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Proactive HIV Testing Among Youth

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UNIVERSITY OF MIAMI

PROACTIVE HIV TESTING AMONG YOUTH

By

Oluwamuyiwa Winifred Adebayo

A DISSERTATION

Submitted to the Faculty of the University of Miami in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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HIV testing is used to identify people at risk for HIV infection, or those who are infected, and provide linkage to appropriate care that will decrease HIV risk or manage HIV infection. However, youth have low rates of HIV testing and participate in testing mainly due to recommendations from healthcare providers. The purpose of this dissertation was to explore the factors that influence proactive HIV testing among youth and how these factors are related to the decision to test for HIV infection. The Information Motivation Behavior (IMB) model, and the Ottawa Decision Support Framework (ODSF) were used to guide the creation of the semi-structured interview guide and the analysis of the data in this study.

A qualitative descriptive study was conducted in Miami-Dade County, Florida. The sample included 30 youth who were aged 18 to 24 years. Participants were recruited from multiple HIV testing sites in South Florida. Individual, face-to-face, semi-structured, audio-recorded interviews were conducted with each participant. Data were analyzed using the directed content analysis method.

The findings from this study described how participants identify and accept HIV risk, seek support or resources to undertake HIV testing, and proactively seek HIV testing. Five supporting themes that further explained these findings included: Testing

This study revealed the resources youth need to seek HIV testing proactively, including modifiable and non-modifiable influences of proactive HIV testing. The results of this study provided recommendations for nursing practice, policy, and future nursing research.
Dedication

This dissertation is dedicated to my parents, Joel Oladesemola and Grace Oladesemola, who celebrated their 25th wedding anniversary while I completed this work. Their love and devotion to each other and our family makes me believe nothing is impossible.
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Chapter One

Introduction

For over three decades, the epidemic of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) has challenged public health. In the United States (US), more than 1.1 million people are living with HIV/AIDS (Centers for Disease Control and Prevention (CDC), 2017a). The state of Florida currently has the second highest number of new HIV diagnoses with approximately 5,000 new cases in 2016 and the highest number of AIDS diagnoses, in the US (Florida Department of Health (FLDOH), 2016a; FLDOH, 2017). Miami-Dade County accounts for over 1 in 5 of all new HIV infections in Florida, and has the highest incidence in the state of Florida (CDC, 2017b; FLDOH, 2016b). The number of HIV diagnoses in the state of Florida has increased every year since 2013 (FLDOH, 2017). Recent statistics show that more work is needed to transform progress to success in combating the HIV epidemic (CDC, 2017a).

A major driving source of this epidemic is HIV infection among youth. For the purpose of the current study, the term “youth” is used to describe persons aged 13 to 24 (CDC, 2017c). In the US, youth account for over one-fifth of all new HIV diagnoses (CDC, 2017c). Youth aged 20 to 24 years account for over 80% of all new HIV infections among youth (CDC, 2017c). Youth aged 20 to 24, have the second highest number of new HIV diagnoses in the US, which is followed closely by persons aged 25 to 29, who have the highest number of HIV diagnoses (CDC, 2017b). Between the years of 2005 and 2014, the diagnoses of HIV infection increased by 87% among
Hispanic/Latino and African American gay and bisexual, male youth, and by 56% among their White counterparts (CDC, 2017c). Youth are also a vulnerable population in the state of Florida and comprise almost a quarter of all new HIV infections (FLDOH, 2016c). Similar to national statistics, youth aged 20 to 24 account for over 80% of all new HIV infections among youth in Florida (FLDOH, 2014).

HIV infected youth have been found to have worse health outcomes in comparison to other age groups in the US (CDC, 2017c). HIV infected youth are the least likely to be linked to care (CDC, 2017c). When linked to care, youth are least likely to achieve viral load suppression; an estimated 16% of youth aged 18 to 24 achieved a suppressed viral load, which was the lowest among all age groups (CDC, 2017c; Kahana et al., 2015). The alarming incidence of HIV infection among youth calls for a multifaceted and multi-targeted approach (CDC, 2017c). Reduction in the rate of HIV infection is one of the goals of the National HIV/AIDS Strategy for the United States (2015).

Vulnerability of Youth to HIV Infection

The majority of youth living with HIV infection were infected behaviorally through unprotected sexual intercourse (CDC, 2017c). Youth are particularly vulnerable to HIV infection by being more prone to sexual risk behaviors. Sexual risk behaviors are behaviors that promote unprotected sexual intercourse and lead to unintended pregnancies and sexually transmitted infections, including HIV (CDC, 2017c). Common sexual risk behaviors among youth include: poor condom use, multiple sexual partners, injection drug use, and alcohol or other drug use, before or during sexual intercourse (Balaji et al., 2012; CDC, 2017c; CDC, 2015; Coeytaux, Kramer, & Sullivan, 2014;
Schrager, Wong, Weiss, & Kipke, 2011). Approximately 50% of sexually active high
school students surveyed in the US reported not using a condom during their last sexual
intercourse, and 1 in 5 sexually active youth reported drinking alcohol or using drugs
before last sexual intercourse (CDC, 2016). The unique factors that fuel this vulnerability
to HIV infection can be grouped into three categories: biological, psychological, and
socio-economical (Olukunle, 2007).

Biologically, youth are in a growth phase of experiencing changes physically,
mostly in sexual maturity (Adams & Berzonsky, 2008). Hormonal surge and sexual
maturation drives sexual debut and exploration among this population (DeLamater &
Friedrich, 2002). Additionally, the prefrontal cortex- the highest order of cognition –
reaches its full level of development at about 25 years of age (Simpson, 2008). This part
of the brain is responsible for reasoning, planning and impulse-inhibition, and assists the
person in weighing prospective actions and consequences before the execution of a
behavior (Simpson, 2008). Among youth, the prefrontal cortex of the brain is not fully
developed and has been linked to impulsive actions and inability to conceptualize long-
term effects of an action (Casey, Jones, & Hare, 2008; Steinber, 2008). Furthermore, the
brains of youth at this age have been found to have more reactive emotional processing of
information, leading to spontaneous and unplanned behaviors which are reward-seeking
and contribute to sexual risk behaviors (Casey et al., 2008; Steinber, 2008). A
combination of the hormonal surge, sexual organ development, and unformed prefrontal
cortex increases vulnerability of youth to sexual risk behaviors which may lead to
increased vulnerability to HIV infection.
Psychologically, the developmental period of youth has been described as a period of transition (Blackwell, Kali, Dweck, & Dweck, 2007; Blakemore & Mills, 2014; Olukunle, 2007). *Transition* describes the process of moving from complete dependence on parents/guardians to independence (Olukunle, 2007). This may lead to conflict with parent/guardian, isolation, and a perceived state of independence that fuels sexual risk behaviors (Blakemore & Mills, 2014; Casey et al., 2008; Olukunle, 2007). Youth tend to embark on activities that are hidden, most times without due guidance and counsel (Olukunle, 2007). Furthermore, youth are very sensitive to peers’ evaluation (Blakemore & Mills, 2014). This heightens social influence that can fuel sexual risk behaviors (Blakemore & Mills, 2014; Steinber, 2008).

Socio-economically, youth do not have the full capacity for financial subsistence (Olukunle, 2007). Most youth depend completely on parents or guardians for subsistence and accommodation (Olukunle, 2007). When this is lacking, youth are vulnerable to engage in sex traffic and drug sale, both of which fuel sexual risk behaviors (Naswa & Marfatia, 2010).

**HIV Testing Among Youth**

In combating HIV infection, HIV testing has been enumerated as a tool to increase linkages to HIV care, and to identify and counsel people at risk for HIV infection or those who are HIV-infected (Branson et al., 2006). Linkages to care will lead to placement on combination antiretroviral therapy, which through high medication adherence, will slow down HIV progression and lead to a decrease in viral load (Castilla et al., 2005; Montaner et al., 2010). This will consequently reduce HIV transmission (Quinn et al., 2000). Additionally, when individuals are aware of their HIV status,
precautions are taken to avoid transmitting HIV infection to other people (Rotheram-Borus, Murphy, Kennedy, Stanton, & Kuklinski, 2001; Tanney, Naar-King, & MacDonnel, 2012). Nevertheless, youth have the lowest rates of HIV testing compared to other age groups in the general population (Balaji et al., 2012; CDC, 2017c; Swenson et al, 2009; Talib, Silver, Coupey, & Bauman, 2013). It is estimated that 44% of HIV-infected youth between the ages of 18 and 24 were unaware of HIV infection, which is in sharp contrast to 16% of the general population living with HIV (CDC, 2017c).

Furthermore, only 10% of all surveyed high school students in the US had ever tested for HIV infection, in contrast to 41.2% that had ever had sexual intercourse (CDC, 2016). Almost 50% of the deaths from HIV infection among youth aged 18 to 24, were from persons living with undiagnosed HIV infection; this was reported to be the highest among any age group in the US (CDC, 2017c). Youth who are unaware of their HIV infection status are responsible for the majority of the HIV transmissions in this population (Marks, Crepaz, & Janssen, 2006; Rotheram-Borus et al., 2001; Tanney et al., 2012).

Most interventions that target HIV prevention have focused on promoting safer sex and reduction of risk behaviors that influence high-risk sex, such as use of drugs and alcohol (CDC, 2012; Johnson, Scott-Sheldon, Heudo-Medina, & Carey, 2011); however, this can only partially address the high incidence of HIV infection among youth. A combination of the vulnerability of youth to HIV infection and poor HIV testing rates creates a quagmire that fuels HIV transmission and progression. Therefore, more effort is needed to promote HIV testing among this population (Van Handel, Kann, Olsen, & Dietz, 2016).
Certain factors affect HIV testing among youth. Female youth are more likely to engage in HIV testing when compared to males (Balaji et al., 2012; Coeytaux et al., 2014; Inungu et al., 2011; Rakhmanina et al., 2014). This is because HIV testing is still largely embedded in reproductive health services, which are largely patronized by women (Leonard, Rajan, Gwadz, & Aregbesola, 2014; Mullins, Braverman, Dorn, Kollar, & Kahn, 2012; Siegel, Lekas, Olson, & VanDevanter, 2010). Additionally, HIV testing has been reported to mostly occur in clinically engaged settings based on recommendations from healthcare professionals (Inungu et al., 2011; Leonard et al., 2014; Mullins et al., 2012; Talib et al., 2013). However, fewer numbers of youth receive services from hospitals or clinics because this age group doesn’t frequently experience illness, and preventive healthcare is not common (Balaji et al., 2012; Talib et al., 2013). These factors that affect HIV testing, point to areas that need to be addressed to improve testing among youth.

**Problem Statement**

Sexual risk behaviors have a high prevalence among youth. A survey of youth who had sex within the past three months revealed that almost 50% did not use a condom and about 21% had drank alcohol or used drugs, during their last sexual intercourse (CDC, 2016). Among youth who had ever had sex, only 10% had ever tested for HIV infection (CDC, 2017d). Despite the predominance of sexual risk behaviors, only a few youth recognize the need to request and/or seek HIV testing (CDC, 2015; Inungu et al., 2011; Smith, Buzi, & Weinaman, 2005; Talib et al., 2013). Additionally, most of the youth that get tested as a result of a recommendation from their healthcare professional are females, mostly because of routine gynecological visits and pregnancy (Burstein,
Male youth do not typically attend routine or preventive health care visits (Burstein et al., 2003; Vaidya, Partha, & Karmakar, 2012); and will not encounter health professionals until experiencing symptoms of illness (Grant et al., 2006; Siegel et al., 2010; Vaidya et al., 2012). Male participants have been reported to test for HIV infection when symptoms of HIV progression were experienced (Siegel et al., 2010).

Current practice guidelines recommends that youth who are sexually active should screen at least once to identify those who are HIV-infected. Routine annual HIV testing for those who engage in sexual risk behaviors, and those who live or receive care in areas with high HIV prevalence (United States Preventive Services Task Force (USPSTF), 2013). Despite the recommendation for routine HIV testing, some healthcare professionals do not recommend HIV testing or provide preventive HIV services to youth (Branson et al., 2006; Burstein et al., 2003; Rizza, MacGowan, Purcell, Branson, & Temesgen, 2012; USPSTF, 2013). In addition, health care professionals are unaware of HIV testing recommendations, and are influenced by personal biases in recommending HIV testing (Leonard et al., 2010). For example, Leonard et al. (2010) reported that physicians did not offer testing to adolescents who should have been offered testing because these adolescents either were never been tested, or had not tested for HIV infection within the past year. Despite these practice guidelines, HIV testing rates among youth are declining (Balaji et al., 2012; CDC, 2012; Kann et al., 2016). This indicates the need to identify additional strategies to promote HIV testing among youth.

To address the high incidence of HIV infection among youth, it is important for youth to routinely test for HIV infection. Although several researchers have examined
HIV testing among youth, the factors that influence proactive HIV testing have not been explored (Mullins et al., 2012; Talib et al., 2013). For the purpose of the current study, proactive HIV testing is defined as testing initiated and completed by youth after an appraisal of the need, process, and benefits of HIV testing without the immediate recommendation of a healthcare professional (Fenton, Chinouya, Davidson, & Copas, 2002; Ma, Malcolm, Diaz-Albertini, & Klinoff, 2016; Mullins et al., 2012; Talib et al., 2013). The current study addresses this gap by exploring the factors that influence proactive testing for HIV infection among youth.

**Significance**

Most HIV testing among youth occurs in clinics, hospitals and doctor’s offices; these sites are described as clinical-engaged and have healthcare professionals that provide other clinical services and recommend HIV testing to youth (Inungu et al., 2011; Talib et al., 2013). Research on youth found that among those reporting previous HIV testing, 3.4% reported testing at a non-clinical engaged test site, without the immediate recommendation of healthcare professional (Inungu et al., 2011). The majority of youth who report HIV testing cite recommendation from healthcare professionals as their reason for testing; youth also reported not being offered HIV testing as a reason for not testing (Haines et al., 2011; Leonard et al., 2014; Mullins et al., 2012; Peralta, Deeds, Hipszer, & Ghalib, 2007). Researchers found that 67% of youth reported an increased likelihood of testing for HIV infection when offered by a healthcare professional, as opposed to requesting it, and 62.8% of youth who had never tested for HIV infection, cited never being offered testing as a reason for not testing (Haines et al., 2011; Peralta et al., 2007). Proactive HIV testing is less common than testing resulting from
recommendation from healthcare professionals (Haines et al., 2011; Leonard et al., 2014; Mullins et al., 2012; Peralta et al., 2007). Proactivity in HIV testing entails multi-layered decision-making, involving assessment, critical thinking, planning, and taking actions. The decision making involved in proactivity accounts for abstract future consequences. Youth have been shown to experience difficulty conceptualizing future and negative consequences (Casey et al., 2008; Simpson, 2008). Youth make decisions that are emotionally gratifying even when these decisions may cause harmful consequences. These behaviors include risky sexual behavior, which may result in delaying or evading HIV testing (Black, Sun, Rohrbach, & Sussman, 2011; Casey et al., 2008; Simpson, 2008; Steinber, 2008). The decisions of youth are also largely influenced by external factors that include: familial relationships, peers, and societal norms (Bangpan & Operario, 2014; Stock, Gibbon, Beekman, & Gerrard, 2015). Therefore, the decision-making pathway of proactivity in HIV testing among youth is unique and needs to be explored.

Although the factors that influence HIV testing have been extensively studied, some gaps exist in the literature. For example, the majority of the studies on HIV testing among youth have been conducted using a quantitative design (Siegel et al., 2010). This limits the findings by providing factors associated with HIV testing without an explanation for how the relationship occurs (Sznitman et al., 2010; Talib et al., 2013; Tolou-Shams et al., 2007). For example, several quantitative studies reported that females test more than males (Balaji et al., 2012; CDC, 2012; Coeytaux et al., 2014; Decker et al., 2015), however a qualitative study by Siegel and colleagues (2010) provided more insight into this gender difference revealing that women test more for HIV.
infection due to routine healthcare and relationship factors such as infidelity and partner sexual risk. There are other factors that influence HIV testing among youth that have not been explored qualitatively to understand the process of their relationships with HIV testing. To address this gap, the current study used a qualitative descriptive design to explore the factors identified by the youth and proactive HIV testing behavior. A qualitative descriptive design was used to explore the experiences and perspective of youth who initiated and completed HIV testing in a non-clinical engaged site.

