

POSITIVE PREVENTION WITH YOUTH LIVING WITH HIV/AIDS IN KINSHASA, DEMOCRATIC REPUBLIC OF THE CONGO

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ABSTRACT

LISA FRASER PARKER: Positive Prevention with Youth Living with HIV/AIDS in Kinshasa,
Democratic Republic of the Congo
(Under the direction of Dr. Suzanne Maman)

This dissertation aims to help develop a Positive Prevention program for Youth Living with HIV/AIDS (YLWH) ages 15-24 in the Democratic Republic of the Congo. To address Aim 1, the systematic adaptation, implementation, and feasibility analysis of a U.S.-developed Evidence Based Intervention (EBI) using the Centers for Disease Control and Prevention Map of Adaption Process was conducted. The adapted intervention, *Supporting Youth and Motivating Positive Action* or SYMPA, a six-session risk reduction intervention targeted for YLWH in Kinshasa, was adapted from the Healthy Living Project and guided by Social Action Theory. The adapted intervention was found to be acceptable to program facilitators (n=4) and participants (n=13) and able to be implemented effectively. It performed well with a new population and showed preliminary efficacy. However, certain aspects of the intervention were identified during the feasibility analysis that must be addressed prior to wider implementation. This study has shown that an EBI developed and implemented in the U.S. can be adapted and implemented successfully for a different target population in a low-resource context. To address Aim 2, In-depth interviews were conducted with providers (n=14) working at the study clinic in order to understand providers' roles in delivering prevention counseling to YLWH. Providers' lack of knowledge and comfort in talking to youth about sex because of cultural and religious beliefs about sexuality, coupled with confusion about their legal obligations related to youth and contraception, made it difficult for them to effectively counsel youth or create an environment where youth felt comfortable talking with their providers about HIV

or sexual health. As a result, the counseling that was provided may have been ineffective. In order for providers to deliver effective prevention counseling to YLWH, clinics should follow adolescent-friendly clinic standards, provide counseling in an adolescent-friendly style, and institute an effective referral system for additional prevention services. Future research should examine the efficacy of a complementary positive prevention program that incorporates: 1) institutionalized adolescent-friendly clinic standards; 2) brief provider-delivered counseling and screening for risk behaviors with an effective referral system for prevention services; and 3) peer group implementation of the SYMPA intervention for higher risk youth.

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LIST OF ABBREVIATIONS

ADAPT:	Map of Adaptation Process: A Systematic Approach for Adapting Evidence-Based Behavioral Interventions
AMO-CONGO:	Avenir meilleur pour les orphelins du SIDA or Better Future for AIDS Orphans
ART:	Antiretroviral Therapy
ARVs:	Antiretrovirals
CARA:	Computer Assisted Risk Assessment
CDC:	Centers for Disease Control and Prevention
CHAMP:	Collaborative HIV Prevention and Adolescent Mental Health Project
CLEAR:	Choosing Life: Empowerment, Action, Results
DHS:	Demographic Health Survey
DRC:	Democratic Republic of the Congo
EBI:	Evidence Based Intervention
EVREJ-CONGO:	Education pour une vie responsable et le bien-être des enfants et jeunes au Congo or Education for a responsible life and the well-being of children and youth in Congo
FGD:	Focus Group Discussion
FHI:	Family Health International
GAP:	Global AIDS Program
HIP:	HIV Intervention for Providers
HIV:	Human Immunodeficiency Virus
HLP:	The Healthy Living Project
HSRA:	Health Resources and Services Administration
IDI:	In- Depth Interview
IRB:	Institutional Review Board

KLL:	Kalembe Lembe
KSPH:	Kinshasa School of Public Health
LIFT:	Living in the Face of Trauma
MSM:	Men who have sex with Men
NICHD:	National Institute of Child Health and Human Development
NIH:	National Institute of Health
PACT:	Providing AIDS Care and Treatment
PASHIN:	Providers Advocating for Sexual Health Initiative
PEPFAR:	President's Emergency Plan for AIDS Relief
PLWH:	People Living with HIV/AIDS
PMTCT:	Prevention of Mother-to-Child Transmission
RCT:	Randomized Control Trial
SARA:	Sustainable Antiretroviral Access
SAT:	Social Action Theory
SPLASH:	Supporting Positive Living and Sexual Health
STEPS:	Striving to Engage People
STI:	Sexually Transmitted Infection
STTR:	Seek, Test, Treat and Retain
SUMIT:	Seropositive Urban Men's Intervention Trial
SYMPA:	Supporting Youth and Motivating Positive Action
TLC:	Together Learning Choices
UNAIDS:	Joint United Nations Programme on HIV/AIDS
UNC:	University of North Carolina at Chapel Hill
UNICEF:	United Nations Children's Fund

USAID:	United States Agency for International Development
VIPs:	Very Important Persons
WHO:	World Health Organization
WILLOW:	Women Involved in Life Learning from Other Women
YLWH:	Youth Living with HIV/AIDS

CHAPTER 1: INTRODUCTION

Chapter Overview

The introductory chapter is divided into three sections. First I provide a summary of the gaps in Positive Prevention research with youth living with HIV/AIDS (YLWH) in low-resource settings such as Kinshasa, Democratic Republic of the Congo (DRC). I will follow with a brief description of the two specific aims for this dissertation. I will end with a brief description of the significance of the dissertation research.

Gaps in Positive Prevention Research

HIV prevention programs for people living with HIV/AIDS (also called Positive Health, Dignity, and Prevention or Positive Prevention) are important to reduce new infections and to ensure people living with HIV/AIDS (PLWH) remain healthy (Global Network of People Living with HIV & UNAIDS, 2009; S. Kalichman, 2005). Since 2003, there have been an increasing number of research studies focusing on Positive Prevention Interventions with PLWH living in the U.S., including a few studies on interventions targeting YLWH (Crepaz et al., 2006). However, there is limited information on Positive Prevention programs for youth in sub-Saharan Africa, where the majority of YLWH live. Positive Prevention is a relatively new area in sub-Saharan Africa where many of those infected have only recently accessed care and treatment. In 2006 authors from the Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO) published a commentary on the ethical and public health imperative to implement effective prevention strategies and treatment for

PLWH in sub-Saharan Africa (Bunnell, Mermin, & De Cock, 2006). They prioritized ten types of interventions with the largest potential impact on HIV transmission and included: 1) behavioral interventions for PLWH to reduce HIV transmission risk, 2) HIV status disclosure by PLWH with an aim to involve partners in prevention, care and support, and 3) prevention of unintended pregnancies among women living with HIV to prevent vertical transmission. Although interventions in these areas have been well-studied in the developing world they have only recently begun to be evaluated in low-resource settings. There are few Positive Prevention interventions that have been implemented and evaluated in sub-Saharan Africa. To our knowledge only one CDC evidence-based intervention (EBI) has been adapted and implemented in sub-Saharan Africa for YLWH (Lightfoot, Kasirye, Comulada, & Rotheram-Borus, 2007). To our knowledge no study has adapted and implemented a Positive Prevention EBI for YLWH in Central Africa.

In 2002 studies began to be published evaluating the extent to which health care providers (henceforth called “providers”) in the U.S. were discussing prevention topics with their HIV-positive patients and examining which factors were associated with provider-delivered routine Positive Prevention counseling and the barriers to prevention counseling. Recently two provider-delivered Positive Prevention Interventions have been adapted for implementation in sub-Saharan Africa with adults living with HIV/AIDS; however, there are no interventions that have been adapted for implementation with YLWH (Bachman, Stuart, & Schietinger, 2007; CDC, National Center for HIV/AIDS Viral Hepatitis STD and TB Prevention, & Global AIDS Program, 2008). In addition, there is no known research examining how providers’ attitudes and perceptions of their YLWH patients’ sexual behavior impact the providers’ sexual transmission prevention counseling in low-resource settings. Research has shown that in U.S. based Positive Prevention studies when multiple delivery modes are used and not integrated they are less effective (Myers et al., 2010). As there are no known Positive Prevention interventions in sub-Saharan Africa or low-resource settings that use

multiple delivery modes and integrate them such as the combination of a peer-group and provider-delivered intervention this dissertation research provides key information on this topic. Evaluating the feasibility of both provider-delivered prevention counseling and peer group Positive Prevention interventions targeted specifically for YLWH in a low-resource context is an important endeavor in that the lessons learned from this study can potentially be applied with youth in other sub-Saharan African countries, the region of the world with the highest HIV incidence in this population (UNAIDS, 2010).

Study Overview

The overarching goal of this study was to conduct research with YLWH and their providers in Kinshasa, DRC in order to develop a Positive Prevention program that addresses the youths' developmental needs and helps them cope with the challenges of their illness in the context of their emerging independence and sexuality (Futtermann, 2004). The central purpose of this study was to evaluate if the incorporation of evidence-based Positive Prevention into the standard of care is feasible and therefore appropriate for wider implementation and evaluation.

Specific Aims

The study had two specific aims:

Specific Aim 1: *To examine the feasibility of an adapted evidence-based clinic-based Positive Prevention intervention (Supporting Youth and Motivating Positive Action - SYMPA) implemented with YLWH ages 15-24 in Kinshasa, DRC.*

Research Objectives:

1. To follow the CDC-ADAPT guidelines to adapt an Evidence-Based Positive Prevention Intervention for YLWH ages 15-24 in Kinshasa, DRC.
2. To implement the adapted Evidence-Based Positive Prevention Intervention for YLWH ages 15-24 in Kinshasa, DRC.
3. To assess the feasibility of an adapted Evidence-Based Positive Prevention Intervention for YLWH ages 15-24 in Kinshasa, DRC.

Research Question:

1. To what extent will the pilot intervention (SYMPA) meet the following feasibility criteria from the perspective of YLWH ages 15-24 and providers in Kinshasa, DRC:
 - a. To what extent is SYMPA suitable, satisfying, or attractive to program deliverers? To program recipients?
 - b. To what extent can SYMPA be successfully delivered to intended participants in some defined, but not fully controlled, context?
 - c. To what extent does an existing intervention such as the Healthy Living Project perform when changes are made for a new format or with a different population?
 - d. Does SYMPA show promise of being successful with the intended population?

To achieve this aim, an evidence-based intervention (EBI), the Healthy Living Project was adapted into *Supporting Youth and Motivating Positive Action* or SYMPA (meaning “cool” in French) and a pilot study was conducted. This study included working with clinic staff to adapt the intervention; an adaptation workshop with clinic providers; training of intervention facilitators; completion of a brief demographic survey with participating youth (n=13) ; implementation of six

single-sex group sessions (6 boys 15-19 yrs of age, 7 girls 15-20 yrs of age); Focus Group Discussions (FGDs) with youth after each session (n=12); post-session evaluations by facilitators (n=6); post-intervention curriculum evaluation FGD with facilitators (n=1); post-intervention in-depth interviews (IDIs) with facilitators (n=3); and participants' intervention activity sheets (n=13).

Specific Aim 2: To explore qualitatively how providers' attitudes and perceptions of YLWH sexual behavior may shape their sexual transmission prevention counseling for YLWH, ages 15 to 24 in Kinshasa, DRC.

Research Questions

1. What are providers' perceptions, attitudes, and beliefs regarding YLWH sexual behavior?
2. What are the providers' experiences in providing prevention counseling to YLWH?
3. What are the barriers and facilitators for providers related to prevention counseling with YLWH?

In-depth interviews were conducted with all providers working directly with YLWH (N=14) at Kalembe Lembe (KLL) Pediatric Hospital in Kinshasa. All interviews were conducted in French, digitally recorded and transcribed and linked to Atlas-ti 5.2.

Significance

Positive Prevention programs are a key method of preventing the spread of HIV, as new infections by definition must come from a PLWH (Indyk & Golub, 2006). In the context of biomedical Positive Prevention interventions, such as the "Seek, Test, Treat, and Retain" (STTR) approach, behavioral measures to prevent the sexual transmission of the virus play an important role in combination prevention strategies (Dodd, Garnett, & Hallett, 2010; Granich, Gilks, Dye, De

Cock, & Williams, 2009; Montague, Vuylsteke, & Buve, 2011). Likewise, recent findings that early initiation of antiretroviral (ARV) treatment by PLWH can prevent the spread of HIV to their sexual partners are promising (Cohen et al., 2011), but will only be effective if the PLWH are adherent to their medications and if their viral loads remain undetectable. Positive Prevention behavioral interventions should reach populations before PLWH are eligible for treatment, and can help keep individual engaged once they are receiving treatment (Walensky, 2009). Positive Prevention may be particularly suited for YLWH, as these interventions can reach an HIV-infected population prior to commencement of sexual activity for youth perinatally infected or during the early stages of their infection for those youth who acquired HIV sexually. However, prevention in this population have not as of yet been adequately addressed in either research or practice.

Formative research conducted with close to 200 YLWH, ages 14-24, clients of four HIV treatment, testing, or counseling centers in Kinshasa, including KLL, was conducted in 2008 (Behets & Pettifor, 2006). This research found that over half of the young women and a quarter of the young men being served by local HIV/AIDS care and treatment centers had already had sexual intercourse, and only 53% of young women and 67% of young men reported using a condom at their most recent sexual act (Pettifor et al., 2008). In addition, just over a third of the young women and only a quarter of young men reported having disclosed their HIV status to their most recent partner. Therefore this population is at risk of transmitting the virus to their partners through unprotected sex and indicates the importance of Positive Prevention programs for YLWH in this environment (Morin et al., 2007).

Although there is convincing evidence that YLWH continue to practice high risk sexual behaviors, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has reported that HIV prevention, care, and treatment in the DRC has been hindered by “chronic inadequacy of preventative and case-management services” (UNAIDS, 2006). Positive Prevention can also help to

improve existing psychosocial support structures at these clinics. The numbers of YLWH is rising as YLWH gain access to ARVs and live longer. Treatment facilities provide an important venue where YLWH receive ARVs, underscoring the opportunity for clinic-based Positive Prevention programs targeting youth to reach this underserved population. The YLWHs continued risk behaviors, the lack of existing Positive Prevention programs, and opportunity for intervention confirms the importance of adapting, implementing, and evaluating evidence-based Positive Prevention programs specifically for YLWH.

CHAPTER 2: BACKGROUND

Chapter Overview

The background section is divided into three sections: 1) HIV and Sexual Behavior of YLWH in Context, 2) Positive Prevention, and 3) Provider Role in Positive Prevention. For the first section I will discuss the current statistics related to HIV in the DRC and provide information specifically on youth and HIV in the DRC. I will then describe the study site of Kalembe Lembe Pediatric Hospital (KLL) and the UNC/DRC Sustainable Antiretroviral Access (SARA) project. I will follow with a description of youth sexual behavior in the DRC as well as YLWH sexual behavior. Next, I will discuss PLWH and YLWH sexual behavior specifically in sub-Saharan Africa and the unique aspects of YLWH sexual behavior in the DRC. Finally I will describe the six primary determinants of high risk sexual behavior for YLWH in Kinshasa.

For the second section, I will first discuss the importance of Positive Prevention and then Positive Prevention specifically for YLWH. I will also describe the expressed need for Positive Prevention interventions at KLL in Kinshasa. I will then move on to an analysis of Positive Prevention Interventions including CDC Best-Evidence and Promising-Evidence interventions. I will then shift to a discussion of Positive Prevention interventions for YLWH and will move on to frame the current thinking around Positive Prevention in sub-Saharan Africa. Next, I will provide an analysis of Positive Prevention interventions in sub-Saharan Africa specifically targeted for PLWH and YLWH. Finally, I will end with a description of the current Positive Prevention services offered at KLL, the study site.

For the third section, I will begin with a review of the literature on barriers to providing routine Positive Prevention counseling. I will then discuss provider Positive Prevention counseling with YLWH in Kinshasa and at KLL. I will follow with an in-depth analysis of provider-delivered Positive Prevention Interventions and end with the lessons learned from these interventions.

HIV and Sexual Behavior of YLWH in Context

HIV in the DRC

The DRC has a population of close to 80 million people with an overall adult HIV prevalence of 1.3% with recent studies reporting an increasing country-wide prevalence (Ministry of Planning Democratic Republic of the Congo, 2007; USAID, 2010). The first AIDS case in the DRC was diagnosed in 1983, one of the first in Africa, but anecdotal evidence supports cases occurring as early as 1977 (Khonde, 2006). Sex workers, at that time called the “Londoners”, whose clients were primarily expatriates, were the first population to be impacted by the disease (Khonde, 2006). Today however there is a generalized epidemic, i.e. more than 1% of the overall adult population is infected with HIV with an estimated 400,000-500,000 Congolese living with HIV/AIDS (USAID, 2010). Heterosexual sex accounts for over 80% of new HIV cases and current studies have reported a possible shift from urban to rural areas (USAID, 2010). This overall adult prevalence of 1.3% is considered a relatively low prevalence; however, some areas of the country have been off limits for survey assessments due to continued conflict-related violence, and thus the prevalence may in actuality be greater (Ministry of Planning Democratic Republic of the Congo, 2007). The adult prevalence in Kinshasa, the capital, is 1.9% (Ministry of Planning Democratic Republic of the Congo, 2007). While the protracted violence has not shown a significant increase in HIV cases for the general population, it has been estimated that 25.6% of women who were victims of sexual violence

are HIV-positive and 7.6% of internally displaced women. Some possible explanations include the possibility that conflict can reduce or break apart sexual networks necessary for transmission or that the disease has not spread from the conflict region to other areas of the country because of a lack of infrastructure to allow for wide-scale cross country migration (Spiegel et al., 2007).

Youth and HIV in the DRC

Worldwide nearly five million youth ages 15 to 24 currently live with HIV, and each year close to 900,000 new HIV infections occur among youth (UNAIDS, 2010). About 80% or 4 million live in sub-Saharan Africa (UNAIDS, 2010). Likewise, of all sexually transmitted infections over half (more than 180 million out of a global annual total of 340 million) of new infections are acquired by youth (UNAIDS, 2010). In the DRC, as in other areas of sub-Saharan Africa, greater numbers of children with HIV are surviving and entering into adolescence with the expansion of access to ARV treatment. In the DRC over 60% of the population is under twenty years of age and the prevalence of HIV among youth 15 to 24 is 0.8% (.9% in urban areas and .6% in rural areas) (Ministry of Planning Democratic Republic of the Congo, 2007). The youth prevalence in Kinshasa, the capital, is 1.4% (Ministry of Planning Democratic Republic of the Congo, 2007). There are conflicting accounts of whether young women are disproportionately affected by the disease than young men with the Demographic Health Survey (DHS) data showing 0.5% prevalence for young women 15-24 and 1% for young men 15-24 (Ministry of Planning Democratic Republic of the Congo, 2007). However, WHO/UNAIDS/UNICEF data, thought to be less accurate than the DHS data, report a prevalence of 0.1%-0.4% for young men 15-24 and 0.7%-1.2% for young women 15-24 thus showing the opposite trend (WHO/UNAIDS/UNICEF, 2008). The proportion of youth living with HIV in the DRC has risen from 13% in 1990 to 19% in 2005 (Programme National Multisectoriel de Lutte contre le VIH/SIDA,

2008). Some have speculated that this could be due to youth initiating sex earlier than in the past (Kayembe et al., 2007).

SARA Project and KLL

The Sustainable Antiretroviral Access (SARA) program, located at the Pediatric Hospital of Kalembe Lembe (KLL) in the Lingwala District of Kinshasa, was created in November 2004 by the University of North Carolina-DRC program in collaboration with the Kinshasa School of Public Health. The program is funded by multiple donors including: the Centers for Disease Control and Prevention (CDC); Global AIDS Program originally as part of the University Technical Assistance Program; the Providing AIDS Care and Treatment in the Democratic Republic of the Congo under the President's Emergency Plan for AIDS Relief; the William J. Clinton Foundation, Elizabeth Glaser Pediatric AIDS Foundation, the Global Fund to Fight AIDS, Tuberculosis, and Malaria, The United Nations Children Fund and the Belgian Cooperation. The program provides comprehensive HIV medical care (including ARV treatment) and psychosocial support to children and their parents and guardians, as well as other household members. As of April 2012, the program had served more than 2,146 HIV-positive patients including 191 YLWH aged 15-24. The center serves as a training site for medical practitioners interested in learning about HIV care and treatment and is aiming to become a Center of Excellence in the region providing comprehensive training services in pediatric HIV care and treatment (UNC/KSPH-CDC/PACT-DRC, 2010). The SARA program staff currently includes five doctors, four nurses, three psychosocial counselors and a lab technician (UNC/KSPH-CDC/PACT-DRC, 2010). Patients come to the clinic from all of the surrounding areas of Kinshasa and it is the largest treatment center for HIV/AIDS in the country.

Youth Sexual Behavior in the DRC

There are few published sexual behavior surveys of the DRC. However, two important surveys provide a glimpse into the sexual behavior of youth in the DRC. The first is a national sexual behavior survey conducted jointly by the Kinshasa School of Public Health and Family Health International (FHI) of over 13,000 youth of unknown HIV serostatus in provincial capitals of the DRC. The authors reported that close to two-thirds of female youth ages 15-24 were sexually experienced. The mean age for sexual debut for both young women and young men was 15 years old with young women's first sexual partners being on average 5 years older while young men's partners were the same age or younger. Condom use during first sex was low with only 12.8% reporting using a condom. Youth living in two-parent households were less likely to have ever had sex than those in other household environments. Interestingly, condom use was greater when there was a transaction of money or gifts. Over one third reported sexual relations with at least two partners within the last 12 months and less than one third reported condom use at last sex (Kayembe et al., 2008).

The nationally representative DHS, where over 6,000 rural and urban youth were surveyed, in 2007, showed that 18% of youth reported having sex before the age of 15 and 61% of young women reported having sex before the age of 18 with 56% of young men reporting the same. A lower percentage of young women reported condom use at first sex as compared to young men, 4.7% vs. 8.6% respectively. Condom use at last sex was also lower for young women with 16.4% vs. 25.6% for young men. Approximately 13% of young women reporting having high risk sex (defined by DHS as sex with a non-cohabitating partner) with men more than 10 years older.

It is also essential to address contraception use for youth as this is an important part of youth sexual behavior. While knowledge of basic contraception is relatively high (over 70% knew a modern method), for young women 15-19, only 5.1% reported currently using a modern method

and only 8.1% of 20-24 year olds young women reported currently using a modern contraceptive method (Ministry of Planning Democratic Republic of the Congo, 2007). It is clear from the results of these two studies that youth are having sex at an early age and are not consistently practicing safe sex.

YLWH Sexual Behavior

Prevention with YLWH is especially important in the context of reported continued high risk sexual behaviors of PLWH. While many research studies have reported that PLWH reduce their sexual risk behavior once having tested positive, some PLWH continue to practice high risk sexual behavior and others may return to pre-testing behaviors over the long term (Bunnell et al., 2008; Denison, O'Reilly, Schmid, Kennedy, & Sweat, 2008; L. J. Koenig et al., 2010; Marks, Crepaz, Senterfitt, & Janssen, 2005; Rowniak, 2009). In the U.S. some YLWH continue to have high risk sex even after being informed of their status and many feel pressured to have sex by peers (The Kaiser Family Foundation, 2003). Research has also shown that some YLWH report high risk sexual behavior that can place both themselves and others at great risk. A study of adolescents perinatally infected in the U.S. reported that close to 60% had sex without a condom since learning their HIV-positive status and over 70% were currently sexually active (L. J. Koenig et al., 2010). Another study reported that sexual activity increased with age for HIV infected youth, similar to non-HIV infected youth (Wiener, Battles, & Wood, 2007). A study comparing risk behaviors among HIV-positive and HIV-negative youth in the United States found that HIV-positive adolescents had higher Sexually Transmitted Infection (STI) rates and used condoms less frequently than HIV-negative adolescents (Hein, Dell, Futterman, Rotheram-Borus, & Shaffer, 1995). In addition, among YLWH ages 13-24 in major cities in the U.S., there was a 37% increase in unprotected sex after the introduction of highly active antiretroviral therapy (Rice, Batterham, & Rotheram-Borus, 2006). However, other studies of

PLWH have reported no impact of antiretroviral therapy on sexual behavior (Crepaz & Marks, 2002). It is also important to consider continued risk behaviors of YLWH in the context of the stage of HIV, as risk behaviors can be influenced by the progression of the disease (Eaton & Kalichman, 2009).

Finally, it is important to describe the reproductive behaviors of YLWH. In a study conducted with YLWH in a U.S. urban center 70% (35/50) of youth reported wanting to have children in the future and of those young women that were sexually active 50% (5/10) had been previously pregnant (Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006). Likewise, in a U.S. based population of YLWH over 80% of those that became pregnancy had not planned for their pregnancy and over 40% were not using any contraception (L. J. Koenig, Espinoza, Hodge, & Ruffo, 2007). Consequences of unplanned pregnancies are twofold: 1) the mother's health will be impacted from the stress on her body, and 2) the child has the potential of being infected with the disease.

PLWH and YLWH Sexual Behavior in sub-Saharan Africa

Although the majority of research on PLWH has focused on the sexual behaviors of adult HIV-positive Men who have sex with Men (MSM) in the United States, there are a limited number of new studies examining the sexual behavior of PLWH in sub-Saharan Africa and a few focusing specifically on youth. In a study in rural Zimbabwe, 61.4% of PLWH reported no condom use during sexual intercourse (Alkatout, Furey, Vineberg, Schulz, & Thistle, 2007). In a South African study close to 50% of the PLWH were sexually active with 30% reporting an unsafe sex act during the last three months (Kiene et al., 2006). In Uganda, 77% of PLWH were sexually active and 45% reported recent unprotected sex with 67% reporting never having used a condom although the majority reported having only one partner (Bunnell, Ekwaru et al., 2006). However a more recent study in Uganda reported that those who knew their HIV status were three times more likely to use a condom at last

sex thus showing that more research is needed before any decisive conclusions can be made (Bunnell et al., 2008).

More recent studies have examined adolescent sexual behavior. In a sample of perinatally infected adolescents in Uganda, 33% were sexually active with 44% reporting the desire to have sex and 37% reporting condom use at first sex (Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009). This study also reported that 37% of adolescents preferred HIV negative partners in order to avoid re-infection (Birungi, Obare et al., 2009). Interestingly, a study of youth 15-19 in Uganda found that there was no difference in the likelihood of having had sex for YLWH and non-infected youth. YLWH did report greater use of condoms 39% vs. 11%; however, less than half reported currently practicing safe sex (Obare & Birungi, 2010). Therefore, similar to in the U.S., PLWH, including youth, continue to be sexually active and struggle with consistent condom use in their sexual relationships.

Likewise, similar to in the U.S. the majority of pregnancies in PLWH are unplanned. In an adult ARV clinic in Uganda, over 90% of reported pregnancies were unintended (Homsy, Bunnell, & Moore, 2008). Of YLWH in Uganda, 37% of young men and women ages 15-17 reported using any form of contraception while 55% of young men and women ages 18-19 reported using any form of contraception (Birungi, Mugisha, Obare, & Nyombi, 2009). While these YLWHs' reported levels of contraceptive use were particularly high, these same YLWH reported inconsistent contraceptive use in the qualitative interviews (Birungi, Mugisha et al., 2009). Therefore the lack of consistent contraceptive use in this population puts them at great risk for unintended pregnancies as well as re-infection or infection with other STIs.

YLWH Sexual Behavior in the DRC

Formative research was conducted in 2008 with close to 200 YLWH, ages 14-24, getting services at one of four HIV treatment, testing, or counseling centers in Kinshasa including KLL

(Behets et al., 2008; Holub, 2010; Holub et al., 2008; Mupenda et al., 2008; Taylor et al., 2008). IDIs with YLWH and their caregivers were conducted as well as FGDs with YLWH. The goal of the formative research was “To collect information that will help to identify needs for and approaches to specific HIV prevention interventions for HIV positive adolescents”. The results from the formative research showed that over half of the young women and 26% of young men had ever had sex, and of those having had sex in the last 12 months only 53% of young women and 67% of young men reported using a condom at their most recent sexual act with no significant difference in sexually activity between youth ages 14-19 and youth 20-24 analyzed in a sub-sample of 103 of the YLWH (Behets et al., 2008; Holub, 2010; Holub et al., 2008; Mupenda et al., 2008; Taylor et al., 2008). Youth in Kinshasa also reported early sexual debuts with young women debuting on average at age 15 and at age 14 for young men. Most practiced primarily vaginal sex although some reported having had anal sex (19% young women and 10.5% young men). Just over a third of the young women and only a quarter of young men reported having disclosed their HIV status to their most recent partner and only 20% knew the status of their most recent sexual partner. These results are troubling in that close to 50% of this population are at risk of transmitting the virus to their partners through unprotected sex. Lifetime number of sexual partners was also high with an average of four partners for young women and two partners for young men. The majority of youth interviewed reported fearing that their partners had sexual relationships with other partners (71% females, 67% males) (Table 1).

Table 1: Sexual Behaviors among YLWH ages 14-24 yrs in Kinshasa, DRC 2007

Characteristic	Female n (%)	Sample Size	Males n (%)	Sample Size
Ever had sex with anyone	100 (71.9)	139	19 (38.0)	50
Ever had anal sex	19 (19.0)	100	02 (10.5)	19
Ever been pregnant	74 (74.8)	100	NA	NA
Forced sex ever	29 (29.0)	100	05 (26.3)	50

Characteristic	Female n (%)	Sample Size	Males n (%)	Sample Size
Lifetime number of sexual partners (mean, SD)	3.9 (5.7)	100	2.4 (1.4)	50
Had sex in past 12 months	53 (54.1)	100	05 (26.3)	50
Condom use at last intercourse with most recent partner	29 (52.7)	53	04 (66.7)	05
Knows HIV status of most recent partner	11 (20.8)	53	01 (20.0)	05
Disclosed HIV status to most recent partner	19 (35.2)	53	01 (25.0)	05

Source: (Pettifor et al., 2008)

The overall adolescent fertility rate in the DRC is quite high at approximately 200 births per 1,000 women ages 15-19 years old (The World Bank, 2008). Alarming, 75% of young women interviewed had previously been pregnant (Pettifor et al., 2008). This is likely due to the fact that young girls may have been targeted for recruitment in the study if they were known to have been pregnant in the past; however, this still shows that there is a great unmet need in reproductive and contraceptive education in this population.

Determinants of High Risk Sexual Behaviors for YLWH in Kinshasa

Literature reviews have reported a relatively consistent group of predictors for high risk sexual behavior among PLWH. These include risk-related cognitive and attitude factors, poor risk reduction skills, relationship factors, and limited social and peer normative supports for risk-reduction behavior change and lastly situational or contextual factors (Kelly & Kalichman, 2002). The following six determinants are the most prevalent in the literature on HIV-positive sexual risk behavior and are supported by formative research findings from Kinshasa and will be discussed in more detail below:

- Lack of HIV/STI Knowledge
- Low Condom Use Skills
- Weak Coping Mechanisms
- Limited Ability in Sexual Communication/Negotiation

-Lack of Disclosure

-Low levels of Social Support

Lack of HIV/STI Knowledge

HIV/STI education has long been the cornerstone of HIV prevention interventions. While there is consensus that HIV/STI education alone is not enough to change behavior it is an important first step (Mavedzenge, Doyle, & Ross, 2010). The lack of knowledge regarding sexual transmission of HIV and the symptoms and transmission of STIs is an important predictor of high risk sexual behavior for YLWH. In a longitudinal study of perinatally infected adolescents HIV knowledge predicted condom use at last sex as well as overall condom self-efficacy (Wiener et al., 2007). In a study of a reproductive health intervention in the DRC it was observed that study staff spoke about sexual activity in highly technical terms such as “genital intercourse” rather than making it a topic more accessible for the youth. Likewise, sex education discussions were framed in such a way as certain behaviors such as condom use was seen as promiscuous rather than self-protective. Therefore, the study found that sexuality was not talked about openly and directly with the youth (Bosmans, Cikuru, Claeys, & Temmerman, 2006). Even when sexual education is conducted, low levels of literacy and education and a lack of previous exposure to information related to sexual health can make understanding sexual risk reduction materials difficult (Lazarus, Himedan, Ostergaard, & Liljestrang, 2006). In a qualitative study conducted with university students in Kinshasa one young woman reported that her partner refused to use a condom because he did not believe that HIV existed, therefore putting both sexual partners at risk (Olin et al., 2006). Alarming, in the nationally representative DHS survey only 15% of young women and 22% of young men were considered to have “complete” knowledge of HIV, meaning they were aware that using condoms and limiting sexual acts to a faithful and non-infected partner reduces the risk of

contracting the virus; that someone in good health can still be infected; and they are able to reject false ideas concerning the transmission of the disease (Ministry of Planning Democratic Republic of the Congo, 2007). From the formative research, it is clear that many YLWH still have misconceptions about how HIV is transmitted. For example, there was low knowledge about the risk of transmitting HIV through pregnancy despite the fact that the majority of young women had been pregnant before. In addition, many youth thought they had been infected through routes that are very unlikely, such as sharing a toothbrush or getting their nails cut (Behets & Pettifor, 2008). It is important that YLWH have a better understanding of HIV and STIs in order to aid them in changing their sexual behaviors.

Low Condom Use Skills

DHS data from the DRC showed that only 37% of young women and 60% of young men knew where to purchase a condom (Ministry of Planning Democratic Republic of the Congo, 2007). This survey also reported that approximately 5% of young women and 9% of young men used a condom during their first sexual intercourse while for adult women having had sex with someone other than their live-in partner or husband only 17% reported condom use while 27% of adult men having had sex with someone other than their live-in partner or wife reported condom use (Ministry of Planning Democratic Republic of the Congo, 2007). Therefore it becomes apparent that the limited condom use education within the country is contributing to the low levels of condom use for men and women of all ages (Ministry of Planning Democratic Republic of the Congo, 2007). In focus groups with youth in Bukavu, DRC it became apparent that most youth did not understand how condoms prevent the spread of disease or their use as a contraceptive (Bosmans et al., 2006). To our knowledge no study has effectively examined the extent to which youth in the DRC understand how to use a condom and ensure proper use, i.e. checking expiration dates, ensuring proper

placement, using only one at a time, taking air out of the tip etc. As mentioned previously the formative research in Kinshasa showed that there are a significant number of YLWH not using condoms on a consistent basis and low condom skills may be a contributing factor to this behavior.

Limited Ability in Sexual Communication/Negotiation

Research in sub-Saharan Africa has found that within sexual relationships men appear to have greater power than women (Luke & Kurz, 2002). Therefore, limited sexual negotiation skills become a factor which can increase high risk sexual behavior. Limited effective communication skills in relation to sexual relations can make negotiating condom use or refusing sex very challenging for youth, and particularly for young women (Worth, Denholm, & Bannister, 2003). These risks can be exacerbated when the young women's partner is significantly older. DHS data showed that 13% of young women ages 15-19 have sexual partners that are more than 10 years older (Ministry of Planning Democratic Republic of the Congo, 2007). Likewise, 20.8% of young women 18-19 reported forced first sex and 16.9% of young women age 20-24 reported ever having experienced forced sex (Ministry of Planning Democratic Republic of the Congo, 2007). In the formative research conducted in Kinshasa close to one third of YLWH reported forced sex showing this is a reality for these youth. Transactional sex has also been widely reported within the DRC and in other contexts has been shown to increase risk of infection because it can create a barrier to condom use (Wamoyi, Wight, Plummer, Mshana, & Ross, 2010). The context of older partners, forced sex, and transactional sex makes it difficult for young women to communicate their desires to their sexual partners. DHS data reported that 53% of young women 15-24 felt they could ask their partners to use a condom if they knew their partner had a STI; however, it is not clear the extent to which these women are able to make this request in real life situations (Ministry of Planning Democratic Republic of the Congo, 2007). Although very little research has been conducted on the

ability of young men to communicate their desires for using protection in sexual relationships it is still important to consider that they too may not have the confidence or necessary negotiation skills to effectively communicate their preferences to their sexual partners.

Weak Coping Mechanisms

A few studies in both the U.S. and abroad have made the connection between maladaptive coping mechanisms (inability to form a valid appraisal of the stressors, inadequate choices of practiced responses, and/or inability to use available resources) and high risk sexual behavior for both the general population and PLWH (NANDA, 2010). In one study of PLWH with a history of sexual abuse, those randomized to a coping intervention reported fewer unprotected sex acts than those in the control arm (Sikkema et al., 2008). In a U.S. based study with YLWH maladaptive coping styles predicted an increased frequency of HIV-related symptoms (Stein & Rotheram-Borus, 2004). Previous research among HIV-positive South Africans has also shown a direct connection between more avoidant type coping strategies and unprotected sex acts (Olley, Seedat, Gxamza, Reuter, & Stein, 2005). In the formative research with YLWH in Kinshasa 56% of YLWH reported a lack of active coping skills, 78% reported low acceptance coping skills and 77% reported denial coping pointing towards a need to address these maladaptive coping styles in this population (Behets et al., 2008). Likewise, coping has been associated with better adjustment to HIV (Namir, Wolcott, Fawzy, & Alumbaugh, 1987) and group interventions with HIV-positive individuals have been effective in increasing coping (Chesney, Chambers, Taylor, Johnson, & Folkman, 2003) which in turn have been associated with reductions in unprotected sex in PLWH (Gore-Felton et al., 2002). Therefore, reducing negative affect and maladaptive coping may reduce HIV transmission behaviors in YLWH.

