomes.

Specific Aim 1: Psychosocial Characteristics of Adult Patients at Enrollment

Specific Aim 1 explored the relationships between psychosocial characteristics of adult SARA patients at enrollment. The following psychosocial characteristics of adult SARA patients were examined: social support, stigma, and quality of life (QOL). Examined separately was psychological status, one of six domains in the WHOQOL-HIV measure (WHOQOL HIV Group, 2003), which this study defined as a sense of worth, ability to concentrate, depressive feelings, acceptance of bodily appearance, and satisfaction with oneself. By better understanding psychosocial characteristics at enrollment, the SARA program psychosocial support activities described in Chapter 1 could be targeted to optimize improvements during the course of patient involvement in this care and treatment program.

Conceptual model

   Two conceptual models are presented below. The relationship between social support

and psychological status was hypothesized to vary by the extent to which patients had

experienced stigma as is illustrated in Figure 2.1.

Figure 2.1: Conceptual Model 1
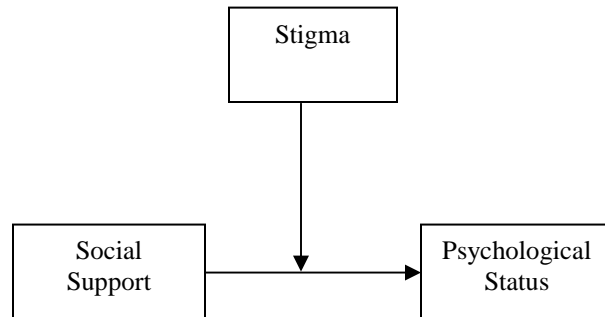
 Similarly, the relationship between social support and QOL was hypothesized to vary by the

extent to which patients had experienced stigma as is illustrated in Figure 2.2. The

hypothesized directionality of the relationship between these variables is presented in

Hypotheses 1.1 and 1.2 below.

Figure 2.2: Conceptual Model 2
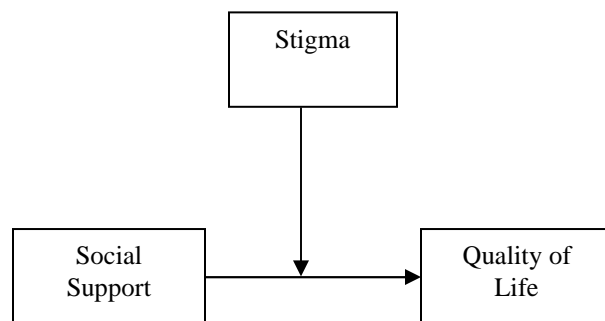
Relationships between variables were examined to determine if patterns are present that are consistent with moderation. Due to the cross-sectional nature of the psychosocial variables in the dataset, this research is exploratory and formative.

Research questions and hypotheses

The following research questions were addressed in accordance with conceptual models 1 and 2.

- What is the relationship between social support, stigma, and psychological status?

  o Hypothesis 1.1 – The relationship between social support and psychological status varies by the extent to which patients have experienced stigma such that the association between social support and psychological status will be positive and stronger for patients who report low stigma than for patients who report high stigma.

An enhancing moderating pattern was predicted as illustrated in Figure 2.3.

Figure 2.3: Hypothesized relationship between psychological status, stigma, and social support
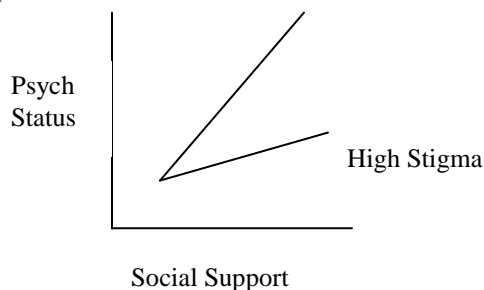
- What is the relationship between social support, stigma, and QOL?

  o Hypothesis 1.2 – The relationship between social support and QOL varies by the extent to which patients have experienced stigma such that the association

between social support and QOL will be positive and stronger for patients who report low stigma than for patients who report high stigma.

Specific Aim 2: Psychosocial Characteristics and Study Outcomes

Specific Aim 2 examined the relation of the psychosocial characteristics of adult (hypothesis 2.1) and pediatric patients (hypothesis 2.3) at enrollment to study outcomes such as mortality and loss to follow-up. Hypothesis 2.2 examined caregiver education and pediatric patient disease severity at enrollment. By examining linkages between psychosocial characteristics at enrollment and study outcomes, long-term retention can potentially be enhanced by identifying risk factors for attrition and intervening upon them early.

Research questions and hypotheses

The following research questions were addressed.

- Is there an association between adult psychosocial characteristics at baseline and study outcomes such as mortality and loss to follow-up?
    - Hypothesis 2.1 – Adult patients who were deactivated from the study (N=28) due to death or failure to maintain clinic appointments will score lower on the social support scale, score lower on psychological status scale, score lower on the quality of life scale and score higher on the stigma scale than adult patients who remained active in the study (N=218).
- Is there a linkage between caregiver's level of education and pediatric patient disease severity at enrollment?

- o Hypothesis 2.2 - Pediatric patients with caregivers that have less education will be more likely to present to the SARA clinic with more advanced HIV disease than pediatric patients with caregivers with more education.
- Is there a linkage between caregiver's level of education and pediatric study outcomes such as mortality and loss to follow-up?
  - o Hypothesis 2.3 - Pediatric patients with caregivers that have less education will be more likely to be deactivated from the study (due to death or failure to maintain clinic appointments) than pediatric patients with caregivers with more education.

CHAPTER 3: LITERATURE REVIEW

The following literature review describes and operationalizes the psychosocial variables addressed in this dissertation: social support, stigma, psychological status, and quality of life (QOL). The multidimensional nature of these variables is discussed along with findings on how these variables relate to quality of life. Also reviewed is the literature on maternal education and health outcomes as well as potential implications for this HIV care and treatment program. A rationale for the current study's hypotheses is presented based upon findings in the literature.

Kinshasa has been described as an "ethnic mosaic" (Shapiro & Tambashe, 2003, p. 253) comprised of a multitude of ethnic groups, languages, religious beliefs, and cultural practices. In efforts to better understand the context in which the SARA program was implemented, I consulted DeBoeck and Plissart's (2004) ethnography for insight into some of the cultural beliefs of Kinshasa residents. Of particular interest to the current study were beliefs about illness and attitudes about healthcare. DeBoeck and Plissart described local explanations of the 1995 Ebola outbreak in Kikwit, a city in southwestern DRC, and also explored the September 1996 boycott of a polio vaccination program among residents in Kinshasa and neighboring provinces. These local explanations reveal "a fundamental distrust of the official medical healthcare services, which are often perceived as instruments used by the authorities against the population" (DeBoeck & Plissart, p. 114). According to DeBoeck and Plissart:

People only go to the hospitals to die, not to get better. The inaccessibility of hospitals and doctors, the pauperization and dilapidation of the public healthcare infrastructure that goes hand in hand with the privatization of healthcare in poorly equipped polyclinics where only a minority can afford, the lack of professionalism in the staggering number of pharmacies run by people without any medical or pharmaceutical training (…) – all of these factors account for the dwindling prestige of public hospitals and biomedical treatment (p. 114).

I also consulted two ethnographies of Congolese families. Warkentin's (1994) ethnography of rural and urban families in eastern DRC during 12 years of anthropological fieldwork (1974 to 1986) described conjugal and kin bonds, polygamy, bride wealth payments, and the custody rights of children if a marriage is dissolved. Warkentin also described the suppression of ancestor worship which she attributed to the arrival of Catholic and Protestant missionaries. However, the pervasive belief of sorcery as a way of explaining illness, death, and misfortune remains. Troubles of urban living such as burglary by petty thieves were also described. Bernard (1968) described family life in Kinshasa and asserted that "a single type of traditional family does not exist: each ethnic group has its own family system, sometimes patrilineal, sometimes matrilineal, sometimes bilineal, sometimes matrilineal with elements of a patriarchal system or patrilineal with traits of a matriarchal system" (p. 17). Through case studies, questionnaires, and interviews with school teachers Bernard explored urbanization and acculturation in Kinshasa while examining marriage, family life, and the role of family members in choosing a spouse.

Social Support

Social support is characterized by "aid and assistance exchanged through social relationships and interpersonal transactions" (Heaney & Israel, 2002, p. 181). Though there is no single agreed upon operational definition or tool for measuring social support, there is

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consensus on key characteristics of social support among researchers examining the relationship between social support and health outcomes. The giver and recipient of support must be within the same social network. Thus, a doctor providing information to a patient is not considered social support unless they are members of the same social network. Also, the recipient must perceive the support as being supportive (Schaefer, Coyne, & Lazarus, 1981). Measuring perceived adequacy of social support is important in interventions designed to enhance social support because the recipient's perceptions of social support have been shown to more strongly influence mental health and well-being than the actual receipt of support (Wethington & Kessler, 1986).

Types of social support. According to House (1981), there are four types of social support: emotional, instrumental, informational, and appraisal support. Emotional support is characterized by the expression of empathy, love, trust, and caring. Instrumental support involves tangible aid and services such as giving a friend a ride to the doctor's office or providing monetary assistance. Informational support is characterized by giving advice, suggestions, or information that can be used, for example, in making a decision or solving a problem. Appraisal support is characterized by information that can be used for self-evaluation such as affirmation or constructive feedback (House).

Social support and the household. Patients in the SARA program receive much of their support from those in their household regardless of whether or not those in the household are knowledgeable of the patient's HIV-positive serostatus. According to the most recent Demographic and Health Survey, households in the DRC consist of 5.4 people on average though 33% of households are made up of seven or more people (EDS-RDC, 2007). Overall, 21% of households in DRC are headed by a woman (EDS-RDC).

Shapiro and Tambashe (2003) reported the results of their 1990 Kinshasa-based survey in which they examined interhousehold resource transfers within extended families and concluded that there is a "high degree of participation of households in solidarity networks, both as donors and recipients" (p. 202). Shapiro and Tambashe asked women of reproductive age who were either the head of household or married to the head of household about giving and receiving assistance for 1) child fostering, which could occur to provide labor to the household or to provide the child with access to education, and 2) children's schooling including help with expenses for tuition, uniforms or school supplies. Child fostering and assistance with children's schooling could be categorized under House's (1981) designation of instrumental support. More than one-fourth of respondents reported ever having received assistance for either children's schooling or child fostering and more than two-thirds had provided such assistance. Given Kinshasa has historically attracted those from rural areas for employment and educational opportunities, Shapiro and Tambashe (2003) posited that the greater number of respondents providing rather than receiving assistance may reflect assistance to extended family in rural areas. Shapiro and Tambashe noted that is not uncommon, even in just one year, to observe reciprocity in what they referred to as "solidarity networks". Those who had received assistance were more likely than the overall sample to have provided that same form of assistance and vice versa (Shapiro & Tambashe).

Support for the current study's hypotheses from the literature. A review of the literature supports the notion that social support is positively associated with quality of life as predicted in the current study's hypotheses (Swindells et al., 1999; Friedland, Renwick, & McColl, 1996; Nunes et al., 1995). There is a body of literature that suggests that social

support can buffer against the adverse effects of stressors on depression (Aneshensel & Stone, 1982), occupational burnout (Greenglass, Fiksenbaum & Burke, 1996), and adjustment to HIV/AIDS (Britton & Zarski, 1993). An HIV-positive diagnosis is a major stressor which is potentially exacerbated for the adults in this study because they are either caregivers or first-line relatives of HIV-positive children. Therefore, the adults in the SARA program are not only coming to terms with their own HIV-positive serostatus but also that of the pediatric index case to which they are related. Understanding the relationship between social support, psychological status, and quality of life at enrollment into this HIV care and treatment program is necessary for targeting psychosocial support activities to optimize improvements during the course of patient involvement in this program.

Stigma

There is consensus in the HIV/AIDS research community that stigma is a major problem. This was highlighted in 2000 during the XIII International AIDS Conference in Durban South Africa titled *Breaking the Silence*. Stigma has been found to be associated with decreased HIV testing (Fortenberry et al., 2002), poor adherence to antiretroviral therapy (Rintamaki et al., 2006), and decreased disclosure of HIV status to others (Hutchinson et al., 2007). Hence, decreasing stigma at the community level and identifying factors that attenuate the negative effects of stigma on people living with HIV/AIDS has become increasingly important in HIV prevention and treatment programs. Those receiving funds from the President's Emergency Plan for AIDS Relief (PEPFAR), as is the SARA program, must routinely report on the number of individuals trained in HIV-related stigma and discrimination reduction. For the purposes of reporting, PEPFAR defines HIV/AIDS-related stigma as a "process of devaluation of people either living with or associated with

HIV and AIDS" and distinguishes between discrimination and stigma: "Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status or being perceived to belong to a particular group" (PEPFAR, 2007, p. 108).

Goffman's (1963) definition of stigma as an attribute that is deeply discrediting, has been built upon in recent decades to include definitions specifically related to HIV/AIDS stigma. Much work has been done to develop and validate measures of HIV/AIDS stigma such as: Berger, Ferrans, and Lashley's (2001) HIV Stigma Scale, generated with respondents from eight American states; Visser et al.'s (2008) work to adapt Westbrook and Bauman's (1996) Perceived Stigma of HIV/AIDS scales to the context in South Africa; as well as Holzemer et al.'s (2007) HIV/AIDS Stigma Instrument-PLWA (HASI-P), based upon data collected in five African countries. These measures were developed to assess the perception of stigma by those who are HIV-positive as individual-level measures. Recent work by Genberg et al. (2008) described the development of a measure to assess stigma at the community-level to evaluate the effect of programs to reduce stigma in developing countries. Genberg et al.'s measure will be used to assess whether the NIMH Project Accept, an ongoing community-randomized controlled intervention trial, is effective in reducing HIV/AIDS-related stigma at the community-level in four different countries (Thailand, Zimbabwe, Tanzania, and South Africa).

Recent work to explain variations in HIV-related stigma across settings has provided insight into factors that contribute to HIV/AIDS stigma. For example, Naidoo et al. (2007) found urban and rural differences in HIV/AIDS stigma in their study of five African countries: Lesotho, Malawi, Tanzania, South Africa, and Swaziland. Urban focus groups of

nurses and people living with HIV/AIDS described more incidents of stigma and discrimination than did rural groups (Naidoo et al.). Maman et al.'s (2009) qualitative study of HIV stigma among community members in Thailand, Zimbabwe, Tanzania, and South Africa reinforced the notion that stigma is associated with incomplete knowledge of HIV transmission as previously described by Boer and Emons (2004) in Thailand. Maman et al. also found that stigma among community members was associated with limited access to antiretroviral therapy as previously described by Castro and Farmer (2005) in Haiti.

Misconceptions about modes of HIV transmission along with limited availability of HIV care and treatment services make the potential for stigmatization a concern in DRC. Nearly half of respondents in DRC (41% of women and 50% of men) and more than half of respondents in Kinshasa (62% of women and 68% of men) participating in the 2007 Demographic and Health Survey said that they would buy fresh vegetables from an HIV-positive shopkeeper (EDS-RDC). This type of sentiment signifies fear of transmission through casual contact which can lead to the social isolation of people living with HIV. More than half of Congolese women and men (63% and 55% respectively) indicated that it was necessary to keep secret that a family member was infected with HIV, whereas 84% of women and 68% of men in Kinshasa expressed this sentiment (EDS-RDC).

In general, access to antiretroviral therapy and knowledge of HIV transmission is better in Kinshasa than in other areas of DRC. While only 45% of women in DRC knew that AIDS cannot be transmitted by mosquito bites, 70% of women were aware of this in Kinshasa (EDS-RDC, 2007). About half of respondents (56% of women and 47% of men) in Kinshasa knew that HIV could be transmitted by breastfeeding which is comparable to DRC overall (55% of women and 53% of men). However, only 23% of women and 19% of men

in Kinshasa knew that the risk of mother-to-child transmission could be reduced by taking medication during pregnancy (14% of women and 15% of men in DRC) (EDS-RDC). This lack of knowledge of prevention of mother-to-child transmission (PMTCT) options could be explained in part by limited access to these services. Access to PMTCT services in rural areas is even more limited than in Kinshasa. Understanding misconceptions about transmission via mosquitoes and mother-to-child transmission was particularly relevant to the current study because DRC is a malaria endemic country and the adults in this care and treatment program are either caregivers or first-line relatives of HIV-positive children, many of whom may have contracted HIV through mother-to-child transmission.

Support for the current study's hypotheses from the literature. A review of the literature supports the notion that there is an inverse relationship between stigma and psychological status as predicted in hypothesis 1.1. There were similarities between the psychological status items used in the current study and items used to screen for depression in general. Galvan et al. (2008) noted a positive association between depression and perceived HIV-related stigma. Those who met the Diagnostic and Statistical Manual of Mental Disorders version 4 (DSM-IV) clinical criteria for a current major depression reported a higher level of perceived HIV-related stigma than those who did not meet the criteria (Galvan et al.). Mupenda et al. (2008) found, in their study of youth living with HIV in Kinshasa, that perceived stigma was positively associated with depression and negatively associated with social support. Both Mupenda et al. and Galvan et al. used the same scale as the current study, Berger, Ferrans, and Lashley's (2001) HIV Stigma Scale. Bird, Bogart, and Delahanty (2004) found that greater perceived discrimination from HIV treatment providers was associated with increased depression in HIV patients. There are also findings

reported in the literature to support the notion that there is an inverse relationship between social support and perceived stigma as predicted in hypothesis 1.1 and 1.2. For example, Galvan et al. (2008) found that high perceived social support from friends was associated with less perceived HIV stigma.

Psychological Status

Psychological status was conceptualized as a sense of worth, ability to concentrate, depressive feelings, acceptance of bodily appearance, and satisfaction with oneself. Because there is overlap between the items used to assess psychological status in the current study and items used to screen for depression as will be described in the Methods section, this literature review includes a discussion of depression among people living with HIV.

There is limited information concerning the association between psychological well-being and outcomes such as QOL among people living with HIV in sub-Saharan Africa. Adewuya et al. (2008) found that depression was associated with poor social support and low QOL among HIV-positive patients in Nigeria and concluded that early identification and referral of patients with depression should be incorporated into HIV care and treatment programs. Poupard et al. (2007) examined depression and QOL scores of HIV patients in Senegal and did not find significant differences among patients receiving protease inhibitor (PI)-based regimens and patients receiving efavirenz (EFV)-based regimens, the latter of which can have side effects such as sleep disturbance, nightmares, irritability, concentration problems, and depression.

Recognizing the importance of cultural context is essential in understanding mental health in developing countries (Bass et al., 2007). This is particularly true with depression as there are often no direct equivalents in local languages to describe this concept. Patel et al.

(2001) discussed local terms and expressions that have overlap with depression: the Shona

language in Zimbabwe has the term *kufungisisa* which denotes 'thinking too much'; in

Botswana, there is the expression *pelo y tata* which denotes 'heart too much'; and 'nerves' in

some South African and Latin American cultures have similarities to depression.

Bass et al. (2008) used a mixed-methods approach to describe a local syndrome

among new mothers in Kinshasa, DRC called *maladi ya souci* that closely approximates the

Western model of major depressive disorder according to Diagnostic and Statistical Manual

of Mental Disorders version 4 (DSM-IV) criteria. *Maladi ya souci* is an expression in the

local language, Lingala, that translates as a syndrome of worry. Both major depressive

disorder and *maladi ya souci* have symptoms of "sadness, irritability, appetite reduction,

sleep disturbance, somatic complaints, tiredness and fatigue, memory difficulties and suicide

ideation" (Bass et al., p. 1537). Symptoms of *maladi ya souci* also involve expressions of

irritability, including "anger and fighting⁄disputing with others for no reason" as well as

anxiety symptoms including "restless⁄agitated heart, worry and lack of peace" (p. 1537). In

efforts to establish discriminant validity, women identified by key informants as suffering

from *maladi ya souci* had higher depression severity scores on adapted versions of the

Edinburgh Post-partum Depression Scale and the Hopkins Symptom Checklist than women

identified as not having this syndrome.

Support for the current study's hypotheses from the literature. A review of the

literature supports the notion that there is a positive association between social support and

psychological status as predicted in hypothesis 1.1 and that there is a positive association

between social support and QOL as predicted in hypothesis 1.2 in the current study. Jia et al.

(2004) found that social support was positively associated with health related quality of life

(HRQOL). When specific dimensions of HRQOL were examined, social support was associated with all dimensions of HRQOL except for physical functioning, role functioning, and pain. Emotional support and informational support were associated with psychological well-being in Hays, Chauncey and Tobey's (1990) study of social networks of HIV-positive gay men. In Namir et al.'s (1989) study of social networks of newly diagnosed HIV-positive gay men, satisfaction with support, instrumental support and emotional support were associated with good psychological adaptation. These findings demonstrate the importance of measuring the different types of social support as well as satisfaction with support when considering the relationship between psychological well-being and social support.