Owing to the insufficiency of implementation of healthcare professional recommendations (Balaji et al., 2012; CDC, 2012), more research is needed to understand factors that influence proactive HIV testing, by understanding how these factors influence decisions to initiate and complete testing. The goal of the current study is to generate hypotheses on how to promote proactive HIV testing. This knowledge is significant because it will inform future research, interventions, and health policy that are geared towards increasing HIV testing rates and reducing the number of new HIV infection among youth. Findings from this study will also influence nursing care of youth at risk for HIV infection by providing recommendations for HIV counseling, and facilitation of proactive HIV testing.

**Overview of Study and Specific Aims**

In addressing these gaps, the current study explored the reason for proactive HIV testing from youth addressing the following aims:

1) Explore the factors that are related to youth’s proactive testing for HIV infection.

2) Explore how identified factors influenced the decision to test for HIV infection.
The current study used a qualitative method to synthesize and analyze the factors that influence proactive HIV testing, and how these factors relate to proactive HIV testing. In exploring the reasons and decision-making involved in proactive HIV testing among youth, the current study used a qualitative descriptive approach (Sandelowski, 2000). This design is well suited for this exploratory study because the information sought needs to be in a raw and unmodified form and is of great importance to clinical practice and health policy (Sandelowski, 2000). Data were collected via a private in-depth interview from youth who completed an HIV test at a non-clinically engaged HIV testing center. The questions were open-ended, semi-structured and minimally theorized based on the responses from previous questions; this allowed for both exploration of themes that emerge as well as capturing the perspectives of the youth (Sandelowski, 2000). The interview guide gave participants the opportunity to use their own words to describe the reasons means of how proactive HIV testing was initiated, identifying factors that played the most important roles. Data from the current study were analyzed using a directed content analysis, which is appropriate for a qualitative descriptive design (Hsieh & Shannon, 2005; Sandelowski, 2000). This analysis approach allowed the obtained data to represent itself, free of external interpretations (Sandelowski, 2000).

**Theoretical Framework**

Two theoretical frameworks guided the exploration of factors that affect proactive HIV testing and their influence on decision-making: (a) The Information-Motivation-Behavior Model (IMB) (Fisher, Fisher, Misovich, Kimble, & Malloy, 1996) and (b) Ottawa Decision Support Framework (ODSF) (O’Connor et al., 1998). The IMB was selected to form the foundation of the conceptual model to explore proactive HIV testing;
it is an HIV/AIDS prevention-specific theory, developed to understand how efforts were made to reduce the risk of HIV transmission (Fisher & Fisher, 1992; Fisher et al., 1996). Since its development, the IMB has been recognized and used as a theory to understand behavioral risk reduction (Kelly, Melnyk, & Belyea, 2012). Studies on various populations with different methods have applied the IMB to study HIV risk reduction through ways that included safe sexual practices and HIV testing (Aliabadi et al., 2015; Espada, Morales, Guillén-Riquelme, Ballester, & Orgilés, 2016; Macapagal, Greene, Andrews, & Mustanski, 2016; Walsh, Senn, Scott-Sheldon, Vanable, & Carey, 2011). This theory was selected because of its focus on individual processes involved in reducing HIV risk transmission (Fisher & Fisher, 1992; Fisher et al., 1996).

The IMB model is limited by its simplicity; it contains three constructs and delineates linear pathways on how the constructs influence each other (Fisher et al., 1996). This simplicity does not account for the complexity of decision-making among youth. For example, the IMB model stipulates that information directly influences behavior (Fisher et al., 1996), but researchers have found that knowledge does not produce a change in behavior for youth (Meadowbrook, Veinot, Loveluck, Hickok, & Bauermeister, 2014; Mullins et al., 2012; Straub et al., 2011). To account for the limitations of the IMB model, the ODSF (O’Connor et al., 1998) was used as a supplement and to explain the decision-making segment of the current study. The ODSF was developed for health decisions initiated by new situations, requiring careful considerations due to the uncertainties surrounding their outcomes (O’Connor et al., 1998). Previous studies have used the ODSF to identify the process of decision-making, gaps in decision-making, and points for intervention (Balneaves et al., 2012; Doull et al.,
2006; Long et al., 2016). In addition to providing an understanding of how decisions to proactively test for HIV infections are made, incorporating this model to the current study could potentially provide an intervention point to facilitate proactive HIV testing.

Testing for HIV infection increases the awareness of HIV vulnerability, provides exposure to HIV prevention tools, and connects infected persons to resources that reduces chances of transmission (CDC, 2017e). Proactive HIV testing could potentially intensify risk-reduction intentions because testing is initiated after an appraisal and/or understanding of HIV risk, with the individual being solely responsible for the steps taken in actual testing. The IMB model proposes that individuals carry out HIV risk reduction behaviors through the interaction of HIV prevention information and motivation to adopt health promoting behaviors (Fisher & Fisher, 1992; Fisher et al., 1996). The ODSF model identifies factors relevant to decision-making and proposes ways that decision-making can be improved through decision aids or interventions (O’Connor et al., 1998). Combining the two theories, the IMB and ODSF model were used to structure the interview questions, and elicit information to further understand proactive HIV testing among youth.

Summary

The high incidence rate of HIV infection among youth in the U.S. calls for a multi-targeted approach. Routine HIV testing offers opportunities to reduce HIV transmission for both HIV-infected and uninfected persons making testing one of the strongest tools for HIV prevention (CDC, 2017e). While remarkable work has been done by researchers and clinicians to increase rates of testing, there are identified lapses that limit the effect of HIV testing. Proactive HIV testing could fill current gaps in promoting
testing. Using the proposed theoretical framework, the current study provided an understanding of proactive HIV testing among youth. The current study provided knowledge that will inform clinical practice and research aimed at increasing rates of HIV testing among youth in the U.S.

In Chapter Two, an in-depth literature review explores factors that influence HIV testing among youth, health-seeking decision-making among youth, the Information-Motivation-Behavior Model (IMB), and the Ottawa Decision Support Framework (ODSF). Chapter Three describes the method and design of inquiry that is used in the study. Chapter Four describes the analysis process and steps involved in the development of themes, and findings of the study aims. Chapter Five discusses the findings, limitations of the study, and conclusions.
In this chapter, an in-depth review of the literature is undertaken to explore HIV testing and health-seeking decision making among youth. The literature review begins with a description of the state of HIV testing among youth in the United States, and South Florida. This is followed by a discussion of the salient factors that facilitate, prevent, and predict HIV testing among youth. The concept of proactivity is then introduced with an exploration of the decision-making of youth related to health seeking behaviors. Two theoretical frameworks that describes the current study is discussed. Topics covered in this chapter include:

1) HIV testing among youth: This section explores factors that influence HIV testing among youth, using the four levels of the socio-ecological model (SEM).

2) Health-seeking decision-making among youth: This section explores factors that influence youth’s decisions to seek health promotion.

3) The Information-Motivation-Behavior Model (IMB): This section explores the origin, previous study application, and the use of IMB in the current study.

4) The Ottawa Decision Support Framework (ODSF): This section explores the theoretical foundation, previous research uses, and application of the ODSF in the current study.

Four databases (MEDLINE, CINAHL, PsycINFO, and Google Scholar) were searched to identify published literature addressing the three aims of this review. The keywords used in this search included: youth, young people, high school, adolescence*, teen*, HIV test* and HIV screen*, decision-making, decision making, health seeking,
Information-Motivation-Behavior Model, IMB, and HIV. Articles included in this review were published between 2000 and 2016, in a peer-reviewed journal.

HIV Testing Among Youth

The social-ecological model (SEM) was selected as a framework for this literature review to categorize factors shown to affect the uptake of preventive health behaviors including HIV prevention and intimate partner violence (CDC, 2009; DiClemente, Salazar, & Crosby, 2006; Latkin & Knowlton, 2005; Latkin, German, & Vlahov, 2013). The articles on HIV testing among youth identified factors associated positively or negatively with HIV testing, and factors that were examined but had no relationship with HIV testing. These reported factors have been grouped into the four levels of the social-ecological model (Bronfenbrenner, 1979).

There are four interacting key levels of influence described in the social-ecological framework (i.e., individual, relationship, community, society). The individual level is used to describe biological, demographic and personal influences on health outcomes. In the case of HIV testing, this may include non-modifiable factors such as age and race/ethnicity and modifiable factors such as risk behaviors. The relationship level describes close relationships among family, friends, peers, and partners. This may include HIV testing practices of the youth's family, friends, and sexual partners. The community level describes social settings such as neighborhood, schools, churches, and the workplace. This may include access to HIV testing in the youth’s school or community. The societal level is the broadest level and encompasses norms, policies, and laws that influence social settings (CDC, 2009). This may include laws around the age in which
youth can be tested without parental consent. Understanding how these different levels may influence HIV testing among youth can contribute to the development of multi-level interventions promoting HIV testing in this high-risk population.

**Individual.** The most salient finding was that female youth were more likely to test in comparison to male youth (Arrington-Sanders & Ellen, 2008a; Balaji et al., 2012; CDC, 2012; Coeytaux et al., 2014; Decker et al., 2015; Inungu et al., 2011; Johns, Bauermeister, & Zimmerman, 2010; Longmore, Johnson, Manning, & Giordano, 2013; Nguyen et al., 2006; Rakhmanina et al., 2014; Siegel et al., 2010; Swenson et al., 2009; Talib et al., 2013). Similarly, youth with a history of pregnancy or a pregnant partner were more likely to report HIV testing (Arrington-Sanders, Ellen, & Trent, 2008b; Longmore et al., 2013; Swenson et al., 2009). In addition, older youth were more likely to test for HIV compared to their younger counterparts (Arrington-Sanders & Ellen, 2008a; Balaji et al., 2012; Coeytaux et al., 2014; Decker et al., 2015; Freeman, Sattin, Miller, Dias, & Wilde, 2009; Hall, Walker, Shah, & Belle, 2012; Moyer, Silvestre, Lombardi, & Taylor, 2007; Rakhmanina et al., 2014; Schrager et al., 2011; Straub et al., 2011; Sumartojo et al., 2008; Swenson et al., 2009; Talib et al., 2013; Trieu, Modeste, Marshall, Males & Bratton, 2010; Tuysuzoglu, Corliss, Fitzgerald, Abascal, & Samples, 2011). African-American youth were more likely to test than other racial groups, and gay, lesbian or bisexual youth were more likely to test compared to heterosexual youth (Balaji et al., 2012; CDC, 2012; Coeytaux et al., 2014; Decker et al., 2015; Hall et al., 2012; Inungu et al., 2011; Moyer et al., 2007; Rakhmanina et al., 2014; Straub et al., 2011; Swenson, Hadley, Houck, Dance, & Brown, 2011; Talib et al., 2013; Tolou-Shams et al., 2007). The majority of the studies that examined the effect of socioeconomic status (SES)
reported that low SES was associated with increased likelihood of testing (Inungu et al., 2011; Johns et al., 2010; Nguyen et al., 2006; Sumartojo et al., 2008; Swenson et al., 2009).

Researchers found that youth who reported behaviors that increase risk contracting HIV were more likely to test for HIV infection (Arrington-Sanders & Ellen, 2008a; Balaji et al., 2012; Caldeira, Singer, O’Grady, Vincent, & Arria, 2012 Coeytaux et al., 2014; Locke & Newcomb, 2008; Longmore et al., 2013; Ma et al., 2016; Moyer et al., 2007; Mullins et al., 2012; Phillips et al., 2012; Sabato, Burnett, Kerr, & Wagner, 2013; Schrager et al, 2011; Straub et al., 2011; Swenson et al., 2009; Swenson et al., 2011; Talib et al., 2013; Teitelman, Calhoun, Duncan, Washio, & McDougal, 2015; Tolou-Shams et al., 2007; Trieu et al., 2010). Some behaviors that were studied included: higher number of current or lifetime sexual partners, use of substances (drugs and alcohol) before or during sexual intercourse, poor condom use, sexual abuse, and sexual debut before age 13 (Arrington-Sanders & Ellen, 2008a; Balaji et al., 2012; Caldeira et al., 2012 Coeytaux et al., 2014; Locke & Newcomb, 2008; Longmore et al., 2013; Ma et al., 2016; Moyer et al., 2007; Mullins et al., 2012; Phillips et al., 2012; Sabato et al., 2013; Schrager et al, 2011; Straub et al., 2011; Swenson et al., 2009; Swenson et al., 2011; Talib et al., 2013; Teitelman et al., 2015; Tolou-Shams et al., 2007; Trieu et al., 2010). Youth who perceived a high risk of contracting HIV infection were more likely to seek testing (Dimmitt Champion, Harlin, & Collins, 2013; Moyer et al., 2007; Mullins et al., 2012; Peralta et al., 2007, Phillips, Ybarra, Prescott, Parsons, & Mustanski, 2015; Rakhmanina et al., 2014; Schnall, Rojas, & Travers, 2015; Sumartojo et al., 2008). Youth who reported engaging in HIV risk-reduction behaviors like negotiating partner condom
use, and not using drugs/alcohol during sex, were more likely to test for HIV infection (Sabato et al., 2013; Tolou-Shams et al., 2007).

Youth’s fear of a positive antibody HIV report was the most common reported barrier to testing (Moyer et al., 2007; Phillips et al., 2015; Schnall et al., 2015; Siegel et al., 2010; Wallace, McLellan-Lemal, Harris, Townsend, & Miller, 2011). Perceiving the benefits of testing such as reduced risk of transmission and reassurance of HIV status by youth, increased the likelihood of HIV testing (Leonard et al., 2014; Schnall et al., 2015; Wallace et al., 2011). Positive attitudes towards testing including the desire to know HIV status and self-initiation of testing were associated with HIV testing (Grant et al., 2006; Ma et al., 2016; Mullins et al., 2012; Phillips et al., 2012). Perceiving negative consequences of HIV testing including stigma of testing for HIV, worry about friends and family finding out about testing or test results, and preference for unknown HIV status deterred testing among youth (Phillips 2nd et al., 2015; Moyer et al., 2007; Schnall et al., 2015; Wallace et al., 2011). Youth who reported a history of history of STI diagnosis, testing and treatment were more likely to report HIV testing (Arrington-Sanders et al., 2008b; Johns et al., 2010; Caldeira et al., 2012; Straub et al., 2011; Swenson et al., 2009; Tolou-Shams et al., 2007; Trepka & Kim, 2010). The majority of the studies that examined the HIV knowledge found no relationship with HIV testing (Meadowbrooke et al., 2014; Mullins et al., 2012; Straub et al., 2007; Sumartojo et al., 2008).

**Relationships.** Sexual relationships of youth played a significant role in the decisions to test for HIV infection. Youth who reported having a new sexual partner or a same-sex partner were more likely to report completion of HIV testing (Leonard et al., 2014; Mullins et al., 2012; Straub et al., 2011; Sumartojo et al., 2008). Similarly,
suspecting a sexual partner was HIV-infected encouraged testing (Leonard et al., 2014; Phillips et al., 2012; Straub et al., 2011). Youth with partners who indulged in risky sexual behaviors such as multiple sexual partners and drug use were more likely to report testing (Decker et al., 2015; Longmore et al., 2013; Straub et al., 2011).

Youth who reported a family or friend who tested or advised testing were more likely to report HIV testing (Grant et al., 2006; Leonard et al., 2014; Phillips et al., 2012). Contrastingly, youth who were accompanied by parents or guardians to a clinical site were less likely to accept testing (Rakhmanina et al., 2014). Other forms of role models, like having a reputable person who shared personal experiences with HIV testing or HIV risk, encouraged youth to test for HIV infection (Wallace et al., 2011).

