Factors Related to Delayed Time for HIV Care Among Youth Living with HIV: a Cross-Sectional Analysis of Social Support Networks and Access to Care

Patricia L. Jones

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FACTORS RELATED TO DELAYED TIME FOR HIV CARE AMONG YOUTH LIVING WITH HIV: A CROSS-SECTIONAL ANALYSIS OF SOCIAL SUPPORT NETWORKS AND ACCESS TO CARE

by

Patricia L. Jones

A Dissertation in Partial Fulfillment of the Requirements for the Degree of Doctor of Public Health in Health Education

December 2005
Each person whose signature appears below certifies that this dissertation, in his/her opinion, is adequate in the scope and quality as a dissertation for the degree of Doctor of Public Health.

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ABSTRACT OF THE DISSERTATION

Factors Related to Delayed Time for HIV Care Among Youth Living With HIV:
A Cross-Sectional Analysis of Social Support Networks and Access to Care

by

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Purpose: This research explored the pattern of influence social support networks had on delayed time between diagnosis and first doctor’s visit after diagnosis of HIV in youth. Results showed that factors related to receiving a referral were prosocial peer behaviors and excessive fibbing in the past 6 months. The study identified sources of social support and described the relationship between the source of support and time of first doctor’s visit after HIV diagnosis. Both descriptive and multivariate analyses were performed on all youth (N=347) and specifically on those seeking care. Methodology: Historical data were extracted from the baseline dataset of a quasi-experimental prospective study conducted between 1994-1996 of youth living with HIV in four metropolitan cities in the U.S. The sample for this study consisted of youth living with HIV who self-reported that they were seen by a doctor or a nurse after their diagnosis or given a referral to do so after they were diagnosed to be HIV positive.
Analyses were performed on variables associated with time of first doctor's visit after diagnosis such as age, gender, ethnicity, religion, education, employment, homelessness/marginally housed, service site, stage of illness, disclosure of HIV status, disclosure of sexual orientation, mental health characteristics, amount of social support regarding their illness, frequency of contact with social network members, and peer behaviors.

Significant predictors of receiving a referral for care were being female, having HIV symptoms, living with extended family members, and education level. Key findings were that youth who fibbed excessively in the past 6 months took longer (22 days) to visit a health provider \( (p<.05) \) and that peer network interaction influenced health care seeking behavior and prosocial peer behaviors took longer to visit a provider (27 days).
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CHAPTER 1
INTRODUCTION

A. Statement of the Problem

We are three decades into the HIV/AIDS epidemic and the face of those most vulnerable is increasingly young, female, and non-white. Globally, in 2001, six out of every ten new HIV infections were among youth under 25 years old (Henry J. Kaiser Family Foundation, 2002). Nearly half of all new HIV infections among adults defined as 15-49 years old occur among youth who are 15-24 years old. Young women and girls are particularly at risk for transmission with a rate of new HIV infections 5-6 times higher than young men and boys in some countries (Henry J. Kaiser Family Foundation, 2002).

Nationally, the U.S. Centers for Disease Control and Prevention report that approximately 25% of all new cases will be among youth 15-24 years old (CDC, 2001). Also, in 2000, 24% of all AIDS cases were among women (www.whitehouse.gov/onap/facts.html). The epidemic has increasingly become non-white with men of color totaling 52% of the AIDS deaths in 1998, most of whom were likely to have been infected during their youth or early adolescents.

Consistent with national reports, mathematical models estimate that in some metropolitan areas, such as Los Angeles County, youth under 24 years old will make up as many as 25% of the newly reported cases of HIV (Los Angeles County HIV Prevention Plan, 2000; Valdesserl et al., 2000). Locally, 16.68% of Los Angeles County’s AIDS cases, 13.94% of Riverside County’s AIDS cases, and 4.25% of San Bernardino County’s AIDS cases reflect the magnitude of this epidemic among young people between the ages of 13 and 29. Efforts to increase early detection and linkage into
HIV care and treatment among young people are fundamental in stemming further transmission and progression of the illness.

Some studies have documented that early HIV detection resulting in early access to HIV care and treatment is the optimal scenario for people living with HIV. Eichler et al., (2002) and Montgomery, Gillespie et al., (2002) suggest that persons testing positive who access outpatient HIV care relatively early in the disease can reduce morbidity and mortality. Montgomery et al., (2002) also indicated that survival time with AIDS is positively correlated with early access to care. Huba and other colleagues (2000) report that youth living with HIV who receives some sort of health care service can be useful in linking youth to more specialized appropriate forms of HIV care. Youth returning for HIV test results oftentimes creates an opportunity to link people living with HIV to necessary services. However, data on adolescents returning for their test results are limited (Lazebnik et al., 2000). Some studies report anywhere from 70% -95% of those testing return for their results (CDC, 2001), and Anderson et al., 2000 report data from the National Health Interview Survey, 1987-1995 indicating that 87% of persons testing for HIV returned for their test results. Reports from the U.S. Health Resources Administration, HIV/AIDS Bureau indicate, “Youth are less likely to return for their HIV test results as compared to others” and that there is a 1-5 year delay in between receiving an HIV diagnosis and seeking care (TA CALL REPORT, September 2000, p. 3.). The statistics and the reasons why youth return for their test results vary greatly, thus underscoring the challenge in closing the gap in providing services to youth living with HIV.
There are reports suggesting that modest numbers of youth are using HIV testing services therefore, the number of youth living with HIV who are entering into care is arguable (Lazebnik et al., 2000; Remafedi, et al., 1998, and Rotheram-Borus & Futterman 1997).

Statistics compiled by the Health Resources and Services Administration suggest that 63% of the youth tested in one sample for HIV returned for their test results and post-test counseling. Consistent with this pattern, Rotheram-Borus and Futterman (1997) report that in a study of youth living with HIV in New York, 63% of the youth had sought HIV testing at least once before. Further, of the 63%, almost 90% returned for their test results and 52% of those referred actually went into HIV care and treatment.

The CDC reports that among all counseling testing services requested at publicly funded test sites in 1998, approximately 28% were among young people 13-29 years old with roughly 3% of these youth testing HIV positive as compared with the prevalence at 0.4% among the general population. The majority of youth seeking HIV testing services and reporting to be HIV positive were African-American and Latino, 60% and 24% respectively. While HIV counseling and testing is a critical component to secondary prevention, there are several factors that facilitate youth accessing services. Some HIV research scientists have argued that due to the burden of having two face-to-face one hour long counseling sessions, current models of counseling and testing services may reduce the probability of attracting people living with HIV continuing to be in at-risk situations to test and enticing them to return for their results and to be linked with additional services (Rotheram & Etzel, 2003). Further, studies suggest that youth accessing care is also influenced by the quality of the physician-patient relationship; patients who are more
comfortable participating with their doctor in making decisions are more medically compliant (Freed et al., 1998; Ginsburg, 1997).

Earlier research conducted by Dr. Rotheram-Borus et al., (1998) demonstrated that the relationship between how the youth perceives him/herself and how a youth behaves, motivated them to change their personal behaviors and ultimately reduce risk for disease transmission. Likewise, Rotheram-Borus et al. (1998) have demonstrated that family and peer networks as well as other social factors are key in shaping the youth’s perception of themselves as an HIV infected person and use of services. Further, the original study upon which this research is based was grounded in the Social Action Theory (Ewart, 1991), which allowed further examination of these motivational factors. The model’s components include: (1) self-regulation by youth; (2) larger environmental factors such as homelessness; and (3) emotional state that influence self-regulation.

The intervention study conducted by Dr. Rotheram-Borus addressed self-regulation by intensively focusing on substance abuse in the modules. Addressing substance abuse in the modules as a means of addressing self-regulation was based on literature establishing a link between drug use and HIV risk and drug use and risky sex among gay men (Leigh & Stall, 1993); among men living with HIV continuing to engage in risky behaviors (Robins, et al., 1996); and men and among women (Chesney et al., 1997). Environmental factors addressed were: exchanging sex for other resources, monogamous or true romantic relationships and casual partners. The literature suggests that HIV risk increases in causal settings for homeless youth (Rotheram-Borus et al., 1995); gay youth involved with partners with incongruent serostatus (Reimen et al.,
1995) and women who are dependent on partners for economic stability (Erhardt & Yingling, 1992; Cohen et al., 1989).

The major focus of the research was the process whereby social network members mediate accessing services and therefore acting as a facilitator or a barrier to accessing HIV care after diagnosis. The AIDS Risk Reduction Model (ARRM) was used to explore concepts related to youth living with HIV delay seeking care (Catania, Kegeles, & Coates, 1990).

**B. Purpose of the Study**

The purpose of the research was to determine whether and how social networks act as a facilitator or a barrier to youth tested and living with HIV who are seeking services.

The research developed a profile of youth living with HIV who are seeking services for their condition and will describe the relationship between the amounts of support received, type of social support network member(s) providing support, the frequency of contact youth have with the social support network member, and the length of time between HIV diagnosis and first visit or ever.

The major constructs to be examined are: descriptive information about the youth social networks and their demographic information; descriptive information regarding the quality and context of the youth’s interaction with their social networks; housing stability of the youth; religion; education; public health insurance; employment and job related health insurance. The primary outcome measured is the time between HIV diagnosis and first visit to the doctor after receiving and HIV diagnosis.
C. Significance to Health Education

HIV is the seventh of the 21 critical objectives listed in Healthy Youth 2010: Supporting the 21 Critical Adolescent Objectives produced by the American Medical Association (Healthy Youth 2010, www.ama-assn.org). There is a dearth of information about the relationship between HIV positive youth accessing care and their social support systems. Making programs and interventions for young people living with HIV/AIDS who are grappling with issues around death and dying aimed at improving their ability to adapt to their disease is desperately needed (Grassi et al., 1998 as reported in Brown et al., 2000). Recognizing that HIV infection can be a costly disease to treat as it progresses and causes more advanced complications, the proposed study will provide an understanding of the factors associated with motivating a young person to access requisite services that could not only prolong but also improve the quality of their lives. Consequently, the health education profession will be able to develop programs aimed at encouraging young people living with HIV/AIDS to know the risks for HIV transmission, get tested for HIV earlier, and to access referred services immediately upon receiving and HIV diagnosis. In addition, health educators and health professionals in general may be better poised to respond to the HIV/AIDS epidemic and produce well-informed interventions for this population.
D. Objectives

The primary objectives were as follows:

1) To describe the role of social support from network members with and any relationship between the behaviors of peers within the youth’s social network at time of first doctor’s visit after HIV diagnosis.

2) To determine whether demographic variables are associated with time of first doctor’s visit.

Secondary Objective

3) To determine if the AIDS Risk Reduction Model is useful in explaining time of first visit to the doctor or nurse after a diagnosis and referral.

E. Research Questions

1) Among youth diagnosed with HIV who were referred to a doctor or nurse for HIV care, is there an association between sources of social support, size of social network, frequency of contact with network members, the amount of support experienced through networks from network members and time of first doctor’s visit after HIV diagnosis?

2) Demographic variables. Among youth diagnosed with HIV who were referred to a doctor or nurse for HIV care, is there an association between demographic variables such as their age, gender, ethnicity, housing, religion, employment, family economic status, and time of first doctor’s visit after HIV diagnosis?

3) Stage of Illness. Among youth diagnosed with HIV who were referred to a doctor or nurse for HIV care, is there an association between stage of illness and time of first doctor’s visit after HIV diagnosis?
4) **Disclosure of sexual orientation and HIV status to family, friends, and service providers.** Among youth diagnosed with HIV who were referred to a doctor or nurse for HIV care, is there an association between disclosure of sexual orientation and disclosure of HIV status and time of first doctor’s visit after HIV diagnosis?

5) **Mental health characteristics** Among youth diagnosed with HIV who were referred to a doctor or nurse for HIV care, is there an association between mental health characteristics defined as depression and conduct problems and time of first doctor’s visit after HIV diagnosis?

**F. Hypothesis**

We hypothesized that youths who have frequent contact with their parents or close friends who engage in protective risk practices, will have sought care sooner than those youths who are not close to their parents, do not have close friends and the friends they do have are involved in negative behaviors. Neaigus et al. (2001) state that social influence networks act as conduits of level of risk. For example, Neaigus suggests that people who pose a risk of some sort also can influence their peers’ behaviors through persuasion, imitation, and pressure or coercion. Consequently, we expect youth who have frequent contact with helpful and supportive individuals to use various mental and physical health services within one month after receiving a HIV diagnosis. While there is a paucity of literature documenting the role of HIV positive youth’s social networks in service-seeking behaviors, the findings were consistent with other literature documenting the influence of social networks of high-risk people and HIV positive individuals and other behaviors.
The research did not measure the dose effect of the intervention on any of the constructs measured in the original dataset but rather described the relationship between social support networks and the time between an HIV diagnosis and entering into HIV care. Consistent with the general literature on adults living with HIV, we expected to find that youth accessing both mental and physical health care services immediately had stronger, and more supportive social networks when compared with youth who did not access these services. We also expected to find statistically significant differences by gender (Montgomery et al., 2002) and ethnicity (Joffe & Radius, 1993), levels of religiosity (Ironson et al., 2002; Nunes et al., 1995), and indices of socioeconomic status (Pescosolido et al., 1998; Mathews et al., 2000). We expected that being female and more religious or spiritual are positive correlates of social ties that provide positive support toward use of services.

Based on conversations with Rotheram-Borus of the original research team, we expected to find that youth recruited from agencies in San Francisco and Los Angeles will have more contact with their providers and therefore, have a slightly larger social network and perhaps having a stronger relationship between support from the network and service use due to the fact that services in the East coast are oftentimes located within hospitals and in the West coast they are oftentimes located within free-standing non-profit organizations. Ultimately, we will explore a logistic regression model that controls for site to determine whether there is a relationship between support from networks and service use.
G. Theoretical Framework

The research addressed the three stages in the arrm model as follows: stage 1: Labeling used condoms since diagnosed HIV +; stage 2: Commitment to participate in health care decisions; stage 3: Enactment was demonstrated by the number of doctor appointments missed over a three month period. The help-seeking construct following stage 3 was measured by the youth asking for assistance with household chores, shopping, or personal care (i.e. bathing, etc.). Positive lifestyle changes to enhance the youth’s health was measured by the self-help construct and the Enactment Solutions construct was measured by the number of times youth requested medical information by phone from a provider. The main components of the arrm model were assessed by selecting items from the survey and generating a correlation matrix to determine if the conceptual framework of the model is applicable to youth living with HIV.