Quality of Life

The World Health Organization (WHO) defines quality of life (QOL) as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." (WHOQOL Group, 1995, p.1405). Though there is no single agreed upon operational definition or tool for measuring QOL, there is consensus that QOL is a multidimensional construct. There are a variety of QOL measures (see Skevington & O'Connell, 2003 for a review) as well as health-related quality of life measures available for individuals with HIV (see Clayson et al., 2006 and Tsasis, 2000 for reviews).

QOL has increasingly been examined as a clinical outcome as advances in antiretroviral therapy have prolonged the lives of people living with HIV/AIDS (Clayson et al., 2006; Skevington & O'Connell, 2003; Tsasis, 2000). Attention has been given to predictors of QOL such as demographic factors including age, gender, and race as well as sociodemographic factors such as employment, marital status, and education status. Though

sociodemographic characteristics can change throughout the lifespan of an HIV-positive individual, they are not readily modifiable and thus are less amenable to intervention. Recent attention has been given to more modifiable predictors of QOL such as psychosocial factors.

QOL among people living with HIV in sub-Saharan Africa. Phaladze et al. (2007) assessed QOL among 743 HIV-positive individuals not on antiretroviral therapy in four sub-Saharan African countries: Botswana, Lesotho, South Africa, and Swaziland. Daily functioning was the most significant predictor of QOL; respondents with impaired ability to carry out their daily activities had the lowest QOL scores. Surprisingly, those with higher QOL scores had more disclosure and financial worries and lower levels of education than those with lower QOL scores. Phaladze et al. concluded that their findings highlight the need for a better understanding of factors associated with QOL among people living with HIV in sub-Saharan Africa.

Mast et al. (2004) adapted the Medical Outcomes Study HIV Health Survey (MOS-HIV) to rural southwestern Uganda and this adapted version was used by Stangl et al. (2007) to assess predictors of QOL prospectively over 12 months among 947 HIV-positive adults initiating antiretroviral therapy in rural eastern Uganda. Stangl et al. found progressive improvements in QOL. Though the majority of improvement occurred by the third month of antiretroviral therapy, improvements continued until the ninth month of therapy and were maintained throughout the 12 month study period (Stangl et al.).

Much of the information on QOL among people living with HIV in sub-Saharan Africa comes from studies of antiretroviral treatment programs in South Africa. QOL inquiries were initially concerned with documenting differences in QOL among HIV-positive patients and community members (Hughes et al., 2004). Concerns shifted to establishing that

highly active antiretroviral therapy (HAART) improved QOL among people living with HIV/AIDS (Jelsma et al., 2005). The focus then turned towards identifying factors associated with improvements in QOL among patients receiving antiretroviral therapy (LeBooysen et al., 2007). Researchers have most recently been interested in exploring the relationships between sociodemographic characteristics, social support, comorbid illness, length of time on antiretroviral therapy, adherence, QOL, and physical functioning of patients receiving antiretroviral therapy (McInerney et al., 2008).

Support for the current study's hypotheses from the literature. Social support, a modifiable predictor of QOL, is the focus of the hypotheses 1.1 and 1.2. Swindells et al. (1999) assessed the influence of social support, coping style and hopelessness on QOL in HIV patients. Satisfaction with social support and more problem-focused coping were associated with better QOL while high Beck hopelessness scores were associated with poorer QOL (Swindells et al.). Friedland, Renwick, and McColl (1996) found that emotional social support, problem-oriented coping, and perception-oriented coping were positively associated with QOL while tangible social support and emotion-oriented coping were negatively associated with QOL in HIV-positive individuals attending ambulatory clinics. Jia et al.'s (2004) concluded that improving social support, coping, and depression of the HIV-infected men in their study would improve QOL. Finally, Adewuya et al. (2008) found that poorer QOL in their sample of 87 HIV-positive adults in Nigeria was associated with depression, lower educational levels, poorer socioeconomic status, and lower social support than those with higher QOL.

Maternal Education

Whether there is a linkage between caregiver education and pediatric study outcomes was examined in Specific Aim 2. Maternal education has increasingly been considered in a variety of resource-limited as well as industrialized nation contexts as a correlate and predictor of maternal health, neonatal outcomes, and uptake of early childhood immunizations. Silva et al. (2008) found that less educated women in the Netherlands had a higher risk of gestational hypertension than more educated women. Shapiro and Tambashe (2003) discussed Nzita's (1989) study of perinatal mortality in which nine large obstetric units in Kinshasa provided data from nearly 27,000 births. These data revealed that increases in maternal education were associated with lower perinatal mortality. A 1991-2000 examination of Quebec birth certificates revealed that low levels of maternal education and neighborhood income were associated with elevated crude risks of adverse birth outcomes such as stillbirth, preterm birth, small-for-gestational-age, as well as neonatal and postnatal death (Luo et al., 2006). Reviewing data from the California Department of Health Services Office of Vital Statistics between 1999 and 2001, Nanyonjo et al. (2008) found that black mothers in San Bernardino County have more than twice the rate of very low birth weight (less than 1,500 grams) infants than white mothers. Among black mothers, the most significant predictors of adverse birth outcomes were gestational age and maternal education (Nanyonjo et al.). Liu et al. (2008) examined maternal education and birth weight in southern China in the 1990s using population-based surveillance data and found that there was a decreasing risk for low birth weight infants among women with more than nine years of formal education.

The benefits of maternal education persist into early childhood. Racine and Joyce's (2007) review of US-based National Immunization Survey data from 1995 to 2003 for children 19 to 35 months revealed that higher maternal education, independent of income and race, was associated with improved child immunization rates. According to Huq and Tasnim's (2008) exploration of the influence of maternal education on health status and the utilization of child healthcare services in Bangladesh, children age 12 to 23 months of mothers with at least a secondary education are six times more likely to complete the full course of vaccination (tuberculosis-BCG, measles, polio, and all three doses of the DPT-diphtheria, pertussis, tetanus) than children of mothers with less than primary education. Furthermore, maternal education was a predictor of overall health status of children under the age of five in Bangladesh, controlling for variables such as residence, poverty status, mother's work status, and sex of the child. Children of mothers with at least a secondary education are more likely to be healthy than children of mothers having less than primary education (Huq & Tasnim).

Mechanisms through which maternal education affects outcomes

Maternal education is thought to influence health behavior which in turn affects child health outcomes. Joshi's (1994) review described two explanations for how maternal education influences health behavior as illustrated in Figure 3.1 below: 1) skills acquisition and 2) identity acquisition. Health behavior is influenced in the household as well as through the uptake of health services. Under the skills acquisition hypothesis, knowledge and context familiarity influence health behavior. Thus, increased education enhances literacy and language abilities, which enable women to better understand health messages as well as better acquire knowledge overall. According to context familiarity proponents, increased

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education and increased literacy enable women to better navigate health care settings and other bureaucracies resulting in a better understanding of and access to available health services (Joshi).

Under to the identity acquisition explanation, schools are viewed as the "transmitters of cultures" according to proponents of the social hypothesis (Joshi, 1994). According to the pyscho-social hypothesis, women internalize the teacher-student relationship, which make them lifelong learners and teachers. In the household, women assume the role as teacher to their children, and in the health care setting, women assume the role of student when responding to physicians' instructions and to health messages in the community (Joshi).

Figure 3.1: Maternal education and child health outcomes (Joshi, 1994)
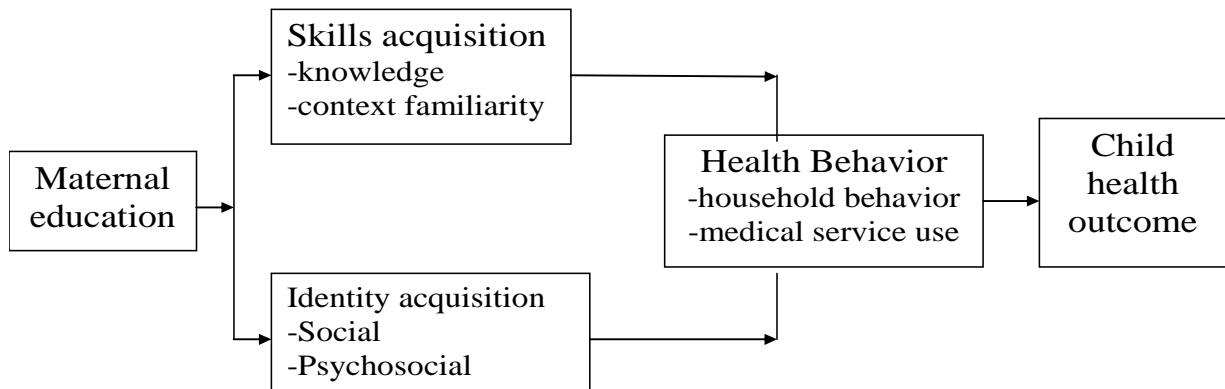
Identifying factors that attenuate the effect of maternal education on outcomes

Findings on maternal education are not presented here to blame mothers for their children's poor outcomes but rather to highlight low maternal education as a potential risk factor so that interventions can be adapted accordingly. Identifying factors that mitigate the negative effect that low maternal education has on health outcomes can be insightful for program planning and for making policy recommendations. For example, Racine and Joyce

(2007) found that residence in a state where free vaccines are provided to all residents attenuated the effect of maternal education on U.S. child immunization rates.

Education in Kinshasa: the impact on fertility and life course transitions

Shapiro and Tambashe (2003) reviewed large-scale demographic and socioeconomic surveys in Kinshasa from 1955, 1967, 1975, and 1984 as well as conducted their own survey of women of reproductive age in 1990. They observed that since independence in 1960, Kinshasa, and the country overall, have experienced increasing levels of education for both women and men though women's education lags behind men's. Peak school enrollment has consistently occurred over the years among children aged 10-14 years and this is due, in part, to the tendency for Congolese children to start school a year or two later than the industrialized nation norm of age six. According to Shapiro and Tambashe, in 1955 a woman in Kinshasa would most likely never have been to school while by 1984 the secondary school level is where the modal group in the education distribution is situated.

Tambashe and Shapiro (1991) conducted a survey of 2,450 women of reproductive age in 1990 for a more in-depth analysis of fertility, school enrolment, educational attainment, and employment. Women in Kinshasa with secondary education tend to have lower fertility than do those with only primary education or no schooling (Shapiro, 1996). By 1990, educational attainment was a more important contributor than ethnicity to observed differences in childbearing among women in Kinshasa according to Shapiro and Tambashe's (2003) analyses.   Increases in women's employment have followed increases in women's education. However women's employment tends to be concentrated in the informal sector of the economy such as self-employed commerce (i.e., street vendors). In 1984, 25% of women aged 15 and over and 37% of women age 25 and over were employed. By 1990, 34% of

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women aged 15 and over and 50% of women age 25 and over were employed (Shapiro and Tambashe, 2003).

Shapiro and Tambashe (2003) calculated predicted probabilities of young women aged 12 to 21 years experiencing three life course transition events (initiating sexual activity defined as first intercourse, marriage, and first birth) by age and school enrollment status and found that being enrolled in school is associated with delays in the timing of these events. Parental education was also associated with delays in the timing of these life course transition events though the greatest differences were observed with paternal education. Paternal education affected these life course transitions directly and indirectly. When school enrollment was controlled for, the direct effects of father's education on these life course transitions were attenuated. According to Shapiro and Tambashe, these findings reflect the influence of father's increased education on increased educational attainment of daughters.

The importance of context in examining linkages in maternal education and child health

In examining the association between maternal education and child health, some researchers have proposed that maternal education may be a proxy for household socioeconomic status and community characteristics (Desai & Alva, 1998). According to this argument, educated mothers tend to reside in wealthier households, live in areas with improved public infrastructure where they enjoy benefits such as cleaner water and sanitation services, and live in communities with better access to medical facilities than their less educated counterparts (Desai & Alva). Large scale surveys such as the Demographic and Health Surveys (DHS) have enabled researchers to examine socioeconomic indicators at

various levels of influence (i.e., national, household, and individual levels) while making cross-country comparisons.

Desai and Alva (1998) found in their examination of DHS data from 22 developing countries that the relationship between maternal education and two child health indicators (infant mortality and height for age) was attenuated when controlling for household socioeconomic characteristics (i.e., husband's education, access to piped water and toilet) and area of residence. However, this attenuating effect was not observed in the relationship between maternal education and child's immunization status when controlling for household and community-level variables. Boyle et al. (2006) examined DHS data from 42 developing countries and found that child health indicators (height and weight for age) were associated with national economic development, which accounted for the largest amount of unique variation in the regression model, followed by maternal education and household wealth.

There is a building consensus on the importance of considering community-level variables when examining associations between maternal education and child health. According to Parashar (2005), living in an area with educated mothers may improve child health through social network information diffusion, parenting norms with a shift towards health promotion, and by living in an area with a high number of vaccinated children. Das, Das, and Coutinho (2000) concluded from their analysis of case studies of child immunization in India, "a critical number of [educated] women in the community makes a sharp difference in the capacity of the community, especially women, to take advantage of services offered to them by the state" (p. 629). The current study examined individual-level covariates within a single city, Kinshasa.

Current Study's Contribution to the Literature

The available studies on the influence of psychosocial factors on QOL in HIV patients have two limitations: 1) modest sample size and 2) the generalizability of findings to women as well as families in resource-limited settings such as sub-Saharan Africa. Adewuya et al.'s (2008) finding that depression was associated with poor social support and low QOL in Nigeria was produced from a study of 87 HIV-positive patients. Jia et al.'s (2004) sample included HIV-infected men in the southern US, 55% were white and 32% believed they contracted HIV through homosexual risk factors only. Swindells et al's (1999) sample, also US-based, was 92% male, 70% white with 67% reporting a homosexual/bisexual lifestyle. Friedland et al.'s (1996) Toronto-based sample was 89% male, 75% identified as being gay, and 9% as bisexual. The sample size of these studies ranged from 87 (Adewuya et al.) to 226 (Jia et al.).

The current study assessed QOL in a family-centered care and treatment program in Kinshasa, DRC in which the adult sample size was 275 and largely women. This study makes a unique contribution to the literature on QOL in HIV-positive individuals in that the adult patients were either caregivers or first-line relatives of HIV-infected children enrolled in the study. Of the adults enrolled in this study, 84% were women and 79% were the pediatric index case's mother. In settings where the HIV epidemic is generalized and disproportionately affects women, there is a particular need for family-centered HIV care and treatment programs that offer psychosocial support services to patients. A better understanding of the relationship between psychosocial characteristics at enrollment into HIV care and treatment will aid in informing these support services.

The current study contributes to the measurement literature related to social support, stigma, psychological status, and QOL by adapting scales to the context in DRC and examining item performance. The social support and stigma scales were developed in the US while the psychological status subscale and QOL instrument were developed cross-culturally. The items used to measure social support in the SARA program were adapted from O'Brien et al.'s (1993) survey of 637 gay and bisexual men as part of the Coping and Change Study (CCS), a psychosocial supplement to the Chicago site of the Multicenter AIDS Cohort Study (MACS). The seven items used to measure perceived stigma in the SARA program items were adapted from Berger, Ferrans, and Lashley's (2001) 40-item HIV Stigma Scale which was developed using a convenience sample of 318 HIV-positive adults who responded to mailed questionnaires in eight American states. The items used to measure psychological status in the SARA program were adapted from the psychological domain of the WHOQOL-HIV BREF (WHOQOL HIV Group, 2003). The questions used to measure QOL in the SARA program were also adapted from the 31-item WHOQOL-HIV BREF, a condensed version of the 120-item instrument, which was developed in 10 field sites in nine countries (Australia, India, Brazil, Cambodia, Italy, Ukraine, Thailand, Zambia, and Zimbabwe).

In reviewing the literature for this dissertation, no articles were located on maternal education and pediatric HIV patient health outcomes. Though the articles discussed here were broad in geographic location and health topics, rarely are implications for program planning and opportunities for intervention discussed. The current study should make a contribution to the literature by providing information on the education level of caregivers of pediatric patients accessing this care and treatment program.

CHAPTER 4: METHODS

IRB Approval

The research study from which the data for this dissertation were derived was approved by the University of North Carolina at Chapel Hill (UNC) Institutional Review Board (IRB) and by the Kinshasa School of Public Health IRB. Consent forms were developed in English and translated into French and Lingala. Informed consent was obtained from adult participants prior to participation in the study. For minors, parental consent and informed assent were obtained. The secondary data analysis for this dissertation research was presented to the UNC IRB and additional approval was not required.

Data Collection

The data reported here were collected using standardized data forms that were developed in English and translated into French and Lingala. Data were collected by trained SARA program staff at KLL Hospital (nurses, physicians, and the psychosocial coordinator) and were entered into an Access database by trained data entry staff. The database was transmitted monthly by the database manager in Kinshasa to UNC. Error reports were produced by UNC staff and sent to the Kinshasa-based data entry staff so that database errors could be corrected.

Sample

The sample for this dissertation research consisted of adult and pediatric patients enrolled in a family-centered HIV care and treatment program in Kinshasa from November 2004 to March 2009. The sample for Specific Aim 1 consisted of the 275 adults enrolled in the SARA program. Adults eligible for this program were HIV-positive parents, guardians, or siblings of enrolled HIV-infected children. Of the 275 adults enrolled, 84% were female (N=230) and the median age of participants was 35 years with a range of 19 years to 60 years. Of the 275 adults in this program, 218 were the index patient's mother, 45 were the father, 8 were the aunt, one was the uncle, and one was the sister. Two patients were enrolled at 19 years of age that had received care at Kalembe Lembe Pediatric Hospital (KLL) and were not related to a pediatric index case.

The sample for Specific Aim 2 consisted of the 780 pediatric patients enrolled in the SARA program. Children were recruited at the public KLL Hospital, which is centrally located in Kinshasa and offers services to about 1,400 children per month. Of the 780 pediatric patients enrolled in this study, one-half were female (53%). Patients ranged in age from 0.1 years to 17.2 years with a median age of 5.7 years.

Inclusion criteria

The inclusion criteria for enrollment into this HIV care and treatment program as stated in the SARA program protocol were:

1. Proof of HIV infection: documented HIV infection from referring institution, which is confirmed at the first clinical visit with an ELISA test;

2. Physical ability and willingness to adhere to scheduled project clinic visits at KLL;

3. No intent to relocate away from Kinshasa; and

4. Ability and willingness of participant, parent, or legal guardian to give written informed consent.

Exclusion criterion

The exclusion criterion for enrollment into this HIV care and treatment program as stated in the SARA program protocol was:

1. Patients coming from families with a monthly income greater than US$500 per month per HIV-positive person in the household.

Measures

This section addresses how the constructs of social support, quality of life, psychological status, and stigma were measured in the SARA program. Whether the scales measuring these constructs address their multi-dimensionality is discussed along with the history of items and whether items were adapted from validated scales. Also described is how clinical stage, CD4, and caregiver education were assessed.

Social support

Types of social support addressed in the SARA program. Social support was measured at baseline by asking patients how strongly they agree or disagree to seven statements about people who are involved in their daily life. There were four response categories: 4-strongly agree, 3-agree, 2-disagree, 1-strongly disagree. The first two statements (E1-E2) addressed emotional support, the next three statements (E3-E5) addressed instrumental support, and last two statements (E6-E7) addressed informational support. The social support items are presented in Table 4.1 below.

Table 4.1: SARA program social support items

Item	Strongly agree	Agree	Disagree	Strongly disagree
E1. There is someone you could talk to if you are upset, nervous, or depressed.	☐	☐	☐	☐
E2. There is someone you could contact if you want to talk about an important personal problem you are having.	☐	☐	☐	☐
E3. There is someone who could help take care of you if you were confined to your bed for several weeks.	☐	☐	☐	☐
E4. There is someone you could turn to if you need to borrow a small amount of money, a ride to the doctor, or some other small immediate need.	☐	☐	☐	☐
E5. There is someone you could turn to if you need to borrow a larger amount of money for a medical emergency.	☐	☐	☐	☐
E6. There is someone in your personal life that could give you information, suggestions, or guidance if you need it.	☐	☐	☐	☐
E7. There is someone you could turn to if you need advice to help make a decision.	☐	☐	☐	☐

History of social support items. The items used to measure social support in the SARA program were adapted from O'Brien et al.'s (1993) survey of 637 gay and bisexual men as part of the Coping and Change Study (CCS), a psychosocial supplement to the Chicago site of the Multicenter AIDS Cohort Study (MACS). All seven items in O'Brien et al.'s perceived availability of support subscale ($\alpha = .873$) were used in the same order in the SARA program though adapted to better fit the context in Kinshasa. For example, O'Brien et al.'s item asked, "Is there someone you could turn to if you needed to borrow $10, a ride to the doctor, or some other small, immediate help?" whereas the item was adapted for the SARA program to state, "There is someone you could turn to if you need to borrow a small amount of money, a ride to the doctor, or some other small immediate need?" Also, as this example illustrates, the items were modified for the SARA program to be phrased as statements with four response items ranging from 4-strongly agree to 1-strongly disagree. O'Brien et al.'s items were phrased as questions with five response items: 1=no, definitely not; 2=no, probably not; 3=yes, possibly; 4=yes, probably; 5=yes, definitely. Social support was evaluated as the sum score of seven items with a possible range of 7 to 28, with higher scores indicating more social support.