Community. A variety of test location factors were found to influence testing among youth. Youth were more likely to test for HIV infection in clinically engaged sites (clinics, hospitals, and physician's office) (Grant et al., 2006; Inungu et al., 2011; Phillips et al., 2012; Trepka & Kim, 2010). Testing sites identified as comfortable, convenient, or confidential, were reported to encourage HIV testing (Peralta et al., 2007; Sumartojo et al., 2008). Youth reported increased likelihood of HIV testing when offered testing or counseling by healthcare professionals (Haines et al., 2011; Leonard et al., 2014; Mullins et al., 2012; Peralta et al., 2007; Phillips et al., 2012; Schnall et al., 2015). Youth who resided in urban neighborhoods reported testing more than those living in rural areas (Rakhmanina et al., 2014; Wallace et al., 2011). Youth who reported living in areas with high HIV prevalence were more likely to test for HIV infection (Johns et al., 2011).
**Societal.** Payment for a HIV test was a deterrent to testing, and free testing increased the likelihood of HIV testing among youth (Peralta et al., 2007; Wallace et al., 2011). The availability of the rapid HIV test, and using saliva or urine in comparison to blood, increased the likelihood of testing among youth (Calderon et al., 2013; Myers et al., 2014; Peralta et al., 2007; Tuysuzoglu et al., 2011). Screening policies in clinical sites like HIV testing as part of routine physical examinations, blood donations, and hospitalization, encouraged testing among youth (Grant et al., 2006; Trepka & Kim, 2010). Although examined by only one study, youth reported that images or music that addressed HIV infection encouraged testing (Wallace et al., 2011).

**Summary of Factors Associated with HIV Test**

Most of the studies included in this review assessed factors at the individual level. Females, older youth, racial and ethnic minority youth, and gay, lesbian and bisexual youth were found to be more likely to get tested for HIV infection compared to youth who are male, White, or heterosexual. Additionally, the engagement in sexual risk behaviors also influenced the likelihood of getting tested for HIV infection among youth.

The literature also revealed several relationship-level factors that influence HIV testing among youth. These factors were found more consistently to predict HIV testing, and included having a partner who is HIV antibody positive, or suspected to have HIV infection, having a partner who engages in risk behaviors (e.g., having multiple partners), access to role models who promote HIV testing, and support from family and peers in obtaining HIV testing. Youth in committed sexual relationships may be protected against exposure to HIV infection risk. However, youth may not always be aware of the partner's
HIV infection risk and therefore diminish the importance of HIV testing. This review also revealed that youth whose partner’s HIV status is unknown or the partner coerced sex without using a condom are less likely to get tested for HIV infection (Longmore et al., 2013; Straub et al., 2011). This is concerning as research has shown that individuals who do not have control over sexual decision-making are at an increased risk for HIV infection (Pulerwitz, Amaro, Jon, Gortmaker & Rudd, 2002).

Although fewer studies have focused on community and societal level influences of HIV infection in comparison to individual and relational level factors, there are important associations that have been established. HIV testing appears to be easily accessed in urban communities (Rakhmanina et al., 2014; Wallace et al., 2011), in neighborhoods identified as being at high risk for HIV infection (Johns et al., 2011), and through testing sites that are located within clinical-engaged test locations (Grant et al., 2006; Inungu et al., 2011; Phillips et al., 2012; Trepka & Kim, 2010), particularly when offered by a healthcare professionals (Haines et al., 2011; Leonard et al., 2014; Mullins et al., 2012; Peralta et al., 2007; Phillips et al., 2012).

Over 95% of youth reporting previous HIV testing, tested at a clinical-engaged test site and approximately 70% reported testing from a recommendation by a health care professional (Haines et al., 2011; Inungu et al., 2011). The absence of recommendation from health care professionals has been reported as a barrier to HIV testing among youth (Peralta et al., 2007). Although clinical-engaged sites and healthcare professionals facilitate testing among youth (Inungu et al., 2011; Talib et al., 2013), it is insufficient to
assess the testing needs of this population because fewer numbers of youth receive services from clinical-engaged sites (compared to what), and preventive healthcare is not common among youth (Balaji et al., 2012; Talib et al., 2013). The current study addresses this gap by assessing HIV testing among youth. This will provide more insight into the factors that fuel testing under these circumstances, and expose a potential intervention point that will increase rates of HIV testing. Table 2.1 contains a summary of the factors that affect HIV testing among youth, identified by the literature review (Adebayo & Gonzalez-Guarda, 2016).

Table 2.1
*A Summary of Salient Factors that Affect HIV Testing among Youth*

<table>
<thead>
<tr>
<th>Individual</th>
<th>Relationship</th>
<th>Community</th>
<th>Society</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Female Gender</td>
<td>+ Committed Relationships</td>
<td>+ Healthcare Professional Recommendation</td>
<td>- Cost of Testing</td>
</tr>
<tr>
<td>+ Black Race</td>
<td>+ Partner Infidelity</td>
<td>+/- Confidentiality</td>
<td>- Healthcare Accessibility</td>
</tr>
<tr>
<td>+ Older Age</td>
<td>+ Peer HIV Communication</td>
<td>+ Family Encouragement</td>
<td>+ Routine Healthcare</td>
</tr>
<tr>
<td>+ Physical Illness</td>
<td>+ Desire to know status</td>
<td>X HIV/STI knowledge</td>
<td>- Fear</td>
</tr>
</tbody>
</table>

Note: + = Increase likelihood of HIV Testing; - = Decrease likelihood of HIV Testing; X = No relationship with HIV Testing
Health-Seeking Decision-Making among Youth

Although youth have been found to express interest in making health-related decisions, youth are limited by the lack of ability to make decisions that involve conceptualizing consequences of the future (Casey et al., 2008; Simpson, 2008). This finding among youth has been linked to the pre-developed pre-frontal cortex that is responsible for inhibiting impulsivity and emotional processing of information (Black et al., 2011; Casey et al., 2008; Simpson, 2008; Steinber, 2008). The prefrontal cortex of the brain that is responsible for the highest order of cognition and reason, matures fully at about the age of 25 (Simpson, 2008). This developed portion of the brain enables older adolescents to better understand risk and consequences of actions in comparison to younger youth (Fair et al., 2013). Older youth are better equipped to decide between different courses of actions as well as their respective consequences (Casey et al., 2008; Steinber, 2008).

Youth perceive themselves as less vulnerable to contracting HIV infection despite engagement in behaviors that increase risk of contracting HIV; inability of youth to conceptualize effects of HIV infection affects decision-making (Casey et al., 2008; Mahat & Scolloveno, 2006). The decisions of youth are often vague and not based on facts or reasons. For example, research on young women’s decision to have a pelvic exam revealed that there was no explanation for the decision to seek healthcare at a particular point in time (Canales, Carr, & Wohlberg, 2005). There is also gender disparity in decision-making among youth, especially regarding sexual health. Women are more likely to defer to male partners regarding protection during sex and other behaviors that promote sexual health (Cooper & Gordon, 2015).
The decisions of youth are significantly impacted by familial relationships, sexual relationships, peers, stereotypes, and societal norms (Bangpan & Operario, 2014; Stock et al., 2015). Parents and guardians continue to make decisions regarding the sexual health of youth, which could interfere with the youth’s ability to make independent decisions (Lee et al., 2015). Parental influence on youth’s decision-making could be detrimental when insufficient or inadequate information regarding health promotion behavior has been provided (Canales et al., 2005; Sieving et al., 2016). Parents could also be a positive influence on decision-making when parents possess adequate knowledge about the benefits of the health promotion behavior, and encourage youth to make health-promoting decisions (Canales et al., 2005). Additionally, fear of reaction from parents/friends can deter the decision to seek sexual health promotion services (Phillips 2nd et al., 2015; Moyer et al., 2007; Rakhmanina et al., 2014; Schnall et al., 2015; Wallace et al., 2011).

Sexual relationships have consistently been a strong influence on decisions youth make regarding sexual health (Bangpan & Operario, 2014; Chambers & Rew, 2003; Fantasia, 2011; Jacques-Tiura et al., 2015). This affects behaviors that prevent HIV infection such as safer sexual practices and HIV testing. Sexual relationships heighten the emotional processing in decision-making among youth (Bangpan & Operario, 2014; Casey et al., 2008). Youth have used length of intimate relationships, and trust in the partner to make sexual health decisions, as opposed to facts about safe sex that had been taught in school (Hoppe et al., 2004). There is a disconnection between knowledge and health-seeking decisions: youth don’t internalize health prevention information, even when engaged in behaviors that increase their vulnerability to adverse consequences.
Peers are also a strong influence on decision-making. Youth are more likely to adopt a behavior if peers accept and recommend that behavior (Stock et al., 2015; Wheldon et al., 2016).

Societal influences on youth’s health-seeking decisions are broader in effect because these factors penetrate other levels of influence like relational, individual, or community (CDC, 2009). Negative societal norms have been found to influence decision-making among youth (Bangpan & Operario, 2014; Fair et al., 2013; Fantasia, 2011). For example, Fantasia (2011) reported that adolescents described one-time sexual encounters without any expectation of a relationship as societal standards. In most cultural settings, there are norms and beliefs about sex such as gender-related expectations towards sex that influence decisions regarding sexual health (Bangpan & Operario, 2014; Brêtas, Ohara, Jardim, & Muroya, 2009; Fair et al., 2013; Fantasia, 2011). Additionally, environmental factors such as poor living conditions and physical stress negatively impact decisions regarding health promotion (Canales et al., 2005). Societal level factors such as policies that make HIV testing a routine procedure normalize testing and encourage making decisions towards testing uptake (Chung & Rimal, 2015).

Sources of information also affect youth decision-making. Media has been found to be a main source of information for sex, sexual habits, and sexually transmitted infections (Brêtas et al., 2009). For example, as high as 75% of the female participants and 52% of the male participants reported television as the main source of information for sexually transmitted infections (Brêtas et al., 2009). Media as a main source of information poses concern because sex is often projected to attract attention and viewership as opposed to promoting health (Brêtas et al., 2009). Incorrect information
regarding sex and sexual health from lay sources like media, family, and peers, affect sexual health decisions adversely (Canales et al., 2005). The presence of a threat with emphasis on losses as opposed to gains, has been found to facilitate decision-making towards health promotion (Macapagal et al., 2015; Wheldon et al., 2016). Researchers have also found that decision-making among youth are facilitated with information that contains statistics, reputable sources, and directions on access to more information (Sundstrom, DeMaria, Meier, Jones, & Moxley, 2015). The conditions of sites for health-related services have also been found to influence decision-making among youth. Youth often seek healthcare services at sites that maintain confidentiality of health information, are easily accessible, and provide privacy (Phillips et al., 2015; Schnall et al., 2015; Wallace et al., 2011).

The Information-Motivation-Behavior Model

Overview. The IMB model is a micro range theory that was developed specifically to address the gaps in HIV/AIDS risk reduction interventions, identified through a literature review and analysis (Fisher & Fisher, 1992; Fisher et al., 1996). The review revealed that successful HIV/AIDS interventions incorporated information, motivation, and behavior skills set, which eventually formed the constructs of the IMB model (Fisher & Fisher, 1992; Fisher et al., 1996). Theoretically, the IMB model proposes that HIV/AIDS risk reduction occurs through behavioral skills that are molded by HIV/AIDS risk reduction information and motivation (Fisher & Fisher, 1992; Fisher et al., 1996). The IMB model’s specific creation for HIV risk reduction fuelled its wide

Some of the recent applications of the IMB model are in development, evaluation, and prediction of HIV-prevention behaviors that include: condom use, sexual negotiation, sexual communication, and HIV testing (Aliabadi et al., 2015; Espada et al., 2016; Macapagal et al., 2016; Walsh et al., 2011). In other fields, the IMB model has been used as a framework to assess health promotion behaviors like physical exercise, engagement in care, and chronic disease management (Kelly et al., 2012; Mayberry & Osborn, 2014; Santillán Torres Torija, Villagrán Vázquez, Robles Montijo, Eguiluz Romo, & de Lourdes Eguiluz Romo, 2015).

**Model Constructs and Assumptions.** The basic concepts of the IMB model are: information, motivator, and behavior. *Information* refers to HIV/AIDS-specific information regarding transmission and prevention. *Information* should address the specific needs of a population that might not necessarily apply to a general population. *Motivation* refers to the will to change behaviors that fuel the risk for HIV/AIDS, and attitude towards acting on knowledge to prevent HIV/AIDS. *Behavioral skills* refer to skill set specific for preventing HIV infection or progression to AIDS (Fisher & Fisher, 1992; Fisher et al., 1996).

The IMB model proposes that *information* and *motivation* have a bidirectional relationship with each other. Information is proposed to fuel motivation to reduce and prevent risk, while motivation fuels the acquisition of more information that will aid in risk reduction. On the other hand, information and motivation are regarded as
independent constructs because knowledge does not always produce motivation and individuals who are motivated may not necessarily have adequate information on prevention. Information and motivation are also assumed to activate behavioral skills individually and together. Individual effects produce relatively simpler behavior skills, while simultaneous effects produce relatively complicated behavior skills. Finally, all three constructs influence HIV/AIDS prevention behavior, individually and collectively. The level of influence also depends on the relative complexity of intended behavior (Fisher & Fisher, 1992; Fisher et al., 1996).

Application of IMB. Information on HIV infection, transmission, and prevention raise awareness of vulnerability to HIV infection and benefits of receiving testing (Wallace et al., 2011). The motivation of youth to adopt HIV testing is influenced by the dynamics of interpersonal relationships; knowing a person that tested or is living with HIV (role modelling); process of testing; the conditions of test sites, and accessibility of the test sites (Ballester-Arnal, Ruiz-Palomo, & Gil-Llario, 2015; Leonard et al., 2014; Phillips et al., 2012; Phillips 2nd et al., 2015; Wallace et al., 2011). Based on the proposition of the IMB model, these variables that fall under the information and motivation constructs will influence each other (Fisher & Fisher, 1992). For example, youth who perceive themselves as vulnerable will be motivated to seek out accessible test sites. Behavior skills that demonstrate self-efficacy for risk reduction have also been found to influence the testing behavior (Sabato et al., 2013). The IMB model proposes that the variables under information and motivation constructs will influence proactive HIV testing independently and through behavior skills like self-efficacy for HIV testing.
There are limitations in the application of the IMB model. Although the model proposes that knowledge from information can directly and independently influence a behavior, several studies on youth have found this relationship insignificant (Harkabus, Harman, & Puntenney, 2013; Kelly et al., 2012; Kiene et al., 2013). For example, HIV prevention information was not associated with condom use (Harkabus et al., 2013). Instead, research on youth showed that the relationship between information and behavior change was significant indirectly when moderated by motivation or skills that facilitate the behavior (Harkabus et al., 2013; Kiene et al., 2013). This limitation is noted in the current study. Knowledge from HIV prevention information may not directly influence proactive HIV testing, but could influence testing through other factors. In assessing proactive HIV testing, the IMB model was be used to frame the semi-structured interview questions.

**The Ottawa Decision Support Framework (ODSF)**

**Overview.** The ODSF is a mid-range theory model, used as a guide for health and social decisions (O’Connor et al., 1998). The theoretical origin of the ODSF is linked to the Expectancy Value Theory, Decisional Conflict Theory, and Social Support Theory (O’Connor et al., 1998). The ODSF (O’Connor et al., 1998) centers on health decisions that are brought on by new circumstances, requiring significant deliberation over the uncertainty of the risks versus the proposed benefits (O’Connor et al., 1998). The ODSF has been widely used in the study of decision-making processes, and creation of decision aids to provide support in making decisions (Balneaves et al., 2012; Légaré et al., 2006; Long et al., 2016). In HIV-related research, the ODSF has been used to examine decision
making needs in pregnant HIV-infected women, and the needs for decision support in immigrant women for the uptake of HIV testing and counselling (Doull et al., 2006; Mitra, Jacobsen, O'Connor, Pottie, & Tugwell, 2006).