The AIDS risk reduction model was selected for the proposed study because other health behavior models may not be comprehensive enough to measure certain constructs within the context of HIV related behaviors (Catania et al., 1990; Montgomery et al., 1989). The ARRM focuses on the individual’s personal risk behaviors as well as the person’s environment in terms of their peer groups. Based on published results of the model being tested for its efficacy in predicting behavior change, the model is a potentially effective framework for the proposed study based on the role of social networks influencing the participant’s decisions about a health risk behavior. Further, The AIDS Risk Reduction Model possesses elements of proven health behavior theories and models such as the Health Belief Model (Janz & Becker, 1984; Becker, 1974; Becker & Maiman (1975); self-efficacy theory (Bandura, 1977); diffusion theory
While the model has been used to address primary prevention among adult women living with HIV, it has not been used to address either primary or secondary prevention behaviors among youth living with HIV/AIDS. Existing information on how the model has been used come from Catania et al., (1990) reporting unpublished studies that this model has been used to empirically test prevention intervention strategies among people attending HIV testing sites, gay and bisexual men, unmarried white, black, and Latino heterosexuals, and female youth attending reproductive health centers (chipts website: http://chipts.ucla.edu, 2002).

This model was used to test all of the theoretical constructs to explain transmission behaviors among high-risk non-injection drug users in rehabilitation for cocaine use (Malow & Ireland, 1996); heterosexual men and women in dating situations with multiple sex partners (Dolcini, et al., 1995); continued sexual risk of women living with HIV (Kline & Van Landingham, 1994); the prevention skills, attitudes, beliefs, and risk behaviors among male veteran’s in an inpatient drug rehabilitation program (Malow et al., 1994); attitudes, emotional, and behavioral factors associated with condom use among Black males dependent on cocaine (Malow, Corrigan, et al., 1993). International applications of this model include women in both urban and rural settings in Bas-Zaire; however, Bertrand et al. (1994) noted that the women had trouble identifying and labeling their risk behaviors, as problematic suggesting that there are perhaps cultural limitations of the utility of the model. The only published article on the model being used
with a youth population is with incarcerated youth in rural settings (Schalpman & Cass, 2000).

The model illustrated how the major components of the research were related with one another (e.g. labeling, commitment, enactment, and help seeking). The model shown in Figure 1 is useful as a method of portraying how the factors of help seeking behavior are related to labeling and commitment.
Figure 1: AIDS Risk Reduction Model.

NO ACTION ← NO

LABELING

←↓

YES
↓

RESIGNATION ← NO

COMMITMENT

↓

YES
↓

RESIGNATION ← NO

ENACTMENT → SELF-HELP

↓

HELP SEEKING → ENACTING SOLUTIONS

H. Definition of Terms

*Social networks:* The three major groups of network members include a) immediate and distal family members; b) friendship networks including romantic partners; c) service providers.

*Services:* Any psychosocial, alcohol and drug, or medical help referred to the youth at the point an HIV diagnosis was made.

*Service Seeking:* The behavior demonstrated by youth living with HIV when they are attempting to access a particular service referred to them as a result of their HIV diagnosis.

*Time of first doctor’s visit:* is referencing the time period between receiving a referral for some type of medical or social service or having been seen by a health care provider.

*Secondary HIV Prevention:* is delivering services aimed at building skills, providing information that assists an HIV positive person to adhere to medical treatment, access necessary legal, housing, and other social and medical care services.

*Serostatus:* HIV Status as determined by a medical provider (e.g. HIV positive or HIV negative).

*Ethnicity:* The youth’s perceived identity based on their own and their familial origin as self-reported in the survey.

*Social Support:* Either a positive or negative source of encouragement to adopt a particular skill or group of attitudes, beliefs, and skills.

*Social Support Network member:* A person who has been identified by the study participant as a person they associate with.
Youth living with HIV: Youth who are determined to be infected with HIV and have had some form of HIV post-test counseling and provided social service referrals.

arrm Stage One: The point in the process where the participant recognizes and labels one’s behavior as a high-risk practice.

arrm Stage Two: The point where the participant makes the commitment to change the high-risk behavior.

arrm Stage Three: The participant enacts the desired behavior acknowledging that carrying out the desired behavior usually requires seeking help from others, either professionals or from their social networks as well as self-help.

Housing situation: Lifetime response indicating with whom youth have lived with over various time periods, including the present living circumstances.

Prosocial: Positive or healthy social behaviors exhibited by the youth’s peer network members. Gainfully employment, regular school attendance, participating in extracurricular activities are examples of prosocial behaviors.
CHAPTER 2
REVIEW OF THE LITERATURE

A. Introduction

The literature review discusses the following areas: (a) the magnitude of delayed time between referral to healthcare services and first visit (b) factors associated with service seeking behaviors, (c) research demonstrating social network’s positive and negative influence on health behaviors, and (d) the role social networks play in providing social support with respect to health behaviors.

B. Magnitude of the Delayed Time of Health Service Utilization

There are few studies exploring the delay in accessing primary care within HIV specifically. Additionally, delayed time to accessing primary care has been documented in other health domains. Delayed time to healthcare utilization among people living with HIV appears to be common (Schietinger, 2001; Turner et al., 2000; Samet, Freedberg, Stein et al., 1998). These delays may not only create an opportunity for more serious illnesses to develop, but also create undue economic hardship on an already fragile national healthcare system. Some studies suggest nearly 40% delayed access to primary care for more than a year after learning of their HIV status and nearly 20% delayed accessing care for more than five years (Schietinger, 2001).

Factors associated with delayed time to healthcare utilization among people living with HIV are: having a history of injection drug use (Hein et al., 1995; Samet, Freedberg et al., 1998; Samet, Freedberg, Savetsky et al., 2001); not having a significant other in their lives (Schietinger, 2001), and race/ethnicity (Turner et al., 2000).
In a sample of symptomatic tuberculosis positive persons in Los Angeles County, non-white ethnicity was a statistically significant factor for patients delaying the time to utilize healthcare services. In a sample of injection drug users who were under the age of 25 years old, recent homelessness was a statistically significant factor associated with delayed time to health care utilization (Cronquist et al., 2001). Reports clearly documenting youth returning for follow-up HIV services are inconclusive at best, underscoring the importance of understanding the service gap (Lazebnik et al., 2001).

Further, other studies suggested that social support systems can decrease the delayed time to seek care. In a study similar to this research, mothers living with HIV who delayed primary care were determined to have low social support from their peers and family members. In fact, support was most commonly reported to come from minor children in the home, suggesting that other children in the home experienced undue parental or adult responsibilities placed on them as a result of the stress the mother’s illness created (Williams et al., 1997).

C. Factors Associated With Service Seeking Behaviors

While most young people living with HIV access medical care through a variety of medical settings, many do not receive the necessary care until physical symptoms manifest themselves and illness has progressed significantly (Huba et al., 2000). There is a dearth of information in the literature documenting how many youth are in need of health care and delay time to health service use. Consequently, the youth did not use health services very often, demonstrated very little intention to seek care, and were at high risk for health problems. This disparity was detected among students who were younger and male. Data from Aten et al., (1996) as cited by Huba et al., (2000) stated that
within a sample size of 3,677 youth in school between the ages of 12-19 years, 13% reported not participating in any health care at all, and 25% reported no health care within past six months. Among male students, 21% of the middle schoolboys reported they had not received care, which was more than double the % for older boys (8%). Males were the least likely to report that they knew about a teen clinic as compared with female students (F=23.3, p<.001).

Factors associated with service seeking behaviors have been documented among various groups. Mc Miller et al., (1995) observed that African-American and Latino families seek professional mental health services less frequently as compared to white families. Further, the evidence suggested that family and peer support is used more readily among non-white families before professional help is sought. In researching help seeking, Petersen et al., (1995) noted that gay and bisexual black men who were diagnosed as HIV positive, and gay men who knew their HIV status, and sought HIV counseling and testing services, were more inclined to seek help from their peers or professionals as compared to those who did not seek testing services. Hays et al. (1990) observed that gay men living with HIV who have been diagnosed at varying stages of their illness sought help from different sources. Men living with AIDS sought help from professional care providers and family members more so than men living with HIV. Men not living with AIDS, or who were unaware of their HIV status, also sought help from their peers more often than those living with AIDS.

Service seeking has been documented in other settings and other health domains. Among women seeking family planning services, and adult HIV positive patients seeking dental health services in Nigeria, data suggested that advice from family, friends and
media messages influenced the type of family planning method, and dental health services selected (Konje et al., 1998; Mc Carthy et al., 1995; Fortenberry et al., 2002). Social network analysis is one form of research that helps explain differentiations in services and goods among various populations. Social support networks oftentimes provide necessary services to their network members. Evidence suggests that the role of social networks and the support provided through the networks can ameliorate service burdens placed on health care providers (Hays, Chauncey, & Tobey, 1990).

The interplay between social support networks and their role as either a facilitator or a barrier to service seeking behaviors among their network members is important in the context of more immediate improvements to the delivery of care. This is particularly so, given that policy and organizational aspects of health care are slower to change than interpersonal or individual level aspects of health.

1. Positive Effects of Social Networks on Health Behaviors

The positive effects of social networks on health are well documented in the literature (Barrera, 1981; Berkman, 1985). Studies show that seeking help and using support systems can have a buffering effect for youth’s response to stress. In separate studies, it was demonstrated that support from social networks may have varying effects on youth and higher levels of informal social support were correlated to poorer performance and school performance among urban youth (Gonzalez et al., 1994; Ebata and Moos, 1991 as reported in Raviv, 2000; Cauce et al., 1982). Adolescents are more inclined to refer their peers for services and help than to seek help themselves (Raviv et al., 2000). Youth may feel vulnerable and dependent when they are experiencing a health problem; therefore, it is suggested that youth may be more inclined to refer their peers for
support, particularly when the problem is very severe, than to address their own needs. This difference in referral styles was noted in youth referring their friends for formal help and to the friend’s parents than to seek formal help for them or go to their own parents for help.

Adolescence is a period of time when peers and close friends oftentimes have a significant impact on behavior, attitudes, and beliefs (Kobus, 2003). Among youth, peers can have both a positive and negative effect on various health behaviors. Youth are susceptible to outside influences such as their peer groups. The most important networks may or may not be positive influences in their lives but they consist of family members, friends, and in some instance the service providers from whom these youth access care.

Durkheim (1951) originated the concept that the individual’s experiences are largely influenced by macrolevel systems such as other family, peer groups, and organizations. Since this theory has been advanced, the relationship between the lack of social interaction with others and the individual’s diminished physical health has been explored among adults and documented in the literature (Berkman et al., 2000; Wilkinson, 1999). There is significantly less literature documenting this relationship on older adolescents (18 years to 25 years of age), but there are some data on younger adolescents and children (Hendry & Reid, 2000). As referenced earlier, social networks have been documented as an influence on both physical health and mental health.

The positive correlation between weak social networks and poor mental health outcomes has been explored and established in the literature as well. Tangentially related to the concept of individuals influenced by others, there is literature documenting the role of social support from social networks that facilitate mental and physical service use
(Dowdney et al., 1999; Olsen, 1998; Brown et al., 2000). Further, Dowdney et al. (1999) reported that bereaved children who were not already connected to the mental health service system were typically least likely to be referred for additional services and support as compared to youth who did have some contact with the system before their parent died. Kincaid (2000) indicated that use of social networks in a sample of Bangladesh married women to increase family planning methods being adopted, was more effective than simply relying on government staff visiting their homes. This study suggested that in the absence of social networks, information and behaviors were not influenced as strongly.

2. Negative Effects of Social Networks on Health Behaviors

Although current literature documents the benefits of friendship and familial networks on a person’s mental and physical health status, there is evidence that social networks can also have a negative influence on health behaviors. Prinstein et al. (2001) examined adolescent health behaviors among 9-12th grade youth (N=527). Youth were interviewed on substance use, violent behaviors, suicidal tendencies, and the health risk behaviors of their peers. Data suggested that there is a social learning effect among some youth and their close peers. The study found that the behaviors of the youth’s close peers had both a positive and a negative impact on their own behaviors. There was a positive association between suicidal ideations, violent behaviors, and substance use of students and their peers. There was, however, a negative association between youth with suicidal ideations, violent behaviors, and substance use and their peers displaying prosocial behaviors. Further, the data suggested that the degree of impact each of these
negative behaviors had on the youth was influenced by family dysfunction, perceived acceptance by their peers, and whether or not they experienced depression.

The role of social support networks influencing poor health outcomes has been under-explored in social science research (Sakata, 1991), but is increasingly being documented in the literature. However, many studies focused on the lack of support or isolation as the primary mechanism by which health is negatively impacted (Simon, 1999; Cohen, 1988). Recent studies noted that negative health outcomes such as disease transmission are a function of where an individual is positioned within his/her social network (Friedman, 1997; Friedman & Aral, 2001). Those closest to social network members exhibiting negative health practices were at a higher risk of becoming infected than those who had a network of lower-risk persons.

Work by Rook (1985) compared both positive and negative effects of support from social networks on emotional health. The author argued that previous studies on negative experiences all suggested that the impact is more extensive than any study demonstrating a positive effect on emotional health. El-Bassel et al. (1998) cited studies documenting the negative impact social networks have by modeling dysfunctional behaviors (Schilling, 1987) and influencing HIV transmission risk behaviors (Price et al., 1995). Other data have established that social networks may act as negative influences on their network members (Morris, Zavisca, & Dean, 1995). Neaigus et al., (2001) used social network analysis to explain HIV transmission risk among injection drug users. A social learning effect demonstrating network members initiated injection drug use based upon their personal networks has been documented in the findings. This finding was consistent with other research on injection drug users and the network of peers who use
drugs (Brook et al., 1990). Studies addressing youth document a negative social learning effect. While Montgomery et al. (2002) found that social networks of young injection drug users may model some prosocial skills such as cleaning needles they also may increase HIV transmission risk for young women who tended to be more embedded in social network and therefore injected more frequently or had more sexual contacts. The mechanism consistent in both positive and negative social network influences is that social support involve specific behaviors such as sharing syringes among injection drug users (IDU), injecting heroin, cocaine, and speedball, injecting in locations commonly associated with drug users (e.g. "shooting galleries"), crack use and social roles like selling syringes on the street to other IDU’S is crucial.