Stigma

Components of stigma. During Berger, Ferrans, and Lashley's (2001) development of the HIV Stigma Scale, four underlying factors emerged: personalized stigma, disclosure concerns, negative self-image, and concerns with public attitudes toward people with HIV. Personalized stigma is characterized by perceived consequences of other people knowing that that one is HIV-positive and relates to personal experiences or fears of rejection for having HIV. Disclosure concerns are characterized by controlling information, keeping one's HIV status a secret, or worrying that involuntary HIV disclosure might occur. Negative self-image is characterized by feelings of shame and guilt, perceiving oneself as being unclean, not as good as others, or a bad person because of HIV. Concerns with public attitudes toward people with HIV involve perceptions of other people's attitudes and beliefs about people with HIV (Berger, Ferrans & Lashley).

Components of stigma measured in the SARA program. Stigma was measured at baseline by asking patients how strongly they agree or disagree to statements describing how they feel. This scale consisted of seven items with four response categories: 1-strongly disagree, 2-disagree, 3-agree, 4-strongly agree. One statement (C1) addressed disclosure concerns as well as negative self-image, one statement (C2) addressed negative self-image, three statements (C6, C8, C12) addressed personalized stigma, one statement (C7) addressed disclosure concerns, and one statement (C13) addressed personalized stigma, negative self-image, as well as concerns with public attitudes. The stigma items used in the SARA program are presented in Table 4.2 below.

Table 4.2: SARA program stigma items

Item	Strongly Disagree	Disagree	Agree	Strongly Agree
C1. I try very hard not to let other people know I have HIV	☐	☐	☐	☐
C2. People's attitudes about HIV make me feel worse about myself	☐	☐	☐	☐
C6. I have been hurt by how people reacted to learning I have HIV	☐	☐	☐	☐
C7. I worry that people who know I have HIV will tell others	☐	☐	☐	☐
C8. I regret having told some people that I have HIV	☐	☐	☐	☐
C12. I have lost friends by telling them I have HIV	☐	☐	☐	☐
C13. People seem afraid of me once they learn I have HIV	☐	☐	☐	☐

History of stigma items.   The seven items used to measure perceived stigma in the

SARA program were adapted from Berger, Ferrans, and Lashley's (2001) 40-item HIV

Stigma Scale. Items were stated as they were on the original scale except for the first item.

In the SARA program, the first item was stated, "I try very hard not to let other people know

I have HIV" whereas Berger, Ferrans, and Lashley's item was stated as, "I work hard to keep

my HIV a secret." Berger, Ferrans, and Lashley reported high internal consistency of the 40-

item scale with coefficient alpha ranging from 0.90 to 0.93 for the subscales. In July 2006,

after 109 patients had been enrolled in the study and completed the 13-item scale, the stigma

scale was reduced from a 13-item scale to a 7-item scale. Items were reduced in response to

the crowded clinic schedule and to reduce time spent completing questionnaires during clinic

visits. Items were dropped according to staff members' impression of questions that were

redundant rather than through empirical data reduction techniques. Stigma was evaluated as

the sum score of seven items with a possible range of 7 to 28. The lower the score, the lower

the stigmatization perceived by the patient.

Psychological status

   Facets of psychological status measured in the SARA program. Psychological status is one of six domains in the cross-cultural assessment of QOL developed by the WHOQOL group (WHOQOL HIV Group, 2003). The psychological domain involves five facets: positive feelings, thinking, learning, memory, and concentration; self-esteem; bodily image and appearance; and negative feelings (WHO, 2002). All five facets were assessed in the SARA program: one item addressed the positive feelings facet (F1), one item addressed the thinking, learning, memory and concentration facet (F2), one item addressed the negative feelings facet (F3), one item addressed the bodily image and appearance facet (F4), and one item addressed the self-esteem facet (F5). There is overlap between the psychological status items and items used to screen for depression. For example, the ability to concentrate item (F2) is similar to the Center for Epidemiologic Studies Depression Scale (CES-D) item, "I had trouble keeping my mind on what I was doing" (Radloff, 1977). The depression item (F3) is similar to the CES-D item, "I felt depressed." The items used to measure psychological status in the SARA program are presented in Table 4.3 below.

Table 4.3: SARA program psychological status items

Item	Strongly agree	Agree	Disagree	Strongly disagree
F1. You find your life worthwhile.	☐	☐	☐	☐
F2. Most of the time you are able to concentrate.	☐	☐	☐	☐
F3. You feel often depressed and have feelings of despair.	☐	☐	☐	☐
F4. You accept your bodily appearance.	☐	☐	☐	☐
F5. In general you are satisfied with yourself.	☐	☐	☐	☐

   History of psychological status items. The items used to measure psychological status in the SARA program were adapted from the psychological domain of the WHOQOL-

HIV BREF (WHOQOL HIV Group, 2003). All five domain-specific items from the WHOQOL-HIV BREF were included in the SARA program's assessment of psychological status; however, the positive feelings item was slightly adapted. The WHOQOL Bref item is stated, "How much do you enjoy life" whereas the SARA item was phrased "You find your life worthwhile." Also, as this example illustrates, the items were modified for the SARA program to be phrased as statements with four response items ranging from 4-strongly agree to 1-strongly disagree. The WHOQOL-BREF items are phrased as questions with five response items: 1=not at all; 2=a little; 3=a moderate amount; 4=very much; 5=an extreme amount. Psychological status was measured at enrollment by asking patients how strongly they agree or disagree to statements about how they feel about themselves. Psychological status was evaluated as the sum score of five items with a possible range of 5 to 20 with higher scores indicating better psychological well being.

Quality of Life (QOL)

Quality of life domains. There are six domains in the cross-cultural assessment of QOL created by the WHOQOL group: physical; psychological; level of independence; social relationships; environmental; and spiritual/religious/personal beliefs (WHOQOL HIV Group, 2003). The physical domain involves pain and discomfort, energy and fatigue, sleep and rest, as well as symptoms of people living with HIV/AIDS (WHO, 2002). The psychological domain involves positive feelings, thinking, learning, memory, and concentration, self-esteem, bodily image and appearance, as well as negative feelings. The level of independence domain involves mobility, activities of daily living, dependence on medication or treatments, and work capacity. The social relationships domain involves personal relationships, social support, sexual activity, and social inclusion. The environment

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domain involves physical safety and security, home environment, financial resources, health and social care (accessibility and quality), opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, physical environment (pollution, noise, traffic, climate), and transportation. The spirituality/religion/personal beliefs domain involves spirituality, religion, and personal beliefs, forgiveness and blame, concerns about the future, as well as death and dying (WHO, 2002).

      Quality of life domains addressed in the SARA program. Three of the SARA program QOL items addressed the physical domain (B4, B9, B14), one item addressed the level of independence domain (B16), two items addressed the social relationships domain (B17-B18). The SARA program item asking how satisfied the patient is with his/her health is a summary statement on the WHOQOL measure and is not grouped with a domain. Though one SARA program item which asked how often the patient had to stay in bed (B7) is not stated as such in the WHOQOL, it closely resembles an item addressing the level of independence domain, "How well are you able to get around?"   The QOL items used in the SARA program are presented in Table 4.4 below.

Table 4.4: SARA program Quality of Life items

In the past week, how often:

Item	None of the time	Some of the time	Most of the time	All of the time
B4. Did you have enough energy for everyday life?	☐	☐	☐	☐
B7. Did you have to stay in bed?	☐	☐	☐	☐
B9. Did you have pain?	☐	☐	☐	☐

Indicate in the chart below the patient's level of satisfaction with these items [completed by SARA staff]:

Item	Very dissatisfied	Dissatisfied	Satisfied	Very satisfied
B13. Your health?	☐	☐	☐	☐
B14. Your sleep?	☐	☐	☐	☐
B16. Your ability to work?	☐	☐	☐	☐
B17. Your personal relationships?	☐	☐	☐	☐
B18. Your sex life?	☐	☐	☐	☐

History of quality of life items. The items used to assess QOL in the SARA program were adapted from the WHOQOL-HIV BREF. QOL was measured at enrollment by asking patients 12 questions about how often certain events happened to them in the past week with four response categories: 0-none of the time, 1-some of the time, 2-most of the time, 3-all of the time. Patients were then asked 11 questions about how satisfied they were in the past week with response categories of 1-very dissatisfied, 2-dissatisfied, 3-satisfied, and 4-very satisfied. In July 2006, after 109 patients were enrolled in the study and completed the 23-item scale, the QOL scale was reduced to an 8-item scale. Items were reduced in response to the crowded clinic schedule and to reduce time spent completing questionnaires during clinic visits. Items were dropped according to staff members' impression of questions that were redundant rather than through empirical data reduction techniques. QOL was evaluated as the sum score of eight items with a possible range of 5 to 29. The lower the score, the lower the QOL.

Clinical stage

The WHO (2006a) Clinical Staging System for HIV was developed in 1990 and revised in 2006. Clinical stage, which is based on the presence of conditions and symptoms, ranges from 1 to 4 with 1 being primary HIV infection and 4 being advanced HIV/AIDS. Clinicians in resource-limited settings, such as DRC, where laboratory services such as CD4 count and viral load are not readily available use clinical staging to guide the diagnosis and management of HIV/AIDS. For example, clinical staging is used to guide decisions such as when to start cotrimoxazole prophylaxis and when to start and, if necessary, switch antiretroviral therapy. Clinical stage was assessed at enrollment by SARA program physicians. The WHO clinical staging system for HIV for adults/adolescents as well for children as stated in the SARA program protocol is included in Appendix A.

CD4

CD4 cell count, an indication of immune system functioning, decreases as HIV disease progresses. The normal range for CD4 cell counts in adults is 500 to 1,500 cells per cubic millimeter of blood. People with HIV often have CD4 counts less than 500 cells/ml whereas those with AIDS have CD4 counts less than 200 cells/ml. In the SARA program, adults and adolescents are started on antiretroviral therapy if CD4 cell count is less than 200 cells/ml.

Absolute CD4 count tends to vary more within an individual child than does CD4% (WHO, 2006b). CD4% indicates the total lymphocytes that are CD4 cells. In general, CD4% is the preferred marker in children under 5 years old and CD4 count is best used for children ages 5 and older in classifying HIV-associated immunodeficiency. The WHO

(2006b) classification of HIV-associated immunodeficiency in infants and children is in

included in Table 4.5 below and was used in the analyses involved in Specific Aim 2.

Table 4.5: WHO classification of HIV-associated immunodeficiency in infants and children

Severity of immunodeficiency	Age-related CD4 values			
	<=11 months (%)	12-35 months (%)	36-59 months (%)	>=5 years (cells/mm^3)
Not significant	>35	>30	>25	>500
Mild	30-35	25-30	20-25	350-499
Advanced	25-29	20-24	15-19	200-349
Severe	<25	<20	<15	<200 or <15%

Source: WHO (2006b)

As is illustrated in the WHO CD4 criteria for severe HIV immunodeficiency

presented in Table 4.6 below, there is not a great difference in the CD4% points across the

different age categories. However, the absolute CD4 count is quite different across the

different age categories ranging from <1500 cells/mm^3 (for children 11 months and younger)

to <200 cells/mm^3 (for children 5 years and older) to denote severe HIV immunodeficiency.

Table 4.6: WHO CD4 criteria for severe HIV immunodeficiency in infants and children

Classification of HIV-associated immunodeficiency	<=11 months	12-35 months	36-59 months	>=5 years
CD4 %	< 25%	< 20%	< 15%	< 15%
Absolute CD4 count	< 1500 cells/mm^3	< 750 cells/mm^3	< 350 cells/mm^3	< 200 cells/mm^3

Source: WHO (2006b)

Caregiver education

Caregiver education was assessed at enrollment by asking the adult that accompanied

the child to the visit, "Education completed by patient's mother or caregiver?" Due to the

wording of the educational status question, we can not be certain whether educational status

has been obtained for the patient's mother or the patient's primary caregiver. Given 62% of

patients' biological mother was alive, we made an assumption that the majority of patients had mothers as their primary caregiver. The response options were collapsed from six response options to three categories for analysis purposes. The *none* and *some primary school* responses were combined to form the *below primary school* response category. The *completed primary school* and *some secondary school* responses were combined to form the *secondary school* category. The *completed secondary school* and the *any post secondary school* responses were combined to form the *higher secondary* category.

Preliminary Analyses

The following preliminary analyses were conducted to determine the adequacy of the measures used in this study. Cronbach's (1951) coefficient alpha was used as a measure of internal consistency. Because an assumption of alpha is unidimensionality, principal component analysis (PCA) was conducted to determine how many components account for most of the variance in the set of items measuring social support, stigma, psychological status, and QOL.

Internal consistency

Internal consistency is concerned with the homogeneity of items within a scale (DeVellis, 2003). Items that did not load strongly on a given component and items that factored separately during PCA were dropped and coefficient alpha was recalculated. Items were considered to load on a given component if the factor loading was .40 or greater for that component. All measures possessed good internal consistency. Coefficient alpha ranged from 0.63 (stigma) to 0.88 (social support) as is presented in Table 4.7 below.

Table 4.7: Coefficient alphas for measures

Variable	N	# items	Coefficient Alpha	N (items removed after PCA)	# items (items removed after PCA)	Coefficient Alpha (items removed after PCA)
Psychological status	258[1]	5	0.769	258[1a]	4	0.868
Social Support	256[2]	7	0.750	257[2a]	5	0.877
QOL	230[3]	8	0.777	235[3a]	6	0.843
Stigma	238[4]	7	0.625	243[4a]	4	0.626

[1] Of 260 patients who answered the psychological status questions, 258 have responses for all 5 items.
[1a] Question F03 removed because it did not load strongly during PCA
[2] Of 261 patients who answered the social support questions, 256 have responses for all 7 items.
[2a] Questions E04 and E05 were removed because they factored separately in PCA.
[3] Of 244 patents who answered the OQL questions, 230 have responses for all 8 items.
[3a] Questions B17 and B18 were removed because they did not load strongly during PCA.
[4] Of 244 patients who answered the stigma questions, 238 have responses for all 7 items.
[4a] Question C01 removed because it did not load strongly during exploratory factor analysis. Questions C12, C13 removed because they factored separately in PCA and exploratory factor analysis.

Principal Component Analysis (PCA)

Principal component analysis (PCA) is a data reduction procedure that is similar to exploratory factor analysis in that both techniques can be used to identify questionnaire items that tend to hang together empirically (Hatcher, 1994). The two techniques differ in their assumptions of underlying causal structure between questionnaire items, or observed variables, and the latent variables that the questionnaire items are assessing. Principal component analysis makes no assumption about the underlying causal structure whereas factor analysis makes the assumption that the latent variables, or factors, exert causal influence on the observed variables (Hatcher). PCA was selected as opposed to exploratory factor analysis because a relatively small number of questionnaire items were selected from validated scales to measure the psychosocial variables of interest. After 109 patients had been enrolled in the study, items were further reduced to shorten clinic visits according to staff members' impression of questionnaire items that were redundant rather than through

empirical data reduction techniques. I chose PCA as the preferred data reduction procedure because I did not want to make assumptions about the underlying causal structure between the observed variables and the latent variables given the low number of questionnaire items used, in comparison to the original validated scales.

PCA of psychological status and QOL

A principal component analysis (PCA) was conducted on the combined psychological status and QOL questions due to a potential overlap in items measuring symptoms of depression. Responses to the five psychological status questions and the eight quality of life (QOL) items were subjected to a PCA (N=214) using ones as prior communality estimates. The principal axis method was used to extract the components, and this was followed by a varimax (orthogonal) rotation.

The first four components displayed eigenvalues greater than 1 (4.32, 2.23, 1.10 and 1.02) which suggested that four components were meaningful. However, the results of the scree test suggested that only the first two components were meaningful. Horn's (1965) parallel analysis revealed that the first two eigenvalues from the actual data exceeded the eigenvalues from random data (1.39 and 1.29) which also suggested that the first two components were meaningful. The amount of common variance accounted for by each individual component was examined. Component 1 alone accounted for 33% of the total variance, the second component alone accounted for 17% of the total variance, the third component alone accounted for 8% of the total variance, and the fourth component alone accounted for 8% of the total variance. The cumulative percent of variance accounted for by components 1, 2, 3, and 4 was 67%. Four components were initially retained for rotation then the rotation was repeated with only two components.

Questionnaire items and their corresponding factor loadings when four components were retained are presented in Table 4.8. In interpreting the rotated factor pattern, an item was said to load on a given component if the factor loading was .40 or greater for that component, and was less than .40 for the other components. Using these criteria, five items loaded on component 1, four items loaded on component 2, one item loaded on component 3, and two items loaded on component 4. One item (B07) loaded strongly on both component 1 and component 3. The low number of items loading on components 3 and 4 suggest that only two components should be retained.

Table 4.8: Rotated (orthogonal) factor pattern and final communality estimates for principal component analysis of psychological status and QOL questions with 4 components retained

Items	Component 1	Component 2	Component 3	Component 4	h^2
F01. You find your life worthwhile	.01	**.79**	.27	-.17	.72
F02. Most of the time you are able to concentrate	.09	**.83**	.20	-.04	.74
F03. You feel often depressed and have feelings of despair	.06	.01	.07	**.63**	.40
F04. You accept your bodily appearance	.22	**.83**	-.13	.06	.75
F05. In general you are satisfied with yourself	.17	**.87**	.02	.16	.81
B04. Did you have enough energy for everyday life?	**.75**	.22	.33	-.05	.72
B07. Did you have to stay in bed?	**.56**	-.05	**.58**	.12	.66
B09. Did you have pain?	**.76**	.01	.09	.00	.59
B13. Your health?	**.82**	.12	.03	.05	.70
B14. Your sleep?	**.68**	.19	-.35	.04	.63
B16. Your ability to work?	**.83**	.14	.18	.06	.75
B17. Your personal relationships?	-.01	.00	-.04	**.77**	.60
B18. Your sex life?	.09	.27	**.73**	.02	.62

Note: N=214. Communality estimates appear in column headed h^2

Questionnaire items and their corresponding factor loadings when two components were retained for rotation are presented in Table 4.9. Six of the eight QOL items loaded on Component 1 and 4 of the 5 psychological status items loaded on component 2. One of the QOL items (B17) and one of the psychological status items (F03) did not load strongly on either component. One of the QOL items (B18) loaded on component 2.

Table 4.9: Rotated (orthogonal) factor pattern and final communality estimates for principal component analysis of psychological status and QOL questions with 2 components retained

Items	Component 1	Component 2	h^2
F01. You find your life worthwhile	-.02	**.83**	.68
F02. Most of the time you are able to concentrate	.05	**.86**	.73
F03. You feel often depressed and have feelings of despair	.13	.01	.02
F04. You accept your bodily appearance	.13	**.80**	.65
F05. In general you are satisfied with yourself	.11	**.86**	.75
B04. Did you have enough energy for everyday life?	**.77**	.31	.69
B07. Did you have to stay in bed?	**.67**	.08	.45
B09. Did you have pain?	**.76**	.06	.58
B13. Your health?	**.80**	.16	.67
B14. Your sleep?	**.59**	.16	.37
B16. Your ability to work?	**.84**	.21	.74
B17. Your personal relationships?	.06	-.02	.00
B18. Your sex life?	.21	**.40**	.20

Note: N=214. Communality estimates appear in column headed h^2

A promax (oblique) rotation was also conducted using exploratory factor analysis since the two factors were correlated (0.33). The results are presented in Table 4.10 below. Six of the eight QOL items loaded on Component 1 and 4 of the 5 psychological status items loaded on component 2. These results suggest that it is acceptable to treat psychological status and QOL as separate constructs despite the slight overlap in items measuring

symptoms of depression. The three items (F03, B17, B18) that did not load strongly on

either component were removed from further analyses.

Table 4.10: Rotated (oblique) factor pattern and final communality estimates for exploratory factor analysis of psychological status and QOL questions with 2 components

Items	Component 1	Component 2	h^2
F01. You find your life worthwhile	-.09	**.78**	.57
F02. Most of the time you are able to concentrate	-.03	**.80**	.63
F03. You feel often depressed and have feelings of despair	.10	.00	.01
F04. You accept your bodily appearance	.05	**.76**	.60
F05. In general you are satisfied with yourself	.02	**.83**	.71
B04. Did you have enough energy for everyday life?	**.74**	.14	.63
B07. Did you have to stay in bed?	**.61**	-.04	.36
B09. Did you have pain?	**.70**	-.07	.46
B13. Your health?	**.77**	.00	.59
B14. Your sleep?	**.52**	.05	.29
B16. Your ability to work?	**.82**	.04	.69
B17. Your personal relationships?	.04	-.02	.00
B18. Your sex life?	.17	.28	.14

Note: N=214. Communality estimates appear in column headed h^2

PCA of stigma

Responses to the seven stigma items were subjected to a principal components

analysis (N=238) using ones as prior communality estimates. The principal axis method was

used to extract the components, and this was followed by a varimax (orthogonal) rotation.