**Model Constructs and Assumptions.** The ODSF is divided into three parts: determinants of decisions, decision support interventions, and evaluation of the success of decision support (O’Connor et al., 1998). *The determinants of decisions* are the factors that influence a decision. These could be demographics, individual perceptions of the decision, perceptions of people important to the individual, and resources available for the decision (O’Connor et al., 1998). *The decision support interventions*, are activities that are directed at the individual’s characteristics and needs, to aid in making decisions (O’Connor et al., 1998). *The evaluation of the success of decision support*, entails appraising effect of the decision on the individual as well as the outcome of the decision (O’Connor et al., 1998).

The ODSF model proposes that decisions are based on an individual’s characteristics, level of knowledge, expected outcomes and the value placed on the decisions (O’Connor et al., 1998). Decisions are also more likely to be taken when perceived as important by people in close relationships with the decision owner, and have an adequate amount of resources to facilitate implementation (O’Connor et al., 1998). Upon evaluation and identification of decision determinants, the ODSF proposes that decision support could be created and tailored to decision determinants with the aim of improving knowledge, self-efficacy, and resources that will influence the decision and decision making process (O’Connor et al., 1998). Finally, the ODSF proposes an evaluation of decision support to appraise the quality of the decision and its outcome.
A high quality decision is described as one where a decision owner is actively involved, and possesses adequate knowledge, clear values that align with personal choices, and realistic expectations (O’Connor et al., 1998).

**Application of the ODSF:** In line with the ODSF, decision-making among youth is influenced by demographic characteristics like age, gender and level of education (O’Connor et al., 1998). Youth’s perception of benefits or fear of a health decision have also been found to influence its uptake (Phillips 2nd et al., 2015; Schnall et al., 2015; Siegel et al., 2010; Wallace et al., 2011). The ODSF proposes decisions are influenced by knowledge about a problem, and the consequences or risks of a health decision (O’Connor et al., 1998). Unlike the IMB that delineates a linear pathway for the relationship between knowledge and HIV testing behavior, which has been found to untrue in research among youth, the ODSF proposes knowledge as one of the factors that influences a decision in addition to other determinants of decisions (Fisher & Fisher, 1992; Fisher et al., 1996; Meadowbrook et al., 2014; Mullins et al., 2012; Straub et al., 2011). An important addition by the ODSF is the factor of decisional conflict (O’Connor et al., 1998). Decision conflict is defined as uncertainty about action towards a decision arising from unclear outcomes, inadequate knowledge and social support, unclear norms and values, unrealistic expectations, and lack of other resources that could support decisions (O’Connor et al., 1998). Researchers have found these contributors to decisional conflict among youth (Casey et al., 2008; Phillips 2nd et al., 2015; Moyer et al., 2007; Rakhmanina et al., 2014; Simpson, 2008). Youth have been found to possess inadequate knowledge about health decisions, are more likely to be influenced by social
pressure from peers, and lack resources such as financial support (Johns et al., 2010; Macapagal et al., 2015; Stock et al., 2015; Wheldon, et al., 2016).

The ODSF also proposes that decisions are influenced by the perceptions of people important to the youth (O’Connor et al., 1998). Research has found that decisions among youth are influenced by social relationships like parents, peers, and sexual partners (Bangpan & Operario, 2014; Jacques-Tiura et al., 2015; Lee et al., 2015; Sieving et al., 2016). Coercion, support, or participation in decision-making, are some proposed ways people in interpersonal relationships with youth can influence a decision (O’Connor et al., 1998). Another category of determinants of decision is resources; it is divided into personal and external resources (O’Connor et al., 1998). Personal resources include previous experience with illness, decision making process, consequences and alternatives; self-efficacy (perceived confidence in ability to make the decision); motivation (readiness and interest in decision); skills and financial resources to implement a decision (O’Connor et al., 1998). External resources include information, support and services from social, professional, or societal networks (O’Connor et al., 1998).

The second part of the ODSF model is decision support (O’Connor et al., 1998). Decision support involves targeting the contributors to decisional conflict also known as the modifiable determinants, with the goal of improving the quality of decision making (O’Connor et al., 1998). One of the goals of the ODSF model is to identify areas that need decisional support and provide decision aids like tailored information, alternatives to clarify values, augment skills, improve benefits and reduce risks (O’Connor et al., 1998). Decision support could also influence demographic factors. For example, decision
aid can be tailored to gender, and can be specified to a particular age, educational level or race (O’Connor et al., 1998). The ODSF model has been used to develop and evaluate over 30 patient decision aids (Ottawa Hospital Research Institute, 2015). Decision support interventions based on the ODSF model have been found to reduce decisional conflict, increase knowledge, and lead to active involvement in decision making (O’Connor et al., 1998). Applying the ODSF model to the current study identified areas of decision conflict for the youth that can benefit from decision aids, which could potentially influence interventions to facilitate proactive HIV testing.

The last part of the ODSF model is the evaluation of decision support (O’Connor et al., 1998). The outcome of the evaluation can be both the decision making process as well as the outcome of the decision (O’Connor et al., 1998). The ODSF model acknowledges that good decisions don’t necessarily lead to good outcomes, factoring the complexity involved health decisions (O’Connor et al., 1998). Decisions considered to be of great quality contain appropriate and adequate knowledge, low decisional conflict, expectations that are realistic and align with clear personal values (O’Connor et al., 1998).

One of the major strengths of the ODSF model is its conceptualization of decision conflict (Légaré et al., 2006; O’Connor et al., 1998). The decision to test for HIV infection has been found to be associated with fear of positive HIV test results and reactions from family member, peers, and sexual partners (Phillips et al., 2015; Schnall et al., 2015; Siegel et al., 2010; Wallace et al., 2011). Uncertainty of how to deal with living with HIV infection has been shown to deter youth from testing for HIV infection (Phillips et al., 2015; Schnall et al., 2015; Wallace et al., 2011). The current study assessed youth
who have proactively completed HIV testing, and applying this model elicited pathways through which youth overcame decisional conflict in their decision to test for HIV infection. Another strength of this model is that it accounts for different levels of factors that influence decision making. The ODSF model contains individual, relational, and societal level factors, all of which interplay to determine the decision making process (Balneaves et al., 2012; Doull et al., 2006; Légaré et al., 2006; Long et al., 2016; Mitra et al., 2006; O’Connor et al., 1998). The decision-making of youth was assessed by exploring the type, level, and sources of information that heightened perception of HIV vulnerability; the motivation to seek and obtain an HIV test was explored by identifying factors that fuelled youth decision towards proactive testing; the behavior of testing was evaluated based on how information and motivation interacted to produce proactive testing.

**Summary**

HIV testing behaviors among youth could be improved when moved beyond clinically engaged institutions, with youth taking the lead in the initiation and execution of HIV testing (Mullins et al., 2012; Talib et al., 2013). There are gaps in knowledge regarding factors that influence youth’s health-seeking decisions and HIV testing.

The majority of the studies investigated HIV testing and decision-making quantitatively (Bangpan & Operario, 2014; Siegel et al., 2010; Stock et al., 2015). Quantitative studies provide a limited understanding of the identified factors that influence HIV testing and decision-making. Although associations were identified that provided insights into factors that influence HIV testing and health seeking decisions, these relationships are unexplained and inconsistent (Bangpan & Operario, 2014;
Longmore et al., 2014; Stock et al., 2015; Siegel et al., 2010). For example, gender has been found to influence both HIV testing and health-seeking decisions in opposite ways. Female youth are more likely to test for HIV infection, but less likely to make decisions regarding sexual health (Balaji et al., 2012; Coeytaux et al., 2014; Inungu et al., 2011; Rakhmanina et al., 2014). Several studies investigating decision making in sexual health revealed that females defer decisions regarding sexual health to their male partners and are more likely to identify trust in the partners as an alternative to adopting sexual health preventive behaviors (Bangpan & Operario, 2014; Casey et al., 2008; Cooper & Gordon, 2015; Hoppe et al., 2004). These findings suggest that gender influences HIV testing and health-seeking decisions through different ways that are unrevealed by noted quantitative associations.

In several studies, reported factors were found to influence HIV testing and health-seeking decisions in more than one way (Canales et al., 2005; Lee et al., 2015; Sieving et al., 2016). For example, parents of youths have been reported to both facilitate and deter HIV testing and health-seeking decisions among youth. Some studies provided explanations for the quantitative associations identified. While youth were less likely to test when accompanied by parents to hospitals, youth were also more likely to test when advised to seek testing by a parent (Rakhmanina et al., 2014). These findings were similar in studies that focused on decision-making, where youth were seen to not take health-seeking decisions when parents had insufficient knowledge of the benefits of health-promoting behaviors and more likely to seek testing when parents had sufficient knowledge and provided counsel that encouraged youth to seek health-promoting behaviors (Canales et al., 2005). However, there is insufficient information on other
complexities that could arise with the effects of similar factors. The studies in the integrative review examined HIV testing and health-seeking decisions separately, leaving a gap in understanding how the same factors affect both HIV testing and health-seeking decisions together.

Current HIV testing among youth is largely facilitated by clinically engaged institutions and healthcare professional counseling (Inungu et al., 2011; Leonard et al., 2014; Mullins et al., 2012; Talib et al., 2013). This limits HIV testing and health-seeking decisions in multiple ways. Firstly, youth are rarely ill and less likely to seek health promoting services (Balaji et al., 2012; Talib et al., 2013; Vaidya et al., 2012). HIV testing among youth with private insurance is less likely to occur in comparison to those with no insurance (Nguyen et al., 2006). Non-clinical engaged settings are easily accessible, less stigmatized, do not possess regimentations of clinically engaged institutions and are easier to use for HIV testing (Weidle et al., 2014).

The current study aimed to investigate the factors that affect proactive HIV testing and the decisions to initiate testing, among youth in multiple HIV testing sites. The current study addressed these gaps in knowledge by studying:

a) Youth who present to testing site, initiate, and complete HIV testing

b) A sample of youth with different demographic compositions from a United States metropolitan city with the highest prevalence of HIV infection among youth in the state of Florida.
Chapter Three

Methods

In this chapter, the approach of inquiry, study setting, study sample, data collection method, and data analysis of the current study is presented. Youth in the United States have the lowest rates of HIV testing, and a new insight is needed to understanding factors that influence testing (CDC, 2017c). The current study used a qualitative descriptive design (Sandelowski, 2000) to explore the factors that are related to proactive HIV testing among youth aged 18 – 24, with attention to how these factors relate to decision-making. This age group was selected because youth aged 20 to 24 years account for over 80% of all new HIV infections among youth (CDC, 2017c).

The majority of the studies that have examined factors that affect HIV testing among youths used quantitative designs (Longmore et al., 2014; Siegel et al., 2010). Findings from quantitative research methods are limited by providing factors associated with HIV testing without an explanation for how the relationship occurs or insights into the complexities of the relationships (Sznitman et al., 2010; Talib et al., 2013; Tolou-Shams et al., 2007). There is a dearth of knowledge available on the factors associated with HIV testing, and insufficient knowledge to explain how the identified associations occur (Siegel et al., 2010). In answering the research questions, a qualitative descriptive method was used to explore how and why these associations occur in addition to exploring the complexity of the associations (O’ Cathain, Thomas, Drabble, Rudolph, & Hewison, 2013). Specifically, the current study addressed the questions: (a) what factors
are related to proactive HIV testing and (b) how do youth conceptualize the relationship of those factors in deciding to test for HIV infection?

Design

Qualitative research methods are instrumental for understanding a phenomenon holistically and are appropriate for studying phenomena that have not be explored (Polit & Beck, 2012). In qualitative inquiry, data is obtained in participants’ words and perspectives, to make meaning of the experiences (Polit & Beck, 2012). Unlike quantitative methods, data from qualitative studies are collected and analyzed to allow for adjustment and inclusion of new data (Polit & Beck, 2012). Owing to the knowledge gap in understanding proactive HIV testing among youth, a qualitative descriptive design was used to explore the experiences and perspective of youth who initiated and completed HIV testing in a test site. This design is particularly suited for the current study because the data required should be obtained from a thorough exploration of the experiences of participants, to provide information that will inform healthcare and policy making (Sandelowski, 2000). A qualitative approach allows the capturing of information specific to a population, as well as the nuances that govern the information (Polit & Beck, 2012). The data in the current study was collected through private individual in-depth interviews. This method of data collection allows the participant to explore the experiences and feelings privately as participants answer the question. A private interview is also appropriate for this age group because participants are easily influenced by peers and this could affect the information obtained when collected from a group setting (Blakemore & Mills, 2014; Steinber, 2008).
Settings

The current study was conducted in Miami, Florida. The state of Florida currently has the second highest number of new HIV diagnoses with approximately 5,000 new cases in 2016 (FLDOH, 2017). Miami is a city located in Miami-Dade County, and accounts for the highest incidence, 1 in 5 new HIV infections in 2015, in the state of Florida (FLDOH, 2016d). Youth in Miami have the highest incidence of HIV infection among youth in Florida (FLDOH, 2016a). Specifically, youth aged 20 -24 accounted for 81% of all new HIV infections among persons below age 25 in Florida (FLDOH, 2014). Furthermore, the highest number of HIV infections among youth are in Miami-Dade County, in Florida (FLDOH, 2016a). Participants were recruited from HIV testing sites in Miami-Dade County. The youth targeted at these locations were those who independently seek and obtain HIV testing. HIV testing sites did not possess individual Institutional Review Boards (IRB); consequently, the IRB was deferred to University of Miami. The study was approved by the University of Miami IRB in March, 2017.

Sample

Eligible youth for the current study were a) ages 18 to 24 years; b) able to speak and understand English language fluently; c) able to provide informed consent; and d) completed HIV testing proactively at a HIV testing sites. This age group is ideal because it contains the age range (20 -24 years) that has the highest rate of new HIV infection compared to other age groups (CDC, 2017c). Ability to speak and understand English is necessary because most of the HIV prevention information is currently in English, and the effect of information is a construct of interest in the current study (Wallace et al.,
The completion of HIV testing by youth is the indication of HIV testing, which is the outcome of interest in the current study.

The participants were recruited from HIV testing sites through purposive sampling. Purposive sampling was used to select youth who sought and completed proactive HIV testing, to further understand reasons for testing (Polit & Beck, 2012). Purposive sampling uses the researcher’s discretion to obtain participants that will provide information-rich data (Polit & Beck, 2012) for the study. This method of sampling is appropriate because the outcome of interest, proactive HIV testing, depends on youth who come independently to these test sites and complete testing. The current study screened and enrolled 30 youth. The flexibility of qualitative inquiry allows adjustment for new information during data collection (Polit & Beck, 2012). Consequently, data was collected until data saturation (Polit & Beck, 2012). Data saturation was established after the PI analyzed data and found that subsequent interviews did not possess any new themes (Creswell, 2014). The PI consulted with dissertation chair and an extra five interviews were conducted to ensure data saturation had been reached.

The PI met with the staff at the community test sites, explained the purpose of the study and obtained letters of support. The staff performing HIV testing introduced the study after the completion of testing to the youth. A screening form was used to ascertain that youth came in proactively. If the youth was interested, the PI further explained the study, screened for eligibility and collected written informed consent. Participants were given $20 in cash following the completion of the study. Data for the study was collected through individual recorded open-ended interviews.
Data Collection Methods

Youth were interviewed and screened for eligibility in a private room at the study site. Data collection included demographic data forms and audio recorded open-ended interview. Each participant completed a demographic form that included: age (years); sex (female or male or transgender); race/ethnicity (African American/Black, Caucasian/White, and Hispanic or Latino/a, other); highest level of completed education; average work-hours in a week; income earned per year; sexual relationships (same-sex or opposite-sex or bisexual); number of lifetime sexual partners; number of sexual partners in the past three months; condom use at last sexual intercourse and during lifetime; number of times HIV testing obtained throughout lifetime; date of last HIV test. The questions on the demographic form are based on the review of the literature to examine youth sexual risk behavior and previous HIV testing. The demographic form used in this study is located in Appendix A.

