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Oriana Mae Campanelli
Understanding the Issues of
HIV/AIDS and Adolescents
Through the Concerns,
Perceptions, and
Recommendations of
Adult Service Providers
to the Teen Population
of Rhode Island:
An Exploratory Study

ABSTRACT

The purpose of this study was to gain further understanding of the attitudes of teens and their service providers toward the HIV/AIDS crisis, currently affecting large numbers of mostly black and Hispanic male and female adolescents engaged in heterosexual sexual relationships. This study focused on adult providers of services to adolescents in Rhode Island in order to gain a clearer understanding of the complex psychosocial issues of a complex disease, and a complex age group, including the special vulnerabilities of at-risk adolescents, and to explore what efforts at prevention and early treatment are being carried out, what efforts are recommended, and what are the attitudes and concerns of both adolescents and their service providers towards this issue.

This qualitative, exploratory study was conducted by interviewing fifteen adult service providers who were working with adolescents in Rhode Island.

Major findings from this study showed all fifteen subjects to be committed and concerned for the adolescents in their care in regards to HIV/AIDS issues, although they demonstrated varying levels of involvement with HIV/AIDS treatment or preventative efforts. Subjects discussed difficulties in preventing this disease which includes psychological factors such as at-risk teen behaviors, societal stigmas surrounding this

disease, and political and religious influences such as emphasis on abstinence-only sex education programs.

The need for leadership, political change, further research, and collaborative efforts from many disciplines such as medicine, education and social work was highlighted by this study.

UNDERSTANDING THE ISSUES OF HIV/AIDS AND ADOLESCENTS THROUGH
THE CONCERNS, PERCEPTIONS, AND RECOMMENDATIONS OF ADULT
SERVICE PROVIDERS TO THE TEEN POPULATION OF RHODE ISLAND:
AN EXPLORATORY STUDY

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Masters of Social Work.

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Smith College School for Social Work
Northampton, Massachusetts 01063

2007

DEDICATION

In loving memory of my Dad, my great buddy

Peter D. Campanelli



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This thesis could not have been accomplished without the assistance of many people whose contributions are gratefully acknowledged:

First and foremost, I want to thank my thesis advisor, Esther Urdang, Ph.D. for her consistent guidance, thoughtful recommendations, and for always keeping the thesis process feeling manageable and possible. Esther, thanks for making this thesis happen, once and for all...

...I also want to thank the fifteen individuals who participated in my study for their respect and time to share their thoughts on the issues of HIV/AIDS and adolescents...

...and with all my heart I want to thank my family, whom I am forever indebted to for their unconditional love, support, and their belief in me. A very special *tanti baci* is in need for Mom, Dad, my brother Lorenzo, and my love Jeff. Know I feel truly blessed to have each other, now and for always.

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CHAPTER I

INTRODUCTION

The purpose of this study is to gain further understanding of the attitudes of teens and their service providers towards the HIV/AIDS crisis. Currently, HIV/AIDS in the United States is affecting mostly black and Hispanic youth who engage in heterosexual sex and the majority of whom are unaware of their condition. Therefore, this research focuses on adolescents who may be at-risk for HIV/AIDS in Rhode Island, as seen through the eyes of their adult service providers, in order to explore the perceptions and concerns of both adolescents and their service providers towards HIV/AIDS, and towards efforts at prevention.

It is hard to remember a world before HIV/AIDS. For the past 25 years this fatal pandemic has taken the lives of millions and continues to infect millions each year as we struggle to find a vaccine smart enough and quick enough to prevent this truly devastating human virus. More than 900,000 cases of AIDS have been reported in the United States since 1981 (CDC, 2007), and although this disease has declined, 40,000 new cases are reported each year, mostly among black and Hispanic youths (McNeil Jr., 2006). American adolescents also account for more than 60% of all sexually transmitted diseases (STDs) reported by the Center for Disease Control (CDC) in 2002 (Voisin, et al., 2006); the presence of STD increases vulnerability for HIV/AIDS. Although, at present there is no cure for AIDS, recent medical advances have prolonged life for HIV-positive

individuals. Therefore, early testing and medical treatment become essential and primary prevention is an optimal goal.

Preventative measures, such as the use of condoms and sterilized needles for IV-drug users can be difficult to implement when related to cultural, religious, and political considerations. On a psychological level, adolescents often engage in risk-taking behaviors, and some youth, with emotional and family problems, are more at risk for such behaviors. Furthermore, HIV/AIDS carries a social stigma, which few other diseases carry; seeking help and confiding in others becomes problematic for young adults. Parents, teachers and other service providers are often impeded from acting by their own conflicts about adolescent sexual behavior, as well as society's mores. Exploration of these challenges is an objective of my thesis.

This study has evolved from my longstanding interest in HIV/AIDS in the adolescent population, which includes my involvement with the non-profit organization Grassroot Soccer, which uses the power of soccer to educate young people about HIV/AIDS throughout Africa. Over the course of 18-months prior to my enrollment in the Smith College School for Social Work masters program, I was involved in the implementation of Grassroot Soccer's innovative HIV/AIDS and life skills education curriculum in the African countries Zimbabwe, Ethiopia, and Zambia. Through my experiences with the youth and young adult populations of these three diverse countries, I have developed a deep respect for the adolescent population and the power of self-empowerment through awareness and education.

It is because of the life-changing relationships I developed with these youth in Africa that I designed this exploratory thesis in order to reach a clearer understanding of

the complexities involved in the prevention of the HIV/AIDS pandemic among teenagers in the United States, and specifically in Rhode Island. I continue to be curious about the perceptions and proposed solutions of social workers, other service providers, and teenagers themselves. I hope that the insights gained during this research will prove helpful in exploring this life-threatening problem further in Rhode Island as well as in other areas of this country.

With this in mind, this research has been designed as a qualitative study of 15-service providers to adolescents in the Rhode Island area. Subjects were seen for an individual one-hour interview, where their concerns about HIV/AIDS and thoughts about prevention were explored. Additionally, their perceptions of adolescents' concerns about this subject were discussed.

The methodology used in this research project is discussed in Chapter III, and the Findings are presented in Chapter IV. The discussion of the major findings and conclusion of this study are presented in Chapter V. The nature of HIV/AIDS, the scope of this disease, adolescent development and their at-risk behaviors, and local, national and international efforts of HIV/AIDS prevention are discussed in the Literature Review Chapter II, which follows.

CHAPTER II

LITERATURE REVIEW

Introduction

The purpose of this research is to further our understanding of the impact of the HIV/AIDS epidemic currently affecting disproportionately large groups of black and Hispanic teenagers in the United States, both male and female, who engage in heterosexual sexual relations. This study focuses on understanding the attitudes of Rhode Island teenagers, as well as understanding the perceptions of their adult service providers about this problem and their views of preventative services. In discussing the background and scope of this problem utilizing relevant literature, the following subjects are highlighted: 1.) description of the course of HIV/AIDS; 2.) the international, national, and local scope of this problem with emphasis on adolescent vulnerability to this disease; 3.) adolescent development, including at-risk behaviors, and parent-teen relationships; 4.) the nature of preventative efforts, internationally, nationally, and locally, with a focus on prevention in adolescents.

The Course of HIV/AIDS

It is hard to remember a world before HIV/AIDS. For the past 25-years this fatal pandemic has taken the lives of millions and continues to infect millions world-wide each year as we struggle to find a cure or vaccine smart enough and quick enough to stop this truly ingenious human virus. More than 900,000 cases of AIDS have been reported in the United States since 1981 (Centers for Disease Control, 2007).

The Human Immunodeficiency Virus (HIV) is a retrovirus which causes Acquired Immunodeficiency Syndrome (AIDS). HIV is only transmittable through the direct contact with HIV+ blood, semen, vaginal fluid, or breast milk. Once the HIV has been transmitted, the virus can remain present in the human body without symptoms for up to ten years. The fact that it can remain quiescent and undetected for a long period of time makes early diagnosis a critical factor, which is an important underlying concern of this study.

According to the Centers for Disease Control (CDC), a person is diagnosed with AIDS when the HIV-infected individual has fewer than 200 CD4+ T cells per cubic millimeter of blood resulting in a suppressed immune system unable to fight off opportunistic infections, leading to serious illness and sometimes death (UNAIDS, 2005). From a historical perspective, Beckerman, Grube, and Strug (2002) discuss how HIV/AIDS has seen three waves of development and is about to enter into a fourth wave where attention to adolescents will be crucial; each of these waves has involved three different types of social work interventions. “The first era started in 1980/81 when the first cases of a mysterious, ‘rare cancer’ which was often disfiguring, and typically terminal, began to be diagnosed and reported, primarily in gay white men” (Beckerman et al., 2002, p. 2). Life expectancy at this point averaged two years and no cause of the disease, including means by which it was transmitted, was known; furthermore, there were no effective medical treatments (Beckerman et al., 2002, Averitt, 2000; Centers for Disease Control, 1983; Dowdle, 1983; Stulberg & Buckingham, 1987). During this period, social workers served individuals affected by helping them cope with the social

alienation involved in the diagnosis and with the processes of dying and experiencing loss (Beckerman et al., 2002, p. 3).