Lack of Disclosure

Community norms surrounding HIV make it difficult for YLWH to inform their sexual partners, friends, or family members without fear of rejection or violence (Tompkins, Smith, Jones, & Swindells, 2006). Formative research with the YLWH in Kinshasa reported that only 53% of YLWH had disclosed their status and many of these youth had only disclosed to one person. When disclosure does not occur in a sexual relationship both the YLWH and his or her partner may be unable to initiate discussion around prevention behaviors. Therefore, the lack of disclosure can lead to avoidance of the topic of prevention entirely. Lack of disclosure can also in some cases lead to an increase in unsafe sexual behaviors. A recent study in Cameroon reported that HIV disclosure to a sexual partner is a predictor of safe sex for women living with HIV (Loubiere et al., 2009). Likewise, a study in Cape Town, South Africa found that not having disclosed HIV status to a sex partner was associated with higher-risk sexual behavior although other research has actually found the opposite (Simbayi et al., 2007; Simoni & Pantalone, 2004). A recent study in the U.S. of perinatally acquired young girls sexual risk behavior suggested that some female youth felt that disclosing their HIV status shifted the responsibility of preventing transmission to that partner (Marhefka et al., 2011). However, one study of perinatally infected youth in Uganda reported that there was no significant difference in condom use between youth who had disclosed to their sexual partner and those that had not. Therefore, there is no real consensus in the literature related to this determinant and more research needs to be conducted to get a clearer understanding of the role disclosure plays in sexual behavior (Birungi, Mugisha et al., 2009).

Low Levels of Social Support

Supportive and caring relationships are important in helping young people protect themselves from risk and help them to live healthy lives. The importance of these relationships may

be even greater for YLWH, who often feel socially isolated and have limited social support in dealing with their illness. Numerous studies on young people have identified the importance of close relationships with supportive adults in dealing with significant adversity (Luthar, Sawyer, & Brown, 2006). Family members and primary caregivers may provide a space in which young people learn about ways to protect themselves from risk (Ungar, 2004). Social support can be thought of as, “aid and assistance exchanged through social relationships and interpersonal transactions (House, 1983). It can be categorized into four types of supportive behaviors or acts: emotional support, instrumental support, informational support and appraisal support (House, 1983). In South Africa, social support was associated with condom use and support group attendance among women living with HIV/AIDS (Gaede et al., 2006). In a U.S. based intervention trial designed to reduce HIV transmission risk behaviors and STIs and enhance HIV-preventive psychosocial and structural factors among women living with HIV (Women Involved in Life Learning from Other Women - WILLOW), after the completion of the intervention those in the intervention group reported having more social network members who provided social support compared to the control group. The authors hypothesized that this may have contributed to the success of the intervention in reducing unprotected sex acts (Wingood et al., 2004). When asked during in-depth interviews during the formative research about gaps in HIV services and the types of interventions YLWH need, 64% of youth (18/28) mentioned needing advice, information or support. One-quarter (7/28) specifically mentioned needing aid that can be classified as social support (Behets & Pettifor, 2008). Likewise, analysis of the quantitative survey from the formative research in Kinshasa showed that low social support was reported by 74% of those who reported unprotected sex at last intercourse, compared to 69% and 66% among those reporting protected sex or no sex, respectively (Holub, 2010). Many YLWH in Kinshasa lack a strong social support network, particularly someone to share their concerns

regarding their HIV status. This is often caused by fear of disclosure and the associated social stigma (Behets & Pettifor, 2008).

Positive Prevention

Importance of Positive Prevention

Prevention interventions with PLWH (also called “Positive Health, Dignity, and Prevention” or “Positive Prevention”) focusing on both primary and secondary prevention are an effective strategy that can ensure that the needs of PLWH are addressed in conjunction with the health needs of the general population (Crepaz et al., 2006; Global Network of People Living with HIV & UNAIDS, 2009; S. Kalichman, 2005). Prevention interventions with HIV-positive persons usually have four primary goals:

- Ensure people who are HIV-positive do not transmit the virus to others (a component of primary prevention);
- Ensure people who are HIV-positive remain healthy over time (a component of secondary prevention);
- Prevent re-infection of people who are HIV-positive (a component of secondary prevention) and;
- Prevent the development of resistant strains of HIV (a component of both primary and secondary prevention) (Klein, Cruz, O'Connell, Scully, & Birkhead, 2005).

Positive Prevention makes explicit the important linkages between care and treatment and prevention. When PLWH are treated with ARVs their viral loads decrease which in turn makes the PLWH less infectious (Cohen et al., 2011; Indyk & Golub, 2006). In addition, when a PLWH acquires an STI this can accelerate the progression of the disease, while HIV infection can change the clinical

presentation of an STI, reduce the accuracy of diagnostic tests, and impact responses to necessary treatments (Clotney & Dallabetta, 1993). Likewise, women living with HIV who desire to become pregnant can use ARV prophylaxis during pregnancy to prevent mother-to-child transmission while those who do not desire becoming pregnant can use contraception to prevent an unintended pregnancy and potential negative outcomes to their health from an unplanned pregnancy (Wilcher, Cates Jr, & Gregson, 2009). Recent research has shown that preventing unwanted pregnancies is even more cost-effective than nevirapine treatment which prevents mother-to-child transmission (Reynolds, Janowitz, Wilcher, & Cates, 2008). Therefore, when primary and secondary prevention are linked together PLWH may be more likely to practice lower-risk sexual behaviors because their motivations can be based on both self-interest and altruism (in this case the desire to protect others) (Indyk & Golub, 2006).

Positive Prevention programs are a key to preventing the spread of HIV, as new infections by definition must come from a PLWH (Indyk & Golub, 2006). As in the U.S. 30-46% of STIs have been reported as being transmitted by PLWH who are aware they are HIV-infected, it becomes crucial to focus on prevention with this population (CDC, 2003; Janssen & Valdiserri, 2004; Marks, Crepaz, & Janssen, 2006). In 2003, the CDC, in conjunction with the Health Resources and Service Administration (HRSA), the National Institutes of Health (NIH), and the HIV Medicine Association, published a Morbidity and Mortality Weekly Report formally recognizing the importance of HIV prevention with PLWH within their HIV prevention strategy (CDC, 2003). These organizations went even further by funding a Special Project of National Significance program based in 26 clinics incorporating HIV prevention services for PLWH which allowed for more extensive research in the area of Positive Prevention. More recently in 2009, the Global Network for People Living with HIV (GNP+) and UNAIDS developed an expanded Positive Prevention strategy entitled, “Positive Health, Dignity and Prevention” which stresses the importance of the health and prevention needs of HIV-

positive individuals in addition to the need to prevent the further spread of the disease, within a human rights framework (Global Network of People Living with HIV & UNAIDS, 2009).

The “Seek, Test, Treat and Retain” (STTR) approach has been put forward as a possible effective strategy for Positive Prevention (Cohen et al., 2011). This approach involves increasing HIV testing and treating those who test positive immediately with ARVs with the aim of reducing their viral load to such low levels that transmission risk is greatly reduced (Granich et al., 2009). However, this approach will only be effective if the PLWH are adherent to their medications and their viral loads remain undetectable. Even if this approach is found to be feasible in the developed world there will be challenges in scale up in less developed countries in relation to both available workforce as well as sufficient funding for wide-scale ARV treatment (Dodd et al., 2010). Thus, Positive Prevention behavioral interventions play an important role in preventing transmission of the virus and can reach PLWH before they are eligible for treatment, and can also help keep individuals engaged once they are receiving treatment. In order to have the most success in preventing the further spread of this disease multiple strategies will need to be attempted as there is no single answer to prevention of HIV/AIDS (Simms, 2008).

Positive Prevention for YLWH

Positive Prevention may be particularly suited for YLWH, as these interventions can reach an HIV-infected population before commencement of sexual activity for youth perinatally infected or during the early stages of their infection for those youth who acquired HIV sexually. For most youth, adolescence is a period of their lives which involves new responsibilities in decision-making about sexual and other risk behaviors as well as the development of their capacity to understand how their own personal decisions may affect the health of others. Adolescence is a time of little impulse control, hormonal changes, and desires for independence which combined together may lead to

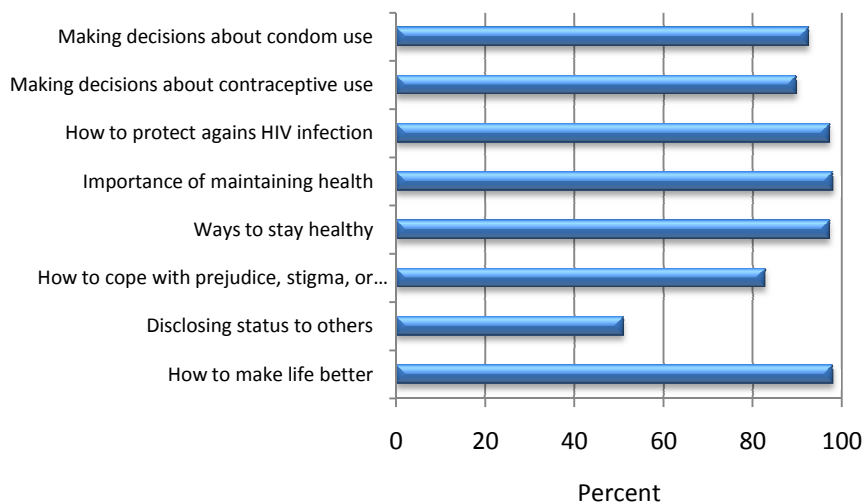
increased risk (Bauermeister, Elkington, Brackis-Cott, Dolezal, & Mellins, 2009). Youth may have difficulty adhering to safer behaviors and often may not have complete control over their own environments which exacerbates an already difficult situation.

Expressed Need for Positive Prevention Interventions at KLL in Kinshasa

Virtually all youth surveyed in formative research expressed interest in Positive Prevention programs, including: making decisions about condom and contraceptive use, how to protect against HIV infection, and how to make life better overall (Behets & Pettifor, 2008) (Figure 1). When asked if they would like to learn how to protect themselves and others against HIV infection during sexual encounters, 25 out of 25 youth asked this question said yes and more than half of the youth who expressed interest in learning to use condoms/negotiate condom use appeared concerned with protecting/not infecting others (Behets & Pettifor, 2008). It is important to note that only 50% of the youth expressed an interest in learning more about how to disclose to others (Behets & Pettifor, 2008). This can be understood within the context of high levels of stigma in this setting. The needs that YLWH most commonly reported in the three months prior to the interview were HIV/AIDS prevention information (88%), food and nutritional supplements (91%), and help or support for health problems (89%) (Behets & Pettifor, 2008)(Figure 2). If Positive Prevention interventions are to be effective YLWH must be receptive to the concepts and engaged in learning. When interviewed during the formative research, 83% of caregivers reported thinking that their child/dependent would benefit from participating in HIV prevention programs or receiving information about HIV prevention and 83% also reported being comfortable having their child/dependent take part in a program with other HIV-positive youth (Behets & Pettifor, 2008). The vast majority (90%) of caregivers expressed an interest in a program for caregivers to help them understand issues related to HIV and cope with caring for an HIV-positive child/dependent (Behets & Pettifor, 2008).

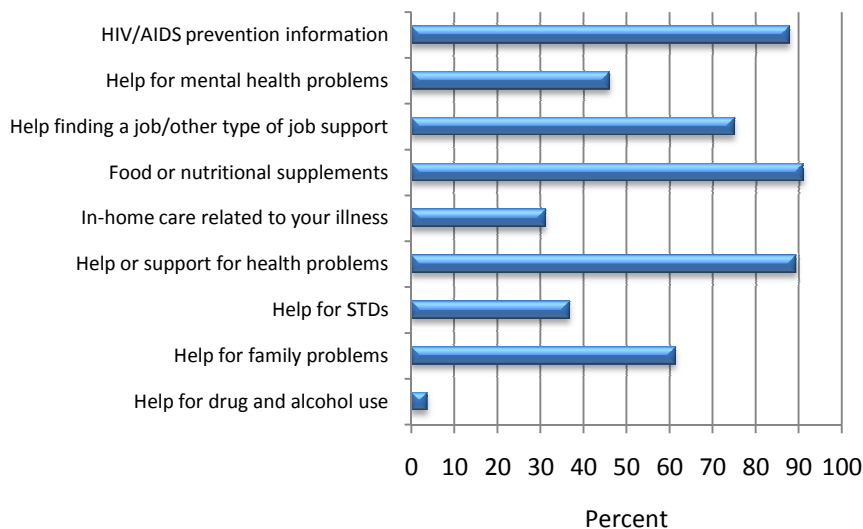
Caregivers are an important part of the lives of YLWH and therefore could prove to be a great addition to a Positive Prevention program if conducted appropriately.

Figure 1 : Services needed in the past 3 months, results from formative research with YLWH 14-24 in Kinshasa, DRC



Source: (Behets & Pettifor, 2008)

Figure 2: Topics of interest for Positive Prevention interventions, results from formative research with YLWH 14-24 in Kinshasa, DRC



Source: (Behets & Pettifor, 2008)

Positive Prevention Interventions

In a review of HIV prevention interventions from 1988 to 2006 included in a CDC database of interventions, only 6.6% of interventions were targeted towards PLWH and the majority of these interventions commenced after the year 2000 (W. A. Fisher, Kohut, & Fisher, 2009). A meta-analytic review conducted in 2006 evaluated 12 intervention trials for PLWH to determine their overall efficacy in reducing HIV risk behaviors and identify effective intervention characteristics and found that Positive Prevention interventions significantly reduced unprotected sex (OR: 0.57; 95% CI: 0.40-0.82) and decreased the acquisition of new sexually transmitted infections (OR: 0.20; 95% CI: 0.05-0.73) (Crepaz et al., 2006). This same study showed that the Positive Prevention approaches that are most effective include those: guided by behavioral theory, specifically focused on HIV transmission behaviors, provide skill building, delivered to individuals on a one-to-one basis, delivered by professional counselors or providers, delivered in settings where people living with HIV receive services, delivered in an intensive manner, delivered over a longer duration, and address a myriad of issues related to coping with one's serostatus, medication adherence, and HIV risk behaviors (Crepaz et al., 2006). Although the majority of Positive Prevention programs focus on preventing sexual or drug-related transmission other modes of transmission may also be included if prevalent in a certain target population.

The CDC has as of January 2012 designated seven "Best-Evidence Interventions" and three "Promising-Evidence Interventions" that are representative of the current state of the field in Positive Prevention (CDC, 2012a, 2012c). The CDC has created four tiers of evidence for HIV prevention interventions with Tier I and II being considered evidence-based and Tiers III and IV considered as theory-based but not yet evidence-based (See Table 2 for descriptions of criteria for level of evidence). The three interventions that are categorized as "Promising-Evidence" were not categorized as "Best-Evidence" because of issues of retention, sample size, and limited follow-up.

All of these interventions were evaluated using a randomized control trial study design, were theory-based and reported positive significant results related to the reduction of high risk sexual behaviors amongst PLWH. A wide range of populations and behaviors were targeted, several intervention methodologies utilized, including group, individual, peer-led, specialist-delivered, and clinician-delivered and ranged from two brief sessions to 23 sessions (See Tables 3 and 4 for detailed descriptions).

Table 2: CDC Criteria for Tiers of Evidence for Categorizing HIV Interventions

<p>Tier I – Best-evidence Behavioral Interventions have:</p> <ul style="list-style-type: none"> • Significant and positive intervention effects on relevant outcomes • No significant and negative intervention effects on relevant outcomes measured in the study • Comparison group • Unbiased assignment • ≥ 3 months follow-up in both groups • ≥ 70% retention in both groups • Analyses adjusted for baseline differences in outcome measures (if non-RCT) • At least 50 participants in the analytic sample in each group
<p>Tier II – Promising-evidence Behavioral Interventions have:</p> <ul style="list-style-type: none"> • Significant and positive intervention effects on relevant outcomes • No significant and negative intervention effects on relevant outcomes measured in the study • Comparison group • Unbiased or moderately biased assignment • ≥ 1 month follow-up in both groups • ≥ 60% retention in both groups • Analyses adjusted for baseline differences in outcome measures (if non-RCT) • At least 40 participants in the analytic sample in each group
<p>Tier III – Theory-based Interventions with positive outcome monitoring have:</p> <ul style="list-style-type: none"> • Behavioral change theory • Logic model • Formative research • Positive process evaluation data demonstrating fidelity, availability, and acceptance • Outcome monitoring showing positive and significant before and after changes in relevant outcomes

Tier IV – Theory-based interventions with no outcome monitoring have:

- Behavioral change theory
- Logic model
- Formative research
- Positive process evaluation data demonstrating fidelity, availability, and acceptance

Source: (CDC, 2012d)

Table 3: Summary of CDC Best-Evidence Positive Prevention Interventions 2001-2012

	Healthy Relationships (S. Kalichman et al., 2001)	Choosing Life: Empowerment, Action, Results! (CLEAR) (Rotheram-Borus, Swendeman et al., 2004)	Women Involved in Life Learning from Other Women (WILLOW) (Wingood et al., 2004)	Seropositive Urban Men's Intervention Trial (SUMIT) (Wolitski, Gomez, & Parsons, 2005)	Living in the Face of Trauma (LIFT) (Sikkema et al., 2008)	Positive Choice: Interactive Video Doctor (Gilbert et al., 2008)	The Healthy Living Project (The Healthy Living Project Team, 2007a)
Study Design	RCT	RCT	RCT	RCT	RCT	RCT	RCT
Target Population	HIV+ heterosexual men and women and HIV+ MSM	Substance abuse using youth	Women living with HIV	HIV+ gay and bisexual men	HIV+ adults with childhood sexual abuse	HIV+ clinic patients	HIV+ men and women at risk for transmitting HIV
Intervention	5 session – group	18 sessions – individual	4 sessions - group	6 session – group	15 session - group	2 session - individual	15 session - individual
Primary Interventionist	One male and one female community based facilitator, one of which was an HIV+ peer counselor	One male and one female trained facilitators	Trained female health educator and an HIV+ female peer educator	HIV+ Peers	Clinical psychologists and clinical social workers	Actor-portrayed physician	Trained facilitators
Primary Outcomes	Decreased anal and vaginal sex, increased condom use, decreased non HIV+ partners	Increased condom use, increased condom use with HIV- sexual partners	Decreased vaginal sex, increased condom use, decreased new STD	Decreased unprotected receptive anal intercourse with HIV- or serostatus unknown sexual partners	Reduced unprotected sex acts with all partners and with HIV- and unknown status partners	Reduced unprotected sex; reduced number of casual sex partners	Reduced transmission risk acts
Theory Utilized	Social Cognitive Theory	Social Action Theory	Social Cognitive Theory and Theory of Gender and Power	Social Cognitive Theory, Information-Motivation-Behavioral Skills Model, Theory of Planned Behavior	Cognitive Theory of Stress and Coping and Cognitive Behavioral Treatment Strategies for Sexual Trauma	Motivational Interviewing Principles	Social Action Theory

	Healthy Relationships (S. Kalichman et al., 2001)	Choosing Life: Empowerment, Action, Results! (CLEAR) (Rotheram-Borus, Swendeman et al., 2004)	Women Involved in Life Learning from Other Women (WILLOW) (Wingood et al., 2004)	Seropositive Urban Men's Intervention Trial (SUMIT) (Wolitski, Gomez, & Parsons, 2005)	Living in the Face of Trauma (LIFT) (Sikkema et al., 2008)	Positive Choice: Interactive Video Doctor (Gilbert et al., 2008)	The Healthy Living Project (The Healthy Living Project Team, 2007a)
Behaviors/ constructs targeted	Stress management, HIV disclosure, safe sexual behavior	Improving affective states, building skills to improve self-regulation, improving physical health, reducing sexual and substance abuse acts, improving mental health	Gender pride, maintaining network, HIV transmission knowledge, communication and condom negotiation skills, health relationships	Sexual relationships , HIV and STI transmission , drug and alcohol use, HIV status of partners, disclosure, mental health	Coping strategies, problem-focused strategies, trigger identification, social support, communication skills, cognitive reformation	Self-reflection, harm reduction, risk reduction	Stress, coping, and adjustment , safer behaviors, health behaviors

Source: (CDC, 2012a)

Table 4: Summary of CDC Promising-Evidence Positive Prevention Interventions 2001-2012

	Partnership for Health (Loss-Frame Intervention) (Richardson et al., 2004)	Together Learning Choices (TLC) (Rotheram-Borus et al., 2001)	Options/Opciones Project (J. D. Fisher et al., 2006)
Study Design	RCT	RCT	RCT
Target Population	HIV+ clinic patients	HIV+ adolescent and young adult clinic patients	HIV+ clinic patients
Intervention	3-5 minute session every visit over 10-11 months - individual	23 sessions – group	Brief 5-10 minute session at each clinic visit over 18 months – individual
Primary Interventionist	Medical provider	One male and one female trained facilitator	HIV care clinicians
Primary Outcomes	Reduced unprotected sex	Increased abstinence or consistent condom use; reduced unprotected sex with HIV- partners	Reduced unprotected vaginal and anal sex
Theory Utilized	Message Framing Theory; Mutual Participation; Stages of Change	Social Action Theory	Information-Motivation-Behavioral Skills Model; Motivational Interviewing Principles

	Partnership for Health (Loss-Frame Intervention) (Richardson et al., 2004)	Together Learning Choices (TLC) (Rotheram-Borus et al., 2001)	Options/Opciones Project (J. D. Fisher et al., 2006)
Behaviors/ constructs targeted	Self-protection, partner protection, disclosure	Coping, disclosure, staying healthy, active participation in health care decisions, self- efficacy of condom use, negotiation skills, controlling negative emotional states	Readiness to change sexual behaviors, moving toward change, and maintaining safer behaviors

Source: (CDC, 2012c)

Positive Prevention Interventions for YLWH

Although there are not a great deal of Positive Prevention interventions targeted to YLWH those that have been conducted have reported positive findings. Together Learning Choices (TLC), previously called Teens Linked to Care, is a group-level two module, 23-session, intervention targeted to youth and young adults ages 13-24 in the U.S. The intervention group reported reduced unprotected sex acts and numbers of sex partners as well as increased social support, compared to the control arm (Rotheram-Borus et al., 2001). The investigators later adapted TLC to an 18-session individually-delivered intervention that targeted minority drug-using youth in the U.S. ages 16-29 years in project CLEAR which was later determined to be a CDC Best-Evidence intervention. The adapted intervention was also found to reduce unprotected sex acts and partners as well as a decrease in the number of HIV negative partners (Rotheram-Borus, Kelly et al., 2004). Healthy choices, a multi-site U.S. based four-session motivational interviewing intervention targeted to YLWH showed improvements in depression and motivational readiness to change (Naar-King, Parsons, Murphy, Kolmodin, & Harris, 2010). However, similar to other multi-session Positive Prevention interventions in the U.S., retention of youth was a definite challenge as less than 50% completed all four sessions (Naar-King et al., 2010). Finally, the Collaborative HIV Prevention and

Adolescent Mental Health Project-Plus or CHAMP+ 10 session group intervention has been implemented in Harlem New York and is a family-based HIV prevention and mental health promotion program targeting perinatally-infected adolescents and their families although this intervention has not been selected as a CDC best-evidence or promising evidence intervention. A preliminary evaluation conducted with six families reported positive findings in relation to caregiver/child relationship, communication, and social network expansion (McKay et al., 2007). I was unable to locate any other Positive Prevention interventions for youth in the public health research literature.

Positive Prevention in sub-Saharan Africa

Authors from the CDC and the WHO published a brief commentary in 2006 on implementing Positive Prevention in Africa and proposed 10 effective approaches for implementing programs that prioritize interventions with the largest potential impact on HIV transmission (Bunnell, Mermin et al., 2006). These include: (1) ensuring PLWH learn their HIV status to facilitate early entry into care and treatment; (2) supporting HIV status disclosure by PLWH with an aim to involve partners in prevention, care and support; (3) testing and counseling of sexual partners of PLWH to identify previously undiagnosed HIV infections and HIV-discordant couples and facilitate transmission prevention; (4) provision of Antiretroviral Therapy (ART) to reduce viral load and risk of HIV transmission; (5) behavioral interventions for PLWH to reduce HIV transmission risk; (6) selection of low-risk blood donors to reduce risk of HIV transmission through blood transfusions; (7) prevention of unintended pregnancies among women living with HIV to prevent vertical transmission and reduce HIV infection risk for HIV negative women in HIV-discordant couples; (8) universal access to more effective Prevention of Mother-to-Child Transmission (PMTCT) for pregnant and delivering women with HIV to reduce vertical transmission; (9) STI screening and treatment for individuals with

HIV and their partners to reduce HIV transmission and acquisition risks; and (10) promotion of leadership by PLWHs to support a human and civil rights approach and ownership by target group. These authors concluded that there was an ethical and public health imperative to implement effective prevention strategies and treatment for PLWH.

Likewise, in 2008 the WHO published a report on essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings. In this report they developed recommendations of evidence-based practices that “in addition to or prior to the initiation of ART, promote health, reduce the risk of HIV transmission to others, and address diseases that most impact the quality and duration of life of adults and adolescents with HIV.” In regards to positive prevention they recommend that: “People with HIV who choose to be sexually active should be counseled about safer sex interventions to prevent HIV transmission to others and how to avoid acquisition of sexually transmitted infections, and should be provided with condoms” (World Health Organization, 2008).

Positive Prevention Interventions in sub-Saharan Africa for PLWH and YLWH

There are a few Positive Prevention interventions that have been implemented and evaluated for YLWH in sub-Saharan Africa. To our knowledge only one CDC EBI has been adapted and implemented in sub-Saharan Africa for YLWH.

Group Interventions for Adults Living with HIV/AIDS

The Human Science Research Council has conducted a pilot project in which they adapted Kalichman’s Healthy Relationships for the context of PLWH in Botswana and South Africa (Cloete et al., 2009). Preliminary results from the pilot reported that participants in the intervention were more confident in using a condom and had more trust that the condom would not break after the

intervention (Cloete et al., 2009). However, even after the intervention over half of the participants had not disclosed their status to others and over one third of those who reported having sex did not use a condom at their last sex act (Cloete et al., 2009). Another group-based intervention for adults living with HIV/AIDS is the adaptation of WILLOW in the Western Cape of South Africa which focuses specifically on women living with HIV/AIDS (Saleh-Onoya et al., 2009). While the WILLOW intervention reported decreased incidence of STIs for the intervention group there were no differences found between the two groups on coping skills or condom use skills (Saleh-Onoya et al., 2009).

Provider-Delivered Interventions during Clinic Visits

The CDC has adapted the Best-Evidence Intervention Partnership for Health for implementation in sub-Saharan Africa, by providers, nurses, or counsellors and has published extensive materials that are available on-line; however, final results of a pilot program have not yet been published (CDC et al., 2008). In addition, FHI/Zambia has developed a guide to integrate HIV prevention in the care setting for delivery by both clinical and non-clinical staff and has disseminated this guide to other FHI country offices and partners (Bachman et al., 2007). While this guide is not specifically based on an EBI it includes many components of successful clinic-based Positive Prevention interventions. Likewise, Fisher's Options intervention has been adapted and implemented in multiple sites across South Africa by different researchers with mixed results. All of the adapted interventions used counsellors instead of providers to deliver the intervention. The first study adapted this brief risk reduction intervention for delivery and reported a decreased number of unprotected sex acts for participants in the intervention arm (Cornman et al., 2008). Two more recent adaptations have not been as successful and reported difficulties with delivering all of the sessions and the skills necessary for conducting Motivational Interviewing techniques (Dewing et

al., 2010b; Evangeli et al., 2009; Mash et al., 2008). Finally, this same adaptation implemented in Mpumalanga, South Africa was found to significantly reduce multiple partners, unprotected sex, alcohol or drug use in a sexual context and transactional sex even though the average number of sessions for each patient was 2.3 (Peltzer, Tabane, Matseke, & Simbayi, 2010).

Individual-based Interventions for Youth Living with HIV/AIDS

The research group that developed TLC and CLEAR recently adapted the 18-session CLEAR intervention for YLWH in Uganda. The study included 100 Ugandan YLWH and was effective in increasing condom use and decreasing the number of sex partners, and found that adapting a US-based intervention to a high HIV prevalence, low-resource setting was possible (Lightfoot, Kasirye et al., 2007). The success of this intervention shows that intensive interventions can be successful in low-income settings similar to the DRC. However, the intervention was delivered individually to YLWH during home visits by nurses therefore there is a need to determine the effectiveness of interventions delivered through different delivery modes that are less resource-intensive, such as in group settings or during routine clinic visits.

Group Interventions for Youth Living with HIV/AIDS

The CHAMP+ intervention has been adapted and is currently being piloted for YLWH in Durban, South Africa. Results have not as of yet been published; however, preliminary findings have suggested that families that participated reported being able to better cope with HIV and being able to better identify problems and possible solutions (Bhana, McKay, Mellins, Petersen, & Bell, 2010).

Positive Prevention Currently Provided at Kalembe Lembe Clinic

There is no published research on Positive Prevention programs in the DRC. There are a few non-governmental organizations that state that they provide general psychosocial support or counseling to PLWH including AMO-Congo (Avenir meilleur pour les orphelins du SIDA or Better Future for AIDS Orphans), Foundation Femme (Foundation Women Plus), and EVREJ-CONGO (Education pour une vie responsable et le bien-être des enfants et jeunes au Congo or Education for a responsible life and the well-being of children and youth in Congo); however, there is no research showing the quality of care being provided and no information as to the specific content of the counseling. In addition, there is likely little to no counseling being conducted related to prevention of transmission for YLWH across the country in the majority of clinics. However, it is certainly possible that organizations such as Doctors without Borders or other religious organizations may be implementing some limited form of Positive Prevention specifically for YLWH getting treatment at their sites and do not have publically available information on these programs. Currently, at KLL peer support groups, individual one-on-one counseling, and home visits are the Positive Prevention services currently provided for YLWH. Individual counseling sessions are conducted on an ad hoc basis between youth and psychosocial counselors or medical doctors. Home visits are conducted if the YLWH is not coming to the clinic and the staff feels the youth needs individual attention. The format of the peer support groups is a general open discussion of disclosure experiences with various different educational topics presented. Youth one by one describe their disclosure experiences (i.e. when they were informed that they were HIV+) to the group and discuss the challenges of living with HIV with other youth. The peer support groups are split by disclosure status (one group undisclosed and the other disclosed) and thus usually by age, meet once a month on a Saturday, and educational topics are repeated as new youth join the group. The groups are facilitated by the psychosocial program staff and doctors attend in order to respond to questions

the group may have about living with HIV. It is important to note that even the existing services at KLL are quite advanced in Positive Prevention when compared with Positive Prevention programs for YLWH in the rest of sub-Saharan Africa.

Provider Role in Positive Prevention

In the past, provider-delivered counseling has been effective in helping patients, including youth, change health-related behaviors, including physical activity, healthy eating, smoking cessation, and alcohol use (Pbert et al., 2008; Vaczy, Seaman, Peterson-Sweeney, & Hondorf, 2010; Whitlock, Polen, Green, Orleans, & Klein, 2004). In the 2003 guidance, the CDC proposed three recommendations to help clinic environments incorporate physician-delivered Positive Prevention: 1) Screening for HIV transmission behaviors and STIs; 2) Providing brief behavioral risk-reduction interventions in the office setting; 3) Facilitating notification and counseling of sex partners of infected persons (CDC, 2003). As a result of these guidelines, a group of clinicians and researchers published a commentary raising three primary concerns (Gerbert et al., 2006). First, providers may fear that their patients will feel stigmatized if they discuss the risk of transmission of the disease. Second, providers may be concerned that their patients would feel as if they are putting the greater public health before their patient's individual needs. Third, ethical concerns have been raised by providers who feel that the CDC recommendation to inform sex partners of PLWH if they are at risk puts them at odds with the principle of beneficence (Gerbert et al., 2006).

These same authors were also among the first to suggest the inclusion of messages related to protecting PLWH's health in Positive Prevention counseling. Accordingly, it has been noted that in studies conducted after 2006 there appears to be more of a focus on re-infection as a component of Positive Prevention counseling in addition to the patient's own health (Myers et al., 2007). It is important to note that although re-infection is a component of the majority of Positive Prevention

efforts there is not a great deal of scientific evidence showing the extent to which it is a frequent occurrence; however, we do know that in rare cases it is certainly possible (Chohan, Lavreys, Rainwater, & Overbaugh, 2005). Currently many Positive Prevention programs take place in clinic environments and are implemented by the doctor, nurse or social worker during clinic visits or support groups and the majority now incorporate these elements of secondary prevention. However, some of these initial concerns remain barriers to effective acceptance of provider-initiated Positive Prevention counseling.

In 2002, studies began to be published evaluating the extent to which providers in the U.S. were discussing prevention topics with their HIV-positive patients and examining which factors were associated with provider-delivered routine Positive Prevention counseling. Although no significant trend is apparent from the published literature, some researchers have suggested that providers have increased their HIV transmission counseling over the years, possibly because of increased training and exposure to the importance of Positive Prevention in the clinic setting (Myers et al., 2007). The diversity of populations, context, and methods used in these studies make it difficult to come to any generalizable conclusions in relation to the receipt or delivery of provider Positive Prevention Counseling with PLWH and the factors associated with provider Positive Prevention (Table 5 and 6).

It is also important to note that of the 12 studies included in Table 5 only two examine prevention counseling in a low-resource setting, and only one was conducted in sub-Saharan Africa. Thus, even in the context of the U.S., providers struggle to find ways in which to incorporate prevention counseling to routine visits with their patients living with HIV. It is clear that not all of the PLWH in need of Positive Prevention counseling are receiving these much needed services. As seen in Table 6 many of these studies have found various characteristics of providers, patients, or clinics that are associated with provider Positive Prevention counseling. Although there is no

definite list of factors directly associated with provider Positive Prevention counseling many of the studies reported associations with different demographics representing populations thought by providers to be less risky in their sexual behaviors and therefore assumed they did not have as great a need to be counseled as other populations. In addition, the majority of studies reported that newly diagnosed patients were counseled more than established patients. Other factors associated with increased Positive Prevention counseling were more communication between patient and physician and exposure to treatment or counseling guidelines. Prevention fatalism, or the belief that counseling will have no impact, was shown to be associated with decreased Positive Prevention counseling. Finally, and perhaps most importantly, the majority of studies found no significant differences in Positive Prevention counseling for patients with higher viral loads or those reporting high risk sexual behaviors in comparison to patients with lower viral loads and those not reporting high risk sexual behaviors. These different factors associated with Positive Prevention counseling reported in these studies aided in the development of the In-Depth Interview Guides for providers in Aim 2 of this dissertation.

Table 5: Summary of Receipt/Delivery of Routine Provider Positive Prevention Counseling with PLWH, 2001-2009

(Author , Year)	Sample Size (population)	Setting	Results
(Margolis, Wolitski, Parsons, & Gómez, 2001)	N= 250 (patients) Survey	San Francisco and New York City	25% of men surveyed did not report receiving safer-sex counseling and men at risk were no more likely to be counseled than men at lower risk.
(Marks et al., 2002)	N=1678 (patients) Survey	6 clinics in California	71% of patients reported having ever experienced prevention counseling.
(Metsch et al., 2004)	N=417 (providers) Survey	4 cities within the U.S.	60% of providers reported providing counseling to more than 90% of newly diagnosed patients. 14% of providers reported providing counseling to more than 90% of their established patients.
(Morin et al., 2004))	N=618 (patients) Survey IDI =80 medical staff/providers; 64 patients	16 cities within the U.S.	25% of patients reported a discussion related to sexual behavior in their clinic visit on the day of the interview. 6% reported a discussion of specific sexual activities.
(Peltzer & Ndlovu, 2005)	N=15 providers IDI	Limpopo, South Africa	40% of providers reported encouraging their patients to change their risky behaviors to prevent the transmission of the virus. 26.6% reported discussion dangers of re-infection and transmission of others. 36% reported giving information and referring patients to other health workers due to lack of time and inadequate counseling skills.
(Steward, Koester, Myers, & Morin, 2006)	N=618 (patients) Survey IDI=144 (providers, administrators, patients)	16 clinics in San Francisco	45% of patients in clinics reporting signs of high fatalism reported prevention counseling within the previous 6 months. 60% of patients in clinics reporting signs of low fatalism reported prevention counseling within the previous 6 months.
(Fehringer et al., 2006)	N=20 Observations with providers and PLWH	Rio de Janeiro, Brazil	Only 3 of the 16 providers discussed sexual behavior with their patients while 3 of 4 social workers discussed sexual behavior with their patients.
(Wilkinson et al., 2006)	N=869 (HIV+ IDU patients) Survey	4 cities within the U.S.	65% of patients reported having discussed HIV prevention with their provider at their most recent clinic visit.