The primary method of collecting data in the current study was open-ended interview questions. All the interviews were conducted by the PI in a private area at the study sites upon consent of the participant. Data was collected with an interview guide that consisted of open-ended questions, allowing the participants to guide responses (Polit & Beck, 2012). The interview questions elicited information from participants about knowledge of HIV testing, decision, and factors related to HIV testing, and experiences initiating and completing testing. The guide allowed participants’ responses to determine the probes for subsequent questions; this prevented external influences on participants’ perspectives. The interviews lasted approximately 30 minutes to 1-hour, to avoid participant burden.
The first five interviews were considered pilot interviews (Polit & Beck, 2012). This enabled the PI to test the questions that were asked to verify if the intended information is obtained, and if the participants understood the questions the way the researcher intended. To accomplish this, the first five participants were asked questions that assessed the clarity of the words used and an understanding of the interview questions. After assessment, the questions proposed for the study were found to be valid and interview questions were unchanged; the five participants were included in the overall study. The questions had a likelihood of bringing back memories that will cause an emotional reaction. In the event of this occurrence, participants were informed to stop the interview at any time and to skip questions that felt uncomfortable to answer. Counseling services and debriefing were provided by staff trained in counselling at the test site for participants that would require it. During the debriefing, participants were given clear short explanations on the rationale for the question asked, and participant questions were answered. However, there was no occurrence of participant discomfort during the study.

The interview questions were semi-structured, open-ended, and tailored to the participants’ comments. For example, when a participant mentioned that a partner’s infidelity was the reason for HIV testing, the PI followed up with a question like: *Tell me how your partner’s infidelity influenced your decision to seek HIV testing?* This follow-up question elicited a response regarding the relationship between partner sexual risk and HIV testing, and also the decision-making of HIV testing for the participant.

The semi-structured interview questions were guided by the IMB model. The first set of questions elicited youth’s knowledge of HIV testing – source of information,
relationship with source, and perceptions or gains from the information. The following set of questions explored how and why youth decided to test for HIV infection. The final set of questions examined youth’s HIV testing experiences. An interview guide with the semi-structured questions is located in Appendix B. Throughout the period of the interview, the PI wrote field notes with recurring words and themes as a reference for initial coding, and future questions that produced new information from the interviews (Creswell, 2014). A sample of the field note template is located in Appendix C.

Data Preparation and Analysis

Upon participant’s consent, the PI conducted and audio-recorded all interviews. There were two audio-recorders with one serving as a back-up. The interview was done with semi-structured interview questions (Appendix B). Following consultation with the dissertation chair, an evaluation of the first five interviews confirmed the participants understood the questions the way the researcher intended. The questions proposed for the study were found to be valid and the same questions were used for other participants; the five participants were included in the overall study. After each interview was completed, the PI transcribed the audio files verbatim into an electronically typed document. The transcribed data was stored in a folder on a password-protected desktop computer with a password-protected server. The transcribed file was only accessible by the PI and dissertation chair.

Qualitative inquiry allows for concurrent data collection and analysis that mutually affect each other; this enables the phenomenon under study to be holistically understood (Polit & Beck, 2012; Sandelowski, 2000). Qualitative content analysis is the analysis method of choice for qualitative descriptive studies, and was used to analyze
data from the current study (Sandelowski, 2000). In qualitative content analysis, data is broken down into small units based on what is represented in the data; and analysis involves naming, grouping, categorizing, and summarizing units of the data (Polit & Beck, 2012; Sanselowski, 2000). This form of analysis also entails continuous adjustment of data to accommodate new data and new perspectives about the data that is obtained (Sandelowski, 2000). Qualitative content analysis allows data to represent itself and not be influenced by external interpretation, and represents the experiences and perspectives of youth accurately (Sandelowski, 2000). The codes derived from the data were systematically applied during the analysis process (Sandelowski, 2000).

The analysis began with the PI reading the transcription several times to obtain an overall idea of what the participants are reporting. This prepared the PI for the process of coding. During the process of coding, the PI identified words, concepts, and themes that recurred throughout the data (Polit & Beck, 2012). During the first level of coding, the PI coded each participant’s sentence using as many keywords as possible, particularly using the participant’s own words. In the second level of coding, the PI put the identified keywords from level one into clusters. These clusters are larger groups that were mutually exclusive; this means, one code in one cluster must not be able to fit in another cluster. In the third level of coding, the PI identified broad themes. These themes formed an umbrella for more than one cluster identified in the second level of coding. A thematic analysis was used to describe and synthesize the identified themes (Polit & Beck, 2012). To elicit the decision-making of youth and the factors that relate to proactive HIV testing, data was assigned according to the timelines and sequences of events, describing the
relationship between the identified factors and the HIV testing decisions along the way. Reported factors and relationships were linked to the IMB and ODSF models.

**Rigor**

Several steps were taken throughout the data collection and analysis to correctly represent the study participants and their experiences, and to ensure the study is credible, dependable, transferable and confirmable (Polit & Beck, 2012). Rigor is essential for the study because findings will inform future research, policies, and intervention geared towards increasing the rates of HIV testing among youth.

In qualitative inquiry, credibility describes confidence in the findings of the study as a representation and interpretation of the data (Polit & Beck, 2012). To establish credibility in the current study, the data has to represent the experiences and perspectives of the youth. This was done by collecting data with a semi-structured interview guide with open-ended questions. These questions allowed the participants to interpret and lead responses. The PI reviewed interview questions with the dissertation chair before beginning the interview with participants. Additionally, data was analyzed using codes that are derived from the data itself as opposed to external codes (Sandelowski, 2000). This ensured that the data gave meaning and interprets itself, as opposed to bending the data to fit a set of predetermined themes and codes (Sandelowski, 2000). To further ensure confidence in the findings, data was collected from youth with different demographics and from multiple test sites. The themes that emerge from the data were verified across the participants’ narratives, to ensure a representation of multiple voices.

Rigor in a qualitative study is ensured by dependability. Dependability is the ability for data to remain stable at various times and conditions (Polit & Beck, 2012).
Data is dependable when there is consistency in the methods of data collection. To ensure dependability, the PI kept audit trails and field notes, detailing the events that surrounded the study and reflections from the study process. Reviewing audit trails verified that data was collected under similar conditions and that findings are dependable. Transferability is another factor that confirms rigor in a study. Transferability refers to the ability of data to be replicated or applied to other settings or groups (Polit & Beck, 2012). To ensure transferability, the PI explicitly described the sample, setting, and procedures used in the study. This enabled future researchers to adapt and use methods for similar studies and samples.

Confirmability is another way to ensure rigor in a qualitative study. Confirmability is the congruence between more than one person about the findings and interpretation of a study’s data (Polit & Beck, 2012). To ensure confirmability, the first five interviews served as a pilot. This enabled the review of the questions, interview process, and responses with the dissertation chair, and ensured the data reflected the study’s aim and interview questions, and also to make necessary changes. Further, the dissertation chair reviewed 20% of transcription and codes, to ensure the emerging themes reflected what the participants reported. This process also ensured objectivity in the report of the findings on the participants.

**Summary**

A qualitative descriptive approach was used to collect and analyze information from a sample of youth who proactively tested for HIV infection in South Florida. Data was collected through semi-structured, open-ended questions. These questions were based on the study’s aims, a review of the literature, and the IMB model. A qualitative
content analysis was used to analyze data and identify themes that described the experiences of the participants. The themes that emerged addressed the factors that relate to proactive HIV testing, and how the relationship between factors affects youth’s decision to seek HIV testing. This was done while respecting and protecting the participants as well as maintaining rigor in the study. Findings from the current study added to the body of knowledge on HIV testing among youth, and informed steps to increase HIV testing rates among you.
Chapter Four

Results

Qualitative descriptive methodology was used to explore the factors that relate to youth’s proactive HIV testing and how those factors are related to decisions to test for HIV infection. Individual face-to-face semi-structured interviews were conducted with 30 youth who completed HIV testing proactively. The purpose of this chapter is to report the findings from the current study.

Five supporting themes emerged from the analysis process that addressed the aims of the study that include: Testing within the Context of a Relationship, Support from Social Relationships, Taking Initiative for Health, HIV Testing Preferences, and HIV Testing Experiences. The supporting theme Testing within the Context of a Relationship reflects participants’ testing due to experiences in sexual relationships. Support from Social Relationships represents participants’ drive to test stemming from encouragement provided by family members, friends, and communities. Youth responded to personal awareness of risk and presence of support by Taking Initiative for Health and seeking HIV testing services. HIV Testing Preferences was described as how the presence of conditions surrounding HIV testing influenced seeking and obtaining an HIV test. The HIV Testing Experience described how youth were treated during prior and current HIV testing and its influence on proactive HIV testing.

The report of the findings will begin with a description of the study settings and participant demographics. This is followed by the themes and subthemes that emerged to describe the factors that influenced proactive HIV testing and the decision to engage in
HIV testing. Each theme is described along with supporting quotes from the interviewed youth. The chapter is concluded with a summary of the research findings.

Sample Characteristics

Sixty individuals were identified as potential participants across HIV testing sites in South Florida by HIV testing counselors and agreed to speak with the PI. After discussing the study requirements, 13 individuals met inclusion criteria, but declined to proceed without reason \( n = 9 \) or a lack of time to participate \( n = 4 \); 17 individuals agreed to proceed with the study, but did not meet inclusion criteria for age. The remaining 30 individuals met inclusion criteria and were enrolled in the study.

Data collection took place between March and June 2017 from different HIV testing sites that included, community testing events \( n = 17; 56.7\% \), a community-based organization for sexual minorities \( n = 2; 6.7\% \), an adolescent health clinic \( n = 6, 20\% \), and a university campus \( n = 5, 16.7\% \). Of the youths that participated in the study, 21 (70\%) identified as female, 8 (26.7\%) as male, and 1 (3.3\%) as transgender, with a mean age of 21.17 years \( (SD = 1.72) \). The majority of the youth were recruited from community testing events \( n = 17, 56.7\% \). The ethnic distribution of youth included 17 (56.7\%) African American/Black – non-Hispanic, 8 (26.7\%) Hispanic/Latino/a, 3 (10\%) Caucasian/White, and one each (3.3\%) identified as Asian or Pacific Islander and more than one race. Of the participants, 22 (73.3\%) completed high school, three each (10\%) completed an associate degree and some college, and one each (3.3\%) completed a Bachelor’s degree and GED. The majority of the youth reported oral and vaginal sex \( n = 14, 46.7\% \) and opposite-sex relationships \( n = 18, 60\% \). Most participants reported
having six or more lifetime sexual partners \((n = 14, 46.7\%)\), and one sex partner in the previous 3-month period \((n = 18, 60\%)\). The majority of the youth didn’t use a condom during the last sexual intercourse \((n = 17, 56.7\%)\). A more complete description of the participants can be found in Table 4.1.

Table 4.1

*Youth Demographic Data*

<table>
<thead>
<tr>
<th>Descriptive Variables ((N = 30))</th>
<th>(N)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
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<tr>
<td>Female</td>
<td>21</td>
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<tr>
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<td>2</td>
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<td>19</td>
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<td>23</td>
<td>4</td>
<td>13.3</td>
</tr>
<tr>
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<td>--------</td>
<td>------------</td>
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<tr>
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<tr>
<td>6 or more</td>
<td>3</td>
<td>1</td>
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<table>
<thead>
<tr>
<th>Condom used during last sexual encounter</th>
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<tbody>
<tr>
<td>No</td>
<td>17</td>
<td>56.7</td>
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<td>Yes</td>
<td>13</td>
<td>43.3</td>
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Factors that Influence Proactive HIV Testing

The findings from this study represent participants’ acknowledgement of risk for HIV infection, and the response to this risk in the form of seeking HIV testing, including the response to the testing experience. Five supporting themes further explained the experiences of youth’s proactive testing for HIV infection.

Testing Within the Context of a Relationship

Youth mainly reported testing because of an event that occurred in their sexual relationships that heightened risk for HIV infection. Four subthemes further describe the supporting theme and these include: Partner’s Infidelity, Individual Infidelity, Sense of Security in a Committed Relationship, and Unprotected Sexual Encounter.

Partner’s Infidelity: Infidelity is described as having sexual intercourse with someone other than a main partner. In the study, youth reported infidelity by both themselves and partners as motivation for HIV testing. Infidelity was reported to produce emotions that include being “nervous”, “skeptical”, “afraid”, and “worried”. These feelings subsequently encouraged HIV testing decisions. Some youth noted that discovering or suspecting infidelity by the partner instilled fear of HIV infection and subsequently led to participation in HIV testing. The effect of Partner Infidelity is summarized by this participant:

Me and my boyfriend got in a big situation there. I just wanted to get tested because he had unprotected sex with another girl, and I was just afraid. I didn't want to get nothing if me and him will still have intercourse. (Female, 22 years)
**Individual Infidelity**: Participants described personal unfaithfulness in a sexual relationship as a risk for HIV infection that stimulated feelings of worry and heightened perception of HIV vulnerability. The feeling of worry was also described when youth were unfaithful to a main partner and was experienced by both the youth and the partner as described by this participant:

> I mean it was mostly just he (boyfriend) was upset when he (boyfriend) found out that I had, ummm, unprotected sex with another person. So he (boyfriend) was worried about his own health. He was worried about my health, so it kinda just caused a little bit of tension. A little bit of tension, and that pushed me more to go get tested… (Male, 20 years)

**Sense of Security in a Committed Relationship**: Additionally, within the context of a relationship, HIV testing provided a sense of security for youth and partners. This was summarized by one participant:

> Yeah, in a way. I did it (HIV testing) a part for me, but part because I wanted him (boyfriend) to have a sense of, like security and, like clear ease of mind, too (Male, 20 years)

Another participant described this sense of security as a way of ensuring that no harm was done to the participant’s girlfriend due to past sexual experiences.

> Ummm…We started off in November, but now that we have actually been pro-creating. I just wanted to make sure am not damaging her in any way. So, I just wanted to be definitely sure at this point. (Male, 22 years)

**Unprotected Sexual Encounter**: Youth acknowledge the risk for HIV infection from unprotected sex. Youth that tested due to unprotected sex reported sexual encounters occurring for the “first time”, with a “few new partners”, “under the influence of alcohol”, and “many sexual partners”. Youth described being motivated to test for HIV infection following engagement in unprotected sex. One participant gave a
contextual description on how failure to use a condom can occur and lead to concern over the risk of becoming HIV-infected.

Under the influence of alcohol, I forgot to use a condom. And that made me nervous because I always like to (use a condom). (Female, 19 years)

Conversely, misconceptions about how HIV infection is transmitted and what types of unprotected sex could lead to HIV infection delayed youth from proactively seeking HIV testing. A participant explained failure to seek HIV testing sooner because of the misconception that oral sex would not lead to HIV transmission:

Like, I consider vaginal or anal sex to be actual sex, and oral sex I do consider to be sex, but I didn’t think about it in the way that you could get an STD. (Female, 19 years)

**Support and Influence from Social Relationships for HIV Testing**

The interviews with the youth revealed a significant role played by relationships with partners, family, and friends in influencing proactive HIV testing. Youth described having “support” from close relationships as one of the main ways the decision to test for HIV infection was influenced. Support was described in the form of family members’ advice to stay healthy and seek HIV testing, and being informed of the availability of free testing.

Youth also described the absence of “judgement” from family members as a motivator to seek HIV testing. Conversely fear of parental reaction to youth seeking HIV testing was reported as a barrier to proactive HIV testing. Support from friends was described in ways that included receiving messages from friends about the availability of
free HIV testing events, going with friends/peers to seek HIV testing, and advice to seek testing from friends.

Among youth that reported same sexual relationships or identified as transgender, being part of the lesbian, gay, bisexual, and transgender community (LGBT) encouraged proactively seeking HIV testing. The LGBT community was reported to provide information about HIV testing, provided other services like social events that provided an opportunity for HIV testing, and provided access to HIV testing counselors that used appropriate terms in discussing sexual behaviors. Under this supporting theme, the subthemes emerged that include: Family Support, The Role of Children, Going with a Friend, Being Part of a Community, and Knowing Someone who is HIV Infected.

**Family Support:** A common factor described was the influence of “support” from family members as a motivation for HIV testing. This support made youth unafraid of the consequences of family members finding out about HIV testing, or the absence of support if the HIV test result was sero-positive. A participant described how the relationship with the participant’s mother encouraged HIV testing.