The second wave was marked by the identification, in 1984, of the human immunodeficiency virus (HIV) as the cause of AIDS, along with the development of a new medication, AZT, in 1986. “HIV/AIDS was diagnosed increasingly throughout this time period among IV-drug users, their sexual partners, and among heterosexual women and their children, largely in communities of color” (Beckerman et al., 2002, p. 3). During this time, social workers faced many professional dilemmas and ethical issues, including conflicts with their clients’ value systems, concerns about knowing their clients’ HIV-positive status and informing those clients’ sexual partners, as well as issues surrounding mandatory testing (Beckerman, Beder, & Gelman, 1996; Beckerman, Grube, & Strug, 2002; Giddens, Kaopa, & Tomaszewski, 2000).

The third wave of the disease is described as an era in which *the face* of HIV/AIDS changed due to medical advancements (Beckerman, Grube, & Strug, 2002, p. 4). Beginning in 1996, with the introduction of protease inhibitors and HAARDT—or what is known as the “AIDS cocktail”—mortality rates declined and quality of life improved for those diagnosed with the disease and who received pharmacological treatment. During this time, however, HIV/AIDS continued to spread among poor people of color in the US, for African-American and Hispanic women with and without children, for people infected heterosexually, and for adolescents and IV-drug users (IVDUs). During this wave, which is coming to its completion, social workers helped clients with adhering to the difficult regimens of HAARDT as well as supporting people living with AIDS (PLWHAs) face issues around intimate relationships, power inequities, and

decisions about whether or not to have children. Social workers also helped support caretakers of children who are HIV-positive and provided general psycho educational interventions with the general public and at-risk groups.

As Beckerman, Grube, & Strug (2002) argue, the HIV/AIDS pandemic currently is entering into a new wave where patterns are shifting concerning the most affected populations; one of these groups is composed of adolescents. Furthermore, as they argue: “Social workers are not currently involved, but will increasingly become involved, in primary prevention efforts in the next wave of the epidemic” (p. 7). This research aims to explore how adolescents and their service providers perceive this critical issue and to understand what preventative efforts are in place, and what further efforts are recommended.

Scope of the Problem

In 2005, HIV/AIDS pandemic killed an estimated 2.9 million people globally while it is estimated that more than 39.5 million people around the world are currently living with HIV (UNAIDS, 2006). The numbers are staggering and the outlook of HIV/AIDS truly looks grim in the years to come. According to the 2006 UNAIDS/WHO report, HIV/AIDS continues to infect the lives of approximately 4.5 million people annually. In a 2005 global HIV/AIDS estimate report done by the World Health Organization (WHO), it is estimated that more than 1.4 % of males and 3.8% of females between the ages of 15 and 24 are currently HIV-positive (World Health Organization, 2007). In the US, the majority of the 40,000 newly HIV-infected Americans each year are mostly Black and Hispanic adolescents and are generally unaware of their condition (McNeil Jr., 2006). American adolescents also account for more than 60% of all sexually

transmitted diseases (STDs) reported by the Center for Disease Control and Prevention (CDC) in 2002 (Voisin, et al., 2006); the presence of STD increases vulnerability for HIV/AIDS.

As the smallest of the fifty US states, Rhode Island continues to feel the negative impact HIV/AIDS has on its diverse people and unique communities state-wide. Of the eight HIV/AIDS prevention programs in Rhode Island to receive funding by the Center for Disease Control (CDC) between 2005-2008, only one program led by the community-based group Youth In Action, is responsible for designing and implementing an HIV/AIDS prevention program for both homosexual and heterosexual youth of Rhode Island (Prevention Programs, 2005). This significant preventative effort being is further discussed in the section on preventative efforts.

According to a 2005 study done by the leading HIV/AIDS community prevention coalition in Rhode Island, Rhode Island Community Planning Group for HIV Prevention (RICPG): “Between 1 January 2001 and 31 December 2005, 733 newly diagnosed HIV cases were reported to the Rhode Island Department of Health” (RICPG Summary Update, 2007). Between 2000 and 2005, it was reported that 13% of all Rhode Island HIV cases were in individuals between 13 and 24 years of age (RICPG Summary Update, 2007). No report can provide the actual number or percentage of HIV-positive Rhode Island residents because HIV-testing is anonymous and is not mandatory. Although the number of infected individuals may be underestimated, there is evidence that this is a growing problem which merits further study.

Adolescents and HIV/AIDS

Theorists have grouped the adolescent years into three sub-categories, “the early (10-14 years), middle (15-17 years) and the late adolescence (18-20 years)” (Dashiff, 2001, p. 343). Adolescence can be defined from many perspectives; Americans aged 12 to 18 do share the common trait of experiencing constant transition (Allan & Land, 1999). Arnold (1992) observes: “Adolescents are neither children - whose rights are clearly limited and protected only by the parent, legal guardian, or the state as *parens patriae* - nor adults. In many ways, adolescence is a kind of limbo.” From their “limbo” position in society, is it possible that the adolescent may have attitudes, opinions, and issues concerning the HIV/AIDS disease which are not being considered by American society? Dashiff (2001) insists, “Adolescent research settings can pose challenges... the application of theoretical and empirical knowledge about adolescent development can strengthen data collection instruments and procedures” (p. 343).

At an earlier date, Rosenthal & Shepherd’s (1993) study claimed the incidence of HIV/AIDS infection to be “low among the adolescent population” (p. 53). Yet, adolescents are arguably one of the most vulnerable groups in society at-risk of HIV/AIDS infection (Sherr, 1997, p. 7). The Kennedy & Eckholdt (1997) study notices, “HIV goes through its greatest acceleration in transmission during adolescence” (p.52). Hundreds of studies which provide the public with information of HIV/AIDS infection rates overlook the adolescent population, or only provide data of identified “at-risk” adolescent sub-groups, such as African-American adolescent females (Rosenthal & Shepherd, 1993; Berger, Ferrans, & Lashley, 2001). The attitude many adolescents have is one of immortality or invincibility. It is possible this adolescent approach to life may

have played out in the previous lack of research and literature about HIV/AIDS issues for the adolescent population.

Sunenblick (1998) describes adolescents as one of the “high-risk” groups for HIV/AIDS because the adolescent years are a time of constant, “change, confusion, and tumultuousness” (p. 387), which includes engaging in risky behaviors such as unprotected sex with numerous partners to experimenting with intravenous drugs.

Sunenblick (1998) continues:

According to the CDC, the number of reported cases of AIDS in twenty-to twenty-nine-year-olds is increasing dramatically. Given the length of time that one can be infected with HIV and show no symptoms—an average of eight to ten years—it is reasonable to conclude that many AIDS patients are likely infected during their adolescence (p. 387).

According to the Rhode Island Community Planning Group for HIV Prevention, a survey distributed to Rhode Island high school students in 2005 indicated that 36.5% of those adolescents surveyed reported to be sexually active (2007 RICPG Summary Update); additionally, among the sexually active adolescents, 34% said they did not use a condom the last time they engaged in sexual intercourse. These findings support the need for adolescent sex education and other efforts aimed at preventing STD and HIV/AIDS, and demonstrate the urgency of further research. This study is one contribution to this effort.

Parent-Teen Relationships

Another issue discussed in the literature concerns the communication between parent and child on issues of sexuality, HIV/AIDS, and STDs. During the adolescent years, most American adolescents are still living with their families and dependent on the

parent(s) for survival (DiIorio, Pluhar, & Belcher, 2002). The studies which address the HIV/AIDS communications between parents and their adolescent children have done so by focusing on the mother as the primary adult influence (Dancy, Crittenden, & Talashek, 2006; Miller, et al., 1998; DiIorio, Pluhar, & Belcher, 2002). These relational studies conclude that “at-risk” adolescent populations are best served by utilizing the mothers as effective tools for educating their sexually-active adolescents to reduce their risk of infection. For example, Dancy, Crittenden, & Talashek (2006) found, through their split-plot, repeated-measures design, that HIV-education and risk reduction curriculum intervention was effective between African-American mothers and their adolescent daughters when both the mother and adolescent were experiencing the same intervention process.

Another empirical study (Miller, et al., 1998) criticizes our society’s over-reliance on the mother or female caretaker to address adolescent sex issues, as adolescent sons may find sex talk with them is an embarrassing taboo topic. DiIorio, Pluhar, and Belchar (2002) have preferred studying the role of the fathers in communicating with their sons about sexuality and HIV/AIDS prevention. This thesis study asks providers their opinions about the role they think families should play in preventative efforts.