3. Social Support Networks Influence on Health Behaviors

The association between social support derived from social networks and the subsequent use of mental and physical health services has also been documented in community level studies (Amaya-Jackson, 1999), among disenfranchised subgroups of youth (Ennett et al., 1999) and among communities of color (Vera et al., 1998). Social support can be manifested in varying ways among different groups of people. Suh et al. (1997) found that among injection drug users those with large social networks provided social support, but sharing needles was also more common. Within the network, needle sharing has a positive value associated with it and is seen as offensive not to participate. However, injection drug users in networks that did not provide social support were more likely to inject in shooting galleries (large gathering places for injecting drugs).

Internationally, social support among children and youth in the context of HIV and other health topics has been examined. French et al., (2001) showed that culture
influences the provision of support by peer and family members among a sample of Indonesian youth. The author’s cited previous work establishing that depending on the societal norms dictating individual versus collective values, the delivery of support may vary. In Asian cultures where family is a central societal theme, the family as a provider of support was reported very high in the study (French et al., 2001). Support can be provided from a variety of sources.

In a sample of families living with HIV in Thailand, Bechtel & Apakupakul (1999) pointed out that the role of cultural norms and beliefs influencing social support provided among family members is significant in responding to the social stigma experienced by families who have lost a member to HIV. The authors also noted that building on a common cultural belief that social rules and order are essential to family and community harmony can be an effective intervention promoting unity and social support. La Greca et al. (2002) reported that close peers tend to be similar in health status. This similarity in health status provides an opportunity for social comparison whereby the opinions of youth’s peers influence their attitudes and beliefs regarding health practices, including medical regimen adherence.

The role of health professionals as social support networks has been documented. Miller et al. (2002) explored adolescent’s adherence to diabetes and other chronic disease management programs due to the support from the professional staff, particularly nurses. Nurses were the primary predictor in whether a youth was compliant with the behavior program. Further, studies looking at factors associated with youth seeking care indicated that satisfaction with their providers is very important to youth (Litt, 1998).
4. **Differences in Social Support Use by Ethnicity**

Studies with pregnant mothers suggested that social support utilization and source may vary by ethnicity (Sagrestano et al., 1999). While white mothers had more social support from larger networks, Latinas had more support from the baby’s father and their mothers, while black mothers reported more support from other relatives than the other two groups. This same study cited research by Norbeck & Anderson (1989) suggesting that recent Mexican immigrant women who were pregnant received less familial support, but more spousal support than women who had been acculturated.

Studies on social support among pregnant adolescents from three ethnic groups indicated that different ethnic groups might experience support from their network in varying ways (Koniak-Griffin, Lominska & Brecht, 1993). This same study found that while “Black pregnant youth identified the least number of network members, the proportion of support experienced through those members was the greatest.”

**D. Gaps in the Literature**

The majority of the literature exploring factors associated with delayed time to seek health services were focused on adults living with HIV. However, this body of research is small. Furthermore, some studies examining the role of social support on behaviors provided evidence that support networks can be both a positive and a negative factor on behavior adoption. Incorporating social network analyses on HIV transmission risk may provide more insights on how support networks impact behaviors. However, these studies vary in terms of study design and level of social network analysis (Morris, 1997). There is no research exploring the relationship between service providers’ support and youth living with HIV initiating health services in a timely manner. Moreover, there
is very little literature on the role social support networks plays in delayed time to accessing HIV health services and there has been no research looking at delayed linkage into care.

There was no study to date exploring whether the type of support networks, frequency of contact with the member, or the size of the network facilitate or prohibit timely initiation of health services among youth living with HIV. Therefore, this research filled a gap by focusing on youth living with HIV, using peer, professional provider, and family variables.

E. Conclusions

The literature review demonstrated that there is a paucity of literature explaining why youth living with HIV delay entry into care. The review also demonstrated that while there is more research addressing the matter with adults, the factors associated with individuals delaying time to seek care vary. Additionally, there was a need to know how socioeconomic factors such as employment and health insurance influence youth’s decision to seek services. Studies showed that the epidemic is primarily among Black and Latino youth who oftentimes come from economically disadvantaged homes and engage in high-risk behaviors. This study identified factors related to delayed time to seek health services, looking specifically at social support and social network members.
CHAPTER 3

METHODOLOGY

A. General Overview

The dataset this research draws from was originally funded by the National Institute of Drug Abuse. It was a five-year study named Project Teens Linked to Care (TLC). Teens Linked to Care (TLC) is an HIV/AIDS preventive intervention targeting young people ranging in ages 13-24 years old living with HIV. The intervention focused on three major areas: reducing sexual and drug-related transmission risk behaviors, encouraging youth to participate in health care decisions, and youth learning how to live in the moment.

TLC is the first evidence-based intervention addressing transmission risk reduction among youth living with HIV/AIDS. Currently the intervention is being adapted by UCLA to determine if community agencies can adopt, implement, and sustain an evidence-based intervention in a service setting. The TLC consortium consisted of various service providers in each of the four cities where youth were recruited to participate in the study. The consortium served as an advisory group to the larger research project to ensure the research was implemented in a youth-appropriate manner.

The primary aims of the original study were 1) to evaluate the effectiveness of an intervention aimed at changing risk behaviors among youth living with HIV, 2) to describe the physical, social, and interpersonal contexts that shape these youth’s lives, and 3) to describe factors that may influence the impact of the intervention such as the youth’s exposure category and background characteristics, the site, and developing targeted skills and normative behaviors. The intervention was administered in three
Modules to 351 youth participating in the Teens Linked to Care (TLC) study. The youth were 13-24 years old and living with HIV. The modules addressed sexual and substance use transmission risk behaviors, engaging health and other service providers, and quality of life. A longitudinal quasi-experimental survey was conducted by the UCLA Neuropsychiatric Institute’s Center for Community Health and the Teens Linked to Care Consortium. The dataset of this study was used to explore factors related to youth delaying time of first doctor’s visit after being diagnosed with HIV. We conducted a cross-sectional analysis of demographic characteristics, and other variables related to social support, peer behaviors, and social networks.

B. Description of Original Study’s Database

The data from the original study were collected during a 21-month time period between 1994 and 1996 from nine agencies in four cities—Miami, New York City, San Francisco, and Lost Angeles. From three hundred youth screened at each of the four cities (1200 total), 347 were eligible for the study. In the original study, the participants were identified if they were HIV positive as a result of sexual and drug-related risk behaviors, between the ages of 13 and 24 years old, non-hemophiliac, and spoke either English or Spanish. The subjects had to have used drugs at least nine times over the past three months and were confirmed to be HIV positive, according to medical chart reviews. The participants for the study were recommended and recruited by agency staff among the four cities represented.
C. Sample Description/ Data Collection

Participants were primarily African-American and Latino, and were recruited from four cities: Los Angeles, New York, San Francisco, and Miami. The mean age of youth was 20.8 years; 253 of the participants were male, of which most were either gay or bisexual. One third were in school, most were employed (84%), and the mean length of time for an HIV positive diagnosis was more than two years prior to the participants entering into the study (mean of 2.1 years, Standard Deviation of 2.0; Median of 1.4 years). The majority did not show signs of HIV/AIDS, one-third did show symptoms of HIV infection, and very few were recruited into the original study with full-blown AIDS. The mean T-Cell count was 483.4 per deciliter (200 or below constitutes an AIDS diagnosis) (see Table 1).

Data were collected by a team of field interviewers, who were ethnically similar to the participants, using a computer-assisted survey program on laptop computers. The participants were compensated $25 for completing each assessment. Each participant completed a baseline survey that measured 26 different constructs including sexual and drug use risk behaviors.

All participants were fully consented for their participation in the study. If a minor youth indicated an interest in participating then parental/legal guardian consent was obtained. In instances where youth were unable to contact their parent to obtain consent then a legal adult guardian, typically a staff member, provided consent “in locos parentis.”
D. Description of the Data for this Study

1. Study Design

Secondary analysis of the baseline data from the previous study was conducted. The database consisted of 347 participants who met the original study’s eligibility criteria. Analyses were conducted on participants who completed the question “Were you seen by a doctor or a nurse or given an appointment with a doctor or a nurse after you tested HIV +?” Preliminary analysis showed that the youth were: mostly Latino (55%), lived on their own for 10 years or more (29%), lived with their parents for 10 years or more (23%) or recently reported living in a shelter for less than a year (4%). Among the sample, 37% of the youth reported receiving Medicaid, 64% received insurance through their current jobs with 44% reporting having a job within past three months.

2. Measures for the Study

The independent variables measured in the study were: age, gender, ethnicity, religion, education, employment, homelessness/marginally housed, service site, stage of illness, disclosure of HIV status, disclosure of sexual orientation, mental health characteristics, source of social support provided by network members, amount of social support regarding their illness, frequency of contact with social network members, and peer behaviors. The outcome variable of the study was time between HIV diagnosis and first doctor’s visit.

Measures were used to determine if the theoretical model was useful in explaining associations in this sample of youth. That is, the construct labeling was assessed by the question since being diagnosed HIV +, have you used condoms?; Commitment was
evaluated by the variable rating how comfortable asking provider questions; Enactment was assessed by the variable service seeking; Help-seeking was assessed by the item receiving assistance with shopping, personal care, or household chores; and the self-help was assessed by the item positive changes made since diagnosed.

3. Variables for This Study

The following variables were recoded into newly named variables: ethnicity, religion, family economic status, and time between HIV diagnosis and first doctor’s visit. After the new names for the variables were created, an analysis was conducted to determine whether there was an association among the background variables, social network members, the source of support provided to the youth (e.g. family, non-family, or service professionals), and the frequency of contact the youth has with their network member, the amount of support experienced through the network member, stage of illness, disclosure of sexual orientation, disclosure of HIV status, and the youth’s mental health characteristics such as depression and conduct problems and time between HIV diagnosis and first visit to the doctor.

4. Data Verification and Cleaning

Permission to use the Teens Linked to Care (TLC) dataset was obtained in writing from Dr. Mary Jane Rotheram-Borus, Principle Investigator and Director of the Center for Community Health. Data was extracted from the original database using the SPSS package, version 11.0. First, data were verified for accuracy and completeness. Then, frequencies and other basic descriptive statistics were generated for all variables to determine the distribution and to confirm statistical assumptions.
Continuous data such as age and time between HIV diagnosis and first doctor’s visit were verified for normality in distribution and the outliers were determined and corrected as needed. If there were some statistical assumptions that were not satisfied, data were transformed to make the data conform to underlying assumptions. When missing values had been identified, data were corrected to permit further analysis. Large numbers of missing values were recoded and analysis was conducted with a smaller sample size. Interpretations of the results were made with caution.

Categorical data such as gender, lifetime employment history, disclosure of sexual orientation and disclosure of HIV status, stage of illness, mental health characteristics, and conduct problems were verified for completeness. Response categories were recoded to be consistent with one another in terms of direction. For example if “1” represented a lower value in a likert scale and “5” represented a higher value for any given item, and for other items “5” represented a lower value and “1” represented a higher value, the response categories were recoded for consistency in direction.

5. Data Analysis of Variables

After data were verified and cleaned, the following procedures were performed: descriptive statistics were produced to examine the frequency for normalcy and to confirm completeness of the specific variables, among those with sufficient sample size and normal distributions, correlations to the dependent variable were produced. The dependent variable was slightly skewed, but the parametric tests are robust enough to address the distribution. There were three variables with multiple responses: housing, mental health and conduct problems, and social support networks. Descriptive analyses were produced for these variables. Next, factor analysis was conducted to
generate a summary score that would later be used in both regression models. Finally, based on these data, a final linear and logistic regression model was produced. The multivariate linear regression model was used, based on the continuous nature of the dependent variable, time of first doctor's visit and the logistic regression model was based on the dichotomous variable, did youth receive a referral for an appointment. A general plan for analysis on each variable is presented in Table 2.

6. Source of Social Support

Source of social support was measured by the question asking youth to report the relationship of each important person listed by youth. The response categories were nominal and were recoded into three groups: family members, peers and romantic partners, and service professionals. The code for the number of family members included (1) parents, (2) brother/sister, (3) grandparent, and (4) other family. The code for the number of peers included peers and romantic partners as well as (5) partner-boyfriend, girlfriend, lover, etc. and (6) friend and (7) acquaintance. Another code indicated a professional person who was considered of social support (8) professional. After creating a new variable representing a hierarchy of important people by relationship to the youth, a new variable was created to represent the relative closeness each person had to the youth by category. Then, the summary count function was used to determine for each case, how many network members were as follows: a parent, peer/romantic partner, or a service provider. A factor analysis was performed on the social support items to summarize the patterns of correlations among this set of items. The count of how many network members fit into any of the three categories was factor analyzed as well.
7. Frequency of Contact With Network Members

Frequency of contact was measured by how often do you see <most important person listed>?” and 7 “how often have you discussed your illness with <most important person listed>?.” Both variables were categorically discrete in nature and the direction of the categories was consistent. (1)= 1-3 times per week – (4) less than once a month.

8. Amount of Support Received

How supportive the important persons were in relationship to the youth’s HIV illness was measured using the question “how supportive is <most important person listed>? This variable was categorically discrete and ranged from (1) very supportive – (5) not supportive at all. The variable was recoded to make the direction consistent with other categorical discrete variables analyzed ranging from 1-5 in the dataset. Bivariate analysis was conducted with this variable to determine if there were any associations using the analyze drop down function then correlations and then means.

9. Social Network Size

The size of the social network was measured using the 10 most important person’s relationship listed. The question specifically asked to “please list the most important people in your life.” This variable was analyzed to determine the number of important people youth indicated and was treated as a continuous variable. Some youth responding to this question indicated up to ten persons. A variable code was created to take a summary count of how many network members each youth reported having. Three separate dichotomous variables were created to determine if youth had any family
members, peers/partners, or professionals within their networks. This variable helped describe not only the size of their networks, but also how many members by category.

