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Factors Contributing to the Increase in HIV/AIDS and Late Diagnoses of the Virus among Older Adults

Lorraine C. Barnett
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Walden University

COLLEGE OF SOCIAL AND BEHAVIORAL SCIENCES

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Lorraine Barnett

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Walden University
2011

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Lorraine C. Barnett

M.S.W., Columbia University, 1997
B. A., Herbert Lehman College, 1993

Dissertation Submitted in Partial Fulfillment
Of the Requirements for the Degree of
Doctor of Philosophy
Human Services
Clinical Specialization

Walden University
June 2011

Abstract

The Centers for Disease Control and Prevention predicted that the incidence of HIV/AIDS among the American population aged 50 years and over would account for 50% of all HIV/AIDS cases in the United States by 2015. Yet there is little research available about the reason for the high prevalence or the availability of interventions available for this population. The purpose of this study was to explore factors related to HIV/AIDS awareness in a group of older recipients of health care and their health care providers. This study was intended to help fill the information gaps in this area by using a conceptual framework based on systems theory and social network theory. A mixed-method design was used to collect data; semi-structured interviews were conducted with a sample of 17 health care providers and analyzed using thematic content analysis. Structured exploratory surveys were distributed to a sample of 99 HIV/AIDS-positive adults, aged 50 and over, to understand common factors likely to have contributed to their infection and the results were compared to common factors already identified in the general population in the literature. Results of this study indicate possible communication barriers that exist between care providers and their older clients when discussing topics related to behavioral factors contributing to HIV/AIDS. This study contributes to social change by adding support to the importance of education programs and awareness campaigns about factors related to HIV/AIDS to curtail the spread of this disease among older adults.

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Chapter 1: Introduction

“Years ago, I came out to my mother about being gay. Recently, I came out to her again, this time about being HIV-positive. “Why bother?” you might ask. Some people don’t ever come out about their HIV status (only their doctor knows). I didn’t want to be one of them. I’m 64, my mother is 85. As my mother ages, she talks about her medical problems. She survived a stroke a few years ago and I was there during part of the recuperation. I saw and heard about medications she takes, the doctors’ visits, the symptoms that came and went. I had a similar medical scenario, but I was afraid and ashamed to describe it because of the risk of hurting her or of being rejected, since HIV remains one of the most highly stigmatized diseases. The irony that my mother could talk about her health issues while I could not (or would not) talk about mine became annoying and unacceptable.” (Story of Mr. J)

On buses and subways, billboards and bus stops, in the media and on television, people are warned about human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) transmission and advised either to abstain from premarital sex or to practice safer sex. The graphics of these public service announcements depict both men and women, heterosexuals and homosexuals, as well as people of most races and ethnicities. Missing from these pictures, however, are the faces of people aged 50 and over, even though there has been a rapidly rising incidence of HIV transmission in this age group. People aged 50 years and over now reportedly account for approximately 11% to 15% of the diagnosed HIV/AIDS population in the United States (Centers for Disease Control [CDC], 2003), and are predicted to make up 50% of all HIV/AIDS cases in the United States by 2015 (Ohio University, 2007).

HIV/AIDS has become an increasingly important aging issue. Statistics from 2003 show that 11% to 15% of all U.S. AIDS cases occur in people over the age of 50 (National Association of HIV over Fifty [NAHOF], 2003), and by 2005 it was reported

by the CDC (2005) that there were a total of 118,370 diagnosed cases of AIDS among people aged 50, representing 12.43% of all cases in the United States. This included 30,996 cases among people aged 60 or over (CDC, 2005), a startling increase from the 1,413 reported AIDS cases among people aged over 60 between 1981 and 1987 (CDC, 2003). As the general population ages and the generation of baby boomers ages, the percentage of older adults at risk for HIV shows signs of increase. In addition, there are currently HIV-positive adults who have transitioned into older adulthood with the virus, and there are an increased number of aging partners (Bartlett, Cheever, Johnson, & Paauw, 2004). Furthermore, with improved treatment options, the nature of HIV/AIDS is projected to change, transforming a lethal, acute disease, into a chronic illness with a significant increase in the number of cases among of older adults (Bartlett et al., 2004).

Despite the fact that this age group accounts for a considerable proportion of all diagnosed HIV/AIDS cases, few large-scale public intervention efforts have been targeted at this group, and levels of testing for HIV/AIDS among older people are relatively low (National Institute on Aging [NIA], 1999). As a result the NIA noted, diagnoses of HIV/AIDS are often delayed among older adults, leading to poor outcomes in terms of rapid health decline and a high level of HIV/AIDS-related mortality. Additionally, relatively few resources have been allocated to research the problem of HIV/AIDS among older people. It has been reported that the NIA in the U.S. recently allocated only \$1.8 million for AIDS related research, compared with the \$174 million allocated by the National Institutes of Health for pediatric HIV/AIDS research (Entwhistle, n.d.)

In order to understand and address the problem of HIV/AIDS among people age 50 and over, there is a need to investigate not only the characteristics and behaviors of older people themselves but also current health care practices that may be contributing to delayed diagnoses and poor outcomes for HIV/AIDS patients such as whether or not there is a perception among health professionals that this population is not at high risk for infection. If this is the case, it may be that current or past sexual or other high-risk behaviors are not taken into account when diagnosing symptoms, which are therefore attributed to the natural ageing process rather than HIV/AIDS.

Background

There is a lack of consensus about the origin of AIDS and HIV, but the most likely explanation is that the virus originated as a result of a mutation of an African monkey's virus (Tulane National Primate Research Center, 2006). The presence of related retroviruses in African monkeys and apes and the close relationship of HIV to a chimpanzee immunodeficiency virus all suggest that Central Africa may have been the site of the evolution of HIV (Brigitte, Bailes, Sharp, & Hirsch, 2010).

In 1978, the HIV virus was detected among heterosexuals in Haiti and Tanzania, and in homosexual men in the United States (Friedland & Klein, 1987). By 1981, 159 deaths had occurred in the United States that are now believed to be due to HIV/AIDS. In July of 1981, the *New York Times* reported a high rate of occurrence of a rare form of cancer among gay men in New York and California. At first called the "gay cancer," it was Kaposi's sarcoma. At about this time, emergency rooms in New York City began to see a large number of previously healthy young men who had fevers, flu-like symptoms, and pneumocystis pneumonia (HI-V, 2011). In June, 1981, the CDC (1981) issued its

first warning about a relatively rare form of pneumonia among a small group of young gay men in Los Angeles, which was later determined to be AIDS-related. About a year later, the CDC linked the illness to blood transmission and coined the term AIDS. Within a year, more than 1600 cases were diagnosed in the United States, and there were around 700 deaths. As time progressed, HIV/AIDS claimed more and more lives. President Reagan, however, did not publicly acknowledge the AIDS crisis until 1987, when he finally used the words "AIDS" in public, while at the same time the United States shut its doors to HIV-infected immigrants and travelers (CDC, 1981).

Since that time, more than 65 million people have been infected with HIV worldwide, including 39.5 million who are estimated to be living with HIV/AIDS at the time of this writing. As of December 31, 2001, there had been 807,075 diagnosed cases of AIDS in the United States and of this total number 462,653 (57%) had reportedly died (CDC, 2001). Another 161,976 were estimated to have human immunodeficiency virus (HIV) infection but were not yet diagnosed with AIDS (CDC, 2007). Globally, the World Health Organization (WHO) estimated in 2002 that around 42 million people were living with HIV or AIDS, and that an additional 5 million people were infected with HIV in 2002 alone (WHO, 2002).

Overall, the AIDS-related mortality rate has declined in recent years largely due to developments in antiretroviral drug therapies which help to prolong life. In the United States, deaths as a result of AIDS declined in 1996 for the first time by 25%, and age-adjusted death rates from HIV infection declined by 47% from 1996 to 1997, reaching the lowest rate since 1987 (CDC, 2001; National Center for Health Statistics, 1998). Those

declines were in large part a result of advances in combination of antiretroviral drug therapy. However, there are still substantial disparities between socio-demographic groups in terms of rates of diagnosis, and these continue to increase in some groups. For example, the increasing numbers of AIDS diagnosis among women, especially older women and ethnic minority women, is a serious public health concern. Women exposed to HIV infection through heterosexual contact reportedly account for the largest number of newly diagnosed cases of HIV infection in the United States, and the percentage of diagnosed AIDS cases among women rose from 7% in 1985 to 18% in 1996.

Statistically, women diagnosed with AIDS do not live as long as men diagnosed with AIDS, although it is not known why this should be the case. There are also differences between ethnic groups, and in 2001, rates of new AIDS diagnoses were reportedly higher among Black women than among any other group (Hariri & McKenna, 2007).

Initially, individuals aged 50 and over did not constitute a large proportion of those diagnosed with HIV/AIDS in the United States, where just 3,684 individuals between the ages of 50 and 59 years were diagnosed with AIDS between 1981 and 1987. This is a small number in comparison to the 23,239 adults, aged 30 to 39 years, who were diagnosed with AIDS during those same years. However, between 1996 and 2000, the number of individuals with AIDS, aged 50 to 59 years, increased to 23,980 (CDC, 2001). There was also an increase over time in diagnosed AIDS cases among individuals aged 60 years and over, from 1,413 between 1981 and 1987, to 8373 between 1996 and 2000 (CDC, 2003). By 2005, CDC reported that there were a total of 118,370 diagnosed cases

of AIDS among people aged 50 years, representing 12.43% of all cases in the United States. This included 30,996 cases among people aged 60 years or over (CDC, 2005).

The increase in numbers of diagnosed AIDS cases among people aged over 50 in the United States has been largely attributed to older Americans' lack of knowledge regarding HIV transmission, a resistance among older people to adopting prevention strategies (Strombeck, 1998), and a corresponding lack of regular testing. The rising incidence of HIV/AIDS among older people may also reflect the fact that they are not often targeted by health care workers and educators for HIV education, and may be less likely to talk about their sex lives in general (National Institute on Aging, 2003). More recently, the use of Viagra has been identified as a likely factor contributing to the spread of HIV/AIDS, particularly among older people, because this drug makes it possible for men to remain sexually active at older ages and thereby increases the likelihood of transmission within this age group. A recent study of 260 HIV-positive older adults, conducted by researchers at the University of Ohio, found that 1 in 3 sexually active older adults who are HIV-positive have unprotected sex. Most of these were male, taking Viagra, and in a relationship (University of Ohio, 2007).

A number of factors are also likely to contribute to the delayed diagnosis of HIV/AIDS among older adults. First, health care providers, caregivers, and educators might hold perceptions that older people are not sexually active or unlikely to participate in high-risk behaviors. As a result, they may fail to consider the possibility that symptoms of ill health might be caused by the HIV/AIDS virus when diagnosing symptoms and may fail to ask for potentially relevant information about sexual behavior or drug-related

experiences. At the same time, the patients themselves may not offer this information voluntarily, either due to embarrassment or a lack of awareness of its possible significance. More generally, the elderly may feel uncomfortable in discussing sexual practices with their primary care providers due to embarrassment and perhaps because of a perception that younger people, including their health care providers, will expect them to know more about protection than they really do (Zablotsky, 2003). The National Social Life, Health and Aging Project, the first nationally representative survey on sexual activity among older Americans, found that although the majority of people aged 57 to 85 years are sexually active, only 38% of men and 22% of women had discussed sex with a doctor since reaching the age of 50 (Lindau, 2007).

Lower levels of HIV testing among the older adult population not only contribute to increased transmission of the virus, but also to the rapid decline of HIV-positive patients into AIDS and ultimately death. Many HIV-positive older adults are not diagnosed until the disease state has progressed considerably (Auerbach, 2003).

Statement of the Problem

The alarming increase in HIV/AIDS cases among older people, and the lack of education and prevention efforts directed at this group, indicate that there is a need to raise awareness of the potential HIV risk among people aged 50 and over, among both medical professionals and older people themselves. However, very little research has been conducted on

- Increase in HIV/AIDS cases among older people,
- The late diagnosis among many people in this age group,
- Underlying factors such as high-risk sexual behaviors in this age group,

- The practices of health care professionals in relation to HIV-testing
- Consideration of HIV/AIDS as a possible cause of medical symptoms.