Preventative Efforts

Of the literature on HIV/AIDS issues faced by adolescents, a great deal of the literature focuses on socio-cultural sub-groups—especially race, gender, and ethnicity—of adolescents. This recent change to a more gender-based approach of HIV/AIDS education with adolescents in the United States may help us better understand the role that gender plays among the adolescent sub-group (Sherr, 1997). Findings indicate that

black and Hispanic populations are specifically at risk, and point out the significant incidences in the female population.

Many internationally-based empirical studies focus on a socio-cultural and developmentally-appropriate approach to HIV/AIDS research. In a cross-sectional study done with 407 adolescent students in India, findings prove further the importance in understanding societal and cultural influence to such a vulnerable population as adolescence (Deb, 2005). International HIV/AIDS studies that specifically target the adolescent population bring several strengths in quantitative methodology into focus. Empirical studies done in India and Thailand emphasize the effectiveness in HIV/AIDS education when faced with the alarming increase in adolescent HIV infection rates (Deb, 2005; Wiwanitkit, 2003).

In a recent study, testing Portuguese adolescents on their knowledge of HIV/AIDS transmission and HIV/AIDS stigmatization resulted in subjects holding more positive attitudes toward HIV-infected individuals if a greater knowledge about the disease was achieved (Dias, Matos, & Gonçalves, 2006). This empirical study is of particular interest as it suggests the immense amount of peer pressure the adolescent population encounters daily.

There can be problems in stereotyping people with AIDS. Rosenthal (1997) explains: “The stereotype serves a distancing function, especially since it enables individuals to focus on differences rather than possible similarities (i.e. sexual practices) between themselves and those who are infected” (p. 97). HIV/AIDS stigma puts the adolescent population at a greater risk because they are affected by peer pressures and stereotypes that are internalized during this stage of life. The research of Dias et al.

(2006) discusses the HIV/AIDS stigma for Portuguese adolescents, and offer suggestions for further adolescent-specific interventions which may help to eliminate the stigma and the peer pressures associated with HIV/AIDS.

As defined by Berger, Ferrans, & Lashley (2001), “The term stigma refers both to a trait and to the outcome of being known to possess that trait” (p. 519). It is the very stigma attached to the HIV/AIDS disease which often discourages individuals, knowingly HIV-positive, from disclosing their status to family, friends, and sexually-intimate partners (Berger, Ferrans, & Lashley, 2001). In the US, avoidance of HIV-status is influenced by fear of associations to homosexuality or IV-drug use. While stigma around HIV-positive individuals continues to play out a major component of fear for South African adolescents, the power and excitement in multiple sex partners and/or unprotected sex overrules negative stigma in the adolescent’s frame of mind (Morojele, et al., 2006). The Morojele, et al. (2006) study claims to be the first focus group study where both genders and the three main racial groups (‘white’, ‘colored’, and ‘African black’) were conducted.

The HIV stigma scale used in the Berger et al., (2001) study exemplifies the importance in conducting comprehensive surveys which include components that aim to measure related issues pertaining to HIV stigmas, such as poor self-esteem, chronic depression, and lack of social services. This study was done with a sample of adults, making it, once again, challenging to apply this data to the adolescent population. In the literary search conducted for this thesis, few US-based studies explain demographics of adolescent sample groups. Such information would greatly improve understanding of the

cultural and socioeconomic diversity of the adolescent age group and how this will impact the social worker's implementation of HIV/AIDS issues.

As concerns the fourth wave of the HIV/AIDS pandemic: "The US Centers for Disease Control and Prevention recently announced the goal of reducing new infections, particularly among young people" (Beckerman, Grube, & Strug, 2002, p. 8); reducing new infections among young people and other groups needs to be carried out "by implementing community and peer-based HIV prevention efforts, school-based prevention programs" as well as programs that "strengthen the capacity" for "decision-making" amongst current high-risk groups (p. 8). The CDC has decided that: "Prevention efforts with youths will focus on their drug-related behaviors and on STD prevention" (p. 8). As the Kaiser Foundation (1999) has found, adolescents do not know where to get tested for HIV and have not been (whether by correlation or cause) tested for HIV.

Complicating the picture of HIV/AIDS prevention among adolescents are general societal and religious values and conflicts regarding sexuality, particularly teenage sexuality, sex education including condom use (as opposed to abstinence) and controversies regarding the role of schools, medical personnel, and parents. Even in HIV-preventative programs which give evidence to reducing HIV risk behaviors among at-risk populations, participation is difficult to maintain for minority groups. Pinto & McKay (2006) explain, "The influence of clients' perceptions of racist attitudes and racial prejudice may explain low involvement of minority populations in health-related programs" (p. 286).

According to a recent New York Times article reported by McNeil Jr. in September, 2006, the CDC has made several attempts to change federal policy by proposing mandatory HIV testing, "...at least once for everyone aged 13 to 64 and annual tests for those with high-risk behavior" (p. A1). This proposal would normalize HIV-testing and reduce the stigma still associated with HIV testing among our adolescent population. Yet, in a country as politically and religiously divided as that of the US so, too, is the nation divided on the policies and issues of HIV-testing, public school sex education, IV-drug needle exchange programs and *condom v abstinence* preventative programs. "In the United States, the emphasis on abstinence and teens taking abstinence pledges also characterizes sex education programs, which many critics feel is to the detriment of preventing AIDS in adolescents" (Urdang, in press). Kristof (2006) reports on the contradictions of these complex issues:

Careful studies of "abstinence only" programs in the U.S. suggest that they do delay sexual intercourse, but that young people are then less likely to use condoms afterward. The evidence indicates that a balanced approach—encouraging abstinence but also promoting condoms—is far more effective at protecting young people in America or abroad from sexually transmitted infections, including H.I.V. (p. A31).

As HIV/AIDS is currently acknowledged to be a critical problem among the male and female minority adolescent population throughout the US, this study attempts to explore the attitudes and perceptions of adolescents and their service providers in Rhode Island to this disease and to efforts at prevention. The following chapter discusses the Methodology for this study.

CHAPTER III

METHODOLOGY

Study Purpose and Questions

This qualitative study focuses on adolescents at-risk for HIV/AIDS in Rhode Island, as seen through the eyes of their adult service providers. Special emphasis is placed on understanding the vulnerabilities of at-risk adolescents, and exploring what efforts at prevention and early treatment are being carried out, what additional efforts are recommended, and what are the attitudes and concerns of both adolescents and their adult service providers toward this issue.

A semi-structured questionnaire was designed and 15-adult providers in the state of Rhode Island who work with the adolescent population of Rhode Island were interviewed for one hour about their work with adolescents, their perceptions of the HIV/AIDS epidemic regarding adolescents' HIV/AIDS knowledge, behaviors, fears, and attitudes. The full questionnaire is in Appendix C. Questions covered the following topics:

- Whether HIV/AIDS treatment or prevention directly/indirectly involved their work with adolescents.
- Whether adolescents in their programs are concerned about becoming infected with HIV/AIDS.
- How comfortable they believe the adolescents they work with are discussing the issues of HIV/AIDS among each other.
- How comfortable they believe these adolescents feel discussing the issues of HIV/AIDS with adults.

- Whether they believe specific sub-groups of adolescents are more or less at risk of HIV-infection.
- Whether they think certain sub-groups of adolescents are more or less concerned about HIV/AIDS.
- Whether they think that the adolescents they work with may be at risk for HIV/AIDS.
- With whom do they believe adolescents need to discuss their questions, concerns, and thoughts about HIV/AIDS.
- Whether they think families should play a role in prevention.
- Whether they think the medical profession should play a role in prevention.
- Whether they think schools should play a role in this problem.
- What their opinions are about the general social and political climate in this state in terms of dealing with HIV/AIDS prevention and early intervention.
- Whether they have any suggestions for preventing the spread of HIV/AIDS among the adolescent population.

Research Methods and Design

The research design was a flexible, descriptive research design. Anastas (1999), in discussing the purpose of flexible, descriptive research design noted that, "...when a phenomenon has been understudied or poorly defined...exploring the nature of the phenomenon in context and in detail through the use of unstructured data and flexible interviewing...seems the only way to proceed" (p. 60). This descriptive research design enables us to gain a better understanding of the HIV/AIDS phenomenon from an overlooked perspective—the adolescents' viewpoint through the perspectives of the adults who work with teenagers.

Descriptive research design under a flexible methods design ultimately requires, "intensive interviewing and observational techniques" (Anastas, 1999, p. 65). By

selecting the descriptive research design, I was enabled to gain more understanding of problems of case finding and prevention of HIV/AIDS in American adolescents through discussions with adolescent service providers in Rhode Island (Anastas, 1999).