10. Age

Age was a continuous variable abstracted from two sources in the original database: participant’s self-report of their age and self-report of their birth date. Only the year of the birth date was used to verify accuracy of the participant’s age. The variables were recoded for further analysis and frequencies were generated to determine and confirm the age distribution of the sample.

11. Gender

Gender was described by one dichotomous question asking what sex the youth were. This variable provides general background information. Because the dependent variable was continuous, bivariate analysis was produced using a student’s t-test. The following SPSS procedures were used to conduct the analysis: analyze-correlate for correlations, analyze-means for means and ANOVA’s.

12. Ethnicity

Ethnicity was described by the question” what ethnicity best describes your background” from the acculturation scale. The items were all categorical; item 1 described the youth’s background they most closely identified with. (1) None – (9) Do not know.

13. Housing

Because the youth in this database tested HIV + on average two years prior to participating in the baseline interview, only questions assessing “lifetime” housing experiences were used to ensure that realistic time frames of events related to the
independent variables. The question stated “the following questions are about all of the places you have ever lived during your lifetime, how long have you lived in each of the following situations?.” The time periods were 1=never, 2=less than one year, 3=1-5 years, 4=5-10 years, 5=more than 10 years, 8=n/a.

14. Education
One question asking youth to report the highest grade they completed was used to measure education. This was continuous in nature. This variable was not recoded for analyses nor was there any missing values recoded for analysis.

15. Employment
Lifetime employment history in the background scale was a dichotomous variable assessing if youth ever reported having a job in their lifetime.

16. Family Economic Status
An indicator of youth’s socio-economic status was their family’s economic status, since several youth reported living with at least one parent. The question asked, “Which of the following best describes the financial situation of your entire family?” The question came from the background scale and was categorical. A frequency was produced and analyzed for completeness. Upon review, the variable was then recoded collapsing categories most reflective of youth’s responses to the question together into one single category, “Very poor or poor” =1. This was compared against those indicating they were not “very poor or poor” = 2.

17. Religion
Two questions that are categorical were used for this variable. One variable described the youth’s perception of how spiritual they were and another
described their religious denominations. Frequencies were produced to determine the number of youth responding to each answer. Then, the scale measuring how spiritual or religious youth identified with was recoded to reflect those responses. Religion was not found to be statistically significant as a correlate to time for seeking healthcare.

18. Stage of Illness

Four questions were used to create a new variable called stage of illness. The first question measured the month, day, and year a youth was diagnosed with HIV. The second question measured whether the youth have had HIV related symptoms. The responses were categorical. The third question measured reported symptoms of AIDS. For questions two and three, the categorical response options were (1)= no, (2)= yes, (9)= don’t know. All “no” responses were recoded into Var1= 1. The variables were created using the compute dialogue box with the transform into a new variable commands. Similar procedures were conducted to create a variable for reflecting only HIV symptoms, and only AIDS to ultimately create three stages of the disease.

19. Disclosure of Sexual Orientation

Four questions measured disclosure of sexual orientation; three were continuous variables and two were categorically discrete. For the continuous variables the mean score was calculated. The categorical items were recoded into one variable as to whether or not the youth had disclosed sexual orientation to the parents. The categorical question asked youth do they consider themselves to be a) lesbian, b) bisexual, c) straight, d)other: specify. The other three questions are continuous and ask the number of
family, friends they disclosed to you and the number of people who learned of their orientation without them telling.

20. Disclosure of HIV Status

"Think about all of the sex partners you have had, since you found out you were HIV positive. How many sex partners have you told you are HIV+ since learning you are HIV+?" in the Romantic Relationship scale was a continuous variable. Descriptive statistics were produced to ensure a sufficient sample size responded to the question and the distribution was normal.

21. Mental Health Characteristics

A question from the General Medical History scale measured mental health. The first question was categorical and the responses were factor analyzed. The second question was related to number of times youth reported going into counseling and was continuous. One item, suicide threats, was used in the multivariate analysis.

22. Conduct Problems

The conduct problems questions came from the delinquency scale. Youth reported types of delinquent behaviors were listed within six months of completing the survey instrument had the most complete number of responses and were used. Descriptive analysis was conducted on the variable recoding to include “don’t know” responses. Data were reduced using factor analysis and later the regression scores were included in both linear and logistic regression models.

23. Time of First Doctor’s Visit

Because youth could respond to this question in either days or weeks, the outcome variable was continuous. A new variable converting the response into days was
created and reduced the number of missing values. The variable was recoded using the compute dialogue box. The equation was read \( \text{ht23new} = \text{ht23b} \times 7 \) if \( \text{ht23a} > 500 \), \( \text{ht23new} = \text{ht23a} \). While the distribution of the new variable is non-normal, the linear test statistics were sufficiently robust to manage the non-normality. Therefore, the results were not influenced by the slightly skewed distribution.

Multivariate regression analyses were performed using SPSS version 11.0. The primary outcome variable represented the number of youth who made a doctor’s visit after receiving a diagnosis by the number of days, was analyzed using the stepwise regression procedure in SPSS.

Based on the exploratory nature of this study, several variables were included in the model to determine the best predictors of the outcome variable. Those variables included in the model are: site (LA, SF, and Miami, with NY as the reference city), gender, age, religious affiliation, very religious, somewhat religious, employment history (lifetime), Latino, African-American, White, Other, had symptoms of HIV infection, been diagnosed with AIDS, and the number of sex partners told HIV + since diagnosed. Also included in the model were factors from the social network scale. Those factors were: delinquent peer behavior, prosocial peer behavior, peer network interaction, friendships: good group of friends, 1-2 good friends, many acquaintances, friendships: 1-2 good friends, few acquaintances, friends know each other: very well, friends know each other: have met, friends know each other: quite separate. Other social network factors in the model were: see friends: everyday, see friends: few times per week, see friends: weekly, see friends: few times per month, number in social network, number of
peer or romantic partners, number of family, number of professionals. Other variables in
the model were highest grade completed, and poor or very poor.

Finally, factors measuring conduct problems were included in the model: robbery-
burglary, arrested/in trouble with the law, suspended/expelled from school, told a lot of
lies, stolen from caregiver-abusive toward others, threatened to steal from others.

The linear regression model produced an output with 12 independent variables as
the best predictors of delay in seeking care. The criteria used for selecting the best
predictors was a $p<.20$ to enter a variable and $p>.25$ to exclude a variable. In the final
model, two variables were significant. Moreover, in the final model there were 274
participants who had a provider visit, of which 199 (73%) were included in the analysis
-Nine participants had missing values on the dependent variable and 22 participants had
missing values on one or more predictor variable.

The stepwise procedure in SPSS was also used to produce the logistic regression
analysis on the additional outcome variable, whether or not youth received an
appointment after testing for HIV. This generated a similar output, with a final model
with 11 independent variables that were the best predictors of whether a provider was
visited or not after diagnosis. For the final logistic regression model predicting whether a
referral to see a provider was given to youth, out of the total sample of 347 participants,
267 participants (77%) were included in the analysis while 22 participants had missing
values on one or more predictor variables.

E. Missing Data

Any missing data from the original dataset were included in the study's dataset
and recoded to reflect the current number of cases in the database. In the instance where
large numbers of missing values were represented in an item, interpretations of those findings were made with caution.

F. Ethical Considerations

This study is a secondary analysis of baseline data extracted from a prospective database collected from 1994-1996. Therefore, ethical concerns regarding the population are more focused on the appropriate handling of the data. All data has been “de-identified” and does not contain any identifying information at the individual level such as name or social security or medical chart numbers. The dataset was used for secondary statistical analysis only.

The original study obtained approval from the UCLA General Campus Institutional Review Board in 1994. Loma Linda University Institutional Review Board approved the retrieval and analysis of data for this study. The primary approval and any codicils to the approval continued to apply to the dataset.

G. Strengths and Limitations to the Study

This study has some limitations in terms of reliability and validity of the data.

1. Instrument Construct Bias

The assessment was based on questions from the original assessment therefore any challenges in how the questions were framed were reflected in the study’s assessment.

2. Ambiguity About the Causal Influence

Since this is a cross-sectional study and correlational in nature any conclusions made about the delay in time between the youth’s HIV diagnosis and their first doctor’s visit may have been influenced by a third variable and cannot be stated in
terms of a variable(s) causing the delay in time. Of the 1200 screened youth, only 347 were eligible to participate. The focus of this research was on the number of youth who responded to the questions

3. Self-Report Bias

The baseline assessment was delivered to respondents. The responses were limited to the truthfulness of the participant.
Table 1: Demographic Variables on Original Sample Size (N=347)

<table>
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<tr>
<th>Descriptors</th>
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<tbody>
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<td>14%</td>
</tr>
<tr>
<td>Age (mean)</td>
<td>347</td>
<td>20.8 years</td>
</tr>
<tr>
<td>Sexual orientation by gender:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gay or bisexual males</td>
<td>328</td>
<td>94.5%</td>
</tr>
<tr>
<td>Heterosexual females</td>
<td>297</td>
<td>85.6%</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>252</td>
<td>72.6%</td>
</tr>
<tr>
<td>Females</td>
<td>95</td>
<td>27.4%</td>
</tr>
<tr>
<td>Education</td>
<td>108</td>
<td>31% (in-school)</td>
</tr>
<tr>
<td>Employment</td>
<td>291</td>
<td>84%</td>
</tr>
<tr>
<td>Length of time since HIV diagnosis</td>
<td>347</td>
<td>2 years (Mean =2.1yrs; SD = 2.0; Median = 1.4 yrs.)</td>
</tr>
<tr>
<td>Stage of illness:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No symptoms</td>
<td>204</td>
<td>59%</td>
</tr>
<tr>
<td>Symptoms</td>
<td>108</td>
<td>31%</td>
</tr>
<tr>
<td>AIDS</td>
<td>31</td>
<td>9%</td>
</tr>
<tr>
<td>T-Cell count</td>
<td>347</td>
<td>483.4 /deciliter</td>
</tr>
</tbody>
</table>
Table 2: Variables and Statistical Procedures

**Research question #1:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between sources of social support and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sources of social support</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #2:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between frequency of contact with social network members and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of support provided by network member</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #3:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between amount of support related to their HIV illness from social network members and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amount of social support</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #4:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between size of social network and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Network size</td>
<td>Continuous</td>
<td>Pearson’s (r) Correlation</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>
Table 2: Variables and Statistical Procedures (continued)

**Research question #5:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between Age and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Continuous</td>
<td>Pearson’s r Correlation</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #6:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between gender and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Dichotomous</td>
<td>Independent samples t-test</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #7:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between ethnicity and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #7:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between homelessness or marginal housing and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>
### Table 2: Variables and Statistical Procedures (continued)

**Research question #8:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between education and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>Continuous</td>
<td>Pearson’s r Correlation (continuous)</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #9:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between religion and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religion</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #10:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between employment and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #11:** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between family economic situation and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family economic situation</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>
Research question #12: Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between mental health characteristics and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental health</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

Research question #13: Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between disclosure of HIV status and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclosure of HIV status</td>
<td>Continuous</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

Research question #14: Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between disclosure of sexual orientation and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disclosure of sexual orientation</td>
<td>Continuous</td>
<td>Pearson’s r (continuous)</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

Research question #15: Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between stage of HIV illness and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage of HIV illness</td>
<td>Dichotomous</td>
<td>Independent samples t-test</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>
Table 2: Variables and Statistical Procedures (continued)

Variables used in the Theoretical Model

**Research question #16 (Labeling):** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association between problems and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Used condoms since diagnosed HIV+</td>
<td>Dichotomous</td>
<td>t-test</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #17 (Commitment):** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association level of comfort in asking health care providers questions and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort in asking provider health care questions</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question #18 (Enactment):** Among youth diagnosed with HIV who were referred to a doctor or nurse for HIV care, is there an association between enactment through actually health care visits and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Missed health care appointments</td>
<td>Continuous</td>
<td>Pearson’s r Correlation</td>
<td>Time between HIV diagnosis and first doctor’s visit</td>
</tr>
</tbody>
</table>
### Table 2: Variables and Statistical Procedures (continued)

**Research question # 19 (Help-seeking):** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association receiving help from others and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received help from</td>
<td>Categorical.</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first</td>
</tr>
<tr>
<td>others</td>
<td></td>
<td></td>
<td>doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question # 20 (Self-help):** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association positive lifestyle changes with and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Made positive lifestyle changes</td>
<td>Dichotomous</td>
<td>Independent samples t-test</td>
<td>Time between HIV diagnosis and first</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>doctor’s visit</td>
</tr>
</tbody>
</table>

**Research question # 21 (Enacting solutions):** Among youth diagnosed with HIV, who were referred to a doctor or nurse for HIV care, is there an association getting the care you need and time of first doctor’s visit after HIV diagnosis?

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Variable type</th>
<th>Procedure</th>
<th>Dependent variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get health care when needed</td>
<td>Categorical</td>
<td>One-way ANOVA</td>
<td>Time between HIV diagnosis and first</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>doctor’s visit</td>
</tr>
</tbody>
</table>
CHAPTER 4

PUBLISHABLE PAPER

Factors Influencing Youth Living with HIV and Delay Seeking Medical Care

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November 2005

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Abstract

Objective: To explore factors related to youths’ delay in seeking care after an HIV diagnosis. Methods: Three hundred and forty-seven subjects were selected from a sample of 351 adolescents who participated in a 1994-1996 survey among youth in four U.S. metropolitan cities. Results: Key findings were that participants with prosocial peer behaviors took longer (34 days) and excessive fibbing influenced seeking care (23 days). Potentially important findings suggest being female, older, having close peer networks, conduct problems, and certain housing settings may influence care seeking behaviors. Conclusions: Multivariate regression analyses identified prosocial peer behaviors and excessive fibbing as significant predictors of why youth delayed seeking care.

Key words: youth living with HIV; delay in seeking medical care; social support networks; service seeking behaviors.
INTRODUCTION

Delayed time between HIV diagnosis and receiving care is a serious, but apparently common, health risk. These delays may not only create an opportunity for more serious illnesses to develop, but also create undue economic hardship on an already fragile national healthcare system. Those who delay health care for HIV diagnosis are commonly uninsured and very ill, creating a burden on facilities where they are treated. Some studies suggest that nearly 40% of adults delayed access to primary care for more than a year after learning their HIV status and nearly 20% delayed accessing care for more than five years.