Purpose of the Study

The purpose of the study was to identify, within a combined systems theory and social network theory framework, the various levels and types of factors that may be contributing to increased rates of HIV/AIDS among older adults. It investigated factors including patients' own behavioral characteristics as well as health care practice on the part of medical professionals, and considered how these factors differ from those known to be associated with HIV/AIDS among younger people. The study was based on primary research with HIV/AIDS-diagnosed older adults and health care professionals, and generated data for use in informing the development of HIV/AIDS awareness campaigns, prevention strategies, and health care options, with the objective of reducing the growing problem of HIV/AIDS among this group and improving health outcomes for those diagnosed with the infection. Raising awareness of the HIV/AIDS risk to older people, not just among this population but among their health providers, is crucial in helping to reduce transmissions of the infection and in increasing early detection so that appropriate treatment can be made available and optimum health outcomes can be achieved.

Nature of the Study

This research is an exploratory, descriptive, mixed-methods study designed to explore behaviors and perceptions of (a) health care workers and (b) adults aged 50 and over with HIV/AIDS may be related to the increase in HIV/AIDS diagnosis in this population. The instruments used included (a) a researcher-designed and administered

questionnaire to probe the frequency of high-risk behaviors among a sample of 99 older adults with HIV/AIDS and (b) a researcher-designed and administered interview to probe HIV/AIDS awareness and practices of a sample of 17 health care workers who work with older adults. The sample size of 99 older adults (50 years or older) with HIV/AIDS is such that the error of estimation is within 5% of its actual parameter with 90% confidence.

Theoretical Framework

Although many research studies have been conducted on issues associated with HIV testing, these have generally focused on discrete aspects of the HIV testing process, such as various behavioral and psychological outcomes, rather than conceptualizing HIV testing as a dynamic process that consists of interrelated elements. The value of this research is arguably limited by a failure to account for all the elements involved in the HIV testing process that might have contributed to the measured outcomes, either individually or in combination.

This study was intended to help fill the information gaps in this area by using a conceptual framework based on systems theory and social network theory. Systems theory contends that it is necessary to consider all interrelated parts of a system in order to properly understand its component parts. On the other hand, social network theory attempts to explore individuals' behaviors and attitudes in connection with the general systems of the social phenomenon. How can health care workers bridge the gap between people age 50 and over and HIV testing and counseling? What can health care workers do to promote health safety and connecting the systems for accessibility? The implication of this theoretical framework for the study is that HIV/AIDS test results and overall health

outcomes must be attributed to the interrelated effects of a range of factors, including the patient's own characteristics and past and present high-risk behaviors, as well as the practices of health care providers in relation to the diagnosis of HIV/AIDS among an older population.

Assumptions and Limitations

Assumptions

First, it was assumed that the research instruments were effective in identifying and collecting information on all main forms of behaviors and skills that might impact provider-client communication.

Limitations

One of the limitations of this study was that of self-report. Although it was assumed that respondents were truthful in their answers, this assumption may not have been justified. It is possible that respondents may have under-reported their inability to read, comprehend, and their ability to act on health information in order to appear more socially acceptable to the researcher. This is always a particularly significant problem in research on sensitive or controversial subjects, such as limited functional health literacy and health status. The researcher attempted to minimize underreporting by doing everything possible to put respondents at ease by creating a comfortable and safe environment for conducting the interview, emphasizing anonymity, and giving assurances of complete confidentiality. Despite this, bias may still have existed due to the established relationship between provider and client.

Although this study argues for the use of systems theory and social network theory as the conceptual framework when conducting research into effective provider-

client communication in medical settings, the primary research stage of this study focused on only two components of the system under study: individuals aged 50 years and over, with HIV or AIDS infection, and primary health care providers. This may not be a weakness of the study in itself, but is a limitation relating to various constraints which demonstrate the need for additional research into the impact of other aspects of the social system.

More significantly in terms of interpretation of the research findings, this study sampled participants who were HIV positive, and age 50 and over, and residing in a nursing home or were hospitalized within the medical hospital. The specificity of the sample may limit the degree to which findings may be generalized to other populations. Although attempts were made to engage and recruit a diverse sample of clients and health care providers, it may be that the participants in this study differed systematically in some way from the general population from which they were drawn.

The study should be regarded primarily as a means of generating useful information to inform interventions, plan programs, and develop policies to address the problem of ineffective communication and its impact on functional health literacy and health outcomes in a high-risk special-needs population.

Research Questions

The research explored the individual behavioral and health care practice-related reasons for the increase in HIV/AIDS cases among older people, and the late diagnosis of the infection in many older HIV/AIDS patients. Specifically, it aimed to answer the following questions:

1. Among a sample of older patients with HIV or AIDS, what common factors can be identified that are likely to have contributed to their infection?
2. Based on qualitative research with a small sample of health care providers, is there any evidence to suggest that current health care practices of older adults might be contributing to, or failing to tackle, the problem of HIV/AIDS among adults aged 50 and over?
3. Taking into account the survey results and qualitative research findings, how can health education and health care practice in relation to older adults be modified to help reduce the growing problem of HIV/AIDS among this group, and to improve health outcomes for those diagnosed with the infection?

Significance of the Study

There is a pressing need for more research into the factors contributing to the epidemic of AIDS, which began towards the end of the last century. HIV/AIDS is now a disease that affects people of all ages, races, and sexual orientations. Whilst people with high-risk sex- or drug-related behaviors are more likely than others to contract HIV/AIDS, those receiving blood transfusions, for example, are also at increasingly high risk as the disease spreads throughout the population. Moreover, there is a need to understand the impact of recent developments among the older population, such as the increased use of Viagra, on the HIV/AIDS epidemic.

For those who are diagnosed with HIV/AIDS at an early enough stage, advances in drug therapies now allow the possibility of a more prolonged, healthy life than was possible for those diagnosed with the disease in the past, when they would have suffered the devastating results of a compromised immune system. Nowadays, the disease process

can be much less devastating as a result of Highly Active Antiretroviral Therapy (HAART). The HAART medications help to improve immunity by maintaining or increasing the number of helper cells (CD4 count), and by suppressing or reducing the viral load. Early diagnosis and treatment is crucial, however, in order to maximize the potential for success in the use of these drugs, particularly among older people, whose immune systems may already be declining as a result of the natural aging process. There is also a need to ensure that elderly people infected with HIV/AIDS receive sufficient assistance from health and social workers, since they may have considerable difficulty in caring for themselves not only due to the disease but to the normal limitations that come with aging.

While medical researchers continue to search for a drug-related cure for HIV/AIDS, social research is also urgently required in order to identify and tackle the factors underlying the continued high levels of transmission of the disease and the late diagnoses of cases. Better information on these factors will enable effective interventions and prevention programs to be designed, programs that are targeted at people of all ages, races, and sexual orientations. An important first step is raising awareness of the risk of contracting HIV/AIDS so that prevention strategies can be adopted and regular testing conducted.

Disparities within the American population in terms of rates of AIDS-diagnosis and AIDS-related deaths suggests that awareness and prevention campaigns, as well as health care provisions that are tailored to the needs of individual groups, might be an effective way of tackling the spread of AIDS. These measures might include more

aggressive advertising of HIV/AIDS information on the part of health care providers and prevention programs, pre- and post-HIV testing, and counseling and appropriate treatment for those diagnosed with the infection. This study is intended to generate information to facilitate the development of health campaigns and health care provisions targeted at the needs of people aged 50 and over who are at risk of, or have been diagnosed with, HIV/AIDS.

The social change implications of this study include increasing health outcomes by ensuring that testing for HIV/AIDS and appropriate health interventions for HIV/AIDS-diagnosed patients can be initiated at an appropriate stage, thereby reducing morbidity and mortality rates, and improving the quality of life. Early detection of the disease is crucial to ensure that appropriate treatment and effective health outcomes can be achieved, and can empower individuals to make choices that impact their quality of life.

Definition of Terms

For the basis of this paper, definitions of HIV, AIDS, older adults, and other terminologies will be expressed in the simplest terms. It should be noted however, that different or more precise definitions are often utilized by researchers and scientists in various contexts.

Older adults: In line with much of the HIV literature, and as defined by the CDC (2008), this study includes all people aged older than 50 years in the category of older adults.

Aids Drug Assistance Program (ADAP): State-based programs funded in part by Title II of the Ryan White CARE Act that provide therapeutics (including devices necessary to administer pharmaceuticals) to treat HIV disease or prevent the serious deterioration of health, including treatment of opportunistic infections. ADAP formularies and eligibility criteria are determined state by state with a focus on serving low-income individuals (Health Resources Services Administration, 2011).

Acquired Immune Deficiency Syndrome (AIDS) is caused by infection with the human immunodeficiency virus (HIV). AIDS is the most advanced stage in the course of HIV infection. The virus attacks and destroys the body's immune system (the system that protects the body from disease).

Center for Disease Control (CDC) is recognized as the lead United States agency for protecting the public health and safety of people by providing credible information to enhance health decisions, and promoting health through strong partnerships with state health departments and other organizations.

Cluster of differentiation 4 (CD4) a protein found on the surface of T helper/inducer lymphocytes. CD4-positive (CD4⁺) cells are involved in cell-mediated immunity and function as "helpers" by regulating the overall immune response to antigen insults. CD4⁺ cell counts diminish in AIDS. Normal levels are 1000-1200. By definition, CD4⁺ cell counts less than 200 and the presence of HIV are diagnostic indicators for AIDS.

Cytomegalovirus (CMV) A virus of the herpes family that, in the ophthalmic context, causes infection and inflammation of the retina in patients with AIDS (CMV Retinitis).

Highly Active Antiretroviral Therapy (HAART) Treatment for human immunodeficiency virus (HIV) infection that uses a combination of several antiretroviral drugs. The drugs inhibit the ability of the virus to multiply in the body, and they slow down the development of AIDS.

Human Immunodeficiency Virus (HIV) is the retrovirus that causes acquired immunodeficiency syndrome (AIDS); symptoms of HIV infection can include opportunistic infections, growth problems, diarrhea, developmental regression and immune system dysfunction.

Pneumocystis Carinii Pneumonia (PCP) a type of pneumonia seen primarily in patients whose immune systems are suppressed. It is relatively rare in normal, immunocompetent people but common among people infected with HIV (the virus which causes AIDS).

Protease Inhibitors (PI) a class of antiretroviral drugs that bind to and block HIV protease to prevent the production of new infectious viral particles. Drugs that suppress HIV replication by interfering with an HIV enzyme called protease.

T CELLS- a white blood cell responsible for the body's immunity. T cells can destroy cells infected by viruses, graft cells, and other altered cells.

Summary

This chapter has provided an overview of the study, and background information relating to the problem of the increase of HIV/AIDS among the American population aged 50 and over. It set out a statement of the problem, the significance of the study in relation to the problem, and the main research questions to be addressed.

Chapter 2 reviews the literature on the increase in HIV/AIDS, and late diagnosis of the infection, among older people. It argues that a conceptual framework based on systems theory and social network theory is most appropriate in conducting research into these issues, since this enables identification of a various levels of factors that are likely to contribute to these problems, including individual behavior, and the practices and policies of health care providers and the government. These levels of factors are discussed in turn, drawing on existing information and research where available.

In chapter 3, the methodology for the empirical part of the study is discussed. An overview of the research design is presented, and information is provided on the proposed sampling procedure, research instruments, and analysis procedures. Chapters 4 and 5 present the results, conclusions, and recommendations of the research.

Chapter 2: Review of Literature

The previous chapter of this study explained the research problem, which was to examine patient behavioral and health care provider factors that contribute to the increase in incidence of HIV/AIDS in Americans aged 50 years and over. The present chapter begins with a review of systems theory and social network theory, which jointly formed the conceptual basis of the study, and goes on to survey relevant literature on race, gender, and older age in HIV/AIDS, modes of transmission in older people, individual behavioral factors, health care practice factors, and policies and perspectives on health care. A summary concludes the chapter.

Literature Search Strategy

The research and scholarly literature was accessed using MD Consult, NCBI, Pubmed, CINAHL, Medline, ERIC, ProQuest, and Health Star. The following keywords were used: *HIV/AIDS older adults*, *HIV/AIDS adults over 50*, *HIV/AIDS race*, *HIV/AIDS gender*, *HIV/AIDS transmission*, *HIV/AIDS health care practices*, and *HIV/AIDS policy*.

Systems Theory

This study was conducted within a conceptual framework based largely on systems theory, a sociological theory that demonstrates how social and other systems play a part in our daily lives. By understanding the interconnections between various parts of the system, it is possible to identify where changes need to be made in order to bring about a desired outcome.

In the case of this study, a systems theory approach underlies the research design. The design was intended to (a) facilitate identification of various factors which may be contributing to the increase in HIV/AIDS and the frequently delayed diagnoses of the

disease among older people and (b) provide an indication of what changes may be needed in various parts of the system. These parts of the system may include older people themselves, health education organizations, the medical profession etc. in order to help to reduce rates of AIDS/HIV among older people and maximize the potential for positive health outcomes among those diagnosed with the disease.