(Author , Year)	Sample Size (population)	Setting	Results
(Vincent, 2007)	N=302 (providers) Survey	304 counties in California	61% of providers agreed that in general providers have a clear understanding of how to incorporate positive prevention into their work while 39% disagreed.
(Myers et al., 2007)	N=316 (providers) Survey	15 cities within the U.S./26 clinics	For initial visits 83% of providers surveyed reported asking their patients if they are sexually active and 79% discussed safe sex with their patients. For regular care visits 67% of providers surveyed reported asking their patients if they are sexually active and 65% discussed safe sex with their patients.
(Drainoni, Dekker, Lee- Hood, Boehmer, & Relf, 2009)	N=31 (providers) IDI	Boston	More prevention education occurs during initial visit than subsequent visits.

Table 6: Summary of Factors Associated with Whether PLWH Received Routine Provider Positive Prevention Counseling, 2001-2009

(Author, Year)	Sample Size (population)	Setting	Results/Authors' Possible Explanations
(Margolis et al., 2001)	N= 250 (patients) Survey	San Francisco and New York City	Men receiving treatment in public clinics were more likely to receive safer sex counseling than men in other clinics such as veteran's clinics or other hospitals. No association between viral load, STI diagnosis, or reported sexual risk behavior and safer sex counseling. The authors hypothesized that the relationship between patient and provider, number of patients, training and type of providers in different settings, and individual or structural barriers to safer-sex counseling (limited time, lack of reimbursement for counseling, patient discomfort discussing sexual behavior) may explain the reported differences. Providers may be unaware of patient's sexual behavior or may even be ignoring the behavior.

(Author, Year)	Sample Size (population)	Setting	Results/Authors' Possible Explanations
(Marks et al., 2002)	N=1678 (patients) Survey	6 clinics in California	MSM and whites were less likely to receive Positive Prevention counseling and physicians were more likely to provide Positive Prevention counseling than other clinic staff. No association between viral load or sexual risk behavior and Positive Prevention counseling. Providers may target those ethnic groups thought to be increasingly affected by HIV or providers may assume a certain level of knowledge of prevention behaviors for MSM and whites. Counseling with physicians may be more common because physicians had more frequent contact with patients.
(Metsch et al., 2004)	N=417 (providers) Survey	4 cities within the U.S.	Newly diagnosed patients were more likely to receive safer sex counseling than established patients. For newly diagnosed patients fewer numbers of patients and perception that there is sufficient time for counseling was associated with increased counseling. For established patients greater time spent with patients and the perception that system barriers are important to HIV care was associated with increased counseling. Those doctors who treated more male patients or were ID specialists were less likely to report counseling. For both newly diagnosed and established patients' familiarity with treatment guidelines was associated with increased counseling. Doctors who perceived their patients as having mental or substance abuse problems were less likely to report counseling. Those doctors treating patients with mental or substance abuse issues may feel they don't have sufficient time to address prevention counseling. Prevention counseling with female patients may be more common as they are more likely to communicate with their physicians and ask more questions than males. ID providers may feel professional counselors are more suited for prevention counseling.
(Morin et al., 2004)	N=618 (patients) Survey IDI =80 medical staff/providers; 64 patients	16 cities within the U.S.	Patients being treated in clinics with established guidelines for prevention counseling, during clinic visits of more than 30 minutes, been a patient of the clinic for more than one year, are sexually active, including those that reported they feared they may have recently transmitted the virus, were more likely to have experienced prevention counseling.
(Peltzer & Ndlovu, 2005)	N=15 providers IDI	Limpopo, South Africa	Providers stated that time constraints were a barrier to prevention counseling. Others reported that counseling is better handled by counselors or other health workers trained in such techniques. The majority of providers conducted an initial evaluation of risk behaviors but few reported following up in subsequent visits. However, almost all the providers reported following up on risk behaviors if the patient presented with a cue such as an STI.

(Author, Year)	Sample Size (population)	Setting	Results/Authors' Possible Explanations
(Steward et al., 2006)	N=618 (patients) Survey IDI=144 (providers, administrators, patients)	16 clinics in San Francisco	Patients in clinics reporting signs of high fatalism related to prevention counseling, i.e. belief that counseling will have no impact, were less likely to report prevention counseling than patients in clinics reporting signs of low fatalism even when controlling for clinic characteristics, patients sexual risk behavior, and health status. However, high fatalism clinics with low provision of prevention counseling had a patient population that was predominantly white, gay, male, educated and older.
(Fehringer et al., 2006)	N=20 Observations with providers and PLWH	Rio de Janeiro, Brazil	Those providers that discussed sexual behavior with their patients only did so as a result of obvious signs of lack of protective sexual behavior such as symptoms of an STI or pregnancy.
(Wilkinson et al., 2006)	N=869 (HIV+ IDU patients) Survey	4 cities within the U.S.	White patients, those with higher education, and those reporting less engagement with their provider reported fewer prevention counseling discussions. Providers may not have targeted white and more highly educated patients because they were focusing on patients they felt most needed prevention messages. Providers may feel more comfortable discussing sensitive behaviors with patients more actively involved in discussions.
(Myers et al., 2007)	N=316 (providers) Survey	15 cities within the U.S./26 clinics	Initial vs. follow up visit, an increased sense of responsibility, and less prevention fatalism were important factors influencing increased Positive Prevention counseling by providers. Fatalistic attitudes may be influenced by providers perceptions of patients complex problems, that needed services are not available, or that previous attempts to provide Positive Prevention counseling were unsuccessful.
(Drainoni et al., 2009)	N=31 (providers) IDI	Boston	Providers counseled patients on safer sex during initial visits or in response to clinical prompts such as STI symptoms. This may have been because of reported time constraints or providers comfort level that they did not routinely provide prevention counseling.

Barriers to Provider Routine Positive Prevention Counseling

There are a wide-range of different barriers to provider routine Positive Prevention counseling (as opposed to formal interventions) discussed in the literature. Time constraints, greater patient load, and provider perception of patient mental health issues were barriers to Positive Prevention counseling for newly diagnosed patients in four cities in the U.S. (Metsch et al., 2004). Barriers to Positive Prevention counseling for providers in 16 cities across the U.S. included lack of time, training, funding, and providers' understanding of their roles and responsibilities (Morin et al., 2004). In California, providers reported lack of resources, client behavior and psychosocial issues, client attitudes, unhelpful systems, lack of provider knowledge, skills and/or experience as real challenges to Positive Prevention counseling (Vincent, 2007). Finally, in Boston, providers mentioned the difficulty eliciting behaviors from patients, difficulty addressing risks related to substance abuse, patient and provider discomfort in speaking about risk behaviors, lack of understanding of different cultures of patients and structural barriers as contributing to reduced provider Positive Prevention counseling (Drainoni et al., 2009). Recent research has pointed to the importance of focusing on provider attitudes and beliefs as well as more administrative or logistical issues (Myers et al., 2007; Patel et al., 2009).

The barriers mentioned in the literature for the U.S. are compounded by additional challenges faced in sub-Saharan Africa such as even more limited resources and staff and more paternalistic patient-provider interactions (Anyangwe & Mtonga, 2007; Labhardt, Schiess, Manga, & Langewitz, 2009). While sub-Saharan Africa is home to 11% of the world's population they bear over 24% of the world's disease burden and yet have only 3% of the global health workforce and spend less than 1% of the world's financial resources on health (Anyangwe & Mtonga, 2007). Therefore, this leads to greater patient loads, less time to spend with patients, and fewer training

opportunities all of which can serve as barriers to Positive Prevention counseling (Anyangwe & Mtonga, 2007).

In addition, because of the institutionalized authoritative style of providing care in sub-Saharan Africa, patients may not take an active role in clinic visit discussions, which leaves little room for a dialogue on prevention of transmission (Kim, Odallo, Thuo, & Kols, 1999). This lack of effective patient-provider relationships may be due to the lack of focus on patient-centered care in medical school curricula, private practitioners not being interested in preventive counseling perceived to be less lucrative, or the goal of providers to increase their income may conflict with the promotion of patient autonomy (Unger, Ghilbert, & Fisher, 2003). Research has shown that more patient-focused communication can increase patient health outcomes in developing countries (Abdel-Tawab & Roter, 2002). In addition, the judgmental manner of many physicians in discussing patients' health beliefs may serve as yet another barrier to Positive Prevention counseling (Labhardt et al., 2009). It is also of interest that research on quality of care has shown that patients' themselves value interpersonal relationships with their providers very highly as a component of quality of care and thus improving these patient-provider interactions may be necessary for any provider-delivered Positive Prevention program to be successful (Ariba, Thanni, & Adebayo, 2007).

Provider Routine Positive Prevention Counseling with YLWH at Kalembe Lembe Clinic

There are no published studies on provider Positive Prevention counseling in the DRC. At the KLL clinic in Kinshasa, research conducted in conjunction with this dissertation research has provided a glimpse into patient-provider interactions (Chalachala, Parker, Pettifor, & Behets, 2010). However, it is important to note that care provided at KLL is not at the same level as other areas in the DRC or even in Kinshasa. A Congolese UNC researcher with a medical degree conducted 10 non-reactive participant observations of routine clinic visits with YLWH. Consultations lasted between 4

to 18 minutes with an average duration of 10 minutes, regardless of whether the consultation was medical or psychosocial. Providers appeared to be very familiar with their patients and focused consultations on the patient's medication regimen and appointment attendance. The providers did not spend much time addressing the patient's medical complaints or discussing sexual behavior.

Other researchers have remarked that provider-delivered prevention counseling may be difficult because of the almost perfect adherence required for affective treatment with ARVs as providers' may focus the majority of their communication on ARV adherence and no time is left for prevention counseling (Metsch et al., 2004). In general, the providers listened attentively to the youth without judgment. On the other hand, certain providers were less understanding when patients described behaviors that did not follow the providers' directives. Many consultations resembled interrogations whereby the provider asked the YLWH to respond to a string of questions without permitting the youth to ask their own questions (Chalachala et al., 2010). In the context of KLL, where there are a multitude of competing demands for providers, finding ways in which HIV transmission risk prevention counseling can be provided to YLWH becomes even more challenging. However, providers at KLL have shown a great deal of interest in learning more about Positive Prevention and have been eager to learn new skills that can be incorporated into their practice.

Provider-Delivered Positive Prevention Interventions

Of the 10 CDC Best-Evidence and Promising-Evidence Positive Prevention interventions, two are provider-delivered during routine health care visits: Partnership for Health and the Options/Opciones Project and both were determined to be Promising-Evidence interventions (J. D. Fisher et al., 2006; Richardson et al., 2004). There are only five provider-delivered Positive Prevention interventions with outcome data described in the current literature as of January 2011 (Table 7). In relation to provider-delivered Positive Prevention Interventions in sub-Saharan Africa,

as mentioned previously, the CDC has adapted Partnership for Health for implementation in sub-Saharan Africa, Options has been adapted for South Africa, and FHI has developed a guide to integrate HIV prevention in the clinic setting for low-resource settings (Bachman et al., 2007; CDC et al., 2008; Cornman et al., 2008).

Table 7: Summary of U.S. Based Provider-Delivered Positive Prevention Interventions, 2004-2010

Intervention Name (Author, Year)	Target population	Intervention mode	Primary Outcomes	Theory Utilized	Behaviors/ constructs targeted
Partnership for Health (Richardson et al., 2004)	HIV+ patients	3-5 minute session every visit over 10-11 months with provider	Reduced unprotected sex	Loss Frame Message Theory; Mutual Participation; Stages of Change	Self-protection, partner protection, disclosure
Options/Opciones (J. D. Fisher et al., 2006)	HIV+ patients	Brief 5-10 minute session at each clinic visit over 18 months with provider	Reduced unprotected vaginal and anal sex	Information-Motivation-Behavioral Skills Model; Motivational Interviewing Principles	Readiness to change sexual behaviors, moving toward change, and maintaining safer behaviors
Positive STEPS (Striving to Engage People) (Gardner et al., 2008; Patel et al., 2009)	HIV+ patients	Behavioral screening every 3 months; quarterly provider-initiated discussion on safer sex; provider initiated risk-reduction plan every 3 months; brochure, posters	Significant reduction in unprotected anal and vaginal sex with HIV+ and at risk partners and was associated with self-report of receiving safer-sex counseling	Lewin's model of organizational change	Sexual risk behavior, substance abuse behavior
HIV Intervention for Provider (HIP) (Rose et al., 2010)	HIV+ patients	Brief provider-initiated discussions over a 6 month period (Providers trained in assessing risk and delivering prevention messages)	Decrease in number of sexual partners; No significant decrease in unprotected sex acts	Theory of planned behavior; Information-motivation-behavior skills model; harm reduction	Decreasing, changing, or eliminating risk behaviors; incorporates quality of life and contextual risk

Intervention Name (Author, Year)	Target population	Intervention mode	Primary Outcomes	Theory Utilized	Behaviors/ constructs targeted
Health Resources and Services Administration (HSRA) Special Projects of National Significance (Myers et al., 2010)	HIV+ patients	Brief risk assessments via computer – provider-initiated prevention counseling over 12 months	Reduction in transmission risk behavior at 12 months	Transtheoretical Model	Sexual risk behavior

More recently articles have been published describing newly developed provider-delivered interventions, all of which used Prochaska’s transtheoretical Model, or Stages of Change Model as their theoretical basis (Callahan, Flynn, Kuenneth, & Enders, 2007; Chen et al., 2008; Grimley, Bachmann, Jenckes, & Erbelding, 2007; Prochaska & Clemente, 1992; Zuniga et al., 2007). The Stages of Change model has been the preferred theoretical model because of its use in aiding the reduction of risk behaviors in small increments over time and provides a method for assessing patient’s difficulties in changing their behavior (Zuniga et al., 2007). In addition, many of these newer interventions, such as the Computer Assisted Risk Assessment (CARA) and the Providers Advocating for Sexual Health Initiative (PASHIN) incorporate a computerized risk assessment as a key component of their intervention and this seems to have high acceptability among both patients and providers (Chen et al., 2008; Grimley et al., 2007; Zuniga et al., 2007). Likewise, electronic reporting of delivery of provider-initiated counseling was more effective than paper reporting in a recent study, as this may have served as a cue for counseling as well as eased the reporting burden (Gardner et al., 2008). Two of these interventions, Supporting Positive Living and Sexual Health (SPLASH) and the Comprehensive Harm Reduction Protocol, as well as some of the HSRA sites included provider referrals to prevention specialists if patients are determined to need support beyond what the provider can deliver (Callahan et al., 2007; Myers et al., 2007; Zuniga et al., 2007).

Some of the multi-provider HSRA sites reported a smaller decrease in risk behaviors in comparison with provider-only sites possibly because of increased staff burden, training demands, lack of integration/synergy and resources necessary (Myers et al., 2010). However, with increased resources and improved collaboration between providers and specialists these multi-provider interventions may be the most effective in changing patient's behaviors. In summary, recent provider-delivered Positive Prevention interventions focus on stages of behavioral change, increasing the use of technology, and the incorporation of multiple modes of intervention.

Lessons Learned from Provider-Delivered Positive Prevention Interventions

A recent review of Positive Prevention interventions from 1998-2008, as well as the experience of 15 HRSA clinic-based projects, have highlighted a few key lessons learned (Gilliam & Straub, 2009). *First*, it is vital that there is buy-in from providers from the outset of the project. Providers can be included in formative research or in the development and adaptation of the actual intervention. *Second*, providers' attitudes and beliefs related to risk reduction must be addressed through workshops, trainings, or discussions as it is imperative that providers have a shared belief in the importance and necessity of Positive Prevention. *Third*, resistance from providers related to prevention counseling must be addressed early on and realistic solutions put forward. *Fourth*, training must be provided to providers and must be ongoing. *Fifth*, changes to clinic organization and flow must be included in the development of the intervention and effectively communicated to both participants and providers. *Sixth*, the roles and responsibilities of all participants in the intervention must be clearly outlined and explained prior to the start of the intervention (Gilliam & Straub, 2009; Koester et al., 2007). Other issues that researchers have put forward are being aware of participants' privacy concerns when completing behavioral risk assessments and the need for

providers to be able to appropriately bill for time providing prevention counseling to their patients (Callahan et al., 2007; Chen et al., 2008).

CHAPTER 3: THEORETICAL FRAMEWORK

Chapter Overview

In this chapter I will first discuss the theoretical framework for Specific Aim 1 including the theoretical origins of the CDC ADAPT guidelines. I will then briefly describe the ADAPT framework steps. I will next describe the evidence-based intervention that was adapted as part of this dissertation research, the Healthy Living Project. This description will include an overview of the theoretical framework that guided the development of this intervention, the Social Action Theory. I will then discuss the way in which the Social Action Theory can be applied to the health protective action of safer sexual behavior for YLWH, as in the adapted SYMPA intervention. Finally, I for Specific Aim 2 I will explain the role of the Social Action Theory in informing the development of the IDI guides for health care providers.

Specific Aim 1: Theoretical Framework for Adaptation

For the purposes of this initial component of the dissertation study I was guided by the *Map of Adaption Process: A Systematic Approach for Adapting Evidence-Based Behavioral Interventions Guidelines*, or ADAPT, developed by the CDC for adapting evidence-based HIV behavioral programs for new settings and target populations and largely based on Rogers' Diffusion of Innovations Theory (McKleroy et al., 2006). The guidelines also include elements of community health education, social work, participatory research, and community empowerment principles (McKleroy et al., 2006; Rogers, 1995).

Rogers' Diffusion of Innovations theory incorporates four major components: 1) Innovation, 2) Communication Channels, 3) Time, and 4) Social System. In these guidelines the EBI is considered to be the innovation, and is communicated through trainings, social media, and peer-reviewed journals. In the time component the innovation-decision process takes place in which an individual first gains knowledge of the innovation (in this case the EBI) then determines if they will adopt or reject the innovation (in this case the EBI). The social system includes interrelated bodies engaged in solving a problem in order to achieve a common objective. Adaptation is thought to take place during the innovation-decision process of the time component. Rogers has defined adaptation as "the degree to which an innovation is changed or modified by a user in the process of its adoption and implementation".

This process consists of five key phases: 1) Knowledge, 2) Persuasion, 3) Decision, 4) Implementation, and 5) Confirmation. The process of an individual, agency, or community learning about an EBI is the knowledge phase. Persuasion involves this body determining if they like or dislike the EBI. The body then determines if they are going to adopt or reject the EBI. If they decide to adopt the EBI they move into the implementation phase. Finally, in the confirmation phase the body attempts to gain support for the plan of implementing the EBI.

In the CDC ADAPT guidance, they have expanded upon Rogers' earlier definition of adaptation to mean, "The process of modifying *key characteristics* of an intervention, recommended activities and delivery methods, without competing with or contradicting the *core elements*, theory, and *internal logic* of the intervention thought most likely to produce the interventions' main effects" (McKleroy et al., 2006) (Table 8).

Table 8: Key Terminology when Adapting EBIs

Core Elements	These are required elements that embody the theory and internal logic of the intervention and most likely produce the intervention's main effects. Core elements should be identified through research and program evaluation. Core elements essentially define an intervention and must be kept intact (i.e., with fidelity) when the intervention is being implemented or adapted, in order for it to produce program outcomes similar to those demonstrated in the original research.
Key Characteristics	These are important, but not essential, attributes of an intervention's recommended activities and delivery methods. They may be modified to be culturally appropriate and fit the risk factors, behavioral determinants, and risk behaviors of the target population and the unique circumstances of the venue, agency, and other stakeholders. Modification of key characteristics should not compete with or contradict the core elements, theory, and internal logic of the intervention.
Internal logic	This is the explanation of the relationships among intervention activities, behavioral determinants, and the intended outcome(s) of the intervention.

Source: (McKleroy et al., 2006)

ADAPT Guidelines

The ADAPT guidance begins with the selection of EBIs that have been shown to be effective and maintain fidelity to core elements, conduct systematic assessments of the target populations' risk factors, behavioral determinants, and risk behaviors as well as take into consideration the organization's capacity to implement such a program. These guidelines also incorporate the possibility of collaboration with community partners and stress the importance of cultural proficiency, or "a way of being that enables both individuals and organizations to respond effectively to people who differ from them" (McKleroy et al., 2006). These guidelines are unique because of their incorporation of the experiences and challenges in implementing EBIs in a practice-based setting while still maintaining fidelity to the original intervention (McKleroy et al., 2006).

The guidance includes five key steps: 1) Assess, 2) Select, 3) Prepare, 4) Pilot, and 5) Implement. The first step, *assess*, includes evaluating the target population, the potential EBIs, and the implementing organizations' capacity. The second step, *select*, involves the decisions around whether or not the EBI will be adapted or implemented as is, or to select a different intervention all

together. The third step, *prepare*, includes adapting intervention materials and curriculum as well as pre-testing these materials and increasing agency capacity as well as necessary partnerships. The fourth step, *pilot*, involves piloting the components of the adapted intervention and developing an intervention plan. The fifth step, *implement*, involves implementing the entire adapted intervention. Finally, it is important to note that the guidance includes feedback loops between the different steps and many of these steps can be conducted simultaneously rather than sequentially and that these steps may be influenced by agency funding, readiness, and capacity (McKleroy et al., 2006) (Figure 3). For this study the five steps of the ADAPT guidance were followed as closely as possible given the resource constraints, capacity and time-frame.

Figure 3: CDC Map of Adaptation Process

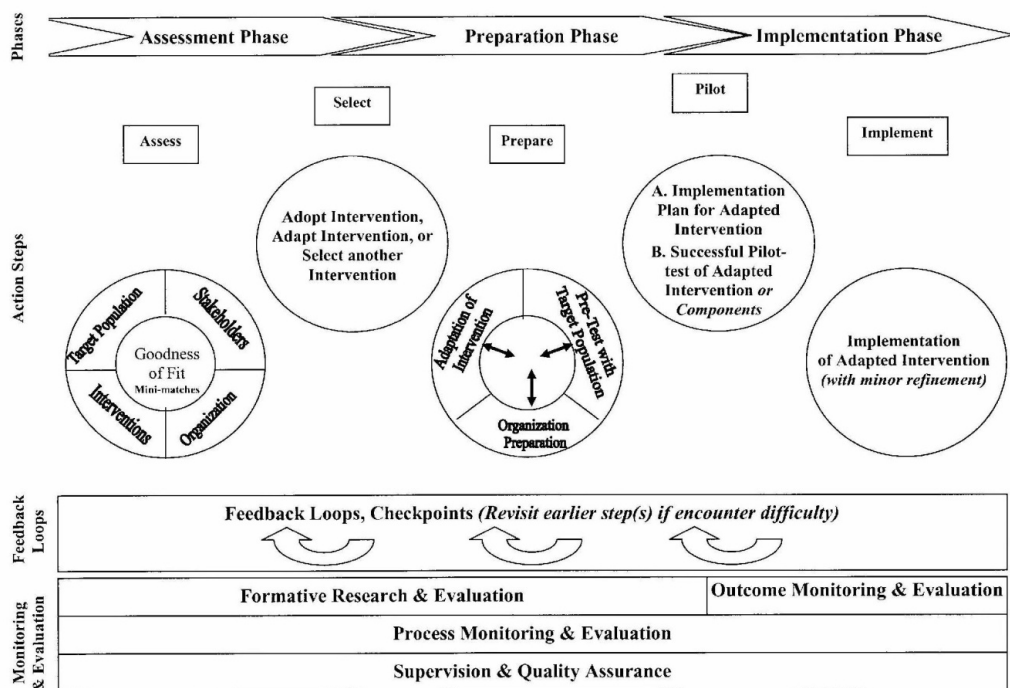


FIGURE 1. Map of Adaptation Process: A Systematic Approach for Adapting Evidence-Based Behavioral Interventions
Note. This is a *working draft*. Investigators will distribute a revised draft at the conclusion of ADAPT project activities.

Source: (McKleroy et al., 2006)

The Healthy Living Project

The HLP is an individual Positive Prevention intervention targeting adults living with HIV in the U.S. The HLP intervention uses individually tailored sessions to develop a “Life Project” which addresses quality of life, coping, methods to realize a positive healthy action state, and the development of social support relationships (The Healthy Living Project Team, 2007a). Over three modules of five sessions each participants learn skills necessary for the reduction of high risk sexual behavior and focus on education to resolve misconceptions regarding HIV transmission and how these misconceptions’ are associated with high risk sexual behavior. Participants are asked to identify their own high risk behavior triggers in order to help them develop mechanisms to modify these high risk behaviors. The program helps increase self-efficacy in condom use and condom negotiation skills and assertive communication. How to disclose HIV status to partners is also a major component of the program. Finally, access to health services, adherence to ARVs, and increased participation in medical decision making is also covered with the participants. Module 1 focuses specifically on stress and coping while Module 2 focuses on self-regulation of behavior and Module 3 focuses on health services and adherence. The intervention is skills-based and incorporates cognitive-behavioral techniques such as trigger identification, problem solving and goal setting so that participants are able to use these strategies in their daily lives to have the tools necessary to overcome challenges in their daily lives (See Table 9 for specific content for each session) (The Healthy Living Project Team, 2004).

Table 9: Healthy Living Project Intervention Overview

<i>Module 1: Stress, Coping, and Adjustment</i>	
Session	Content
1. Orientation and overview	Preview intervention and identify personal strengths and challenges; setting attainable goal
2. Stress and Coping I	Identify personal stressors; changeable vs. unchangeable stressors; problem-solving skills

Module 1: Stress, Coping, and Adjustment	
Session	Content
3. Stress and Coping II	Problem-focused vs. emotion-focused coping; matching coping to stressing type
4. Social Support	Three types of social support (emotional, informational, and tangible); identify ways to increase positive support
5. Adaptive Coping	Develop plan to continue decreasing stress by increasing adaptive coping strategies
Module 2: Safer Behaviors	
Session	Content
1. Knowledge	Risk continuum; identify personal risk limits and problem solve triggers to risky behavior
2. Safer Behavior	Proper condom use; knowledge of STIs
3. Assertive Communication/negotiation skills	Components of assertive communication; role plays to increase communication/negotiation skills
4. Disclosure decisions	Identify person and environmental factors related to disclosure decisions
5. Keeping Safe	Maintaining/increasing safer behaviors, assertive communication/negotiation skills, and disclosure self-efficacy
Module 3: Health Behaviors	
Session	Content
1. Current health behaviors	Identify factors that influence medical regimen adherence
2. Maintenance	Assertive communication with health care providers and others who influence adherence
3. Social Support and adherence	Problem-solve challenges to self-efficacy and to obtaining social support for adherence
4. Staying on Track	Develop plan for maintaining adherence
5. Future Choices	Identify successes and problem-solve challenges to maintain behavioral and attitudinal changes

Source : (Johnson, Charlebois, Morin, Remien, & Chesney, 2007)

Theoretical Framework for the Healthy Living Project

The Healthy Living Project was guided by Social Action Theory (SAT), developed by Craig Ewart in the early 1990s and updated in 2009 (Ewart, 1991, 2009). The theory purports that “health-related behavior is bound to the social environment in which we live. In order to change behavior one must *appraise* a behavior to require changing, must develop *self-regulatory processes* (such as coping, social support, and stress management) that facilitate changing that behavior, and

may need to address *environmental influences* that promote the risk behavior. One must also work to maintain behavior change by reinforcing relevant skills and generalizing new skills to different situations” (Rotheram-Borus, Swendeman et al., 2004). Initially SAT was applied to such health issues as heart disease, cancer, and healthy eating. The theory was influenced by Bandura’s social cognitive theory and social learning theory principles and modes of self-regulation (Ewart, 1991).

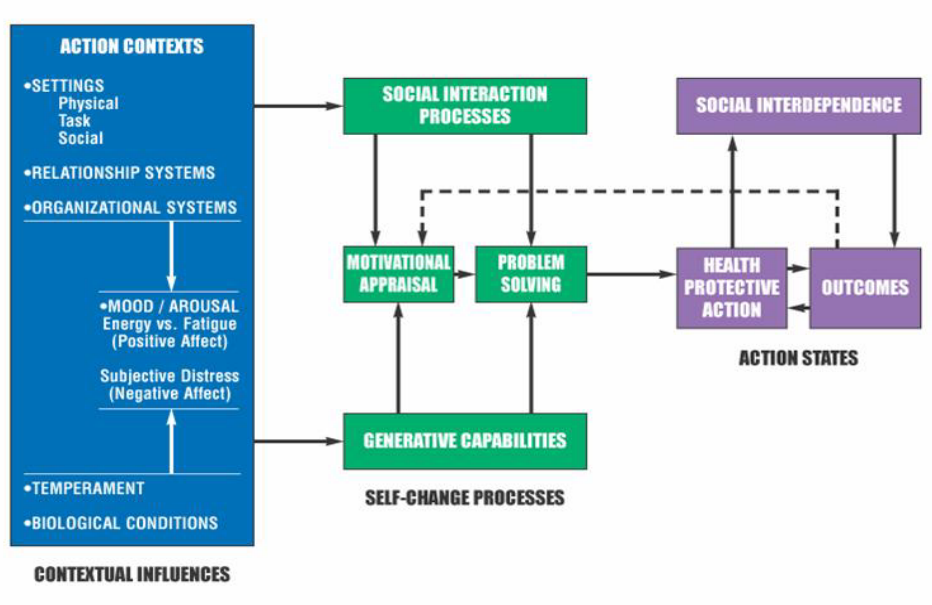
The conceptual model for this theory highlights the three interrelated domains of the theory: Contextual Influences, Self-Change Processes, and Action States (See Figure 4). Contextual influences include action contexts, or habitual behavior contexts, which encompass the settings where these behaviors take place, the relationships and organizations that influence these behaviors and the individuals’ temperament and biological makeup. These action contexts explain how the environment affects self-change processes (behavior change) in that the environment can serve to either prevent or maintain a particular behavior. The setting includes physical features of the environment, tasks such as routinely practiced behaviors, and social networks. The relationship systems involve a spectrum of benefits and expectations and obligations that influence behavior change goals and strategies. Organizational systems include government, economic, and health systems that work to shape an individuals’ behavior change goals, expectations, and strategies. Both the social and biological factors influence the positive (mood/arousal) and negative affect (subjective distress) of the individual (Ewart, 1991).

The self-change processes are the processes involved in developing new behaviors or adapting behaviors that are not effective. The self-change processes include social interaction processes, generative capabilities and motivational appraisal and problem solving. Social interaction processes involve the interpersonal abilities of the individual and those individuals within their social network. Generative capabilities allow the individual to evaluate and translate knowledge into behavior change strategies and alternative goals. Both the social interaction processes and the

generative capabilities work together to influence motivational appraisal and problem solving. Motivational appraisal is the process of imagining the potential outcomes, evaluating specific capabilities, and developing goals that guide the problem solving process. Problem solving relates to the ability to identify potential obstacles to behavior change and develop appropriate strategies to overcome them (Ewart, 1991).

Finally, action states are the relationship between health-endangering behaviors and their experienced effects. Social interdependence, health protective action and outcomes encompass the action states. Social interdependence encompasses the social relationships that facilitate or impede a social network contacts ability to achieve goals or change their behavior. Health protective actions are those behaviors that aim to protect an individual from harmful health outcomes and the extent to which they are integrated into the individuals' life. These actions then serve to influence their social relationships. Outcomes are the result of those health protective actions and the social relationships. The outcomes also in turn influence the motivational appraisal for future behavior change (Ewart, 1991).

Figure 4: Social Action Theory Conceptual Model



Source: (Ewart, 1991)

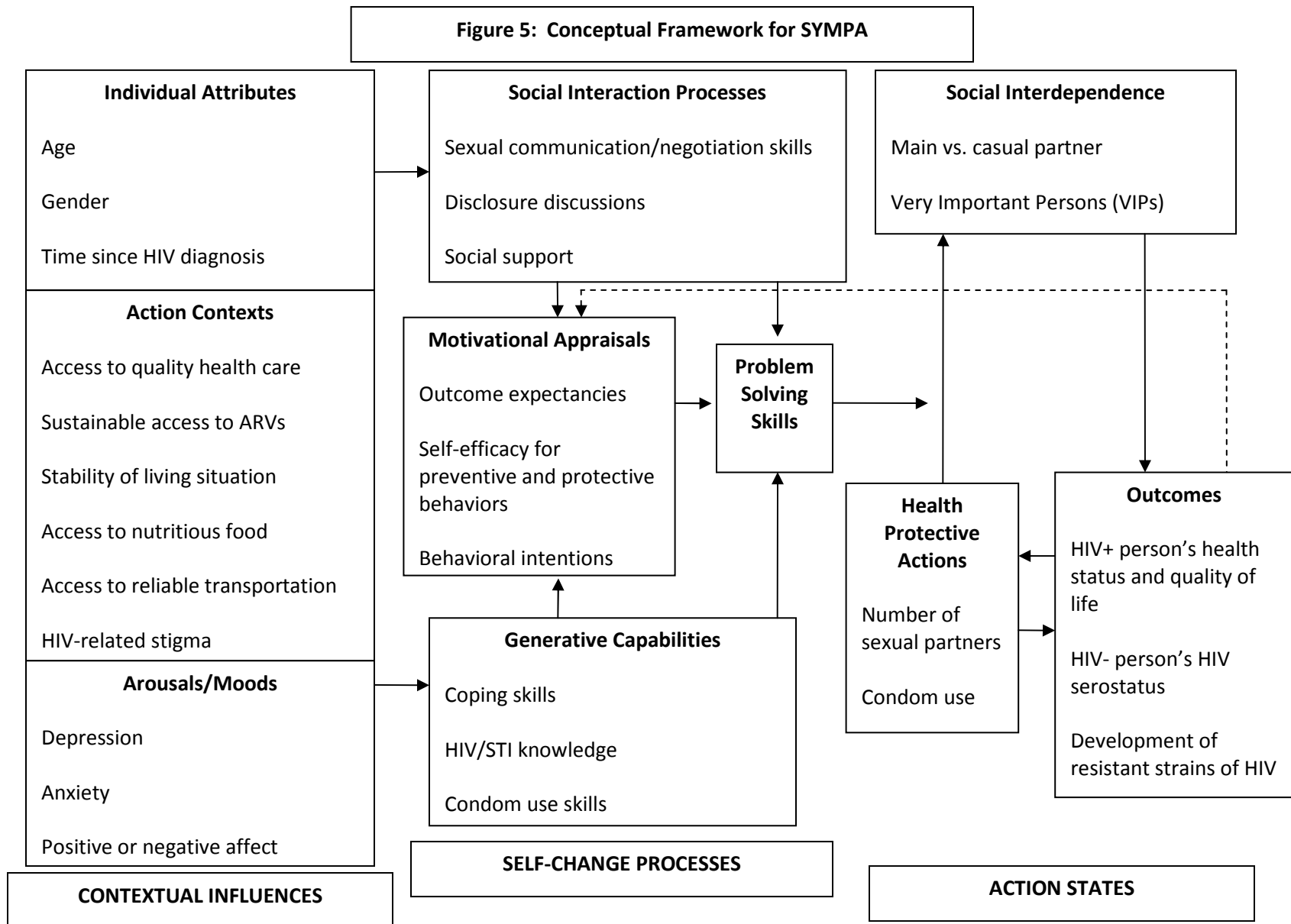
In 2009, Ewart expanded the Theory of Social Action to incorporate “an ecology of health-protective action” within the contextual influences domain. He describes three interrelated phases making up the theory. During Phase I an individual must select habitual behaviors to be increased or decreased and specify how these can be incorporated into their daily routines. The individual must then examine how these behaviors are embedded within their social interactions and physical settings in order to guide environmental change to support positive health behaviors. During Phase II the individual engages in self-regulatory processes that are utilized to establish new positive health behaviors. These processes include proactive awareness and social engagement and aid in acquiring and sustaining the positive health behaviors. Finally, in Phase III the individual identifies regulatory resources needed to support the self-change processes. This contextual analysis of regulatory resources includes social-emotional competence, objective assets, and social power. Social-emotional competence includes a mastery of values, having an accurate knowledge of oneself and one’s word, and the capacity to act upon that knowledge. Objective assets include access to

goods, information, and services. Finally, social power involves the influential relationships and the ability to affect other people. Both social-emotional competence and social power are new additions to the theory (Ewart, 2009).

Social Action Theory in Adapted Intervention

When Social Action Theory, which guided the development of the SYMPA intervention, is applied to the health protective action of safer sexual behavior for YLWH, as in the adapted SYMPA intervention, one can see that these behaviors are the result of an interaction between three major domains: a) **contextual influences** including *individual attributes* such as age, gender and time since HIV diagnosis, *action contexts* such as access to quality health care, sustainable access to ARVs, stability of living situation, access to nutritious food, HIV-related stigma, and access to reliable transportation and *arousal/moods* such as anxiety, depression, and positive or negative affect; b) **self-change processes** including *social interaction processes* such as sexual communication/negotiation skills, disclosure discussions, and social support, *motivational appraisals* including outcome expectancies, self-efficacy for preventive and protective behaviors, and behavioral intentions and *generative capabilities* such as coping skills, HIV/STI knowledge and condom use skills. Social interaction processes, motivational appraisals, and generative capabilities all lead to improved problem solving skills; and c) **action states** including *health protective actions* such as number of sexual partners and condom use and *outcomes* including HIV+ persons' health status and quality of life and HIV- persons' HIV serostatus and the development of resistant strains of HIV. The health protective actions influence *social interdependence* including type of sexual partner and VIPs while social interdependence influences outcomes. Both the health protective actions and outcomes influence each other simultaneously. Finally there is a feedback loop between the outcomes and the motivational appraisals (See Figure 5).