The majority of studies exploring factors associated with delays in seeking health services are focused on adults living with HIV. Even at that, little research is available to shed light on this issue. There is also very little research on the role social support networks play in delayed time to accessing HIV services and there has been little research looking at delayed linkage into care. Moreover, there is no research exploring the relationship between service providers’ support and youth living with HIV initiating health services in a timely manner.

Factors associated with delayed time to seek care among people living with HIV are: having a history of injection drug use, not having a parent or a significant other in their lives, receiving diagnosis by mail or phone, and ethnicity. Reports documenting youth returning for follow-up HIV services are inconclusive at best, underscoring the importance of understanding the issue of accessing service. Further, other studies
suggest that social support systems can decrease the delayed time to seek care. In a study similar to this research, mothers living with HIV who delayed seeking primary care were found to have low social support from their peers and family members. In fact, support was most commonly reported to come from minor children in the home. This suggests that other children in the home experienced undue parental or adult responsibilities placed on them as a result of the stress the mother's illness created. 8

Factors Related to Delayed Time

Factors associated with service seeking behaviors have been documented among various groups. It has been observed that gay men living with HIV who had been diagnosed at varying stages of their illness sought help from different sources. 8 Men living with AIDS sought help from professional care providers and family members more so than men living with HIV or who were not living with HIV. Men not living with AIDS or who were unaware of their HIV status, sought help from their peers more often than those living with AIDS.

Social network analysis is one form of research that may help explain differences in how different populations access services. Social support networks oftentimes provide necessary services to their network members. At least one study 9 suggested that the role of social networks and the support provided through the networks could ameliorate service burdens placed on health care providers. 9

The interplay between social support networks and their role as either a facilitator or a barrier to service seeking behaviors among their network members is important in the context of more immediate improvements to the delivery of care.
Negative Effects of Social Networks on Health Behaviors

Although current literature documents the benefits of friendship and familial networks on a person’s mental and physical health status, there is evidence that social networks can also have a negative influence on health behaviors. It has been found when examining adolescent health behaviors among secondary school youth (N=527) that there is a social learning effect among some youth and their close peers. There were positive associations between suicidal ideations, violent behaviors, and substance use of students and their peers. There was, however, a negative association between youth with suicidal ideations, violent behaviors, and substance use and their peers displaying pro-social behaviors. Further, the data suggested that the degree of impact each of these negative behaviors had on the youth was influenced by family dysfunction, perceived acceptance by their peers, and whether or not they experienced depression.

One study compared both positive and negative effects of social support on emotional health. Other studies on negative experiences also suggested that the impact is more extensive than any study demonstrating a positive effect on emotional health. Other data have established that social networks may act as negative influences on their network members. For example, Neaigus used social network analysis to explain HIV transmission risk among injection drug users. A social learning effect demonstrating that network members initiated injection drug use based upon their personal networks has been documented in the findings. Studies addressing youth document a negative social learning effect. It has been found that social networks of young injection drug users may model some prosocial skills, such as cleaning needles, they also may increase HIV transmission risk for young women who tended to be more embedded in social network
and therefore injected more or had more sexual contacts.\textsuperscript{15} The mechanism consistent in both positive and negative social network influences is that social support involving specific behaviors such as sharing syringes among injection drug users (IDU), injecting heroin, cocaine, and speedball, injecting in locations commonly associated with drug users (e.g. "shooting galleries"), crack use and social roles like selling syringes on the street to other IDU’S is crucial.

**Social Support Networks Influence on Health Behaviors**

The association between social support derived from social networks and the subsequent use of mental and physical health services has also been documented in community level studies, among disenfranchised subgroups of youth.\textsuperscript{16, 17} Social support can be manifested in varying ways among different groups of people. Among injection drug users those with large social networks provided social support, but sharing needles was also more common. Within the network, needle sharing has a positive value associated with it and is seen as offensive not to participate. However, injection drug users in networks that did not provide social support were more likely to inject in shooting galleries (large gathering places for injecting drugs).\textsuperscript{18}

Youth represent the majority of new HIV infections worldwide and the paucity of information regarding youth living with HIV accessing care after learning their HIV status emphasizes the importance of this study. Moreover, the literature primarily reports outcomes on the adult populations, who have different HIV transmission risk patterns than youth. This was an exploratory study with the primary focus of identifying factors that best predict youth delay seeking care. To this end, this study considered background
factors such as age, gender, and religious affiliation, along with social support network characteristics, and stages of HIV illness as potential predictors to delay in seeking care.

**PURPOSE**

The purpose of the study was to explore predictors of youth delay seeking care after being diagnosed with HIV. Only the baseline data were used for the analysis. Of particular interest, was the relationship among social networks, background variables such as age, education, employment history, mental health, conduct problems, stage of HIV illness, and housing situations to the time between diagnosis and the youth’s first visit.

**METHODS**

**Study Design**

Data for this study were extracted from a database of youth living with HIV. The data were collected over a 21-month period from 1994-1996 in four geographical regions of the United States. Three hundred (300) youth were identified and screened at each of the four city sites (1200 total) from which 347 were deemed eligible for the study. Youth were identified and recruited by agency staff. Obtaining copies of youth’s ELISA test results verified self-reported HIV status. Of 1200 screened youth, 347 were eligible to participate. These were the subjects whose answer to the secondary research question of “who received an appointment” made them eligible for the study. Youth responding to the item asking how many days or weeks did they wait before seeing a doctor or nurse were included in the linear regression analyses (n=338). Survey questions addressed background information including age, gender, ethnicity, employment, housing, mental health and conduct problems, social network information, social support information,
disclosure of HIV status and disclosure of sexual orientation. This study used a cross-sectional design. Secondary analyses were conducted the baseline dataset that contained a sample of youth 13-24 years (n=347). The youth in this study represent four study sites. The sites were: Miami (n=47), New York (n=133), San Francisco (n=100), and Los Angeles (n=67).

Sample

Inclusion criteria for this study were all youth who responded to the item measuring whether or not they answered if they were seen by a doctor or nurse after they tested positive for HIV were included in the descriptive analyses. Among those youth, participants who completed the item asking “how long did they take to visit the doctor or nurse after receiving a diagnosis?” were included in the multivariate analyses. In the sample, there were more males (72.3%) than females (27.7%). Most youth identified as somewhat spiritual or religious (51.6%) and reported their religious affiliation as Catholic (31.2%), Protestant (19.2%), Other (13.2%) and Jewish (13.3%). While most youth were Latino (36.2%), the majority was born in the U.S. (68.6%). Just about half of the youth reported completing beyond the 10th grade (43.4%) and had work experience (84.7%). Family poverty was reported among 66.0% and nearly a third (34%) reported their families to be very poor.

Criterion Measure. The criterion variable was time from HIV diagnosis and first doctor’s visit.

Predictor Measures. The predictor variables hypothesized to correlate with the outcome variable were measured using dichotomous and continuous items, and regression scores were produced by various factor analyses.
Dichotomous Variables

The dichotomous variables were: gender (male = 1, female = 2), lifetime employment history, family economic status (poor or very poor), and recruitment sites. The recruitment sites were simplified from a seven-category item to either a clinical or non-clinical setting. Finally, stage of HIV illness was the result of two variables: 1) “have you had symptoms of HIV infection” and 2) “have you been diagnosed with AIDS.”

Originally, there were three response categories, namely “yes,” “no,” and “don’t know.” Respondents indicating “don’t know” were included in the “no” responses to ensure completeness of data. Then, descriptive analysis was produced to examine the variable’s distribution and determine if the sample size was sufficient for further analyses.

Categorical Variables

Ethnicity was recoded from nine categories to four—Latino, African-American, white, or other. Religious affiliation was recoded from nine categories to the following five groups: None, Protestant, Catholic, Jewish, Other.

Continuous Variables

The continuous items were age, number of partners who were told about the subject’s HIV status, number of family and friends to whom respondents disclosed sexual orientation, level of education completed the number of family members in the social network. Other continuous variables were the number of peers or romantic partners in the network and the number of health service providers considered to be in the social network.

Since there were a number of items measuring youth’s social networks (e.g. how often have you discussed you illness with <most important person listed>); how often do
you see your friends: 1) every day, 2) a few times a week, 3) once a week, 4) less than once a month), general mental health (lifetime) (at anytime in your life have you seen a psychiatrist, psychologist, or social worker for any of the following reasons: a)school-academic, school-behavior, home-behavior, aggression/conduct problems, hyperactivity, phobias, anxiety, depression, suicide threat/attempt, drugs/alcohol abuse, other) and how many times have you gone into counseling?; housing (lifetime) (during your lifetime how long have you lived in the following situations? 0=none, 1=less than 1 year, 2= 1-5 years, 3=5-10 years, More than 10 years); and conduct problems within the past 6 months, and it was necessary to perform factor analyses to determine the variables that were most predictive of each of the aforementioned constructs. As a result, social networks scores from the results of these factor analyses were used as predictors in the regression analyses.

Data Analysis Procedures

Data were analyzed using the Statistical Package for the Social Sciences (SPSS), Windows software, version 11.0. Frequencies and percentages were produced on all the variables proposed to influence the length of time it took youth to initiate medical care after receiving an HIV positive diagnosis. A linear regression model was used to predict factors related to youth delay seeking care after diagnosis. The sample size used in the linear regression model was n= 199 (72.6% of the N=274); this was based on the completeness of the responses.

Factor analyses were performed to appropriately reduce the number of variables associated with key factors used in the study. Variables measuring social network, housing, mental health, and conduct problems were reduced using this method and their
scores were included in the regression model (see table 1). Regression analyses were also performed to determine the predictors of youth delay seeking care. The analyses used the stepwise regression procedure in SPSS version 11.0 to find the best predictors of whether an appointment was made following HIV diagnosis, and, if so, how long it took for a participant to visit a provider. The stepwise regression procedure omitted the variables that were not good predictors of youth delay seeking care and retained those variables that were the best predictors.

RESULTS

Descriptive analysis on the youth in this research showed that the majority were non-white with the Latino youth making up the largest proportion (37.2%), Black youth the second largest proportion (26.5%), and white youth making up the third largest group (18.4%); mean age = 20.78 years old, with 24.8% reporting to be 23 years old; had a 12th grade education (20.2%); and were mostly male (72.3%). (see table 2).

Of interest was the size and type of the youth’s social networks, as previous research had shown a relationship between the nature of the social network and HIV status. In general, youth maintained moderate to small networks and had regular contact with them. A majority of the youth (81.2%) reported having family in their networks; 76.1% reported having peers/romantic partners in their networks; and 2.9% reported having service providers in their networks. Among those reporting to have family in their social network, 21% reported having at least one person and 11% reported six people in their network. When analyzing how many providers were reported to be in the networks, 8.9% indicated they had at least one provider in their network. The mean number of
network members was 4.52 persons; mean family members = 2.53; mean /romantic partners = 1.80 peers; mean number of service providers = 0.19.

The linear regression revealed unexpected results regarding the effect of the social network (see Table 3). Demonstrating prosocial peer behaviors and excessive fibbing in the past six months both predicted delay seeking medical care. While not significant, there was a p-value trend suggesting that there is potential importance in the fact that female participants took longer to make their first visit than males, the older the youth the more likely they were to delay seeking care, having friends who knew one another well, those self-reporting to come from a poor family, living in alternative housing situations. Those participants who engaged in more prosocial peer behaviors took longer to visit a provider. It seems that the exact type of network is very important in its influence on the behavior of the youth with peer influence being very strong, especially in the absence of other types of persons available for social support. If the peer influence is negative, the impact on the individual detrimental to seeking health assistance.

Prosocial peer behaviors and excessive fibbing in the past six months predict delay in seeking care. Females, in general took 35 days longer to visit a provider than males, a surprising finding. It is unknown why females were more reluctant to seek medical care after their diagnosis. Perhaps the delay is because of the negative stereotypes related to the disease or other responsibilities demanding their attention and time. Also of interest is age; for each year of additional age, it took participants 8.5 days longer to visit a provider, and participants from a poor or very poor family took 35 days longer to visit a provider than those who did not identify their family as poor. The age factor in time to see a physician is perplexing. It is possible that older youth had more
life responsibilities and did not prioritize health care appointments as highly as other responsibilities.

Of particular interest is the link between excessive stealing in the past 6 months and a shorter time to see a doctor (ns, p-value trend). Perhaps this is related to impulse control in general or larger mental health or substance abuse issues not detected by this study’s instrument. However, it is possible that these youth are already in some type of service system or justice system were medical services are more readily available to them as compared to youth who do not steal.

**DISCUSSION AND CONCLUSION**

The final model excluded a number of variables that were insignificant. Among those not significant in predicting the outcome, was ethnicity. Literature suggests that White youth have better access to services as compared with minority youth (Elster et al., 2003)^20^.

The data did not support this information. Ethnicity may not have been a predictor of delay in seeking care due to the affect economic status has on access to services. Nearly two-thirds of the sample reported that their families were either poor or very poor; therefore, experiences, attitudes and beliefs about the quality of care lower income people may receive or assumptions about the medical costs associated with HIV treatment could have prevented youth from entering into care more quickly.

Additionally, based on common knowledge, we expected that having symptoms of HIV infection or AIDS would predict youth entering into care sooner than those not reporting either of these conditions. However, neither of these conditions predicted the outcome. This may have been related to ability to the youth’s access to services. The
instrument did not allow for respondents to indicate whether or not they had medical insurance at the time of diagnosis. Therefore it is not clear, but possible that youth ignored their symptoms due to inadequate health insurance.

Finally, we expected that youth engaging in prosocial peer behaviors would be a group whose positive attributes could be generalized across domains; therefore, these youth would enter into care sooner as compared to those who did not possess these attributes. This expectation was not met by the data. This effect could be a result of the peers' attributes the youth were interacting with being negative and more influential on behaviors than their own personal behaviors.