Sample

Participants were recruited through the purposive snowball sampling method. The only exclusion criteria were that individuals must work in Rhode Island with the adolescent age group, must be older than 21, and able to converse in English. Both females and males were encouraged to participate, and I did not control for subjects' race/ethnicity, gender, religion, HIV/AIDS status, or degree of education. My goal was to obtain a diverse set of 15 adults employed in the social work, medical, teaching and/or human service field of Rhode Island and to gather their perceptions and concerns about HIV/AIDS among the adolescent population with whom they work. I expected that this purposive sample would allow us to “develop a photograph” of the relationship between adults, adolescents and HIV/AIDS in this group (Anastas, 1999, p.138).

Originally, I planned to interview a group of adolescents directly for my study because this would provide first-hand data of their own perceptions around issues related to HIV/AIDS. However, due to complications including the sensitive nature of this topic, and the need for parental consent, I decided to interview adults who work with adolescents.

Eighteen potential participants were contacted via phone call during the months of January, February, and March 2007. Out of this group, fifteen people agreed to take part in my 60-minute interview process after I explained the purpose and requirements of my study to them (Appendix B).

Description of Subjects

Seven men and eight women participated, ranging in age between 22 and 65; the mean age was 39. Eight participants defined themselves as either “Caucasian” or “White”, two as “French Canadian”, two as “Cape Verdean”, one as “Black/African”, one as “African American”, and one as “Puerto Rican.” Subjects had a range of job descriptions and employment. More detailed descriptions of the subjects can be found in Chapter IV Findings.

Data Collection Methods

For this qualitative research project, narrative data was collected in the form of a semi-structured, open-ended interview questionnaire. I began to develop the interview questions with my thesis advisor during October and November 2006 in order to formulate questions that would receive comprehensive as well as subjective responses to this sensitive and complex topic. I submitted my Thesis Proposal and Questionnaire to the Smith College School of Social Work Human Subject Review Board, and received their approval for my study on January 18, 2007. Approval Letter is in Appendix D.

I then began contacting potential participant for my interviews who worked for Rhode Island hospitals, HIV/AIDS agencies, and schools providing services to teens. I collected contact information about potential participants via internet research and through word of mouth. I contacted each potential participant individually, and did not go through agencies to recruit my participants.

The initial contact of an individual was done via phone call. Following a flexible outline of a preliminary “Informational” phone call (Appendix B, Section I), I initiated conversation with the potential participants with a brief explanation of my study, why I

was contacting them, and what I hoped to accomplish with their participation. I also asked questions to gather more information, e.g. whether they work with adolescents, and if they have any programs related to AIDS and adolescents. I was able to screen the potential participant for eligibility in my study during this initial phone contact.

If the individual meet all the requirements for participation and verbally agreed to be a subject, I then moved directly into the “Recruitment” phase of the phone call (Appendix B; Section II) where more detailed information about my study, and the requirements for subjects were further discussed. During the “Recruitment” phase of the phone call, I also scheduled a convenient date, time, and location for the 60-minute face-to-face interview to take place. I then sent a letter of confirmation and a copy of my Informed Consent Form (Appendix A) to a mailing address provided by the participant.

This snowball recruitment process was a success. I was able to conduct all 15-interviews by March 15, 2007. Limitations of this study include the sample size, which is not a total representation of the adult providers who work with the Rhode Island adolescent population, and, due to the limited timeframe, I was not be able to reach out to potential participants who do not speak conversational English.

As in all qualitative studies, the subjectivity of the researcher is inevitable. While conducting my research and interview, I was aware of my biases toward the prevention of HIV/AIDS in adolescents. Remaining mindful of this subjectivity became important throughout the interview process and therefore enhanced the reliability of this study through the development of a non-biased questionnaire, as well as conducting each interview in a consistent manner by asking each participant all questions of the

questionnaire and never withholding questions from participants because of bias. I respond to their answers in an accepting, non-judgmental way.

Data Analysis

The interviews were completed by March 15, 2007. I then transcribed and analyzed the data from the recorded taped interviews, taking every precaution to ensure the confidentiality of each participant in this study. The names and all identifying information of participants were removed from the data collected. Also, all signed Informed Consent Forms have been separated from other materials and will remain locked in a secure location for the next 3-years. In accordance with federal guidelines, all Informed Consent Forms and all other data collection materials produced during the course of this study will be destroyed in 3-years in order to retain the confidentiality of all participants. If I need to keep the material for more than three years, it will be kept in a secure place and will be destroyed when no longer needed.

By using a qualitative methods design, I was able to collect the responses to each interview and develop a basic coding system. After each tape recording of the interview was reviewed and recorded in written form, I began coding the interview responses in accordance to the thirteen Questionnaire questions. The following chapter discusses the study's findings.

CHAPTER IV

FINDINGS

This chapter presents the findings from. The qualitative study exploring the HIV/AIDS crisis which is currently affecting, at an alarming rate, male and female black and Hispanic adolescents engaged in heterosexual sexual relations. The aims of the study were twofold: to understand the perceptions of adolescents about this crisis, as viewed through the eyes of their service providers, as well as to understand the concerns and recommendations of service providers about coping with this crisis.

Eighteen service providers were contacted by phone, and of these, fifteen agreed to participate in this study.

Description of Subjects

There were seven men and eight women participating, who ranged in age between 22 and 65; the mean age was 39. Eight participants defined themselves as either “Caucasian” or “White”, two as “French Canadian”, two as “Cape Verdian”, one as “Black/African”, one as “African American”, and one participant as “Puerto Rican.”

Agency Function

Of the fifteen adult service providers, eight were employed in adolescent school-based agency settings where the basic function of the agency is to educate adolescents. Two subjects had private, therapeutic outpatient practices specializing with the adolescent population; three worked in publicly-funded healthcare settings providing services to adolescents and young adults; one worked for a privately-funded adoption

agency focusing on adolescents and families in the process of adoption; and finally, and one held a position in a privately-funded soccer club as a coach to a group of adolescent males.

Position in Agency

The range of job positions held by these service providers is diverse. Of the eight subjects who work in a school-based agency, two defined their positions as “school social workers”; one as a “teaching assistant”; one as a “social work supervisor of social work staff”; one as the “director and social worker of health and wellness center”; two as “school psychologists”; and one as a “health and physical education teacher.”

The two subjects, who held private, therapeutic outpatient practices, defined their roles as “clinical social workers.”

Two subjects in publicly-funded healthcare settings were “nurse practitioners” and the third a “nurse.”

The subject working in an adoption agency was a “clinical social worker.”

One subject working for the soccer club is “a soccer coach.”

Overall, the breakdown of positions at different agencies shows that of the fifteen participants, two are teachers; seven are social workers; two are school psychologist; three are healthcare providers; and one is a sport coach.

Services to Adolescents

All participants held jobs in Rhode Island which provide services specific to the adolescent population of Rhode Island. No limitations were made to specific sub-groups of adolescents served. Two participants described their service as educators, and seven providing social work-related services, offered support, guidance, therapy, and advice to

adolescents on topics involving individual, family, school, and systemic issues. The two school psychologists did testing and offered support to individual adolescents struggling with academics or personal issues. The health care providers offered information about health-related issues, as well as providing medical health tests and treatment for health-related issues. The athletic coach described himself as a mentor as well as a coach.

Characteristics of Adolescents Served

Subjects were sampled from a diverse socioeconomic makeup of towns, cities, and rural areas, and therefore, responses were diverse in characterizing adolescents served. No subjects were asked to define their adolescent populations by sociocultural or socioeconomic characteristics, though some participants responded to the question in this manner: “14-15 year old white males”...“upper-class and educated”...“urban, mostly working-class, and minorities”. Six participants defined these adolescents as, “resilient...kids who have overcome major difficulties.” Three participants used the word “experimental” to define the adolescents they serve, while all participants seemed to portray their adolescents as “risk-takers” or as simply “difficult youth”: “Many of the teens I work with are in the 'at-risk population'...common issues are family history of drug and alcohol abuse, teen pregnancy, history of trauma and sexual assault.”

Question 1: Is HIV/AIDS treatment or prevention directly/indirectly involved with the work you do with your adolescent population?

Six participants responded that HIV/AIDS treatment or prevention was “directly” involved in their work with adolescents, while nine responded that HIV/AIDS treatment or prevention was “indirectly” involved. Several subjects who reported “indirect” association of HIV/AIDS related treatment or prevention mentioned they are more

subject to discuss “healthy decision-making and life-skills” with adolescent individuals who disclose their sexual history or current relationship information. One participant who reported to have “indirect” involvement of HIV/AIDS treatment or prevention mentioned (though it is not clear if the subject meant “emotional support” and or actual “HIV/AIDS prevention support”), “If a kid comes to me and tells me they have a family member who is HIV-positive or they know of someone who is infected, then I will support them around this issue.”