Figure 5: Conceptual Framework for SYMPA



Source: Adapted from (Ewart, 1991; Lightfoot, Rotheram-Borus, & Tevendale, 2007)

Specific Aim 2: Theoretical Framework for In-Depth Interviews

The Theory of Social Action was used in the development of the in-depth interview question guides administered to providers working with YLWH (Ewart, 1991). Questions focused on examining providers' understanding of the environmental context in which YLWH have unsafe sex and the extent to which providers believe these different contexts influence YLWH sexual behaviors. For example, the guide included questions related to different psychosocial factors and asked how providers felt these may or may not influence high risk sexual behavior among YLWH. These psychosocial factors included depression, stigma, mental health, and coping abilities. The question guide also focused on providers' perceptions of the role of friends, family, and the community play in providing support to YLWH and the extent to which providers believe this support may influence high risk sexual behaviors among the YLWH. By asking providers about recent Positive Prevention discussions with YLWH, the providers' perceptions of the youths' self-change processes including their social interactions, motivations to change, problem solving abilities, and generative capabilities in relation to their sexual behavior could be illuminated. Finally, questions pertaining to why providers believe YLWH engage in risky sexual behaviors aimed to explore providers' views on the potential feedback loop between YLWH sexual behaviors, subsequent outcomes, and social interdependence.

CHAPTER 4: MANUSCRIPT 1: ADAPTATION OF A U.S. EVIDENCE-BASED POSITIVE PREVENTION INTERVENTION FOR YOUTH LIVING WITH HIV/AIDS IN KINSHASA, DEMOCRATIC REPUBLIC OF THE CONGO

INTRODUCTION

Effective HIV prevention programs for people living with HIV/AIDS (also called “Positive Health, Dignity, and Prevention” or “Positive Prevention”) are important to reduce new infections and to ensure people living with HIV/AIDS (PLWH) remain healthy (Global Network of People Living with HIV & UNAIDS, 2009; S. Kalichman, 2005). In the context of Positive Prevention interventions, such as the “Seek, Test, Treat, and Retain” approach, behavioral measures to prevent the sexual transmission of the virus play an important role in combination prevention strategies (Dodd et al., 2010; Montague et al., 2011). Furthermore, recent findings that early initiation of antiretroviral (ARV) treatment by PLWH can prevent the spread of HIV to their sexual partners are promising (Cohen et al., 2011), but will only be effective if the PLWH are adherent to their medications and if their viral loads remain undetectable. Positive Prevention behavioral interventions can reach PLWH before they are eligible for treatment, and can also help keep individuals engaged once they are receiving treatment (Walensky, 2009).

Youth and HIV in the DRC

Worldwide, nearly five million youth ages 15-24 currently live with HIV, and each year close to 900,000 new HIV infections occur among youth (UNAIDS, 2010). About 80% of YLWH or four million live in sub-Saharan Africa (UNAIDS, 2010). In the Democratic Republic of the Congo (DRC) over 60% of the population is under twenty years of age and the prevalence of HIV among youth

aged 15-24 is 0.8% overall and 1.4% in Kinshasa, the capital (Ministry of Planning Democratic Republic of the Congo, 2007). The proportion of PLWH between the ages of 15-24 in the DRC has risen from 13% in 1990 to 19% in 2005 (Programme National Multisectoriel de Lutte contre le VIH/SIDA, 2008). Some have speculated that this could be due to youth initiating sex earlier than in the past (Kayembe et al., 2007).

Youth Sexual Behavior in the DRC

Preliminary formative research conducted in Kinshasa, Democratic Republic of the Congo with close to 200 Youth Living with HIV/AIDS (YLWH) ages 14-24, clients of four HIV treatment, testing, or counseling centers was conducted in 2008 (Behets & Pettifor, 2006). This research found that over half of the young women and a quarter of the young men had already had sexual intercourse, with only 53% of young women and 67% of young men reporting using a condom at their most recent sexual act (Pettifor et al., 2008). In addition, just over a third of the young women and only a quarter of young men reported having disclosed their HIV status to their most recent sexual partner. Therefore this population is at risk of transmitting the virus to their partners through unprotected sex and indicates the importance of Positive Prevention programs for YLWH in this environment (Morin et al., 2007).

Positive Prevention for YLWH

Since 2003, there have been an increasing number of research studies focusing on Positive Prevention interventions with PLWH living in the U.S., including a few studies on interventions targeting youth living with HIV/AIDS (YLWH) (Crepaz et al., 2006). Positive Prevention may be particularly suited for YLWH, as these interventions can reach an HIV-infected population before commencement of sexual activity for youth perinatally infected or during the early stages of their

infection for those youth who acquired HIV sexually. However, Positive Prevention is a relatively new area in sub-Saharan Africa where many of those infected have only recently accessed care and treatment (Bunnell, Mermin et al., 2006). The numbers of YLWH in sub-Saharan Africa is slowly rising as they gain access to antiretrovirals and live longer. Treatment facilities provide an important venue where YLWH receive ARVs, underscoring the opportunity for clinic-based Positive Prevention programs targeting youth to reach this underserved population.

Adaptation of Positive Prevention Interventions in Sub-Saharan Africa

Most Positive Prevention Evidence-Based Interventions (EBI) have been designed in the United States for American populations and therefore it is crucial that they be adapted systematically and appropriately prior to implementation in other settings. Adaptation is important because of the necessity of ensuring that the intervention is appropriate and relevant for the target population as well as the needs and capacity of the implementing organization (McKleroy et al., 2006). A few positive prevention EBIs have recently been adapted for implementation in sub-Saharan Africa, predominantly targeted to adults living with HIV/AIDS and primarily adapted for the South African context. Healthy Relationships and WILLOW, all group-based interventions for adults living with HIV/AIDS, have been adapted in South Africa (Cloete et al., 2009; Saleh-Onoya et al., 2009). Preliminary results from the pilot adaptation of Healthy Relationships showed that participants in the intervention were more confident in using a condom yet over one third reported not using a condom at last sex (Cloete et al., 2009). While the WILLOW intervention reported decreased incidence of STIs for the intervention group there were no differences found between the two groups on coping skills or condom use skills (Saleh-Onoya et al., 2009).

Provider-delivered interventions such as Partnership for Health and Options have been adapted for implementation in clinics in sub-Saharan Africa (CDC et al., 2008; Dewing et al., 2010a;

Evangelini et al., 2009; Peltzer et al., 2010). Partnership for Health is a brief, provider-delivered, counseling program for PLWH that focuses on improving patient-provider communication about safer sex, disclosure of serostatus, and HIV prevention (Richardson et al., 2004). A multi-site evaluation is currently being conducted in Kenya, Namibia, and Tanzania but no papers have been published to date (Bachanas, 2011; CDC et al., 2008). Options is an intervention based on motivational interviewing techniques whereby providers evaluate the risk behaviors of their HIV positive patients and assess the patient's readiness to change risky behaviors if necessary and support them through this process (J. D. Fisher et al., 2006). Options has been adapted and implemented in multiple sites across South Africa with mixed results. All of the adapted interventions used counsellors instead of providers to deliver the intervention. One study of 152 HIV positive patients over the age of 18, reported a decreased number of unprotected sex acts for participants in the intervention arm as compared to the control arm (Cornman et al., 2008). This same adaptation was implemented at 13 public HIV counseling and testing sites in Mpumalanga, South Africa (n=488), and was found to significantly reduce multiple partners, unprotected sex, alcohol or drug use in a sexual context and transactional sex, even though the average number of sessions attended by each patient was only 2.3 out of three sessions (Peltzer et al., 2010).

Another adaptation implemented by a Non-Governmental Organization (NGO) serving peri-urban communities in the Western Cape Province of South Africa, evaluated the effectiveness of the training of lay counselors (n=14) in the motivational interviewing techniques used in the Options intervention and found that only 3 of the 14 counselors achieved beginning proficiency in Motivational Interviewing techniques (Evangelini et al., 2009). Likewise, a case study of one lay counsellor implementing an Options adaptation in an ARV clinic in Cape Town, South Africa, reported that the intervention was not delivered with fidelity and less than one-third of intended recipients received the intervention (Dewing et al., 2010a).

Only one CDC EBI, Together Learning Choices (TLC), an intervention for YLWH that focuses on enhancing health behaviors, increasing condom use, eliminating or reducing unprotected sex, and eliminating or reducing drug and alcohol use, has been adapted for YLWH in Uganda (Lightfoot, Kasirye et al., 2007; Rotheram-Borus et al., 2001). Those YLWH who participated in the 18-session intervention (n=50) reported more consistent condom use and reduced numbers of sexual partners than compared to the control group (n=50) (Lightfoot, Kasirye et al., 2007).

In sum, while promising, these adaptations have reported challenges related to recruitment and retention, counsellor mastery of skills, ability to connect outcomes to the intervention, and in achieving targeted behavioural changes. The challenges these studies have reported have provided lessons learned that were applied during the study described in this paper. Likewise, the majority of adapted interventions have been implemented in South Africa with adult populations and therefore there is a need to adapt EBIs for contexts in sub-Saharan Africa outside of this region and with YLWH. The one intervention adapted for YLWH was delivered individually during home visits by nurses; therefore, there is a need to determine the effectiveness of interventions delivered through different delivery modes that are less resource-intensive, such as in group settings or during routine clinic visits. The adaption process described in this paper includes the decision to pilot an intervention targeting YLWH in the context of a country outside of South Africa using delivery methods more appropriate for a low-resource context.

While there are some examples in the literature that detail the intervention adaptation process, very few have been conducted in low-resource contexts (Poulsen et al., 2010; Saleh-Onoya et al., 2008; Wainberg et al., 2007) and only one in sub-Saharan Africa (Saleh-Onoya et al., 2008). This paper attempts to fill this gap in the research by describing the systematic adaption of a U.S. EBI using the Map of Adaption Process: A Systematic Approach for Adapting Evidence-Based Behavioral

Interventions Guidelines, or ADAPT, developed by the CDC for adapting evidence-based HIV behavioral programs for new settings and target populations (McKleroy et al., 2006). This paper will describe in detail results from each of the steps of the ADAPT guidance so that other researchers and practitioners can learn about the specific steps necessary to conduct a systematic adaptation of an EBI. These important steps are often omitted from the peer-reviewed literature because of space limitations or due to a preference for reporting results rather than processes.

METHODS

Study Overview

The study presented here was part of a larger project with aims to adapt, implement and conduct a feasibility study of an evidence-based, clinic-based Positive Prevention Intervention with YLWH ages 15-24 in Kinshasa, DRC to develop a Positive Prevention program that addresses the youths' developmental needs and helps them cope with HIV in the context of their emerging independence and sexuality. The central purpose of the larger study was to determine whether the incorporation of evidence-based Positive Prevention into the standard of care is feasible for both the target population of YLWH and the implementing organization. This paper will describe the systematic adaptation process used as well as the lessons learned from the adaption process.

Study Site

A family-centered HIV care and treatment program at a pediatric hospital in Kinshasa was the site of this study. The program provides comprehensive HIV medical (including ARV treatment) and psychosocial support to children and their parents and guardians, as well as other household

members. As of April 2012, the program had served more than 2,146 HIV-positive patients and followed 191 YLWH aged 15-24.

Theoretical Framework for Adaptation

The ADAPT guidelines are largely based on Rogers' Diffusion of Innovations Theory and also include principles of community health education, social work, participatory research, and community empowerment (McKleroy et al., 2006; Rogers, 1995). The CDC ADAPT guidance defines adaptation as, "The process of modifying *key characteristics* of an intervention, recommended activities and delivery methods, without competing with or contradicting the *core elements*, theory, and *internal logic* of the intervention thought most likely to produce the interventions' main effects" (McKleroy et al., 2006). Core elements are those "most likely to lead to the intervention's main effects" while key characteristics are "important but not essential attributes of an intervention's recommended activities and delivery methods" (McKleroy et al., 2006). The internal logic is the explanation of "relationships among activities, behavioral determinants, and the intended outcome(s)" (McKleroy et al., 2006). The guidelines include five key steps: 1) Assess 2) Select 3) Prepare 4) Pilot and 5) Implement.

We followed the first four steps of the ADAPT framework for this study. The steps were followed as closely as possible given the resource constraints, organizational capacity and time-constraints. The first step, *assess*, includes evaluating the target population, the potential EBIs, and the implementing organizations' capacity. The second step, *select*, involves the decisions related to whether the EBI will be adapted or implemented as is, or a different intervention all together will be selected. The third step, *prepare*, includes adapting intervention materials and curriculum as well as pre-testing these materials and increasing agency capacity as well as necessary partnerships. The fourth step, *pilot*, involves pilot testing the components of the adapted intervention and developing

an intervention plan. The fifth step, *implement*, involves implementing the entire adapted intervention. Finally, it is important to note that the guidance includes feedback loops among the different steps and many of the steps can be conducted simultaneously rather than sequentially (McKleroy et al., 2006). The results section that follows will describe the results of each of the steps of the adaptation process.

RESULTS

Action Step 1: Assess

Target Population

The target population was determined to be YLWH between the ages of 15-24 seeking care at KLL in Kinshasa, DRC. Prior to the adaptation process, preliminary formative research was conducted to explore sexual behaviors, knowledge of HIV prevention, health seeking behaviors, psychosocial wellbeing, alcohol and drug use, and attitudes, perceptions and norms around sexuality (including marriage and child-bearing) and HIV prevention amongst HIV positive youth (Behets & Pettifor, 2006). Information from this study was analyzed in combination with results from an in-depth literature review in order to determine the risk behaviors and their determinants for this specific population. In addition, the study team reviewed relevant theories and their common theoretical constructs and evaluated these constructs based on their relevance and changeability using Intervention Mapping as a guide (Bartholomew, Parcel, & Kok, 1998; Noar, 2007). Likewise, the study team assessed empirical data from previous research with YLWH in both the U.S. and in sub-Saharan Africa. After this extensive process the research team decided that the intervention would focus on the following six determinants of HIV-positive sexual risk behavior: Lack of HIV/STI

Knowledge; Low Condom Use Skills; Weak Coping Mechanisms; Limited Ability in Sexual Communication/Negotiation; Lack of Disclosure; and Low Levels of Social Support. It was determined that the best location for any intervention with this target population would be the KLL clinic as this was a central location where all YLWH were comfortable visiting and was easily accessible for most youth and that the intervention would take place on the weekend so that it would not interfere with youths schooling.

Interventions

Next, potential EBIs were identified that could be adapted for this population. Four EBIs for Positive Prevention were selected to be considered for adaptation: Healthy Relationships, CLEAR, TLC, and The Healthy Living Project (S. Kalichman et al., 2001; Rotheram-Borus, Kelly et al., 2004; Rotheram-Borus et al., 2001; The Healthy Living Project Team, 2007b). These four interventions were chosen based on the extent to which they incorporated the risk behaviors and their determinants identified during the assessment of the target population. Likewise, interventions focusing only on women or only gay/bisexual men were not selected and interventions using only peer counselors or health care providers during routine office visits were not selected. Each of the four EBIs identified were compared based on their core elements, key characteristics, delivery methods, and theoretical bases. This information was obtained from peer-reviewed journal articles as well as implementation manuals publically available and through contact with the research authors (AED, 2011; CDC, 2012a, 2012c; Rotheram-Borus, 1999, 2001; The Healthy Living Project Team, 2004).

When examining the selected EBIs we noted that they shared many of the same core elements and key characteristics as identified during the CDC best-evidence intervention selection. Delivery methods for the four EBIs were also similar with all four using exercises, goal setting, and

role plays. All four EBIs incorporated elements of the Social Cognitive Theory (Bandura, 1989), while TLC and the HLP were also based on Social Action Theory (SAT) (Ewart, 1991). Finally, we considered the resources and costs necessary for implementing each program although only the 23 session group intervention TLC had published cost-effectiveness data available. The cost of implementing TLC in four urban areas of the U.S. was \$522 per YLWH and the authors estimated that over three months, intervention participation could prevent two new infections per 1,000 YLWH (Lee, Leibowitz, & Rotheram-Borus, 2005).

Goodness of Fit

The risk behaviors and behavioral determinants addressed in each of the EBIs were examined to determine the extent to which they matched the determinants selected for our target population. Interestingly, Healthy Relationships, TLC, CLEAR, and the HLP addressed almost all of the same risk behaviors and behavioral determinants. All of the interventions included exercises on assertive communication about sex and condom use as well as activities teaching problem solving skills and helping youth to identify triggers to unsafe sexual behavior which are especially important for young women in the context of high levels of sexual violence. Likewise, CLEAR, TLC, and the HLP all included goal setting, problem-solving, and improved communication/assertiveness as core elements while both Healthy Relationships and the HLP included coping skills and disclosure. In addition, these interventions shared many of the same key characteristics. In at least two of the EBIs being assessed the following key characteristics were included: incentives, limited session times, time between sessions, and using experienced facilitators. Delivery methods for the four EBIs were also similar with all four using exercises, goal setting, and role plays. Healthy Relationships and CLEAR used lectures while CLEAR and TLC used skill practice and CLEAR and the HLP used problem-solving. Both Healthy Relationships and TLC used video as well as written materials. Finally, TLC and

Healthy Relationships were group-delivered CLEAR and the HLP was delivered one on one (See Table 10).

Table 10: Assessment of EBIs Considered for Adaptation for YLWH in Kinshasa, DRC

	Healthy Relationships	Choosing Life: Empowerment, Actions, Results (CLEAR)	Together Learning Choices (TLC)	The Healthy Living Project (HLP)*
Core Elements	<p>Defining stress and reinforcing coping skills - disclosing to family and friends, disclosing to sexual partners, and building healthier and safer relationships.</p> <p>Using modeling, role-play, and feedback to teach and practice skills related to coping with stress.</p> <p>Teaching decision-making skills about disclosure of HIV status.</p> <p>Providing personal feedback reports to motivate change of risky behaviors and continuance of protective behaviors.</p> <p>Using movie clips to set up scenarios about disclosure and risk reduction to stimulate discussions and role-plays.</p>	<p>Development of emotional awareness through use of a Feeling Thermometer and identification of the link among feelings, thoughts, and actions.</p> <p>Identification of Ideal Self to help motivate and personalize behavior change.</p> <p>Teaching, modeling, and practicing Short-and Long-Term Goal Setting</p> <p>Teaching, modeling, and practicing SMART Problem-Solving</p> <p>Teaching, modeling, and practicing Assertive Behavior and Communication</p>	<p>Help clients develop awareness and identify feelings, thoughts and actions.</p> <p>Teach, model, and practice emotional regulation, SMART problem solving, goal setting, and assertiveness.</p> <p>Reinforce positive client behavior through the use of thanks tokens.</p> <p>Help clients identify their Ideal Self to help motivate and personalize behavior change.</p> <p>Deliver sessions in highly participatory, interactive small groups.</p>	<p>Core repertoire of cognitive-behavioral techniques covered in each session, including trigger identification, problem solving, and goal setting.</p> <p>Content of each session will need to be tailored to the life-context of individual participants.</p> <p>Focus on addressing quality of life, psychologic coping, achieving positive affect and supportive social relationships.</p> <p>Focus on addressing self-regulatory issues, such as avoiding sexual and drug-related risk of HIV transmission or acquisition of additional sexually transmitted diseases, and disclosure of HIV status to potential partners.</p> <p>Focus on addressing accessing health services, medication adherence, and active participation in medical care decision making.</p>

	Healthy Relationships	Choosing Life: Empowerment, Actions, Results (CLEAR)	Together Learning Choices (TLC)	The Healthy Living Project (HLP)*
Key Characteristics	<p>Have clients meet in small groups (5 to 12 people). New members cannot join once the series of sessions has begun.</p> <p>Have clients sit face to face in a circle.</p> <p>Have clients meet for at least 5 sessions, 2 hours each.</p> <p>Ensure that groups contain members of the same gender and sexual orientation.</p> <p>Have 2 facilitators per group.</p> <p>Ensure that facilitators are of both genders, experienced counselors, HIV infected if possible, and same ethnicity of clients.</p>	<p>Use incentives to encourage clients to return to sessions.</p> <p>Complete each session in 60 to 75 minutes.</p> <p>Conduct sessions once per week to allow clients time to practice new skills before next session.</p> <p>Use experienced counselors or mental health professionals who have received formal clinical training.</p> <p>Deliver the intervention with a client-centered approach.</p> <p>Hold sessions in room that ensures privacy and confidentiality and is free from interruptions.</p>	<p>Encourage clients to attend all sessions, but give them flexibility to drop in for particular sessions on their own schedule.</p> <p>Consider use of incentives and providing food/snacks.</p> <p>Conduct sessions about once a week, limit session times, and modify time intervals.</p> <p>Let group needs determine facilitators.</p> <p>Be flexible about group composition, start with small groups, and build group cohesion.</p> <p>Use visual aids.</p> <p>Consider your location.</p>	<p>Sessions occur about every week.</p> <p>Each module separated from the next by three months to allow participants time to incorporate the information from the program into their lives and to evaluate impact of each module on their wellbeing.</p> <p>Facilitator as coach who helps the participants achieve goals and make changes in their lives.</p> <p>Participants received incentives for each module.</p> <p>Fifteen 90-minute individual counseling sessions.</p> <p>Core activities to be delivered as active part of program, open to be tailored to each participant, and beginning and end of each session to be adapted to each participant.</p>
Delivery Methods	<p>Exercises</p> <p>Goal setting</p> <p>Group discussions</p> <p>Lectures</p>	<p>Exercise/Games</p> <p>Goal setting</p> <p>Demonstration</p> <p>Lectures</p>	<p>Exercises</p> <p>Goal Setting</p> <p>Group Discussion</p> <p>Practice</p>	<p>Exercises</p> <p>Coping strategies</p> <p>Goal Setting</p> <p>Demonstration</p>

	Healthy Relationships	Choosing Life: Empowerment, Actions, Results (CLEAR)	Together Learning Choices (TLC)	The Healthy Living Project (HLP)*
	Role plays Printed materials Video Coping Strategies	Role plays Practice	Role plays Video Problem-solving	Problem-solving Role plays
Theoretical Basis	Social Cognitive Theory	Cognitive Behavior Therapy Social Action Theory	Social Action Theory Social Cognitive Theory	Social Action Theory Social Cognitive Theory
Goodness of Fit	Pronounced focus on self-efficacy for disclosure – not determined to be a major determinant identified in target population. Least comprehensive. Did not include option for participants who were abstinent or those who had never had sex. Thus not appropriate for youth population.	Substance abuse highly integrated within entire intervention. Not deemed a good fit with target population needs.	Combined multiple determinants and behaviors in same module. Determined to be too complex for target population.	Used less sexually explicit language than CLEAR or TLC. Specific case studies provided for participants not sexually active. Most comprehensive and flow and progression of session and activities best organized. Sessions user-friendly and more easily adaptable thus deemed appropriate for adaptation.

*Core elements and Key Characteristics for the HLP have not yet been established as the intervention is not part of the CDC Diffusion of Effective Behavioral Intervention project. Therefore information was adapted from the HLP Intervention manual and published articles. Interestingly, the primary investigators for the HLP have published extensively on the need for “common factors” and “common processes” and “common principles” rather than core elements and key characteristics (Johnson et al., 2007; Rotheram-Borus, Swendeman, & Chovnick, 2009). Source: Adapted from CDC Best-Evidence website <http://www.cdc.gov/hiv/topics/research/prs/best-evidence-intervention.htm> (CDC, 2012a), Diffusion of Effective Behavioral Intervention website <http://www.effectiveinterventions.org/en/home.aspx> (AED, 2011), and Intervention Manuals (CDC, 2012b; Rotheram-Borus, 1999, 2001; The Healthy Living Project Team, 2004).

Preliminary areas where EBIs need Adaptation

Though it would be ideal to implement an intervention covering all of the relevant risk behaviors included in the EBIs the study team felt that this would not be feasible in a resource-deprived setting such as the DRC. Therefore regardless of which EBI was selected it would need to be significantly pared down to focus on risk behaviors that were most relevant for YLWH in Kinshasa. Likewise, we decided that the extensive use of video in the adapted intervention would be difficult because culturally relevant and language specific videos were not widely available.

Organizational Capacity: Resources and Experience

Next, an analysis of the capacity of KLL to implement the pilot intervention was conducted. First, after an extensive review of the intervention materials for each of the EBIs, the resources necessary to implement each of the EBIs were assessed including program staff supplies, space, and funding for participant incentives. Second, we evaluated the extent to which the organization had access to the target population of YLWH and the program fit with the clinic's mission. Through informal discussions with program staff and administrators we identified the gaps in experience of the organization and program staff regarding the target population, implementation, monitoring, analysis, fiscal accountability, and specific intervention skills necessary for adaptation and implementation of this intervention at KLL. KLL program staff had extensive experience conducting both qualitative and quantitative research as well as providing HIV treatment services to YLWH. Therefore they had adequate experience working directly with the target population and the facilitators had been working at the clinic on average for three and a half years.

Gaps were identified in the areas of advanced facilitation and counseling skills for peer groups, implementation of EBIs, and data analysis. In many of the EBIs considered the sessions were facilitated by individuals who held degrees, in psychology or social work. In this setting requiring

these qualifications would have made the routine implementation of the intervention impossible if found to be effective. In addition, most providers at KLL lacked extensive experience or training in Positive Prevention. Finally, none of the program staff had implemented a multiple session prevention intervention or analyzed intervention data. Therefore, these areas were necessary to strengthen before implementation.

Stakeholders

As the final part of step 1, *assess*, existing and potential stakeholders and areas of capacity building were identified. Research staff at the UNC/DRC office as well as administrative providers at KLL, were consulted and their input incorporated into the intervention planning. One community-based HIV/AIDS care and treatment center serving YLWH, AMO-Congo, and two HIV support centers, Fondation Femme Plus, and EVREJ-CONGO participated in the preliminary formative research. As a result, relationships between KLL and these organizations were adequate. Finally, the research team attempted to locate competing programs in order to prevent any overlap but none were identified.

Action Step 2: Select

Decide to Adopt, Adapt, or Select another Intervention

After the extensive analyses in step 1, *assess*, the Healthy Living Project appeared to address the expressed needs of YLWH in Kinshasa and their caregivers, and was suitable to adaptation for a youth population in a low-resource setting. Therefore we selected the HLP to adapt during the pilot study (The Healthy Living Project Team, 2007a).

The Healthy Living Project

The HLP is an individual Positive Prevention intervention targeting adults living with HIV in the U.S. and was guided by Social Action Theory, developed by Craig Ewart in the early 1990s and updated in 2009 (Ewart, 1991, 2009). The theory purports that “health-related behavior is bound to the social environment in which we live. In order to change behavior one must *appraise* a behavior to require changing must develop *self-regulatory processes* (such as coping, social support, and stress management) that facilitate changing that behavior, and may need to address *environmental influences* that promote the risk behavior. One must also work to maintain behavior change by reinforcing relevant skills and generalizing new skills to different situations” (Rotheram-Borus, Swendeman et al., 2004).

The HLP intervention uses individually tailored sessions to develop a “Life Project” which addresses quality of life, coping, methods to realize a positive healthy action state, and the development of social support relationships (The Healthy Living Project Team, 2007a). Over three modules of five sessions each participants learn skills necessary for the reduction of high risk sexual behavior. Participants are asked to identify their own high risk behavior triggers in order to help them develop mechanisms to modify these high risk behaviors. The program helps increase self-efficacy to use condoms and skills to negotiate condom use. It also teaches participants how to disclose their HIV status to their partners. Finally, access to health services, adherence to ARVs, and increased participation in medical decision making is also covered with the participants.

Action Step 3: Prepare

Make Necessary Changes to EBI

Next, the study team identified areas where the selected EBI needed to be adapted and made the necessary changes to the EBI. *First*, we changed the name of the intervention from the Healthy Living Project to *Supporting Youth and Motivating Positive Action* or SYMPA (meaning “cool” in French) to make it more relevant for the target population. *Second*, the HLP was originally implemented on an individual basis. However, in low-resource Kinshasa, having multiple, individual sessions was not feasible and could potentially limit roll out; therefore, the intervention was adapted to be delivered in a group setting. In this setting YLWH already had the experience of meeting monthly in educational sessions with their peers and the youth themselves expressed in formative research that they wanted to be in groups with peers. Therefore, rather than individuals developing goals and objectives on their own, adaptations were made to activities to incorporate feedback from both facilitators and other members of the group and the development of each group member’s goals became a collaborative effort.

Third, we reduced the number of sessions from 15 to six, a number that could be more realistically implemented within this setting and was able to effectively cover the primary determinants identified for the target population. This was done through combining similar sessions and eliminating content not directly relevant for the target population. For example, the original module three of the Healthy Living Project focused on accessing health services, adherence, and active participation in medical care decision making. As these sessions did not reflect the identified risk behaviors and their determinants for the target population the first four sessions of this module were not included in the adapted intervention (The Healthy Living Project Team, 2007a). Likewise, stress and coping was originally covered over two sessions but was combined into one session for

the adapted intervention. In addition, the disclosure session was combined with the social support session and the safer behavior session was combined with the assertive communication session. Also, the last session of the original module three was included in the adapted intervention as the final session as there was an important emphasis on maintaining behavioral change after the end of the intervention.

Fourth, as study staff reported that in Congolese society sexuality is not traditionally discussed in mixed gender groups it was decided that the groups would be separated by sex – one for young women and the other for young men so that participants would be comfortable discussing sensitive issues. *Fifth*, the original intervention was targeted to PLWH who also had substance abuse problems. Substance abuse was not determined to be a problem for most YLWH at KLL during the formative research. Therefore, the curriculum was adapted so that references to substance abuse were taken out. *Sixth*, the original intervention was targeted towards an adult population; thus, the adapted intervention incorporated specific role plays better targeted for a youth population and references to adult issues such as work were replaced with school. Likewise, certain activities such as the condom demonstration and the Sexually Transmitted Infection (STI) activities were simplified to aid the youth in understanding the instructions.

Seventh, after extensive discussion, study staff determined that the intervention would target youth thought to have already been sexually active since the original intervention was intended for a sexually active adult population. However, staff was not confident that youth would be open and honest about their previous sexual activity if asked these questions in the context of a screening form and therefore activities were adapted to incorporate the possibility that youth had not yet had sexual intercourse. For example, for YLWH who had not yet had sex, activities allowed the youth to consider issues around sexual risk once they became sexually active. Likewise, abstinence was included as an option for those youth already sexually active. *Eighth*, the entire

curriculum was translated into French and specific activities requiring YLWH to complete forms were translated into the colloquial Lingala most used in Kinshasa. *Ninth*, a large part of module three of the HLP focused on adherence to ARVs while formative work showed that this was already being adequately addressed at KLL through psychosocial counseling. Thus, the components of the original intervention focusing on medication adherence were eliminated.

Tenth, the entirely new Very Important Person (VIP) component was added to the intervention to help provide support to YLWH over the long term in achieving their goals and objectives developed during the intervention. The VIP is an individual the YLWH identifies as a trusted person to whom he/she would be willing to or has already disclosed his/her HIV status and to whom the YLWH would go to for support. YLWH were to identify a VIP who could aid them in maintaining lower risk sexual behavior practices and staying healthy after the program ends. In conjunction with their VIP, youth were to identify resources and skills to support their plan to reduce risk behaviors and improve coping and problem solving skills. Given that many YLWH in our population had only disclosed their HIV status to one person, having someone who knows their status, who is supportive of them in numerous ways, and whom the youth respects, can confide in, trust and rely on may be the key to them obtaining much needed social support and help them to make healthy decisions (Luthar et al., 2006).

The final topics of the adapted six sessions include: 1) Living with HIV 2) Coping and Problem Solving 3) Safer Sex I 4) Safer Sex II 5) Social Support and Disclosure 6) Wellbeing and Health Maintenance. A description of each of these sessions is included in Table 11.

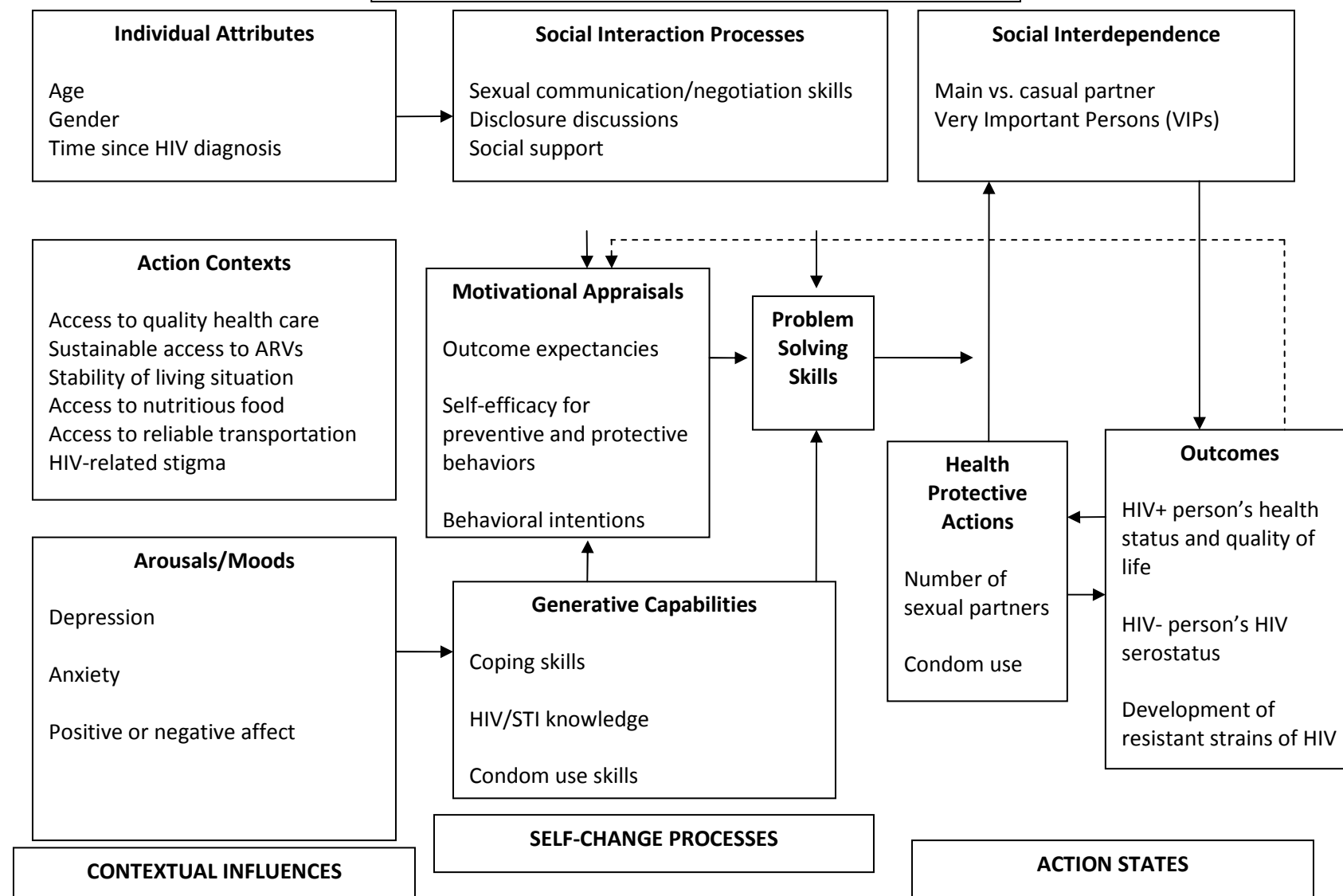
Table 11: SYMPA Intervention Session Content Overview

Session Number	Session Title	Content
Session 1	Living with HIV	Preview intervention and identify personal strengths and challenges; setting attainable goal.

Session Number	Session Title	Content
Session 2	Coping and Problem Solving	Identify personal stressors; changeable vs. unchangeable stressors; problem-solving skills; Problem-focused vs. emotion-focused coping; matching coping to stressing type.
Session 3	Safer Sex I	Risk continuum; identify personal risk limits and problem solve triggers to risky behavior.
Session 4	Safer Sex II	Proper condom use; knowledge of STIs; Components of assertive communication; role plays to increase communication/negotiation skills.
Session 5	Social Support and Disclosure	Three types of social support (emotional, informational, and tangible); identify ways to increase positive support; Identify person and environmental factors related to disclosure decisions. Youth identify Very Important Person (VIP) in their support network who has been supportive and who could assist them after the intervention ends with maintaining healthy behaviors.
Session 6	Wellbeing and Health Maintenance	Identify successes and problem-solve challenges to maintain behavioral and attitudinal changes. Focus on developing a plan to maintain healthy behaviors after the intervention ends and the role of the VIP in supporting the youth in this process.

In conclusion, a conceptual model based on the Social Action Theory was developed and adapted to reflect the specific contextual influences, self-change processes, and action states to incorporate elements specific to the target population (Ewart, 1991; M. Lightfoot, Rotheram-Borus, & Tevendale, 2007). The adapted conceptual model for the SYMPA intervention is included in Figure 6.