The term *system* refers to a variety of interdependencies among component parts and processes, involving discernable regularities of relationships. It also refers to a particular type of interdependency between such component parts and processes and their surrounding environment (Parsons, 1971). According to Parsons, if any regularity of the relationship is to be adequately understood, the whole complex of multiple interdependencies of which it forms a part needs to be taken into account.

Systems theories are widely employed across the social and natural sciences today, and this conceptual approach is favored as a flexible method of scientific inquiry, which enables scientists to shift focus between various systems or subsystems according to their interests or emerging research findings (Laszlo, 1972).. Depending on the level of enquiry, Laszlo stated, systems theory enables a researcher to investigate cells or atoms, the family, the community, the nation, the economy and the whole ecosystem, for example. The systems view is the contemporary view of organized complexity (Laszlo, 1972). This conceptual framework views man as interlinked with the world he lives in. As explained by Laszlo (1972), for example, humans are a biological organism in origin, a “social role carrier” in work and play, and he is a link integrating and coordinating the biological and social worlds, in terms of conscious personality. In research conducted

within a systems theory framework, there is a need to investigate the role of each dimension of an individual in determining outcomes, as well as other parts of the social system that are external to that individual.

Parsons (1971) distinguished between theoretical and empirical systems. According to Parsons, a theoretical system is a composite of assumptions, concepts, and propositions that have a rational combination, while an empirical system is an observable set of phenomena that can be described and analyzed by the social researcher (Parsons, 1971). This perspective demonstrates the importance of the idea that when researching social phenomena, one must investigate not only what can be directly observed, but also non-observable social or “cultural” systems that connect structure to action and result in observable outcomes (Parsons, 1971).

Bertalanffy, who proposed the general systems theory (GST), postulated that real systems are open to and interact with their environment, and that they acquire qualitatively new properties through emergence, resulting in continual evolution (Bertalanffy, 1969). Bertalanffy indicated that organization determines a system, which is independent of the concrete substance of the elements. The same concepts and principles of organizations underlie the different disciplines (physics, biology, technology, sociology, etc.) which provide a basis for unification (Bertalanffy, 1969).

While formulating the concepts or systems in which to function, Bertalanffy (1969) provided the basic ingredients of systems. He indicated that systems concepts include system-environment boundary, in-put, out-put, process and state, hierarchy, goal-directedness, and information (Bertalanffy, 1969). In GST, there exist models, laws, and

principles that apply to generalized systems or their sub-classes, irrespective of their particular kind, the nature of the component elements, and the forces involved.

Bertalanffy conveniently defined the concept of systems and determines it as a category by which the relations between objects and phenomena are known (Bertalanffy, 1969).

How important such systems come to be when addressing HIV/AIDS among people aged over 50. Bertalanffy's (1969) systems concept represents a set of interrelated components of complex entities in space-time, which show structural similarities (isomorphism). All systems have these common elements: input, output, throughout or process, feedback, control environment and goal (Bertalanffy, 1969).

Within the context of this study, a systems theory approach enables identification and consideration of a broad range of factors that might be contributing to the increasing problem of HIV/AIDS among older adults. For example, it becomes important not only to explore high risk behaviors among those diagnosed with the disease, but also to look at the role of health education organizations, medical professionals, and the government in contributing to the problem, or in failing to address it adequately.

Social Network Theory

The conceptual framework for the study also draws on social network theory, as epitomized by the work of Kadushin (2004). Social network theory provides a framework for understanding how the relationships between individual actors in any social network can be more important than the behavior or attributes of the individual actors themselves in explaining social phenomena, which might include attitudes or behavior related to sexual activity (Kadushin, 2004).

Kadushin (2004) explained that a network consists of any set of objects (including people) and the relationships which link them. Relationships are based on shared, attributes or characteristics, as well as various types of flows and exchanges between the objects, including flows of information which may influence individual behavior. Within the social world, three main types of networks can be identified: ego-centric, socio-centric and open-system networks. Kadushin (2004) defined ego-centric networks as those networks which are connected with a single individual or organization, and whose members share some attribute in common rather than just consisting of a list of names. Socio-centric networks are usually closed systems which are enclosed within a particular location (e.g. a classroom) or organization, and include, for example, co-workers in the same company. Finally, open-system networks often lack defined boundaries and consist of loosely connected objects or relationships, such as corporations, or subjects adopting new practices (Kadushin, 2004).

Kadushin observed that inter-connected loose networks with weak ties between their members are often more important as drivers of social or behavioral change than small tightly-knit networks, since the former are more likely to result in new ideas and opportunities being introduced to the members of individual networks via their weak ties with other individuals in other networks. As Kadushin noted: “[I]ndividuals with few weak ties will be deprived of information from distant parts of the social system and will be confined to the provincial news and views of their close friends (2004, p. 30).

Social network theory can usefully be employed to investigate and interpret the increase in HIV/AIDS among the older population of the United States, and indeed has

been used to study the epidemiology of AIDS (Poulin, Boily, & Masse, 2000). It might be the case, for example, that the small tight networks within communities and the relative lack of interconnecting wider, looser networks among this population might be preventing the spread of new attitudes and practices among older people and may therefore help to explain the spread of HIV/AIDS in this population. For example, awareness of the risks of HIV/AIDS, a willingness to discuss sexual behavior with medical practitioners and attitudes towards the use of preventative measures to prevent contracting the disease may be slow to change in tight-knit social networks, such as retirement communities.

In this respect, a particularly important concept within social network theory is the threshold or tipping point (Granovetter & Soong 1983). This relates to the way in which a social phenomenon, or form of behavior, spreads throughout a network, and the idea is that once it has spread to a certain extent, it is likely that all of the nodes or individuals within the network, will follow that form of behavior (Kadushin, 2004):

The probability of any individual node acting is a function of the number of other nodes in the network that have acted in a given way or possess the given quality. It is a step function, rather than a linear one. Thus, the action is not necessarily dependent upon one's immediate partner(s), but on the relative number of nodes throughout the network that have adopted the given behavior or attribute. (p. 32).

This may have important implications for the design and delivery of health education campaigns targeted at reducing the spread of HIV/AIDS among older people,

since it can be assumed on the basis of the theory that changing the behavior of a certain proportion of older people through health education is likely to have positive knock-on effects to the wider population. Social network theory can also be used to help understand the nature of information flows and the types of relationships and linkages that underpin these, within the population of older Americans, in order to help design education strategies that are most likely to be effective. It can usefully complement systems theory, which ensures that all relevant aspects of a social system are taken into account when investigating social phenomena. By providing an understanding of how the relationships between different parts of the system operate in practice to affect the way a phenomenon is manifested in a population in practice. It can also provide an insight into how these existing relationships can be used to influence future trends.

Overview of Previous Research and Information Gaps

Since the AIDS and HIV epidemic was first noted, enormous strides have been made in a relatively short period of time in advancing scientific understanding of the pathology of the disease and in developing treatments for those who are infected, although, as yet, a cure has not been found. Within behavioral and social science, there have been a number of studies (Holtzman et al., 2001; World Bank, 2010) of high-risk groups and those already diagnosed with HIV, in order to gain understanding of the factors associated with its transmission, and to provide direction for possible interventions to help reduce the spread of the disease. However, older people with HIV, and the older population as a possible high-risk group have largely been neglected in this body of research (CDC, 2008). According to Goodroad (2003), the preponderance of published work concerning to HIV and AIDS older people consists of review articles and

opinion pieces. These articles, while providing insight and direction for clinicians, are not research-based and thus limited in generalizability and applicability. Despite the continually growing population of older people in the United States, and the increasing numbers diagnosed with HIV, this population has been largely ignored in the biomedical, social or behavioral, and prevention literature.

Quantitative research on older people and HIV/AIDS is limited mainly to physiological differences in the progression of HIV disease and presentation in older people (Chu & Selwyn, 2008). The few sociological or behavioral studies only examine the risk taking and adoption of risk reduction behavior.

Older People and HIV/AIDS

Research clearly shows that no age group is immune from the threat of AIDS, including the elderly. Initially, individuals aged 50 and over did not constitute a large proportion of those diagnosed with HIV/AIDS in the United States, where just 3,684 individuals between the ages of 50 and 59 were diagnosed with AIDS between 1981 and 1987 (CDC, 2001). This is a small number in comparison to the 23,239 adults aged 30 - 39 who were diagnosed with AIDS during those same years. However, between 1996 and 2000, the number of individuals aged 50 - 59 with AIDS increased to 23,980 (CDC, 2001). There was also an increase over time in diagnosed AIDS cases among individuals aged 60 and over, from 1,413 between 1981 and 1987, to 8373 between 1996 and 2000 (CDC, 2003). By 2005 it was reported by the CDC that there were a total of 118,370 diagnosed cases of AIDS among people aged 50 or over, representing 12.43% of all cases in the United States. This included 30,996 cases among people aged 60 or over (CDC, 2005).

Up to June 1999, approximately 75,000 persons in the U.S. in total were 50 years of age or older when they were diagnosed with AIDS (CDC, 1999). While research has consistently found that adults in this age group accounts for at least 11% of all U.S. AIDS cases, new evidence suggest that perhaps as much as 15% of the current U.S. AIDS caseload is age 50 and older (Ory & Mack, 1998). By 2003 official statistics from the Centre for Disease Control were showing that people over 50 accounted for approximately 11%-15% of the diagnosed HIV/AIDS population in the U.S. (CDC, 2003). Table 1 shows the estimated number of AIDS cases in the U.S. in 2005, by age at time of diagnosis. It can be seen that older people, even the most elderly aged over 65, account for a substantial number of all cases.

Race, Older Age and HIV/AIDS

Within the population of older Americans, the rapidly growing rate of HIV infection among African American and Hispanic people is of particular concern, as this represents the fastest growing number of reported cases in this age group (CDC, 2000). In 2000, the CDC reported that there had been 35,490 AIDS-related deaths among African American and Hispanic people aged over 50, compared with 34,002 AIDS-related deaths in the European American population (CDC, 2000), while according to the NIA (1999), African American and Hispanic people at that time accounted for more than half (52%) of all those aged over 50 with AIDS. African Americans and Hispanics were reported to account in total for 49% of all men and 70% of all women aged 50 and over with AIDS (NIA, 1999). The Kaiser Foundation have reported that in 2005, racial and ethnic

minorities represented the majority of new AIDS cases (71%) and people living with AIDS (64%) (Kaiser Foundation, 2007).

Race, Gender, Older Age and HIV/AIDS

The difference in numbers of diagnosed AIDS cases between African-American and Hispanic women compared with European American women in this age group was even higher than among African-American and Hispanic men compared with European American men of the same age (CDC, 2002). According to the CDC statistics (2002), there were 6,000 more reported cases among African-American and Hispanic women than European American women aged 50 and over, compared with 3,000 more reported cases among African-American and Hispanic men compared with European American men. Browne (1998) has also observed that HIV/AIDS is increasing rapidly among minority women, with 50% of all new HIV/AIDS cases in older women being among women of African American ethnicity. The Kaiser Foundation reports that black women accounted for 66% of all new cases of AIDS among women in the U.S. in 2005 (Kaiser Foundation, 2007).

Table 1

AIDS Cases by Age

| Age | Estimated # of AIDS Cases in | |
|-------------|------------------------------|---|
| | 2005 | Cumulative Estimated # of AIDS Cases, Through 2005 ^a |
| Under 13: | 58 | 9,089 |
| Ages 13-14: | 66 | 1,015 |
| Ages 15-19: | 476 | 5,309 |
| Ages 20-24: | 2,004 | 34,987 |
| Ages 25-29: | 3,739 | 114,519 |
| Ages 30-34: | 5,635 | 194,529 |

| | | |
|-------------------|-------|---------|
| Ages 35-39: | 7,867 | 209,210 |
| Ages 40-44: | 8,925 | 165,497 |
| Ages 45-49: | 6,953 | 103,326 |
| Ages 50-54: | 4,277 | 57,336 |
| Ages 55-59: | 2,237 | 30,631 |
| Ages 60-64: | 1,068 | 16,611 |
| Ages 65 or older: | 894 | 14,606 |

^a Includes persons with a diagnosis of AIDS from the beginning of the epidemic through 2005. Source: CDC, 2005

Modes of Transmission among Older People

It is known that the most common modes of transmission of AIDS among older adults differ from those for younger people. HIV infection in elderly adults was initially limited to those who had received blood transfusions for surgical procedures (Friedland & Klein, 1987). However, older Americans with HIV have increasingly acquired their infection via sexual activity, and transmission through high-risk sexual behavior now reportedly accounts for a higher percentage of infection in older people than for other age groups (NIA, 1999). Within the population of older adults, male-to-male sexual contact accounts for the greatest percentage of all transmissions although this pattern is changing, with a dramatic drop in the percent of male-to-male sexual contact transmissions from 90% in 1982, to 49% in 1997 (NIA, 1999).