My relationship with my mom helped a lot, considering she’s getting the bill for the HIV testing. And it’s not expensive, she said it’s around $50 or something. And I was like, honestly, it’s worth it, I just want to get tested, why not? I think that if I didn’t have a good relationship with my mom, and she was a very judgmental person, I would be so, think very differently of it, of getting it done (Female, 21 years)

Similarly, another participant who was seeking testing for the first time, described the lack of support from the family on issues related to sex as a deterrent to seeking HIV testing. Another noted barrier in familial relationships that discouraged proactive HIV testing was not discussing “sex” at home. This led to fear of parents finding out about
sexual activity and HIV testing. The consequence of this discovery deterred HIV testing.

This was summarized by a participant:

Some barriers are like my family and stuff. My family don’t even talk about sex or STD or STI, none of that. I don’t hear about that in my family. I don’t think that they’re trying to shame me, but I think they’re doing unintentionally because they don’t talk about it either. So telling them that I’m going to get tested, they would probably be concerned one, that I’m having sex. And two, that you know. Sex is just really taboo in my family. So, I had to like I had to pick a convenient time. Like I had to be here already. Otherwise, I would say I have to go to this place to get tested, and my parents would be really weirded out. And that’s hard, for me. Because we don’t talk about it that much, so that was a big one. Umm so, just being here (HIV Testing site) was good. And they don’t have to know about it, so it’s okay. (Transgender Female, 19 years)

The Role of Children: Youth described having children as a factor that encouraged proactive HIV testing. These participants were mothers and discussed how having children provided the motivation to seek HIV testing because participants wanted to stay healthy and alive to take care of children. This was summarized by a participant below:

I have two kids. I want to make sure I live as long as I can to watch them grow because I have a girl and a boy... My son is 10 months. I want to make sure I could be there with them. (Female, 22 years)

Going with a Friend: Participant described experiencing support when HIV testing was sought with friends. One participant described how a friend’s suggestion and going with a friend encouraged HIV testing.

So, one of my friends suggested that I go. And another friend said, Hey I’ll go and I’ll support you. Um, so she came with me. And I have a very loving friend group, so it encouraged me to go. (Female, 19 years)
Another participant described how a friend going for HIV testing motivated HIV testing.

I was like if she’s gonna go, I’ll go and we’ll get tested together. We’re like friends who test together, stay together. (Female, 19 years)

**Being Part of a Community:** Participants described the influence of social relationships that resulted from being part of a community. Youth who identified as LGBT described how identifying with the LGBT community and participating in LGBT-related events encouraged HIV testing. This was summarized by a participant:

I started doing more LGBT-related events, lately. And I would look and think more like the flyers that they had. Like before. I would be like let me not look at it. Because I can’t. It’s like embarrassing to even look at the flyers. But I would look at the flyer. I would take the flyers, and I would look at them. I would look at the places and the times, stuff like that. Um. That was. That was one of the biggest steps. Actually, looking at the information that they were giving me, because I was ashamed to even look at the information. Then when I started looking at the information, I started thinking about going and doing testing or whatever. Um. And then yeah. Finally, I went to testing. (Transgender Female, 19 years)

**Knowing Someone Who is HIV Infected:** Consistent with social relationships, knowing someone close who is infected with HIV or who has died from AIDS was reported to make HIV infection “real” and facilitated proactive HIV testing. This is summarized by a participant:

Umm my friend actually got HIV. He was in college when I was in high school. And so, I knew it was like a real thing, especially when it happens to someone close to you, it just becomes more real for you. (Female, 19 years)
Taking Initiative for Health

The interviews revealed a theme of youth taking initiative for health by testing for HIV infection proactively. When youth recognized events and behaviors that increase risk for HIV infection, HIV testing was sought proactively without an immediate recommendation by a healthcare professional. Youth discussed reasons for the steps taken to initiate HIV testing and how those reasons influenced decisions to test through the following subthemes: Peace of Mind, Catching HIV Infection Early, and Noticed Symptoms of Infection.

Peace of Mind: As previously discussed, participants responded to exposure to HIV infection with fear and anxiety. Youth described a sense of calm and assurance that stemmed from the knowledge of HIV status following testing. Aside from knowing HIV status, HIV testing also confirmed a state of good health to youth. This was reported to drive seeking a HIV test and was summarized by a participant:

It felt good to know that I did. And also, um. I mean just for the peace of mind, and also just to know that physically I’m taking care of myself well. And to continue taking care of myself that way I have been. (Female, 21 years)

Catching HIV Infection Early: Youth expressed the desire to catch HIV infection early as opposed to its later stages. Identifying HIV infection early would provide youth with the option to get treatment early, take steps to stay healthy, and reduce the likelihood of sudden death. This was described as a drive for proactively testing for HIV infection and summarized by one participant:

I feel like it’s very important because...like...if it was to happen to me...I will wanna catch it before it gets too late so I can...you
know…keep it down to take care of my body. I wouldn’t want it to like…eat me up (Female, 21 years)

**Noticed Symptoms of Infection:** In line with early identification of HIV infection, noticing vague symptoms congruent with sexually transmitted infections fueled the decision to seek HIV testing. This was summarized by a female participant who experienced “pain”, “frequency” and “a little bit of discomfort” while urinating. These symptoms were described to motivate testing by this participant:

Honestly, I just like remembered the symptoms. And remembered, oh like I need to get tested. So I was kinda like, I want to know if I have chlamydia or not again. And then, also like the other, gonorrhoea, syphilis, or HIV…And then I saw this, and I was like I think this is time to go get tested, just in case. (Female, 21 years)

**HIV Testing Preferences**

Youth described different preferences for receiving HIV testing that influenced proactivity. Being able to obtain HIV testing in a short amount of time was discussed by several youth to motivate the decision to test for HIV infection. A lengthy process of testing or receiving results made the participants question the decision to test for HIV infection. The convenience of accessing a HIV testing site was also found to motivate testing. Youth reported how mobile testing vans that were close to home or work locations, or testing sites in areas that are frequently visited, fueled proactive HIV testing. Not having to pay for HIV testing was a major facilitator of testing among youth, including the availability of time that doesn’t conflict with other activities such as work and school obligations.

The method of HIV testing was also found to influence testing. Youth discussed both preferences for needle stick and mouth swab with different reasons for how HIV
testing decisions were facilitated. Some youth also reported a preference of adhering to a routine of testing every number of months as a way proactive HIV testing was facilitated. Youth described preferences for HIV testing under the following subthemes: *Fast Testing/Results, Convenience, Needle Stick versus Mouth Swab, Free Testing, Free Time, and Personal Routine.*

**Fast Testing/Results:** Testing with a short wait time was described as going into testing sites and leaving in “fifteen minutes” as opposed to spending “long hours”. Fast testing was seen to influence testing as youth could test in between busy activities such as work, as opposed to waiting long hours. This was summarized by a participant who tested during a work break at a testing van:

…So by you guys coming out here, it makes it easier and then we have our breaks so that we just get tested and then the situation of it, the way of it is fast. It's not like we're going to be sitting there for long hours, trying to wait on somebody to call us. You go in, get tested and walk right out. It's a fast process basically, the process is fast. (Female, 22 years)

In line with rapid testing, the availability of immediate results as opposed to returning at a later date was found to facilitate testing. Receiving results immediately assured participants of health status in a shorter period of time. This was not the case when youth had to return for results, as youth reported not going back for test results that were not issued immediately. Getting results immediately encouraged proactive testing as summarized by a participant:

You find out right there. With doctors, you have to wait for another appointment to get the results. Like when you get it right now, if I was to get it now, they'll be like, "Okay, come back in next week or you come back in two weeks for your results". Here, they gave it to me right there and then. And that’s why I love the…because they to do it right there. (Female, 22 years)
Not getting the results immediately was identified as a barrier to proactive HIV testing. Participants reported not returning for HIV test results due to a busy work schedule. This was summarized by a participant:

I had already had a test at my personal clinic, but I never really went back for the results...because I got this job, and I’ve been so busy since. (Female, 21 years)

**Convenience**: Youth also discussed the importance of convenience in accessing test sites for HIV testing. Youth described a convenient HIV testing site as a location visited regularly like a “club”, or a community-based organization for sexual minorities. Locations were also described as convenient when within walking distance and didn’t require transportation or a long commute. For example, one youth reported:

Well I don’t have a car, so transportation that one is better because one bus and I’m there. (Female, 21 years)

Youth described being able to “just walk in” and schedule appointments under short notice as ways test sites made testing convenient. The availability of mobile testing vans that came to areas that were accessible to youth was one of the common convenient testing sites. Mobile testing vans were described as fast, and did not require planning that interfered with other activities. This was summarized by a participant:

...So you don’t have to go out of your way to go to the clinic. The clinic I had to actually go there, wait for my number to be called and it takes hours. So, with stuff like that, you have to plan earlier throughout the day and prepare for that. Rather than the van, where it actually comes to where you are, and it doesn’t come in a way of anything. I don’t--What’s the word I’m looking for...inconvenience you. It doesn’t inconvenience you. (Male, 21 years)

**Needle Stick versus Mouth Swab**: The preference for a needle stick versus a mouth swab for a HIV test was discussed as an influence of proactive HIV testing. Youth
were split in the preference for either method of testing with different reasons. Youth described mouth swabs as “quick” and without pain in comparison to a needle stick. This was summarized by a participant:

I'll prefer the swab...Because the finger stick do have a sting. It stings, it does”. (Male, 24 years)

Other youth preferred a finger stick, describing the tests as more accurate with blood instead of saliva. This was summarized by a participant:

I would have preferred getting stick. The swab helps too, but I rather prefer getting stick with the needle, just because I prefer-- I'm not saying it's not accurate, but AIDS do run through your blood, so I'd rather get stick than a swab. (Female, 22 years)

**Free Testing:** Youth reported not having to pay for a HIV test as one of the important influences of proactive HIV testing. Free testing was described by participants without health insurance, or those that didn’t want the bill of HIV testing sent to parents. The absence of availability of free testing was reported as a barrier to testing. This was summarized by the participant below:

Honestly. I don’t… I’m not aware where other test locations are. I really don’t. I’ve been wanting. Like I googled it to see where I can get it for free and I couldn’t find places online. And I think that also pushed me back also as whether to get tested for it or not, because I remember two years ago I got it for free. So, I was like, there had to be places where they come and do locations for free. So, I was like Oh my God, that’s perfect. They did it right here. (Female, 21 years)

**Free Time:** Similarly, the availability of free time was discussed as a facilitator of proactive HIV testing. Youth reported being busy with work or school leading to difficulty in finding time for HIV testing. Free time was important because youth needed enough time to deal with the uncertainties that surround the testing process. For example:
Today is usually my really free day. I’m a really busy person, in general, so like. I’ve never been tested before, so like I didn’t know how long it would take. So, I didn’t want to go, have them tell me it’s going to take a hour, and not have that hour. (Female, 19 years)

The availability of free time that coincided with the presence of a HIV testing site made proactive HIV testing possible. This was summarized by this participant:

Honestly. It’s cause I’m here on campus. Like I…I had class till, like 2. And then, I saw it during lunch. But I didn’t have time during lunch because we had like a thirty-minute break. And that was time to eat. So, I was like okay. I gotta get back and then I was like, since they’re here till 3 so I was like perfect because I have class at 5. So, it was like I had 2-5, so it was perfect. So yeah. I just was like, might as well do it. (Female, 21 years)

**Personal Routine:** Some youth reported adhering to a HIV testing routine, which facilitated proactive HIV testing. Youth reported testing routinely every “3 months”, “3 to 6 months”, and “6 months”. Youth reported routine testing because of sexual orientation. For example, a male youth reported testing every 3 months because he is a gay man

...Just I know that since I’m a gay man, I have to get tested every three months. (Male, 23 years)

A routine for testing also served as a reminder to youth when an opportunity for HIV testing was presented. This was summarized by this participant:

I always get tested every 6 months for HIV and AIDS. That's a regular doctor's appointment. You know what I'm saying? When I've seen the truck, I was like, "Okay, let me just get tested." Because I missed my last appointment, so I just wanted to be on the safe side. (Female, 22 years)
HIV Testing Experiences

Youth described experiences in HIV testing sites that fueled the decision for proactive HIV testing. Youth described “comfort” resulting from the interaction with the HIV testing counselors or the staff that encouraged testing. This comfort was described in the form of conversations with HIV testing counselors that discouraged the “stigma” surrounding HIV infection and testing, made HIV testing less “awkward”, and reduced the anxiety that came with testing for HIV infection. Youth described having privacy in HIV test sites as a major influence for HIV testing. Youth desired privacy from the public, other staff members in HIV test sites, peers, and family members. Youth were more likely to go to HIV test sites that offered other services in addition to HIV testing. Under this supporting theme of HIV testing experiences, there are four subthemes: Relationship with HIV Testing Counselor, Cultural Identification, Privacy, and Provide Other Services.

Relationship with HIV Testing Counselor: The interactions with HIV testing counselors was highlighted significantly in youth’s description of influences of proactive HIV testing. There is still stigma related to HIV infection that extends to HIV testing. Youth expressed feeling better when the HIV testing counselor explained the process of testing in a way that mitigated the stigma. This was summarized by a participant:

Initially, there’s kinda like a stigma. Kind of. But um. I think in general when someone is explaining to you the process more and explaining to you the term, you feel kind more engageful in that experience and so I think it’s kinda like positive, I think more comfortable, is the word to describe it, if anything. Yeah. I think. (Male, 23 years)
Youth described being “anxious” about seeking HIV testing, and experiencing relief from talking to the HIV testing counselors. Youth particularly appreciated conversations that were not solely centered on HIV testing. For example:

Oh yeah like I said, comfortable, like comfort. She talked to me the whole time. We didn’t just talk about HIV test. We talked about other things, like we talked about school and other things like that. It was, it was cool, like it wasn’t weird. (Female, 19 years)

Other attributes were counselors that introduced humor into conversations. This was summarized by a participant:

The people were funny. They were really nice, they were funny. They made it a simple process and they didn’t make me feel bad about, I mean like they’re not supposed to make you feel bad, but they definitely didn’t make me feel bad about getting tested. (Female, 19 years)

**Cultural Identification:** Having a counselor that shared a similar cultural identification with youth, was also reported as an influence of proactive HIV testing. Youth who identified as gay or transgender expressed comfort from having an HIV testing counselor who identified with the same community and understood the appropriate terms that applied to experiences with sexuality and sexual health. This was summarized by a participant:

Well to be honest cause he’s gay probably. That’s a big one because I’m a trans. Even though he wasn’t trans. It’s just something about someone in your community, especially as a trans person. Knowing that there in your community and also by your side is important… His language was appropriate, I think. I mean he asked how many partners I slept with and what like my partners identified. I think that was important for me. Because sometimes it’s complicated because a lot of the language in like the medical setting is very like, female, male, and that’s okay, but it’s a little confusing for trans people when it comes to like sexual experiences. So that was important. (Transgender, 19 years)
Privacy: Privacy was described as another influence of proactive HIV testing. Youth didn’t want the knowledge of getting tested for HIV infection or information about test results being discovered by people without giving consent. For example:

I want to…I want to keep private. I’m not that comfortable for people knowing that I am. (Female, 21 years)

The absence of privacy was reported as a barrier to proactive HIV testing. This youth in describing the reason a friend didn’t come for HIV testing reported:

I think maybe….Cause, if it was private more, then she probably would have came. (Female, 21 years)

Different test sites were described as having different levels of privacy. Mobile testing vans were reported to have less privacy because people could see youth walk in and out of the van with bold HIV testing signs. This was similar to test sites that had waiting rooms, or multiple people attending to the youth. This was summarized by a participant:

Yeah, the van. It’s kind of like people sometimes look at you getting off. And you don’t know if they relooking at you like, I don’t know like. Like oh she’s getting. I don’t know, like. I don’t want to say judge but I’m guessing they’re judging you. You’re not sure what they’re thinking though. Just people looking you don’t know what they’re thinking about me. Like. Oh why is she getting tested? You know. (Female, 21 years)

Test sites that ensured privacy were facilitators of HIV testing. One youth reported privacy as the reason for coming routinely to a testing site despite distance from place of residence. This is summarized below:

It’s pretty far but like, I just like the environment, the people and it’s very like low key. like there’s a lot of people around here but everyone is going about the business so no one is worried about where you’re going it’s not out there but it’s like cozy, it’s
like a low-key spot, like it’s in the…so no one know where I’m going… Yeah privacy too? (Female, 18 years)

**Provide Other Services:** Finally, HIV testing sites that provided services beyond testing encouraged youth to proactively seek testing. Testing sites that fostered a sense of community for LBGT youth was found to motivate youth to seek testing. HIV testing sites that provided incentives like free condoms also influenced youth to seek testing. Youth appreciated being able to obtain other testing for sexually transmitted infections, and to see a healthcare professional for other needs. This was summarized by a participant below:

…They tend to test everything all together. So, I was okay with that because I wanted to check everything at once. And the practitioner that I went with, was very. She made me feel very comfortable about it. (Female, 21 years)

A complete description of the supporting themes and subthemes discovered in the qualitative study are found in Figure 4.1
Summary

The current study explored the factors that influenced proactive HIV testing and how these factors resulted in the youth’s decision to test for HIV infection. A total of 30 youth were enrolled in the study. Upon analysis of the interviews, five supporting themes emerged. The findings explained how youth acknowledged personal risk for HIV infection, and sought and accepted resources needed to proactive test for HIV infection. The five supporting themes included: Testing with the Context of a Relationship, Support from Social Relationships, Taking Initiative for Health, HIV Testing Preferences, and HIV Testing Experiences. These supporting themes explained different factors and interactions with the decision and action to proactively test for HIV infection.