Suicide threats was a single item from the Mental Health scale (alpha=0.691) most appropriate for the regression model. Factor analyses on housing showed that six factors loaded: living with a stable family member, living with extended family; living with independently or with a partner; living with children, and living with parents, or living in other situations (alpha=0.843). Factor analysis on conduct problems reported in the past six months showed six themes: robbery-burglary, arrested-trouble with the law, suspended/expelled from school, told a lot of lies, stolen from caregiver-abusive toward others, threatened to steal from others (alpha=0.799) (see table 3). Factor analyses on social support networks showed eight themes: delinquent peer behaviors; prosocial peer behaviors; supportive characteristics; positive parental relationships; peer group interaction; sexually promiscuous peers; and peers support one another (alpha=0.947).

The results from the full regression model suggest that youth living with HIV most likely to delay receiving necessary medical treatment are youth who were engaged in more prosocial peer behaviors and who exhibited delinquent behaviors such as
excessive fibbing. While excessive fibbing may not have an obvious relationship to youth delay seeking care, it may be an indicator of larger mental and emotional health issues not observed in this study's data. These youth would most likely require additional services that are responsive to a client's access to spiritual support, economic situation, and related to this, their ability to obtain and maintain stable housing and a regular health care provider. Other research has also found that a low income is positively correlated with HIV status. Being poor and uninsured is connected with lack of medical care for those with AIDS. Consistent with other findings in this study and in other studies there is a relationship between ethnicity and HIV status. The ethnicity breakdown is similar to that found in the previous research, especially that of Montgomery and Turner.

The data suggests that youth living with HIV are more likely to avoid seeking care if they have negative peer influences around them and do not have steady linkages to medical care. Other research has shown the importance of the social network and whether the network is a positive or negative influence. Relationships are powerful in shaping the behavior of an individual, including those with AIDS. This research corroborated similar work showing that later entry into medical care was observed among males, those with lower incomes, people with no health insurance, those with little education, and persons referred from prison. This study found that the older the male youth, the longer taken to seek care. A difference was that females delayed seeking care by 34 days as compared to males, (p<.05).

There are several limitations to this study. The data are self-reported by youth and therefore may not be completely reliable. Therefore, future studies should utilize multiple methods of data collection and a more objective assessment of the factors may
influence youth delay seeking care. Additionally, because a cross-sectional study design does not allow for a statement of causality to be made about the dependent variable researchers may want to design studies that are not limited to a single time point. Finally, a limitation to this study is the nature of archival data not allowing for important questions related to the main purpose of the research for example, medical insurance at time of diagnosis. Also the dataset of TLC was several years old, and conditions do change in the AIDS community over time.

This study focused on identifying factors predicting youth delay seeking care after an HIV diagnosis. Timely information was revealed in this study that can inform future research using a more rigorous design. Nevertheless, given the seriousness of the illness and continued absence of a cure, evidence-based interventions addressing inadequate linkage between HIV identification and access to services that target the most vulnerable populations are urgently needed in public health.
Acknowledgments

I would like to acknowledge the Principal Investigator of the original study, Dr. Mary Jane Rotheram-Borus for granting permission to use the TLC database for this study. Her support and encouragement to complete this study has been priceless. I also would like to acknowledge Mr. Philip Batterham for providing consultation related to the dataset and codebook.
Table 1: Summary of Factors and Related Alphas

<table>
<thead>
<tr>
<th>Scale</th>
<th>Cronbach's alpha</th>
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<tr>
<td>Mental health scale</td>
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</tr>
<tr>
<td>Social support network scale</td>
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<tr>
<td>Housing situation scale</td>
<td>0.843</td>
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<td>Conduct problems scale</td>
<td>0.799</td>
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Table 2: Sample Characteristics (N=347)

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>N</th>
<th>%</th>
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</thead>
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<tr>
<td>Ethnicity:</td>
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<tr>
<td>Latino</td>
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<tr>
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<td>White</td>
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<tr>
<td>Education:</td>
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<tr>
<td>Completed 12^{th} grade</td>
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<td>Gender:</td>
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<tr>
<td>Female</td>
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<td>Poor or very poor family economic situation</td>
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<tr>
<td>Service organization characteristics:</td>
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</tr>
<tr>
<td>Type of agency recruited youth: clinical</td>
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<td>86.2</td>
</tr>
<tr>
<td>Type of agency recruited youth: non-clinical</td>
<td>39</td>
<td>13.8</td>
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</table>
Table 3: Linear Regression Model (N=199)

<table>
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<tr>
<th>Independent variable</th>
<th>B</th>
<th>Significance level (p&lt;.05)</th>
</tr>
</thead>
<tbody>
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<td>Gender</td>
<td>35.0294</td>
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<td>Age</td>
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<td>Delinquent peer behaviors</td>
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</tr>
<tr>
<td>Prosocial peer behaviors</td>
<td>26.752</td>
<td>0.020*</td>
</tr>
<tr>
<td>Friends know each other very well</td>
<td>43.829</td>
<td>0.076</td>
</tr>
<tr>
<td>Friends have met each other</td>
<td>30.390</td>
<td>0.247</td>
</tr>
<tr>
<td>Number of professional in social network</td>
<td>-9.200</td>
<td>0.457</td>
</tr>
<tr>
<td>Family is poor or very poor</td>
<td>34.835</td>
<td>0.075</td>
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<tr>
<td>Involved in robbery-burglary in past 6 months</td>
<td>21.432</td>
<td>0.057</td>
</tr>
<tr>
<td>Excessive fibbing in past 6 months</td>
<td>22.700</td>
<td>0.048*</td>
</tr>
<tr>
<td>Every seen a psychologist-for suicide threat</td>
<td>11.559</td>
<td>0.553</td>
</tr>
<tr>
<td>Living in other situation</td>
<td>14.077</td>
<td>0.077</td>
</tr>
</tbody>
</table>

Note: (Outcome = number of days to see a provider after diagnosed HIV +)

* p<.05
References


CHAPTER 5

OTHER FINDINGS

A. Introduction

This chapter contains study findings that were not previously discussed in Chapter 4. Factors associated with service-seeking behaviors in young HIV positive persons, factors related to receiving a referral, the AIDS Risk Reduction Model as a framework for explaining delay in seeking care, and other results.

B. Factors Associated With Service Seeking Behaviors

While most young people living with HIV access medical care through a variety of medical settings, many do not receive the necessary care until physical symptoms manifest themselves and illness has progressed significantly. Consequently, the youth did not use health services very often, demonstrated very little intention to seek care, and were at high risk for health problems. This disparity was detected among students who were younger and male. It seems that there is a feeling of invincibility among the younger gay males, and this creates a problem for more exposure to AIDS when they partner with older males who have been exposed to the disease for a longer period of time.

C. Factors Related to Receiving a Referral

A logistic regression analysis was conducted to determine the factors relating to whether or not youth were referred into care after diagnosed HIV positive. Using SAS 8.0, the regression model was created using the all subsets selection. All predictors entered in the linear regression model were used to predict receiving a referral. The model demonstrated that females, lifetime employment, having stronger social support attributes, having a good group of friends, having 1-2 good friends, but many
acquaintances, 1-2 good friends, but a few acquaintances and lower levels of education each predicted receiving a referral for care. Participants demonstrating stronger social support attributes were more likely to receive an appointment as compared to those not demonstrating strong attributes (p<.01).

Older youth were less likely to receive a referral by 3.3% (p<.05).

Social networks were an important predictor of receiving a referral.

While the results were not significant, they were interesting Delinquent peer behaviors did not predict receiving a referral, but youth demonstrating these characteristics were more likely to receive a referral than youth without delinquent peer behaviors. It is possible that youth with delinquent peer behaviors had more contact with other service systems and received medical care through alternative sources. Moreover, we expected the finding to be significant and youth with network members demonstrating these behaviors would be at a higher risk for a number of social problems, thus putting them in contact with other providers and ultimately linking them to care.

Additionally, we expected that youth with a group of good friends were 50% more likely to get an appointment than those who were not close to anyone to be significant, but it was not. We speculated that this association maybe related to the positive support trusted friends provide and were surprised that it was not significant.

Some of the descriptive statistics on the background and moderating variables used to predict whether youth initiated seeking care or not, were as follows: mean number of days between the baseline survey and being diagnosed with HIV = 815.17 days; mean age = 20.8 years old; having a romantic partner in their social network (X² = 14.53, p<.000), 1-2 good friends with several acquaintances (X² = 7.631, p<.006) or a
few acquaintances ($X^2 = 9.012, p<.003$). Among those seeking care, 83.43% were tested for HIV in a non-clinical setting as compared to 75% tested in a clinical setting.

When asked how religious or spiritual they considered themselves, 80% did not consider themselves to be very spiritual. However, among those reporting their religious affiliation, and that they initiated care, Catholic (31.2%), Protestant (19.2%), Other (13.2%) and Jewish (13.3%). Other religions were not listed, except as a general category of “Other.” Further bivariate analyses performed indicated that the time between HIV diagnosis and the baseline interview were strongly associated with delays in care. This may be reflective of a reporting bias in those that had been HIV positive for a longer period of time. Alternatively, it may have been a time-dependent trend, suggesting that youth more recently diagnosed were more likely to receive care in a timely manner. Future research may show whether there has been a real improvement in channeling youth into appropriate care following HIV diagnosis.

A similar secondary analysis indicated that increased time with the current health care provider was strongly associated with a decreased delay in care seeking, suggesting that consistency in the care setting is important for reducing the time it takes to initiate care. There were problems with measuring the time with the health care provider, as the questions were asked at baseline rather than in reference to the time of HIV diagnosis. Nevertheless, there appears to be some association between the consistency of care prior to diagnosis and initiation of care. Additional research will be necessary to more clearly delineate which aspects of the client-patient dynamic are conducive to improved, timelier care.
D. AIDS Risk Reduction Model as a Framework for Delay in Seeking Care

Bivariate correlations were performed on the major components of the AIDS Risk Reduction Model to determine if it is useful in explaining factors related to youths' delay in seeking care for HIV. The association between youth who reported using condoms since learning they were HIV + and the number of medical appointments missed was not significant (r= -.060, NS). However, statistically significant associations were observed between youth who were more comfortable asking questions and missing fewer appointments. Likewise, as to be expected, youth who were not comfortable asking their provider questions, did not receive the health care they wanted (r= .272, p<.001). Youth who were somewhat comfortable asking questions received the care they wanted (r= .160, p< .01) However, youth who were less comfortable asking their provider questions, reported making fewer healthy lifestyle changes (r= -.108, p<.05). Respondents were asked to state how many times they received assistance with their household chores in the past three months, and there was an inverse relationship between youth who hardly ever received help and not receiving the health care they wanted (r= -.135, p<.05)

While not significant, youth with a history of employment were 81% more likely to receive an appointment than those without a history. It is possible that history of employment is related to health insurance at time of referral and therefore, increases the likelihood of youth seeking care.

Paradoxically, while the results were not significant, those who had symptoms of HIV infection were 16 percent less likely to get an appointment than those who did not have symptoms. Also participants with more delinquent peer behaviors were more likely to get an appointment. Delinquency was indicated by a robbery or burglary during the
past six months. It is not known why more delinquent behavior was correlated with getting an appointment. The finding of the non-health-seeking behavior of those with HIV infection corroborates the research of Schietinger (2001) and Samet and others (2001). Samet terms these patients “long-term non-presenters,” some of whom did not seek primary care for as long as 8.1 years or more. Some were aware of their infection and some were not. Samet’s work discovered psycho-social ties to the delay in seeking treatment, as did this research.

E. Gender

Gender was a significant predictor of receiving a referral. However, we expected that females would be more likely to receive a referral than males. The literature suggests that male youth are oftentimes unaware of health services and do not utilize them very often. Youth who are female were nearly three times as likely as males to receive a referral for an appointment (p < .05).

F. Social Network

In the realm of the effects of the social network, the type of network and the number of persons considered a part of the network are important factors. Those with stronger social support attributes were more likely to get an appointment (p < .01), and while it was not significant, those with a group of good friends were 50 percent more likely to get an appointment than those who were not close to anyone. Those with one or two good friends and many acquaintances were over five times more likely to get an appointment than those who were not close to anyone (p < .001), and those with one or two good friends and only a few acquaintances showed about the same likelihood of getting an appointment (p < .007).
It seemed, therefore, that the number of acquaintances was not important in determining whether or not a youth with AIDS sought a medical appointment. This study substantiates the findings of Hays, Chauncey, and Tobey (1990), who reported that an individual’s social network plays an important role in coping, adaptation, and recovery from illness. It seems that professional support is very important, but the fact that the relationships are not reciprocal makes them somewhat less effective than the support of friends and family (Hays, Chauncey, & Tobey, 1990).

The research gleaned some information about the frequency of contact with the social network, and it seemed that the size of the network was not as important as the closeness of some of the contacts, even if there were few.

G. Education

Surprisingly, for every year of education completed, the odds of a participant visiting a provider decreased by 3.3 percent. This finding is most unusual, as the opposite correlation was expected. For every year of education completed the chances of getting an appointment decreased by 3.3%. For Public Health Educators, service planning and linkage to care and treatment will be hinged upon educating medical providers and paraprofessionals providing post-test counseling on the dangers of assuming patients will initiate treatment based on their education status, gender, or their peer networks.

H. Ethnicity

Ethnicity seems to be a recurring factor in the behavior of youth with AIDS, including delays in seeking medical help. Delay in treatment was greater for Latinos, and, to a lesser extent, African Americans as compared with whites. It is possible that lack of
insurance or language skill could be a part of the difficulty. Although medical facilities often have someone to translator for staff available, conducting one’s medical business through an interpreter could be a daunting procedure and one that a person of non-white ethnicity would simply want to avoid. Ethnicity possibly indirectly correlates with economic circumstances, one of the correlates to time in seeking care.

I. Homelessness

The fact of homelessness creates challenges for youth who need medical care. A phone may not be available for verifying appointments and the lifestyle does not lend itself to remembering and keeping appointments.

J. Low Income

In general, poverty was found to be inhibiting in seeking a medical appointment following HIV positive diagnosis, both the youth’s personal low income and the family’s economic situation. Again, as with ethnicity, lack of insurance and difficulties with transportation could make it difficult to get medical assistance.