Research and statistics relating to the HIV and AIDS virus usually categorize people according to high-risk behavior types, in order to understand the dynamics of the infection and how it can spread. While the proportion of total diagnosis represented by older people reportedly remained stable between 1982 and 1999 for example, there were reported changes in the number of AIDS case by exposure category in older adults over time (CDC, 1999). The available information shows, for example, that the incidence of

AIDS diagnosis in men who have sex with men (MSM), as well as the incidence among MSM who also inject drugs is decreasing (CDC, 1999). In total, these two risk categories represented almost 75% of people with AIDS in 1985, but decreased to 49% of AIDS cases by the end of 1998 (CDC, 1999). Conversely, the number of heterosexually transmitted cases of AIDS has increased steadily over time and now represents approximately 11% of the total cases of AIDS in people older than 50 (CDC, 2003).

The greatest behavior potential for further spread of HIV infection among late middle-aged or older Americans derives from sexual behavior (Entwhistle, n.d.). Sexual desire and activity do not necessarily decrease with age. In some cases, sexual activity may increase (Entwhistle, n.d.). In fact, 40% to 65% of older adults between ages 60 to 71 reported being sexually active (Entwhistle, n.d.). Almost 58% of all cases of AIDS in people older than 50 report that sexual contact is the sole risk factor for infection (CDC, 1999). However, high-risk older individuals are less likely to have adopted AIDS prevention strategies, including use of condoms and regular HIV testing, than younger high-risk individuals (Entwhistle, n.d.).

Factors Contributing to the Increase in HIV/AIDS among Older People

There are many possible factors which may be contributing to the increase in the number of older adults with HIV/AIDS or adults that are diagnosed with the disease later in life. These include, for example, the following:

1. Older adults or their health care providers are failing to recognize that the sexual activities among this age group constitute a risk. Many older adults

may not use any kind of protection and may not consider themselves at risk for the transmission of STDs or HIV.

2. Health care professionals are uncomfortable exploring older patients' sexual behavior.
3. Physicians' misattribution of symptoms associated with HIV infection to normal aging or other illnesses is still prevalent.
4. Patients' misattribution of their HIV-related symptoms to other less threatening causes prevents them from seeking HIV testing, such as normal aging, stress, co-morbid conditions (Gordon & Thompson, 1995).

Some of these factors are discussed further below, with supporting references from previous research.

Individual Behavioral Factors

Many of the high-risk sexual behaviors which contribute to the likelihood of contracting HIV/AIDS are similar for younger and older adults, so continuing high rates of sexual activity among older people are likely to result in similar rates of transmission as among younger adults (Gordon & Thomson, 1995). Recent survey research among the American population has revealed that up to 65% of older adults ages 60 - 71 have sexual intercourse (Ohio University, 2007) and it might be expected that the rate of sexual activity among people aged 50-60 would be even higher.

There are also relevant behavioral factors which are more specific to older people. The increase in numbers of diagnosed AIDS cases among people aged over 50 in the United States has been largely attributed to older Americans' lack of knowledge

regarding HIV transmission, a resistance among older people to adopting prevention strategies (Entwhistle, n.d.), and a corresponding lack of regular testing. In a nationwide health survey conducted in 1992, 77% of respondents aged 50 or over said that they believed that they had no chance of getting the virus, and 16% reported having no knowledge of AIDS (Schoenborn, Marsh, & Hardy, 1994). Even among those older people who are aware of the HIV/AIDS transmission risks and the possible consequences of their own activities, it might be difficult to modify lifelong behaviors and habits, established over many years, to reduce their risk of catching the virus. The concept of HIV-risky behavior may not be pervasive in the geriatric community because HIV was not a problem during the adolescence or young adulthood of older people (Schoenborn et al., 1994).

In addition, a factor which has been highlighted as a likely contributor to the increase of HIV/AIDS among older adults in particular (e.g., AMfAR Aids Research, n.d.) is the increasing use of the drug Viagra. Viagra is more commonly used by older men who may be experiencing erectile dysfunction, and thus introduces a risk factor which is fairly specific to this group. The drug enables men to continue to be sexually active at older ages, thus increasing the overall risk of transmission of HIV/AIDS among the older American population. Although no statistical information was located on trends in Viagra use in the American population, anecdotal evidence suggests that its use is increasing, especially among older men.

No information could be found on the likely reasons for the particularly large numbers of AIDS cases among older African-American and Hispanic women

specifically, but several possible reasons have been identified in previous studies to explain the high rates of infection among older females generally. One is that the onset of menopause, or the utilization of sterilization as a birth control practice post child-bearing, may act as a deterrent to safe sex practices among this age group (Zablotsky, 2003). As the fear of pregnancy is removed, women may be less inclined to use safe sex-related contraception, such as condoms, for example. In addition, the menopause increases vaginal dryness and thinning, often resulting in small tears and abrasions during sexual intercourse, which can increase the likelihood of viral transmission (Center for Women Policy Studies, 1994; Wallace, Paauw, & Spauch, 1993; NIA, 1999; Vlahov, 2003). Moreover, if it is the case that awareness of HIV transmission risks is lower among older women, this factor combined with increasing life spans and increased divorce rates may result in a situation where many older women are dating and exposing themselves to unsafe sex practices. Zablotsky (2003) has argued that promiscuity among some older women may also contribute to the higher rates of AIDS among this group.

One of the main behavioral factors believed to be contributing to the overall increase in AIDS-related mortality among older people is nonadherence to drug therapy, as more than half of elderly patients have been found to be noncompliant with medication regimens (Office of the Inspector General, 1990). Recent years have brought about dramatic changes in the medical treatment of HIV infection, including the advent and increasingly widespread use of a new class of medications, protease inhibitors (PIs) (Condra, Miller, Hazuda, & Emini, 2002). Used in combination with other antiviral medications, PIs have been shown to substantially reduce the number of viral particles

within the bloodstreams, thereby leading to improved immune functioning, reduced incidence of opportunistic infections, and lower rates of viral mutation, thus effectively slowing the disease progression and enhancing survival for many patients (Condra et al., 2002).

However, these drugs require strict adherence to complicated dosing schedules and dietary conditions in addition to management of distressing side effects. Despite the promising benefits of PIs, many HIV-infected patients are either unable or unwilling to adhere to the prescribed regimes for taking these medications. However, due to the extremely rapid viral replication rate of HIV, non-adherence for even limited periods of time can be problematic. Even occasional non-adherence, including late or missed doses, may have very negative long-term consequences, including increased viral mutations, which may produce drug-resistant strains of the virus (Condra et al., 2002), cross-resistance to similar medications (Condra et al., 2002), and eventual treatment failure. Thus, understanding and preventing protease inhibitor non-adherence is an important part of HIV/AIDS treatment strategies.

It is widely recognized that a variety of factors, e.g. the complexity of the regimen, the perceived side effects, and the availability of social support, may influence patient adherence to medication (Jani, 2004; Office of the Inspector General, 1990). Prior research has demonstrated that beliefs and attitudes about specific medications and their effects on the body are central to understanding medication non-adherence. The relationships among adherence to treatment and patients' attitudes regarding self-

efficacy, the medication efficacy and potential benefits and/or side effects of a medication have been reported in a number of patient populations (Jani, 2004).

Attitudes have also been linked to medication adherence among persons with HIV/AIDS, although these studies have not focused on older adults specifically. Investigations of adherence to antiviral immunotherapy (e.g. Zidovudine/AZT) found that belief in the drug's potential benefits and effectiveness is associated with better adherence (Aversa & Kimberlin, 1996). Other research has demonstrated that the experience or fear of medication side effects is associated with poorer adherence to antiviral medications (Chesney, 2003). Trust in the physician, confidence in one's ability to follow the regimen, and the attitudes of friends have also been found to influence adherence (Schilder et al., 1998). For example, among HIV-infected women, the beliefs that Zidovudine did more harm than good, that doctors prescribed the drug indiscriminately and promoted its use for the wrong reasons, were common explanations offered for non-adherence or refusal to use the medication (Siegel & Gorey, 1997). The beliefs that you can't trust doctors and that medications may do more harm were also given as reasons for rejecting or delaying treatment (Siegel et al., 1992).

While the AIDS epidemic in the USA at first affected primarily white gay male communities, the largest increases in diagnosed cases have been in the ethnic minority communities—especially the African American community. There have been only a few studies examining racial/ethnic differences in attitudes toward HIV medications specifically, but research has demonstrated that health related beliefs and attitudes do differ considerably across racial/ethnic groups (Meyerowitz et al., 1997).

Siegel and Gorey (1997) found in a sample of HIV-infected women that while negative attitudes toward Zidovudine were prevalent in the sample as a whole, those held by the African American women were particularly critical in terms of language and tone of their remarks. Some of these women also expressed concern that Zidovudine had not been well evaluated in people of color and thus believed that much less was understood regarding the potential risks, benefits or side effects African Americans in particular might experience from its use.

Dalton (1990) also noted particularly suspicious attitudes on the part of African Americans with AIDS in regard to health care and antiviral medications in part due to historical injustices allegedly committed by health professionals.

Health Care Practice

The rising incidence of HIV/AIDS among older people may reflect the fact that they are not often targeted by health care workers and educators for HIV education, and may be less likely to talk about their sex lives in general (National Institute on Aging, 2003). Similar factors are likely to be contributing to the delayed diagnoses of HIV/AIDS among older adults. First, health care providers, caregivers, and educators might hold perceptions that older people are not sexually active or unlikely to participate in high-risk behaviors. As a result, they may fail to consider the possibility that symptoms of ill health might be caused by the HIV/AIDS virus when diagnosing symptoms and may omit to ask for potentially relevant information about sexual behavior or drug-related experiences. At the same time, the patients themselves may not offer this information voluntarily, either due to embarrassment or a lack of awareness of its possible significance. More generally, the elderly may feel uncomfortable in discussing sexual practices with their primary care

providers due to embarrassment and perhaps because of a perception that younger people, including their health care providers, will expect them to know more about protection than they really do (Zablotsky, 2003).

As a result, older adults are less likely than younger adults to include HIV testing as part of their regular health checks (Puelo, 1996). The situation may be exacerbated by a reluctance on the part of the adult children of older people to acknowledge that their parents are still sexually active, which prevents them from recognizing the possibility that a parent's symptoms might be caused by HIV/AIDS. Age-related factors such as memory loss, depression and other mental disorders may also reduce the likelihood that elderly people will seek an HIV/AIDS test.

Additionally, many older adults have relatively small support networks, and these tend to be focused around family care giving, which decreases their ability to access HIV-related and other age-related services. Few commonly accessed social networks offer HIV/AIDS education, particularly as it relates to the concerns of mature adults (Auerbach, 2003; Puelo, 1996; Zablotsky, 2003).

Some of the symptoms of the AIDS virus replicate those of normal ageing processes, thereby making it more difficult to make an accurate diagnosis. Available studies suggest that nonspecific symptoms such as forgetfulness, anorexia, weight loss, and recurrent pneumonia may often be dismissed as age-related symptoms, and HIV testing can be delayed as a result. Among older women, in particular, AIDS-related symptoms such as night sweats, weight loss, poor appetite and a lack of interest in intimacy might be attributed to the menopause. Additionally, the T cells which are the

immune cells used by medical professionals to identify various infections including HIV and AIDS are also the most age-sensitive component of the immune system (Aupperle, 1996; Nokes, 1996).

Despite the significant proportion of older adults who are HIV-infected or at risk of becoming infected, adults fifty years of age and older (even those with one or more HIV risk factors) are less likely to be tested for HIV than younger adults (Mack & Bland, 1999). Studies have indicated that compared to younger adults, those aged 50 and older tend to be diagnosed later in the disease course only after experiencing symptoms, or becoming hospitalized (Justice & Weissman, 1998). Despite the large literature that has documented the important factors associated with HIV testing among younger adults, very little attention has been paid to the issue of HIV testing among older adults, regardless of the many high-risk factors. Lower levels of HIV testing in this population, however, not only contribute to increased transmission, but also to the rapid decline into AIDS and death. Many HIV-positive older adults are not diagnosed until the disease state has progressed noticeably (Auerbach, 2003). As a significant number of older adults continue to engage in high HIV-risk sexual and drug-use behaviors, a substantial increase in the number of older adults living with HIV disease can be anticipated. A delay in testing may deprive HIV-infected individuals of the optimal time in the initiation of life-prolonging treatment, and prevent them from adopting behaviors that protect others from becoming infected.