Of the six subjects who responded that HIV/AIDS treatment or prevention had a direct influence on their work, their major focus centered around education, awareness and prevention of HIV/AIDS with adolescents and all six seemed to feel personally compelled to include discussions of HIV/AIDS prevention individually with adolescents, regardless of the adult service provider’s agency and/or job position in agency.

Question 2: Do you think adolescents in your program are concerned about becoming infected with HIV/AIDS?

If so, what do they say or do to give you this impression?

Twelve participants responded that they did not think becoming infected with HIV/AIDS was a major concern of adolescents. One participant commented: “I don’t think they [adolescents] are too concerned. HIV/AIDS is discussed primarily as a joke or in reference to promiscuous girls, Africa, or homosexuals.” Another noted: “You have to realize that these kids have never lived in a world without AIDS. If anything, they will lump HIV/AIDS together with other STDs. I think these kids are more worried about other STDs and pregnancy than HIV/AIDS.”

Two subjects felt that adolescents were concerned about HIV/AIDS. One stated: “I have had several students ask me to go with them to get tested and they have talked to me about their concern for their boyfriends or girlfriends.” Another commented: “They come to me with a ton of questions about how you can become infected with HIV.”

One participant was uncertain: “Many teenagers are pretty fallible when it comes to this sort of thing...I hear my teens talk about STDs like herpes, but I have never overheard any discussions about AIDS. I don’t really know!”

These findings raise the question of reliability of the providers’ observations in terms of whether teens are unconcerned about HIV/AIDS or are not communicating their concerns to these providers. This point is discussed further in the concluding summary.

Question 3: How comfortable do you believe the adolescents you work with are in discussing issues of HIV/AIDS among each other?

Eight subjects felt that overall, adolescents are comfortable with discussing the issues of HIV/AIDS among each other. Several expanded their responses: “I think they are comfortable to discuss the topic if there is trust in the relationship with the friends.”...“Yes. The older they are, I think the more mature and comfortable a conversation about HIV/AIDS can become.”

Three subjects believed that adolescents are not comfortable discussing issues of HIV/AIDS amongst their peers. One noted: “This is an experimental age group we are talking about here. I don’t think there is any comfort in talking about something as serious as HIV/AIDS and especially when these kids are way more worried about social issues...”

Four subjects were “unsure” or “didn’t know”. One person explained: “It is hard to say because normally, I would think talking about anything with a peer—especially teenagers to teenagers—would be more comfortable than talking about it with someone else. But HIV/AIDS is such a hard topic to be comfortable about anyways, I don’t know what it is like for them [adolescents].” The responses to this question involve speculation on the subjects’ part, rather than substantiated evidence.

Question 4: How comfortable do you believe adolescents you work with feel in discussing the issues of HIV/AIDS with adults?

Most of the subjects (14 out of 15) implied their belief that discomfort exists in discussions between adults and adolescents on issues related to HIV/AIDS. One exclaimed: “They won’t even talk about issues like alcohol or drug use with an adult! I don’t think HIV/AIDS would be any easier—or comfortable—to talk about.” Another subject claimed: “I don’t think it is the kid’s responsibility to have a comfortable conversation with an adult. It’s the adult’s job to be comfortable and be able to initiate conversations about AIDS. It depends on the individual—like a trusted teacher or counselor.” A third adult service provider responded, “Definitely not comfortable...especially if the adult is the parent of the adolescent.”

Participants expressed stronger opinions about whether or not they believe adolescents are comfortable talking with adults about issues of HIV/AIDS than they expressed about teens talking to each other. One responded: “Yes, I believe they are comfortable with this. I think this because I do a lot of talking with teens about HIV/AIDS issues. I do most of the initiating, but it never seems like they are uncomfortable about it.”

Responses to this question raise questions about the comfort level in discussions between adolescents and adults about HIV/AIDS. While some subjects imply that adolescents are uncomfortable in bringing up this subject, there are also suggestions made that providers may be uncomfortable about this. There were some thoughts expressed that it is the adults' responsibility to initiate this subject with adolescents.

Question 5: Do you believe specific sub-groups of adolescents are at more or less risk for HIV-infection and why?

This open-ended, question produced a number of different answers which all stemmed from each participant's understanding or personal definition of "sub-group". Only two participants responded that there is no specific sub-group of adolescents at more or less risk of HIV-infection; "They all seem to be at equal risk for infection." Thirteen participants however, defined a sub-group of adolescents by race, gender, sexual orientation, sexual activity, risky behavior, socioeconomic status, and family dynamics/parent-teen relationship. Some of the diverse responses were:

"I see sub-groups of adolescents to mean those who are engaging in high-risk behaviors and those adolescents who are not. It's all about the behavior of the individual."

"I can't really answer that because I am a person of color and I work with teens that are also of color. Maybe I am biased but I think the stigma in this country shows people of color to be more of a target for HIV-infection—and that goes for the adolescent population, too."

“I think girls are at most risk for infection because they are most often the ones with low self-esteem and they don’t have the self-respect to protect themselves from pregnancy or STDs like HIV.”

“I think girls who are dating a lot older men would be a sub-group of adolescents I am more worried about having higher risk of HIV-infection.”

“I would have to say homosexual male teenagers are at most risk because their sexual behavior is just more risky.”

“Any youth that comes from a school with a poor health education program.”

“I think I would have to say any teenager who has a history of trauma like sexual abuse or even teens who are struggling with attachment issues. This trauma history can lead to low self-esteem issues and risky behaviors as a result.”

There are a variety of responses to this issue and some highlight gender, and two refer to females being at risk, which has been confirmed by researching findings. Some refer to mental health problems including at-risk behaviors, low self esteem, and trauma histories, which is discussed further in the concluding chapter.

Question 6: Do you believe certain sub-groups of adolescents are more or less concerned about HIV/AIDS and if so, why?

Only one participant felt that there is no certain sub-group of adolescents more or less concerned about HIV/AIDS. Fourteen participants believed that certain sub-groups of adolescents are more or less concerned about HIV/AIDS and responded in a number of ways, with common themes again being related to race, gender, sexual orientation, sexual activity, risky behavior, socioeconomic status, and family dynamics/parent-teen relationship. Some of the comments were:

“Yes! Impulsive teens are less concerned.”

Yes. Definitely the gay teenage boy is going to be more concerned about HIV than the heterosexual teenage boy. Also, I think African American teenagers, in general, are more concerned because it is just more prevalent among African Americans than White Americans.

More comments to this question were:

I think girls are more concerned about HIV than boys are. I mean, girls and women are generally more concerned about health overall in this society. Boys are trained—or brought up—to not show any fear or any concern about health issues and I know from being a parent myself that this is a serious thing for our boys.

“Yes, I think the more concerned teenagers are probably the ones who are more aware...those who are getting a better education and more access to knowledge about HIV/AIDS.”

Yes, though I would have to say the straight, White, affluent youth I work with seem to feel as though AIDS doesn't affect them...so maybe it's a race and class thing. I wish it wasn't this way—I mean, the reality is that any kid who is sexually active is potentially at risk, right? But, I don't see my kids worried in the least bit. Not even an issue.

There are a variety of interesting answers to this question, but answers seem to represent mostly informed opinions rather than having a specific factual base.

Question 7: Do you think that the adolescents you work with may be at risk for HIV/AIDS?

All fifteen participants felt that the adolescents they work with are at risk for HIV/AIDS. Some elaborated: “It's [HIV/AIDS] not an epidemic in our school, but it doesn't make it any less of a risk for our kids.”... “I say yes because I don't see any planning going on. These kids are highly sexually active—boys and girls—and there's no planning!” ... “Yes, I feel all adolescents are unless they practice abstinence.”

Question 8: With whom do you believe adolescents need to discuss their questions, concerns, and thoughts about HIV/AIDS?

Here, participants provided an array of answers about when adolescents need to discuss their questions, concerns, and thoughts about HIV/AIDS. Common characteristics used to describe a person whom adolescents need to talk with included someone who is: “trusted”, “knowledgeable”, and “non-judgmental”. No participant felt that adolescents have no options as to with whom they need to discuss their questions, concerns, and thoughts about HIV/AIDS; all subjects provided examples of people with whom adolescents need to discuss their questions, concerns, and thoughts about HIV/AIDS.

All fifteen participants answered this question in an affirmative manner; five identified “adults” to be whom adolescents should go to with questions, concerns, and thoughts about HIV/AIDS. Three participants answered without giving characteristic limitations, “Everyone or anyone who will listen!” Four participants believe “parents” are the ones adolescents should go to with concerns regarding HIV/AIDS. One participant replied, “With educated professionals” and two participants described themes of, “A role model or anyone who has a deep connection with the teenager.”