Because factors 1 and 2 were correlated (0.43), a promax (oblique) rotation was also

conducted using exploratory factor analysis.

The first three components displayed eigenvalues greater than 1 (2.53, 1.28, and 1.12)

which suggested that three components were meaningful. The results of the scree test were

not obvious for separating the meaningful components from the trivial components. Horn's (1965) parallel analysis revealed that the first three eigenvalues from the actual data exceeded the eigenvalues from random data (1.25, 1.14, and 1.06) which also suggested that the first three components were meaningful. Therefore, three components were retained for rotation. The amount of common variance accounted for by each individual component was examined. Component 1 alone accounted for 36% of the total variance, the second component alone accounted for 18% of the total variance, and the third component alone accounted for 16% of the total variance. The cumulative percent of variance accounted for by components 1, 2, and 3 was 70%.

Questionnaire items and their corresponding factor loadings when three components were retained are presented in Table 4.11. In interpreting the rotated factor pattern, an item was said to load on a given component if the factor loading was .40 or greater for that component, and was less than .40 for the other components. Using these criteria, two items (C12, C13) loaded on component 1, two items (C06, C07) loaded on component 2, and one item (C01) loaded on component 3. Two items loaded strongly on more than one component (C02 and C08).

Table 4.11: Rotated (orthogonal) factor pattern and final communality estimates for principal components analysis of stigma items with 3 components

Items	Component 1	Component 2	Component 3	h^2
C01. I try very hard not to let other people know I have HIV	.02	-.15	**.87**	.79
C02. People's attitudes about HIV make me feel worse about myself	-.03	**.60**	**.56**	.67
C06. I have been hurt by how people reacted to learning I have HIV	.23	**.81**	.06	.72
C07. I worry that people who know I have HIV will tell others	.05	**.72**	-.25	.59
C08. I regret having told some people that I have HIV	**.50**	**.50**	.02	.50
C12. I have lost friends by telling them I have HIV	**.91**	.10	-.02	.84
C13. People seem afraid of me once they learn I have HIV	**.90**	.10	.01	.81

Note: N=238. Communality estimates appear in column headed h^2

A promax (oblique) rotation was also conducted using exploratory factor analysis and the results are presented in Table 4.12 below. Four items (C02, C06, C07, C08) loaded on component 2. The item (C01) that did not load strongly on any of the components was dropped from further analyses along with the two items (C12, C13) that loaded on component 1 because two items are not enough to adequately represent a component.

Table 4.12: Rotated (oblique) factor pattern and final communality estimates for exploratory factor analysis of stigma items with 3 components

Items	Component 1	Component 2	Component 3	h^2
C01. I try very hard not to let other people know I have HIV	.03	-.06	.36	.13
C02. People's attitudes about HIV make me feel worse about myself	-.05	**.45**	.30	.30
C06. I have been hurt by how people reacted to learning I have HIV	.05	**.71**	-.01	.53
C07. I worry that people who know I have HIV will tell others	-.04	**.52**	-.18	.27
C08. I regret having told some people that I have HIV	.28	**.41**	-.03	.34
C12. I have lost friends by telling them I have HIV	**.81**	.00	-.01	.65
C13. People seem afraid of me once they learn I have HIV	**.79**	.00	.03	.62

Note: N=238. Communality estimates appear in column headed h^2

PCA of social support

Responses to the seven social support items were subjected to a principal component analysis (N=256) using ones as prior communality estimates. The principal axis method was used to extract the components, and this was followed by a varimax (orthogonal) rotation.

The first two components displayed eigenvalues greater than 1 (3.39 and 1.52). The results of the scree test suggested that the first two components are meaningful. Horn's (1965) parallel analysis revealed that the first two eigenvalues from the actual data exceeded the eigenvalues from random data (1.11 and 1.07) which also suggested that the first two components were meaningful. Therefore, two components were retained for rotation. The amount of common variance accounted for by each individual component was examined. Component 1 alone accounted for 48% of the total variance and the cumulative percent of variance accounted for by components 1 and 2 was 70%.

Questionnaire items and their corresponding factor loadings when two components were retained are presented in Table 4.13 below. In interpreting the rotated factor pattern, an item was said to load on a given component if the factor loading was .40 or greater for that component, and was less than .40 for the other components. Using these criteria, five items (E01, E02, E03, E06, E07) loaded on component 1 and two items (E04, E05) loaded on component 2. The two questions that loaded on component 2 assessed instrumental support and were dropped from the moderation analysis since two items are not enough to adequately measure a component. Seventy-two percent of 260 patients strongly disagreed or disagreed to the statement indicating whether there is someone from whom they could borrow a small amount of money, ride to the doctor, or some other small immediate need. Ninety-four percent of 261 patients strongly disagreed or disagreed to the statement indicating whether there is someone from whom they could borrow a larger amount of money for a medical emergency.

Table 4.13: Rotated (orthogonal) factor pattern and final communality estimates for principal component analysis of social support items with 2 components

Items	Component 1	Component 2	h²
E1. There is someone you could talk to if you are upset, nervous, or depressed.	**.87**	-.04	.76
E2. There is someone you could contact if you want to talk about an important personal problem you are having.	**.86**	-.13	.75
E3. There is someone who could help take care of you if you were confined to your bed for several weeks.	**.70**	.12	.51
E4. There is someone you could turn to if you need to borrow a small amount of money, a ride to the doctor, or some other small immediate need.	-.03	**.87**	.75
E5. There is someone you could turn to if you need to borrow a larger amount of money for a medical emergency.	.04	**.86**	.74
E6. There is someone in your personal life that could give you information, suggestions, or guidance if you need it.	**.85**	.00	.72
E7. There is someone you could turn to if you need advice to help make a decision.	**.82**	.04	.67

Note: N=256. Communality estimates appear in column headed h^2

Analysis Plan

All analyses were conducted using the SAS System for Windows, version 9.1.3 (The

SAS Institute Inc., 2002-2003).

Data analysis for Specific Aim 1

This study was exploratory in nature due to its cross-sectional nature. Relationships

between variables were examined and whether there were patterns that were consistent with

moderation was assessed. A correlation matrix was produced and the Pearson correlation

coefficients were examined. In general, a positive association was anticipated between social

support and QOL. A negative association was anticipated between stigma and QOL such that the higher perceived stigma that patients report, the lower QOL they would report.

Applying principles of moderation to guide analysis of hypothesis 1.1 and 1.2

A total of 222 patients answered all social support, stigma, and psychological status questions at enrollment. Psychological status, one of six domains in the WHOQOL-HIV measure, was examined separately and as a combined psychological status/QOL variable.

- Hypothesis 1.1 – The relationship between social support and psychological status varies by the extent to which patients have experienced stigma such that the association between social support and psychological status will be positive and stronger for patients who report low stigma than for patients who report high stigma.

Hierarchical multiple regression as described in Frazier, Tix, and Barron's (2004) discussion of moderation was used to guide data analysis for hypothesis 1.1. A moderator is a variable that alters the direction or strength of the relation between a predictor and an outcome. In other words, the association between the independent variable and the dependent variable will vary by levels of the moderator variable. In the current study's regression analysis, psychological status was the dependent variable, social support was the independent variable and stigma was entered into the regression model as an independent variable. The interaction between social support and stigma was also entered into the model. The regression equation is as follows:

$$Y = b_0 + b_1 (x) + b_2 (m) + b_3 (xm) + e$$

where b_0 is the intercept, b_1 is the beta value for social support, b_2 is the beta value for stigma, b_3 is the beta value for the social support X stigma interaction, and e is the error term.

As summed scores of their respective scales, social support, stigma and psychological status were maintained as continuous variables for data analysis. Frazier, Tix, and Barron (2004) recommend that continuous independent and moderating variables be either centered or standardized because these variables tend to be highly correlated with the interaction terms created from them and these transformation techniques reduce problems when variables in the regression equation are highly correlated. The social support and stigma values were standardized using the mean and standard deviations from the current study's sample data to produce Z scores where x is the raw score, μ is the mean, and σ_x is the standard deviation as indicated in the following equation:

$$Z = \frac{x - \mu}{\sigma_x}$$

Given psychological status is one of six domains in the WHOQOL-HIV measure, hypothesis 1.1 was re-tested with the combined psychological status/QOL variable included as the dependent variable as indicated in hypothesis 1.2. A total of 216 patients answered all social support, stigma, and QOL questions at enrollment.

- Hypothesis 1.2 - The relationship between social support and QOL varies by the extent to which patients report perceived stigma such that the association between social support and QOL will be positive and stronger for patients who report low stigma than for patients who report high stigma.

Hierarchical multiple regression as described in Frazier, Tix, and Barron's (2004) discussion of moderation was used to guide data analysis for hypothesis 1.2 as was done for hypothesis 1.1. The moderation hypotheses were then re-examined controlling for the following demographic and clinical variables: age, marital status, education, employment

status, as well as CD4 cell count and clinical stage at enrollment. The WHO clinical staging system for HIV for adults as stated in the SARA program protocol is included in Appendix A.

Missing data for Specific Aim 1

Missing data for the psychosocial variables are detailed in Table 4.14 below. Of 275 adults enrolled in the SARA program, 14 were missing one item on the psychological status, social support, QOL, or stigma scales. In addition, one patient was missing two scale items, and another patient was missing three scale items. For the16 patients missing 1-3 scale items, the item mean was imputed and the moderation hypotheses were re-tested. Data were not imputated for patients missing the entire data collection form or for those missing the entire scale but were administered the rest of the data collection form.

Table 4.14: Missing data for the psychosocial variables

Scale (Data form)	1 scale item missing	2 scale items missing	3+ scale items missing	Entire scale missing	Entire form missing	Forms with complete data	Total
Psychological status (ESE)	2	0	1	14[1]	0	258	275
Social support (ESE)	4	0	0	14[1]	0	257	275
QOL (PSPA)	8	1	0	1	30	235	275
Stigma (PSPA)	1	0	0	1	30	243	275

[1] The first 13 adults enrolled into the SARA program were not administered the psychological status or the social support questions. An additional patient was not administered the psychological status or social support questions.

Data analysis for Specific Aim 2

Specific Aim 2 addressed psychosocial characteristics at enrollment and study outcomes of adult patients (hypothesis 2.1) and pediatric patients (hypothesis 2.2). Study status by age group is presented in Table 4.15 below.

Table 4.15: Study status by age group for those eligible for analysis of study outcomes

Study Status	Pediatric Patients	Adult Patients	Total
Deactivated[1]	146	28	174
Active	514	218	732
Total	660	246	906

[1] The 174 deactivated patients are those deactivated due to poor adherence (9 pediatric, 5 adult), patient opted to discontinue treatment (6 pediatric, 4 adult), deceased (89 pediatric, 11 adult) or lost to follow-up (42 pediatric, 8 adult). Those that are HIV negative (81 pediatric), moved (16 pediatric, 17 adult), and those that transferred to another HIV treatment program (7 pediatric, 5 adult) are not included in the deactivated count. Those enrolled within the last 3 months (16 pediatric, 7 adult) are not included in the analysis of study outcomes.

- Hypothesis 2.1 – Adult patients who were deactivated from the study (N=28) due to death or failure to maintain clinic appointments will score lower on the social support scale, score lower on psychological status scale, score lower on the quality of life scale and score higher on the stigma scale than those who remained active in the study (N=233).

A series of two-sample t-tests were conducted to test hypothesis 2.1. For example, mean social support scores were calculated and the mean score of those active in the study were compared to the mean score of those deactivated from the study to determine if there were differences between the two groups. Given the small number of patients in the two groups (28 deactivated vs. 218 active), this study may fail to detect real effects that exist due to low statistical power. Therefore, hypothesis 2.1 was exploratory in nature.

- Hypothesis 2.2 - Pediatric patients with caregivers that have less education will be more likely to be enrolled with more advanced HIV disease than pediatric patients with caregivers with more education.

Hypothesis 2.2 was first tested using the WHO (2006a) HIV clinical staging system as an indicator of disease stage which relies on the presence of conditions and symptoms. Hypothesis 2.2 was then re-tested using the WHO (2006b) classification of HIV-associated immunodeficiency as an indicator of disease stage which relies on CD4 results.

The caregiver education response options were collapsed from six response options to three categories for analysis purposes. The *none* and *some primary school* responses were combined to form the *below primary school* response category. The *completed primary school* and *some secondary school* responses were combined to form the *secondary school* category. The competed secondary school and the any post secondary school responses were combined to form the *higher secondary* category.

Whether caregiver education was associated with clinical stage at enrollment was assessed by examining the Mantel-Haenszel correlation statistic, which accounts for ordinally scaled row and column variables. Whether caregiver education was associated with severity of immunodeficiency at enrollment was also assessed by using the Mantel-Haenszel correlation statistic.

- Hypothesis 2.3 - Pediatric patients with caregivers that have less education will be more likely to be deactivated from the study (due to death or failure to maintain clinic appointments) than pediatric patients with caregivers with more education.

The level of education completed by pediatric patients' caregiver for the 660 patients eligible for the analysis of study outcomes is presented in Table 4.16 below.

Table 4.16: Level of education completed by pediatric patients' caregiver for 660 patients eligible for analysis of study outcomes

Education level	Frequency	Percent
Total[1]	**660**	**100.0**
None	29	4.4
Some primary school	43	6.5
Completed primary school	47	7.1
Some secondary school	304	46.1
Completed secondary school	134	20.3
Any post secondary school	88	13.3
Do not know	3	0.5
Missing	12	1.8

[1]Those that are HIV negative (81), moved (16), transferred to another HIV treatment program (7), and those enrolled within the last 3 months (16) were excluded from the analyses concerning caregiver education and pediatric study outcomes.

As was done for hypothesis 2.2, the caregiver education response options were collapsed from six response options to three categories for analysis purposes. Whether there was a discernable trend in proportions of pediatric patient study status (active vs. deactivated) over levels of caregiver's education was assessed by examining the Mantel-Haenszel correlation statistic. Therefore, the data were treated as a 3 X 2 table as indicated in Table 4.17 below.

Table 4.17: Pediatric patient study status by caregiver education for those eligible for analysis of study outcomes

	Pediatric Study Status	
	Active (%)	Deactivated (%)[1]
Total	501 (100.0)	144 (100.0)
Below primary	55 (11.0)	17 (11.8)
Secondary	269 (53.7)	82 (56.9)
Higher Secondary	177 (35.3)	45 (31.3)

[1] The 144 deactivated pediatric patients are those deactivated due to poor adherence, patent opted to discontinue treatment, deceased, or lost to follow-up. Those that are HIV negative (81), moved (16), transferred to another HIV treatment program (7), and those enrolled within the last 3 months (16) are not included in the deactivated count.

Logistic regression was used to determine if caregiver education affected whether or not the child was active in the study, controlling for variables such as child's age at

enrollment, sex, baseline severity of immunodeficiency, and clinical stage at enrollment. The

logistic model considers the relationship between a binary dependent variable, in this case the

child's study status (active, deactivated), and a set of independent variables (caregiver

education, child's age at enrollment, sex, baseline severity of immunodeficiency, and clinical

stage at enrollment). The logistic model for 'k' independent variables (x_1, x_2, x_3,... x_k) is:

$$\text{Logit } P(x) = \alpha + \sum_{i=1}^{k} \beta_i x_i$$

where Exp (β_1) indicates the odds ratio for a child having characteristic i versus not having

characteristic i, β s the regression coefficient and α is a constant. An odds ratio equal to one

indicates that there is no effect of the characteristic under consideration.

CHAPTER 5: PAPER 1 - SOCIAL SUPPORT, PERCEIVED STIGMA AND QUALITY OF LIFE IN A FAMILY-CENTERED HIV CARE AND TREATMENT PROGRAM IN KINSHASA, DRC

Abstract

Introduction.   In settings where the HIV epidemic is generalized and disproportionately affects women, there is a particular need for family-centered HIV care and treatment programs that offer psychosocial support services. This study explored the relationships among social support, perceived stigma, and quality of life (QOL) in adult HIV patients in a family-centered HIV care and treatment program in Kinshasa, Democratic Republic of Congo (DRC). Also considered were measurement issues in adapting scales developed elsewhere to the context in DRC.

Methods.   Data were obtained from baseline interviews with 275 HIV-positive adults who were either caregivers or first-line relatives of enrolled HIV-infected children.

Results.   Our sample was 84% female and largely mothers. There was a positive association between social support and psychological status, one of six domains in the WHOQOL-HIV measure, $r = 0.42(224)$, $p<.001$ and a negative association between perceived stigma and psychological status, $r = -0.31(226)$, $p<.001$. The relationship of social support to psychological status was moderated by perceived stigma ($\beta=0.191$, $p<.05$). However, the relationship of social support to overall QOL was not moderated by perceived stigma ($\beta=0.089$, $p=.397$).

Conclusions. These results highlight the importance of adequately assessing multiple QOL domains. Baseline assessment is an important first step in informing as well as evaluating support services offered to patients. As advances in antiretroviral therapy continue to prolong the lives of people living with HIV/AIDS, QOL will increasingly be examined as a clinical outcome. As access to these life-saving medications is improved, interventionists will become increasingly interested in modifiable predictors of QOL such as the psychosocial factors explored here.

Introduction

An estimated one million people were living with HIV/AIDS in Democratic Republic of Congo (DRC) in 2005 (UNAIDS & WHO, 2006). The HIV epidemic in DRC is generalized with an estimated 87% of infections occurring through heterosexual contact (USAID, 2008). Only 8.6% of people living with HIV/AIDS in DRC were receiving antiretroviral therapy in 2006 (USAID). HIV disproportionately affects women in Kinshasa, the capital city, where the prevalence for women is estimated to be 2.3% and the prevalence for men is 1.3% (EDS-RDC, 2007). This paper explores the relationship between psychosocial characteristics and quality of life (QOL) in a family-centered HIV care and treatment program where the adult sample was 84% female and largely (79%) mothers of HIV-positive children who were also participating in the program.

In addition to human rights considerations, there are important reasons from both clinical and public health perspectives for monitoring and improving QOL among people living with HIV/AIDS. From a clinical perspective, poorer QOL among HIV patients has been associated with increased mortality (Cunningham et al., 2005). Decreasing mortality among HIV-positive parents is particularly important so that their children are not orphaned

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and further marginalized. As access to antiretroviral therapy is improved, focus will shift towards chronic disease management outcomes such as physical functioning and QOL. According to Jelsma'a et al's (2005) argument, if patients experience substantial medication side effects then they may experience a decline in QOL. In this sense, monitoring QOL during the course of care and treatment may provide an indication of whether the patient is experiencing side effects that may deter medication adherence (Jelsma et al.). Poor adherence can lead to insufficient viral load suppression as well as drug resistance, both of which have serious implications for public health.

QOL has increasingly been examined as a clinical outcome as advances in antiretroviral therapy have prolonged the lives of people living with HIV/AIDS (Clayson et al., 2006; Skevington & O'Connell, 2003; Tsasis, 2000). The World Health Organization (WHO) defines QOL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." (WHOQOL Group, 1995, p.1405). Attention has been given to many possible predictors of QOL such as demographic factors including age, gender, and race as well as sociodemographic factors such as employment, marital status, and education status. Though sociodemographic characteristics can change throughout the lifespan of an HIV-positive individual, they are not readily modifiable and thus are less amenable to intervention. Recent attention has been given to more modifiable predictors of QOL such as psychosocial factors.

According to Swindells et al. (1999), overall satisfaction with social support and the use of problem-focused coping were associated with better QOL among HIV patients while high Beck hopelessness scores were associated with poorer QOL. Friedland, Renwick, and

McColl (1996) found that emotional social support, problem-oriented coping, and perception-oriented coping were positively associated with QOL while tangible social support and emotion-oriented coping were negatively associated with QOL in HIV-positive individuals attending ambulatory clinics. Adewuya et al. (2008) found that poorer QOL in their sample of 87 HIV-positive adults in Nigeria was associated with depression, lower educational levels, poorer socioeconomic status, and less social support. Finally, Jia et al. (2004) concluded from their findings that improving social support, coping, and depression of the HIV-infected men in their study would improve QOL.

A better understanding of the relationship between psychosocial characteristics at enrollment into HIV care and treatment should aid in designing programs to intervene upon these factors in attempts to improve QOL. This paper examines the relationships among social support, stigma, and QOL. More specifically, we assessed whether stigma acts as a potential moderator of the relationship between social support and QOL. We also considered measurement issues in adapting scales developed elsewhere to the context in DRC.