Moreover, older adults living with HIV disease face a number of factors likely to complicate their coping and adjustment efforts, which are likely to be more difficult in any

case if they are diagnosed at a relatively late state of the disease. Older individuals often have few systems for community support, may lack siblings or parents to care for them, frequently confront the stigma of ageism and may exhibit a variety of co-morbid conditions that often accompany older age, such as chronic pulmonary disease, diabetes, hypertension and congestive heart failure (Justice & Weissman, 1998).

Policies and Political Perspectives on Health Care

The following sections discuss the current health policy context in the United States and the implications of this for older people with HIV/AIDS. These people have significant requirements for medical and other forms of care, over and above the health care requirements which are a normal part of the ageing process. Given the increasing numbers of older people diagnosed with HIV/AIDS as well as the expanding numbers of elderly people more generally in the United States, there are immense pressures on governments to deliver adequate and affordable medical care and social support, particularly as many older people have limited incomes and are unable to afford private health care insurance.

Conservative Policies and Perspectives

Although there are few government policies or programs which specifically address the needs of the elderly population with HIV/AIDS there are, however, a number of programs that separately address the needs of those with HIV/AIDS and those of the elderly. The conservatives have made a concerted effort to maintain and improve programs geared towards helping vulnerable populations, while at the same time taking steps to address the financial constraints that potentially limit the scope and effectiveness of such programs.

Many prominent conservatives have offered exceptionally strong support for those suffering from HIV and AIDS. In a recent article by Salyer (2002), Secretary of State Colin Powell was applauded for his willingness to renew a national discussion of HIV/AIDS and to appear ready to focus on global AIDS strategies (Salyer, 2002). Furthermore, President Bush has implemented new initiatives intended to tackle the problem of HIV/AIDS in Africa and parts of the Caribbean, as well as domestically. Domestic measures are largely focused on prevention campaigns for the HIV-negative population, particularly those considered at risk. The majority of these programs, such as the abstinence education programs promoted by President Bush, are directed towards adolescents and young adults, who are perceived to be at greatest risk, rather than older adults, but their content is often equally relevant to seniors. The President also appointed members to the Presidential Advisory Council on HIV/AIDS (PACHA). Health and Human Services', the purpose of which is the development of "effective tangible steps to arrest the advance of AIDS" (Secretary Tommy G. Thompson, cited in Clifton, 2002).

Additionally, the current conservative administration has made the funding of faith-based organizations a priority, in view of the "unique ability that these organizations have to meet the special needs of their communities" (President Bush, cited in Department of Health and Human Services, 2001), and has made several grants available to faith-based organizations specifically to address the issue of HIV/AIDS within their communities. The organizations funded are mainly churches, working in partnership with health providers such as hospitals or with the Office of HIV/AIDS Policy in HHS Office of Public Health and Science. The HIV/AIDS-related outreach work of these

organizations consists largely of education and prevention programs which are tailored to the specific ethnic or cultural characteristics of the communities concerned.

Conservative plans to reform health care within the United States also include budgetary measures to salvage both Medicare and Medicaid, programs which are in serious danger of being financially drained, and to address the problem of the rising cost of prescription drugs. The cost of prescription drugs has been rising over the past few years, and has now reached a point at which expense is often a deterrent to medication compliance, especially for certain vulnerable populations such as the elderly and those diagnosed with HIV/AIDS. The increased cost of prescription drugs has also put enormous strain on Medicaid insurance, as well as state budgets. Huff (2002) reported that, in 2001, at least 18 states passed laws on the containment of state and/or consumer drug expenditures, as well as implementing other initiatives to control public spending on drugs.

Medicaid programs trends are particularly significant to those living with HIV/AIDS, as these trends may influence programming and budgeting in other health assistance programs, such as AIDS Drug Assistance Programs (ADAP). The expectation is that Medicaid and other programs will come under increasing pressure unless changes are made and costs contained. According to the National Conference of State Legislatures (2003), only 10% of Medicare recipients aged sixty-five or older qualifies for Medicaid, but in total these recipients account for approximately 31% of service costs, which pay largely for nursing home care. If elderly people experiencing the normal aging process consume such a large proportion of Medicaid funds, it is likely that growing numbers of

elderly people with HIV/AIDS-related medical and care requirements will impose immense pressures on Medicaid budgets. Additionally, the size of the elderly population is increasing over time, with significant budgetary implications for Medicaid and other health programs.

The conservative response has been to propose that program costs need to be contained, or even cut, in order to make public savings. States are now required to evaluate potential health savings that can be made over time, taking into account acute care, long-term care and eligibility criteria, or to explore means of containing health care costs. These include, for example, managed care initiatives, decreasing (or freezing) providers' rates, reducing eligibility, limiting services, and/or requiring co-payments, evaluating provider payment rates and increasing home and community-based care (National Conferences of State Legislature, 2003).

No current government health plan, however, caters specifically to the needs of the elderly living with HIV/AIDS. Most elderly individuals over 65 receive Medicare, and, depending on socioeconomic status, an individual may have secondary insurance, which is often Medicaid. Medicare insurance is currently in crisis. According to the National Center for Policy Analysis (NCPA), both the Social Security and Medicare systems are significantly under-funded, and it has been estimated that Medicare may be bankrupt as early as 2008, as a result of the ageing of the population and fewer younger people making contributions to the insurance system. The lack of adequate funding for Medicare is problematic not only in terms of basic medical provision for the increasing numbers of ageing Americans, but also in terms of a lack of financial support for the

technological developments and related costs which will be crucial in dealing with specific health issues such as HIV/AIDS.

In response to the Medicare crisis, conservatives have proposed several new options for a reformed and privatized Medicare system, which include a subsidized prescription drug benefit, coverage for preventive care and serious illness, keeping the traditional plan with no changes, providing better health insurance options, and strengthening the program's long-term financial security (White House, 2003). In support of this reform of the Medicare initiative, President Bush designated \$400 billion over the next ten years in his 2004 fiscal year budget.

The President's new plan addresses the needs of seniors from all socioeconomic strata who receive Medicare, including low-income groups. Enhanced Medicare will allow seniors to select from several health plans offering prescription drug benefits, full coverage of preventive benefits, and protection against high out-of-pocket drug costs and cost-sharing that does not penalize participants who need the most medical care. The intention is that "Medicare Advantage" will allow seniors to enroll in low-cost and high-coverage managed care plans, similar to those available today under Medicare, but also offering additional benefits including subsidized drug costs. Low income seniors will, under the new plans, be provided immediately with a prescription drug card and a \$600 annual subsidy for drug coverage for those who stay in the traditional Medicare program (White House, 2003).

This new plan is structured to help those who have greatest need in terms of their medical condition, rather than penalizing those with serious illnesses by forcing them to

pay more for their ongoing treatment as Medicare did in its original form. In this way, the proposed new system is likely to be beneficial for older people who have HIV/AIDS. For example, seniors who are hospitalized will not be required to pay anything for their first two hospitalizations and only a small deductible for the next several (White House, 2003). The proposed reforms will also allow “HIV/AIDS in the Aging Population” recipients to retain their Medicare benefits in their present format, as well as receiving “a prescription drug discount card - estimated to achieve savings of 10-25% on the cost of prescription drugs - as well as coverage to protect them against high pocket prescription drug expenses” (White House, 2003).

The government argues that the advantages of privatizing Medicare include reducing costs, ensuring high quality care, and helping to address the long-term financial challenges faced by Medicare due to demographic changes (White House, 2003).

Liberal Views on Prevention and Health Care Access

As the HIV/AIDS crisis continues to evolve through several phases and to affect many different demographic groups, it truly proves that it is not a discriminatory disease. Access to medication, however, lacks such equality. While AZT “cocktail” drugs have been proven effective in their ability to greatly prolong a patient’s life, such miracle drugs do not come with a small price tag. It is largely through Medicaid and ADAP that the United States provides HIV/AIDS patients with medical coverage to best manage their condition. To be eligible for such services, however, individuals must live near, or below, the poverty line, regardless of socioeconomic status prior to diagnosis.

Those living with HIV/AIDS over the age of 50 have unique concerns, such as impending (or current) retirement and its related effects on their health care benefits, as well as the additional ailments of older age that they may experience. To add to these concerns, these individuals are also often casualties of the political arguments about whether health care coverage is a right or a privilege in American society. With ever-changing political and fiscal philosophies dependent upon the current administration, and medical coverage programs being organized at state as well as federal level, vulnerable groups such as older people with HIV/AIDS are often shifted around the system as health care costs rise and funding wanes.

Medicaid acts as the main source of funding for those in need of HIV/AIDS-related medical care. The AIDS Treatment DATA Network (2003) reports that state and federal governments provided roughly \$7.7 billion for HIV/AIDS care in FY 2002 through the Medicaid program, which served more than 200,000 people diagnosed with HIV/AIDS. Currently, if the states have a need to increase Medicaid spending due to the need of their constituents, then the federal government matches this with increased federal funding. By cutting back on the Medicaid program or reducing funding for it, as proposed by the Bush administration, the government puts the care of these people at risk. The Bush proposals include fixing the level of federal contributions to state programs, regardless of whether or not the state's Medicaid costs increase due to recession, epidemic, changing technology, or other needs (AIDS Treatment DATA Network, 2003). Such cutbacks may leave many Americans without medical coverage or with only a portion of the necessary care that their condition requires. In addition, the

proposals include changing the income eligibility criteria for the elderly from 130% of the poverty line to 100%, thus potentially decreasing the quality of life of the recipients' further (Center on Budget and Policy Priorities, 2003).

The Center on Budget and Policy Priorities (2003) reports that one million people risk losing their health insurance coverage under budget cuts that have been approved or proposed in eleven state Medicaid programs. With Medicaid acting as the absolute final safety net for those who have fallen into the lowest socioeconomic status, such budget cuts will leave all of these citizens without the care that they so desperately need. For those that had been entitled to Medicaid and were receiving medication and care for HIV/AIDS, they will be, most likely, unable to receive the appropriate level of care due to the high cost of such prescriptions and treatments. Full and proper medication for HIV/AIDS now costs, on average, \$10,000 per year per patient. A state-level ADAP act as an important safety net and monetary supplement to Medicaid, but Aldridge (2003) reported that a majority of agencies does not offer the full complement of highly recommended drugs for opportunistic infections. The Bush administration worked to make fundamental changes in Medicaid such as proposing that, "optional services like prescription drug coverage will no longer be mandated by Federal law. Such a change in Medicaid coverage would create a huge additional demand on ADAP for antiretroviral and other medications" (AIDS Treatment DATA Network, 2003). While ADAP is not currently facing economic difficulties, such added financial burdens on ADAP will make it difficult in the near future to fund prescription coverage.

While states face severe difficulties regarding fiscal stability, the liberal viewpoint argues that the federal government must intervene and act as the ultimate safety net for those Americans who lack medical coverage. Although the federal government may run a large budget deficit; almost all states are required by law to balance their budgets (Center for Budget and Policy Priorities, 2003). The Center on Budget and Policy Priorities (2003) reported that “states are now facing their most severe budget crisis since World War II”. From a liberal perspective, states cannot be held responsible for such economic responsibilities at the expense of their citizens’ health. This viewpoint generally holds that a right to health is universal, and that health care requires proper and consistent funding, ideally at a federal level. Liberal politicians argue that compared to those of other countries, even countries with much weaker economies, America’s social security system is shockingly inadequate. Liberals believe that America can learn much from reviewing the experience of other countries that provide for the needs of their citizens with more extensive and comprehensive social security plans (Social Security Administration, 2000).

Liberals also argue that the current administration’s emphasis on the use of faith-based organizations to deliver prevention programs is troubling. Some contend that the Bush administration’s work to promote the work of faith-based and community organizations is an attempt to compensate for the cutbacks in funding of services provided by programs such as Medicaid and Medicare (Department of Health and Human Services, 2001). While many of these programs are working to the benefit of all in their communities, programs providing care for people with HIV/AIDS present a complex

quandary. HIV/AIDS is a disease that carried a stigma within certain religious circles, Placing prevention efforts in faith-based organizations may prohibit access to others in the community who do not share the tenets of a particular faith, or have, in fact, been persecuted by members of religious communities in the past, for example, gay men.