Figure 6: Conceptual Framework for SYMPA



Source: Adapted from (Ewart, 1991; Lightfoot, Rotheram-Borus et al., 2007)

Organization Preparation

A Congolese medical doctor working for the UNC/DRC program was chosen to serve as the Kinshasa-based program coordinator for the intervention study under the supervision of the U.S. based study coordinator. Four facilitators were recruited, one male and three female. Three were psychosocial counselors and one was a nurse with training in family planning. All were already working at KLL and had been there for between 7 months to close to 6 years. One male and one female would facilitate the young men's group while the two female staff would facilitate the young women's group. All roles and responsibilities for each member of the study team were clearly laid out in eight Standard Operating Procedure documents.

Pre-test

Next, intervention materials were pre-tested. A half day adaptation workshop was conducted in which members of the study team and key providers and administrators at the KLL HIV care and treatment clinic were invited to review the intervention materials to further tailor the program for usability and cultural relevance. Each session of the program was presented and cognitive interviewing techniques with "think aloud" reactions to each activity were used to assess the program. As part of this adaptation workshop the cultural or social factors that are important to the study population were discussed and participants made suggestions to remove information or activities that they did not feel were relevant.

The VIP component raised important confidentiality concerns among staff and became the primary topic explored during the adaptation workshop. Adaptation workshop participants discussed the role that the VIPs play in the lives of YLWH and the perceived challenges in incorporating VIPs into the SYMPA intervention. Adaptation workshop participants were concerned about confidentiality, recruitment, and the issue of who gets to choose the VIP (i.e. the facilitator or

the youth themselves). We also discussed the type of skills required of VIPs that would be most helpful in this intervention for sustaining the YLWHs' healthy behaviors and mental wellbeing after the end of the program. It was decided that the VIPs would be included in the final session and that confidentiality would be stressed to youth throughout the intervention. Likewise, although the YLWH would have the final say as to who he or she chose to be their VIP the facilitator was encouraged to provide advice and support in the decision making process.

Training

A two-day training on the SYMPA intervention was held with the Kinshasa-based program coordinator and the four facilitators. Before reviewing the curriculum, fundamental aspects of Positive Prevention were covered in order to increase the program staffs' capacity for effective implementation of the intervention. During the training each session was reviewed in detail and each activity practiced as a group so that the facilitators became confident in their knowledge and understanding of intervention content as well as their ability to conduct each activity. Small adjustments were made to specific activities to ease the understanding for the YLWH. Likewise, role plays were further adjusted to ensure cultural relevance and to match the developmental level of youth. This training provided a forum for the facilitators to exchange ideas about Positive Prevention with YLWH and to learn from both each other and the trainer.

Action Step 4: Pilot

Implementation Plan for Adapted EBI

After the pre-test, training, and final adaptations were made to the intervention, a plan was developed for piloting the adapted intervention. This plan included a time line for recruitment,

implementation, data collection, and analysis as well an outline of the key activities to be conducted for each of these phases. Likewise, the final budget for the program was developed and approved. The SOPs were finalized and discussed further with all program staff. Communication protocols were established and final preparations for implementation were conducted. It was determined that the intervention would be piloted with two single sex groups with between 5- 10 participants each. Each session was planned to last approximately 90 minutes and the six sessions would be spread over a period of 6 weeks. Results from the pilot test of SYMPA intervention will be reported in an upcoming manuscript.

LESSONS LEARNED

Throughout the structured adaptation, we faced key challenges and learned important lessons. The *first* challenge was implementing an EBI in a very different setting, both culturally and geographically, with very little existing guidance or literature. This challenge was overcome by closely adhering to the ADAPT process which allowed for changes to intervention elements to address this unique context. From this challenge the study team learned that the quality of work conducted during the first step of the ADAPT framework, *assess*, will determine the success of the future steps. The extensive preliminary studies conducted with YLWH in Kinshasa prior to this adaptation process allowed the researchers to more accurately adapt specific components of the intervention content and logistics related to implementation. Likewise, the exhaustive assessment of the core elements, key characteristics, and delivery methods of the Positive Prevention EBIs allowed the research team to become familiar with Positive Prevention intervention core principles and processes (Rotheram-Borus, Ingram, Swendeman, & Flannery, 2009; Rotheram-Borus, Swendeman et al., 2009). In addition, the extensive review of the selected EBIs' theoretical

foundations, content, sessions, and activities permitted research staff to make the best decision for the targeted population.

The *second* challenge faced was the lack of existing Positive Prevention EBIs that targeted YLWH. However, the study team felt that Positive Prevention interventions that targeted adults living with HIV addressed similar theoretical constructs and behavioral determinants. Therefore an important lesson learned for study staff was that it is not necessary to use an EBI that targeted the exact same population. However, extensive modifications were required as part of the adaptation process to ensure that intervention content was relevant and appropriate for youth ages 15-24.

Third, a related challenge was the paucity of published data on the cost-effectiveness of existing Positive Prevention EBIs. This meant that assessing the goodness of fit of the selected EBIs was difficult especially because in a resource constrained environment such as the DRC considerations of cost are of utmost importance. The study team chose not to rely on the extensive use of technology and the number of sessions was significantly reduced to address any resource constraints. Likewise, the research team remained cognizant that only those adaptations that could be feasibly implemented within the existing health structure and with existing resources could be included. Therefore, the study team learned that an EBI previously implemented successfully in a high resource country can be suitably adapted for low-resource countries.

Fourth, before the research began the study team had limited experience adapting or implementing structured programs or EBIs and this was considered a significant potential challenge in successful implementation. However, the process of adaptation not only aided in adapting the intervention but also served as a type of training in concepts and strategies for implementing HIV prevention research, particularly for the intervention facilitators. Therefore, the study team became aware that the process of adapting the intervention itself has the potential to greatly increase the staff's capacity to effectively implement the intervention.

Fifth, as the study team moved through the steps of the adaptation framework it became evident at certain points in the process that it would be helpful to repeat some components of earlier steps. For example, during this adaptation process the study team felt that it was important that the capacity of the organization was assessed not only during the preliminary step but also during all subsequent steps so that gaps in capacity could be addressed as they arose. This was initially seen as a challenge in the process as this can be a time-intensive process. However, the study team came to understand that adaptation is an iterative process – the feedback loops between steps are crucial to ensure that appropriate decisions are being made and that the eventual adapted intervention will be successful.

Sixth, an important challenge faced by the study team was that none of the existing EBIs incorporated caregivers in the intervention. Preliminary studies showed that YLWH reported feeling isolated in their daily lives and received very little psychosocial support outside of the clinic. Likewise, caregiver support was believed to be an important potential factor for helping YLWH maintain the success of any Positive Prevention intervention. Therefore, the study team felt this aspect would need to be incorporated into the final adapted intervention. The study team learned from this challenge that the adaptation process needed to be flexible enough to allow the addition of new content when necessary to address specific needs not included in the original intervention. Thus, the VIP component was added to the final adapted intervention in order to bolster the existing curriculum and to provide YLWH with new systems of support. The addition of the VIP component also ensured a greater possibility of sustaining any positive behavior changes the YLWH made as a result of the intervention. Finally, by incorporating caregivers into the intervention the reach of the health messages in the adapted intervention grew wider and support of the youth's participation in the intervention increased. Therefore, the study team learned that it is not only appropriate to include additional components to the original intervention but that by doing so the intervention

may be strengthened overall. All of these challenges described led to the development of key lessons learned that other researchers may find useful in their own adaptations of EBIs in different contexts.

DISCUSSION

This study was the first to use the CDC ADAPT framework to adapt a Positive Prevention EBI for implementation with YLWH in sub-Saharan Africa. This paper described the process of following the first four steps in the ADAPT framework: 1) Assess 2) Select 3) Prepare and 4) Pilot. The results from step four, *pilot*, will be used to further adapt the intervention for larger-scale implementation and potentially expanded implementation in other low-resource countries beyond the DRC in order to complete the ADAPT framework with *Action Step 5: Implementation of the Adapted EBI*. This step was beyond the scope of this study. Additional funding must be obtained to implement the adapted EBI using a randomized control study design with enough power to establish whether significant changes in behavior occurred as a result of the intervention. This study has shown that an EBI developed and implemented in the U.S. can be adapted successfully for a different target population and for a low-resource context through an iterative process following the CDC Adapt Framework. This process included carefully reviewing the existing literature, adapting and adding components as necessary, and focusing on increasing staff capacity throughout the adaptation process. This paper provides a rare detailed description of the adaptation process and may aid other organizations that seek to adapt and implement other HIV prevention EBIs in sub-Saharan Africa or beyond.

CHAPTER 5: MANUSCRIPT 2: FEASIBILITY ANALYSIS OF AN EVIDENCE-BASED POSITIVE PREVENTION INTERVENTION FOR YOUTH LIVING WITH HIV/AIDS IN KINSHASA, DEMOCRATIC REPUBLIC OF THE CONGO

INTRODUCTION

Effective HIV prevention programs for people living with HIV/AIDS (also called “Positive Health, Dignity, and Prevention” or “Positive Prevention”) are important to reduce new infections and to ensure people living with HIV/AIDS (PLWH) remain healthy (Global Network of People Living with HIV & UNAIDS, 2009; S. Kalichman, 2005). In the context of Positive Prevention interventions, such as the “Seek, Test, Treat, and Retain” approach, behavioral measures to prevent the sexual transmission of the virus play an important role in combination prevention strategies (Dodd et al., 2010; Montague et al., 2011). Furthermore, recent findings that early initiation of antiretroviral (ARV) treatment by PLWH can prevent the spread of HIV to their sexual partners are promising (Cohen et al., 2011), but will only be effective if the PLWH are adherent to their medications and if their viral loads remain undetectable. Positive Prevention behavioral interventions can reach PLWH before they are eligible for treatment, and can also help keep individuals engaged once they are receiving treatment (Walensky, 2009).

HIV and Youth Sexual Behavior in the Democratic Republic of the Congo

In the Democratic Republic of the Congo (DRC), over 60% of the population is under twenty years of age and the prevalence of HIV among youth 15 to 24 is 0.8% overall and 1.4% in the capital of Kinshasa (Ministry of Planning Democratic Republic of the Congo, 2007). Research has shown that over half of the young women living with HIV ages 14-24 and a quarter of the young men ages

14-24 living with HIV in Kinshasa already had sexual intercourse, with only 53% of young women and 67% of young men reporting using a condom at their most recent sexual act (Pettifor et al., 2008). Therefore, this population is at risk of transmitting the virus to their partners through unprotected sex (Morin et al., 2007). This risk makes Positive Prevention programs important for YLWH in this environment.

Positive Prevention Interventions

Since 2003, there have been an increasing number of research studies focusing on Positive Prevention Interventions with PLWHA living in the U.S., including a few studies on interventions targeting Youth Living with HIV/AIDS (YLWH) (Crepaz et al., 2006). However, there are few Positive Prevention interventions that have been implemented and evaluated for YLWH in sub-Saharan Africa. Positive Prevention is a relatively new area in sub-Saharan Africa where many of those infected have only recently accessed care and treatment (Bunnell, Mermin et al., 2006). To our knowledge, only one Centers for Disease Control and Prevention (CDC) Evidence Based Intervention (EBI) has been adapted and implemented in sub-Saharan Africa for YLWH (Lightfoot, Kasirye et al., 2007). We aimed to evaluate the feasibility of an evidence- and clinic-based, Positive Prevention intervention adapted specifically for YLWH ages 15-24 in Kinshasa, DRC, anticipating that lessons learned would be relevant in other sub-Saharan African countries where the HIV incidence among youth is the highest in the world (UNAIDS, 2010).

Framework for Feasibility Study Analysis

A recent examination of the feasibility of public health interventions led to the development of guidelines to help evaluate and prioritize those interventions deemed “feasible” and that have the greatest likelihood of being efficacious (Bowen et al., 2009). These guidelines, hereafter

referred to as the Bowen Feasibility Framework, served as the framework for the analysis of study data collected prior to, during, and after the implementation of the adapted pilot intervention to assess the feasibility of the intervention. The Bowen Feasibility Framework describes eight possible areas of focus that can be chosen based on the specific goals and objectives established by the researchers: acceptability, demand, implementation, practicality, adaptation, integration, expansion, and limited-efficacy testing. Four of the eight possible areas of interest were chosen for this study: Acceptability, Implementation, Adaptation, and Limited-Efficacy Testing (see Table 4 for detailed descriptions). The goal of this analysis was to examine if the adapted Positive Prevention intervention was feasible and is therefore appropriate for wider implementation and evaluation.

METHODS

Study Overview

This research was part of a larger study to develop a holistic Positive Prevention program for YLWH ages 15-24 in the DRC that addresses the youths' developmental needs and helps them cope with HIV in the context of their emerging independence and sexuality. This paper will focus specifically on the feasibility analysis of the adapted intervention.

Study Site

A family-centered HIV care and treatment program at a pediatric hospital in Kinshasa was the site of this study. The program provides comprehensive HIV medical care (including ARV treatment) and psychosocial support to children and their parents and guardians, as well as other household members. As of April 2012, the program had served more than 2,146 HIV-positive patients including 191 YLWH aged 15-24.

Recruitment and Eligibility

To be eligible for participation in the pilot intervention, YLWH had to: 1) know their HIV-positive status (i.e., must have had their positive HIV status revealed to them and not be in denial about their status); 2) be a patient at the study clinic; 3) be 15-24 years of age; 4) agree to participate in digitally recorded focus group discussions (FGDs); 5) be mentally competent and healthy enough to participate in the study; and 6) be willing to attend six intervention sessions. Youth at the study site were infected through various routes (perinatally, parenterally, or sexually) and as such HIV acquisition mode was not an eligibility criterion for participation (Behets & Pettifor, 2008). The intervention was suitable for both sexually experienced youth and for those not yet sexually active, as the need for HIV prevention information and skill development was similar for all youth, irrespective of infection mode (L. Koenig, Chandwani, Peralta, Stein, & Barnes, 2005). Recent studies have concluded that Positive Prevention interventions must be integrated into the care of both perinatally and behaviorally HIV-infected adolescents (L. J. Koenig et al., 2010). Including both populations of YLWH in the same intervention was found to be feasible in a study in the U.S. (L. J. Koenig et al., 2010).

After parental or guardian informed consent was obtained for youth aged 15-17, these youth provided their assent to participate. Written informed consent was obtained from YLWH aged 18-24. All study procedures were approved by the UNC Institutional Review Board and by the Kinshasa School of Public Health Ethics Committee. YLWH were reimbursed \$3 for travel at the completion of each session. Family members or caregivers who attended the final session received a small gift and a \$3 travel reimbursement.

Adapted Intervention

The intervention, *Supporting Youth and Motivating Positive Action* or SYMPA, is a six-session risk reduction intervention targeted for YLWH in Kinshasa, DRC, adapted from the Healthy Living Project which was guided by the Social Action Theory (The Healthy Living Project Team, 2007a) (Table 12). An adaptation workshop was held to discuss the cultural and social factors that were important to the study population, and participants made suggestions to remove information and activities from the intervention that they did not feel were relevant. There were three major adaptations made to the original intervention: 1) reduction of the number of sessions from 15 to six (by combining similar sessions and eliminating content not directly relevant for the target population. For example, the original module on accessing health services, adherence, and active participation in medical care decision making was removed as these sessions did not reflect the identified risk behaviors and their determinants for the target population.); 2) change from an individual adult format to a single-sex youth group format; and 3) the addition of a “Very Important Person (VIP)” social support component. Details of the adaptation process are available elsewhere (Parker et al., 2012).

Table 12: SYMPA Intervention Session Content Overview

Session Number	Session Title	Content
Session 1	Living with HIV	Preview intervention and identify personal strengths and challenges in relation to living with HIV; set attainable goal.
Session 2	Coping and Problem Solving	Identify personal stressors; changeable vs. unchangeable stressors; problem-solving skills; problem-focused vs. emotion-focused coping; match coping to stressing type.
Session 3	Safer Sex I	Risk continuum; identify personal risk limits and problem solve triggers to risky behavior.
Session 4	Safer Sex II	Proper condom use; knowledge of Sexually Transmitted Infections (STIs); assertive communication; role plays to increase communication/negotiation skills.
Session 5	Social Support and	Identify three types of social support (emotional, informational, and tangible); brainstorm ways to increase positive support;

Session Number	Session Title	Content
	Disclosure	identify personal and environmental factors related to disclosure decisions; identify Very Important Person (VIP) in support network who could assist youth with maintaining healthy behaviors.
Session 6	Wellbeing and Health Maintenance	Identify successes and problem-solve challenges to maintaining behavioral and attitudinal changes; focus on developing a plan to maintain healthy behaviors after the intervention ends and the role of the VIP in supporting the youth in this process.

The Kinshasa-based study coordinator and the four intervention facilitators participated in a training in which each session was reviewed in detail and each activity was practiced as a group so that they became confident in their understanding of intervention content. Each session of the intervention implemented during the pilot study was planned to last approximately 90 minutes and scheduled over a period of six weeks, with one session each week. Following the training of the local coordinator and facilitators, youth were recruited for the pilot study. Two single-sex groups with 6 boys in the male group and 7 girls in the female group were recruited with ages ranging from 15-20 (See Table 13 for participant demographics). One participant had completed secondary school and all the other participants had attended some years of secondary school. None of the participants were married and 10 of the 13 participants were financially supported by their parents or caregivers. Within the DRC, 18% of women 15-19, and 54.2% of women 20-24 are married (1% and 19.8% respectively for men) (Ministry of Planning Democratic Republic of the Congo, 2007). Close to half of the participants reported not having enough food during the last three months, pointing to an extreme lack of resources.

Table 13: SYMPA Pilot Intervention Participant Demographics, n=13

Age	Gender				Total	
	M		F			
	N	%	N	%	N	%
15	1	7.7%	2	15.4%	3	23.1%
16	1	7.7%	1	7.7%	2	15.4%

Age	Gender				Total	
	M		F			
	N	%	N	%	N	%
17	0	0.0%	1	7.7%	1	7.7%
18	2	15.4%	2	15.4%	4	30.8%
19	2	15.4%	0	0.0%	2	15.4%
20	0	0.0%	1	7.7%	1	7.7%
Total	6	46.2%	7	53.8%	13	100.0%

Data Collection

Data were collected from multiple sources including: 1) demographic questionnaires collected at the beginning of the intervention with the 13 YLWH participants; 2) in-depth interviews (IDIs) with facilitators (n=3); 3) reports completed by the facilitators after each session; 4) focus group discussions (FGDs) with facilitators; 5) single-sex FGDs with YLWH participants conducted after each session ; and 6) activity sheets completed by each of the 13 YLWH participants during the intervention (See Table 14 for a summary of the data collection instruments). All interviews and FGDs were digitally recorded and transcribed verbatim by trained local transcribers and linked within Atlas-ti version 5.2.

Table 14: Data Collection Instruments

Type	N	Contents
Demographic Questionnaires with YLWH	13	Questions on education, marital status, socio-economic status, and food and income security
Facilitator IDIs	3	Questions on what they liked best and least in the intervention, challenges faced, logistical issues, comfort level discussing sensitive topics such as sexual behavior, incorporation of VIPs, and suggestions for scale-up
Facilitator Session Reports	6	Questions on strengths and weaknesses of the intervention sessions and areas where the program could be improved for future scale-up
Facilitator FGD	1	Questions on the intervention curriculum including an evaluation of specific sessions and activities
Single-Sex Participant FGDs with YLWH	12	Questions on what the participants enjoyed most and least, what the participants learned or found helpful, subjects they would have liked covered, whether the session increased their confidence in identifying

Type	N	Contents
		high risk behaviors, in what ways they changed their behavior as result of their participation in the previous session and views related to intervention logistics.
Participant Activity Sheets with YLWH	13	Documentation of activities specific to each session completed by participants and goals developed by participants.

Feasibility Framework and Data Sources

Table 15, adapted from the Bowen Feasibility Framework describes the four key areas of focus for this feasibility analysis, the questions that were asked, the outcomes of interest, and the data sources used to answer the questions and assess the outcomes of interest (Bowen et al., 2009).

Table 15: Key Areas of Focus, Outcomes of Interest, and Data Sources for the SYMPA Intervention

Area of focus	Description	The Study Asks ...	Outcomes of Interest	Data Sources
Acceptability	How the intended individual recipients – both targeted individuals and those involved in implementing programs – react to the program.	To what extent is SYMPA suitable, satisfying, or attractive to program participants? To program facilitators?	<ul style="list-style-type: none"> • Satisfaction • Perceived appropriateness • Intent to continue use 	<ul style="list-style-type: none"> • FGDs with youth after each session (n=12) • Evaluations post-session by facilitators (n=6) • FGD curriculum evaluation with facilitators (n=1) • IDIs post-intervention with facilitators (n=3) • Youth activity sheets (n=13)
Implementation	The extent, likelihood, and manner in which an intervention can be fully implemented as planned and proposed, often in an uncontrolled design.	To what extent can SYMPA be successfully delivered to intended participants?	<ul style="list-style-type: none"> • Degree of execution • Amount, type of resources needed to implement • Factors affecting implementation ease, efficiency, or quality 	<ul style="list-style-type: none"> • FGDs with youth after each session (n=12) • Evaluations post-session by facilitators (n=6) • FGD curriculum evaluation with facilitators (n=1) • IDIs post-intervention with facilitators (n=3) • Youth activity sheets (n=13)
Adaptation	Changing program contents or procedures to be appropriate in a new situation including modifications made to accommodate the context and requirements of a different format or population.	To what extent does an existing intervention such as the Healthy Living Project perform when changes are made for a new format or with a different population?	<ul style="list-style-type: none"> • Assessment acceptability and implementation factors specific to the intervention modifications 	<ul style="list-style-type: none"> • Adaptation workshop with health care providers • Training of facilitators • FGD curriculum evaluation with facilitators (n=1) • IDIs post-intervention with facilitators (n=3)
Limited Efficacy	Test an intervention in a limited way with a convenience sample with intermediate rather than final outcomes.	Does SYMPA show promise of being successful with the intended population?	<ul style="list-style-type: none"> • Evidence of trends in the predicted direction for better outcome compared to usual practice 	<ul style="list-style-type: none"> • FGDs with youth after each session (n=12) • Evaluations post-session by facilitators (n=6) • FGD curriculum evaluation with facilitators (n=1) • IDIs post-intervention with facilitators (n=3) • Youth activity sheets (n=13)

Source: Adapted from (Bowen et al., 2009)

Data Analysis

Qualitative content analysis was used to interpret text data through the “systematic classification process of coding and identifying themes and patterns” (Hsieh & Shannon, 2005). The first author followed five interrelated steps in this content analysis: reading, coding, displaying, reducing, and interpreting (Miles & Huberman, 1994; Ulin, Robinson, & Tolley, 2005). A codebook was developed based on the IDI and FGD guides as well as additional topical and emergent codes that were identified from the review of transcripts. Codes were then applied to the data and code reports produced. Code summaries were developed from the code reports and these summary documents were coded based on the four areas of focus within the feasibility framework in order to examine the evidence supporting these sub-themes. Data were then synthesized as key elements and themes began to form and essential concepts and relationships between the different themes and sub-themes came together to provide a more holistic view of the data.

RESULTS

Acceptability

Program Participants

Satisfaction

YLWH overwhelmingly reported being satisfied with the SYMPA intervention, and felt the intervention addressed their specific needs. YLWH described enjoying their participation in the SYMPA intervention because of three key aspects: 1) open discussion of sexual health and behavior; 2) knowledge and skill development; and 3) mechanisms to increase social support. Youth described

feeling free to talk about issues of sexuality, a topic that traditionally is considered taboo within this cultural context, in front of their peers and facilitators.

“Before, I considered myself as a child and so I thought that questions related to sex didn’t concern us. But, I was surprised to see them speaking with us, like friends. This really touched me because these are subjects that no one in our families dares to bring up.”- Male participant, 18 years old

Perceived appropriateness

Intervention participants felt the intervention was filling an important gap in their education and expressed their gratitude that particular topics were included in the intervention. Specifically, youth mentioned that they enjoyed learning about risk behaviors, including determining where specific behaviors fall on a risk gradient, and how to identify triggers to high risk sexual behavior. Youth liked learning how to develop their problem-solving capacity, improving communication with family members and sexual partners, increasing their understanding of the role of social support, learning negotiation strategies with sexual partners, learning condom use skills, and improving their ability to set positive goals for the future. Youth also described enjoying activities to identify different types of social support and learning how to expand their social support network.

“Lots of important things like informational support, because we, youth, we really love to learn because one day we will be adults and faced with lots of problems. If I’m not prepared, I won’t know how to respond.” - Male participant, 18 years old

However, youth identified two ways in which the intervention could be more applicable to their specific circumstances: 1) including content to address their concerns related to disclosure of their HIV status; and 2) incorporating more in-depth information related to marriage in the context of living with HIV. Both young men and women mentioned their apprehension related to talking about disclosing their status to friends and family because of fear that those persons would tell others or that they would be stigmatized. This was especially relevant when youth were asked to bring in someone from their social network to serve in a social support role for the last session. Those who did not have someone already aware of their status to bring to the session expressed concerns

about disclosing their status. Likewise, youth pointed out that this was contradictory to how they had been previously counseled on the topic.

“The activity that I didn’t like was the one about disclosing our HIV status. I don’t feel like that activity had its place. You have always told us that our HIV status is a secret between me and my doctor. You are contradicting yourselves now and telling us to disclose this information. I don’t agree and I don’t see the utility of it.” - Female participant, 17 years old

It is important to note that youth were not pressured to disclose to others if they felt uncomfortable; indeed, a few chose to bring a staff person from the clinic to serve in this specific social support role. Interestingly, although youth initially reported being uncomfortable with this topic, many expressed their contentment in having disclosed their status to family members due to their participation in the intervention and reported feeling more confident in their ability to negotiate the complexities of the disclosure process. Many youth designated disclosing to a family member as their specific goal for the session on their post-session activity sheets. While youth raised some concerns related to disclosure to friends and family members, most youth reported great interest in learning strategies for how to disclose their status to their sexual partners.

“It’s good to know the HIV status of our partners because I can believe that a man I am living with is healthy but actually it might be him that is worse. It’s important for us to know their status but it’s not easy. Since we know our status it is for us to look for strategies to inform them like that they can feel called upon to respond and can perhaps open up to us and be honest with us.” – Female participant, 20 years old

During the FGDs held after the first two sessions most female youth mentioned wanting specific information about marriage, becoming engaged, couple testing, and specific strategies for informing sexual partners of their status. Female YLWH wanted more details from facilitators on whether and how young women living with HIV can engage in relationships and get married.

“I would have liked for them to explain...we are sick should we get married or not? How should we behave with our sexual partners? Because we also have needs, we have desires. Me I have a sexual partner but he doesn’t know my status that’s why I really would have liked to talk about this subject so that it can help me and give the courage to disclose my status.” – Female participant, 17 years old

While much of the information about marriage and relationships was discussed during sessions four and five, the youth wanted this information to be introduced earlier, or at least be given reassurance that this information was going to be covered.

Intent to continue use

Youth reported enjoying the intervention and many stated their interest in participating in the intervention a second time if that was permitted.

“My wish is that this intervention could continue every Saturday until we get married” – Female participant, 18 years old

Youth also described wanting others in the community to be able to benefit from this program as well.

“We have learned a lot. We have gained access to information that we don’t get in our families or from our friends. The time that we have passed here has permitted us to access information that is fundamental for our future lives. Unfortunately there were only six sessions, if they were to do it again so that we could learn more, then we would agree.” – Male Participant, 15 years old

Thus, youth were highly interested in continuing to participate in the intervention if it were available.

Program Facilitators

Satisfaction to program facilitators and program participants

Overall, SYMPA facilitators were eager to implement the program, further develop their competence in group facilitation, and expand their skills in Positive Prevention counseling and services. Thus, they felt the intervention was attractive and met their expectations. They reported enjoying the SYMPA intervention training and felt it increased their capacity to implement Positive Prevention interventions with this specific target population. Program facilitators also reported

being satisfied with the intervention content and felt it addressed specific gaps in the services they were providing to youth before introduction of the intervention.

“All the more reason, as we are in charge of the support groups for the children and the adolescents. So there were certain concerns that arose during these meetings and that we were able to find solutions to during this study. Our youth don’t know that they should have a goal in life – that helps the youth to aim for these goals and to know how to make decisions when faced with a problem.” – Facilitator

Perceived appropriateness

The facilitators reported feeling encouraged that this intervention provided youth with the necessary skills and tools needed to face the numerous challenges related to living with HIV.

“So what I liked the most was first we gave the youth a chance to express themselves, not only to express themselves but to reflect and to reflect in a positive way. Because these youth are often faced with problems they face them indiscriminately, without a plan. But with this study I was really happy to notice that the youth have acquired a certain autonomy, a certain way of facing their problems. This way of responding has also led to the youth acquiring a certain maturity.” – Facilitator

One facilitator, echoing similar views of the other facilitators, reported that the SYMPA intervention resulted in youth being able to see the importance of counseling in the context of clinic services provided to YLWH.

“I was first of all happy because, for me, the youth were getting it, they were telling themselves that they don’t come to the clinic only for medical treatment, but that there is also another way of being instructed.” - Facilitator

Many of the facilitators stressed the extent to which their own understanding of YLWH needs were expanded through their participation in the intervention.

“Sexuality, condoms, it’s taboo. They are still children, we can’t talk about sex, but during this session, we understood that this was a need that the children had that we, the health care providers, ignore. We couldn’t have believed that this could interest them. And curiously, we understood that the youth have begun to be sexually active but they don’t know how to use a condom. It’s really a new notion for us and it is really interesting.” – Facilitator

While youth described their frustration with not having extensive information early on about relationships and marriage, program facilitators described the importance of building trust over the

first three sessions so that when the more sensitive topics were introduced in the fourth session youth would be comfortable sharing their experiences.

Intent to continue use

Facilitators expressed an interest in continuing to deliver this intervention to other YLWH at the clinic so that youth are able to benefit from the intervention and so that they are able to remain implicated in the care of these youth. YLWH and facilitators were pleased with the intervention content and both parties clearly showed an interest in continuing their participation in the intervention in the future.

Implementation

Degree of execution

The SYMPA intervention was fully implemented as planned and all the topics included within the six sessions successfully delivered to the YLWH participants with very high retention of participants. Of the 13 participants, all but two completed all six sessions, with the two participants (one boy and one girl) missing one session each.

Factors affecting implementation ease, efficiency, and quality

Two primary challenges to implementation were raised by both the participants and facilitators during the intervention implementation and the FGDs and IDIs: 1) length/timing of sessions; and 2) education/literacy level of youth participants. Although sessions were intended to be 90 minutes, the average length of the sessions was approximately 3 ½ hours with additional time spent in the FGDs after each session. Thus, the sessions were deemed too long by facilitators and

youth. Youth indicated this issue was particularly challenging because longer sessions delayed their return home made it difficult for them to access public transportation. Program facilitators were obligated to put in longer hours and to ensure that all participants were able to find a means to return home. In addition, both youth and facilitators reported that a 3 ½ hour session was too long to maintain the interest of the youth.

“It’s that the material took longer than the time designated. The amount of time we had didn’t permit us to explain things in depth. If there was more time we could have gone into more detail, done more exercises, this would lead to a better comprehension.” – Facilitator

Although the program was implemented over six successive Saturdays afternoons to avoid interfering with youth schooling, many youth participants had difficulty arriving on time to sessions because they were required to attend school on Saturday mornings. Program facilitators felt this caused the youth to be distracted and that this was not an ideal time to hold the intervention.

“If the facilitator finds himself in front of a child who has just come from school, tired and hungry, their task becomes difficult” – Facilitator

Both the facilitators and the youth reported that the youth participants struggled with some of the terminology in the curriculum and had trouble understanding the more complex topics, such as categorizing the different types of triggers for high risk sexual behavior and certain scientific terms related to human sexuality. While the original intervention was targeted to an adult population, the study team adapted the intervention for this age group and incorporated role plays better targeted for a youth audience, with references to adult issues such as work replaced with school. Likewise, certain activities such as the condom demonstration and the Sexually Transmitted Infection (STI) activities were simplified to aid the youth in understanding the instructions. However, the study team was not prepared for the degree to which the youth were delayed in their ability to read and write, potentially as a result of cognitive development deficiencies due to HIV. Those youth who were unable to write at even a very basic level were assisted by the facilitators and this delayed the progress of the group.

“The main difficulty we had during this study, it was the education level of the youth. We understand that they are youth that have been sick for a long time; that they have been held back in school. The level of the youth is really very low. But to write, it’s difficult for them. We had a really hard time reading what some of the youth had written.” - Facilitator

While facilitators indicated this as a challenge, youth did not raise this as an issue. This supports the reports from facilitators that they patiently took extra time explaining complex topics and worked individually with youth struggling to keep up. Thus, while there were certainly challenges to the implementation of this intervention, the facilitators and youth were able to work to overcome these challenges and deliver and participate in a high quality Positive Prevention intervention.

Resources needed for implementation

The facilitators worked outside of their regular working hours, putting in extensive unpaid overtime in order to facilitate the intervention on Saturdays.

“With the amount of work that we have, Saturday, outside of our visits to the sick in the clinic, we can find ourselves at the clinic from the morning until 6 at night...it’s not easy for us.” – Facilitator

While facilitators repeatedly raised the issue of the extra burden of their participation in the intervention, they were clearly devoted to the program and went above and beyond what was required of them. In one case, at the request of an YLWH participant, a facilitator conducted a make-up session because the child had been unable to attend due to illness.

Adaptation

Assessment of acceptability and implementation factors specific to the intervention modifications

Overall, the adapted intervention was well-received by the new target population of YLWH in the DRC. There are two aspects of the adapted intervention that warrant a more detailed discussion: 1) the adaptation from an individual format to a single-sex group format; and 2) the

addition of the VIP social support component. In low-resource settings such as Kinshasa, having multiple, individual sessions was not thought to be feasible and could potentially limit scale up; therefore, the intervention was adapted to be delivered in a group format. In this setting YLWH already had the experience of meeting monthly in educational sessions with their peers, and the youth expressed in formative research that they wanted to be in such groups. Likewise, as study staff reported that in Congolese society sexuality is not traditionally discussed in mixed gender groups, it was decided that the groups would be separated by sex – one for young women and the other for young men – so that participants would be comfortable discussing sensitive issues. While we were confident that peer support groups were successful with this target population, we were not sure how this specific intervention would fare in this format. The group format appeared to be acceptable and was an aspect of the intervention that both the YLWH participants and facilitators indicated as a major factor in its success. Youth and facilitators reported that rather than individuals developing goals and problem solving on their own, feedback from both facilitators and other members of the group was incorporated and thus the development of each group member's goals and solutions to their problems became a collaborative effort.

“What I preferred, it was the fact that we shared our life projects with each other because this can always enrich our initial ideas and the project becomes even better.”- Female participant, 20 years old

This attests to the fact that not only was the group format acceptable, but also that there was value added by having the youth work together to identify risks, problem solve, and set goals.

The VIP component was added to the intervention to help provide support to YLWH over the long term in achieving their goals and objectives developed during the intervention. Each YLWH was asked to identify an individual who was a trusted person to whom s/he was willing to disclose or had already disclosed his/her HIV status and to whom the YLWH could go to for support. The VIP was also identified as someone who could aid them in maintaining lower risk sexual behavior

practices and staying healthy after the program ends. Initially, both the youth and facilitators were hesitant about the idea of bringing in a VIP to participate in the sixth session of the intervention. During the adaptation workshop the program staff raised important concerns about the VIP component including confidentiality, recruitment, and the issue of who gets to choose the VIP (i.e., the facilitators or the youth themselves). Through interactive discussions, the study team decided to include the VIPs in the final session ensuring confidentiality by incorporating discussions on specific strategies to help YLWH maintain confidentiality into the first session and continuing throughout the intervention. The YLWH had the final say on choice of VIP, with facilitators free to provide advice and support in the decision making process.

“We, we believed at the beginning that the VIP would be a barrier. We asked ourselves if the youth would be capable of speaking in front of their VIP. But, curiously, the children weren’t bothered; they spoke easily and expressed their problems in front of their VIP. That was an innovation for me.” – Facilitator

Facilitators reported that three YLWH participants disclosed their status to a close family member in preparation for session six with the VIPs. To their surprise, most facilitators felt that the VIP component was the most important aspect of the entire intervention. Facilitators reported that youth spoke openly in front of their VIPs and weren’t embarrassed to discuss these sensitive topics. They described the VIPs actively participating and noted that the youth appeared to enjoy reviewing what they had learned during the previous five sessions.

“I liked the presence of the VIP who contrary to what we thought, they weren’t simply present but they expressed their desire to support the youth.” – Facilitator

The facilitators reported that the VIPs were very impressed with what the youth had accomplished and that they had noticed positive improvements in the behavior of youth since they had started the intervention. Likewise, the facilitators stated that the VIPs expressed that they previously had difficulty talking about their child’s sexual behaviors and so appreciated that the intervention was addressing these issues. During the final session, a facilitator described an instance where one VIP

described carrying condoms with him at all times to model this behavior to the youth. Participants chose their mothers, sisters, health care providers, uncles, and grandmothers as their VIPs.