HIV infection risk was identified by youth in ways that included personal or partner’s infidelity in sexual relationships, recent unprotected sex with a non-
monogamous partner, vague symptoms of HIV infection following a sexual relationship, and a lack of HIV testing since sexual debut. The majority of the participants needed support from social relationships including sexual partners, family and friends as an encouragement to initiate or complete HIV testing. Participants also initiated HIV testing due to factors like immediate availability of testing services and time off work or school to seek testing.

During the interviews, participants acknowledged prior knowledge of HIV testing information, but had a recent event that encouraged HIV testing services. In most individuals, sexual risk behaviors were recognized to heighten risk for HIV infection, which led to fear, worry, or concern that was mitigated by participant’s availability of social support and/or the quality of HIV testing services and experience. A few participants had established a routine of testing that ranged from every 3-months to every year based on a personal assessment of risks and benefits perceived and experiences from previous HIV testing.

There were emotional reactions by the youth during the experience of proactive HIV testing. Participants described feelings of anxiety and fear or worry over the possibility of being HIV infected following recent or prolonged exposure to sexual risk behaviors. These feelings of fear and worry were also reported to delay seeking HIV testing. Work obligations, stigma, financial concerns, and absence of social support systems also contributed to delays in seeking HIV testing. Participants reported relief of these feelings when the decision was made to seek HIV testing and testing was initiated.
Chapter 5
Discussion

The purpose of this qualitative descriptive study was to explore the factors that are related to proactive HIV testing among youth, and how these factors are related to the decision to proactively seek HIV testing. These aims were important because youth still represent a significant number of new HIV infections (CDC, 2017c), and HIV testing can assist in reducing this burden (CDC, 2017e). HIV testing puts youth in contact with HIV testing counselors or other healthcare professionals who provide counseling to youth for HIV risk, and link youth who are HIV infected to care (CDC, 2017e). Linkage to care coupled with adherence to antiretroviral therapy reduces HIV viral load and consequently the rates of HIV transmission (Castilla et al., 2005; Montaner et al., 2010).

A review of the literature revealed that HIV testing was significantly influenced by immediate recommendation from healthcare providers (Inungu et al., 2011; Leonard et al., 2014; Mullins et al., 2012; Talib et al., 2013). Little is known about the factors that influence proactive HIV testing among youth without immediate recommendation from healthcare providers (Fenton et al., 2002; Ma et al., 2016; Mullins et al., 2012; Talib et al., 2013). The current study’s main findings will be discussed in relationship to the literature reviewed. The findings from the current study will add to the growing body of knowledge regarding HIV testing among youth and how to promote proactive HIV testing. This chapter will also discuss the study limitations and recommendations for future research, practice, and health policy.
Factors that Influence Proactive HIV Testing

Testing within the Context of a Relationship: There were factors reported by the youth that related to proactive HIV testing under the supporting theme of Testing within the Context of a Relationship. Participants described factors that include personal or partner infidelity and unprotected sexual encounters. Infidelity by youth or sexual partners was highlighted, and was one of the main ways a risk for HIV infection was identified. Similarly, concern over engagement in high risk sexual behaviors have been reported by previous quantitative studies as facilitators of HIV testing among youth (Grant et al., 2006; Leonard et al., 2014). Unprotected sexual encounters with new or multiple partners also heightened the perception of HIV risk in previous quantitative studies and increased the likelihood of HIV testing (Decker et al., 2015; Longmore et al., 2013; Straub et al., 2011). This finding was qualitatively explained by participants as unprotected sexual encounters and sex with multiple partners, and was reported to occur under the influence of alcohol.

Support and Influence from Social Relationships for HIV Testing: The findings from the current study under theme of Influence and Support from Social Relationships qualitatively explained some previous quantitative associations with HIV testing. Support from family, sexual partners, and friends was identified by participants as a major influence on proactive HIV testing. This finding is similar to previous quantitative studies that revealed youth were more likely to test when advised to test by family, peers, or partners (Grant et al., 2006; Leonard et al., 2014; Phillips et al., 2012).

The absence of family support has been reported in a quantitative study as a barrier to HIV testing among youth (Nguyen et al., 2006). This finding was further
qualitatively described in the current study as fear of parental reaction to HIV testing. In line with social relationships, having children was specifically reported by female participants as an influence of proactive HIV testing. This finding was not previously noted in the literature specifically examining factors that encourage HIV testing among youth.

Furthermore, in a quantitative study, Moyer and colleagues (2007) found a negative association between HIV testing among youth and not knowing someone living with HIV. The current study qualitatively described this finding as participants explained that the knowledge of someone who was infected or died from HIV infection made HIV infection real and encouraged proactive HIV testing.

**Taking Initiative for Health:** Following the acknowledgement of risk for HIV infection and available support for testing, youth described the factors that encouraged steps to *Take Initiative for Health*. Previous quantitative studies noted that youth experiencing symptoms of illness increased the likelihood of HIV testing (Grant et al., 2006; Peralta et al., 2007; Phillips et al., 2012; Siegel et al., 2010). Findings from the current study further explained this finding; youth described that the presence of vague symptoms of infection in participants or partners heightened the desire to know HIV status, and supported proactive HIV testing.

**HIV Testing Preferences:** There were *HIV Testing Preferences* that were related to youth’s proactive HIV Testing. Similar to previous studies, the presence of rapid testing and results encouraged youth to seek HIV testing (Calderon et al., 2013; Myers et al., 2014; Peralta et al., 2007; Tuysuzoglu et al., 2011). For example, in a previous quantitative study, 85.6% (*n* = 107) of youth reported rapid testing increased the
likelihood of HIV testing (Tuysuzoglu et al., 2007). This finding was further explained qualitatively in the current study as participants described rapid testing to decrease wait time and hence encouraged proactive HIV testing.

Previous quantitative studies also reported an association between convenient test locations and an increased likelihood of HIV testing (Peralta et al., 2007; Sumartojo et al., 2008). The current study explained this finding further, as participants described locations that were easily accessible with little to no transportation, and appointments could be scheduled under short notice, as convenient.

In line with the current study’s findings, the literature also revealed that the method of HIV testing was related to HIV testing uptake. Previous quantitative studies noted that a preference for mouth swabs or needle sticks was associated with HIV testing (Moyer et al., 2007; Peralta et al., 2007). The current study further explained the nuances related to the preferences for HIV testing methods. Youth described mouth swabs to be painless and needle sticks as more accurate.

Previous quantitative findings reported that youth sought HIV testing at sites that offered testing at no direct cost, and paying for a HIV test discouraged HIV testing (Peralta et al., 2007; Wallace et al., 2011). Findings from the current study supported and highlighted the effect of cost on youth’s uptake of proactive HIV testing. Youth sought HIV testing proactively in sites that offered free testing and concerns about having to pay discouraged HIV testing. A previous qualitative study reported that concerns about accessing health care and ability to afford insurance were barriers to obtaining an HIV test (Wallace et al., 2011). The current study had similar findings as youth described
delays in seeking HIV testing related to the absence of health insurance, and concerns about needing health insurance to access HIV testing.

Finding free time from school or work, or when testing opportunities coincided with the absence of conflicting activities, hence encouraging proactive HIV testing, was a new finding from the current study. Another new finding was participants’ experience of having a personal routine in seeking HIV testing. Youth described the presence of a routine was a reminder to seek testing periodically and supported proactivity in HIV testing.

**HIV Testing Experiences:** The experiences that youth had while getting tested for HIV infection was related to proactive HIV testing in the current study. Previous quantitative studies revealed that privacy of test sites and the HIV testing experience positively influenced HIV testing (Phillips et al., 2015; Schnall et al., 2015). In the current study, youth qualitatively described privacy as testing sites without bold HIV testing signs, having fewer personnel enter the room during HIV testing, and the absence of waiting for HIV testing or test results that could lead to identification by a familiar face. A previous qualitative study revealed that the absence of privacy in HIV testing was related to HIV stigma among youth (Wallace et al., 2011). Similarly, youth from the current study reported stigma related to HIV testing leading to concerns about parents finding out about HIV testing.

New factors identified under this theme included: relationship with HIV testing counselors, cultural identification, and the provision of other services by the HIV testing sites. Participants described that having HIV testing counselors that were easy to talk to and identified with the same community encouraged proactive HIV testing. Furthermore,
HIV testing sites that provided other services such as free condoms, other testing for sexually transmitted infections, and access to a healthcare professional, encouraged proactive HIV testing among youth. The youth reported having limited time for seeking HIV testing supported their decisions to go to sites with a one-stop shop healthcare experience. This finding is validated by previous studies on access to care with youth that have highlighted the effectiveness of one-stop shop facilities where youth can receive multiple healthcare services at the same time (Hagel & Lamb, 2016).

**Decision-Making for Proactive HIV Testing**

In the current study participants explained how factors are related to decisions to seek proactive HIV testing. Under the theme of *Testing with the Context of a Relationship, Partner’s Infidelity, Individual Infidelity, Unprotected Sexual Encounter with New or Multiple Partners*, were described to encourage the perception of risk and vulnerability to HIV infection. This is supported by previous quantitative studies on youth that have shown that increased perception of risk for HIV infection facilitated HIV testing among youth (Leonard et al., 2014; Mullins et al., 2012; Schnall et al., 2015). For example, Leonard and colleagues (2014) reported that almost 50% ($n=37$) of youth tested because of a higher perception of risk for contracting HIV infection. Previous quantitative and qualitative studies have revealed that youth had an increased likelihood of HIV testing in the context of committed relationships (Talib et al., 2013; Teitelman et al., 2015; Trieu et al., 2010). This finding was further explained in the present study as youth described the desire to feel secure in sexual relationships, and as a motivation for proactive HIV testing in committed relationships.
Decisional influences within the *Support and Influence from Social Relationships for HIV Testing* revealed similarities in the way the different identified factors were related to proactive HIV testing. Having support from family members, friends, and sexual partners have been identified in previous studies, as well as the current study, as one of the major influences of HIV testing (Grant et al., 2006; Leonard et al., 2014; Phillips et al., 2012).

The current study revealed that support from family members gave youth the confidence to test for HIV infection, and this removed the fear of family members finding out about HIV testing. Findings from the current study further explained that support from family members meant the absence of judgement, and assurance of support if the HIV results came back sero-positive. A new finding from the current study was that going with friends to test for HIV infection discourages the stigma and anxiety related to HIV testing.

Participants with children described that the desire to stay alive and healthy to care for children drove the decision to test for HIV infection. Additionally, youth that identified as Gay or Transgender explained that being part of the LGBT community, and attending its social events helped youth in the decision to seek testing by making testing normal. This type of social support is a new finding in the current study and signified that social support is broad and multilayered in influencing proactive HIV testing. Although the literature quantitatively identified that knowing someone who was infected with HIV was associated with HIV testing, the identified association is unexplained (Moyet et al., 2007). In line with social relationships, youth explained that knowing someone living
with HIV infection encouraged decisions to test proactively because youth saw that HIV infection from high risk sexual behaviors was a possibility.

The decision of participants were also described under the supporting theme of *Taking Initiative for Health*. The risk for HIV infection came with feelings of anxiety and fear of HIV infection. This was reported in the literature as concern over sexual risk behaviors and worry about the possibility of becoming infected with HIV infection (Grant et al., 2016; Leonard et al., 2014). The concern for HIV infection led to participants’ desire for peace of mind – an absence of the anxiety and fear, which facilitated decisions and actions to proactively seek testing. Also, participants described that the decision to test proactively for HIV infection would lead to “catching” the infection in its early stages, resulting in timely treatment, and a prolonged life.

*HIV Testing Preferences* were also related to youth’s decisions. Rapid testing and results were reported to encourage testing because participants could test between busy activities that included school and work. Although convenient HIV test sites have been quantitatively associated with HIV testing (Peralta et al., 2007; Sumartojo et al., 2008), participants in the current study further described that convenient test sites supported decisions because planning and transportation expenses were not required.

With regards to preference of HIV testing methods, some participants indicated a preference for mouth swabs, noting the fear of needles as the reason which has also be described in a previous quantitative study (Moyer et al., 2007). The current study further notes that some youth preferred blood testing because of perceived accuracy, and participants had doubts about the accuracy of saliva in detecting HIV infection. This contradicted previous findings that youth were more likely to test for HIV infection with
saliva and urine, as opposed to blood (Peralta et al., 2007). This finding identifies the presence of knowledge gaps and misconceptions on methods of HIV testing among youth.

Participants also described the relationship that *HIV Testing Experiences* had on decisions to proactively test for HIV infection. Stigma and anxiety are still related to HIV testing (Tanney, Naar-King & MacDonnel, 2012). Having counselors that explained the HIV testing process, asked less invasive questions, talked about other subjects outside HIV testing, and introduced humor during conversations, were reported to reduce anxiety and made participants more comfortable with HIV testing. Similarly, having a HIV test counselor that identified with the same community as youth was also reported to facilitate the decision to test for HIV infection among LGBT youth. Privacy also facilitated decisions by making participants feel secure that HIV testing or test results would not be discovered by other people without consent. This has also been corroborated in the previous quantitative studies on youth that reported fear of family member or friends discovering HIV tests or results was associated with not testing for HIV infection (Phillips 2nd et al., 2015; Schnall et al., 2015)

**Research Implications**

The findings from the current study have contributed to existing knowledge on HIV testing among youth. The current study makes unique contributions because of the focus on the concept of proactivity in the uptake of HIV testing and aims to understand how the decision to test is influenced. The findings of the current study may support evidence-based practice and research to facilitate HIV testing among youth. Based on the findings of the current study, future research will benefit from a mixed-method approach
to understand the predictive abilities of the factors identified and the development of an intervention to facilitate proactive HIV testing. Research has revealed misconceptions in the understanding of HIV testing that could encourage the current low rates of HIV testing among youth (Phillips et al., 2015). The current study will guide future research in preventing misconceptions in understanding HIV testing among youth.

The current study provided recognition of some of the psychological factors related to proactive HIV testing. Worry, anxiety and fear were seen in previous studies and described in this current study as deterrents to HIV testing (Phillips et al., 2015; Schnall et al., 2015; Wallace et al., 2011). From the current study, reasons for these feelings included absence of social support, HIV stigma, and misconceptions about HIV testing process and results. More research is needed to uncover other sources of these psychological factors related to proactive HIV testing among youth. Additionally, research is needed to understand how the foundations of these psychological factors interact and relate to the decision-making process to seek HIV testing.