Whilst the United States constitution formally ensures a separation between church and state, it cannot guarantee that religious and cultural biases against certain sexual practices and drug use will not prevent those suffering from HIV/AIDS from getting the treatment and attention that they need. Ultimately, the government does oversee the work of faith-based organizations, but when the line between church and state is blurred, it is argued, it becomes easier to cross it. In 2002 the American Civil Liberties Union (2002) highlighted to HHS the need for federal monitoring of faith-based institutions to ensure that they are adequately protecting the civil rights of their employees and clientele, particularly regarding the use of proselytism in the provision of services. Such concerns are especially pertinent to those at highest risk for HIV infection, whose risk behavior may be regarded as immoral by many conservatives and religious communities. Furthermore, while faith-based initiatives can be positive mechanisms to provide aid for specific needs in particular communities, there is a danger that their funding by government reduces funding available for federal programs that provide equal access to care for all people under federally regulated guidelines.

For those living with terminal illnesses such as HIV/AIDS, proper and consistent care is imperative to maintain both longevity and as high a level of health as possible. For this reason, adequate and consistent funding, preferably from federal sources, is

necessary to provide equal access to the drug combinations now available. More generally, access to high quality, affordable health care is particularly crucial for older adults who have HIV/AIDS, a potentially vulnerable group who are often living on reduced incomes due to retirement, and who have a range of health and care requirements related to the normal ageing process as well as the HIV/AIDS virus.

Summary

This chapter has reviewed existing literature, information and arguments regarding the factors which are likely to be contributing to the increase in HIV/AIDS among older people, as well as the problem of late diagnoses in this group, which has an adverse impact on the outcomes of treatment.

A systems theory conceptual framework facilitates consideration of the various levels of factors which might be relevant to these problems. The chapter has demonstrated how the increase in AIDS/HIV among older people, as well as the health outcomes for those diagnosed with the virus, can be influenced by the individual behaviors of older adults themselves, by the practices of their health care providers, and by government policies on health care and health care funding. This framework also helps to highlight the need for action at each of these levels to address the problems, since they are all part of an inter-related system. Education and intervention efforts need to be directed not only at the population at risk, but also at health care providers, caregivers, and politicians. While the inclusion of older faces in targeted public service announcements, for example, may increase societal awareness, it may not have a significant influence on at-risk behaviors and levels of testing for HIV/AIDS, nor enable older adults living with HIV/AIDS to obtain access to the health care services they need.

The next chapter of the study describes the data collection and analysis procedures used to answer the research questions.

Chapter 3: Methodology

“A research design is the logic that links the data to be collected (and the conclusion to be drawn) to the initial questions of study.” (Robert Yin, 2003)

Chapters 1 and 2 of this study described the research problem and its significance, and reviewed existing research relating to the increased rate of HIV/AIDS among older adults. A conceptual framework, based on systems theory and social network theory, was used to identify various factors that might be contributing to this issue—including the individual behaviors of older adults and the practices of health care professionals towards older patients—and to understand how these operate in practice via the relationships that exist within and between networks of older adults. Since it was based on a non-representative sample of HIV/AIDS patients and health care providers, the study were primarily descriptive, aiming to identify the factors that are likely to be contributing to the increase in HIV/AIDS among older people. This information can be used in the design of more effective HIV/AIDS awareness and health promotion campaigns among older people, and in the design of future research to investigate causal relationships between these factors and the trends in HIV/AIDS awareness among older people.

The current chapter describes the methods that were used to investigate the research problem. First, it sets out the research questions that were the focus of the study and provides an overview of the research. Subsequent sections describe the sampling procedure, the research instruments used to collect the data, and the data analysis procedures. The concluding section sets out the assumptions and limitations of the study.

Research Questions

The research was intended to explore the individual behavioral and health care practice-related reasons for the increase in HIV/AIDS cases among older people, and the late diagnosis of the infection in many older HIV/AIDS patients. Specifically, it aimed to answer the following questions:

1. Among a sample of older patients with HIV or AIDS, what common factors can be identified which are likely to have contributed to their infection?
2. Based on qualitative research with a small sample of health care providers, is there any evidence to suggest that current health care practices in relation to older adults might be contributing to, or failing to tackle, the problem of HIV/AIDS among adults aged over 50?
4. Taking into account the survey results and qualitative research findings, how can health education and health care practice in relation to older people be modified to help reduce the growing problem of HIV/AIDS among this group, and to improve health outcomes for those diagnosed with the infection?

Overview of Research Design

This was a mixed-methods study, based on both quantitative and qualitative methods. It consisted of:

1. A survey questionnaire will be conducted to adults aged 50 and over who have HIV/AIDS to generate quantifiable data on the characteristics, personal history and behavioral factors that appear to be associated with HIV/AIDS and with stage of diagnosis of the disease;

2. Semi-structured interviews with health professionals to explore their attitudes and health care practices towards older patients, particularly in relation to high-risk sexual behaviors and the consideration of HIV/AIDS as a cause for medical symptoms.

An interviewer-administered structured questionnaire was used for the survey of 99 adults, aged 50 and over, who have been diagnosed as HIV-positive. This sample size was selected because it offered a large but manageable amount of data. The questionnaire focused on presenting symptoms, the timing of the HIV diagnosis, past and present risk behaviors (sexual and substance abuse history) and current medical treatment. Questions were also included about socioeconomic background—including highest educational level, current employment status and income—in order to provide comprehensive information regarding the factors that may be associated with health literacy and with the likelihood of contracting HIV/AIDS.

One-to-one semi-structured interviews were also conducted with a sample of 17 health care professionals. These explored, for example, the circumstances in which HIV/AIDS counseling and testing are initiated in the case of older patients, and when and how health care workers explore a patient's high-risk behaviors in order to consider the possibility of HIV/AIDS as a cause of medical symptoms.

Sampling Procedure

Following IRB approval (St. Barnabas Hospital Auth# 2008.39 and Walden IRB approval for the study # 09-23-08-0090263) participants for both the questionnaire survey and the interviews were drawn from a nursing home in The Bronx district of New York. It was decided to draw the sample members from a single institution since it was

considered likely that the Institutional Review Board would be more likely to give approval for the research to be undertaken in a single institution than in several, and that the study would be less expensive and time-consuming if conducted in a single nursing home. For the purpose of this study there were no significant disadvantages to conducting research in a single setting rather than several, as long as there were no obvious biases or over-representation in terms of the characteristics of the patients or medical professionals within the selected nursing home.

A nursing home known to the researcher was contacted by letter, and then with a follow-up telephone call, requesting their co-operation in participating in the survey by seeking volunteers for interview from among their HIV-positive patients or members and their health care professionals. A further letter provided information about the study for the organization to pass on to eligible individuals, with details of how to take part. All HIV-positive adults over the age of 50 were eligible for inclusion in the survey sample, including both men and women, and heterosexual and homosexual people. Up to 106 volunteers were to be included in the sample for interview.

The proposed sample size (n) of 106 was obtained by solving the maximum error of the estimate for the population proportion:

$$n = \left(\frac{Z_{\alpha/2}}{E} \right)^2 p(1-p)$$

where $Z_{\alpha/2}$ is the critical value, the positive Z value is at the vertical boundary for the area of $\alpha/2$ in the right of the standard normal distribution, E is the margin of error and p is

the sample proportion. Specifically, the sample size is estimated based on CDC's report that 11% (to 15%) of all US AIDS cases occur in people over the age of 50 (p), and a margin of error of 6% with a confidence of 90% (i.e., $\alpha = 0.10$). With this sample, one is 90% (i.e., $\alpha = 0.10$) confident that the proportion of HIV/AIDS will be within 5% of the true population value.

For the qualitative research sample, the nursing home was asked to nominate up to 17 of their health care professionals to participate in an interview. In order to be eligible for interview, health care workers must have had direct contact with patients, and be responsible for making assessments or diagnoses of their medical symptoms. They could be interns, residents, primary MDs, social workers, and HIV counselors.

In order to encourage eligible individuals to participate in the research, they were notified that a small donation would be made by the researcher to an HIV/AIDS charity for every interview completed.

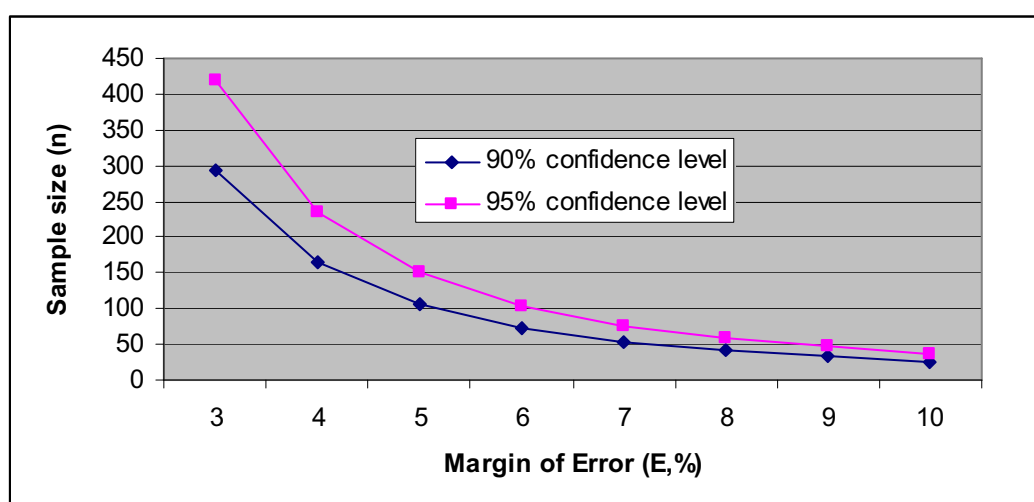


Figure 1. Sample size determination based on $p = 11\%$.

Table 2

Sample Size Determination

| Error of estimation (B) | Confidence level (1-) | |
|-------------------------|-----------------------|-----|
| | 90% | 95% |
| 0.03 | 294 | 418 |
| 0.04 | 166 | 235 |
| 0.05 | 106 | 150 |
| 0.06 | 74 | 104 |
| 0.07 | 54 | 77 |
| 0.08 | 41 | 59 |
| 0.09 | 33 | 46 |
| 0.10 | 26 | 38 |

All calculation is based on $p = 11\%$.

Note: An $\alpha = 0.10$ implies 90% confidence level $\rightarrow Z_{\alpha/2} = 1.655$

An $\alpha = 0.05$ implies 95% confidence level $\rightarrow Z_{\alpha/2} = 1.96$

Ethical Issues

The letter of invitation to participate in the research (Appendix B) made it clear that participation was completely voluntary, and that no one would be disadvantaged in any way by a refusal to take part. Assurances were also given that the information they provided to the researcher would be treated in complete confidence and anonymity.

Inclusion of participants in the study was based strictly on the principle of informed consent, in which they were provided with sufficient, readily understandable information about the nature of the project and the nature of their involvement in the project, to enable them to make an informed, voluntary decision as to whether to take part.

The role of the researcher is particularly important in a study addressing sensitive issues such as sexual behavior and HIV/AIDS, particularly when the sample consists of older patients who may not be used to discussing these topics openly. The researcher made her own professional medical background known to the research participants in order to help put them at their ease, but more generally assumed a neutral role when interviewing HIV/AIDS patients, taking care not to react or respond to their answers in any way which might influence their willingness to take part or to give truthful information. Similarly, when interviewing health care professionals, it was very important for the researcher to maintain a neutral role and to ensure that her own medical background and experience did not introduce any bias into the interviews or the information generated.

Research Instruments

A structured survey questionnaire was developed for use in the interviews with HIV-positive individuals. This included questions on personal characteristics, medical history in relation to HIV and other STDs, sexual practices and history, and substance abuse behavior. Research was conducted into previous survey research into sexual and other high-risk behaviors in order to provide guidance on appropriate questions and question wording. A copy of the questionnaire is included as Appendix C.

For the interviews with health care workers, a topic guide was used by the researcher to ensure that all relevant issues were explored. Factual information was collected on the person's role, place of practice, and own socio-demographic characteristics. The interviews covered topics including perceptions of high-risk behaviors among older patients, and their practice with regard to discussing HIV/AIDS

risks with older patients and considering or testing for HIV/AIDS as a cause of symptoms. The topic guide is attached as Appendix D.

Analysis Procedures

The data from the interviews with HIV-positive individuals were analyzed using descriptive quantitative techniques. Descriptive statistics are methods of deriving summary measures from the data collected in the survey, so that patterns in this data can be easily identified (Creswell, 1998). Frequencies and percentages were calculated for the responses to each survey question, and the data were cross-tabulated in order to compare sub-groups in the sample, for example by age, gender, ethnicity, and sexual orientation, by their prevalence of high-risk sexual or drug-taking behaviors. The results were compared with published data on high-risk behaviors in the American population generally, using sources such as Smith (1998).