Question 9: Do you think families should play a role in prevention?

If so, how?

Eleven participants believed families should play a role in prevention. Some expanded their answers: “Parents need to first become comfortable with the issues of sex before they appear available to discuss HIV or prevention issues with their teenager.”...“Yes. Ultimately, I believe it is the parent’s role to talk prevention. As a

social worker, I believe it is part of my job to train parents on how to talk to their kids about tough issues like sex and how to approach their kids about AIDS in a non-judgmental way and with more ease.”

Four participants were ambivalent or uncertain about the role families should play. One ambivalent response was:

Ideally, yes, the parent should play a role in the HIV prevention. But, realistically speaking, this is not going to happen for many—most teenagers today. There is this huge disconnect going on between kids and their parents and I am not just talking about AIDS here! I mean, so many things come before a parent takes the time to talk to their kid about prevention—and that’s for a kid who is going home to a home where there is a parent! I don’t know. I think it is nice to sit here and think, yeah, parents should be involved and all, but I have no idea how to—as a parent myself—control my kids behavior and talk to them about stuff that is not very comfortable to talk about in the first place! I think the parent is not always the best person to go to for this sort of thing.

Question 10: Do you think the medical profession should play a role in prevention? If so, how?

All fifteen participants felt that the medical profession should play a role in prevention. Eight in this group did not supply a further response to this question because they all felt that the medical profession “already plays a role” in prevention and found it unnecessary to explain their answer further. Seven provided some examples of insight into how the medical profession can do this “with more impact”: “They [medical profession] have, but they don’t seem to talk about it as much anymore. I don’t think they are concerned as they should be and they need to figure out a better way to get their preventative efforts out there to the younger kids because kids are getting younger and younger when it comes to having sex.”...“Yes! The healthcare community needs to be more accessible to more people and find some way to make teenage boys realize that

condoms are cool and necessary if abstinence is not chosen.” Five participants mentioned they felt that the overall approach by the medical professionals of Rhode Island did not include a “serious” or “active” enough role in HIV/AIDS prevention geared specifically towards the adolescent population. On how to change this problem, one participant suggests, “Maybe doctors could talk to young people more often about condoms—like during yearly check-ups—make it a Rhode Island state-mandate.”

Question 11: Do you think schools should play a role in this problem?

If so, how?

All fifteen participants felt that schools should play a role in the HIV/AIDS problem. However, the degree and approach to how schools should play a role in the HIV/AIDS problem differed. Three participants believe: “The school needs to play the biggest role. It is where teenagers spend most of their time and are building important life skills.” For five participants, the theme of earlier intervention was discussed: “HIV/AIDS education and awareness in schools is happening way too late for most teens today. Kids are having sex earlier in life and I think if schools are going to play a significant role in prevention, we need to all get on the same page and start educating kids earlier about AIDS.”...“Health class is just a start to the whole HIV/AIDS thing. I think schools should take a more holistic approach to the AIDS problem. Maybe develop a curriculum where the issues of HIV/AIDS can be addressed in the different subjects and by different teachers so there is a better chance of a teenager to get the message.”

Question 12: What is your opinion about the general social and political climate in this state in terms of dealing with HIV/AIDS prevention and early intervention?

There were many varied opinions about the general social and political climate in this state in terms of dealing with HIV/AIDS prevention and early intervention, including uncertainty about this situation. Four participants responded: “I do not know”, or “I don’t know enough about the issue at the state-level to make any comment”. The remaining eleven participants gave eleven different answers to this question:

“To be honest with you, I am pretty disturbed by the whole thing. I don’t feel as though Rhode Island has put enough of the funding into programs for teenagers where issues like AIDS can be addressed.”

“I don’t feel like Rhode Island is doing enough to stop the spread of HIV in our teen population. I feel like religion gets in the way, which is so ironic because it results in so many teen pregnancies.”

“The only proof of HIV prevention in Rhode Island is the TV ads and billboards that promote abstinence. This is not going to work for everyone. This state needs to be fair and give options to everyone on this issue.”

“I think over saturation is happening and we are all beginning to tune out the HIV/AIDS thing. Now we all think AIDS is a problem in Africa. Our government is not doing a good enough job in reaching out to the youth. We need to do a better job at really trying to meet the kids at their level—not ours.”

“Sex is still such a taboo subject in our state and in our country. We need to first be able to change the way our culture views the issues of sex before we see any major change over the way we deal with HIV/AIDS. Something has gotta give.”

Question 13: Do you have any suggestions for preventing the spread of HIV/AIDS among our adolescent population?

There were many suggestions made regarding preventing the spread of HIV/AIDS among our adolescent population. Only two participants gave no suggestions. Examples of these suggestions include:

This is a hard question. I feel like my biggest struggle is seeing the same people coming back over and over again to get tested for STDs. I mean, how can I control someone's behavior? I think what I am realizing—and I am not very proud to admit this, but—I think this is a problem bigger than you and me, you know? There needs to be more of collaboration of efforts from everyone—the schools, the politicians, the healthcare system, and even the church. A lot of these kids who come into my clinic with STDs have so many other problems going on in their lives, it's like you have to pick and choose your battles.

“We need to listen to teens more. I think they know more than we give them credit for.”

“We need to educate our youth earlier in life.”

“I worry our kids are not getting the whole picture. We as adults need to be more equipped with this information and be able to initiate conversations with our kids more often. Another thing is that I feel like all schools should have free condoms readily accessible.”

“We need to educate them about the dangers of unprotected sex by letting them feel comfortable talking to adults about it.”

Summary of Findings

This chapter represents major findings from a study exploring the views and perceptions of adults working with adolescents in Rhode Island on the issues of HIV/AIDS and adolescents. While responses were diverse in characterizing the

sociocultural and socioeconomic makeup of the adolescents served by the subjects of this study, all participants seemed to portray their adolescents as “risk-takers” or as “difficult youth”. All participants seemed to feel personally compelled to include discussions of HIV/AIDS prevention individually with adolescents, regardless of the adult service provider’s agency and/or job position in agency. All participants report having some level of HIV/AIDS involvement in their interactions with adolescents served, though there is variance in the approach and level of involvement.

Twelve of the fifteen subjects believe teens are not concerned about becoming infected with HIV/AIDS. However, there is question about the reliability of the providers’ observations of teens’ attitudes in terms of whether teens are unconcerned about HIV/AIDS or are not communicating their concerns to these providers. This finding has implications for further understandings on whether adults and adolescents are communicating their concerns, like risk of HIV-infection, and only strengthens the argument to hear first-hand accounts from adolescents on the HIV/AIDS issue.

While subjects remain uncertain about how comfortable they believe adolescents to be in discussing issues of HIV/AIDS amongst peers; almost all (14 out of 15) participants responded that they believe that discomfort does exist in discussions between adults and adolescents on issues of HIV/AIDS. While it was implied that adolescents are uncomfortable in discussing HIV/AIDS, it was my impression that some providers may also be uncomfortable with this subject. This raises the issue of exploring further the providers’ attitudes and feelings, which was beyond the scope of this study; this point is elaborated in the final chapter.

All participants believed that the adolescents they served, regardless of sociocultural and socioeconomic background, are at risk for HIV/AIDS. All participants agree that incorporating the family in preventative HIV/AIDS efforts with teenagers is a complicated and difficult task, yet important, all the same; subjects were ambivalent and uncertain about the role of the family in HIV/AIDS preventative work. All participants agreed that the medical profession must have a role in HIV/AIDS prevention; degree of involvement and approach of this service group differed. All fifteen subjects agreed that schools should play role in HIV/AIDS preventative efforts; differences fall among issues with curriculum content and appropriate grade-level for HIV/AIDS topic.

In response to subjects' opinion of current, general, social and political climate of Rhode Island in terms of HIV/AIDS prevention and early intervention, answers varied. Those eleven subjects who had opinions were overall critical and seemed to desire stronger leadership to address the issues of religion, abstinence, political and social climate, and program funding. Finally, findings from subjects on recommendations for preventing the spread of HIV/AIDS among the adolescent population were many and diverse. Only two of the fifteen participants did not suggest a recommendation. Most recommendation responses seemed to imply a level of concern in response to the current serious situation. The participants were not content with the actions taken thus far in stopping the spread of HIV/AIDS among our youth population. The implications for future study of these findings are discussed in the following chapter.

CHAPTER V

DISCUSSION AND CONCLUSIONS

Adolescents, mostly black and Hispanic youths engaged in heterosexual sexual relationships, are currently being infected by HIV/AIDS in large numbers, although this disease is declining in the general US population. This qualitative study focused on adolescents at-risk for HIV/AIDS in Rhode Island, as seen through the eyes of their adult service providers. Special emphasis was placed on understanding the vulnerabilities of at-risk adolescents, and exploring what efforts at prevention and early treatment are being carried out, what additional efforts are recommended, and what are the attitudes and concerns of both adolescents and their adult service providers toward this issue. This chapter presents a summarization of the findings, discusses implication for practice, critiques the methodology of the study, and proposes future research.