Social support. There is a body of literature that suggests that social support can buffer against the adverse effects of stressors on depression (Aneshensel & Stone, 1982) and adjustment to HIV/AIDS (Britton & Zarski, 1993). An HIV-positive diagnosis is a major stressor which was potentially exacerbated for the adults in this study because they were either caregivers or first-line relatives of HIV-infected children. Adults in this study had to come to terms with their own HIV-positive serostatus in addition to that of the pediatric index case to whom they were related. Shapiro and Tambashe (2003) concluded from their 1990 Kinshasa-based survey examining inter-household resource transfers within extended families that there is a "high degree of participation of households in solidarity networks,

both as donors and recipients" (p. 202). It is not well understood how an HIV-positive

diagnosis may affect these social networks and the reciprocity of social support. An

improved understanding of social support at enrollment into HIV care and treatment could

inform psychosocial support services offered to patients. Support groups, home visits to

patients with missed appointments, and counseling during clinic visits were offered to

patients in this care and treatment program.

　　　　Stigma. Goffman (1963) defines stigma as an attribute that is deeply discrediting.

This definition has been built upon in recent decades to include definitions specifically

related to HIV/AIDS stigma which, in turn, have given rise to the development of HIV

stigma-specific measures. Recent work to explain variations in HIV-related stigma across

different settings has helped identify factors that contribute to HIV/AIDS stigma. For

example, Maman et al.'s (2009) qualitative study of HIV stigma among community members

in Thailand, Zimbabwe, Tanzania, and South Africa reinforces the notion that stigma is

associated with incomplete knowledge of HIV transmission as was previously described by

Boer and Emons (2004) in Thailand. Maman et al. also found that HIV stigma among

community members was associated with limited access to antiretroviral therapy as was

previously described by Castro and Farmer (2005) in Haiti. Though access to antiretroviral

therapy and knowledge of HIV transmission is generally better in Kinshasa than in other

areas of DRC, much work remains to be done. Misconceptions about modes of HIV

transmission along with limited availability of HIV care and treatment services make the

potential for stigmatization a concern.

　　　　Given that stigma has been found elsewhere to be associated with decreased HIV

testing (Fortenberry et al., 2002), poor adherence to antiretroviral therapy (Rintamaki et al.,

2006), and decreased disclosure of HIV status to others (Hutchinson et al., 2007), considering perceived stigma at enrollment into care and treatment may help improve adherence and HIV status disclosure. An inverse relationship between social support and perceived stigma has been observed. Mupenda et al. (2008) found in their study of youth living with HIV in Kinshasa that perceived stigma was positively associated with depression and negatively associated with social support. Furthermore, Galvan et al. (2008) found that high perceived social support from friends was associated with less perceived HIV stigma among African Americans.

 Psychological status. In this study, psychological status, one of six domains in the WHOQOL-HIV measure (WHOQOL HIV Group, 2003), was conceptualized as a sense of worth, depressive feelings, ability to concentrate, acceptance of bodily appearance, and satisfaction with oneself. Though the HIV epidemic is the most devastating in sub-Saharan Africa, there is limited information concerning the association between psychological well-being and outcomes such as QOL among people living with HIV in this region. Adewuya et al. (2008) found that depression was associated with poor social support and low QOL among HIV-positive patients in Nigeria and concluded that early identification and referral of patients with depression should be incorporated into HIV care and treatment programs.

Methods

 The data described in this article come from a larger operational research project, "Effective and Affordable Comprehensive HIV Care and Antiretroviral Treatment in the Democratic Republic of Congo" hereafter referred to as the Sustainable Antiretroviral Access (SARA) program. The project provides comprehensive HIV care and treatment including free antiretroviral therapy to HIV-positive children and their first-line relatives at the public

Kalembe Lembe Pediatric Hospital (KLL) in Kinshasa, DRC. This study was approved by the University of North Carolina at Chapel Hill Institutional Review Board (IRB) and by the Kinshasa School of Public Health IRB. Though pediatric patient results have been published elsewhere (Callens et al., 2009; Edmonds et al., 2009), this is the first publication to date reporting adult patient results.

Sample

The sample for this paper included 275 adults enrolled in the SARA program from November 2004 to March 2009. Adults eligible for this program were HIV-positive parents, guardians, or siblings of enrolled HIV-infected children. Children were recruited at the public Kalembe Lembe Pediatric Hospital (KLL), which is centrally located in Kinshasa and offers services to about 1,400 children per month. Of the 275 adults in this program, 218 were the index patient's mother, 45 were the father, 8 were the aunt, one was the uncle, and one was the sister. Two patients were enrolled at 19 years of age that had received care at KLL Hospital and were not related to a pediatric index case.

Measures

Internal consistency. Cronbach's (1951) coefficient alpha was used as a measure of internal consistency. Because an assumption of alpha is unidimensionality, principal component analysis (PCA) was conducted to determine the number of components that account for most of the variance in the set of items measuring social support, stigma, psychological status, and QOL. Items that did not load strongly on a given component and items that factored separately during PCA were dropped and coefficient alpha was recalculated. Items were considered to load on a given component if the factor loading was

.40 or greater for that component. All measures possessed good internal consistency.

Coefficient alpha ranged from 0.63 (stigma) to 0.88 (social support) as presented in Table 5.1

below.

Table 5.1: Coefficient alphas for measures

Variable	N	# items	Coefficient Alpha	N (items removed after PCA)	# items (items removed after PCA)	Coefficient Alpha (items removed after PCA)
Psychological status	258[1]	5	0.769	258[1a]	4	0.868
Social Support	256[2]	7	0.750	257[2a]	5	0.877
QOL	230[3]	8	0.777	235[3a]	6	0.843
Stigma	238[4]	7	0.625	243[4a]	4	0.626

[1] Of 260 patients who answered the psychological status questions, 258 have responses for all 5 items.
[1a] Question F03 removed because it did not load strongly during PCA
[2] Of 261 patients who answered the social support questions, 256 have responses for all 7 items.
[2a] Questions E04 and E05 were removed because they factored separately in PCA.
[3] Of 244 patents who answered the OQL questions, 230 have responses for all 8 items.
[3a] Questions B17 and B18 were removed because they did not load strongly during PCA.
[4] Of 244 patients who answered the stigma questions, 238 have responses for all 7 items.
[4a] Question C01 removed because it did not load strongly during exploratory factor analysis. Questions C12, C13 removed because they factored separately in PCA and exploratory factor analysis.

Social support. All seven items in O'Brien et al.'s (1993) perceived availability of

support subscale were used in the SARA program though slightly adapted to better fit the

context in Kinshasa. Two items factored separately during principal components analysis

(PCA) as described in greater detail in the Data Analysis section so only five items were

included in the summed social support score for data analysis. The possible range for the

summed score was 5 to 20, with higher scores indicating more social support.

Stigma. The seven items used to measure stigma were adapted from Berger, Ferrans,

and Lashley's (2001) 40-item HIV Stigma Scale. These items were subjected to a PCA in

which the principal axis method was used to extract the components, followed by a varimax

(orthogonal) rotation. Because the factor rotation was correlated, a promax (oblique) rotation

was also conducted using exploratory factor analysis. Two items factored separately and one item did not load strongly during exploratory factor analysis so only four items were included in the summed stigma score for data analysis. The possible range for the summed score was 4 to 16, with higher scores indicating higher perceived stigma reported by the patient.

Psychological status. The five items used to measure psychological status were adapted from the psychological domain of the WHOQOL-HIV BREF (WHOQOL HIV Group, 2003). Psychological status, one of six domains in the WHOQOL-HIV measure, is defined as a sense of worth, ability to concentrate, depressive feelings, acceptance of bodily appearance, and satisfaction with oneself. One item did not load strongly during PCA so only four items were included in the summed psychological status score for data analysis. The possible range for the summed score was 4-16, with higher scores indicating better psychological well being.

Quality of Life. The eight items used to assess QOL were adapted from the WHOQOL-HIV BREF (WHOQOL HIV Group, 2003). Two items did not load strongly during PCA so only six items were included in the summed QOL score for data analysis. The possible range for the summed score was 3-21, with higher scores indicating higher QOL.

Clinical stage. The WHO Clinical Staging System for HIV for adults and adolescents was used to assess clinical stage at enrollment (WHO, 2006a). Clinical stage, which is based on the presence of conditions and symptoms, ranges from 1 to 4 with 1 being primary HIV infection and 4 being advanced HIV/AIDS.

CD4 cell count. CD4 cell count, an indication of immune system functioning, decreases as HIV disease progresses. The normal range for CD4 cell counts in adults is 500 to 1,500 cells per cubic millimeter of blood.

Study status. Of the 275 adult patients enrolled in the study, 246 were included in the analysis of study outcomes. As described in Figure 5.1 below, 218 patients were active in the study and 28 patients were deactivated as of March 2009. The deactivated count included those who had died (N=11) and those who failed to maintain clinic appointments which encompassed poor adherence (N=5), patient opted to discontinue treatment (N=4), and loss to follow-up (N=8), defined as failed tracking after three attempts.

Only patients who had been enrolled in the study for a minimum of three months were included in the active count for the analysis of study outcomes. Those who had moved (N=17), and those who transferred to another HIV treatment program (N=5) were excluded from the analysis of study outcomes because this could not be considered a poor outcome. Similarly, whether the patient was alive and continued to receive treatment was unknown so this could not be considered a good outcome.

Figure 5.1: Overview of adult patient study status, November 2004 to March 2009
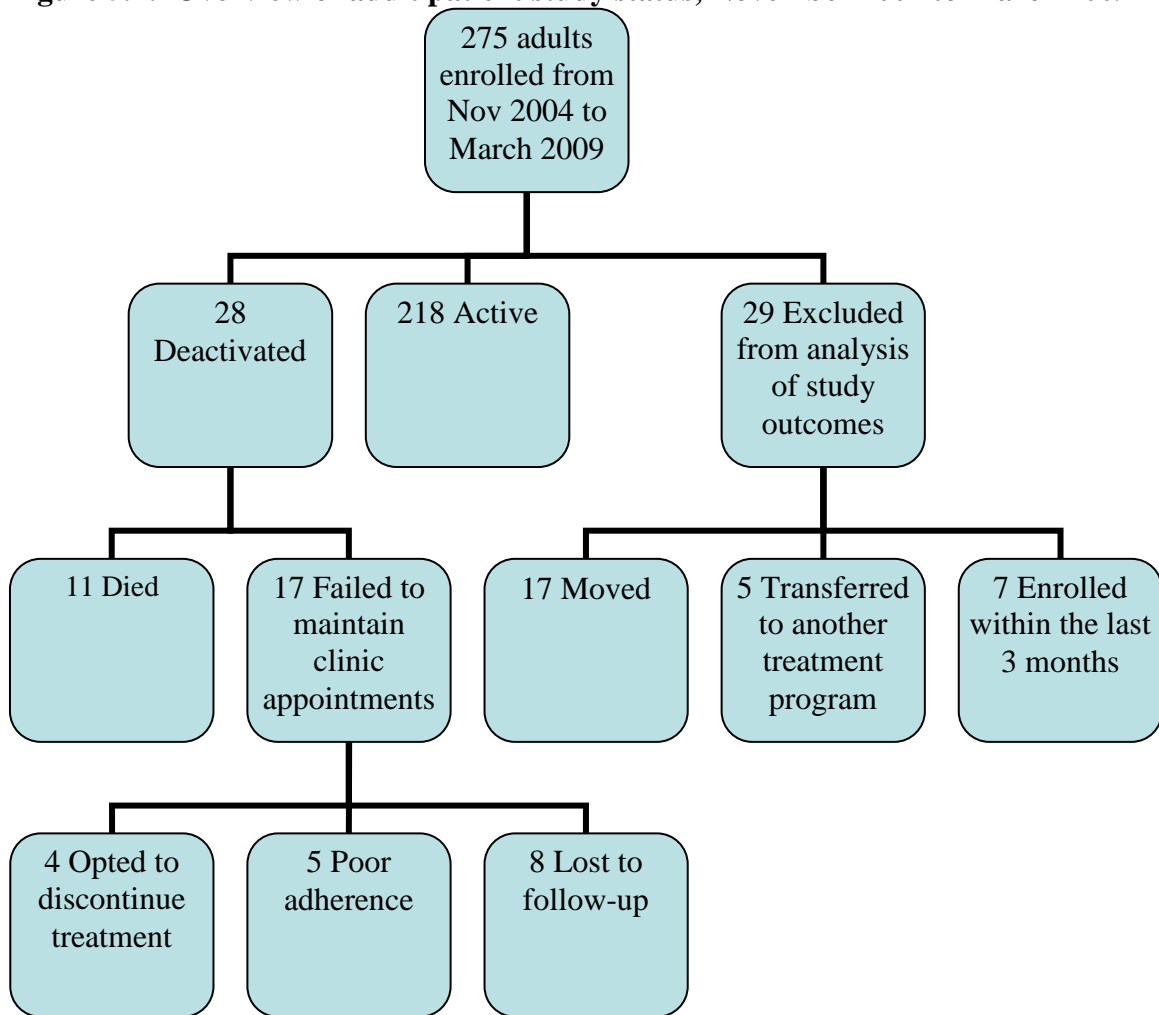
```
                    ┌─────────────┐
                    │ 275 adults  │
                    │enrolled from│
                    │ Nov 2004 to │
                    │ March 2009  │
                    └─────────────┘
        ┌─────────────────┼─────────────────────┐
   ┌─────────┐      ┌───────────┐        ┌─────────────┐
   │   28    │      │218 Active │        │29 Excluded  │
   │Deactivated     │           │        │from analysis│
   │         │      │           │        │ of study    │
   │         │      │           │        │ outcomes    │
   └─────────┘      └───────────┘        └─────────────┘
      ┌──────┴──────┐            ┌──────────────┼──────────────┐
 ┌────────┐  ┌───────────┐  ┌──────────┐ ┌────────────┐ ┌────────────┐
 │11 Died │  │17 Failed to│ │17 Moved  │ │5 Transferred│ │7 Enrolled  │
 │        │  │ maintain   │ │          │ │to another  │ │within the last│
 │        │  │ clinic     │ │          │ │treatment   │ │3 months    │
 │        │  │appointments│ │          │ │program     │ │            │
 └────────┘  └───────────┘  └──────────┘ └────────────┘ └────────────┘
      ┌──────────────┼──────────────┐
 ┌──────────┐  ┌──────────┐  ┌──────────┐
 │4 Opted to│  │5 Poor    │  │8 Lost to │
 │discontinue  │adherence │  │follow-up │
 │treatment │  │          │  │          │
 └──────────┘  └──────────┘  └──────────┘
```

Data analysis

All analyses were conducted using the SAS System for Windows, version 9.1.3 (The

SAS Institute Inc., 2002-2003). Hierarchical multiple regression as described in Frazier, Tix,

and Barron's (2004) discussion of moderation was used to guide data analysis for the

hypothesis that stigma acts as a moderator of the relationship between: 1) social support and

QOL, 2) social support and psychological status, and 3) social support and the combined

psychological status/QOL variable. A moderator is a variable that alters the direction or

strength of the relation between a predictor and an outcome. The variables were standardized

because the independent and moderating variables tend to be highly correlated with the interaction terms created from them.

A total of 14 patients were missing one item on the psychological status, social support, QOL, or stigma scales. In addition, one patient was missing two scale items, and another patient was missing three scale items. For the16 patients missing 1-3 scale items, the item mean was imputed and the moderation hypotheses were re-tested.

Results

Characteristics of SARA patients. Of the 275 adult patients enrolled in this study, 84% were women and 79% were the pediatric index case's mother. Patients ranged in age from 19 to 60 with a median age of 35 years (interquartile range [IQR] 30-40). Nearly half of respondents indicated that they were formally married while an additional 13% indicated they were living with a partner. Twenty-two percent were widowed, 11% were single, 5% were separated, and 1% was divorced. Only 41% of patients reported that they were employed. While 40% of patients had some secondary schooling, only 29% had completed secondary school. Only about 5% of patients were classified as clinical stage 4 at enrollment, whereas the remainder of the groups contained roughly even distributions of one-third of patients each. CD4 count ranged from 5 to 1366 with a median CD4 of 327 (IQR 188-529). Sociodemographic and clinical characteristics of adult patients are included in Table 5.2 below.

Table 5.2: Characteristics of 275 adult patients enrolled between November 2004 and March 2009

Characteristic	N	%
Sex (N=275)		
Female	230	83.6
Male	45	16.4
Relationship to pediatric index case (N=275)		
Mother (includes 1 female guardian)	218	79.3
Father (includes 1 step-father)	45	16.4
Aunt	8	2.9
Uncle	1	0.4
Sister	1	0.4
19-year-old patient referred from KLL	2	0.7
Marital status (N=274)		
Single	30	11.0
Formally married	129	47.1
Living with a partner	35	12.8
Separated	16	5.8
Divorced	3	1.1
Widowed	61	22.3
Education (N=270)		
None	7	2.6
Some primary school	21	7.8
Completed primary school	12	4.4
Some secondary school	115	42.6
Completed secondary school	75	27.8
Any post-secondary school	40	14.8
Currently employed (N=274)		
Yes	103	37.6
No	171	62.4
Clinical stage (N=275)		
1	84	30.6
2	90	32.7
3	86	31.3
4	15	5.5

	Median (IQR)	Range
Age (N=275)	35.0 (30-40)	19-60
CD4 count (N=268)	327.0 (188-529)	5-1366

At enrollment, adult patients were asked if they had received any assistance or support in the last month, the type of assistance received and from whom (Table 5.3). One-third of patients indicated that they had received assistance within the last month; 62% of them had received food and 46% had received monetary assistance. Nearly half (46%) of patients who had received assistance reported that relatives were the source whereas non-governmental organizations were the next largest source of assistance. Only half of patients thought their family had sufficient food on a daily basis and only one-third indicated that they usually ate three meals per day.

Table 5.3: Assistance received by adult patients at enrollment, between November 2004 and March 2009

Characteristic	N	%
Assistance/support received in the last month? (N=272)		
Yes	87	32.0
No	185	68.0
Type of assistance received		
Money	40	46.0
Food	54	62.1
School fees for children	4	4.6
Hospital fees	10	11.5
Shelter	6	6.9
Clothing	9	10.3
Spiritual, employment searching, income generating aid	0	0.0
Other	2	2.3
From whom		
Parents	4	4.6
Other relatives	35	40.2
Friends or neighbors	8	9.2
People at church	2	2.3
Priest/nuns from an organization	2	2.3
Non-governmental organizations	23	26.4
Employer	1	1.1
KLL/SARA	9	10.3
Other	2	2.2
Do you think your family has sufficient food on a daily basis? (N=256)		
Yes	131	51.2
No	125	48.8
How many times do you usually eat per day? (N=240)		
1	37	15.4
2	136	56.7
3	67	27.9

Associations between psychosocial variables. As shown in Table 5.4, there was a positive association between social support and psychological status, r = 0.42(224), p<.001. There was a negative association between perceive stigma and psychological status though the association was modest, r = -0.31(226), p<.001. Finally, there was a weak, negative association between social support and perceived stigma, r = -0.17 (225), p<.01.

Table 5.4: Correlation matrix for study variables with psychological status and QOL as separate variables

	1	2	3	4
(1) Social support	1.0			
(2) Stigma	-0.17**	1.0		
(3) Psychological status	0.42***	-0.31***	1.0	
(4) QOL	0.10	-0.03	0.28***	1.0

*p < .05; **p< .01; ***p< .001

As shown in Table 5.5, when psychological status and QOL were combined as a single variable, the associations with the other variables weakened. There was a positive association between the combined psychological status/QOL variable and social support, r = 0.27(214), p<.001. There was a negative association between the combined psychological status/QOL variable and perceived stigma, r = -0.16(217), p<.05.

Table 5.5: Correlation matrix for study variables with psychological status and QOL combined as one variable

	1	2	3
(1) Social support	1.0		
(2) Stigma	-0.17**	1.0	
(3) Psychological status/QOL	0.27***	-0.16*	1.0

*p < .05; **p< .01; ***p< .001

Moderating hypotheses. The relationship of social support to QOL was not moderated by perceived stigma (β=0.028, p=.79) nor was the relationship of social support to the combined psychological status/QOL variable (β=0.089, p=.397). However, the relationship of social support to psychological status, one of six QOL domains, was moderated by perceived stigma (β=0.191, p<.05). More specifically, the relationship of social support to psychological status was significant when level of perceived stigma was at the mean (β=0.483, p<.0001), one standard deviation above the mean (β=0.602, p<.0001), and one standard deviation below the mean (β=0.343, p<.0001). There was a positive association between social support and psychological status. The relationship between social

support and psychological status varied by the extent to which the patient had experienced stigma such that the association between social support and psychological status was positive and stronger for patients who reported higher stigma than for patients who reported lower stigma as is depicted in Figure 5.2 below.