Data from the semistructured interviews with health care professionals were organized and analyzed using what was described by Burnard (1991) as thematic analysis and also commonly referred to as content analysis. The transcribed interview material was reviewed and coded by common themes and patterns. These were subsequently recategorized as necessary to incorporate additional research material, until a final list of key points and themes was arrived at. The presentation of results was organized by these themes, with relevant quotes from interviewees to illustrate the points being made. Throughout this form of analysis the researcher continues to move back and forth from the details of individual interviews to an overview of the study findings and back to details, until final results have been generated that are consistent with the interview material as a whole. Through continual reading of the data, the researcher identifies any

categories, themes, and patterns that may emerge. The purpose is to test any developing theory against the data, search for alternative explanations of the data, and finally write a research report (Marshall & Rossman, 1995).

Assumptions and Limitations

In conducting this research, a number of key assumptions were made. First, it was assumed that the research instruments are effective in identifying and collecting information on all main forms of behaviors that might put an individual at risk of contracting HIV/AIDS.

Second, older adults were defined for the purpose of the research as being aged 50 and over. This is a somewhat arbitrary definition, but is intended to be consistent with the definition of older people normally used by the CDC in its statistical reporting on HIV/AIDS. The relatively low starting age for the definition of older adults also allows for investigation of the views and experiences of people of different ages within the population of older adults.

Finally, it was assumed that respondents were being truthful in their survey answers. This assumption may not have been justified, as it is possible that respondents may have under-reported risky behaviors in order to appear more socially acceptable to the researcher. This is always a particularly significant problem in research on sensitive or controversial subjects such as high-risk sexual behaviors. However, the researcher attempted to minimize under-reporting by doing everything possible to put respondents at their ease by creating a comfortable and safe environment for the interview, by emphasizing their anonymity, and by giving assurances of complete confidentiality and anonymity in storing and reporting data.

Although this study argues for the use of a systems theory conceptual framework when conducting research into HIV/AIDS among older people, the primary research stage of the study focused only on two components of the system under study: individuals with HIV/AIDS and health care providers. This is not a weakness of the study in itself, but is a limitation relating to time and budget constraints that highlights the need for additional research into the impact of other aspects of the social system. Similarly, although the overall conceptual framework for analysis also drew on social network theory, the nature of the study did not allow for an extensive analysis of social networks among older people.

More significantly, in terms of interpretation of the research findings, this study was limited by the use of a convenience method of sampling participants for the research with older adults with HIV/AIDS and health care professionals, using a single nursing home in The Bronx, New York, which means that the findings cannot be generalized to the wider population of older adults with HIV/AIDS and health care professionals. Although attempts were made to recruit a diverse sample of older adults and health care professionals from the selected nursing home, it may be that the participants in this study differed systematically in some way from the wider population from which they were drawn.

Additionally, since a control group of non-HIV/AIDS patients was not included in the study, it is not possible to use the findings to demonstrate any statistical association between individual characteristics and behaviors and the likelihood of contracting HIV/AIDS. The study should be regarded primarily as exploratory and illustrative, and as a

means of generating useful information to inform interventions, policies, and campaigns to help address the increasing problem of HIV/AIDS among older people.

A final limitation has to do with the questionnaire used to gather data. This was a researcher-developed questionnaire that has not been tested for validity or reliability.

Summary

This chapter of the study described the methods used to determine sample size, gather and analyze data, and ensure participant confidentiality. Recruitment and instruments were also discussed. The next chapter of this study presents and analyzes the data collected via the methods described here.

Chapter 4: Results

This study aimed to provide empirical evidence regarding factors that are likely to be contributing to the increase in transmission of HIV/AIDS among older adults, including their own behavioral characteristics and medical professionals' health care practice with this group. It was based on primary research with HIV/AIDS-diagnosed older adults and health care professionals.

A conceptual framework based on systems theory and social network theory was used to identify various factors that might be contributing to the rise of HIV/AIDS among older adults, including individual behaviors as well as the practices of health care professionals with older patients, and to understand how these operate in practice via the relationships that exist within and between networks of older adults. These factors were used in the design of a survey questionnaire to investigate (a) the frequency of high-risk behaviors among a sample of older adults with HIV/AIDS, and (b) a semistructured interview topic guide to explore HIV/AIDS awareness and practices among health care workers who work with older adults.

Participants for both the survey and the in-depth interviews were contacted via a nursing home in the Bronx district of New York, and drawn from the nursing home as well as the adjoining hospital and community clinics affiliated with the hospital. A total of 99 adults with HIV/AIDS participated in the survey; in-depth interviews were conducted with 17 health workers.

The study aimed to answer the following key research questions:

1. Among a sample of older patients with HIV or AIDS, what common factors can be identified which are likely to have contributed to their infection?
2. Based on qualitative research with a small sample of health care providers, is there any evidence to suggest that current health care practices in relation to older adults might be contributing to, or failing to tackle, the problem of HIV/AIDS among adults aged 50 and over?
3. Taking into account the survey results and qualitative research findings, how can health education and health care practice in relation to older people be modified to help reduce the growing problem of HIV/AIDS among this group, and to improve health outcomes for those diagnosed with the infection?

Previous chapters of the study presented the research problem and its significance, reviewed relevant research, and described the methods used to collect and analyze data. The current chapter presents the results of these data collection efforts, focusing primarily on Research Questions 1 and 2. First, the characteristics of the sample of older adults with HIV/AIDS and the sample of health care workers are described. Following this, the findings from the survey of adults with HIV/AIDS are presented in order to answer Research Question 1. These findings are then considered in the context of existing knowledge about HIV/AIDS risk factors. Next, the findings from the interviews with health care workers are presented in order to address Research Question 2. Research Question 4 will be addressed in chapter 5, which synthesizes the results from both stages of the study and considers their implications.

Characteristics of the Research Participants

Survey Sample of Older Adults

In response to the request for volunteers to participate in the study, 99 eligible older adults living with HIV/AIDS contacted the researcher and were included in the sample. The distribution of this sample by gender, age, ethnicity and sexual orientation is shown in Table 3.

Just over half 52.5% of this sample were aged between 50 and 57 years old and the remainder were 58 years or older. Roughly half were male 54.5%. In terms of ethnicity, the highest percentage was African American 39.4%, followed by Hispanic 28.3%, European American 24.2%, and Asian 6.1%, with 2.0% being of other ethnicities (Table 3).

In terms of sexual orientation, nearly half 48.5% of the participants described themselves as heterosexual, with 19.2% being bisexual, 14.1% homosexual, 10.1% transgender, and the remainder 8.1% either unsure or reporting some “other” sexual orientation (Table 3).

Fuller details of the demographic, socioeconomic and sexual identity characteristics of the sample are shown in Table A1 (Appendix A), including the distribution by household income; educational attainment, employment status, residence and gender identity. Gender identity was described as female for 48.5% of the participants, male for 46.5% of the participants, and transgender for 3.0% of the participants. About one quarter of the participants reported being resident in the nursing home 25.3%.

Table 3
Socio-Demographic Characteristics of Sample

| | Percentage |
|------------------|------------|
| Gender | |
| Male | 54.5 |
| Female | 45.5 |
| Age Group | |
| 50 through 57 | 52.5 |
| 58 or older | 47.5 |
| Ethnicity | |
| White | 24.2 |
| African American | 39.4 |
| Hispanic | 28.3 |
| Asian | 6.1 |
| Other | 2.0 |
| Sexual Identity | |
| Heterosexual | 48.5 |
| Transgender | 10.1 |
| Homosexual | 14.1 |
| Bisexual | 19.2 |
| Not sure | 3.0 |
| Other | 1.0 |
| Missing | 4.0 |

Interview Sample of Health Care Professionals

The demographic characteristics of the health care professionals sample are shown in Tables A4 and A5 (Appendix A). Nearly two-thirds (64.7%) of the sample was female; nearly half (47%) were aged over 45; with 11.7% aged 36 to 45 and 35.2% aged 26 to 35. In terms of ethnicity, the largest percentage was African American 41.1%, followed by European American 29.4%, Asian 23.5%, and Hispanic 5.8%. Nearly half (47%) were medical doctors, 29.4% were registered nurses; and the remaining four respondents were other health care professionals (Table A3, Appendix A).

When asked about the percentage of patients in their practice over the age of 50 years, respondents reported a wide range, 0 - 90%, with the average respondent reporting that 56.6% of patients were age 50 or older. Regarding the percentage of patients who were HIV-positive, respondents also reported a wide range (1 – 80%), with an average of 34.7% ($SD = 29.2$). Respondents estimated that, among patients older than age 50, between 0 and 50% had HIV/AIDS, with a mean response of 20.1% ($SD = 22.6$). Respondents estimated that among patients over the age of 50, 10 – 60% ($m = 25%$, $SD = 19.3$) were practicing risky behaviors (Table A4, Appendix A).

Research Question 1: Among sample of older patients with HIV or AIDS, what common factors can be identified which are likely to have contributed to their infection?

In order to identify factors which may have contributed to or been associated with HIV/AIDS infection among the research participants, the survey questionnaire collected a range of information about the socioeconomic background of respondents, as well as their past and present risk behaviors (sexual and substance abuse history) and preventative health behavior. In this way, the survey was designed to provide comprehensive information regarding the factors which may be associated with health literacy and with the likelihood of contracting HIV/AIDS. The data from the interviews with HIV-positive individuals were analyzed using descriptive quantitative techniques. The main findings are presented and discussed below.

HIV and STD Testing

As can be seen in Table 4, among the survey sample, the most common reason for HIV testing was “at a doctor’s request” (40.4%), followed by “a perception of risk” 33.3%, and “as part of a regular checkup” 17.2%. Most of the participants 56.6% had not been tested for HIV before, although nearly one-third of the sample (31.3%) had been tested before with negative test results. Most of the participants (61.6%) reported not having regular checkups prior to the HIV diagnosis. Less than half of the participants (46.5%) stated that they had not previously been diagnosed with an STD. Of those who reporting having been diagnosed with an STD, the average age of diagnosis was 23.23 years old ($SD = 7.74$ years).

Table 4
Descriptive Statistics for HIV and STD Variables
($N=99$)

| | Percentage |
|--|------------|
| Reasons for HIV Testing* | |
| Regular check up | 17.2 |
| Might be at risk | 33.3 |
| Doctor’s request | 40.4 |
| Other | 8.1 |
| Prior HIV Testing | |
| Yes | 40.4 |
| No | 56.6 |
| Missing | 3.0 |
| Prior HIV Testing Results | |
| Negative | 31.3 |
| Positive | 8.1 |
| Didn’t get results | 1.0 |
| Missing | 59.6 |
| Regular Check Ups Prior to HIV Diagnosis | |
| Yes | 33.3 |
| No | 61.6 |
| Missing | 5.1 |
| Diagnosed with STD | |
| Yes | 46.5 |
| No | 50.5 |
| Missing | 3.0 |
| Age When Diagnosed with STD | 7.74 |

* Multiple responses allowed.

Sexual History and Practices

The majority of the participants 60.6%, reported currently being sexually active and nearly all (89.9%) reported being sexually active within the past 5 years. Just over half (52.5%) said that they currently have a main partner, and most reported either having only one partner in the past 12 months 33.3% or less than five partners in the past 12 months 34.3%. When asked about the number of sexual partners over their lifetime, the largest number of respondents 44.4% reported having between 11 and 50 sexual partners. Only 6% had had just one sexual partner in their lifetime but 11% had had less than five (Table 5).

The most commonly practiced form of sex was reported to be oral sex 86.9%, followed by anal sex 81.8% and vaginal sex 75.5%. The participants' role in sexual practice tended to be either oral receptive 63.6% or anal receptive 61.6%, with relatively few participants reporting oral insertion sexual practices 14.1%. For their sexual practices with regular partners once a month, the majority of the participants endorsed each category: anal 62.6%, oral 61.6%, and vaginal 55.6%. Only 10.1% of the participants reported taking Viagra 10.1% and very few reported taking Levitra 2.0% or Cialis 1.0% for sexual enhancement purposes (Table 5).