Facilitators mentioned that they hoped that the VIPs would continue to stay involved in the lives of their children. One facilitator described a meeting with a VIP, held after the intervention had ended, that encouraged the VIP that this was indeed possible.

“At the end (of session six), we asked for the help of the VIPs who were there. She really gave advice and after I met with the child’s VIP and she told me that since that time the situation has been evolving really nicely. So I understood that the support of the VIPs was really important because we have seen the fruits of their efforts.” – Facilitator

Similarly as with the facilitators, youth were very hesitant at first about the idea of incorporating VIPs in the final session. This was the case especially for those who had not yet informed the potential VIP of their status. However, many YLWHs also repeatedly mentioned how much they enjoyed this part of the intervention and many remarked that this was their favorite part of the intervention. The youth participants felt that the VIPs gained a better understanding of the importance of what they learned during the sessions and that the VIPs could now support them in learning additional topics and in their prevention efforts.

“Me, I’m happy because today the VIP learned our different secrets. Personally, I was going to explain to my uncle what we were learning here but he wouldn’t have really understood the importance of these lessons. Today since he participated he understood and will surely continue to help me with things that I don’t know.” – Male participant, 18 years old

Youth mentioned that during the session the VIPs contributed by proposing multiple solutions for the various problems youth were having in realizing their life projects. In conjunction with their VIPs, youth were able to identify resources and skills to support their plan to reduce risk behaviors and improve coping and problem solving skills.

“The activity that I liked best was when they explained that the VIPs should help us learn and help us at home. Before, we could go out without saying anything at home, but now, there is a dialogue that has been established, such that before going out, even if they won’t directly give us condoms, at least, they will be satisfied with giving us counsel on how to protect ourselves and prevention.”- Male participant, 18 years old

Therefore, these modifications made to accommodate the context and specific requirements of this target population performed successfully and, in fact, strengthened the intervention as a whole.

Limited Efficacy

Evidence of trends in the predicted direction for better outcome compared to usual practice

The intervention showed promise of success with the target population, as assessed by youth and facilitators' reports of the effects of the intervention on YLWHs' HIV prevention knowledge and skills. YLWH reported improving their problem-solving skills, increasing their knowledge of sexual prevention topics, improving their condom use skills, improving their ability to deal with triggers for unsafe sex, and increasing their capacity to assess the level of risk of different behaviors. YLWH also reported increasing their autonomy in decision making, improving their ability to negotiate safer sexual relationships, increasing their openness to discuss sexual behavior with their caregivers, and improving their ability to develop positive goals for their future. Youth described having changed their outlook on life and learning a wide-range of skills, and consequently felt better prepared to deal with potential problems that may arise in their lives.

"I've gained intelligence, no, no, it's more than intelligence, rather it's wisdom." – Male participant, 15 years old

This was particularly important as the youth mentioned that this was a type of education that they were not getting elsewhere and described specific skills they had developed during the intervention that they were now applying in their lives. One participant described learning new information about STIs, including which STIs are symptomatic and which are not, and how this information led to him using protection.

"We learned about the infections that speak and the infections that don't speak. For the infections that speak, it's difficult to know that you are sick that's why, me, I won't accept to have sex without condoms." – Male participant, 18 years old

Participants also mentioned being able to identify a lack of condom use as a risk behavior and the importance of thinking ahead and preparing to use condoms. One female participant described how she has developed strategies that could help her reduce conflict in her relationship.

"I could resist at first and refuse, but if he insists, I would be obligated to accept...he could harass me and threaten me if I refuse...I am happy because I've learned the strategies that would permit me to calmly refuse these things that I judge as a risk" - Female participant, 18 years old

Another female youth described a lively discussion during an intervention session about the gradient of sexual risk behaviors.

"Today's session helped us with a lot of things, for example, we now know how to identify the risk level of behaviors. A friend stated that sucking a man's penis is a low risk activity, but me I consider that very risky in case the penis has cuts or ulcerations. Another said that if a man ejaculates in her mouth she would become pregnant. We responded that this wasn't possible." – Female participant, 20 years old

Others stated that negative peer influences encouraged risky behaviors, and reported developing methods to avoid these influences. Some youth mentioned focusing on school and studying as a means to avoid high risk behaviors. Youth also thought that the risk exercise (determining the level of risk of different sexual acts) helped to clarify misconceptions about certain sexual acts and to understand which acts are high risk and which are not.

Some youth reported being able to incorporate these lessons into their everyday behaviors. Male youth mentioned being better able to avoid dangerous situations after participating in SYMPA. Some mentioned visiting their girlfriends less or not spending as much time alone with their girlfriends, instead hanging out in groups in order to avoid triggers that had been identified during the intervention.

"This really helped me because before I was really angry...And my only distraction to help me calm down after an episode of anger was to go find my girlfriend...And this would often end up with us having sex...but, now, I've developed other mechanisms to distract myself, I can go watch a soccer match or play or even go walking." - Male participant, 18 years old

One female youth reported that due to her participation in the intervention she does not do everything her boyfriend asks, and another female youth mentioned now wanting to know her boyfriend's status. Likewise, others described their increased ability to negotiate with sexual partners.

"This session helped us because they showed us how to negotiate, because you could have someone who lives with their boyfriend but not know how to ask him to wear a condom when having sex. This gave us strategies to develop good communication. Me, for example, I have already discussed with my boyfriend and I succeeded in convincing him that for now we will have sex using condoms." - Female participant, 20 years old

Thus, participants reported a wide range of changes in their behaviors following participation in the intervention sessions.

Importantly, facilitators stated that they had noticed changes in the youth over the course of the intervention.

"One youth said that now he understands that in life you must have multiple solutions to a problem and chose the best solution. And when you need something you may think that the solution can only come from one person but that there are multiple ways of finding a solution. So, each participant learned a lesson in this study. Globally, we remarked that this study led to behavioral changes for these youth" – Facilitator

Likewise, facilitators reported that VIPs remarked that the youth had also changed their behavior at home.

"The VIPs were surprised to learn that youth knew of their serostatus and stated that 'They have become wiser, they take their medication without asking, they are clean, they have become more studious, and they don't go out whenever they want'." – Facilitator

Facilitators mentioned that in addition to specific improvements in the youth's behaviors, the youth and their VIPs had developed an open dialogue on sexual behavior and prevention.

"The inclusion of the VIPs was a good thing because many parents abandon the monitoring of their youth to the health care providers. They don't follow their child's evolution and they only help with reminding their child to take their medications. Their participation in the program opened the horizons of the caregivers." - Facilitator

There is ample evidence that this intervention shows great promise for success with this specific target population.

DISCUSSION

The goal of this study was to determine the feasibility of an adapted six-session Positive Prevention intervention for YLWH in Kinshasa, DRC. Using the Bowen Feasibility Framework, findings from this study show that the adapted intervention was suitable, satisfying, and attractive to both program facilitators and participants, able to be implemented effectively, performed well with a new population, and showed preliminary efficacy. Although the intervention was determined to be highly feasible in this environment, there are certain aspects of the intervention that must be addressed prior to moving forward with wider implementation and evaluation. First, in order to address the acceptability issues identified by youth, including more content on how to navigate marriage while living with HIV could further increase acceptability of the intervention, particularly among the young women. Also, the topic of disclosure could be further tailored to: 1) include a discussion on the differences between disclosing to friends and family members versus sexual partners; and 2) be explicit about not pushing youth to disclose, thus better addressing youth concerns. Potential solutions to the implementation challenges related to conflict with youth schooling and long hours required of facilitators could be to hold the intervention during the school summer vacation. This would address both the timing of the intervention as well the burden on staff, as the intervention would be held during normal working hours. Hiring additional staff and providing financial incentives to current counselors are worth considering in order to further encourage their participation in the intervention. The length of each session should be reduced to a maximum of 90 minutes, up to 10 total sessions. This could be achieved by spreading the existing content over a greater number of sessions while also cutting content from specific activities which both the YLWH and facilitators did not find to be helpful, such as an exercise about self-confidence and another on decision-making processes. As retention and youth interest in the program were

strong, the study team does not foresee the addition of sessions to be a barrier to youth participation. The curriculum could be easily further simplified without compromising content in order to reflect the actual education level of many participants, and specific activities requiring written responses could be adapted for those youth unable to write. Addressing this limitation would also help to reduce the length of the sessions. Having VIPs participate in more than one session would further strengthen this highly successful component of the intervention.

Limitations

One limitation of this study is potential social desirability bias in the reporting of the facilitators as they might have reported positively on the intervention so that it appeared they did a good job implementing the intervention. However, as the facilitators were aware that they will most likely be involved in any future efficacy trial or implementation of this intervention, the facilitators may have felt a vested interest in making sure that the intervention is improved as much as possible and that challenges are addressed, thus, moving them to provide more honest and thoughtful responses to the questions. A second limitation is that by using a convenience sample of YLWH, these youth may have been more interested in learning about Positive Prevention than other YLWH in Kinshasa, and program staff may have identified those most likely to succeed. However, the goal of this study was not generalizability but rather the ability to assess the explicit aims of the feasibility analysis; therefore, a convenience sample was appropriate to meet these predefined areas of focus of acceptability, implementation, adaptation, and limited efficacy. An additional limitation of this study is the lack of quantitative data on behavior change outcomes resulting from the intervention, which was beyond the scope of this study.

Conclusion

The National Institute of Health (NIH) plan for HIV-related research for fiscal year 2012 has indicated “translational research to foster the scale-up and optimize the use of existing efficacious interventions to prevent and treat HIV infections” as a research priority. The NIH has stated that priority should be given to “developing methodologies needed for designing, conducting, and interpreting such research” (Whitescarver, 2012). This study used an innovative framework to examine the feasibility of an adapted evidence-based Positive Prevention intervention implemented in a low-resource setting, and found the intervention to be feasible and appropriate for wider implementation and evaluation, thus responding directly to these research priorities.

CHAPTER 6: MANUSCRIPT 3: BARRIERS TO PROVIDER-DELIVERED SEXUAL BEHAVIOR COUNSELING FOR YOUTH LIVING WITH HIV/AIDS IN THE DEMOCRATIC REPUBLIC OF THE CONGO

INTRODUCTION

Youth Living with HIV/AIDS in the DRC

Worldwide, nearly five million youth ages 15-24 currently live with HIV, and each year close to 900,000 new HIV infections occur among youth (UNAIDS, 2010). About 80% of YLWH or four million live in sub-Saharan Africa (UNAIDS, 2010). In the Democratic Republic of the Congo (DRC) over 60% of the population is under twenty years of age and the prevalence of HIV among youth aged 15-24 is 0.8% overall and 1.4% in Kinshasa, the capital (Ministry of Planning Democratic Republic of the Congo, 2007). Formative research conducted in Kinshasa with close to 200 YLWH aged 14-24 found that over half of the young women and a quarter of the young men had already had sexual intercourse, with only 53% of young women and 67% of young men reporting using a condom at their most recent sexual (Pettifor et al., 2008). Therefore, this population is at risk of transmitting the virus to their partners through unprotected sex. This illustrates the importance of effective HIV prevention programs for people living with HIV/AIDS (PLWH) – also called Positive Prevention – and specifically for YLWH in this type of low-resource environment (Morin et al., 2007).

Effective Positive Prevention Strategies

Positive Prevention programs are important to reduce new infections and to ensure PLWH remain healthy (Indyk & Golub, 2006; Kennedy, Medley, Sweat, & O'Reilly, 2010). In 2009, the

Global Network for People Living with HIV and The Joint United Nations Program on HIV/AIDS developed an expanded Positive Prevention strategy entitled, “Positive Health, Dignity and Prevention” that stressed the role that such programs played in maintaining the health of HIV-positive individuals in addition to preventing the further spread of HIV to others, within a human rights framework (Global Network of People Living with HIV & UNAIDS, 2009). In the context of Positive Prevention interventions such as the “Seek, Test, Treat, and Retain” approach, behavioral measures to prevent sexual transmission of the virus play an important role in combination prevention strategies (Dodd et al., 2010; Montague et al., 2011). Furthermore, recent findings that early initiation of antiretroviral (ARV) treatment by PLWH can prevent the spread of HIV to their sexual partners are promising (Cohen et al., 2011), but will only be effective if the PLWH are adherent to their medications and if their viral loads remain undetectable. Positive Prevention behavioral interventions can reach populations before they are eligible for treatment, and can also help keep individuals engaged once they are receiving treatment (Walensky, 2009). One important delivery mechanism for Positive Prevention is provider-delivered counseling.

The World Health Organization has suggested that to be effective, comprehensive provider-delivered sexual prevention counseling for PLWH in low-resource countries should include: psychosocial counseling, an assessment of possible HIV transmission behaviors, risk reduction counseling, counseling to improve condom use skills and access to condoms, family planning counseling and provision, and counseling on the prevention of mother to child transmission. For those programs specifically targeting youth, counseling should be provided within the context of adolescent development and sexuality (World Health Organization, 2008). Recent recommendations for improving Positive Prevention interventions in sub-Saharan Africa suggest that health care provider attitudes, beliefs, and inabilities to discuss sex with their patients should be priority targets for intervention (Bunnell, Mermin et al., 2006).

To our knowledge only one peer-reviewed publication has focused specifically on provider-delivered Positive Prevention counseling for PLWH in sub-Saharan Africa outside of routine Voluntary Counseling and Testing (Peltzer & Ndlovu, 2005). This was a qualitative study conducted with 15 medical providers who treated HIV positive adults living in Limpopo, South Africa. The study reported that the majority of providers did not make prevention counseling with their patients a priority during medical visits; however, those providers with a “collaborative” patient-provider interaction style were more likely to deliver prevention counseling in addition to their clinical services as compared to those providers with a more “consultant” style (Peltzer & Ndlovu, 2005). However, there are no peer-reviewed studies that have looked specifically at the unique experiences of provider-delivered Positive Prevention counseling with YLWH in sub-Saharan Africa, nor in other low-resource settings. This study aims to fill this gap by qualitatively exploring how providers’ attitudes and perceptions of YLWH sexual behavior may influence the HIV transmission risk prevention counseling that they deliver for YLWH, ages 15 to 24 in a low-resource setting, in this case Kinshasa, DRC.

METHODS

Study Overview

We aimed to inform the development of a holistic Positive Prevention counseling program that addresses the developmental needs of YLWH ages 15-24 in Kinshasa DRC and helps them cope with their HIV infection in the context of their emerging independence and sexuality. This paper describes interviews with health care providers conducted to better understand their perceived role in delivering prevention counseling to YLWH.

Study Site

A family-centered HIV care and treatment program at a pediatric hospital in Kinshasa was the site of this study. The program provides comprehensive HIV medical care (including ARV treatment) and psychosocial support to children and their parents and guardians, as well as other household members. As of April 2012, the program had served more than 2,146 HIV-positive patients including 191 YLWH aged 15-24. Youth at the study site were likely infected through various infectious routes (perinatally, parenterally, or sexually) and HIV acquisition mode was mostly unknown (Behets & Pettifor, 2008). At the study site medical doctors, counselors, and PLWH volunteers deliver basic positive prevention messages via peer support groups and individual one-on-one counseling. The individual counseling sessions are conducted on an ad hoc basis between youth and providers and peer groups meet once a month. There is some fluidity between provider roles at the site with counselors providing adherence support and medical doctors discussing some aspects of prevention with the YLWH (Chalachala et al., 2010).

Data Collection

The first author conducted face-to-face, semi-structured, In-Depth Interviews (IDIs) in French with all fourteen of the health care providers working at the HIV care and treatment program. To be eligible participants had to: 1) be a health care provider at the clinic; 2) have direct contact with YLWH patients aged 15-24; and 3) agree to be digitally recorded. Written informed consent was obtained before the interview. Interviews were conducted in a private conference room and lasted from 1-2 hours. All interviews were digitally-recorded, transcribed verbatim and analyzed within Atlas-ti version 5.2. The interview guide assessed the following topic areas: providers' definitions and perceptions of psychosocial support, HIV prevention, and high-risk sexual behavior for YLWH; providers' experiences imparting psychosocial support and HIV prevention

counseling to YLWH; perceptions, attitudes, and beliefs related to HIV prevention counseling for YLWH; perceived roles and responsibilities in providing HIV prevention information to YLWH; and personal comfort level and confidence in dealing with HIV prevention with YLWH.

Participant Demographics

The health care providers that participated in this study included counselors, nurses, doctors, nutritionists, and PLWH volunteers. Volunteers are responsible for conducting home visits with patients at the clinic and have been trained in basic psychosocial support techniques. Nine of the participants were women and six were men. Ages ranged from 34-52 and participants had worked directly with YLWH for an average of 5 years (See Table 16 for participant demographics).

Table 16: Participant Demographics, n=14

Job Title	Gender	Age	Time working with YLWH
Nurse/Psychosocial Counselor	Female	48	7 years
Nurse/Psychosocial Counselor	Female	52	2 years
Nurse	Female	35	9 years
Doctor	Female	36	5 years
Nurse	Female	49	10 years
Doctor	Female	36	2 months
Nutritionist	Female	39	5 years
PLWH Volunteer	Female	47	1 years
PLWH Volunteer	Female	34	2 years
Doctor	Male	36	6 years
Nurse	Male	41	7 years
Doctor	Male	47	5 years
Psychosocial Counselor	Male	39	3 years
Doctor	Male	46	7 years

Data Analysis

The first author conducted qualitative content analysis using a post-positivist/realist epistemological paradigm (Grbich, 2007; Hsieh & Shannon, 2005; Ulin et al., 2005). This paradigm allows for the assumption that the social world is created through symbolic meaning such that the meaning given to data is derived from perceptions, experience, and actions within a specific context (Ulin et al., 2005). The first author spent three months at the study site. Throughout this research study she used the insights gained during the time in country to critically reflect on her role as researcher in carrying out the data collection, in interpreting the data, and in writing up the manuscript (Elliott, 2005; Saldaña, 2009). The first author followed five interrelated steps for the data analysis: reading, coding, displaying, reducing, and Interpreting (Miles & Huberman, 1994; Ulin et al., 2005). For the first step of *reading* the first author immersed herself in the data, read all of the transcripts multiple times, and began to develop questions about the data and identify preliminary emergent themes. For the second step of *coding*, the first author developed an initial codebook with topical codes based on questions from the IDI guide. She conducted an initial round of coding, assigning topical codes to sections of text so that the text could be more easily and meaningfully searched and extracted. Next, she formulated thematic codes (those based on general themes related to the interview questions) and identified emergent codes (codes developed based on new concepts and ideas not directly linked to the interview questions) and combined and separated codes as needed. The revised codes were then applied during a second round of coding. In order to ensure that codes were being applied in accordance with codebook definitions, 20% (three) of the transcripts were randomly selected and independently coded by another researcher. Any discrepancies in the coding were assessed and resolved as needed and adjustments to code applications made. Next, the first author produced code reports for the final 40 codes. For the third step, *displaying*, code summaries were developed for each of the final codes in order to identify key

sub-themes within each code and to examine the evidence supporting these sub-themes. In the fourth step, *reducing*, key elements and themes began to form and essential concepts and relationships between the different themes and sub-themes began to come together to provide a more holistic view of the data. Finally, during the fifth step of *interpretation* the first author attempted to identify and explain the core meaning of the data and synthesized and communicated the findings through the process of writing up and presenting the data. This process involved multiple re-writes and the re-organization of themes and sub-themes to most accurately reflect both the participants' perspectives and the essential meaning of the data.

RESULTS

An environment of cultural, religious and legal constraints

When asked what role providers saw in delivering HIV prevention information to YLWH, all of the health care providers felt strongly that their role included delivering sexual behavior counseling to YLWH. Interestingly, all types of providers including doctors, nurses, counselors, and PLWH volunteers, shared many of the same views and beliefs and there were no clear distinguishing characteristics in their responses to the questions in the interview guide. Providers' views of the sexuality of adolescents were reflective of those of the local culture. For example, many providers viewed youth sexual relationships as unstable, spontaneous, and short-lived. They believed youth had sex only out of curiosity or for sexual pleasure. Providers did not value the sexual relationships of adolescents because they did not occur within the context of a marital relationship. Most providers deemed youth too young to have sexual relationships and were not confident that youth could have sex without putting themselves at risk. These views led providers to at times deny the

existence of sexual activity and sexual desire among the YLWH, avoid discussion of sexual behavior, and denigrate those sexual relationships of which they were aware.

Providers described a cultural environment in which discussing adolescent sexual behaviors was “taboo”. Providers felt that this environment discouraged youth from talking about sexual behavior. Likewise, while providers said they wanted to broach the topic of sex with YLWH, they reported that their cultural context constrained them from seeking out sensitive sexual information from youth and from providing more extensive sexual behavior counseling and services.

“Prevention for youth infected by HIV is still a challenge, especially in our country where sexuality is considered a taboo...you start to realize that this taboo consists, our taboo consists of a trap for the domain of prevention.”- IDI 212

It is important to note that while providers considered sexual discussions with youth culturally inappropriate, within other spheres of Congolese life, such as in popular music or in private discussions between adults, sexuality is discussed freely. Likewise, there exist a range of cultural views on this topic that vary by socio-economic status, ethnic background, and geographic origins. Providers also acknowledged a conflict between their religious beliefs and prevention strategies, such as condom use, as reflected in the following quote.

“Here, my religion says that a young person should not have sex before marriage and using a condom is already a sin...communicating with children on condom use, to teach them that, you find that you are sinning yourself, you are pushing them to sin, you push them to sin. So you are participating in their sin, that’s why we tell them to abstain, that they have to wait until marriage, but we give, we go beyond religion because it is better to prevent than heal, it is a type of prevention, we tell them that they have to use condoms for those that are already sexually active.”- IDI 110

In addition, providers described confusion regarding their legal and professional ethical obligations to provide YLWH prevention counseling and services.

“The laws need to be clear. To know is it permitted for providers in our context to offer condoms? That I think needs to be clarified. We need to clarify the laws that exist...already we know that we can’t offer family planning but is it ok to offer condoms?” - IDI 209

In combination these perceived cultural, religious and legal constraints led to three primary impediments to effective provider-delivered sexual behavior counseling for YLWH: 1) providers' limited knowledge of youth sexual behavior; 2) providers' failure to create an environment where youth can speak openly about sexual behavior and; 3) providers' delivery of prevention services primarily limited to abstinence only counseling messages to the exclusion of other prevention services, such as access to condoms and family planning. These impediments are discussed in detail below.

Providers' Limited Knowledge of YLWH's Sexual Behavior

The majority of providers expressed the view that they had no idea how many of the YLWH were currently sexually active. When asked by the interviewer to estimate the percentage of sexually active YLWH, the responses ranged from 5% to 100% with most responses between 30% and 60%. Providers made assumptions about who was sexually active based on external cues, such as makeup or revealing clothing among young women.

"One time when we were speaking...she had a clothing style that was a bit sexy and she liked short skirts and she liked showing her bra, her cleavage, things like that so during our meetings I asked her the question if she had ever known a man."- IDI 203

Medical cues such as being pregnant, having a sexually transmitted infection (STI), or a recurrence of Tuberculosis (considered by providers a sign of non-adherence to medications and thus risky behaviors) were also used by providers to broach the topic of the youth's sexual behavior. Pregnancy was by far the most common medical cue described by providers. One provider mentioned that the only "proof" providers had of sexual activity was pregnancy. Relying on these external and medical cues contributed to providers practicing counseling in a reactive and selective rather than a proactive or preventive way. In the case below, a provider uses a young women's loss of her infant as an opportunity to counsel the youth on safe sex.

“Unfortunately the child died...since she was really shocked by the death of her daughter, I, we, I took advantage of the situation that day...and I began to speak with her..., ‘what do you plan on doing, continuing with this sexual activity without protection?’.”- IDI 105

Therefore, external cues were used to trigger counseling with the youth as providers did not have any other information to help inform the need for counseling. None of the providers described external cues for young men and many admitted that they were unaware as to whether male youth were having sex. These gender differences in how providers assessed youth sexual activity led to providers limiting their minimal sexual behavior counseling to primarily young women. One provider, after discussing how external cues are used to determine who might be sexually active, spoke about the problems associated with this approach.

“She could talk too much and not be sexually active, she could explain herself well but not be sexually active and another could be calm and she is the one who is sexually active so you can’t judge appearances to know who is sexually active and who is not...A boy, you can’t know if he is sexually active, because there are no signs, there are no external signs that show that he is sexually active unless he tells you.”- IDI 102

The above quote indicates that there was some level of understanding amongst a minority of the providers that the strategy of relying on external cues to guide prevention counseling may not be effective. It is clear that providers did not have an adequate foundation of information on YLWH sexual activity; however, they made assumptions based on the limited information they did have.

“Well, it’s difficult to know [if the youth are sexually active] because the majority deny it, after all, we don’t ask them questions openly either” -IDI 212

The consequence of the providers’ limited knowledge of youth sexual behavior is that they therefore had no systematic means of determining which youth were at risk and thus they did not know where to direct their more intensive prevention counseling efforts.

Providers’ Failure to Create an Environment Where Youth Can Speak Openly About Sexual Behavior

Providers acknowledged that they did not have a complete understanding of YLWH sexual behavior. They overwhelmingly attributed this to the lack of willingness on the part of YLWH to admit sexual activity and felt that this precluded real understanding of YLWH sexual behavior. Some providers believed youth refused to open up or even lied to them because of shame related to the lack of acceptance of youth sexual activity outside of marital relationships in their culture.

“They (the youth) are really closed, if there are some that speak they are rare – maybe two or three but it is really rare...Because they aren’t married they are single, adolescents, if they do that, they are cheating and when you are cheating, you don’t announce it, when you are cheating you hide it.” - IDI 102

Providers assumed youth shared their belief that adolescent sexual relationships were not acceptable behavior and thus felt this explained why youth did not admit to having sex. However, youth may not have felt comfortable sharing this information with providers because they were aware that providers did not condone adolescents having sex. A few providers felt that youth did not share sexual information because the YLWH considered them as “parental” figures and did not want to disappoint them. Providers in general appeared uncomfortable discussing specific sexual behaviors with youth or posing direct questions and instead insisted their role was to provide information to the youth but not to inquire about their sexual behaviors.

“I only give counsel without demanding whether or not she has had sex or not I just give counsel.”- IDI 113

Providers believed that direct questioning related to sexual behavior was not an effective way of learning about youth sexual behavior. As providers were uneasy posing pointed questions to the youth about their sexual behavior, they described using less direct ways to provide counseling. Providers attempted to use humor to approach the sensitive topic of sexual behavior including joking about the youth having a boyfriend or girlfriend to “relax the atmosphere”.

“You watch the girl grow and develop secondary sexual characteristics and you can weave in certain questions...at times you pose questions like you were joking. Like how is your boyfriend? She responds ‘doctor I don’t have a boyfriend!’ You see she responds directly that she doesn’t have a boyfriend and that directly blocks you...she says ‘no I don’t have a

boyfriend.’ ‘Oh good, that’s good, continue like that.’ And you provide prevention counseling”. - IDI 203

As soon as she responded that she did not have a boyfriend, the provider gave positive encouragement, clearly acknowledging that the youth responded with the “right” answer. In some cases, providers described delivering directive and reprimanding counseling to youth. These reprimands were usually given in response to a medical cue, for example when a young girl showed up at the clinic pregnant, as in the case below, or with an STI.

“It’s like the condom has nothing to do with you...So you are sabotaging yourself, you are not using them, now you have two children with two different fathers that don’t support you, you live with your parents, it’s good, your parents are still alive but one day when your parents won’t be there anymore, you won’t be able to study, you see, to sleep with men it’s a real pleasure for you, tomorrow when the men learn that you are seropositive they will abandon you with the children and what will become of you?”- IDI 107

Providers felt frustrated that even though they had spent time counseling youth on prevention strategies, they felt the youth were not listening to them. In their frustration they scolded the youth and continued to communicate the same messages repeatedly. This seemed to create an environment where youth may have felt judged and scolded resulting in youth feeling uncomfortable expressing their real needs.

Providers’ Delivery of Prevention Services Limited to Abstinence Only Counseling Messages to the Exclusion of Other Prevention Services

Counseling Messages

The providers’ counseling stressed the importance of YLWH protecting themselves from re-infection and protecting others from becoming infected based on the different modes of transmission. Providers concentrated their counseling mainly on modes of transmission not related to sexual behavior, such as blood transfusions or the re-use of razor blades, rather than discussing

more sensitive topics related to sex. Providers encouraged abstinence in their counseling as they believed that was the only means to ensure that youth were not putting themselves and others at risk. Providers believed that once youth became sexually active it was very difficult for YLWH to control their behavior and to practice safe sex.

“Abstinence is better for protecting the youth...so that these youth don’t put themselves in situations that could bring them down, that could push them to have another type of sexual life”- IDI 108

Providers’ beliefs on adolescent sexual behavior also influenced their counseling related to fidelity.

“An adolescent that’s not married, he would be faithful to whom?”- IDI 102

Providers did not consider the promotion of “faithfulness” to be relevant for the types of relationships engaged in by YLWH.

Providers did at times communicate messages related to condom use, primarily for youth already sexually active who the providers believed could not control their sexual urges. Providers appeared to choose what they may have considered a middle ground between the importance of prevention and the cultural, religious, and legal context in which they worked — they offered condom use to YLWH as a potential strategy targeted to a selected group of youth but did not encourage it for all youth and in many cases discouraged it. Condoms were recommended as a preventive last resort. During the interviews, a few providers said that they “promoted” condoms but then quickly corrected themselves to say that they “offer” condoms as a possible option. Most providers felt strongly that they did not want to come across as promoting engagement in sexual activity through encouraging the use of condoms, but rather they wanted to provide the information and allow the youth to make decisions as to how they would use this information. However, this led them to deliver mixed messages, as in the quote below, and thus they potentially missed the opportunity to effectively counsel youth on condom use.

“So, I give the counsel, ‘stop with this life! But if you end up doing it you must wear a condom. You must require condoms even if the person refuses you tell the person: I don’t

know you, I don't know your serostatus, you don't know my serostatus either, protect yourself and I too will protect myself. That's the ideal – like that you will protect yourself and others but I'm not asking you to do that, me, I'm counseling you to be abstinent'." - IDI 212

This quote is particularly illuminating as the provider delivers the message of condom use as a preventive strategy, but couches this counsel within a firm request that the youth not follow this guidance but instead remain abstinent. Therefore, while providers believed they were counseling youth on safe sex and condom use, they were not aware that the way the information was presented may have influenced youth condom use decisions.

Access to Condoms

Providers reported that condoms were available in the pharmacy and that a system had been put in place for providers to write condom prescriptions for patients. However, after probing it became clear that the majority of providers were not comfortable prescribing condoms to YLWH.

"Well I don't know if someone else has given them, but me, personally, I've never offered them, no one has ever asked me and I've never offered."- IDI 102

As condoms at the clinic were available only at the pharmacy, providers were unaware if YLWH were accessing condoms. However, many stated that they believed it was unlikely that youth were accessing condoms due to the shame involved in requesting condoms. Many providers were aware that by not accessing condoms in the clinic, YLWH were at greater risk and some proposed ideas for how the situation could be rectified. Some suggested putting condom distribution boxes in the bathrooms at the clinic or including condoms with each prescription of medications, whether or not condoms were requested. In contrast to other areas of their counseling, providers acknowledged that the clinic environment impeded youth from learning about and using condoms. However, the providers struggled to find ways to adapt their counseling messages and create an open dialogue with youth within a context of what they saw as legal, ethical, and moral barriers.

Family Planning

Similarly, the majority of providers were adamant that family planning, like condoms, was not appropriate for YLWH to prevent unwanted pregnancies or mother-to-child transmission. Youth were not referred to the clinic's designated family planning nurse unless they were married or had already given birth to a child. Most providers felt that adolescent sexual relationships were fleeting as opposed to more stable marital relationships and this may have contributed to their not recommending these services for YLWH. These providers felt that there was no need for family planning services for youth, as their understanding was that this was only indicated for couples having sex regularly.

"So the difference is that often for young women we don't focus on family planning like that, because sexual activity for young women is not the same as sexual activity for adult women...It's different; adolescents who do that do it for sexual pleasure or do it only occasionally"- IDI 101

Many providers felt that it was the youth's responsibility to request family planning services; however, few ever did. In one case when a young girl who had previously been pregnant approached a provider to inquire about family planning options, she was told that it was not appropriate.

"And so she came here and said she wanted family planning. Me, I said 'you aren't married, when you want family planning it is to continue without condoms so you are not doing anything special. It's true you will avoid getting pregnant, but re-infection, you won't avoid that with family planning. You are a girl, you are younger than 18 and you aren't even married why do you want to do family planning?'"- IDI 107

Even the fact that the young woman had already been pregnant was not sufficient for the provider to offer family planning counseling. This provider felt that using family planning would lead the young woman to have unprotected sex and therefore put herself at risk of re-infection, and thus prioritized this potential risk over the risk of an unwanted pregnancy or mother-to-child transmission. A few of the providers mentioned believing that it was illegal to provide family planning counseling to youth under the age of 18 in the DRC and that family planning required the

permission of the male husband or partner. This further complicated the ability of providers to deliver family planning services to youth.

DISCUSSION

Providers believed it was their role to deliver Positive Prevention counseling and felt the counseling they were providing was in the youths' best interest. However, providers' lack of knowledge and comfort in talking to youth about sex because of cultural and religious beliefs about sexuality, coupled with confusion about their legal obligations, made it difficult for them to effectively counsel youth or create an environment where youth felt comfortable talking with their providers about HIV or sexual health. This seriously compromised the delivery of comprehensive adolescent counseling and services. Counseling, when provided rarely went beyond this discussion of whether or not the youth had a boyfriend or girlfriend, yet providers believed that this act of casual inquiry served as prevention counseling. Few youth admitted to having a partner, and thus for the majority of YLWH this was the extent of prevention counseling they received. Likewise, providers did not adapt the counseling to the individual needs of each youth and delivered highly general and didactic counseling, targeted only to those youth they assumed to be at most risk.

In a study on contraceptive use by South African adolescents, the inability of nurses to recognize their views of adolescent sexuality as a barrier to services was recognized, similar to themes revealed in our study (Wood & Jewkes, 2006). In the same study, nurses felt that youth requesting contraception was equivalent to a public admission of having sex and was therefore was not encouraged and thus perpetuated the negative view of adolescent sexual behavior. Providers at the study site in Kinshasa were similarly hindered by their views of adolescent sexual behavior and this led to reduced effectiveness of the counseling and services they were able to provide. Recent research on Positive Prevention has pointed to the importance of focusing on provider attitudes and

beliefs to improve programs, in addition to the administrative or logistical issues most frequently cited in studies based in the U.S. (Gilliam & Straub, 2009; Koester et al., 2007; Myers et al., 2007; Patel et al., 2009). Effective potential mechanisms to address provider attitudes and beliefs that may get in the way of effective prevention counseling are “values clarification” trainings. These trainings help providers become aware of how their beliefs and assumptions can negatively influence prevention counseling. They can also help providers address the disconnect between their perceptions of the impacts of their counseling and the actual effects of their counseling. “Values clarification” training should include three components: 1) self-reflection to uncover the providers attitudes, beliefs, prejudices and fears and how these may cause barriers to prevention counseling; 2) contextualization of the counseling in the context of public health by helping providers fully understand the need for such services and their own role implementing the services; and 3) sensitization of providers to their youth patients’ rights, needs, and specific individual circumstances (Reproductive Health and HIV Research Unit, 2005).

Studies in the U.S., Brazil, and South Africa have also shown that providers tended to focus their counseling on PLWH that they perceived to be at higher risk or presented with clinical prompts, such as an STI or pregnancy (Drainoni et al., 2009; Fehringer et al., 2006; Peltzer & Ndlovu, 2005; Wilkinson et al., 2006). Thus, in order to ensure that prevention counseling is reaching all youth, and is not dependent on external cues, clinics should develop systematic guidelines recommending that providers engage *all* youth in discussions related to their sexual behavior and screen these young patients for HIV transmission risk and counsel them on sexual risk, condom use, disclosure to sexual partners, treatment adherence, and mental health.

Providers placed blame on youth reticence and societal norms and taboos rather than considering alternative reasons why youth were unable to engage in discussions of sexual behavior with medical providers. There was no acknowledgement that providers may be contributing to an

environment in which YLWH did not feel safe to share their feelings and experiences related to sexual behavior, and that this is something that could be rectified with improved counseling. This was most likely due to the providers' entrenchment within their own cultural norms and attitudes. The institutionalized, authoritative style of providing care that pervades sub-Saharan African medical institutions may have also contributed to challenges providers faced in creating an environment conducive to open discussions of adolescent sexual behavior (Woods et al., 2006). Patients were not encouraged to take an active role in discussions, which left little room for dialogue about prevention of transmission (Chalachala et al., 2010; Kim et al., 1999). To improve patient-provider relationships and create a more open environment, providers should be trained to dialogue more collaboratively with patients. This training could help providers learn effective methods to: 1) explore patient feelings about sexual activity, 2) use youth's existing knowledge of HIV as a means of engagement, 3) address barriers identified by the youth for safe sex, 4) understand youth's perceptions that could influence high-risk sexual behaviors, and 5) give tools to youth to plan for safer sex (Pinto, 2001).