To engage in HIV testing, youth need readily available resources. The findings from the current study revealed some of these include financial resources, HIV testing counsellors trained to meet the cultural and psychological needs of youth, social support, and accessible and private testing sites. Research is needed to understand how to decrease the financial burdens related to HIV testing, provide adequate youth-centred training to healthcare professionals and HIV testing counsellors, other forms of social support, and how to improve the accessibility and privacy of current testing sites.
Furthermore, research is needed to understand how to address the gaps when these resources are absent. For example, how can the resource-needs of youth who live in areas where HIV testing sites are not easily accessible and youth who lack support from family/friends, be met? Home-based HIV testing may meet the privacy and convenience needs of youth for proactive. However, there is paucity of knowledge in understanding the availability and acceptability of home-based HIV testing among youth, as well as the factors that encourage its uptake. More research is needed to further understand home-based HIV testing as a form of proactive HIV testing.

The normalization of HIV testing was discussed as a factor that supports proactive HIV testing. Normalization is described as HIV testing being part of conversations among peers and family members, and offered among other services in routine healthcare visits (Grant et al., 2006; Leonard et al., 2014; Phillips et al., 2012). Treating conversations about HIV infection as special or different has been negatively associated with stigma in previous quantitative studies (Tanney, Naar-King & MacDonnel, 2012). More research is needed to uncover other sources of barriers to normalization of HIV testing.

The current study revealed potential points of intervention to facilitate proactive HIV testing. Seeking testing with trusted friends was found to provide social support, and avert stigma, feelings of fear, worry and anxiety. A HIV testing intervention that incorporates the role of friends could potentially increase the rate at which youth seek HIV testing proactively. More research is needed to understand the uniqueness of the peer relationships that encourage HIV testing, and how to incorporate peer support in information and services for HIV testing.
Youth also reported the relationship of routine testing with proactive HIV testing. Research on ways to create reminders for youth to seek testing routinely will enable the creation of an intervention that will target youth that benefit from routine testing. Reminders could be in the form of apps, text messages or other forms of communications from HIV testing sites or healthcare professionals.

**Practice Implications**

Healthcare providers are in the position to develop, implement and evaluate programs that target health promotion among youth. Practice implications from the current study include educating nurses, other healthcare professionals and HIV testing counsellors on the needs of youth. The findings from the current study revealed that youth have psychological, cultural, and age-appropriate needs for proactive HIV testing. With the conditions of HIV testing sites like privacy and convenience impacting proactive HIV testing (Peralta et al., 2007; Sumartojo et al., 2008), healthcare providers can facilitate HIV testing by making testing sites more private, confidential, and accessible.

Healthcare providers also play an important role in providing information that impacts health to this population (Inungu, et al., 2011; Leonard et al., 2014; Mullins et al., 2012; Talib et al., 2013). In the current study, health care professionals were described to discourage fear and anxiety through open and relaxed conversation with youth during HIV testing. HIV testing counsellors and healthcare professionals need to adequately explain HIV transmission, testing processes, and results to youth. Nurses are critical to the care of youth and in counselling to encourage proactive HIV testing.
Findings from this study will inform nursing practice in the care of youth in clinical settings and in the community.

Questions should be asked to uncover and address misconceptions about HIV infection and testing that could discourage proactive HIV testing. From the current study, feelings like fear, worry, and anxiety have been found to have root causes that can be addressed through counselling or other forms of intervention. Healthcare professionals should communicate with youth to discover and address any sources of psychological concerns influencing the uptake of proactive HIV testing.

Current clinical guidelines recommend one-time HIV testing for youth and adults aged 15 – 65, and routine screening for individuals engaging in sexual risk behaviours or living in areas with high HIV prevalence (Branson et al., 2006; USPSTF, 2013). Most efforts on increasing the rates of HIV testing have focused on encouraging healthcare professionals to offer HIV testing (Branson et al., 2006; USPSTF, 2013). The findings from this study describe the experiences of youth proactive seeking HIV testing and can inform current clinical guidelines in facilitating HIV testing among youth. For example, routine testing for youth at risk for HIV infection can include proactive HIV testing and findings from this study provide an understanding of factors that influence proactive HIV testing.

Policy Implications

There are needs for policy development that will facilitate the availability of HIV testing services to members of this population. Nationally, healthcare providers need to
advocate for the provision and allocation of funding directed to HIV testing services for youth. This is particularly important as having to pay for an HIV test has been consistently identified as a barrier to testing among this population (Peralta et al., 2007; Wallace et al., 2011). Similarly, youth sought HIV testing proactively in sites where services were provided for free.

On a community level, healthcare providers should advocate for increased privacy of HIV testing sites. Privacy of the HIV testing process and sites was highlighted as one of the key factors related to HIV testing. Similar interactions with the privacy of HIV testing sites and HIV testing behaviour have been noted in the literature among youth (Phillips et al., 2015; Schnall et al., 2015; Wallace et al., 2011). Some examples of policies based on the findings of the current study include, 1) General description of healthcare services on clinical vans that provide HIV testing in the community; 2) Strict policies that allows only pertinent personnel to come in contact with youth when seeking HIV testing; 3) General waiting rooms as opposed to waiting rooms specific to HIV testing services; and 4) The absence of signs on the doors of the rooms where HIV testing is performed in HIV testing sites.

In public policy, the findings from the current study can assist in meeting one of the objectives of National HIV/AIDS Strategy for the United States (2015), to increase HIV testing rate to 90%. The overall goal is to increase the number of people who are aware of HIV status and consequently reduce the transmission rate (National HIV/AIDS Strategy for the United States; 2015). The current study provides an understanding for the factors related to HIV testing among youth who decided without the immediate recommendation of a healthcare professional to seek HIV testing. The findings of the
current study may lead to the creation of an intervention to assist youth in independently seeking HIV testing, and consequently increase the rates of HIV testing.

**Limitations**

Despite its contribution to knowledge, the current study has several limitations. The study sample were mainly females ($n = 21, 70\%$), African American ($n = 17, 56.7\%$) and recruited from community testing events with mobile testing vans ($n = 17, 56.7\%$). Consequently, the current study has to be interpreted within these contexts.

The current study was conducted in Miami-Dade County, hence, the experiences of youth in other geographical or cultural settings, may vary. Youth tested mostly with mobile vans that came to areas that were near to participants’ schools or work places, hence, there is not enough data from youth who sought testing in other test sites that are further removed from these locations. The current study also included only youth that were fluent in English language. South Florida is a culturally diverse area with multiple languages, therefore, this finding may not apply to youth who speak languages other than English.

The current study also did not include youth who are younger than 18 years, who would have different experiences proactively seeking HIV testing. Youth younger than 18 years may be more dependent on parental permission to access HIV testing services, and may have different experiences in testing for HIV infection proactively.

The youth in this study all had HIV sero-negative HIV test results. This sample may not accurately represent youth who are at risk for HIV infection in Miami-Dade County.
Youth with sero-positive HIV test results may have different experiences with sexual risk behaviors and facilitators or barriers to proactive HIV testing may differ.

**Summary**

This is the one of the first qualitative study conducted to understand the factors that are related to the decision and behaviour of proactive HIV testing among youth. Analysis revealed that youth recognized personal risk for HIV infection, recognized and identified forms of support, and took responsibility for personal health.

Suggestions for future research include a further understanding of the resources needed to encourage youth to proactively test for HIV infection. Youth would also benefit from research on the relationship and inclusion of the role of peer support in HIV testing initiatives. Clinical recommendations include offering youth free rapid HIV testing and results, and making the HIV testing sites and process private and accessible to youth. Some policy recommendations include advocating for fund allocation and facilitating youth’s access to HIV testing services.

With HIV testing based on healthcare professional recommendations falling short of meeting the HIV testing needs of youth, proactive HIV testing offers an alternative way youth can seek testing services independently. The current study provided an understanding of the resources youth need to seek HIV testing proactively, as well as modifiable and non-modifiable influences of proactive HIV testing. The collaboration between researchers, clinicians, and policy makers in addressing the identified needs, and facilitating the uptake of proactive HIV testing, will increase the rates of HIV testing
among youth, and consequently decrease the HIV risk and HIV transmission in this population
References


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Appendix A
Demographic Form

1) How old are you? (in years) ______________

2) What is your sex?
   a) Female
   b) Male
   c) Transgender

3) What is your Race/Ethnicity? (Select all that apply)
   a) African American/Black – not Hispanic
   b) Caucasian/White – not Hispanic
   c) Hispanic or Latino/a
   d) Asian or Pacific Islander
   e) Native American or Alaskan Native
   f) Other __________

4) What is your highest level of completed education? __________

5) On average, how many hours do you work in a week? __________

6) What is your income per year? __________

7) What kind(s) of sexual intercourse have you had?
   a) Oral
   b) Vaginal
   c) Anal

8) What kind(s) of sexual relationships have you had?
   a) Same-sex
   b) Opposite-sex
   c) Bisexual

9) During your life, with how many people have you had sexual intercourse?
   a) 1 person
   b) 2 people
   c) 3 people
   d) 4 people
   e) 5 people
f) 6 or more people

10) During the past 3 months, with how many people did you have sexual intercourse?
   a) I have had sexual intercourse, but not during the past 3 months
   b) 1 person
   c) 2 people
   d) 3 people
   e) 4 people
   f) 5 people
   g) 6 or more people

11) The last time you had sexual intercourse, did you or your partner use a condom?
   a) Yes
   b) No

12) During your lifetime, how many sexual partners did you not use a condom with?

13) How many times have you obtained HIV testing in your lifetime?

14) When was your last HIV test (date) (if applicable)?
Appendix B
Interview Guide
Proactive HIV Testing among Youth

Information

1) Tell me about when you first heard about HIV testing?
   a. What was your most recent source of HIV testing information (media, person, etc.)?
   b. What is your relationship with the person that told you about HIV testing?

2) How did it make you feel?
   a. Describe your reaction(s) to hearing about HIV testing?
   b. Tell me about the situations/events/happenings that occurred around the time you heard about HIV testing.

3) What did you gain from the information on HIV testing?
   a. Tell me about your impression/perception/understanding of the meaning of HIV testing.
   b. What were the benefits you perceived? (Tell me about what you expected to gain from HIV testing)
   c. What were the risks or fears you perceived? (Tell me about any concerns you had about HIV testing? Tell me about anything/person/event/expectation that stopped or would have stopped you from testing?)
Motivation

1) When did you decide to test for HIV infection?
   a. Tell me about the situation/event/occurrence that prompted your decision to test?
   b. How long has elapsed between the situation/event/occurrence, and coming to test today?

2) Do you consider yourself vulnerable to HIV infection? – Why or why not?
   a. Tell me about anything that happened that makes you think you could become HIV infected?

3) Describe the step by step process of how you came to the decision to test for HIV infection? – What happened, and what followed next?
   a. Did you make the decision to test for HIV infection on your own?
   b. Did anyone/anything influence your decision into testing?
   c. Describe how anyone/anything influenced your decision to test?

4) Why did you choose to test today?
   a. Tell me what makes today the most appropriate day for you to test? (What makes today better than other days before or tomorrow and days after?)
   b. Tell me about anyone/events that made you decide to test today? (What led you to test for HIV infection today?)

5) Why did you choose this test location?
   a. Tell me about your choice of this test location
   b. Do you know any other HIV testing location?
c. Tell me about what makes this location better than other locations (if applicable)?

d. Tell me about anything you like about this HIV testing location?

6) What are some barriers that you had to overcome to test today?
   a. Tell me about any challenges you went through before testing today?

Behavior

1) Tell me about your experience with testing for HIV infection today?
   a. Tell what did you like about your testing experience? (Was there anything that happened during testing that you appreciated?)
   b. Tell me what didn’t you like about your testing experience? (Was there anything that happened during testing that upset you?)

2) Can you describe your feelings before taking the HIV test?
   a. What were your expectations about HIV testing?

3) Tell me about the testing procedure?
   a. Can you explain what happened during testing today?

4) Can you describe your feelings after you completed the test/ waiting for your results?

5) Looking back at your decision to get tested today, what would you change about that decision? (if anything)

6) Tell me about how testing for HIV infection affects you?
   a. What will testing do to your sexual relationships?
   b. Will testing affect your personal life in any way? Can you explain?
c. Will testing affect any aspect of your life (family, work, education) in any way? Can you explain?

7) Tell me of what could improve your experience of HIV testing today?

8) When next would you test for HIV infection?

9) What advice would you give to other youth like you regarding HIV testing?
   a. Tell me of what you have learned from your HIV testing experience
   b. When would you advice someone to seek HIV testing?
Appendix C

Researcher’s Field Notes

Proactive HIV Testing among Youth

Participant Number: ___________________

Interview Date: ________________ Start time: _____________ Ending Time: ________________

Location of Interview:

Description of environment (including personal belongings):

Nonverbal behavior:

Content of interview:

Researcher’s impressions:

Analysis (questions, tentative hunches, trends in data, patterns, etc.):

Technological problems:
Appendix D
Consent Form

University of Miami
CONSENT TO PARTICIPATE IN A RESEARCH STUDY
Proactive HIV Testing Among Youth in South Florida

The following information describes the research study in which you are being asked to participate. Please read the information carefully. At the end, you will be asked if you agree to participate.

PURPOSE OF STUDY:

The purpose of this study is to understand what influences proactive HIV testing among youth. Proactive HIV testing means that you decided to get tested on your own without encouragement from a healthcare professional.

PROCEDURES:

If you agree to participate in this study, you will be taken to a private room and asked questions about what made you decide to get HIV tested. You will also be asked to complete a background questionnaire. This questionnaire includes some potentially sensitive and personal information such as sexual behaviors, substance use behaviors, stressful events, or mental issues. The interview will be audio-recorded. The length of time you would spend in this study would range from 45 minutes to 1 hour. This would be a one-time activity.

RISKS AND/OR DISCOMFORTS:

We do not anticipate that there is any risk to you from being in this study. However, you may feel uncomfortable or upset due to the questions asked. In the event of any of the above occurring, you are free to stop answering the questions or skip any questions you feel uncomfortable answering. Additionally, the Study Coordinator (who has experience in emergency room nursing and care of youth in the study’s age group), will perform a brief assessment and will refer you for a more in-depth assessment and possible treatment if needed.

You should report any uncomfortable feelings to the researcher, should you have any questions and/or concerns.
**BENEFITS:**

No direct benefit can be promised to you from your participation in this study. The study is expected to benefit society by helping understand what influences proactive HIV testing among people of your age group.

**CONFIDENTIALITY:**

All information provided would be entered into a secure password-protected computer and server. Information provided would only be accessible to research team for the sole purpose of research.

All information collected from you will be stored for a period of 3 years and then will be deleted.

Your information may be looked at and/or copied for research or regulatory persons by:

- Department of Health and Human Services (DHHS).
- other government agencies.
- other University of Miami employees for audit and/or monitoring purposes.

**COMPENSATION:**

A $20 cash compensation would be available after completing the interview. In order to receive the $20 in cash, you must complete the entire study.

**RIGHT TO DECLINE OR WITHDRAW:**

Your participation in this study is voluntary. You are free to refuse to participate in the study or withdraw your consent at any time during the study. The investigator reserves the right to remove you without your consent at such time that they feel it is in the best interest for you.

**CONTACT INFORMATION:**

Winifred Adebayo (owal@miami.edu) is the Study Coordinator, and will gladly answer any questions you may have concerning the purpose, procedures, and outcome of this project. Ms. Adebayo is supervised by Dr. Joseph De Santis (305) 284-5039. If you have questions about your rights as a research subject you may contact the Human Subjects Research Office at the University of Miami, at (305) 243-3195.
PARTICIPANT AGREEMENT:

I have read the information in this consent form and agree to participate in this study and be audio recorded. I have had the chance to ask any questions I have about this study, and they have been answered for me. I am entitled to a copy of this form after it has been read.

COMPLETION OF THE STUDY IS CONSIDERED YOUR CONSENT TO PARTICIPATE.