Figure 5. 2: Social support by psychological status for high, medium, and low stigma
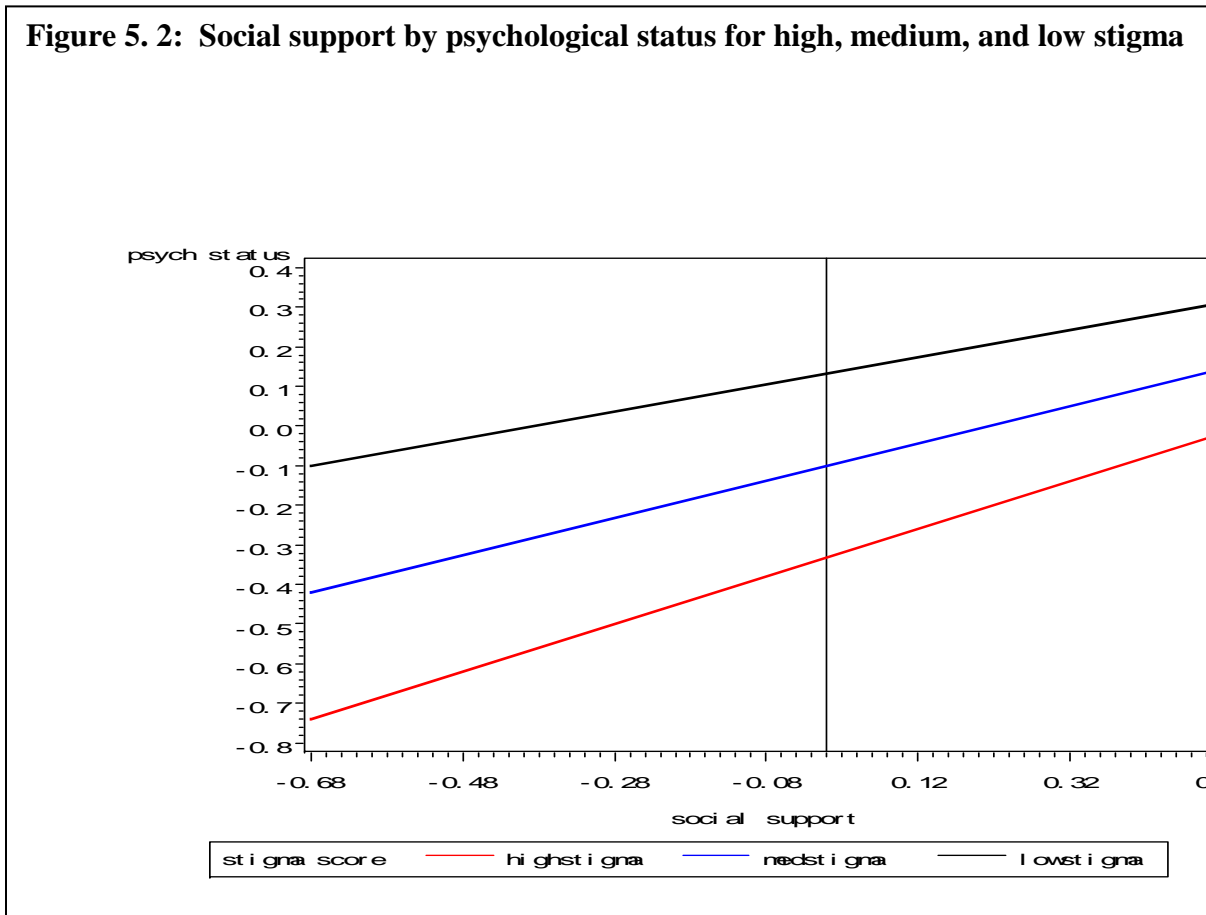
The moderation hypotheses were re-tested controlling for the following demographic and clinical variables: age, marital status, education, employment status, as well as CD4 cell count and clinical stage at enrollment. As was observed in the models without controlling for demographic and clinical variables, the relationship of social support to QOL was not moderated by perceived stigma (β=0.0018, p=.99) nor was the relationship of social support

to the combined psychological status/QOL variable (β=0.070, p=.50). Also, the relationship

of social support to psychological status was moderated by perceived stigma (β=0.195,

p<.05), as observed in the original model.

The moderation hypotheses were re-tested imputing missing data for the16 patients

missing 1-3 scale items while controlling for demographic and clinical variables. As

observed in the original models, the relationship of social support to QOL was not moderated

by perceived stigma (β=0.021, p=.82) nor is the relationship of social support to the

combined psychological status/QOL variable (β=0.093, p=.31). However, unlike what was

observed in the original model, the relationship of social support to psychological status was

not significantly moderated by perceived stigma (β=0.154, p=.06).

Psychosocial characteristics and study outcomes.   As shown in Table 5.6, the mean

social support scores at enrollment of adults deactivated from the study due to death or

failure to maintain clinic appointments (M = 19.2, SD = 3.6) did not differ from those still

active in the study (M = 19.4, SD = 2.8), t(227) = -0.41, p = 0.68. The mean perceived

stigma scores of adults deactivated from the study (M = 16.2, SD = 3.0) did not differ from

those still active in the study (M = 16.8, SD = 2.3), t(210) = -1.08, p = 0.28. The mean

psychological status scores of adults deactivated from the study (M = 16.4, SD = 2.2) were

not significantly different from those who were active in the study (M = 15.9, SD = 2.2),

t(228) = 1.22, p = 0.22. The mean QOL scores of adults deactivated from the study (M =

20.5, SD = 3.7) did not differ from those still active in the study (M = 20.5, SD = 3.5), t(202)

= 0.02, p = 0.98.

Table 5.6: Mean scores at enrollment by study status

	Active Mean (SD)	Deactivated Mean (SD)
Social support	19.4 (2.8)	19.2 (3.6)
Stigma	16.8 (2.3)	16.2 (3.0)
Psychological status	15.9 (2.2)	16.4 (2.2)
QOL	20.5 (3.5)	20.5 (3.7)

Discussion

Prior research suggests that improving social support, coping, and depression may improve QOL of people living with HIV/AIDS (Swindells et al., 1999; Jia et al., 2004; Adewuya et al., 2008). Our results add to the accumulating data on the relationship between psychosocial factors and QOL among HIV patients in resource-limited settings. Our data are unique in that the adult patients were either caregivers or first-line relatives of HIV-infected children enrolled in the study. Of the 275 adults in this study, 84% of which were women and 79% were the pediatric index case's mother. More than half (60%) of the adults in this study were formally married or living with a partner. They were largely unemployed (60%) and had low levels of educational attainment; more than half of patients had not completed secondary school. Given these sociodemographic characteristics, our results are more generalizable to resource-limited settings in sub-Saharan Africa than much of the available literature on the relationship between psychosocial factors and QOL in HIV patients. In settings where the HIV epidemic is generalized and disproportionately affects women, there is a need for family-centered HIV care and treatment programs that offer psychosocial support services. A better understanding of the relationship between psychosocial characteristics at enrollment into HIV care and treatment will aid in informing these support services.

Our results highlight the importance of adequately assessing multiple QOL domains. Psychological status, one of six domains in the WHOQOL-HIV measure, was examined separately and as a combined psychological status/QOL variable. Social support was more strongly associated with psychological status, $r = 0.42(224)$, $p<.001$ than with QOL, $r = 0.10(217)$, $p=.14$, or with the combined psychological status/QOL variable, $r = 0.27(214)$, $p<.001$. We found that the relationship of social support to psychological status was moderated by perceived stigma ($\beta=0.191$, $p<.05$). However, the relationship of social support to QOL was not moderated by perceived stigma ($\beta=0.028$, $p=.79$) nor was the relationship of social support to the combined psychological status/QOL variable ($\beta=0.089$, $p=.397$). These results suggest that social support may be particularly important for those reporting high perceived stigma in improving psychological status.

Study limitations

The results reported here should be considered in light of several study limitations. The primary objective of the larger study was to develop a model of comprehensive HIV care treatment for children and adults in Kinshasa, DRC. Though providing psychosocial support was an objective of the larger study, exploring relationships between variables to determine whether there are patterns consistent with moderation was not a goal.

There was insufficient evidence to suggest that there were differences in social support, perceived stigma, psychological status, and QOL of adult patients deactivated from the study and those still active in the study. However, these findings should be interpreted with caution given the small number of patients in the deactivated group. This study may have failed to detect real effects that exist in the population due to low statistical power.

Validated scales assessing psychosocial characteristics were not administered in their entirety due to crowded clinic schedules and the time required to complete the full scales. This had implications for internal consistency, particularly for perceived stigma (coefficient alpha = 0.63). Berger, Ferrans, and Lashley (2001) reported subscale coefficient alphas ranging from 0.90 (disclosure concerns) to 0.93 (personalized stigma as well as public attitudes toward people with HIV) for their 40-item HIV Stigma Scale which was used in the current study. The HIV Stigma Scale was developed using mailed questionnaire responses from HIV-positive adults in eight American states which is notably different from the context in DRC. Mupenda et al. (2008) used all 40 items of the scale in their study of youth living with HIV in Kinshasa and reported subscale coefficient alphas ranging from 0.74 (disclosure concerns) to 0.89 (personalized stigma). Therefore, we cannot conclude that the HIV Stigma Scale is inappropriate for use in this context. However, we can conclude that it is optimal to include additional items to measure stigma and suggest that in situations where it is not practical to use the entire 40-item scale, an entire subscale should be administered.

Adapting scales developed elsewhere to the context in DRC

Two of the social support items addressed monetary support and were dropped because they factored separately and two items are not sufficient to adequately measure a component. Because 71% of people in DRC live on less than $1 US per day (UNPF, 2007), we concluded that items addressing monetary support may not have been appropriate for measuring instrumental social support in this setting. Of 260 patients, 72% strongly disagreed or disagreed to the statement indicating whether there is someone from whom they could borrow a small amount of money, ride to the doctor, or some other small immediate need. Nearly all (94%) of 261 patients strongly disagreed or disagreed to the statement

indicating whether there is someone from whom they could borrow a larger amount of money for a medical emergency. Asking HIV patients to provide examples of small and large favors during program planning stages and substituting items mentioning monetary support with these examples should improve the measurement of instrumental social support among HIV patients in resource-poor settings.

One of the psychological status items, "You feel often depressed and have feelings of despair" did not load strongly and was dropped. Of 260 patients, 63% strongly disagreed or disagreed to this statement. Bass et al. (2008) described a syndrome among new mothers in Kinshasa called *maladi ya souci* which translates in the local language, Lingala, as a syndrome of worry and closely approximates the Western model of major depressive disorder, according to Diagnostic and Statistical Manual of Mental Disorders version 4 (DSM-IV) criteria. Given symptoms of *maladi ya souci* also involve expressions of irritability and anxiety, we concluded that simply asking patients if they feel "depressed" may not have been culturally appropriate in this setting. Recognizing the importance of cultural context is essential to understanding mental health in developing countries and this is particularly true with depression as there are often no direct equivalents in local languages to describe this concept (Bass et al., 2007).

Conclusion and next steps

We found that assessing social support, perceived stigma, and QOL at enrollment was informative. Enhancing social support may be particularly important for those reporting high levels of stigma in improving psychological status, one of six QOL domains. Baseline assessment is an important first step in informing as well as evaluating support services offered to patients. Additional research such as evaluating changes over time will help to

determine whether these psychosocial characteristics improve during the course of HIV care and treatment. We recommend that HIV care and treatment programs offering support services document which patients receive home visits by volunteers, attend support groups, or receive counseling during clinic visits, for example, so that dose-response relationships can be examined.

CHAPTER 6: PAPER 2 - CAREGIVER EDUCATION AND HIV CARE AND TREATMENT PROGRAM OUTCOMES AMONG PEDIATRIC PATIENTS IN KINSHASA, DRC

Abstract

Introduction. Given the large number of children living with HIV/AIDS in resource-limited countries and the increasing access to treatment, understanding risk factors for delayed enrollment and attrition from existing care and treatment programs is of great importance. This paper examined possible associations among caregiver education, disease stage upon enrollment, and program attrition among pediatric patients in a family-centered HIV care and treatment program in Kinshasa, Democratic Republic of Congo.

Methods. We evaluated caregiver education, disease stage at enrollment into HIV care and treatment as well as program attrition among 780 children of whom 660 were eligible for the analysis of study outcomes.

Results. We observed a negative association between caregiver education and HIV clinical stage at enrollment. However, children of caregivers with less education were not more likely to be deactivated from the study than children of caregivers with more education.

Conclusions. Lower caregiver educational status may have been a risk factor for delayed enrollment into this HIV care and treatment program. The absence of a trend for active patients to have caregivers with higher education than deactivated patients may have been due, in part, to the psychosocial support services offered to patients and their caregivers

through the program. Factors associated with delayed enrollment into HIV care and treatment as well as program attrition deserve further study so that interventions can be adapted accordingly.

Introduction

Maternal education has increasingly been considered in a variety of resource-limited as well as industrialized nation contexts as a correlate or predictor of maternal health (Silva et al., 2008), neonatal outcomes (Luo et al., 2006; Liu et al., 2008), early childhood immunizations (Racine & Joyce, 2007), uptake of child health care services as well as overall child health status (Huq & Tasnim, 2008). Whether caregiver education has implications for pediatric HIV patient outcomes is not well understood. There is evidence that maternal education is associated with the uptake of child health care services in general (Huq & Tasnim, 2008) though there is a dearth of information on whether maternal education is associated with disease stage upon enrolling into HIV care and treatment as well as program attrition, both of which have implications for patient outcomes. Given the large number of children living with HIV/AIDS and the increasing access to treatment, understanding risk factors for poor care and treatment outcomes is of great importance.

The number of children younger than age 15 years living with HIV/AIDS increased from 1.6 million in 2001 to 2.1 million in 2007. Of these 2.1 million children, 90% live in sub-Saharan Africa (UNAIDS, 2008). The annual AIDS deaths among children has begun to fall since 2003 due in large part to prevention of mother-to-child transmission (PMTCT) and treatment scale-up (UNAIDS); however, much work remains to be done. Only 200,000 children were receiving antiretroviral therapy (ART) in 2007 in low- and middle-income countries though this was a marked improvement from the 75,000 receiving therapy in 2005

(WHO, 2008). Wealthy nations have made strides in PMTCT and in screening donated blood units which leaves resource-limited countries with the burden of sorting through the challenges of pediatric HIV/AIDS. The difficulty in diagnosing HIV in children younger than 18 months, limited availability of pediatric formulations of antiretroviral medications, and the need for medical staff training in pediatric HIV care and treatment present substantial challenges in resource-limited settings (Kline, 2006).

Maternal education is thought to influence health behavior in the household as well as through the uptake of health services which, in turn, affects child health outcomes (Joshi, 1994). Being the caregiver of an HIV-positive child presents a variety of challenges. In addition to responding to routine childhood illnesses and immunization schedules, caregivers must ensure or facilitate (depending on age) that children adhere to their HIV treatment regimens and clinic appointments and must demonstrate good care seeking behavior in response to opportunistic infections and medication side effects. These challenges can be further complicated if the caregiver has not yet disclosed the child's HIV status and the child is unaware of the importance of medication and clinic visit adherence. By examining linkages between caregiver characteristics at enrollment and study outcomes, long-term retention could potentially be enhanced by identifying risk factors for attrition and intervening upon them early.

Maternal education has been hypothesized to influence health behavior through several different mechanisms (Joshi, 1994). Increased education enhances literacy and language abilities which enables women to better understand health messages, better acquire knowledge overall, as well as better navigate health care settings and other bureaucracies resulting in a better understanding of how to gain access to available health care services.

Schools are viewed as "transmitters of cultures" and health behavior is influenced through modeling the behavior of those in the modern sector (Joshi). Furthermore, women may internalize the teacher-student relationship in which they assume the role as teacher to her children in the household and they assume the role of student when responding to physicians' instructions as well as to health messages overall (Joshi).

Maternal education in Kinshasa. Shapiro and Tambashe (2003) calculated the predicted probabilities of young women aged 12 to 21 years experiencing three life course transition events (first intercourse, marriage, and first birth) by age and school enrollment status and found that being enrolled in school was associated with delays in the timing of these events. Women in Kinshasa with secondary education tend to have lower fertility than do those with only primary education or no schooling (Shapiro, 1996). By 1990, educational attainment was a more important contributor than ethnicity to observed differences in childbearing among women in Kinshasa according to Shapiro and Tambashe's (2003) analyses. Increases in women's employment have followed increases in women's education. However, women's employment tends to be concentrated in the informal sector of the economy such as self-employed commerce (i.e., street vendors) (Shapiro & Tambashe).

This paper explores whether there are associations between caregiver education, disease stage upon enrollment, and program attrition among pediatric patients in a family-centered HIV care and treatment program in Kinshasa, Democratic Republic of Congo (DRC).

Methods

The data used in this analysis come from a comprehensive HIV care and treatment program including the provision of free ART to HIV-positive children and their first-line

relatives at the public Kalembe Lembe Pediatric Hospital in Kinshasa, DRC. This operational research project has been approved by the University of North Carolina at Chapel Hill Institutional Review Board (IRB) and by the Ethics Committee of the School of Public Health, University of Kinshasa. Callens et al. (2009) reported factors associated with mortality among children receiving ART from this study while Edmonds et al., (2009) estimated the effect of ART on incident tuberculosis. Previous work from this study has not explored caregiver education which is the focus of this article.

Sample

All 780 enrolled children enrolled in the program from November 2004 to March 2009 were eligible for the analysis of caregiver education and HIV disease progression at enrollment. Of these 780 children, 660 were included in the analysis of study outcomes. Children that were later confirmed to be HIV negative (N=81), moved out of Kinshasa (N=16), transferred to another HIV treatment program (N=7), and those that enrolled within the last three months (N=16) were excluded from the analyses concerning caregiver education and study outcomes. Children were recruited at Kalembe Lembe Pediatric Hospital, which is centrally located in Kinshasa and offers services to about 1,400 children per month.

Measures

Caregiver education. Caregiver education was assessed at enrollment by asking the adult that accompanied the child to the visit, "Education completed by patient's mother or caregiver?" Due to the wording of the educational status question, we can not be certain whether educational status has been obtained for the patient's mother or the patient's primary

caregiver. Given 62% of patients' biological mother was alive, we made an assumption that the majority of patients had mothers as their primary caregiver. The response options were collapsed from six response options to three categories for analysis purposes. The *none* and *some primary school* responses were combined to form the *below primary school* response category. The *completed primary school* and *some secondary school* responses were combined to form the *secondary school* category. The *completed secondary school* and the *any post secondary school* responses were combined to form the *higher secondary* category.

Clinical stage. The WHO Clinical Staging System for HIV for children was used to assess clinical stage at enrollment (WHO, 2006a). Clinical stage, which is based on the presence of conditions and symptoms, ranges from 1 to 4 with 1 being asymptomatic, 2 being mild, 3 being advanced, and 4 being severe.

Severity of immunodeficiency. CD4 cell count, an indication of immune system functioning decreases as HIV disease progresses. Absolute CD4 count tends to vary more within an individual child than does CD4% (WHO, 2006b). In general, CD4% is the preferred marker in children under 5 years old and CD4 count is best used for children ages 5 and older in classifying HIV-associated immunodeficiency. The WHO (2006b) classification of HIV-associated immunodeficiency in infants and children was used to classify severity of immunodeficiency for analysis purposes. According to age-related CD4 values, severity of immunodeficiency was classified as not significant, mild, advanced, or severe.

Study Status. As described in Figure 6.1, 514 pediatric patients were active in the study and 146 patients were deactivated as of March 2009 due to death (N=89) and failure to maintain clinic appointments which encompassed poor adherence (N=9), patient opted to discontinue treatment (N=6), and loss to follow-up (N=42), defined as failed tracking after

three attempts. Therefore, 660 pediatric patients were included in the analysis of study outcomes. Those who had moved (N=16) and those who transferred to another HIV treatment program (N=7) were excluded from the analysis of study outcomes because this could not be considered a poor outcome. Similarly, whether the patient was alive and continued to receive treatment was unknown so this could not be considered a good outcome. Only patients who had been enrolled in the study for a minimum of three months were included in the active count so16 patients were excluded from the analysis of study outcomes for this reason. Those who were confirmed to be HIV-negative (N=81) after enrollment were also excluded from the analysis of study outcomes.