Providers' delivery of counseling messages were not comprehensive in nature and were primarily abstinence only messages. Similarly, a few studies in the U.S. showed a decrease in delivery of Positive Prevention counseling and provision of services at those clinics where providers reported signs of high "fatalism" or believed that counseling would have no impact (Myers et al., 2007; Steward et al., 2006). This corresponds to our findings that many providers focused primarily on abstinence and refused to provide condoms and family planning services because, among other reasons, they were not confident YLWH engaging in sexual behavior could follow more nuanced counseling messages. It is only once providers have a greater understanding of youth sexual behavior and trust that youth are capable of following prevention counseling that their counseling and services may be improved.

The lack of clear information and guidance concerning legal and ethical issues surrounding the provision of prevention counseling and services to YLWH also contributed to the delivery of limited sexual behavior counseling. In order to address this issue, clinic administrators should become aware of how local and national laws affect what providers can and cannot discuss in the context of services for youth. For example, while there was previously a 1958 law in the DRC that outlawed family planning due to the government's aim of increasing the population, this law is no longer enforced and had specific exceptions for health reasons (Kashamuka Mwandagilirwa, 2010). Providing relevant legal and medical ethics information to providers through clinic-level policies and through specific training for providers working with youth would help address this challenge.

In order for providers to deliver effective prevention counseling to YLWH, clinics should follow adolescent-friendly clinic standards, provide counseling in an adolescent-friendly style, and institute an effective referral system for prevention services. Current best practices for adolescent-friendly clinics include: 1) comfortable surroundings; 2) short wait times; 3) policies and processes that support the rights of youth; 4) youth involvement in design and continuing feedback; and 5) systems in place to train staff to provide effective adolescent-friendly services (Dickson-Tetteh, Pettifor, & Moleko, 2001; Senderowitz, Hainsworth, & Solter, 2003). Ongoing trainings should teach providers how to: 1) create an atmosphere of empathy and active listening; 2) exhibit patience and encourage trust; 3) create a confidential atmosphere; 4) use a direct and explicit style; and 5) allow adolescent patients to verbalize their understanding of HIV, clarify misconceptions, and fill in gaps in knowledge (The Pennsylvania/MidAtlantic AIDS Education and Training Center, 2006). Finally, a referral system should be instituted that formalizes the process of referring YLWH patients to appropriate prevention services.

In the context of human resource shortages and overburdened staff in low-resource settings, adolescent-friendly systems can help make providing services to YLWH a multi-disciplinary

team effort. If providers are able to provide adolescent-friendly clinical care they can more effectively respond to YLWH prevention needs by focusing on providing appropriate care and treatment while making referrals to counselors or trained PLWH volunteers for access to condoms, family planning, and more extensive HIV transmission prevention counseling.

Limitations

Providers may have presented a more positive picture about their commitment to Positive Prevention than is actually the case. However, providers were informed that there were no right or wrong answers to any of the questions and that their responses would be confidential and were encouraged to be candid in their responses. In addition, these providers are not representative of all providers working with YLWH in the DRC. They reflect a specific population of health care providers working in an HIV care and treatment program at a pediatric hospital in Kinshasa. Despite these limitations, this study provides an important new understanding of the barriers to provider-delivered prevention counseling for YLWH.

Conclusion

HIV prevention services for YLWH can be improved through the creation of a more adolescent-friendly environment as well as by providing “values clarification” and skill-based trainings so that providers are able to assess the role of their own beliefs as well as learn new skills. This may give providers the confidence and skills they need to improve the prevention services provided to YLWH and the ability to confront the constraints of their work environment.

CHAPTER 7: CONCLUSION

This conclusion chapter begins with a brief summary of findings for each of the specific aims, then describes the strengths and limitations of the dissertation, and concludes with a discussion of implications for research and practice.

Summary of Findings: Specific Aim 1

To address Specific Aim 1 *“To examine the feasibility of an adapted evidence-based clinic-based Positive Prevention intervention (Supporting Youth and Motivating Positive Action - SYMPA) implemented with YLWH ages 15-24 in Kinshasa, DRC”* three research objectives were achieved:

4. The CDC-ADAPT guidelines were followed to adapt an Evidence-Based Positive Prevention Intervention for YLWH ages 15-24 in Kinshasa, DRC;
5. The adapted Evidence-Based Positive Prevention Intervention for YLWH ages 15-24 in Kinshasa, DRC was implemented and;
6. The feasibility of an adapted Evidence-Based Positive Prevention Intervention for YLWH ages 15-24 in Kinshasa, DRC was assessed.

Research Objective 1 and 2

To achieve research objectives 1 and 2 the first four steps of the ADAPT guidelines: *assess*, *select*, *prepare*, and *pilot* were conducted. There were key activities involved in completing each of the four action steps as described in Chapter 4. Throughout the structured adaptation we learned six important lessons:

- 1) The quality of work conducted during the first step of the ADAPT framework, *assess*, determines the success of the future steps.
- 2) It is not necessary to use an EBI that targets the exact same population.
- 3) Many EBIs previously implemented successfully in high resource countries can be suitably adapted for low-resource countries.
- 4) The process of adapting the intervention itself has the potential to greatly increase the staff's capacity to effectively implement the intervention.
- 5) Adaptation is an iterative process – the feedback loops between steps are crucial to ensure that appropriate decisions are being made and that the eventual adapted intervention will be successful.
- 6) The adaptation process needs to be flexible enough to allow the addition of new content when necessary to address specific needs not included in the original intervention. Thus, it is not only appropriate to include additional components to the original intervention but doing so can strengthen the intervention overall.

Research Objective 3

A recent examination of the feasibility of public health interventions led to the development of guidelines to help evaluate and prioritize those interventions deemed “feasible” and that have the greatest likelihood of being efficacious (Bowen et al., 2009). Data were collected on the following four areas of the framework: acceptability, implementation, adaptation, and limited-efficacy testing. Thus in order to achieve research objective 3 the following research questions were asked:

2. To what extent will the pilot intervention (SYMPA) meet the following feasibility criteria from the perspective of YLWH ages 15-24 and providers in Kinshasa, DRC:

- e. *Acceptability*: To what extent is SYMPA suitable, satisfying, or attractive to program facilitators? To program recipients?
- f. *Implementation*: To what extent can SYMPA be successfully delivered to intended participants in some defined, but not fully controlled, context?
- g. *Adaptation*: To what extent does an existing intervention such as the Healthy Living Project perform when changes are made for a new format or with a different population?
- h. *Preliminary Efficacy*: Does SYMPA show promise of being successful with the intended population?

Acceptability

Findings from the feasibility analysis showed that YLWH overwhelmingly reported being satisfied with the SYMPA intervention, and felt the intervention addressed their specific needs. However, youth identified two ways in which the intervention could be more applicable to their specific circumstances: 1) including content to address their concerns related to disclosure of their HIV status; and 2) more in-depth information related to marriage in the context of living with HIV. Overall, SYMPA facilitators were eager to implement the program, further develop their competence in group facilitation, and expand their skills in Positive Prevention counseling and services.

Implementation

The SYMPA intervention was fully implemented as planned and all the topics included within the six sessions successfully delivered to the YLWH participants with a very high retention of participants. Two primary challenges to implementation were raised by both the participants and facilitators during the intervention implementation and the FGDs and IDIs: 1) length/timing of sessions and 2) education/literacy level of youth participants.

Adaptation

There were three major adaptations made to the original intervention: 1) reduction of the number of sessions from 15 to six (by combining similar sessions and eliminating content not directly relevant for the target population); 2) change from an individual adult format to a single-sex youth group format; and 3) the addition of a “Very Important Person (VIP)” social support component to help provide support to YLWH over the long term in achieving their goals and objectives developed during the intervention. Overall, the adapted intervention was well-received by the new target population of YLWH in the DRC and the VIP component was particularly well-received.

Preliminary Efficacy

The intervention showed promise of success with the target population, as assessed by youth and facilitators’ reports of the effects of the intervention on YLWHs’ HIV prevention knowledge and skills. YLWH reported improving their problem-solving skills, increasing their knowledge of sexual prevention topics, improving their condom use skills, improving their ability to deal with triggers for unsafe sex, and increasing their capacity to assess the level of risk of different behaviors. YLWH also reported increasing their autonomy in decision making, improving their ability to negotiate safer sexual relationships, increasing their openness to discuss sexual behavior with their caregivers, and improving their ability to develop positive goals for their future.

Improving Feasibility

Using the Bowen Feasibility Framework, findings from this study show that the adapted intervention was suitable, satisfying, and attractive to both program facilitators and participants, able to be implemented effectively, performed well with a new population, and showed preliminary efficacy. Although the intervention was determined to be highly feasible in this environment, there are certain

aspects of the intervention that must be addressed prior to moving forward with wider implementation and evaluation including: 1) incorporating more content about navigating marriage while living with HIV; 2) further tailoring discussions on disclosure; 3) addressing timing and length of sessions by conducting shorter sessions over the summer vacation holiday; 4) further simplifying content to reflect the education level of the participants and adapt specific activities requiring written responses for those youth unable to write; and 5) having VIPs participate in more than one session.

Summary of Findings: Specific Aim 2

To address Specific Aim 2: *To explore qualitatively how providers' attitudes and perceptions of YLWH sexual behavior may shape their sexual transmission prevention counseling for YLWH, ages 15 to 24 in Kinshasa, DRC* the following research questions were addressed:

4. What are providers' perceptions, attitudes, and beliefs regarding YLWH sexual behavior?
5. What are the providers' experiences in providing prevention counseling to YLWH?
6. What are the barriers and facilitators for providers related to prevention counseling with YLWH?

Perceived cultural, religious and legal constraints led to three primary impediments to effective provider-delivered sexual behavior counseling for YLWH: 1) providers' limited knowledge of youth sexual behavior; 2) providers' failure to create an environment where youth can speak openly about sexual behavior and; 3) providers' delivery of prevention services primarily limited to abstinence only counseling messages to the exclusion of other prevention services, such as access to condoms and family planning.

Providers believed it was their role to deliver Positive Prevention counseling and felt the counseling they were providing was in the youths' best interest. However, the majority of providers expressed the view that they had no idea how many of the YLWH were currently sexually active. They therefore had no systematic means of determining which youth were at risk and thus they did not know

where to direct their more intensive prevention counseling efforts. Providers overwhelmingly attributed their limited knowledge of YLWH sexual behavior to the lack of willingness on the part of YLWH to admit sexual activity. This seemed to create an environment where youth may have felt judged and scolded resulting in youth feeling uncomfortable expressing their real needs. Providers encouraged abstinence in their counseling as they believed that was the only means to ensure that youth were not putting themselves and others at risk. Most providers felt strongly that they did not want to come across as promoting engagement in sexual activity through encouraging the use of condoms, but rather they wanted to provide the information and allow the youth to make decisions as to how they would use this information. In this case providers acknowledged that the clinic environment impeded youth from learning about and using condoms. However, the providers struggled to find ways to adapt their counseling messages, provide appropriate prevention services, and create an open dialogue with youth within a context of what they saw as legal, ethical, and moral barriers.

Consequences of Current Counseling Practices

Providers' lack of knowledge and comfort talking to youth about sex because of cultural and religious beliefs about sexuality, coupled with confusion about their legal obligations related to youth and contraception, made it difficult for them to effectively counsel youth or create an environment where youth felt comfortable talking with their providers about HIV or sexual health. This seriously compromised the delivery of comprehensive adolescent counseling and services. Counseling, when provided rarely went beyond this discussion of whether or not the youth had a boyfriend or girlfriend, yet providers believed that this act of casual inquiry served as prevention counseling. Few youth admitted to having a partner, thus for the majority of YLWH this was the extent of prevention counseling they received. Likewise, providers did not adapt the counseling to the individual needs of each youth and delivered highly general and didactic counseling, targeted only to those youth they

assumed to be at most risk. As a result, the counseling that was provided may have been ineffective in helping youth remain sexually healthy.

Suggestions for Improving Provider-Delivered Prevention Counseling

Effective potential mechanisms to address provider attitudes and beliefs that may get in the way of effective prevention counseling are “values clarification” trainings which help providers become aware of how their beliefs and assumptions can negatively influence prevention counseling (Reproductive Health and HIV Research Unit, 2005). In order to ensure that prevention counseling is reaching all youth, and is not dependent on external cues, clinics should develop systematic guidelines recommending that providers engage *all* youth in discussions related to their sexual behavior and screen these young patients for HIV transmission risk and counsel them on sexual risk, condom use, disclosure to sexual partners, treatment adherence, and mental health. Likewise, to improve patient-provider relationships and create a more open environment, providers should be trained to dialogue more collaboratively with patients. In addition, providing relevant legal and medical ethics information to providers through clinic-level policies and through specific training for providers working with youth would help address providers’ confusion about how to advise youth about contraception. Finally, for providers to deliver effective prevention counseling to YLWH, clinics should follow adolescent-friendly clinic standards, provide counseling in an adolescent-friendly style, and institute an effective referral system for prevention services.

Strengths

This dissertation research has shown that an EBI developed and implemented in the U.S. can be adapted successfully and was feasible for implementation with a different target population in a low-resource context. This research also provides an important new understanding of the barriers to

provider-delivered prevention counseling for YLWH. This research has provided a foundation for other organizations seeking to adapt EBIs for low-resource settings, examine the feasibility of an adapted intervention, and improve provider-delivered prevention counseling. For Aim 1 this is the first Positive Prevention evidence-based intervention adapted using the ADAPT framework for implementation with YLWH in a low-resource setting. Thus, a primary strength of this dissertation research is that a systematic and participatory process was followed during adaptation. This process was carefully documented and results from each of the steps of the ADAPT guidance were reported so that other researchers and practitioners can learn about the specific steps necessary to conduct a systematic adaptation of an EBI. These important steps are often omitted from the peer-reviewed literature because of space limitations or due to a preference for reporting results rather than processes. Thus this research provides a rare detailed description of the adaptation process that may aid other organizations that seek to adapt and implement other HIV prevention EBIs in sub-Saharan Africa or beyond.

A second strength of this research is that the adapted intervention was assessed for feasibility using an innovative framework for the analysis of study data collected prior to, during, and after the implementation of the adapted pilot intervention. Using these guidelines allowed for a structured means of assessing feasibility that may be compared across other similar studies and provide a meaningful assessment of whether or not the adapted intervention is ready for wider implementation and evaluation. Likewise, the fact that both YLWH and facilitator perspectives were represented in the feasibility analysis is a strength of this research.

For Aim 2 this is the first study that has looked specifically at the unique experiences of provider-delivered Positive Prevention counseling with YLWH in sub-Saharan Africa. Understanding provider attitudes, beliefs, and perspectives on prevention counseling is important not only to inform provider-delivered counseling but also to ensure that their values and beliefs can be addressed so that they are able to affectively facilitate and implement group interventions such as SYMPA. An advantage

of the provider interviews is that they were both conducted and analyzed interviews in French; thus no loss of meaning occurred as the transcripts were never translated into English. In addition, the author spent three months at the study site. Throughout this research study, the author used the insights gained during the time in country to critically reflect on her role as researcher in carrying out the data collection, in interpreting the data, and in writing up the manuscript which led to a more rigorous qualitative analysis of the findings. Finally, the interview guide was developed based on extensive review of the literature and was adapted to be culturally appropriate for this specific setting.

Limitations

One limitation of the research conducted for Specific Aim 1 is the potential social desirability bias in the reporting of the facilitators as the facilitators might have reported positively on the intervention so that it appeared they did a good job implementing the intervention. However, as the facilitators were aware that they will most likely be involved in any future efficacy trial or implementation of this intervention, the facilitators may have felt a vested interest in making sure that the intervention is improved as much as possible and that challenges are addressed, thus, moving them to provide more honest and thoughtful responses to the questions. A second limitation is that by using a purposive sample of 13 of the 191 youth currently being followed at the clinic, these youth may have been more interested in learning about Positive Prevention than other YLWH in Kinshasa, and program staff may have identified those most likely to succeed. However, the goal of this study was not generalizability but rather the ability to assess the explicit aims of the feasibility analysis; therefore, a purposive sample was appropriate to meet these predefined areas of focus of acceptability, implementation, adaptation, and limited efficacy. An additional limitation of Specific Aim 1 is the lack of quantitative data on behavior change outcomes resulting from the intervention, which was beyond the scope of this study.

For Specific Aim 2, providers may have presented a more positive picture about their commitment to Positive Prevention than is actually the case. However, providers were informed that there were no right or wrong answers to any of the questions and that their responses would be confidential and were encouraged to be candid in their responses. In addition, these providers are not representative of all providers working with YLWH in the DRC. They reflect a specific population of health care providers working in an HIV care and treatment program at a pediatric hospital in Kinshasa.

Implications for Future Research and Practice

The International Association of Physicians in AIDS Care Panel has recently published guidelines for improving entry into and retention in care and ARV adherence for PLWH. In their evidence-based guidelines they recommend: 1) multidisciplinary education and counseling intervention approaches; 2) intensive youth-focused case management for adolescents and young adults living with HIV; and 3) pediatric- and adolescent-focused therapeutic support interventions using problem-solving approaches and addressing psychosocial context (Thompson et al., 2012). Findings from this dissertation research suggest that the way forward may be to incorporate multidisciplinary efforts in order to meet the unique needs of YLWH living in low-resource countries. Based on these findings it is recommended that prevention programs should provide the following services: 1) institutionalized adolescent-friendly clinic standards; 2) brief provider-delivered counseling and screening for risk behaviors with an effective referral system for prevention services; and 3) peer group implementation of the SYMPA intervention for higher risk youth. In the context of human resource shortages and overburdened staff in low-resource settings, adolescent-friendly systems can help make providing services to YLWH a multidisciplinary team effort. If providers are able to provide adolescent-friendly clinical care they may be able to more effectively respond to YLWH prevention needs by focusing on providing appropriate care and treatment, screening for risk, and providing brief prevention counseling. They can then make referrals to counselors or trained PLWH volunteers, as necessary, for access to condoms, family

planning, and more extensive HIV transmission prevention counseling. Youth screened by providers as higher risk can be referred for participation in the SYMPA intervention where they can receive additional provider, peer, and VIP support in developing the tools necessary to prevent further transmission of the disease and so that they remain healthy over the long term.

Both the provider-delivered counseling and risk screening and the SYMPA intervention must be delivered within a clinic setting where prevention services are available and accessible (i.e. youth have access to condoms and other forms of contraception) and nurses, counselors, pharmacists, or PLWH volunteers providing these services are trained in adolescent-friendly counseling techniques. These services should be provided within a context in which structural factors such as poverty, community level stigma, and gender inequality are acknowledged and the counseling provided reflects a comprehensive understanding of the ways in which these structural factors impact individual decision making. Likewise, environmental issues such as availability of food, housing, and transportation must be addressed and referrals to organizations providing these services locally, if available, must be pursued as part of any holistic adolescent-friendly service package. Thus, as a component of any clinic prevention program, all staff and volunteers working with youth patients at the clinic should be trained on adolescent-friendly standards. Clinics that have institutionalized adolescent-friendly standards have been shown to better support the rights of adolescents and that program staff assist youth in a nonjudgmental manner (Dickson, Ashton, & Smith, 2007).

The National Institute of Health (NIH) Plan for HIV-related research for fiscal year 2012 has indicated “translational research (i.e. dissemination, implementation, or operational) research to foster the scale-up and optimize the use of existing efficacious interventions to prevent and treat HIV infections” as a research priority. The NIH has stated that priority should be given to “developing methodologies needed for designing, conducting, and interpreting such research” (Whitescarver, 2012). This dissertation used the CDC ADAPT process to systematically adapt and implement an evidence-based

positive prevention intervention as well as an innovative framework to examine the feasibility of this intervention for application with YLWH in a low-resource setting, thus responding directly to these research priorities. Likewise, findings from the research examining provider-delivered counseling point to the importance of instituting adolescent-friendly clinic standards which has been evaluated and found to improve the quality of services provided to adolescents in other low-resource settings (Dickson et al., 2007; Larke et al., 2010). Future research should examine the efficacy of a complementary positive prevention program that incorporates 1) institutionalized adolescent-friendly clinic standards; 2) brief provider-delivered counseling and screening for risk behaviors with an effective referral system for prevention services; and 3) peer group implementation of the SYMPA intervention for higher risk youth. Once this program is deemed efficacious in a low-resource context the program can be disseminated to other low-income settings seeking to improve services and meet the needs of the growing YLWH population.

UNAIDS has recently reported that HIV incidence has reduced in 33 countries globally, with 22 of these countries being in sub-Saharan Africa, the region most greatly impacted by the AIDS epidemic (UNAIDS, 2011b). While this is certainly encouraging, as of 2010 there are an estimated 34 million PLWH (UNAIDS, 2011b). While this likely reflects the expansion of ARVs and the subsequent reduction in AIDS deaths, this is still a substantial number of PLWH in need of services, particularly in sub-Saharan Africa (UNAIDS, 2011b). Sixty-eight percent of the 34 million PLWH live in sub-Saharan Africa, even though that region makes up only 12% of the global population (UNAIDS, 2011b). Likewise, in 2010, 70% of all new infections occurred in sub-Saharan Africa (UNAIDS, 2011b). This shows the urgency in continuing to target treatment and prevention efforts to this region of the world. Globally, in 2009, young people ages 15-24 accounted for 41% of all new infections and there were over 5 million young people living with HIV (UNAIDS, 2011a). With over 76% of YLWH located in sub-Saharan Africa, and with

their increased access to HIV testing and treatment, this growing population will be in need of comprehensive prevention services (UNAIDS, 2011a).

UNAIDS, in 2011, put forward an investment framework encouraging the allocation of resources to the following six areas: 1) Focused interventions for key populations at higher risk; 2) Elimination of new HIV infections among children; 3) Behavior change programs; 4) Condom promotion and distribution; 5) Treatment, care and support for people living with HIV; and 6) Voluntary medical male circumcision in countries with high HIV prevalence and low rates of circumcision (UNAIDS, 2011b). The Positive Prevention programs suggested here include the majority of the areas included in the UNAIDS investment framework. Positive Prevention programs such as those suggested in this conclusion have a greater possibility of truly providing “complementary prevention” in which key clinical and public health interventions are combined and integrated in such a way that they result in a greater impact than the sum of their parts (Holtgrave, Maulsby, Wehrmeyer, & Hall, 2012). For example, complementary Positive Prevention programs will be particularly important within the context of Treatment as Prevention interventions (Cohen et al., 2011). In order for Treatment as Prevention interventions to be effective, behavioral programs must complement these interventions so that YLWH remain engaged in care and remain adherent to their medications, particularly as YLWH will need to continue their care throughout their lives (Kippax & Stephenson, 2012; Walensky, 2009). This is but one example of how Positive Prevention behavioral interventions can be combined with more biomedical interventions so that patients’ needs are addressed effectively. The Positive Prevention programs described throughout this dissertation are vital to meet the increasing needs of the growing YLWH population in sub-Saharan Africa. With effective complementary Positive Prevention programs there is indeed hope of getting to the UNAIDS’ vision of “zero new HIV infections, zero discrimination, and zero AIDS-related deaths” (UNAIDS, 2011b).

Appendix 1:
SYMPA Intervention Session Activities

SESSION 1

Outcome: Client will identify at least one attainable goal related to the Life Project

Skill 1: Client will identify personal strengths related to the Life Project

Skill 2: Client will identify challenges related to the Life Project

Session 1..... 90 minutes

Check-In20 minutes

- Facilitator begins to establish a safe, supportive rapport with Client
- Provide an overview of project content
- Discuss Client's expectations for participation in this project

Life Context50 minutes

Discuss Client's perceptions of personal strengths and challenges in the following areas:

- Physical/medical history
- Psychiatric history
- Substance use/abuse history
- Stigma/discrimination experience(s)

Client identifies personal strengths and challenges in the following areas:

- Client's current living situation
- Social and professional relationships
- Background and family history
- Disclosure issues

Wrap-Up.....20 minutes

- Discuss Life Project concept
- Review of identified personal strengths
- Assist Client in developing his or her personal Life Project by identifying a clear, realistic, and measurable goal related to the Life Project

SESSION 2:

Outcome: Client will identify personal stressors and will be able to appropriately apply emotion-focused and/or problem-focused coping strategies to identified personal stressors

Skill 1: Client will be able to discern changeable and unchangeable stressors

Skill 2: Client will identify how his/her thought processes affect moods and perceptions of stressors

Skill 3: Client will apply an emotion-focused coping strategy to an unchangeable stressor

Skill 4: Client will apply a problem-focused coping strategy to a changeable stressor

Session 2..... 100 minutes

Check-In/Life Context..... 15 minutes

- Review last week's life events
- Discuss progress of goal and Life Project
- Discuss session content as it relates to the Client's life context

Skills-Building 20 minutes

- Enhance Client's understanding of the impact of stress on everyday life
- Assist Client to develop Personal Stressors List
- Assist Client to narrow identified stressors from global conditions to specific situations, using Personal Stressors Worksheet
- Assist Client to classify identified stressors as changeable or unchangeable (Personal Stressors Worksheet)
- List identified stressors and assist Client to classify each as emotion-focused or problem- focused coping strategies (Stress and Coping Worksheet)

Problem-Solving 50 minutes

- Assist Client to complete the "Reasons Why" column of the Personal Stressors Worksheet
- Use emotion-focused strategies to problem- solve one Client identified unchangeable stressor (Emotion-Focused Worksheet)
- Use problem-focused strategies to problem- solve one Client identified changeable stressor (Problem-Focused Worksheet)

Wrap-Up..... 15 minutes

- Assist Client in identifying how effectively dealing with stress impacts other areas of his/her life
- Client sets goal related to personal specific stressors
- Review Client's Life Project
-

SESSION 3

Outcome: Client will decrease personal risky sexual behaviors

Skill 1: Client will identify at least one trigger that may lead him/her to engage in risky behaviors

Skill 2: Client will develop a plan to reduce risk for one identified personal behavior

Session 3.....90 minutes

Check-In/Life Context..... 20 minutes

- Review last weeks life events
- Discuss progress of goals and Life Project
- Discuss session content as it relates to the Client's life context

Skills-Building 20 minutes

- Discuss Client's personal risky behavior
- Do Continuum of Risk activity

Problem-Solving35 minutes

- Client identifies and problem-solves trigger(s) related to personal risky behavior

Wrap-Up.....15 minutes

- Client sets goal related to personal risky behavior
- Review Client's Life Project

SESSION 4

Outcome 1: Client will successfully demonstrate proper placement of the male condom using a wooden penis model and will successfully demonstrate proper placement of the female condom using a vaginal model

Outcome 2: Client will successfully demonstrate (through in-session role-plays) increased skill in negotiating safer sex practices with all sexual partners

Skill 1: Client will identify at least one challenge related to the male and/or the female condom use

Skill 2: Client will successfully identify and incorporate three key components of assertive communication in negotiating safer behaviors

Session 4..... 100 minutes

Check-In/Life Context20 minutes

- Review last week's life events
- Discuss progress of goal and Life Project.
- Discuss Session content as it relates to the Client's life context

Skills-Building40 minutes

- Brief discussion of male anatomy
- Male condom demonstration and Client practice
- Brief discussion of female anatomy
- Female condom demonstration and Client practice
- Brief discussion of STDs
- Assess Client's ability to communicate assertively
- Engage Client in a role-play to enhance their assertive communication skills
- Assist Client to apply assertive communication skills to negotiation of condom use/safer sex practices

Problem-Solving.....20 minutes

- Client identifies and problem solves triggers related to barriers to condom use
- Client identifies and problem-solves trigger(s) related to barriers to negotiating safer sex

Wrap-Up..... 20 minutes

- Client sets goal related to condom use
- Client sets goal related to negotiating safer sex
- Review Client's Life Project

SESSION 5

Outcome 1: Client will increase positive supportive relationships

Outcome 2: Client will increase decision-making skills surrounding disclosure decisions

Skill 1: Client will identify three types of social support (emotional, informational, and tangible)

Skill 2: Client will identify positive sources of social support for each of the three categories

Skill 3: Client will identify personal and environmental factors related to disclosure decisions

Session 5.....145 Minutes

Check-In/Life Context..... 15 minutes

- Review last week's life events
- Discuss progress of goal and Life Project
- Discuss session content as it relates to the Client's life context

Skills-Building 50 minutes

- Discuss the three types of social support
- Discuss positive vs. negative social support
- Assist Client to identify his/her personal social support network(s)
- Assist Client to identify members of his/her personal support network appropriate to each supportive category
- Discuss Client's attitudes and beliefs surrounding disclosure
- Engage Client in a dialogue about past disclosure decisions and experiences (if any)
- Assess Client's decision-making skills and self-efficacy surrounding disclosure

Problem-Solving 60 minutes

- Review Personal Stressor Worksheet
- Assist Client to determine which supportive category would be most appropriate for each of the identified stressors
- Assist Client to identify who in their social network(s) would be most helpful in providing support for each stressor
- Client identifies and problem-solves trigger(s) that impact his/her decision-making process

Wrap-Up..... 20 minutes

- Facilitator assists Client to role-play social support situations
- Client sets goal related to increasing positive social support
- Client sets goal related to disclosure or the decision-making process
- Review Client's Life Project

SESSION 6

Outcome: Client will identify at least one area of his/her life that was enhanced while participating in each of the modules

Skill 1: Client will identify and problem-solve challenges to maintaining behavioral and attitudinal changes

Session 6 90 minutes

Check-In/Life Context..... 25 minutes

- Welcome to VIPs
- Review past week's life events
- Discuss progress of goal and Life Project
- Discuss session content as it relates to the Client's life context

Skills-Building 25 minutes

- Discuss the differences between self- defeating thoughts and self-enhancing thoughts
- Discuss Client's successes and challenges with goals set in all previous sessions and have VIPs help to provide support

Problem-Solving10 minutes

- Assist Client to identify one challenge that continues to impede progress to successful accomplishment of a goal and have VIPs help to provide support

Wrap-Up.....30 minutes

- Client sets goal related to maintaining coping skills, safer behaviors, and adherence to medical regimen with support from VIP
- Review Client's Life Project
- Prepare Client for end of interactive part of program
- Discuss potential roles of VIP in realizing future goals

Appendix 2:
Screening Checklist

Strengthening and evaluating psycho-social support provided to youth ages 15 to 24 in Kinshasa, DRC during routine clinic visits and during youth support groups.

Version 1.0, Last Revised: 29th June 2009

SCREENING CHECKLIST

(ONLY for children who have been disclosed to – the first three inclusion criteria must already have been confirmed prior to completing this form with the youth)

All three of the following questions must be checked yes in order for the potential participant to be eligible for this study.

Are you between the ages 15-24 years?

☐ YES ☐ NO

Do you agree to be audiotaped during focus group discussions?

☐ YES ☐ NO

Are you willing to attend 6 sessions, each approximately 3 hours in length?

☐ YES ☐ NO

Appendix 3:
Parental Informed Consent Form

Parental Permission Form for participation of minor participants ages 15-17
[Support Group Program]

IRB Study: #

Consent Form Version Date: September 15th, 2009

Title of Study: Strengthening and evaluating and improving psycho-social support provided to youth ages 15 to 24 in Kinshasa, DRC during routine clinic visits and during youth support groups.

Principal Investigator:

Frieda Behets, PhD, Department of Epidemiology, University of North Carolina at Chapel Hill, U.S.

Co-Investigators:

Lisa Parker, MSc Department of Health Behavior Health Education, University of North Carolina at Chapel Hill, U.S.

Audrey Pettifor, PhD, Department of Epidemiology, University of North Carolina at Chapel Hill, U.S.

Funding Source: NICHD

Name of Local Study Contact: Bavon Mupenda

Location: UNC-DRC, Kinshasa

Telephone of Local Study Contact: 0997701091

Hello, my name is Your child is being asked to take part in a research study. In order for your child to take part in this study, we must first receive your permission. We will also ask your child if she/he wants to take part in the study. Even if you give your permission, your child can decide to not be in the study or to leave the study at any time.

The research study is called “Strengthening and evaluating and improving psycho-social support provided to youth”. This form explains what this research study involves, so you can decide whether you want your child to join or not.

Before you make your decision, there are some things I want you to know. First, you do not have to give permission for your child to be in the study if you do not want to. Second, your child may stop being in the study at any time.

I will now tell you all about the research. It is important that you understand this information so you can decide if you want your child to take part or not. After I finish, I will ask you if you want your child to take part or not. As I read this form to you, please stop me if you have any questions. If you

decide to give your permission, we will then give information about the study to your child so he/she can decide whether or not he/she wants to take part.

I will now tell you why your child is being asked to be in this study. I will also tell you more about what this study is all about.

We are asking your child to take part in this study because we want to find out if they will enjoy and learn from a support group intervention focused on providing psycho-social support and learning safer sex behaviors. The reason we want to know all these things is because we want to help other adolescents and young adults.

There will be approximately 10 youth participating in this study in total. We will also get information from health care providers and other professionals who work with HIV positive children. Your child is being asked to take part in this study because he/she is living with HIV and we value your child's experiences.

Now I will tell you what will happen if you agree for your child take part in the study

If you and your child agree, your child will attend six support group intervention sessions that will each last approximately 90 minutes and will be spread out over a period of 6 weeks. Prior to the beginning of the first session and at the last session your child will be asked to complete a short demographic and sexual behavior questionnaire. A discussion will take place after each session and will last for approximately 90 minutes.

The discussions after each session will be recorded on audiotape, and notes will be taken by the researcher. By agreeing to allow your child to participate, you also agree to have these discussions audio taped. However, your child may ask to have the tape recorder turned off and your child is free to leave the session at any time if they become uncomfortable.

Your child will be able to participate in a support group intervention with other youth that may help them to improve their problem solving and coping skills as well as identify high-risk behaviors. However, information we learn from your child may be used to develop services which may benefit others children like yours in the future. At the end of each intervention session, your child will be given \$3 (____ Congolese francs) for his/her time. Refreshments will also be served.

Now I will explain what we will do so that others do not learn what happens during your child's clinic visits

Only the people who are doing the study will look at what was discussed during the support group sessions. Your child's name will not be written on any of the notes, and he or she will be given a participant ID number so that no one will know that he or she was the one who is participating in this study. Your child's name will not be used in any report or publication about this study. The researchers will keep all the information they learn in the study in a locked cabinet at the UNC offices in Kinshasa.

I will now tell you about risks that might be involved if your child takes part in this study.

Your child may feel embarrassed about talking about his or her private behavior with other children in the room. Please be assured that you can withdraw your permission at any time, and if you do, no one will be angry or upset with you. This will not affect the medical care or services that either you or your child receive at this center. Your child is also able to withdraw their consent to participate at any time.

I will now tell you who to contact if you or your child has any questions after the participant observation is over

If you or your child has any questions about this study after we finish the participant observation, you may contact Bavon Mupenda by telephone at 0997701091. The researchers will also tell you anything they learn from the study that may affect you or your child.

This study has been reviewed and approved by a group who make sure that you and your child's rights and welfare are protected. If you have questions about you or your child's rights as a study participant, or are unhappy at any time with any part of this study, you may contact Prof. Kiyombo, Chair of the Ethics Committee at the Kinshasa School of Public Health. You may reach him at 0815186872 for Vodacom or 0999059919 for Celtel. If you need help contacting Dr. Kiyombo, you can ask a nurse or counselor for help. You may also call the Public Health-Nursing IRB at University of North Carolina at (1) 919 966 3113. You do not need to provide your name if you call.

Do you want your child to take part in the study?

Subject's Agreement:

By signing your name on this sheet of paper, it means that you agree to permit your child to take part in this study.

Do you want your child to take part in this research study? Your child must also give her/his agreement before he or she can take part in this study.

Verification of Permission

STAFF OBTAINING Permission: You must sign below and confirm parental permission. Your signature certifies that the objectives and procedures for this study have been read to the parent/guardian. It certifies that you have answered all the questions that the parent/guardian had about the research, and that he or she has agreed for his or her child to take part in the research.

X _____ Signature of Research Participant	_____ Date	X _____ Printed Name of Research Participant
X _____ Signature of Person Obtaining Consent	_____ Date	X _____ Printed Name of Person Obtaining Consent

Appendix 4:
Informed Assent Form YLWHA 15-17

Assent Form for the Minor Participants ages 15 to 17
[Support Group Program]

IRB Study: #

Assent Form Version Date: September 15th, 2009

Title of Study: Strengthening and evaluating psycho-social support provided to HIV+ youth ages 15 to 24 in Kinshasa, DRC during routine clinic visits and during youth support groups.

Principal Investigator: Frieda Behets, PhD, Department of Epidemiology, University of North Carolina at Chapel Hill, U.S.

Co-Investigators:

Lisa Parker, MSc Department of Health Behavior Health Education, University of North Carolina at Chapel Hill, U.S.

Audrey Pettifor, PhD, Department of Epidemiology, University of North Carolina at Chapel Hill, U.S.