This study followed a qualitative, flexible, descriptive research design. A semi-structured questionnaire was designed and 15-adult providers in the state of Rhode Island who work with the state's adolescent population were interviewed for one hour about their work with adolescents, regarding their own perceptions of the HIV/AIDS epidemic, and their perceptions of adolescents' knowledge, behaviors, fears, and attitudes regarding HIV/AIDS.

Discussion of Major Findings

The fifteen participants included two teachers; seven social workers; two school psychologists; three healthcare providers; and one sports coach. They all expressed concern about HIV/AIDS, and they all made attempts in varying ways to deal with this problem with the adolescents they worked with, regardless of their agency's function or their own position and function within the agency.

It had been my assumption that we would be able to learn from the subjects about adolescents' attitudes towards HIV/AIDS. However, the uncertainties, and at times contradictory reports from different providers raises the question of the reliability of their observations. It is not certain whether teens reported as being unconcerned are actually so, or are not communicating their concerns to these providers. There were also speculations by the subjects, rather than substantiated evidence, concerning whether adolescents were comfortable sharing their concerns about this subject with peers. Furthermore, while some subjects implied that adolescents are uncomfortable in bringing up HIV/AIDS with them, there are also comments made by providers suggesting that they themselves may be uncomfortable discussing this with adolescents. Two important implications follow from this: first, more research needs to be done regarding adolescents' response to HIV/AIDS prevention; secondly greater understanding is needed about the feelings and attitudes of adolescent service providers.

There were diverse responses to the question of which sub-groups of adolescents are more at-risk for this infection and sub-groups were classified in various ways by the participants. Some subjects highlighted gender, noting that females are at risk, a fact confirmed by other research findings. Some subjects referred to mental health problems

including at-risk behaviors, low self esteem, and trauma histories, which are important points which were beyond the scope of this study, and which need further exploration. HIV/AIDS has been shown to be high in the homeless population. Exposure to HIV/AIDS is also associated with alcohol and drug abuse (as well as contaminated needles) and may also be motivated by depressive and self-destructive behaviors. Suicide is the third leading cause of death in adolescents; forms of "disguised" suicide, such as some provoked homicides and some one car accidents have been shown to be suicidal in nature, which raises the question of whether, for some, risk-taking behaviors regarding AIDS is also suicidal in nature (Urdang, in press).

While many subjects felt families should play a role in prevention, complications to doing this were raised, such as problems in parent-child communications, and mutual parent-child discomfort in discussing sexual matters. All subjects felt that both the medical profession and schools should take proactive roles in HIV/AIDS prevention, although there was not unanimity in how this should occur and complications in implementing this were presented.

In response to subjects' opinion of the current, general, social and political climate of Rhode Island in terms of HIV/AIDS prevention and early intervention, answers varied. Eleven subjects who responded were generally critical and seemed to desire stronger leadership to address the issues of religion, abstinence, political and social climate, and program funding. "Sex is still such a taboo subject in our state and in our country. We need to first be able to change the way our culture views the issues of sex before we see any major change over the way we deal with HIV/AIDS" . . . "I am pretty disturbed by the whole thing. I don't feel as though Rhode Island has put enough of the

funding into programs for teenagers where issues like AIDS can be addressed.” Most of the responses from participants mirror the complications of what is happening at the national-level on how to address the problem of HIV/AIDS among our adolescents. One participant provides insight into the complexity of the psychological and systemic aspects of this issue:

This is a hard question. I feel like my biggest struggle is seeing the same people coming back over and over again to get tested for STDs. I mean, how can I control someone’s behavior? I think what I am realizing—and I am not very proud to admit this, but—I think this is a problem bigger than you and me, you know? There needs to be more of collaboration of efforts from everyone—the schools, the politicians, the healthcare system, and even the church. A lot of these kids who come into my clinic with STDs have so many other problems going on in their lives, it’s like you have to pick and choose your battles.

Findings from this study suggest the need for further research on the topics of HIV/AIDS and other adolescent problems which is discussed at the end of the chapter; this follows the critique of the implications of this study for both micro and macro-level practice.

Implications for Social Work Practice

Today HIV/AIDS is a pandemic which is affecting the lives of millions around the world. As social workers in the US continue to fight for those individuals who are underserved because of injustice and societal discrimination, HIV/AIDS continues to thrive and infect such at-risk populations as the minority adolescent population of this country. I believe that social workers, regardless of agency or practice model, hold the potential for both micro-level and macro-level change as it applies to the issues of HIV/AIDS and adolescents.

On the macro-level, community organization efforts are badly needed, and as some subjects of this study advocate, collaborative efforts are essential including work with government policy-makers, the public healthcare system, and the education system. Outreach efforts, including the provision of constructive medical, social and educational programs should be offered to homeless teens, and also need to be expended in black and Hispanic communities, where they are often impeded due to negative community attitudes towards homosexuality, which often extend to AIDS.

The stigma associated with homosexuality in the black and Hispanic communities is very strong, making it harder for gay people to identify themselves as such; this (in addition to the stigma against drugs) keeps many people in these groups from seeking medical services for AIDS, even if they are not gay. Serious outreach efforts to these communities and to the vulnerable young people at risk are needed (Urdang, in press).

Efforts to promote needle exchange for IV- drug users have been suggested as helpful, and while successful in some localities, more work is needed. Promoting sex education programs in schools, other than exclusive emphasis on abstinence has been recommended by many, but often opposed for political and religious reasons.

The United Nations as well as the U.S. government have been actively promoting treatment and prevention of AIDS throughout the world. Yet, although markedly increased spending on AIDS by the U.S. government is expected to prevent 9 million deaths in coming years, the "administration has taken information about condoms off government web sites, and its AIDS prevention efforts abroad, when aimed at young people, have emphasized abstinence to the exclusion of condoms" (Kristof, 2006, p. A31). In the United States, the emphasis on abstinence and teens taking abstinence pledges also characterizes sex education programs, which many critics feel is to the detriment of preventing AIDS in adolescents. "The evidence indicates that a balanced approach - encouraging abstinence but also promoting condoms - is far more effective at protecting young people in America or abroad from sexually transmitted infections, including H. I. V." (Kristof, 2006, p. A31) (Urdang, in press).

I believe it is also the responsibility of micro-level social workers to empower themselves to become aware, informed members of society and of the social work profession on issues of HIV/AIDS, and to hold more informed conversations with adolescents about topics of sexuality, personal values, stigmas, and risk-taking behaviors; this can be empowering to teens. Clinical social workers should also assess teens for substance abuse as well as depressive and suicidal behaviors, which may be significantly associated with the acquisition of HIV/AIDS.

In working on family relationships, helping parents address sexuality in general, and AIDS prevention in particular can be helpful. One of the research subjects commented: “As a social worker, I believe it is part of my job to train parents on how to talk to their kids about tough issues like sex and how to approach their kids about AIDS in a non-judgmental way and with more ease.”

Critique of Methodology

There were several positive aspects involved in the methodology of this study. Through the process of researching potential participants, I was able to contact a wide variety of individuals throughout the state of Rhode Island; the snowball sampling process proved to be an effective method for recruitment. Out of the eighteen potential subjects I contacted by phone, only three contacts declined to participate. All eighteen people were helpful in suggesting other potential participants for my study.

Another advantage of this study’s methodology was the utilization of a qualitative research model, which proved effective for the purpose of the research. Data collected

from this study can be a source for further research as well as a source for discussion among other interested individuals working with adolescents.

Limitations of the Study

Limitations of this study include that the findings only pertain to a narrow geographic area, and only allowed for a partial representation of adolescent service providers. The time period in which I was carrying out my fifteen interviews was another limitation because, during the months of January, February, and March 2007, I encountered several potential subjects who were eager to participate, but were unable to, due to the busy time of year where schools are experiencing holidays and week-long vacations, as well as termination of school terms; medical personnel were struggling to keep up with the high influx of winter health issues; and social workers were simply busy! If more time was given to conduct the interviews, I believe there may have been chance for a stronger, more diverse cross-section of participants.

Also, the design of this study did not allow for in-depth exploration of case histories, which would have provided greater insight into the complex psychosocial issues of adolescents, especially those at high risk.

Another limitation was the actual subject group; originally, my intention was to interview the adolescent population to obtain their first-hand accounts of concerns, perceptions, and recommendations on the issue of HIV/AIDS. Yet, because this population is considered a high-risk group for being marginalized in a human study, and parental consent would have been necessary, I chose the adult population.