Figure 6.1: Overview of pediatric patient study status, November 2004 to March 2009
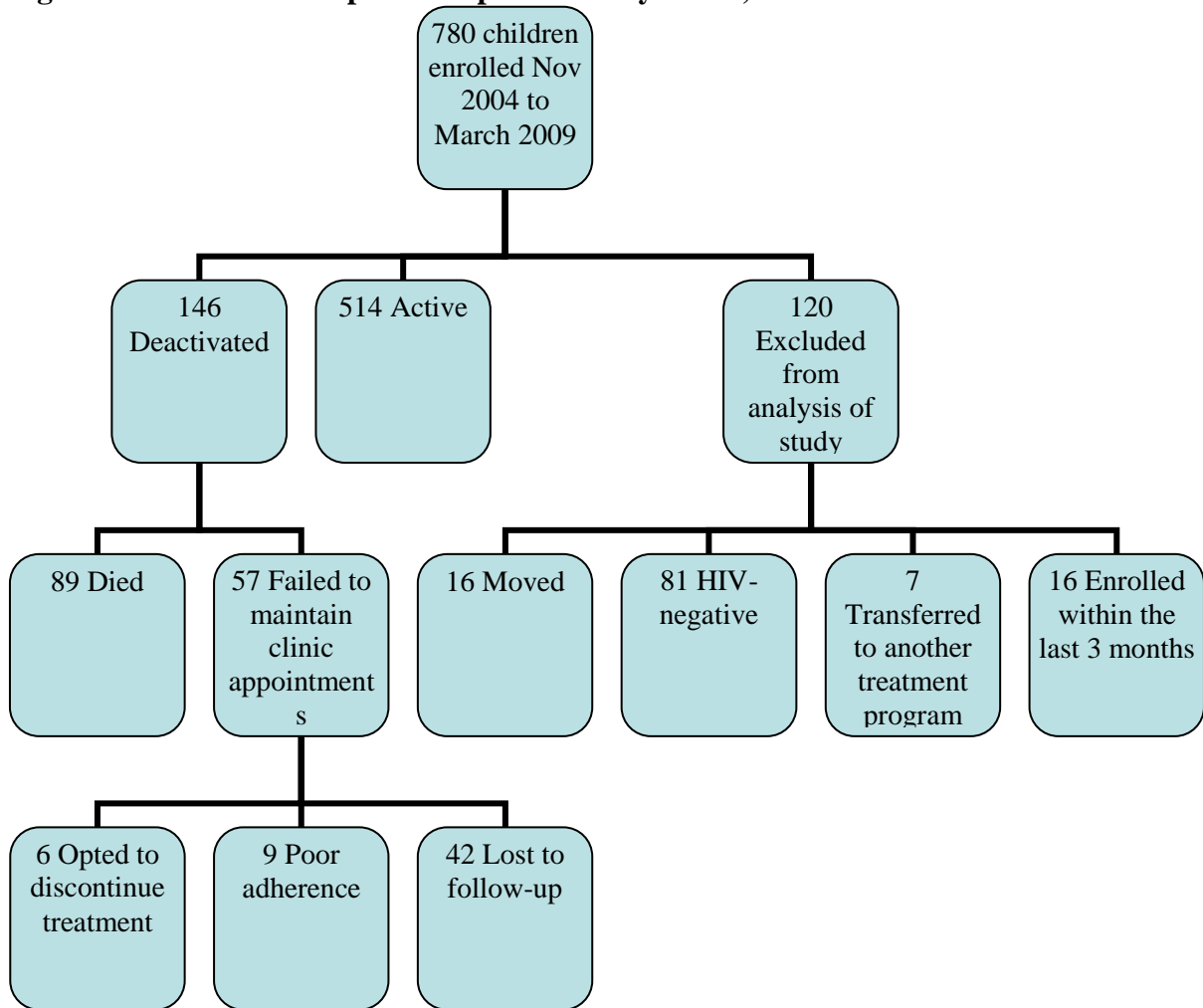
```
                        ┌─────────────┐
                        │ 780 children│
                        │ enrolled Nov│
                        │   2004 to   │
                        │ March 2009  │
                        └─────────────┘
          ┌────────────────┬─────────────────────────┐
   ┌──────────┐   ┌──────────┐              ┌──────────┐
   │   146    │   │514 Active│              │   120    │
   │Deactivated│  │          │              │ Excluded │
   └──────────┘   └──────────┘              │  from    │
                                            │analysis of│
                                            │  study   │
                                            └──────────┘
```

89 Died	57 Failed to maintain clinic appointments	16 Moved	81 HIV-negative	7 Transferred to another treatment program	16 Enrolled within the last 3 months

6 Opted to discontinue treatment	9 Poor adherence	42 Lost to follow-up

Data analysis

All analyses were conducted using the SAS System for Windows, version 9.1.3 (The

SAS Institute Inc., 2002-2003). Whether caregiver education is associated with clinical stage

at enrollment was assessed by examining the Mantel-Haenszel correlation statistic, which

accounts for ordinally scaled row and column variables. Whether caregiver education is

associated with severity of immunodeficiency at enrollment was also assessed by using the

Mantel-Haenszel correlation statistic. Caregiver education and pediatric patient outcomes

was examined in two steps. First, whether there is a discernable trend in proportions of

pediatric patient study status (active vs. deactivated) over levels of caregiver's education was assessed by examining the Mantel-Haenszel correlation statistic to account for the ordinally scaled row variable. Second, logistic regression was used to determine if caregiver education affects whether or not the child is active in the study, controlling for variables such as child's age at enrollment, sex, baseline severity of immunodeficiency, and clinical stage at enrollment. The logistic model considers the relationship between a binary dependent variable, in this case the child's study status (active, deactivated), and a set of independent variables (caregiver education, child's age at enrollment, sex, baseline severity of immunodeficiency, and clinical stage at enrollment). An odds ratio equal to one indicates that there is no effect of the characteristic under consideration.

Results

Of the 780 pediatric patients enrolled in this study, one-half were female (53%). Patients ranged in age from 0.1 years to 17.2 years with a median age of 5.7. Nearly half (47%) of patients had caregivers that had some secondary schooling. According to the information obtained at enrollment, 62% of patients' biological mother was alive and 63% of patients' biological father was alive. Households were most often headed by the patient's father (37%), followed by the patient's mother (21%) and grandparent (18%). Sociodemographic characteristics of all pediatric SARA patients as well as those eligible for the analysis of study outcomes are included in Table 6.1 below.

Table 6.1:. Sociodemographic characteristics of pediatric patients at enrollment, November 2004 to March 2009

Characteristic	Total N	%	N eligible outcome analysis[1]	%
Sex (N=780)			660	100.0
Female	410	52.6	348	52.7
Male	370	47.4	312	47.3
Caregiver education (N=766)			648	100.0
None	32	4.2	29	4.5
Some primary school	52	6.8	43	6.7
Completed primary school	54	7.1	47	7.3
Some secondary school	359	46.9	304	46.9
Completed secondary school	164	21.4	134	20.7
Any post-secondary school	101	13.2	88	13.6
Don't know	4	0.5	3	0.5
Biological mother alive (N=777)			659	100.0
Yes	483	62.2	388	58.9
No	288	37.1	265	40.2
Unknown	6	0.8	6	0.9
Biological father alive (N=773)			657	100.0
Yes	484	62.6	395	60.1
No	239	30.9	218	33.2
Unknown	50	6.5	44	6.7
Head of household (N=778)			660	100.0
Mother	165	21.2	132	20.0
Father	290	37.3	235	35.6
Grandparent	142	18.3	126	19.1
Aunt	101	13.0	91	13.8
Uncle	47	6.0	46	7.0
Sibling	9	1.2	9	1.4
Street child	2	0.3	1	0.2
Other	22	2.8	20	3.0
	Median (IQR)	**Range**	**Median (IQR) N=660**	**Range**
Age in years (N=780)	5.7 (2.1-9.8)	0.1-17.2	6.4 (3.1-10.0)	0.1-17.2

[1]Those that are HIV negative (81), moved (16), transferred to another HIV treatment program (7), and those enrolled within the last 3 months (16) were not eligible for the analyses concerning caregiver education and pediatric study outcomes.

Roughly one-half (52%) of patients had moderate to severe HIV disease progression, classified as WHO clinical stage 3 or 4, at enrollment into HIV care (Table 6.2). One-half (51%) of the 753 patients who had CD4 results available were classified as having severe

immunodeficiency as per the WHO (2006b) classification of HIV-associated

immunodeficiency in infants and children.

Table 6.2: Clinical characteristics of pediatric patients at enrollment, November 2004 to March 2009

Characteristic	Total N	%	N eligible for outcome analysis[1]	%
Severity of immunodeficiency (N=753)			638	100.0
Not significant	203	27.0	159	24.9
Mild	100	13.3	74	11.6
Advanced	70	9.3	54	8.5
Severe	380	50.5	351	55.0
HIV Clinical stage (N=780)			660	100.0
1	161	20.6	107	16.2
2	211	27.1	181	27.4
3	366	46.9	334	50.6
4	42	5.4	38	5.8

[1]Those that are HIV negative (81), moved (16), transferred to another HIV treatment program (7), and those enrolled within the last 3 months (16) were not eligible for the analyses concerning caregiver education and pediatric study outcomes.

We observed that caregiver education and HIV clinical stage at enrollment were

associated (Q_{CS} = 5.30, p<.05 with 1 df). Pediatric patient HIV clinical stage at enrollment

by caregiver education is included in Table 6.3 below.

Table 6.3: Pediatric patient clinical stage at enrolment by caregiver education, November 2004 to March 2009

Clinical stage	Stage I N (%)	Stage II N (%)	Stage III N (%)	Stage IV N (%)	Total
Total	156 (100)	205 (100)	360 (100)	41 (100)	762
Caregiver education					
Below primary	11 (7.1)	17 (8.3)	50 (13.9)	6 (14.6)	84
Secondary	83 (53.2)	117 (57.1)	192 (53.3)	21 (51.2)	413
Higher Secondary	62 (39.7)	71 (34.6)	118 (32.8)	14 (34.1)	265

Pediatric patient baseline severity of immunodeficiency by caregiver education is included in Table 6.4. Caregiver education and baseline severity of immunodeficiency were not associated (Q_{CS} = 1.32, p=.25 with 1 df).

Table 6.4: Pediatric patient baseline severity of immunodeficiency by caregiver education, November 2004 to March 2009

Severity of immunodeficiency	Not significant N (%)	Mild N (%)	Advanced N (%)	Severe N (%)	Total
Total	196 (100)	99 (100)	70 (100)	371 (100)	736
Caregiver education					
Below primary	24 (12.2)	12 (12.1)	3 (4.3)	41 (11.1)	80
Secondary	110 (56.1)	55 (55.6)	40 (57.1)	196 (52.8)	401
Higher Secondary	62 (31.6)	32 (32.3)	27 (38.6)	134 (36.1)	255

Caregiver education and study outcomes. Pediatric patient study status by caregiver education is included in Table 6.5 below. A trend for active patients to have caregivers with higher levels of education than deactivated patients was not observed (Q_{CS} = 0.67, p=0.41).

Table 6.5: Caregiver education level by pediatric study status for those eligible for analysis of study outcomes

Study Status	Active N (%)	Deactivated[1] N (%)
Total (N=645)	501 (100.0)	144 (100.0)
Caregiver education		
Below primary	55 (11.0)	17 (11.8)
Secondary	269 (53.7)	82 (56.9)
Higher Secondary	177 (35.3)	45 (31.3)

[1] The 144 deactivated pediatric patients are those deactivated due to poor adherence, patent opted to discontinue treatment, deceased, or lost to follow-up. Those that are HIV negative (81), moved (16), transferred to another HIV treatment program (7), and those enrolled within the last 3 months (16) were not included in the deactivated count.

Table 6.6 presents the results of the logistic regression model used to determine if caregiver's education was associated with whether the child was deactivated from the study while controlling for variables such as child's age at enrollment, sex, baseline severity of

immunodeficiency, and HIV clinical stage at enrollment. Children with caregivers with higher secondary education were not less likely to be deactivated from the study than children with caregivers with less than a primary education. Children enrolled at age 2-4 years had 0.41 times the odds of being deactivated as compared to children enrolled at less than 2 years of age. Conversely stated, children had 2.4 times the odds of remaining active in the study if they were enrolled at age 2-4 years as compared to less than 2 years of age. Children classified as WHO clinical stage 3 at enrollment had 2.2 times the odds of being deactivated as compared to children classified as clinical stage 1.

Table 6.6: Adjusted odds ratios and 95% confidence intervals for the association of pediatric patient study status and caregiver's education

Variable	Deactivated study status	
	Odds ratio	95% confidence interval
Main effect variable:		
Caregiver's education		
Below primary	ref	
Secondary	1.02	(0.53, 1.95)
Higher secondary	0.80	(0.40, 1.59)
Covariates:		
Child's age at enrollment		
<2 years	ref	
2-4 years	0.41*	(0.22, 0.75)
5-12 years	0.49	(0.29, 0.84)
13-18 years	0.97	(0.48. 1.98)
Sex		
Female	ref	
Male	0.90	(0.60, 1.33)
Severity of immunodeficiency (WHO)		
Not significant	ref	
Mild	0.73	(0.33, 1.63)
Advanced	1.52	(0.70, 3.27)
Severe	1.09	(0.65, 1.84)
HIV clinical stage (WHO)		
1	ref	
2	1.04	(0.51, 2.14)
3	2.20*	(1.16, 4.16)
4	2.10	(0.77, 5.72)

*$p < .05$

Discussion

Others examining maternal education and child health indicators have concluded that to improve child health, improving maternal education must be a priority in addition to improving quality of services, increasing health awareness, and improving vaccination programs (Huq & Tasnim, 2008). Associations between women's educational status and

reproductive health indicators have been observed in Kinshasa. For example, increased educational status has been found to be associated with decreased fertility (Shapiro, 1996) along with delays in timing of life course transition events such as age at first intercourse, marriage, and first birth (Shapiro & Tambashe, 2003).

Findings on maternal education are not presented here to blame women for their children's poor outcomes but rather to highlight low maternal education as a potential risk factor so that interventions can be adapted accordingly. Identifying factors that attenuate the effect that maternal education has on health outcomes can be insightful for program planning and for making policy recommendations. For example, Racine and Joyce (2007) found that residence in a state where free vaccines are provided to all residents attenuated the effect of maternal education on U.S. child immunization rates.

We aimed to determine whether caregiver education was associated with disease severity upon enrolling into this HIV care and treatment program as well as program attrition. Though we observed an association between caregiver education and HIV clinical stage at enrollment, we did not observe an association between caregiver education and baseline severity of immunodeficiency, which is based on CD4 results. The correlation between WHO clinical staging and CD4 results can vary depending on provider training and range of disease severity of patients being evaluated (Lynen et al., 2006; Kagaayi et al., 2007, Jaffar et al., 2008; Edathodu et al., 2009). The results of the current study suggest that clinical stage and CD4 results should be periodically reviewed for individual patients because discrepancies may indicate that additional provider training is needed. We did not observe a trend for active patients to have caregivers with higher levels of education than deactivated patients. This may have been due, in part, to the psychosocial support services offered to

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patients and their caregivers through the program. Given that education is linked to socioeconomic status, and those with higher socioeconomic status will have greater access to food, future studies should consider controlling for malnutrition in examining associations between caregiver education and pediatric patient outcomes.

Our observation that children had 2.4 times the odds of remaining active in the program if they were enrolled at age 2-4 years as compared to less than 2 years of age is consistent with previously reported SARA program findings. Of the 299 ART-naive pediatric SARA patients who started ART between December 2004 and July 2006, children age 3 to 8 years had the lowest mortality risk as compared to children less than 3 years of age, children age 8 to12 years, and children age 12 to 18 years (Callens et al., 2009). Given the advanced stage that SARA patients were enrolled for care, Callens et al. concluded that mortality at the start of ART may reflect the mortality distribution in HIV-infected children who are not on ART in which roughly half die before the age of 2 years (Newell et al., 2004). Advanced disease progression at enrollment was observed in the current study where roughly one-half (52%) of patients were enrolled with moderate to severe HIV disease progression, as per WHO clinical staging, and roughly one-half (51%) of the 753 patients with baseline CD4 results available were classified as having severe immunodeficiency.   These results highlight the need to develop programs that encourage early enrollment into HIV care and treatment.

Study limitations

The results reported here should be considered in light of several study limitations. The primary objective of the larger study was to develop a model of comprehensive HIV care treatment for children and adults in Kinshasa, DRC. Determining whether maternal education was associated with disease stage upon enrolling into this HIV care and treatment

program as well as program attrition were not goals of the larger study. As a result, we can not be certain whether educational status has been obtained for the patient's mother or the patient's primary caregiver due to the wording of the educational status question. Given 62% of patients indicated that their biological mother was alive, we made an assumption that the majority of patients had mothers as their primary caregiver.

CD4%, though to a lesser extent than absolute CD4 count, can fluctuate within an individual child and can vary so serial measurements are considered to be more informative than single values as they reflect trends over time. The current study only examined CD4 at enrollment and acknowledges that serial measurements may be more insightful than a single measurement for future research.

Conclusion and next steps

We found that assessing caregiver education was informative. We observed a negative association between caregiver education and HIV clinical stage at enrollment. This suggests that lower caregiver educational status may be a risk factor for delayed enrollment into HIV care and treatment. This finding emphasizes the importance of developing visual cues and materials for low-literacy patients when planning outreach components to encourage early enrollment. Children with caregivers with lower levels of education were not more likely to be deactivated from the study than children with caregivers with higher levels of education. This may have been due, in part, to the psychosocial support services offered to patients and their caregivers. These services included home visits to patients with missed clinic appointments, support groups, and counseling for patients and their caregivers. We recommend that programs document which patients receive support services so that dose-response relationships can be examined. We also recommend that factors associated

with delayed enrollment into HIV care and treatment as well as program attrition be

examined so that interventions can be adapted accordingly.

CHAPTER 7: DISCUSSION

The goal of this dissertation was to explore the relationship between psychosocial characteristics of patients in a family-centered HIV care and treatment program in Kinshasa, Democratic Republic of Congo (DRC). The study had two specific aims to address this goal. Specific Aim 1 explored relationships between psychosocial characteristics of adult SARA patients at enrollment while Specific Aim 2 examined linkages between psychosocial characteristics at enrollment and study outcomes of both pediatric and adult patients. This chapter begins by summarizing findings associated with each specific aim followed by a description of how the Specific Aims fit together. Strengths and limitations are then discussed followed by a discussion of measurement issues in adapting scales developed elsewhere to the context in Kinshasa. This dissertation concludes with implications for practice and recommendations for future research.

Summary of Findings

Specific Aim 1 explored the relationships between psychosocial characteristics of adult SARA patients at enrollment. The following psychosocial characteristics of adult SARA patients were examined: social support, perceived stigma, and quality of life (QOL). Examined separately was psychological status, one of six domains in the WHOQOL-HIV measure (WHOQOL HIV Group, 2003).

As predicted, there was a positive association between social support and psychological status and a negative association between perceived stigma and psychological

status. Furthermore, the relationship of social support to psychological status was moderated by perceived stigma. The relationship between social support and psychological status varied by the extent to which the patient reported perceived stigma such that the association between social support and psychological status was positive and stronger for patients who reported higher stigma than for patients who reported lower stigma. In other words, the positive association between social support and psychological status was stronger for those reporting high stigma than for those reporting low stigma. From this finding I concluded that social support may be particularly important for those reporting high levels of stigma in improving psychological status, one of six QOL domains.

The results of this study highlight the importance of adequately assessing multiple QOL domains. When psychological status and QOL were combined as a single variable, called overall QOL, the associations with the other variables weakened. As predicted, there was a positive association between social support and overall QOL and a negative association between perceived stigma and overall QOL. However, the relationship of social support to overall QOL was not moderated by perceived stigma. When the QOL items were examined separately, social support was not associated with QOL nor was perceived stigma associated with QOL.

Specific Aim 2 examined linkages between psychosocial characteristics of adult patients at enrollment and study outcomes such as mortality and loss to follow-up (hypothesis 2.1). Specific Aim 2 also examined whether caregiver education was associated with pediatric patient disease severity upon enrolling into this HIV care and treatment program (hypothesis 2.2) as well as program attrition (hypothesis 2.3).

Hypothesis 2.1was not supported. Adult patients who were deactivated from the study due to death or failure to maintain clinic appointments did not score lower on the social support, psychological status scale, or QOL scales and did not score higher on the stigma scale than adult patients who remained active in the study. However, these findings should be interpreted with caution given the small number of patients in the deactivated group. This study may have failed to detect real effects that exist in the population due to low statistical power.