K. Mental Health

The study did not glean complex information regarding mental health and its relationship with receiving a referral after HIV diagnosis, only the presence or absence of depression, not the degree of mental health difficulty. After conducting the factor analysis for the mental health variable, the themes emerging from the scores were: depression, and school behaviors. Hays and others found in a longitudinal study of gay men that there were high levels of anxiety present (Hays et al., 1990), but the study using the TLC dataset did not factor out anxiety as a discrete mental health characteristic. Also it was not possible to interpret data in terms of an association between disclosure of HIV
status and the time of the first doctor’s visit after HIV diagnosis. In like manner, there was little useful information regarding the association between disclosure of sexual orientation and the time of the first doctor’s visit after HIV diagnosis. In contrast, the stage of HIV illness does seem to have an effect on the visit to the physician, as those in later stages of the disease, showing identifiable symptoms, are more likely to seek help.

L. Conclusions

This study did not provide any new information on the various types of sexual networks, such as those discussed by Morris (1995) nor the important factor of age of the sexual partner. The age of the partner is very important because of the likelihood of a greater number of years of exposure to AIDS. Older men who partner with younger men increase the likelihood of the younger men contracting the disease, creating what Morris terms “the leading edge of the epidemic in their cohort” (Morris, Zavisca & Dean, 1995). Morris et al. states that younger men are getting infected at a rate of about double that of older men, facing a 50 percent chance of infection after 25 years of sexual activity (Morris, Zavisca & Dean, 1995). This specific factor, the age of the partner, deserves more research in connection with younger persons, especially those who are involved in sex for money behavior, as well as more enduring relationships.

The factor analyses for the four variables were conducted on youth (N=347). Factor analyses on mental health showed that three factors loaded—depression, and school behaviors (alpha=0.691). Factor analyses on housing showed that four factors loaded: living with a romantic partner, living with both parents; living with any family; and living in temporary housing (alpha=0.843). Factor analysis on conduct problems reported in the past six months showed six themes: robbery-burglary, arrested-trouble
with the law, suspended/expelled from school, told a lot of lies, stolen from caregiver-abusive toward others, threatened to steal from others (alpha=0.799) (see table 4). Factor analyses on social support networks showed eight themes: delinquent peer behaviors; pro-social peer behaviors; supportive characteristics; positive parental relationships; peer group interaction; sexually promiscuous peers; and peers support one another (alpha=0.947).

The logistic regression model included the factor analysis regression scores for social networks and background variables including: age, gender, sexual orientation, attending religious services; testing in either a medical or non-medical setting; family economic situation; having a provider for one year or longer, and a summary count of family, peer, romantic partner and providers in the youth’s network. The results from the full model suggest that seeking medical care is predicted gender, having HIV symptoms, education level, and living with extended family members. Females were 2.8 times more likely to receive a referral for care after diagnosis than males, youth with HIV symptoms were 41% less likely to receive a referral than youth without symptoms, for every year of education completed, 4.3 times less likely to receive a referral than those with less education, and youth living with extended family members as compared with those not living with extended family.
Table 1
Logistic Regression Model: Got Appointment with Provider after HIV Test: Yes/No
(n=267)

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>B</th>
<th>Significance level</th>
<th>Odds ratio</th>
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<tr>
<td>Gender</td>
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<td>Ever had a job</td>
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<tr>
<td>Had HIV symptoms</td>
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<td>Social support</td>
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<td>1 or 2 good friends, many acquaintances</td>
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<td>Ever seen psychologist for suicide threats</td>
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<tr>
<td>Living with extended family members</td>
<td>0.369</td>
<td>0.043*</td>
<td>1.446</td>
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</table>

*p<.05
CHAPTER 6
CONCLUSIONS

This study investigated the factors related to delayed time to consult with a health care provider following HIV diagnosis and delays in initiating care among youth living with HIV. The finding that many youth living with HIV delay consulting a provider following diagnosis, or never seek an appointment at all, is similar to that shown in previous studies of adults seeking care following diagnosis (Schietinger, 2001). Such delays in initiating care at the time of diagnosis are likely to lead to poorer health outcomes (Schietinger, 2001; Turner et al., 2000; Samet, Freedberg, Stein et al., 1998), particularly in populations that can least afford the associated decline in health due to HIV infection and associated serious illness.

Investigating the antecedents of care seeking behaviors was accomplished by examining the relationship between care seeking behavior and a wide range of measures of social network and relationships, demographics, sexual behavior, substance use, educational background, sources of care, religion, mental health and physical health. In analyzing the data, both univariate and multivariate techniques were used to examine these relationships.

Past research among adult and youth seropositive populations has found that a history of injection drug use leads to delays in initiating care (Hein et al., 1995; Samet, Freedberg et al., 1998; Samet, Freedberg, Savetsky et al., 2001). This finding could not be confirmed by this study. It is possible that the sample may not have been appropriate for investigating this particular relationship. Since very few of the youth interviewed
were injection drug users, there may have been insufficient power to find a relationship between injection drug use and initiation of health care.

Two other factors previously implicated in delay seeking health care following diagnosis were: not having a significant other (Schietinger, 2001), and race/ethnicity (Turner et al., 2000). These relationships were also investigated in the present study and could not be reproduced, although there were slight tendencies. However, this outcome could also have been an artifact of the way these questions were asked of the participants. The existence of a significant other was not asked directly but inferred from the social network scale. The social network scale was asked at time of the baseline, rather than in reference to the time of HIV diagnosis. It could be that those who had a significant other at baseline had either no significant other at the time of diagnosis or a different significant other. Likewise, those who had no significant other at baseline may have had one at the time of diagnosis. This temporal mismatch suggests that further investigation of this relationship is warranted. Also of interest for future studies is the age of the partner, as older partners have a greater number of years of exposure to the disease.

In addition, the ethnic breakdown and sampling of participants may not have been equivalent to the methods used by previous studies to investigate the effects of race/ethnicity on initiation of care. Turner et al. (2000) used a large probability sample of adults to investigate this relationship. The current study may have had insufficient power to find this relationship. Furthermore, the ethnic identification of youth living with HIV may be different to that of adults and this relationship may consequently be diluted in the youth population.
The factor analyses for the three variables were conducted on youth (N=347). The factor analysis for the lifetime housing variable, the themes were: living with romantic partners; living with both parents; living with family, and being marginally housed (e.g. shelter or job corps, etc.). The social network factor analysis themes were: delinquent peer behaviors; pro-social peer behaviors; supportive peer characteristics; and first important person characteristics. The logistic regression model included the factor analysis regression scores for housing, social networks, and a mental health item, and background variables including: age, gender, sexual orientation, attending religious services; testing in either a medical or non-medical setting; family economic situation; having a provider for one year or longer, and a summary count of family, peer, romantic partner and providers in the youth’s network. The results from the full model suggest that seeking medical care is predicted by age, having large peer networks, and peers with fewer prosocial behaviors. It appears as though youth with delinquent peers are more likely to avoid seeking immediate medical care and treatment. Education was found to be an important factor in appointment seeking behavior. Similar findings for adult patients counseled by medical providers on safer sex practices were documented in Richardson et al. (2003) baseline publication. That study reported that there was an inverse relationship between providers addressing safer sex practices and having more education.

A. Predictors of Delay in Seeking Care

Factors that were found to be associated with initiating care following diagnosis were prosocial behavior and delinquent behaviors such as excessive fibbing in the past 6 months. While female youth were more likely to initiate care following diagnosis, they
tended to exhibit a longer delay in making contact with a provider. This finding could be indicative of a disparity in services for males and females or more likely, a difference in care-seeking behaviors. Stein et al. (2000) found similar results in a sample of 2,864 HIV-infected adults, suggesting that competing caregiver duties were responsible for the delay of care in females. While most of the youth in the present sample were too young to exhibit such conflicting responsibilities, such as caring for children, the broader social context of gender roles may be an important reason for delay of care.

1. Prosocial Peer Behaviors as a Predictor of Delay Seeking Care

Youth who demonstrated prosocial peer behaviors tended to take longer to seek care than those who did not demonstrate this attribute at the time of the baseline interview. This effect could be due to a social learning effect among peers, that is, youth with positive attributes maybe more involved with their friends and other social outlets, and not prioritize seeking care. Or, youth with positive behaviors may have a higher self-efficacy to cope with their diagnosis and not view seeking care as a positive choice initially and revert to an avoidant coping style. While such results are not evident in the studies of HIV-positive adults, additional research could examine coping styles among at-risk youth, exhibiting differences in social networks and available resources, and how these differences impact care seeking behavior. This finding corroborates that of previous research, that social networks can have a negative influence.

Moreover, this relationship suggests that overall a strong, positive social network is influential in encouraging care seeking behaviors, yet a peer network alone without inclusion of parents and other adult role models is not sufficient to influence initiation of care. Youth with one or two good friends were significantly more likely to seek care than
youth with either a large group of good friends or those with few friends. Youth who were influenced solely by their peers, be it positively or negatively, appeared to be more likely to delay initiation of care, or even avoid care altogether following HIV diagnosis, than those youth who have a strong and more diverse social network. While this study has identified many of the social issues related to initiation of care, the complex relationship between the youths’ social networks and their care seeking behavior certainly merits further investigation. The research also indicated that the quality of a few good relationships is more influential than the number of acquaintances.

2. Excessive Fibbing as a Predictor of Delay Seeking Care

Among the predictors that were found to be strongly associated with care seeking behavior, was excessive fibbing within the past 6 months. While it is not an intuitive predictor of delay to seeking care, it could be indicative a bigger mental emotional health issue not observed in the data. This finding could also be a reflection of the negative influence of a social network and it could also be related to the social status of the youth, such as a distrust of authority and an inclination toward independence from adult figures. This finding corroborates that of previous research, that social networks can have a negative influence.

Another related finding that had a p-value trend was that youth living with HIV who identified as either coming from a poor or very poor background had a significantly longer delay in seeking care following diagnosis. While the fact it was not statistically significant was surprising, the suggested relationship between poverty and delay seeking care is not surprising, given the established relationship between socioeconomic status and the ability to receive appropriate health care. Those youth who were living in
poverty were less likely to have health insurance or a consistent source of health care. This finding is also supported by Stein et al. (2000), who found that HIV-positive adults without insurance were significantly more likely to delay seeking care. The lack of insurance factor likely interacts with ethnicity as well.

It is evident from the findings that prevention services need to target youth living with HIV in specific ways. Males must be encouraged to seek care at a greater rate, while females need to seek care in a timelier manner. Addressing the reasons why males do not seek care and why females delay care is a multidisciplinary task that must involve health care providers, the healthcare industry in general, policymakers, and researchers.

It is possible that misconceptions regarding AIDS as solely a disease of gay males inhibits females from seeking testing and medical care. Likewise, it is clear that the needs and resources of younger and older youth differ in some way that creates a disparity in the care they receive. Addressing this gap will also require further research, improved public health programs and policy decisions. Addressing the issue of poverty, reflected in underinsurance and lack of insurance, is by no means simple and is entangled in the perennial issue of equitable access to health care in America. Intervening at some stage in the prevention and treatment process through outreach programs and provider education will be necessary to ensure that all youth diagnosed with HIV have health care options available to them and are aware of these options.

It seems that youth are often reliant on the resources of adult associates, most commonly their parents, for them to receive health care. This finding suggests that more education and support should be provided to those youth with limited family support and negative peer influences. Support from health professionals has been found to be
important but not as influential as family or friends. Both the youths themselves and the peers they associate with should be targeted to ensure that the message is better communicated that early health care is associated with improved outcomes. Intervention should occur at the point of first contact, that is, at the time of testing, and should be focused on the care options available for those with limited resources.

This study was cross-sectional in design and, therefore conclusions cannot be drawn about causation. Associations between various social factors and care seeking behavior could be due to some extraneous factor such as socioeconomic or ethnic background. However, socioeconomic background was included in the multivariate linear regression model, using a measure of poverty, so it is unlikely that the effect of the social network is simply a result of socioeconomic circumstances. Likewise, ethnicity was not found to be at all predictive of either care seeking or the nature of the social network. Although temporal associations are also hard to draw for some of the relationships, such as whether the social network influenced delay of care, most of the factors implicated in care seeking were long-term and relatively fixed qualities.

Another problem with the design of the study is that it was retrospective, with participants reporting past events, and the data is not recent. Consequently, many of the measures used were current at baseline but not necessarily reflective of the situation at the time of diagnosis. Furthermore, the reporting of past events is prone to a variety of biases due to the effects of memory, interpretation and social desirability. As a solution, future studies that target high-risk youth prior to HIV diagnosis would be better able to disentangle the temporal relationships between the influence of the social network and past risk behavior on seeking care following diagnosis. Standardized measures of these
attributes would also bolster the present findings. Additional research that specifically targets the antecedents of care seeking would benefit the ability of youth diagnosed as HIV positive to receive the care they require in a timely manner.

This study did not provide any new information on the various types of sexual networks, such as those discussed by Morris (1995) nor the important factor of age of the sexual partner. The age of the partner is very important because of the likelihood of a greater number of years of exposure to AIDS. Older men who partner with younger men increase the likelihood of the younger men contracting the disease, creating what Morris terms “the leading edge of the epidemic in their cohort” (Morris, Zavisca & Dean, 1995). Morris states that younger men are getting infected at a rate of about double that of older men, facing a 50 percent chance of infection after 25 years of sexual activity (Morris, Zavisca & Dean, 1995). This specific factor, the age of the partner, deserves more research in connection with younger persons, especially those who are involved in sex for money behavior, as well as more enduring relationships.

This study highlighted the unique problems faced by youth in seeking care and how these obstacles are related to their social, health and demographic background. Further research should focus on the specific aspects of delay in seeking care that are identified, particularly the roles of the social network, gender, age, health status and healthcare provider status. The nature of the social network appears to be particularly important in care seeking behaviors – a positive, strong social network encourages care seeking while a negative, antisocial, weak social network, particularly one dominated by peers, tends to be detrimental to care seeking.
B. Implications for Public Health Promotion and Education

In light of the multivariate analyses, the main findings suggest that youth who delay seeking care after receiving an HIV diagnosis are likely to be female, older in age, level of social support, prosocial behavior, having more peer network interaction, poorer family socioeconomic status, demonstrating conduct problems or antisocial behaviors predict delay in seeking care. Moreover, youth having positive, strong social networks encourage care seeking while a having an antisocial or delinquent, weak social network, particularly one dominated by peers in a negative manner, tends to be detrimental to care seeking.