Lastly, another limitation to this study was in the interview process with each participant; more time for expansion to subject's responses to questions would have

provided more data for interpretation and would have added to the quality of this study's findings.

Directions for Future Study

This is just the beginning. There is great potential for conducting future diverse studies in the social work field with HIV/AIDS and adolescents. A major priority of future study is to work directly with the adolescent population. Just as Dashiff, (2001) insists, "Adolescent research settings can pose challenges... the application of theoretical and empirical knowledge about adolescent development can strengthen data collection instruments and procedures" (p. 343).

A serious shortcoming of this thesis study was my inability to interview adolescents directly about their thoughts on the HIV/AIDS pandemic. First-hand accounts by adolescents of what concerns, perceptions, and recommendations they hold toward the issues of HIV/AIDS and preventative measures will not only strengthen the research on this topic but may contribute insight into to issues which affect adolescents. Focus group research with adolescents might be productive.

Another area for future study could involve issues of mental health, such as teenage depression and suicide and see if they are associated with the risk of HIV-infection.

Discovering what methods and measures for successful preventive HIV/AIDS programs have been implemented with the adolescent population over the last 25-years since the HIV/AIDS pandemic began would provide the social work community with valuable information.

Conclusion

It is my hope that this study will bring a level of urgency and concern about the HIV/AIDS crisis to both the social work profession and the familial, educational, medical, and political communities of the United States. More research is urgently needed to focus on the issues and concerns of the adolescent population related to HIV/AIDS prevention, education, and treatment. The priority in this fight to stop the spread of HIV/AIDS is a strong recommendation that early testing and medical treatment become essential, and primary prevention becomes an optimal goal.

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Appendix A

Informed Letter of Consent Form

Dear Participant _____:

My name is Oriana Campanelli and I am currently a student in the Smith School for Social Work Master's program, and am interested in studying HIV/AIDS in the teen population in Rhode Island. As a service provider to adolescents, your viewpoint about this serious problem is of great value, and will contribute to knowledge about impediments to prevention, positive efforts at prevention and early treatment being carried out, and recommendations for future action. This study will fulfill my thesis requirement, at Smith College School for Social Work, and data obtained may also be used for future presentations and publications on this topic.

You have been asked to participate in this study because you are a service provider to teenagers in Rhode Island. I understand that you are at least 21-years old and speak fluent conversational English. I ask you to allow for one, 60-minute interview, in order to discuss your observations and concerns about this subject. During the semi-structured interview, I will take written notes, and audiotape the session, which I will later transcribe myself. I expect all of my interviews to be completed by March 15, 2007.

Minimal risk to you of emotional discomfort or stress from participation in this study is anticipated, as interviews will not require personal, behavioral information from you.

The benefits to participating in this study are many! First and foremost, the information you will provide will benefit our understanding of the HIV/AIDS issues in the at-risk age group of adolescents in R.I. This can lead to the development of strategies for overcoming this preventable disease. By participating in my study, I hope you will recognize how grateful I am to your invaluable insight on a critical subject affecting the lives of young people.

Every effort will be made to ensure the confidentiality of your participation. Your name and all identifying information will be removed from the data collected. Your signed Informed Consent form will be kept separate from the other materials. All informed consents will be kept locked for 3-years, according to federal guidelines, after which I will destroy any form of recorded information, as well as all consent forms of all participants to retain your confidentiality.

My research advisor will have access to the interview data after identifying information has been removed. If I use interview material for presentations or publications within the 3-year time frame, utmost care will be taken so that subjects will not be identified. If I need to keep the material for more than three years, it will be kept in a secure place and will be destroyed when no longer needed.

Of course, your participation in this study is completely voluntary. If you no longer want to participate in this study, prior to, during, or after the interview process, you may withdraw without repercussion. You have the right to refuse to answer any question. The final date for withdrawal from this study will be March 15, 2007, when I end my data collection, and start preparing the research results.

You can contact me in case you have any additional questions or wish to withdraw by using my contact information at the bottom of the form. I look forward to having you as part of my research study and thank you for your participation.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Signature of participant:

Date:

Signature of Researcher:

Date:

If you have any questions or wish to withdraw your consent before March 15, 2007, please contact me:

Oriana Mae Campanelli
E-mail: ocampane@email.smith.edu

Please keep this copy for your records so you can contact me!

Appendix B

Recruitment Letter Section I: Informational Phone Call

This is an outline of what my preliminary phone call will look like with all potential participants of my study. Please note that this will be my first form of contact with all individuals and this phone call outline is subject to change depending on the response from the potential participant.

- 1.) Research the individuals work phone number and call during service hours.
- 2.) Introduce myself (my name; Smith SSW; thesis topic; etc.).
- 3.) Explain my reason for contacting this individual.
- 4.) Ask questions to gather more information about this potential participant (e.g. Do you work with adolescents; Do you have any programs related to AIDS and adolescents; Would you be interested in discussing this subject with me?)
- 5.) Ask individual if he/she is interested in participating in my study-

IF NO- Thank the individual for their time; maybe ask individual to refer me to another potential participant and end phone call.

IF YES- Move onto Question 6 and the “Recruitment” Phone Call Phase (Section II, below)

- 6.) Clarify recruitment requirements with individual (work with youth in RI; observe level of conversational English; verify individual’s age).

Section II: Recruitment Phone Call

This is a brief outline of what my phone conversation will look like when talking with an individual who has verbally agreed to participate in my study. Please note that this outline is subject to change depending on the response from the participant.

- 1.) Greeting (ONLY if this is the call-back to the individual who has agreed to participate in my study).
- 2.) Explain in further detail the requirements of the participant in my study, including time, recording of interview, and note taking.
- 3.) Ask participant if there are any questions about the study at this time.
- 4.) Schedule interview date, time, and location
- 5.) Request mailing address from participant where a confirmation letter/email along with a copy of the Consent Form (See Attachment B), will be sent for their review and records.
- 6.) Ensure participant of their confidentiality throughout the entirety of their participation in this study.
- 7.) Ask if there are any further questions or concerns at this time from participant.
- 8.) Thank participant and end conversation.

Appendix C

Oriana Mae Campanelli
HSR Application
Questionnaire

Date of Interview: _____ Location of Interview: _____

Interview Start Time: _____ Finish Time: _____

Additional notes/comments: _____
_____.

Demographics and Introduction-

Age:

Gender:

Race/Ethnicity: (optional)

Agency:

What is the function of your agency? [Is it e.g. a school, hospital, public health setting, recreation center, etc.]

Auspices: Public- Private. [Who funds it? - e.g. state, federal, United Way, etc.]

Position:

What is your job title?

What are your major job responsibilities?

Adolescents:

What services does your agency offer to adolescents?

Are you directly involved in working with adolescents? If so, how?

How would you characterize the adolescents who are involved in your program?

-
1. Is HIV/AIDS treatment or prevention directly/indirectly involved with the work you do with your adolescent population?
 2. Do you think adolescents in your program are concerned about becoming infected with HIV/AIDS? If so, what do they say or do to give you this impression?
 3. How comfortable do you believe the adolescents you work with are discussing the issues of HIV/AIDS among each other?

4. How comfortable do you believe adolescents you work with feel discussing the issues of HIV/AIDS with adults?
5. Do you believe specific sub-groups of adolescents are at more or less risk of HIV-infection and why?
6. Do you believe certain sub-groups of adolescents are more or less concerned about HIV/AIDS and if so, why?
7. Do you think that the adolescents you work with may be at risk for HIV/AIDS?
8. With whom do you believe adolescents need to discuss their questions, concerns, and thoughts about HIV/AIDS?
9. Do you think families should play a role in prevention? If so, how?
10. Do you think the medical profession should play a role in prevention? If so, how?
11. Do you think schools should play a role in this problem? If so, how?
12. What is your opinion about the general social and political climate in this state in terms of dealing with HIV/AIDS prevention and early intervention?
13. Do you have any suggestions for preventing the spread of HIV/AIDS among our adolescent population?

Ending questions-

Is there anything I left out that you think is important for us to include?

Do you have any additional questions, comments, and/or concerns?

How did you feel about this interview?

Why did you decide to participate in this study?

Do you have any suggestions for further research?

Do you have any additional contacts that you believe may be interested in participating in my study interview?

Appendix D

January 18, 2007

Oriana Mae Campanelli
XXXXXXXXXX
XXXXXXXXXX

Dear Oriana,

Your amended materials have been reviewed. You have done a very careful job in attending to all of the revisions requested and we are now happy to give final approval to your project. Please send a cleaned up final copy to Laurie for the permanent files (All in black with the deletion removed, etc.)

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain signed consent documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project. This is a very important area and it will be interesting to discover how much attention this issue is really getting.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Esther Urdang, Research Advisor