Hypothesis 2.2, which examined caregiver education and pediatric patient disease severity upon enrollment, was partially supported. I first tested this hypothesis using the WHO (2006a) HIV clinical staging system as an indicator of disease severity which relies on the presence of conditions and symptoms. There was a negative association between caregiver education and HIV clinical stage at enrollment. From this finding I concluded that lower caregiver educational status may have been a risk factor for delayed enrollment into HIV care and treatment. I then re-tested hypothesis 2.2 using the WHO (2006b) classification of HIV-associated immunodeficiency as an indicator of disease severity which relies on CD4 results. Caregiver education and baseline severity of immunodeficiency were not associated. It is important to note that caregiver education was known and baseline CD4 results were available for 736 of the 780 children enrolled in this study. Therefore, due to missing CD4 results the possibility that there may have been an association between caregiver education and baseline severity of immunodeficiency cannot be excluded. Furthermore, the correlation between WHO clinical staging and CD4 results can vary depending on provider training and range of disease severity of patients being evaluated (Lynen et al., 2006; Kagaayi et al., 2007, Jaffar et al., 2008; Edathodu et al., 2009). The

results of the current study suggest that clinical stage and CD4 results should be periodically reviewed for individual patients because discrepancies may indicate that additional provider training is needed.

Hypothesis 2.3, which examined caregiver education and program attrition, was not supported. Children with caregivers with lower levels of education were not more likely to be deactivated from in the study than children with caregivers with higher levels of education. This may have been due, in part, to the psychosocial support services offered to patients and their caregivers through the program.

Synthesizing Results of Specific Aim 1 and Specific Aim 2

The overall goal of this research was to better understanding patient characteristics so that support services can be improved which, in turn, should improve outcomes. This research revealed that enhancing social support may be particularly important for those with high perceived stigma. This is helpful for focusing intervention efforts. For example, new social network linkages can be developed through support groups. The SARA program has worked hard to create and train a network of volunteers to lead support groups and to make home visits with patients who miss clinic visits. Findings in the literature support the notion that stigma can be reduced through empowering HIV-positive people, through community-based programs to increase knowledge of HIV transmission (Boer & Emons, 2004), and by increasing access to antiretroviral therapy (Castro & Farmer, 2005). This research also revealed that delayed enrollment into care and treatment is a problem in this setting. In particular, low caregiver education may be a risk factor for delayed enrollment for pediatric patients. These results suggest that developing visual cues and materials for low-literacy

patients is important to keep in mind when planning outreach components to encourage early enrollment.

This dissertation explored data from a family-centered HIV care and treatment program so characteristics of both adults and children were examined. Data were available for the psychosocial characteristics of adults (i.e., quality of life, social support, and perceived stigma). However, these variables were not collected for the pediatric patients given children are unable to answer these types of questionnaires. Caregiver education was one of the few sociodemographic characteristics that was collected for pediatric patients that could be linked to a conceptual framework explaining outcomes. To guide my hypotheses concerning caregiver education and pediatric outcomes, I used Joshi's (2004) conceptual framework which posits that caregiver education affects health behavior (in the household and through the uptake of health care services) which, in turn, affects child health outcomes.

Reported in the literature are associations between maternal education and uptake of child health services such as immunizations (Racine & Joyce, 2007) as well as child health in general (Huq & Tasnim, 2008). In reviewing the literature for this dissertation, no articles were located on caregiver education and pediatric HIV patient outcomes. I hypothesized that the uptake of this care and treatment program may be associated with caregiver education. My rationale for this was increased education enhances literacy and language abilities which enables women to better understand health messages, better acquire knowledge overall, as well as better navigate health care settings and other bureaucracies resulting in a better understanding of how to gain access to available health care services (Joshi, 1994). Because late stage enrollment into HIV care and treatment has been found to be associated with

increased mortality among HIV patients (Girardi et al., 2007), I also hypothesized that caregiver education may also be associated with mortality.

In addition to responding to routine childhood illnesses and immunization schedules, a variety of caregiver behaviors contribute to pediatric HIV outcomes. These caregiver behaviors include adherence to scheduled clinic visits, adherence to treatment regimens, and good care seeking behavior in response to opportunistic infections and medication side effects. This dissertation research is formative. Though data were available on caregiver education and pediatric outcomes, data were not available on specific health behaviors. If a pattern consistent with mediation does exist between caregiver education, health behavior, and child outcomes, then I expected to observe a relationship between caregiver education and child outcomes based upon Frazier, Tix and Barron's (2004) discussion of mediation.

If I had developed this study, rather than conducting a secondary analysis, I would have identified specific behaviors to measure. For example, medication adherence is a behavior that is associated with outcomes. Though adherence to treatment regimens was measured by an adherence questionnaire, nearly all patients reported nearly 100% adherence so there was not enough variability in the data to be used for analysis purposes. Electronic pharmacy records would have been helpful for assessing adherence. The SARA program pharmacy is currently shifting from paper logs to an electronic pharmacy database which will be useful for future inquiries.

Strengths and Limitations

A strength of this dissertation research is that questionnaire items assessing social support, stigma, psychological status, and QOL were from validated scales. At the same time, questionnaire items were a limitation because the validated scales were not used in their

entirety, which threatens scale validity. Administering partial scales had implications for internal consistency, particularly for perceived stigma as will be further discussed in the "Measurement Issues in Adapting Scales to the Context in DRC" section. The SARA program is an ongoing HIV care and treatment program so extensive time was needed for clinical exams and completion of clinical data forms. Validated scales assessing psychosocial characteristics were not administered in their entirety due to crowded clinic schedules and the time required to complete the full scales.

Modest sample size is a limitation of this dissertation research. A total of 213 patients answered all social support, stigma, psychological status, and QOL questions in this study. With the exception of Stangl et al.'s (2007) assessment of QOL among 947 individuals initiating antiretroviral therapy in Uganda, the current study's sample size is comparable to the available literature. The sample size of other studies reviewed here on the influence of psychosocial factors on QOL in HIV patients ranged from 87 (Adewuya et al., 2008) to 226 (Jia et al., 2004).

All seven items in O'Brien et al.'s (1993) perceived availability of support subscale were used in the SARA program. A limitation in only using this subscale to measure social support is that the four types of social support (emotional, instrumental, informational, and appraisal support) are not adequately addressed. Two items addressed emotional support, three items addressed instrumental support, and two items addressed informational support. Two of the three items assessing instrumental support addressed monetary support and loaded separately during PCA and were dropped (as discussed in greater detail in the "Measurement Issues in Adapting Scales to the Context in DRC" section). Furthermore, the patient's perceived adequacy of social support was not measured. Measuring perceived

adequacy of social support is important in interventions designed to enhance social support because the recipient's perception of social support has been shown to more strongly influence mental health and well-being than the actual receipt of support (Wethington & Kessler, 1986).

This dissertation research is a secondary analysis. Exploring relationships between variables to determine whether there are patterns consistent with moderation was not a goal of the larger study. The primary objective of the larger study was to develop a model of comprehensive HIV care and management, including antiretroviral treatment, for children and adults in Kinshasa. The cross-sectional nature of the psychosocial variables in this dataset prohibits temporality required for moderation analysis. As a result, this research is exploratory in nature and assessed whether there were patterns among the psychosocial variables that are consistent with moderation.

Measurement Issues in Adapting Scales to the Context in DRC

Measurement issues were considered in adapting the validated scales assessing social support, stigma, psychological status, and QOL to the context in DRC. The social support and stigma scales were developed in the US while the psychological status and QOL items were developed in 10 field sites in nine countries, though none of which were DRC.

Conclusions about dropped social support items. Two of the social support items addressed monetary support and were dropped because they factored separately during principal component analysis and two items are not enough to adequately measure a component. Given 71% of people in DRC live on less than $1 US per day (UNPF, 2007), we concluded that items addressing monetary support may not have been appropriate for measuring instrumental social support in this setting. Of 260 patients answering this item,

72% strongly disagreed or disagreed to the statement indicating whether there is someone from whom they could borrow a small amount of money, ride to the doctor, or some other small immediate need. Nearly all (94%) of 261 patients strongly disagreed or disagreed to the statement indicating whether there is someone from whom they could borrow a larger amount of money for a medical emergency.

Conclusions about dropped stigma items. Berger, Ferrans, and Lashley (2001) reported high internal consistency with coefficient alpha ranging from 0.90 to 0.93 for the subscales of their 40-item HIV Stigma Scale, of which seven items were used in the current study (coefficient alpha = 0.63). One of the stigma items, "I try very hard not to let other people know I have HIV" did not load strongly in the current study and was dropped. Nearly all (91%) of 244 patients answering this item agreed or strongly agreed to this statement. Two additional items factored separately and were dropped. Nearly all (93%) of 239 patients answering the dropped item, "I have lost friends by telling them I have HIV" disagreed or strongly disagreed to this statement. Of the 244 patients answering the dropped item, "People seem afraid of me once they learn I have HIV," 88% disagreed or strongly disagreed to this statement. The responses to these items suggest that though patients try hard not to let others know they have HIV, they do not tend to loose friends when they disclose their status. It is possible that patients disclose their status to those they feel certain will not react negatively.

The HIV Stigma Scale was developed using mailed questionnaire responses from HIV-positive adults in eight American states which is notably different from the context in DRC. Mupenda et al. (2008) used all 40 items of the scale in their study of youth living with HIV in Kinshasa and reported subscale coefficient alphas ranging from 0.74 (disclosure

concerns) to 0.89 (personalized stigma). Therefore, we cannot conclude that the HIV Stigma Scale is inappropriate for use in this context. However, we can conclude that it is optimal to include additional items to measure stigma and suggest that in situations where it is not practical to use the entire 40-item scale, an entire subscale should be administered.

Conclusions about dropped QOL items. The two QOL items assessing the social relationships domain did not load strongly during principal component analysis and were dropped. Only 10% of 244 patients answering the personal relationships item indicated that they were very dissatisfied or dissatisfied with their personal relationships whereas nearly half (43%) of 239 patients indicated that they were very dissatisfied or dissatisfied with their sex life. To determine whether these two items would factor with the items on the social support scale, all of the social support, stigma, psychological status, and QOL items were subjected to a principal components analysis followed by a promax (oblique) rotation using exploratory factor analysis. However, these two items did not load strongly on any of the four factors that corresponded to the four scales. To better understand why these two items did not load strongly, we examined the responses of 252 patients who answered questions about their sexual relationships at enrollment. Sixty-six percent indicated that they were not currently sexually active. About one-third (33%) indicated that they had sex with a primary partner within the last month and only two patients indicated that they had sex with a primary partner and another partner within the last month. It is unclear why the two QOL items assessing the social relationships domain did not perform well.

Conclusions about the dropped psychological status item. One of the psychological status items, "You feel often depressed and have feelings of despair" did not load strongly during principal component analysis and was dropped. Of 260 patients answering this item,

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63% strongly disagreed or disagreed to this statement. Bass et al. (2008) described a

syndrome among new mothers in Kinshasa called *maladi ya souci* which translates in

Lingala as a syndrome of worry and closely approximates the Western model of major

depressive disorder. Given symptoms of *maladi ya souci* involve expressions of irritability

and anxiety we concluded that simply asking patients if they feel "depressed" may not have

been culturally appropriate in this setting.

Implications for Practice

This research is exploratory in nature and contributes to the formative process needed

to further investigate the importance of evaluating and intervening upon psychosocial

characteristics of patients enrolled in family-centered HIV care and treatment programs in

resource-limited settings such as DRC. Specific Aim 1 explored relationships between

psychosocial characteristics of adult patients at enrollment. Baseline assessment is an

important first step in informing as well as evaluating support services offered to patients.

By better understanding psychosocial characteristics at enrollment, psychosocial support

activities can be targeted to optimize improvements during the course of HIV care and

treatment. The results of this study suggest that enhancing social support may be particularly

important for those with high perceived stigma in improving psychological status, one of 6

QOL domains. HIV care and treatment programs can develop new social network linkages

through support groups. The SARA program has worked hard to create and train a network

of volunteers to lead support groups and to make home visits with patients who miss clinic

visits. As advances in antiretroviral therapy continue to prolong the lives of people living

with HIV/AIDS, QOL will increasingly be examined as a clinical outcome. As access to

these life-saving medications is improved, practitioners will become increasingly interested

in intervening upon modifiable predictors of QOL such as the psychosocial factors explored here.

Specific Aim 2 examined whether caregiver education was associated with pediatric patient disease severity upon enrolling into this HIV care and treatment program. It is important for programs to examine factors associated with delayed enrollment into HIV care and treatment so that interventions can be adapted to encourage earlier enrollment. Late stage enrollment into HIV care and treatment has been found to be associated with increased mortality among HIV patients (Girardi et al., 2007). Advanced disease progression at enrollment was observed in the current study where roughly one-half (52%) of children were enrolled with moderate to severe HIV disease progression, as per WHO clinical staging, and roughly one-half (51%) of the 753 children with baseline CD4 results were classified as having severe immunodeficiency. These results highlight the need to develop programs that have outreach activity components that encourage HIV testing and early enrollment into care and treatment. Strategies are needed for patients with low-literacy, in particular, such as posters in clinics or showing short films or testimonials in waiting areas. Linkages between antenatal care clinics and HIV care and treatment centers should be strengthened to improve referrals of HIV-positive women, their partners, and their children.

Also examined in Specific Aim 2 were linkages between psychosocial characteristics at enrollment and study outcomes such as mortality and loss to follow-up. By examining psychosocial characteristics at enrollment and study outcomes, long-term retention can potentially be enhanced by identifying risk factors for attrition and intervening upon them early.

Implications for Future Research

This dissertation research makes an empirical contribution providing data on the relationship between psychosocial characteristics and QOL from a family-centered HIV care and treatment program where the adult sample was 84% female and largely mothers. These data are unique in that the adult patients were either caregivers or first-line relatives of HIV-infected children enrolled in the study. Of the 275 adults enrolled in this study, 79% were the pediatric index case's mother. Additional research such as evaluating changes over time will help to determine whether these psychosocial characteristics improve during the course of HIV care and treatment. I recommend that HIV care and treatment programs offering support services document which patients receive home visits by volunteers, attend support groups, or receive counseling during clinic visits, for example, so that dose-response relationships can be examined.

The current study makes an empirical contribution providing data on the education level of caregivers of pediatric patients accessing this care and treatment program. Though maternal education has been observed in a variety of geographical contexts to be associated with a variety of child health outcomes, there is a dearth of information on whether maternal education has implications for pediatric HIV patient outcomes. Lower caregiver education was associated with more advanced clinical stage upon enrolling into HIV care and treatment in the current study. Consistent with previously observed associations between late stage enrollment into HIV care and treatment and mortality (Girardi et al., 2007), children classified as clinical stage 3 had 2.2 times the odds of being deactivated from the current study due to death or failure to maintain clinic appointments as compared to children classified as clinical stage 1. However, a trend for active patients to have caregivers with

higher levels of education than deactivated patients was not observed in this study. I can not

be certain whether educational status was obtained for the patient's mother or the patient's

primary caregiver due to the wording of the educational status question. Given 62% of

patients indicated that their biological mother was alive, I made an assumption that the

majority of patients had mothers as their primary caregiver. I suggest that future studies

document maternal education as well as the educational status of the primary caregiver, if not

the mother.

There is a building consensus on the importance of considering community-level

variables when examining associations between maternal education and child health

outcomes. According to Parashar (2005), living in an area with educated mothers may

improve child health through social network information diffusion, health promoting

parenting norms, and by living in an area with a high number of vaccinated children. Das et

al. (2000) concluded from their analysis of case studies of child immunization in India, "a

critical number of [educated] women in the community makes a sharp difference in the

capacity of the community, especially women, to take advantage of services offered to them

by the state" (p. 629). If future research moves towards a cross-country comparison of

maternal education and pediatric HIV care and treatment program outcomes, I recommend

also considering household socioeconomic measures, community characteristics, and

national economic development indicators.

APPENDICES

Appendix A. WHO Clinical Staging System for HIV Infection and Disease

The WHO clinical staging system for HIV for adults and adolescents as stated in the

SARA program protocol is included below.

Revised WHO Clinical Staging and Immunological Classification of HIV for Adults and Adolescents, 2006
Source: WHO (2006a). *Antiretroviral Therapy for Adults and Adolescents in Resource-Limited Settings: Towards Universal Access."* 2006 revision.
Accessed at http://www.who.int/hiv/pub/guidelines/adult/en/index.html

Primary HIV infection
Asymptomatic   Acute retroviral syndrome
Clinical stage 1
Asymptomatic   Persistent generalized lymphadenopathy (PGL)
Clinical stage 2

Moderate unexplained weight loss (<10% of presumed or measured body weight)
    Recurrent respiratory tract infections (sinusitis, bronchitis, otitis media, pharyngitis)
    Herpes zoster
    Angular cheilitis
    Recurrent oral ulcerations
    Papular pruritic eruptions
    Seborrhoeic dermatitis
    Fungal nail infections

Clinical stage 3

Severe weight loss (>10% of presumed or measured body weight)
    Unexplained chronic diarrhea for longer than one month
    Unexplained persistent fever (intermittent or constant for longer than one month)
    Persistent oral candidiasis
    Oral hairy leukoplakia
    Pulmonary tuberculosis
    Severe bacterial infections (e.g. pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteremia)
    Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis
    Unexplained anemia (< 8 g/dl), and or neutropenia (< 0.5 x 10^9/I) and/or thrombocytopenia (<50 x 10^9/I)

Clinical stage 4
HIV wasting syndrome

Pneumocystis pneumonia
Recurrent severe bacterial pneumonia
Chronic herpes simplex infection (orolabial, genital or anorectal of more than one month's duration *or visceral at any site*)
Oesophageal candidiasis *(or candidiasis of trachea, bronchi or lungs)*
Extrapulmonary TB
Kaposi sarcoma
Cytomegalovirus infection (retinitis or of *other organs*)
Central nervous system toxoplasmosis
HIV encephalopathy
Extrapulmonary cryptococcosis including meningitis
Disseminated non-tuberculous mycobacteria infection
Progressive multifocal leukoencephalopathy (PML)
Chronic cryptosporidiosis
Chronic isosporiasis
Disseminated mycosis (*extrapulmonary* histoplasmosis, coccidiomycosis)
Recurrent septicaemia (*including* non-typhoidal salmonella)
Lymphoma (cerebral or B cell non-Hodgkin)
Invasive cervical carcinoma
Atypical disseminated leishmaniasis
Symptomatic HIV-associated nephropathy or HIV-related cardiomyopathy

* The UN defines adolescents as persons aged 10–19 years but, in the present document, the category of adults and adolescents comprises people aged 15 years and over for surveillance purposes.

The WHO clinical staging system for HIV for children as stated in the SARA

program protocol is included below.

Revised WHO Clinical Staging and Immunological Classification of HIV for Children, 2006
Source: WHO (2006a). *Antiretroviral Therapy of HIV Infection in Infants and Children Resource-limited Settings: Towards Universal Access.* Accessed at
http://www.who.int/hiv/pub/guidelines/art/en/index.html

Clinical Stage 1
Asymptomatic
Persistent generalized lymphadenopathy

Clinical Stage 2
Unexplained persistent hepatosplenomegaly
Papular pruritic eruptions
Extensive *wart* virus infection
Extensive molluscum contagiosum
Recurrent oral ulcerations
Unexplained persistent parotid enlargement
Lineal gingival erythema
Herpes zoster
Recurrent or chronic respiratory tract infections (otitis media, otorrhoea, sinusitis*, tonsilitis*)
Fungal nail infections

Clinical Stage 3
Unexplained moderate malnutrition not adequately responding to standard therapy
Unexplained persistent diarrhea (14 days or more)
Unexplained persistent fever (*above 37.5 ºC,* intermittent or constant, for longer than one month)
Persistent oral candidiasis (*after first 6 weeks of life*)
Oral hairy leukoplakia
Acute necrotizing ulcerative gingivitis/periodontitis
Lymph node TB
Pulmonary TB
Severe recurrent bacterial pneumonia
Symptomatic lymphoid interstitial pneumonitis (LIP)
Chronic HIV-associated lung disease including bronchiectasis
Unexplained anemia (<8g/dl), and or neutropenia (<0.5 x $10^9/L^3$) and or thrombocytopenia (<50 x $10^9/L^3$) for more than one month

Clinical Stage 4
Unexplained severe wasting*, stunting* or severe malnutrition not responding to standard therapy
Pneumocystis pneumonia
Recurrent severe bacterial infections (e.g. empyema, pyomyositis, bone or joint infection, meningitis, but excluding pneumonia)
Chronic herpes simplex infection; (orolabial or cutaneous of more than one month's duration*, or visceral at any site*)
Extrapulmonary TB
Kaposi's sarcoma
Oesophageal candidiasis *(or Candida of trachea, bronchi or lungs)*
CNS toxoplasmosis (*after* the neonatal period)
HIV encephalopathy
Cytomegalovirus (CMV) infection; retinitis or CMVinfection *affecting another organ,*; onset at age one month or more)
Extrapulmonary cryptococcosis (including meningitis)
Disseminated endemic mycosis (extrapulmonary histoplasmosis, coccidiomycosis)
Chronic cryptosporidiosis *(with diarrhea)*
Chronic isosporiasis
Disseminated non-tuberculous mycobacteria infection
Cerebral or B cell non-Hodgkin lymphoma
Progressive multifocal leukoencephalopathy (PML)
HIV-associated cardiomyopathy or nephropathy

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