Funding Source: NICHD

Name of Local Study Contact: Bavon Mupenda

Location: UNC-DRC, Kinshasa

Telephone of Local Study Contact: 0997701091

Hello, my name is ... I would like to talk to you because you are being asked to participate in a research study called “Strengthening and evaluating psycho-social support provided to youth”. This form explains what this research study involves, so you can decide whether you want to join or not. Please review the form carefully (or listen to me carefully) and ask any questions about the study before you agree to join. You may also ask questions at any time after joining the study.

Before you take part in this study, there are some things I want you to know. First, you do not have to be in this study if you do not want to. Second, you may stop being in the study at any time.

We have already asked your parent or guardian about the study and she has given her/his permission for you to take part. If you agree to join, I will give you a copy of this form, if you want one.

The study involves your participation in a six session support group program focusing on providing psycho-social support to HIV+ youth and increasing safe sex behaviors. There will be approximately 10 youth participating in this study in total.

I will now tell you why you are asked to be in this study.

You are asked to take part in this study because we want to find out if you will enjoy and learn from a support group program focused on providing psycho-social support and safer sex. The reason we want to know all these things is because we want to help other adolescents and young adults.

Now I will tell you what will happen if you agree to take part in the study.

If you agree, you will attend six support group intervention sessions that will each last approximately 90 minutes and will be spread out over a period of 6 weeks. Prior to the beginning of the first session and at the end of the last session you will be asked to complete a short demographic and sexual behavior questionnaire. A discussion will take place after each session and will last for approximately 90 minutes.

The discussions after each session will be recorded on audiotape, and notes will be taken by the researcher. By agreeing to participate, you also agree to have these discussions audio taped.

You will be able to participate in a support group intervention with fellow youth that may help you to improve your problem solving skills, coping skills, as well as identify high-risk behaviors. However, information we learn from you may be used to develop services which may benefit others like yourself in the future. At the end of each intervention session, you will be given \$3 (_____ Congolese francs) for your time and refreshments will be provided.

Now I will explain what we will do so that others do not learn what you tell us.

Only the people who are doing the study will look at what was discussed during the support group sessions. Your name will not be written on any of the notes, and you will be given a participant ID number so that no one will know that you are the one who is participating in this study. Your name will not be used in any report or publication about this study. The researchers will keep all the information they learn in the study in a locked cabinet at the UNC offices in Kinshasa.

I will now tell you about possible risks if you take part in this study.

You may feel embarrassed about talking about your private behavior with other youth in the session. Please be assured that you can decide to stop participating at any time, and if you do, no one will be angry or upset with you. This will not affect the medical care or services that either you or your parents receive at this center.

Do you have any questions for me?

If you have any questions about this while you are participating in the support group intervention, you may contact Bavon Mupenda by telephone at 0997701091. The researchers will also tell you anything they learn from the study that may affect you.

This study has been reviewed and approved by a group who make sure that your rights and welfare are protected. If you have questions about your rights as a study participant, or are unhappy at any time with any part of this study, you may contact Prof. Kiyombo, Chair of the Ethics Committee at the Kinshasa School of Public Health. You may reach him at 0815186872 for Vodacom or 0999059919 for Celtel. If you need help contacting Dr. Kiyombo, you can ask a nurse or counselor for help. You may also call the Public Health-Nursing IRB at University of North Carolina at (1) 919 966 3113. You do not need to provide your name if you call.

Do you want to take part in the study?

Subject's Agreement:

By signing your name on this sheet of paper, it means that you agree to voluntarily take part in this study. We will also ask your parent or caregiver if it is okay for you to take part in this study.

Do you want to take part in the study? Your parent or caregiver must also give her/his permission for you to take part in this study.

Verification of Assent

STAFF OBTAINING ASSENT: You must sign below and confirm parental permission before proceeding with the participant observation. Your signature certifies that the objectives and procedures for this study have been read to the participant. It certifies that you have answered all the questions that the participant had about the research, and that the participant has agreed to take part in the research.

Subject's Agreement:

By signing your name on this sheet of paper, it means that you agree to voluntarily take part in this study.

X _____ Signature of Research Participant	_____ Date	X _____ Printed Name of Research Participant
X _____ Signature of Person Obtaining Assent	_____ Date	X _____ Printed Name of Person Obtaining Assent

Appendix 5:
Informed Consent Form YLWHA 18-24

Consent Form for Young Adults ages 18 to 24
[Support Group Intervention]

IRB Study: #

Consent Form Version Date: September 15th, 2009

Title of Study: Strengthening and evaluating and improving psycho-social support provided to youth ages 15 to 24 in Kinshasa, DRC during routine clinic visits and during youth support groups.

Principal Investigator: Frieda Behets, PhD, Department of Epidemiology, University of North Carolina at Chapel Hill, U.S.

Co-Investigators:

Lisa Parker, MSc Department of Health Behavior Health Education, University of North Carolina at Chapel Hill, U.S.

Audrey Pettifor, PhD, Department of Epidemiology, University of North Carolina at Chapel Hill, U.S.

Funding Source: NICHD

Name of Local Study Contact: Bavon Mupenda

Location: UNC-DRC, Kinshasa

Telephone of Local Study Contact: 0997701091

Hello, my name is ... I would like to talk to you because you are being asked to participate in a research study called “Strengthening and evaluating and improving psycho-social support provided to youth”. This form explains what this research study involves, so you can decide whether you want to join or not. Please review the form carefully (or listen to me carefully) and ask any questions about the study before you agree to join. You may also ask questions at any time after joining the study.

Before you take part in this study, there are some things I want you to know. First, you do not have to be in this study if you do not want to. Second, you may stop being in the study at any time. If you agree to join, I will give you a copy of this form, if you want one.

The study involves your participation in a six session support group intervention focusing on providing psycho-social support and increasing safe sex behaviors. There will be approximately 10 youth participating in this study in total. You may also be asked to participate in a two-day adaptation workshop where SARA study staff and other youth will discuss how to ensure that the curriculum is culturally appropriate for youth in the DRC.

I will now tell you why you are asked to be in this study.

You are asked to take part in this study because we want to find out if you will enjoy and learn from a support group intervention focused on providing psycho-social support and safer sex. The reason we want to know all these things is because we want to help other adolescents and young adults.

Now I will tell you what will happen if you agree to take part in the study.

If you agree, you will attend six support group intervention sessions that will each last approximately 90 minutes and will be spread out over a period of 6 weeks. Prior to the beginning of the first session and at the end of the last session you will be asked to complete a short demographic and sexual behavior questionnaire. A discussion will take place after each session and will last for approximately 90 minutes.

The discussions after each session will be recorded on audiotape, and notes will be taken by the researcher. By agreeing to participate, you also agree to have these discussions audio taped. However, you may ask to have the tape recorder turned off and you are free to leave the session at any time if you become uncomfortable.

You will be able to participate in a support group program with fellow youth that may help you to improve your problem solving skills, coping skills, as well as identify high-risk behaviors. However, information we learn from you may be used to develop services which may benefit others like yourself in the future. At the end of each intervention session, you will be given \$3 (_____ Congolese francs) for your time and refreshments will be provided.

Now I will explain what we will do so that others do not learn what you tell us.

Only the people who are doing the study will look at what was discussed during the support group sessions. Your name will not be written on any of the notes, and you will be given a participant ID number so that no one will know that you are the one who is participating in this study. Your name will not be used in any report or publication about this study. The researchers will keep all the information they learn in the study in a locked cabinet at the UNC offices in Kinshasa.

I will now tell you about possible risks if you take part in this study.

You may feel embarrassed about talking about your private behavior with other youth in the session. Please be assured that you can decide to stop participating at any time, and if you do, no one will be angry or upset with you. This will not affect the medical care or services that either you or your parents receive at this center.

Do you have any questions for me?

If you have any questions about this while you are participating in the support group intervention, you may contact Bavon Mupenda by telephone at 0997701091. The researchers will also tell you anything they learn from the study that may affect you.

This study has been reviewed and approved by a group who make sure that your rights and welfare are protected. If you have questions about your rights as a study participant, or are unhappy at any time with any part of this study, you may contact Prof. Kiyombo, Chair of the Ethics Committee at the Kinshasa School of Public Health. You may reach him at 0815186872 for Vodacom or

0999059919 for Celtel. If you need help contacting Dr. Kiyombo, you can ask a nurse or counselor for help. You may also call the Public Health-Nursing IRB at University of North Carolina at (1) 919 966 3113. You do not need to provide your name if you call.

Do you want to take part in the study?

Subject's Agreement:

By signing your name on this sheet of paper, it means that you agree to voluntarily take part in this study.

Do you want to take part in the study?

Verification of Assent

STAFF OBTAINING CONSENT: You must sign below before proceeding with the study. Your signature certifies that the objectives and procedures for this study have been read to the participant. It certifies that you have answered all the questions that the participant had about the research, and that the participant has agreed to take part in the research.

Subject's Agreement:

By signing your name on this sheet of paper, it means that you agree to voluntarily take part in this study.

X _____ Signature of Research Participant	_____ Date	X _____ Printed Name of Research Participant
X _____ Signature of Person Obtaining Consent	_____ Date	X _____ Printed Name of Person Obtaining Consent

Appendix 6:
Word Version of IRB Approval Letter



OFFICE OF HUMAN RESEARCH
ETHICS Medical School Building 52
Mason Farm Road
CB #7097
Chapel Hill, NC 27599-7097
(919) 966-3113

Web site: ohre.unc.edu
<https://my.research.unc.edu> for
IRB status Federalwide Assurance
(FWA) #4801

To:

Frieda

Behets

CB:743

5

From: Biomedical IRB

A handwritten signature in blue ink, appearing to be "JHD".

Authorized signature on behalf of IRB

Approval Date: 7/08/2009

Expiration Date of Approval: 2/01/2010

RE: Notice of IRB Approval by Full Board

Review **Submission Type:** Modification

Study #: 04-1007 (Former IRB Number 04-MED-168)

Study Title: Effective and Affordable Comprehensive HIV Care and Antiretroviral Treatment in the Democratic Republic of Congo

Sponsors: CDC & Prevention

This submission has been approved by the above IRB for the period indicated. Unless otherwise noted, regulatory and other findings made previously for this study continue to be applicable.

Submission Description:

This modification adds a sub-study which will provide additional evaluation and support to participants. In addition, Lisa Parker and Audrey Pettifor have been added as co-investigators and Doris Ngemasong has been added as personnel.

Regulatory Findings:

For the substudy, this research meets criteria for waiver of parental or guardian informed consent according to 45 CFR 46.116(d) and 45 CFR 46.408(c)

Investigator's Responsibilities:

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

This study was reviewed in accordance with federal regulations governing human subjects research, including those found at 45 CFR 46 (Common Rule), 45 CFR 164 (HIPAA), 21 CFR 50 & 56 (FDA), and 40 CFR 26 (EPA), where applicable.

CC:

Jamie Newman, Health Behavior
Annelies Van Rie, Epidemiology
Lisa Parker, Epidemiology
Audrey Pettifor, Epidemiology
Doris Ngemasong Epidemiology

Appendix 7:
Demographic Questionnaire

Strengthening and evaluating psycho-social support provided to HIV+ youth ages 15 to 24 in Kinshasa, DRC during routine clinic visits and during youth support groups.

Version 1.0, Last Revised: 11th June 2009

Demographic and Sexual History for SYMPA Participants

[Interviewer Instructions: Mark the appropriate number in the box for each question. For all of the following questions if the respondent says: “I don’t know” mark 88 and if the respondent “declines to answer” mark 98. It is VERY important that these response categories are marked appropriately]

Part A: General Information

#	Question	Answer
A1	Date of Interview:	_ _ / _ _ / _ _ _ _ (DD/MM/YYYY)
A2	Interviewer Name:	_____
A3	Participant ID#:	_____

Part B: Demographic Information

#	Question	Answer	
B1	<i>(Do not read aloud)</i> Sex of respondent:	1 = Male 2 = Female	
B2	How old are you?	_ _ age in years <i>(note: write year of birth if age is unknown)</i> _ _ _ _ birth year	
B3	What is the highest grade in school that you completed?	1= None 2 = Some primary school 3 = Completed primary school 4 = Some secondary school 5 =Completed secondary school 6 = Any tertiary education/post-secondary school	

#	Question	Answer	
B4	What is your marital status?	1 = Never married 2 = Married 3 = Separated 4 = Divorced 5 = Widowed	
B5	During the last 3 months, where did you get most of your money? (Choose one)	1 = Parents 2 = Job 3 = Unemployment 4 = Grants (child support, disability, etc.) 5 = Significant Other/Spouse 6 = Other Sex Partner(s) 7 = Other Family members 8 = Friends 9 = Alimony/Child Support 10 = Sex Work 11 = Selling drugs 12 = Panhandling/Shoplifting/Etc. 13 = Other 13a =Specify: _____	
B6	Do you or your household have any of the following?	1 = Tap water in the house or on property 2 = Hot running water 3 = Electricity 4 = Flush toilet inside or outside 5 = Built-in kitchen sink 6 = Home phone 7 = Cell phone 8 = More than one radio (not car radios) 9 = Hi-Fi / music centre 10 = TV 11 = Satellite TV subscription 12 = Personal computer 13 = Fridge (including combined fridge/freezer) 14 = Microwave oven 15 = Floor polisher/Vacuum cleaner 16 = Washing machine 17 = Tumble drier 18 = Electric stove/Hot plate 19 = Motor car 20 = Domestic worker	
B7	In the past 3 months, have you been worried about having enough food for you or your family?	1 = Yes 2 = No	
B8	In the past 3 months, how often have you run out of money for your basic needs? (Choose one)	1 = More than 5 times 2 = 3-5 times 3 = 1-2 times 4 = Never	

Interviewer script: *Thank you for your time and for participating in the interview. Do you have any questions or concerns about anything we discussed here today? Please remember that all of the information you shared with me today will be kept completely confidential.*

Appendix 8:
Post Intervention IDI with Facilitators

In-Depth Interview for Facilitators of SYMPA Intervention

1. What did you like most about SYMPA?
2. What were the biggest challenges in the implementation of SYMPA?
3. Do you think we should reduce or increase the number of sessions (assume that adapted sessions would be approximately 90 minutes long)?
4. Did you like the incorporation of VIPs in the last session?
5. Did you face any challenges with their incorporation?
6. Were there issues of confidentiality that posed a problem in the implementation of SYMPA?
7. What are your suggestions for future implementation of SYMPA in relation to the amount of work for the facilitators in balance with their other responsibilities? How could we improve this?
8. What did you think about the group format?
9. What did you think about having male and female groups separate?
10. Were there any problems talking about sexual behavior with the participants (either for yourself or participants)?
11. Do you think the intervention materials should all be in Lingala or was having the majority of materials in French ok?

Thank you for your time!

Appendix 9:
Post Intervention Curriculum Evaluation FGD with Facilitators

FGD Guide for SYMPA Curriculum

1. **SEANCE 1** : Le Client identifiera au moins un but réalisable dans le cadre de son Projet de vie.

Commentaires général sur Séance 1:

2. ACTIVITÉ: « FORMULAIRE DU CONTEXTE DE VIE »

Commentaires :

3. **SEANCE 2** : Le Client identifiera ses propres agents stressants et sera capable d'appliquer à bon escient, aux agents stressants identifiés, des stratégies d'adaptation axées sur les émotions ou sur les problèmes. **Commentaires général sur Séance 2 :**

4. ACTIVITÉ: LISTE DES AGENTS STRESSANTS (GENERAUX) DU CLIENT

Commentaires :

5. ACTIVITÉ: FEUILLE DE TRAVAIL SUR LES AGENTS STRESSANTS DU CLIENT

Commentaires :

6. ACTIVITÉ: FEUILLE DE TRAVAIL SUR LE STRESS ET LES STRATÉGIES D'ADAPTATION

Commentaires :

7. ACTIVITÉ: FEUILLE DE TRAVAIL SUR LES STRATÉGIES AXÉES SUR LES ÉMOTIONS

Commentaires :

8. ACTIVITÉ: FEUILLE DE TRAVAIL SUR LES STRATÉGIES AXÉES SUR LES PROBLEMES

Commentaires :

9. Aider le Client à identifier un objectif en ce qui concerne les autres agents stressants identifiés sur la liste de ses agents stressants.

Commentaires :

10. ACTIVITÉ: GRADATION DES RISQUES

Commentaires :

11. **SEANCE 3:** Le Client réduira ses comportements sexuels à risques. **Commentaires général sur Séance 3 :**

12. Aider le/la Client(e) à identifier au moins un élément déclencheur qui peut le mener à se livrer à un ou des comportement(s) à risque. Aider le/la Client(e) à élaborer des solutions afin de réduire les risques pour cette éléments déclencheur identifiés.

Commentaires :

13. Aider le/la Client(e) à identifier un objectif en ce qui concerne l’(es) élément(s) déclencheur(s) identifié(s).

Commentaires :

14. **SEANCE 4:** Le client réussira à démontrer comment mettre le préservatif masculin correctement sur un modèle en bois du pénis à démontrer comment mettre le préservatif féminin correctement à l’aide d’un modèle du vagin et Le/la Client(e) réussira à démontrer (à travers des jeux de rôle durant la séance) une plus grande compétence relative aux négociations de pratiques sexuelles à moindre risque avec tous partenaires sexuels. **Commentaires général sur Séance 4:**

15. ACTIVITÉ: ANATOMIE MASCULIN ET DÉMONSTRATION DU PRÉSERVATIF MASCULIN

Commentaires :

16. ACTIVITÉ: ANATOMIE FÉMININ ET DÉMONSTRATION DU PRÉSERVATIF FÉMININ

Commentaires :

17. ACTIVITÉ: MALADIES SEXUELLEMENT TRANSMISSIBLES COURANTES ET TRAITEMENT

Commentaires :

18. ACTIVITÉ: TROIS COMPOSANTS D’UNE COMMUNICATION MARQUÉE PAR LA CONFIANCE EN SOI

Commentaires :

19. VIGNETTES DE JEUX DE RÔLE

Commentaires :

20. Aider le/la Client(e) à identifier au moins un ***élément déclencheur*** en ce qui concerne les ***obstacles à l’utilisation du préservatif***. Aider le/la Client(e) à résoudre les problèmes relatifs à au moins un des éléments déclencheurs identifiés.

Commentaires :

21. Aider le/la Client(e) à identifier au moins **un élément déclencheur** en ce qui concerne les **obstacles aux négociations de pratiques sexuelles** à moindre risque. Aider le/la Client(e) à élaborer des solutions afin de réduire les risques pour au moins un des éléments déclencheurs identifiés.

Commentaires :

22. SEANCE 5: Le/la Client(e) augmentera le nombre de relations positives qui peuvent lui fournir du soutien et Le/la Client(e) développera ses compétences décisionnelles en ce qui concerne la décision de révéler sa séropositivité. **Commentaires général sur Séance 5:**

23. ACTIVITÉ: FEUILLE DE TRAVAIL SUR LE SOUTIEN SOCIAL

Commentaires :

24. ACTIVITÉ: MON PROPRE PROCESSUS DÉCISIONNEL

Commentaires :

25. Aider le/la Client(e) à déterminer **laquelle des catégories de soutien** (c.à.d. informationnel, émotionnel, matériel) conviendrait le mieux **pour chacun des agents stressants** identifiés.

Commentaires :

26. Aider le/la Client(e) à identifier au moins **un élément déclencheur** qui peut l'induire à prendre une décision négative en ce qui concerne **la révélation de sa séropositivité**. Aider le/la Client(e) à élaborer un processus décisionnel positif pour au moins un des éléments déclencheurs identifiés.

Commentaires :

27. Aider le/la Client(e) à s'imaginer dans des scènes de soutien social 1) Une situation de nature sociale où le/la Client(e) peut trouver un soutien social positif ; ou 2) Une situation où le/la Client(e) décide de mettre fin à une relation existante qu'il/elle considère comme une source de soutien social négatif

Commentaires :

28. Aider le/la Client(e) à identifier deux objectifs visant à 1) obtenir plus de soutien social positif et 2) sur la décision de révéler son statut ou d'améliorer son processus décisionnel.

Commentaires :

29. SEANCE 6 : Le/la Client(e) identifiera au moins un domaine de sa vie qui a été amélioré pendant qu'il/elle a participé à chacun des modules. **Commentaires général :**

30. Le/la Client(e) devrait identifier une idée productive pour chaque but (à la fois ceux qui ont déjà été atteints et ceux qui ont posé des problèmes).

Commentaires :

31. Aider le/la Client(e) à identifier une difficulté qui continue de bloquer les progrès du/de la Client(e) et l'empêche de réussir à atteindre un but.

Commentaires :

32. Le/la Client(e) développe un objectif visant le maintien de ses comportements à moindre risque.

Commentaires :

33. Aider le client à développer un plan d'action pour assurer la réalisation de l'objectif. Le plan d'action doit détailler le rôle que le VIP va jouer dans le soutien de jeunes pour réaliser leur plan d'action.

Commentaires :

34. Passer en revue le Projet de vie, en reconnaissant tout progrès enregistré. Discuter des plans supplémentaires pour exécuter le Projet de vie avec l'inclusion du VIP.

Commentaires :

35. Commentaires général sur comment améliorer ou adapter mieux le curriculum SYMPA.

Merci !

Appendix 10:
FGD Guides for Youth Participants

Focus Group Discussion Guide for Youth Support Group Intervention SYMPA

Strengthening and evaluating psycho-social support provided to HIV+ youth ages 15 to 24 in Kinshasa, DRC during routine clinic visits and during youth support groups.

Version 1, Last Revised: 11 June 2009

*Thank you for agreeing to participate in this discussion today. Today we are going to talk about your experience participating in **SESSION** ___ of the SYMPA program. I am interested in hearing about what you liked and what you didn't like about today's activities. There are no right or wrong answers to these questions. If there are parts of the discussion that you are not comfortable with, you do not need to respond. OK let's begin.*

For Sessions 1-6

Interviewer script: Tell me about what you liked most in today's session?

- Tell me about your favorite activity?

Interviewer script: Tell me about what you like least in today's session?

- Tell me about your least favorite activity?

Interviewer script: What were some of the most important things you learned in today's session?

Interviewer script: Tell me about what you found helpful in today's session?

- How do you think these things will help you?
- What were the things you found to be unhelpful?
- Was there anything that you wanted to learn on this topic that was not included?

Interviewer script: In what ways, if any, did this session help you to feel more confident in identifying your risky behaviors?

For Session 1

Interviewer script: In what ways do you feel, if at all, the "Life Project" helped you?

- Can you provide a specific example?

For Sessions 2-6

Interviewer script: In what ways have you done things differently, if at all, in your life as a result of your participation in SYMPA?

- Can you provide a specific example?
- Sexual behavior, coping, social support network etc.

For Session 2

Interviewer script: In what ways do you feel, if at all, identifying personal stressors and coping strategies have helped you?

- Can you provide a specific example?

For Session 3

Interviewer script: In what ways do you feel, if at all, identifying triggers for risky sexual behavior has helped you?

- Can you provide a specific example?

For Session 4

Interviewer script: In what ways do you feel, if at all, the skills you have learned about condoms and human anatomy has helped you?

- Can you provide a specific example?

Interviewer script: In what ways do you feel, if at all, the communication skills you have learned have helped you?

- Can you provide a specific example?

For Session 5

Interviewer script: In what ways do you feel, if at all, the identification of sources of social support has helped you?

- Can you provide a specific example?

Interviewer script: In what ways do you feel, if at all, the identification of personal and environmental factors related to disclosure of your HIV status to friends and family has helped you?

- Can you provide a specific example?

For Session 6

Interviewer script: What expectations did you have from participating in SYMPA?

- Tell me about the expectations you had that the program did not meet. What can be done to change this?
- Tell me about the instances where your expectations were exceeded.

Interviewer script: Tell me about your experience participating in SYMPA?

- How do you feel about the numbers of sessions in SYMPA?
- How do you feel about the length of the SYMPA sessions? (If didn't like the length of the sessions) What do you feel would have been an appropriate length?
- What about the location of the program?
- How satisfied were you with the facilitator who worked with you in SYMPA? Is there anything the facilitator could have done to make you more satisfied?
- Can you tell me if you felt comfortable or not expressing your thoughts and opinions during the sessions?
- How do you feel confidentiality about issues discussed during the sessions was maintained or not maintained?

Interviewer script: During SYMPA you learned about goal setting. Tell me about the goals that you set for yourself.

- How have you managed following through with these goals?
- What factors have assisted you in reaching or maintaining your goals?
- What factors have challenged you in reaching or maintaining your goals?

Interviewer script: Tell me about your experience having your VIP involved in the program?

- Would you have preferred more or fewer sessions involving your VIP?

Interviewer script: Can you think of any suggestions for changing SYMPA for other youth who might participate in the future?

THANK YOU VERY MUCH FOR YOUR FEEDBACK! IT WILL HELP US TO MAKE SYMPA EVEN BETTER FOR FUTURE PARTICIPANTS.

Appendix 11:
Informed Consent Form for Health Care Providers IDI

Consent Form for Health Care Providers
IDI, Participant Observation and Adaptation Workshop

IRB Study: #

Consent Form Version Date: June 29th, 2009

Title of Study: Strengthening and evaluating and improving psycho-social support provided to HIV+ youth ages 15 to 24 in Kinshasa, DRC during routine clinic visits and during youth support groups.

Principal Investigator:

Frieda Behets, PhD, Department of Epidemiology, University of North Carolina at Chapel Hill, U.S.

Co-Investigators:

Lisa Parker, MSc Department of Health Behavior Health Education, University of North Carolina at Chapel Hill, U.S.

Audrey Pettifor, PhD, Department of Epidemiology, University of North Carolina at Chapel Hill, U.S.

Funding Source: NICHD

Name of Local Study Contact: Bavon Mupenda

Location: UNC-DRC, Kinshasa

Telephone of Local Study Contact: 0997701091

Hello, my name is ... I would like to talk to you because you are being asked to participate in a research study called “Strengthening and evaluating and improving psycho-social support provided to HIV+ youth”. This form explains what this research study involves, so you can decide whether you want to join or not. Please review the form carefully (or listen to me carefully) and ask any questions about the study before you agree to join. You may also ask questions at any time after joining the study. If you agree to join, I will give you a copy of this form, if you would like one.

Before you take part in this study, there are some things I want you to know. First, you do not have to be in this study if you do not want to. Second, you may stop being in the study at any time. Third, if you decide to stop at any time, no one will be angry or upset with you.

The study investigates patient-provider communication between health care providers and HIV positive youth in Kinshasa on HIV transmission risk behaviors in order to develop appropriate interventions in the future. The study involves observations of routine clinic visits with young people in Kinshasa living with HIV and interviews with health care providers like yourself. We would

like to know more about services that are provided to HIV+ youth during clinic visits, because we would like to help create services that can help young people living with HIV. There will be approximately 10 youth participating in the participant observations, 10 health care providers participating in the participant observations, in-depth interviews, and a two-day adaptation workshop for the curriculum.

I will now tell you why you are asked to be in this study.

You are being asked to take part in this study because you are a health care provider at Kalembe Lembe Pediatric Hospital (KLL) in Kinshasa, Democratic Republic of Congo (DRC) and you provide care for persons living with HIV, including adolescents and young adults. We want to help develop appropriate interventions for youth with HIV in Kinshasa, and we value the opinions of persons who have experience of providing care for this population. We would like to conduct an in-depth interview and ask you about your views working with HIV+ youth, your perceptions and attitudes around HIV prevention with HIV+ youth, your thoughts on the role and responsibilities of health care providers in providing HIV prevention information to HIV+ youth, your personal comfort level and confidence in dealing with HIV prevention issues with HIV+ youth, and how we can be responsive to the needs of health care providers.

Now I will tell you what will happen if you agree to take part in the study.

If you agree, an interviewer from the research team will first ask you questions about the topics I have just mentioned. The interview will take place in a private room at this center, and it will last between 1 – 1½ hours. We may also ask you to participate in the participant observations and a two-day adaptation workshop to discuss how to ensure that the curriculum is culturally appropriate for youth in the DRC.

The in-depth interview and participant observation will be recorded on audiotape, and notes will be taken by the interviewer during the clinic visit. By agreeing to participate, you also agree to have your interview audio taped. However, you may ask to have the tape recorder turned off or can ask the researcher to leave at any time.

There will be no direct benefit to you if you take part in this study. However, information we learn from you may be used to develop services which may benefit children living with HIV in Kinshasa and the DR Congo in the future.

Now I will explain what we will do so that others do not learn what you tell us.

During the interview, notes will be taken to help us remember your responses. Only the people who are doing the study will look at the answers given during the interview. Because your name will not be asked or written down, no one will know that it was you who gave the information. The researchers will keep all the information they learn in the study in a locked cabinet at the UNC offices in Kinshasa.

I will now tell you about possible risks if you take part in this study.

You may become sad when talking about your work with HIV positive children in Kinshasa. If you do not want to answer a question, you do not have to answer it.

Do you have any questions for me?

If you have any questions about this study after we finish the interview, you may contact Bavon Mupenda by telephone at 0997701091. The researchers will also tell you anything they learn from

the study that may affect you.

This study has been reviewed and approved by a group who make sure that your rights and welfare are protected. If you have questions about your rights as a study participant, or are unhappy at any time with any part of this study, you may contact Prof. Kiyombo, Chair of the Ethics Committee at the Kinshasa School of Public Health. You may reach him at 0815186872 for Vodacom or 0999059919 for Celtel. You may also call the Public Health-Nursing IRB at University of North Carolina at (1) 919 966 3113. You do not need to provide your name if you call.

Do you want to take part in the interview?

Verification of Consent

STAFF OBTAINING CONSENT: You must sign below and ask the participant to sign below before proceeding with the interview. Your signature certifies that the objectives and procedures for this study have been read to the participant. It certifies that you have answered all the questions that the participant had about the research, and that the participant has agreed to take part in the research.

Subject's Agreement:

By signing your name on this sheet of paper, it means that you agree to voluntarily take part in this study.

X _____ Signature of Research Participant	_____ Date	X _____ Printed Name of Research Participant
X _____ Signature of Person Obtaining Consent	_____ Date	X _____ Printed Name of Person Obtaining Consent

Appendix 12:
IDI Guide for Providers

IDI Question Guide for Health Care Providers

Strengthening and evaluating psycho-social support provided to HIV+ youth ages 15 to 24 in Kinshasa, DRC during routine clinic visits and during youth support groups.

Version 1, Last Revised: 29 May 2009

Hello. My name is Lisa Parker. Thank you for agreeing to talk with me today about evaluating and improving psycho-social support provided to HIV+ youth. The information you provide will help us improve ongoing psycho-social support for HIV+ youth. We would like to hear your views about working with HIV+ youth, how health care providers can support HIV+ youth, and about how we can be responsive to the needs of both health care providers and HIV+ youth. We would also like to hear about what you feel are the challenges providers may experience when providing psycho-social support and when conducting HIV risk reduction counseling with HIV+ youth, and what skills are needed to provide effective psycho-social support and prevention counseling. In this interview when I mention HIV+ youth I am talking about male and female patients between the ages of 15-24.

There are no right or wrong answers. We are here to learn from you. Your personal thoughts and experiences are important in helping us to strengthen services for HIV+ youth. All information you provide is confidential, so we encourage you to be candid. Whatever information is reported will NOT have your name attached to it.

SECTION A: INTRODUCTORY QUESTIONS

A1. Date of Interview: _____

A2. Respondent ID# of the Health Care Provider: _____

A3. Time Interview Started: _____

A4. Time Interview Completed: _____

SECTION B: DEMOGRAPHIC QUESTIONS

Interviewer script: I would like to begin by asking questions about you.

#	Question	Response categories
B1	(Do not read aloud) Sex of respondent:	<input type="checkbox"/> Male ⁽¹⁾ <input type="checkbox"/> Female ⁽²⁾
B2	How old are you?	_____ years
B3	What is the highest level of education you completed?	
B4	What is your profession?	

#	Question	Response categories
B5	How long have you been a _____?	_____ years
B6	How long have you worked directly with HIV+ youth?	_____ years

TURN ON TAPEREORDER HERE

- Please describe in general the type of work that you do with HIV+ youth.
- How would you define HIV psycho-social support for HIV+ youth?
- How would you define HIV prevention for HIV+ youth?
- What do you consider to be high-risk sexual behaviors for HIV+ youth?
 - What do you consider unsafe sex?

SECTION C: OPEN-ENDED QUESTIONS ABOUT PSYCHO-SOCIAL SUPPORT AND HIV PREVENTION WITH HIV+ YOUTH

Interviewer script: *Now I would like to ask you questions about the psycho-social support provided to HIV+ youth. For the purpose of this interview I will be referring to psycho-social support as any activity a provider does to support youth living with their emotional, psychological, personal, social, or legal needs. For the following questions please think about your work with HIV+ youth patients during their routine clinic visits.*

- Have you ever provided psycho-social support to an HIV+ youth?
If yes, tell me about it. If no, why isn't this something that you provide to HIV+ youth?
 - Have you asked if the HIV+ youth feels depressed?
 - Have you discussed different coping strategies?
 - Have you discussed how stress may impact their mental health?
 - Have you discussed with them ways to deal with HIV-related stigma?
 - Have you discussed ways to help them disclose their illness?
 - Have you suggested ways to increase the support they get from friends and family?

Interviewer script: *Now I would like to ask you questions about your prevention work with HIV+ youth. For the purpose of this interview I will be referring to prevention work as any activity a provider does to support youth living with HIV in their understanding and management of their personal risks. Risk in this context refers to behaviors that impact the potential transmission of HIV or the overall health of the person living with HIV. Behaviors that relate to personal risk can include sexual activity, drug use, accessing medical care and accessing social support. For the following questions please think about your work with HIV+ youth patients during their routine clinic visits.*

- Was there ever a time when you spoke with an HIV+ youth patient about being sexually active.
If yes, tell me about it. If no, can you tell me why this is something not discussed?
 - What made you decide to talk to the youth about their sexual activity?

- Did you ask if the patients had recent unsafe sex/or not used a condom?
 - Did you ask about the recent number of sex partners this patient had?
 - Did you ask about different types of sexual behaviors?
 - Is it culturally acceptable to discuss sexual activity with the youth?
 - Did you feel uncomfortable discussing their sexual activity?
 - Did you feel you were able to assess the level of transmission risk described?
 - Did you explain the risk of reinfection to your HIV-infected patients?
 - Are there any differences discussing sexual behavior with male or female youth?
 - What questions did the youth ask of you?
 - How comfortable did the youth seem when discussing their sexual behavior?
- Was there ever a time when you counseled an HIV+ patient on family planning options? If yes, tell me about it. If no, can you tell me why this is not something you counsel on?
 - What made you decide to talk to the youth about their sexual activity?
 - In what ways is this different from counseling HIV+ adult patients on family planning options?
 - Was there ever a time when an HIV+ youth asked a question related to their sexual risk behaviors? If yes, tell me about it. If no, why do you think none of the youth have brought this up?

Interviewer script: *Now I will ask questions pertaining to your perceptions and attitudes around HIV prevention with HIV+ youth. Remember we just want your views on these issues – there are no right or wrong answers.*

- How sexually active are the HIV+ youth that you see?
 - To what extent are they engaging in risk behaviors?
 - How are these behaviors different than for HIV+ adult patients?
- How is doing prevention work with HIV+ clients different from doing prevention work with HIV- clients, if at all?
- Why do you think HIV+ youth engage in risky sexual behaviors?
 - Does stigma play a role?
 - Do mental health issues play a role?
 - What about disclosure of HIV status?
 - What about the friends and family that may or may not support them?
 - What about the length of time they have been living HIV?
 - What about their overall health status?
- To what extent do you believe that the HIV+ youth patients have a clear understanding of how to incorporate prevention into their lives?

- In what way, if at all, do you feel family or community members can be more involved in helping HIV+ youth deal with preventing the transmission of HIV and improving their overall well-being?

Interviewer script: *Now I will ask you questions related to the role of health care providers in providing HIV prevention information to HIV+ youth.*

- How concerned are you about prevention of sexual transmission of HIV for HIV+ patients including the transmission of HIV to their sexual partners as well as the possibility of reinfection for the patient?
- How do you feel you are addressing the needs of their HIV positive patients with regards to preventing the sexual transmission of HIV?
 - What needs are not currently being met?
- What do you believe are the most important things that health care providers need to know about living with HIV in order to do effective prevention work with HIV+ clients?
 - Are there areas that you would like to learn more about to help in your prevention work with HIV+ clients?
- What role do you see yourself having in providing HIV prevention information to clients living with HIV?
 - Do you feel other types of health care providers are better placed to do this work?
 - Do you ever feel that talking about safer sex with your HIV-infected patients is not your responsibility?
- How important is your religion in influencing your work with HIV+ youth?
 - Does this specifically impact your work in HIV prevention counseling?
- What are some of the factors that make talking about prevention of HIV transmission with your HIV+ patients easier or more difficult for you personally?
- Do you sometimes feel that no matter how much you counsel some patients with HIV, they are still going to infect others?
- What have been the major challenges you have faced working with HIV+ youth?
- Have you ever collaborated with other agencies in the community to support your clients around prevention needs?
 - Have you ever referred HIV+ youth to OPEC?
 - Do you feel that there exists sufficient outside resources available to support your clients around prevention needs?

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