These results have a significant bearing on health promotion services developed to link HIV positive youth to care. The U.S. Centers for Disease Control and Prevention calls for integrated prevention services for HIV Positive persons in medical settings (CDC, 2003). Most of the youth in this study were linked to medical settings at time of recruitment, suggesting that the medical setting is the usual connecting point for HIV assistance. Future services and programs will need to be responsive to the needs of young women and older youth seeking care. When planning services, it is crucial to build on the positive, healthy social networks around youth and perhaps create programs that employ a “buddy” system as one mechanism for youth to start and sustain medical care. Lyon et al.(2003) reports that youth living with HIV attending behavioral intervention group sessions with a medication treatment support “buddy” were more medically compliant and adhered to their regimen more so than those who did not have a treatment “buddy.”
In conclusion, HIV prevention is increasingly becoming a routine and standard service in medical settings that neither provides adequate time for providers to thoroughly assess patient needs and create treatment plans that facilitate linkage to care. In light of this trend, Health Educators and others planning services will need to consider macro issues impacting service linkages. These behaviors would include creating mechanisms that support males getting care and mitigate biased assumptions that prosocial behaviors such as patients having a better education or a job history are more likely to initiate care. It also seems evident that the small peer networks supplemented with adult support is the strongest combination to help sustain compliant behaviors.
References


Fisher


Gamella


March 21, 2002

To whom it may concern:

As the Director of the Center for Community Health at UCLA and the Principal Investigator of the Teams Linked to Care research project (TLC), I hereby give permission to Patricia Jones to use the TLC Project dataset collected from 1994-1996 for the purposes of secondary data analysis as a dissertation research project.

Additionally, to clarify any questions regarding the methodologies or data collection activities concerning this dataset, Dr. Marguerite Lightfoot has agreed to be available for consultation to the dissertation committee upon their request.

If you have further questions or require additional information regarding authorization to use the TLC dataset, please do not hesitate to contact me at (310) 794-8280.

Sincerely,

Dr. Mary Jane Rotheram-Borus
Professor of Psychiatry
Director, UCLA-NPI Center for Community Health
Director, Center for HIV Identification, Prevention and Treatment Services

Dr. Marguerita Lightfoot
Assistant Research Psychologist
Center for Community Health
UCLA AIDS Institute
UCLA Neuropsychiatric Institute
Division of Social and Community Psychiatry
Appendix B. Survey Questionnaire From Original TLC Study Assessment for Proposed Research Study Extracted from Original TLC Study

Service site

1. [ ] L.A.- Gay and Lesbian Community Services Center
2. [ ] L.A.-Childrens Hospital
3. [ ] S.F.-Larkin Street Youth Center
4. [ ] N.Y.-Montefoire Medical Center
5. [ ] N.Y.-Mt. Sinai Medical Center
6. [ ] N.Y.-St. Lukes/Roosevelt Hospital
7. [ ] N.Y.-Kings County Hospital Center

1. **Gender**
   - What is your biological sex?
   1. [ ] Male
   2. [ ] Female

2. **Age**
   - How old are you? __ Years
   a. What is your date of birth? MM/DD/YY

3. **Religion**
   - What is your religious affiliation?
   1. [ ] None
   2. [ ] Protestant
   3. [ ] Jewish
   4. [ ] Catholic
   5. [ ] Baptist
   6. [ ] Pentecostal
   7. [ ] Muslim
   8. [ ] Atheist-humanist
   9. Other (Specify: ____)

4. How religious or spiritual do you consider yourself to be?
   1. [ ] Very religious or spiritual
   2. [ ] Somewhat religious or spiritual
   3. [ ] Not at all religious or spiritual

5. **Education**
   - What is the highest grade (as in year) in school you have completed so far? Grade
Appendix B (continued)

6. **Housing**
   The following questions are all about places where you have ever lived. Please read living situation 1-17 and choose the best answer for each situation.
   a. During your lifetime how long have you lived in each of the following situations?

   [ ] 0= Never
   [ ] 1= Less than 1 year
   [ ] 2= 1-5 years
   [ ] 3= 5-10 years
   [ ] 4= More than 10 years

**Living Situation in your Lifetime**
1. With your partner
2. With both parents biological/guardian)
3. With one parent
4. With grandparent (s)
5. With brothers and/or sisters
6. With other relatives
7. Independently, alone or with friends
8. With a foster family
9. In a group home/foster care institution
10. In a detention center, jail
11. In a shelter/single room occupancy (SRO)
12. In a drug or alcohol treatment center
13. In a hotel or motel center
14. Job Corp
15. On the streets, in public spaces (stations., parks, etc)
16. Other (Specify: __)

9. **Ethnicity**
   Tell me which ethnic group you feel you belong to?
   1. [ ] None
   2. [ ] Latino/a
   3. [ ] White, but not Latino/a nor Hispanic
   4. [ ] Black, but not Latino/a nor Hispanic
   5. [ ] Asian
   6. [ ] Other
   7. [ ] Biracial/mixed
   9. [ ] Do not know
Appendix B (continued)

9a. [If Latino/a or Hispanic] Which of the following best describes your ethnic background?

1. [ ] Dominican
2. [ ] Puerto Rican
3. [ ] Cuban
4. [ ] Mexican
5. [ ] Central American
6. [ ] South American
7. [ ] Other (Specify: ________)
8. [ ] N/A

10. Where were you born?

1. [ ] U.S.
2. [ ] Dominican Republic
3. [ ] Puerto Rico
4. [ ] Cuba
5. [ ] Mexico
6. [ ] Central America
7. [ ] South America
8. [ ] Africa
9. [ ] Asia
10. [ ] Other (Specify: ___)

If response to Q. 17 is other than U.S.

Employment

11. Have you ever in your lifetime had a job?

1. [ ] No
2. [ ] Yes

Family economic status

12. Which of the following best describes the financial situation of your entire household?

- Very poor, struggling to survive - 1
- Poor, barely paying the bills - 2
- Have the necessities - 3
- Comfortable - 4

Disclosure of HTV Status

13. Think about all the sex partners you have had, since you found out you were HIV positive. How many of these partners have you told that you are HTVH? _____ Farmers
Appendix B (continued)

Disclosure of Sexual Orientation

14. Do you consider yourself to be?
   a. Lesbian or Gay
   b. Bisexual
   c. Straight
   d. Other (specify: ___)

15. How many people in your family have you told that you are (lesbian/gay/bisexual)?
   ______ times

16. How many of your friends have you told that you are (lesbian/gay/bisexual)?
   ___ times

17. How many people learned from someone else that you are (lesbian/gay/bisexual)?
   ___ Times

Stage of Illness

18. When were you diagnosed with HTV, if you don't know the exact date, estimate - when you think?
   ___ mm/___ doV ___ yy

19. Have you had symptoms of HIV infection?
   1. [ ] No
   2. [ ] Yes
   8. [ ] N/A

20. Have you had symptoms of AIDS?
   1. [ ] No
   2. [ ] Yes
   8. [ ] N/A

21. When were you diagnosed with AIDS? mm/__ dd/__ yy
Appendix B (continued)

Mental Health and Depression,

22. At anytime in your life have you seen a psychiatrist, psychologist, or social worker for any of the following reasons:
   a. School-academic
   b. School- behavior
   c. Home- behavior
   d. Aggression/conduct problems
   e. Hyperactivity f. Phobias (i.e. intense fears)
   g. Depression
   h. Suicide threat/ attempts
   i. Drugs/alcohol abuse
   j. Other (specify: __)

23. How many times have you gone into counseling? _

24. Have you ever in your lifetime been arrested for a crime?
   1. [ ] No
   2. [ ] Yes

25. Have you ever in your lifetime been convicted of a crime?
   1. [ ] No
   2. [ ] Yes

26. Have you ever skipped a class, meaning "played hookey"?
   1. [ ] No
   2. [ ] Yes

Social Support Networks

27. Social Network Member
   Please list for me the most important people in your life.
   1.
   2.
   3.
   4.
   5.
   6.
   7.
   8.
   9.
   10.
Appendix B (continued)

28. What is [important person] relationship to you?
   1. [ ] Parent
   2. [ ] Brother/sister
   3. [ ] Grandparent
   4. [ ] Other family member
   5. [ ] Partner-boyfriend, girlfriend, lover, etc.
   6. [ ] Friend
   7. [ ] Acquaintance
   8. [ ] Professional (e.g., teacher, therapist, etc.)

29. What is [important person] age? _____ age

30. How long have you known [important person]?
   1. [ ] A few days
   2. [ ] A few weeks
   3. [ ] 1-3 months
   4. [ ] 4-11 months
   5. [ ] 1-5 years
   6. [ ] More than 5 years

31. Overall how would you describe your friendships?
   1. [ ] A group of good friends
   2. [ ] One or two good friends, lots of acquaintances
   3. [ ] One or two good friends, less acquaintances
   4. [ ] Not close to anyone

32. How well do your friends know each other?
   1. [ ] Very well
   2. [ ] They have me each other
   3. [ ] Are quite separate
   4. [ ] Not at all

33. Overall, how often do you see your friends?
   1. [ ] Everyday
   2. [ ] A few times a week
   3. [ ] Once a week
   4. [ ] A few times a month
   5. [ ] Less than once a month
Appendix B (continued)

34. How supportive is _______ [important person] about your illness?

1. [ ] Very supportive
2. [ ] Mostly supportive
3. [ ] OK
4. [ ] Mostly un supportive
5. [ ] Very unsupportive
8. [ ] N/A

35. Does [important person] help you when you are in trouble?

1. [ ] No
2. [ ] Yes
8. [ ] N/A

36. How often has [important person] helped you with a place to stay, food, money, and getting a job within the past three months?

1. [ ] Weekly
2. [ ] Monthly
3. [ ] Once or twice
4. [ ] Never
5. [ ] N/A

37. How often do you see [important person]?

1. [ ] 1-3 times a week
2. [ ] 4-7 times a week
3. [ ] 1-3 times a month
4. [ ] Less than once a month

38. Overall, how would you describe your friendships?

1. A group of good friends
2. One or two good friends, lots of acquaintances
3. One or two good friends, less acquaintances
4. Not close to anyone

39. Were you seen by a doctor or nurse or given an appointment with a doctor or nurse after you tested HIV +?

1. [ ] No
2. [ ] Yes

40. How long did it take you before you went to your first doctor's visit?

______ Days
Appendix B (continued)

Social Network Peer Behavioral Profile Negative Peer Behaviors:
How often in the past three months did you have sex, do drugs, get into trouble at school or on the job, or with the police while with _____ [important person]?

37. Does [important person] have unprotected sex that would place this person at risk of getting HIV?
   1. [ ] No
   2. [ ] Yes  8. [ ] N/A

38. Does ____ [important person] use alcohol or drugs more than once per week?
   1. [ ] No
   2. [ ] Yes
   8. [ ] N/A

39. Does ____ [important person] get into trouble with the law?
   1. [ ] No
   2. [ ] Yes
   8. [ ] N/A

40. Does ____ [important person] come to you for help often?
   1. [ ] No
   2. [ ] Yes
   8. [ ] N/A

41. How often has ____ [important person] helped you with a place to stay, food, money, getting a job within the past three months?
   1. [ ] No
   2. [ ] Yes
   8. [ ] N/A

Positive Peer Behaviors:
41. Do most of your friends:

   None  Some  Most  almost all  All  D/K
   a. Do well in school
   b. Play on sports teams
   c. Go to school regularly
   d. Use alcohol
   e. Get along with their mothers
   f. Use drugs
   g. Get along with their fathers
   h. Stand by their friends
   i. Perform at their grade level at school
   j. Have sexual intercourse
Appendix B (continued)
k. Feel depressed often
l. (have) tried to kill themselves
m. Use condoms
n. Have jobs
o. Get along with their brothers & sisters
p. Worry about HTV
q. (have) been arrested
r. Have sex with several different people
s. (have) been to jail
t. Lie often
u. Hang out with a gang
v. Steal from others
w. Shoplift

Questions related to the AIDS Risk Reduction Theoretical Model (ARRM)

Labeling
42. During the past three months how many times have you received assistance with your household chores, shopping, or personal care (e.g. bathing or dressing)?
   None 0
   Once or twice 1
   A few times 2
   Monthly 3
   Weekly 4
   Daily 5

Commitment
43. How comfortable are you asking questions of your doctor or health care provider?
   Not at all 1
   A little 2
   Sometimes 3
   Quite a bit 4
   Always 5

Enactment
44. How many appointments with your doctor or health care provider have you missed in the past three months? __ Number of appointments
Appendix B (continued)

Help-seeking
45. During the past three months, how many times have you received assistance with your household chores, shopping, or personal care (e.g. bathing, etc.)?
   - None: 0
   - Once or twice: 1
   - A few times: 2
   - Monthly: 3
   - Weekly: 4
   - Daily: 5

Self-Help
46. What types of positive changes, if any, have you made in your lifestyle since learning you were HTV +?
   - Yes
   - No
   a. increased exercise
   b. changed your diet
   c. quit smoking
   d. quit non-prescription drugs
   e. yoga
   f. psychological counseling
   g. used (more) vitamins
   h. joined a support group
   i. joined stress management group
   j. became involved in HIV prevention (e.g. going to HTV lectures)
   k. became politically involved
   l. educated others about HTV*
   m. your living situation became more stable
   n. you started playing more sports (i.e. basketball)
   o. went back to school
   p. other: specify

Enacting Solutions
47. When you feel you need to see a doctor or health care provider, do you usually get the health care you need?
   - No: 1
   - Yes, sometimes: 2
   - Yes, always: 3
Appendix C: Model of Predictors of Delay in Seeking Care

Background Variables
- Disclosure of HIV Status
- Disclosure of Sexual Orientation
- Age
- Religion
- Gender
- Housing situation
- Education
- Employment
- Ethnicity
- Family economic situation
- Service sites
- Stage of Illness
- Mental Health Characteristics

Social Network Members
- (Family)
- Non-family (peers & romantic Partners)
- (Professional service providers)

Social Support
- Amount of social support provided
- Source of social support provided
- Frequency of contact with support provider

Time of first doctor’s visit