Fuller details of the sexual history and practices characteristics of the sample are shown in Table A2 (Appendix A), including the distribution by gender of sexual partners, age at which sexual intercourse first occurred, and number of sexual partners over time, by gender. It is notable that nearly one-third of the participants 29.3% reported having been sexually abused in their lives, with genital contact 15.2% or penetration 15.2% the

Table 5
Descriptive Statistics for Sexual History and Practices Variables
 (N=99)

| | Percentage |
|--|------------|
| Sexually Active | |
| Yes | 60.6 |
| No | 36.4 |
| Missing | 3.0 |
| Sexually Active in Past Five Years | |
| Yes | 89.9 |
| No | 8.1 |
| Missing | 2.0 |
| Number of Lifetime Sexual Partners | |
| One | 6.1 |
| Less than 5 | 11.1 |
| Between 5 and 10 | 27.3 |
| Between 11 and 50 | 44.4 |
| Over 50 | 8.1 |
| Missing | 3.0 |
| Currently Have a Main Partner | |
| Yes | 52.5 |
| No | 40.4 |
| Missing | 7.1 |
| Sexual Practices* | |
| Vaginal | 75.5 |
| Oral | 86.9 |
| Anal | 81.8 |
| Role in Sexual Practices* | |
| Vaginal receptive | 40.4 |
| Vaginal insertion | 34.3 |
| Oral receptive | 63.6 |
| Oral insertion | 14.1 |
| Anal receptive | 61.6 |
| Anal insertion | 42.4 |
| Sexual Practices with Regular Partners Once Per Month* | |
| Vaginal | 55.6 |
| Oral | 61.6 |
| Anal | 62.6 |
| Medications Taken for Sexual Enhancement* | |
| Viagra | 10.1 |
| Livitra | 2.0 |
| Cialis | 1.0 |

most common types of sexual abuse. The sexual abuse these participants have undergone may have been the cause of their disease acquisition.

High-Risk Behavior

Transmission through high-risk sexual behavior now reportedly accounts for a higher percentage of infection in older people than for other age groups (Strombeck, 1998). The survey questionnaire investigated the use of various practices which might be expected to increase the risk of contracting HIV/AIDS, including high-risk sexual behavior as well as the use of drugs and alcohol, and the key findings are shown in Tables 6 and 7.

Only 9.1% of the sample reported always using condoms during sex, while 18.2% reported never using condoms and more than half of the respondents 61.6% reported using condoms only sometimes. In most cases 69.7%, latex condoms were being used. More than half of the participants 53.4% indicated that they had provided sex for either money or drugs, while a smaller but still percentage had paid money or drugs for sex 28.3% (Table 6).

Most of the participants 59.6% reported having sex while under the influence of drugs or alcohol in the past five years. In terms of the frequency of alcohol usage, 16.2% of the sample reported daily use, with 28.3% using two or more times per week, and 19.2% using once per week.

Table 6
Descriptive Statistics for Sexual Behavior Variables
 (N=99)

| | Percentage |
|--|------------|
| Condom Usage | |
| Always | 9.1 |
| Sometimes | 61.6 |
| Never | 18.2 |
| N/A | 11.1 |
| Had Sex in Past Five Years Under Influence of Drugs or Alcohol | |
| Yes | 59.6 |
| No | 31.3 |
| Missing | 9.1 |
| Provided Sex for Money or Drugs | |
| Yes | 53.5 |
| No | 43.4 |
| Missing | 3.0 |
| Paid Money or Drugs for Sex | |
| Yes | 28.3 |
| No | 67.7 |
| Missing | 4.0 |

Note: Many of these high risks were identified by the assistance of DAC (Designated AIDS Center at St. Barnabas Hospital).

When asked about drug usage, 42.4% of the participants stated that they had used cocaine in their lifetime, while a further 32.3% stated that they had used cocaine in combination with heroin. In addition, 28.3% had used heroin by itself. Only slightly lower percentages reported using cocaine or heroin, by themselves or in combination, over the past six months or every week. The frequency of usage for other drugs for recreational purposes, including Viagra, was low. The statistics for lifetime drug usage as well as recreational drug usage over the past six months, and per week, by different drug types is shown in Table 7. Only 2% reported the use of Viagra either in the past week, past six months or ever in their lifetime, for recreational purposes (Table 7), although 10% of the sample had reported taking Viagra as a medication for sexual

Table 7
Descriptive Statistics for Alcohol and Drug Usage Variables
 (N=99) Multiple responses allowed

| | Percentage |
|--|------------|
| Frequency of Alcohol Usage | |
| Every day | 16.2 |
| Once a week | 19.2 |
| Twice a week | 28.3 |
| Other | 35.4 |
| Missing | 1.0 |
| Lifetime Drug Usage* | |
| Cocaine by itself | 42.4 |
| Heroin by itself | 28.3 |
| Cocaine and heroin together | 32.3 |
| Demerol, codeine, Dilaudid | 2.0 |
| Speed or methamphetamine | 9.1 |
| Viagra or similar drug | 2.0 |
| Other | 5.1 |
| Recreational Drug Usage in Past Six Months* | |
| Cocaine by itself | 34.3 |
| Heroin by itself | 21.2 |
| Cocaine and heroin together | 21.2 |
| Demerol, codeine, Dilaudid | 1.0 |
| Speed or methamphetamine | 3.0 |
| Viagra or similar drug | 2.0 |
| Other | 5.1 |
| Recreational Usage Per Week* | |
| Cocaine by itself | 32.3 |
| Heroin by itself | 18.2 |
| Cocaine and heroin together | 19.2 |
| Demerol, codeine, Dilaudid | 0.0 |
| Speed or methamphetamine | 1.0 |
| Viagra or similar drug | 2.0 |
| Other | 5.0 |
| Mode of Drug Usage* | |
| Smoke | 15.2 |
| Inhaled or sniffed | 41.4 |
| Injected | 32.3 |
| Intravenous Drug Usage* | |
| Prescription | 25.3 |
| Recreational | 32.3 |
| Other | 1.0 |
| Ever Shared Needles | |
| Yes | 36.4 |
| No | 61.6 |
| Missing | 2.0 |
| Shared Needles Past Five Years | |
| Yes | 33.3 |
| No | 62.6 |
| Missing | 4.0 |
| Source of Needles | |
| Doctor | 5.1 |
| Friends | 24.2 |
| Hospital/Nursing home/Pharmacy | 13.1 |

enhance purposes (Table 5). Across all types of drugs, the most common mode of drug usage was inhaling or sniffing 41.4%, followed by injecting 32.3%, and smoking 15.2%. When asked about intravenous drug usage, 32.3% of the sample reported that they had used drugs intravenously for recreational purposes, while 25.3% said they had used drugs intravenously with prescription drugs. Over one-third of the sample (36.4%) had shared needles, and one-third 33.3% had done so in the past five years. Nearly one-quarter of the sample had obtained needles from friends or on the street 24.2%, with 13.1% obtaining needles from a hospital, nursing home, or pharmacy, and only 5.1% receiving needles from a doctor (Table 7).

Precautions against HIV/AIDS

The research respondents were also asked what special precautions they had taken prior to their HIV diagnosis. The most commonly reported precaution was the use of condoms 65.7%, followed by limiting the number of partners 32.3%, having sex less frequently 17.2%, avoiding prostitutes 15.2%, and avoiding homosexual sex 15.2% (Table 8).

Table 8

Descriptive Statistics - Special Precautions Taken Before HIV Diagnosis
(N=99)

| | Percentage |
|--------------------------------|------------|
| Less frequent sex | 17.2 |
| Avoiding oral sex | 4.0 |
| Avoiding anal sex | 6.1 |
| Avoiding prostitutes | 15.2 |
| Avoiding homosexual sex | 15.2 |
| Avoiding kissing | 5.1 |
| Limiting partners | 32.3 |
| Monogamy | 3.0 |
| Abstinence | 4.0 |
| Using condoms | 65.7 |
| Avoiding HIV positive partners | 7.1 |

^aMultiple responses allowed.

Risk Factors by Demographic and Sexual Identity Variables

From the above findings, twelve apparent HIV risk factors were selected and the relationships between these risk factors and the variables of gender, age, ethnicity, and sexual orientation were examined. This approach was in line with the systems theory and social network theory conceptual framework adopted in this study, and was intended to help promote a better understanding of how the apparent risk factors to understand how these operate in practice via the relationships that exist within and between networks of older adults. The results are shown in Tables 9 to 12 and discussed below.

Gender and HIV risk. Table 9 shows the percentages of males and females respectively who responded in the affirmative in relation to each of the 12 risk factors. The largest difference between males and females was that 38.9% of males reported paying money or drugs for sex, compared to only 15.6% of females. Next, a substantially higher percentage of males 48.1% than females 31.1% reported that they had used heroin. However, females were more likely to have injected drugs recreationally 37.8% than males 27.8%. Finally, males were more likely than females to have had five or more sexual partners in the past 12 months (22.2% of males compared to 11.1% of females). The percentages of males and females who responded affirmatively in relation to each of the remaining eight risk factors were similar (i.e. less than a 10% difference between males and females).

Age and HIV risk. Table 10 shows the comparison between the younger portion of the sample (those aged 50 through 57) and the older portion of the sample (aged 58 or older), in relation to the twelve risk factors. The differences between the younger and

older participants were in general smaller than those between male and female participants, with only two risk factors showing a difference of 10% or more. The largest difference between the two age groups was that 46.8% of older participants reported having shared needles compared with only 26.9% of younger participants. In addition, 59.6% of older participants reported providing sex for money or drugs compared to only 48.1% of younger participants.

Table 9
HIV Risk Factors as a Function of Gender
(N=99)

| | Male (n = 54) | Female (n = 45) |
|---|------------------|--------------------|
| Having over 50 lifetime partners. | 9.3% | 6.7% |
| Having 5 or more sexual partners in the past 12 months. | 22.2% | 11.1% |
| Never using condoms or only sometimes using condoms. | 83.3% | 75.6% |
| Having anal sex. | 85.2% | 77.8% |
| Providing sex for money or drugs. | 57.4% | 48.9% |
| Paying money or drugs for sex. | 38.9% | 15.6% |
| Ever using heroin. | 48.1% | 31.1% |
| Ever injecting drugs recreationally. | 27.8% | 37.8% |
| Ever sharing needles. | 38.9% | 33.3% |
| Acquiring needles from friends. | 22.2% | 26.7% |
| Having sex under the influence of alcohol or drugs. | 61.1% | 57.8% |
| Daily alcohol usage. | 14.8% | 17.8% |

Table 10
HIV Risk Factors as a Function of Age
 (N=99)

| | Aged 50 through 57 (n = 52) | Aged 58 or older (n = 47) |
|---|-----------------------------------|------------------------------|
| Having over 50 lifetime partners. | 11.5% | 4.3% |
| Having 5 or more sexual partners in the past 12 months. | 21.2% | 12.8% |
| Never using condoms or only sometimes using condoms. | 82.7% | 76.6% |
| Having anal sex. | 80.8% | 83.0% |
| Providing sex for money or drugs. | 48.1% | 59.6% |
| Paying money or drugs for sex. | 25.0% | 31.9% |
| Ever using heroin. | 36.5% | 44.7% |
| Ever injecting drugs recreationally. | 34.6% | 29.8% |
| Ever sharing needles. | 26.9% | 46.8% |
| Acquiring needles from friends. | 23.1% | 25.5% |
| Having sex under the influence of alcohol or drugs. | 57.7% | 61.7% |
| Daily alcohol usage. | 13.5% | 19.1% |

Ethnicity and HIV risk. Table 11 shows the 12 HIV risk factors as a function of ethnicity. There were several large differences (greater than 10%) between the percentages of different ethnic groups responding in the affirmative in relation to the HIV risk factors. A larger percentage of European Americans 29.2% had had five or more sexual partners in the past 12 months than was the case for Hispanics 17.9%, African Americans 10.3%, or those in the “other” ethnic category 12.5%. Additionally, a larger percentage of European Americans 95.8% reported having anal sex than Hispanics 85.7% or those in the “other” ethnic category, with a relatively low percentage of African Americans reporting having anal sex 69.2%. African Americans were also less likely to provide sex for money or drugs 42.6% than European Americans 58.3%, Hispanics

Table 11
HIV Risk Factors as a Function of Ethnicity
 (N=99)

| | European American (n = 24) | African American (n = 39) | Hispanic (n = 28) | Other (n = 8) |
|---|----------------------------------|---------------------------------|----------------------|------------------|
| Having over 50 lifetime partners. | 8.3% | 7.7% | 7.1% | 12.5% |
| Having 5 or more sexual partners in the past 12 months. | 29.2% | 10.3% | 17.9% | 12.5% |
| Never using condoms or only sometimes using condoms. | 83.3% | 82.1% | 75.0% | 75.0% |
| Having anal sex. | 95.8% | 69.2% | 85.7% | 87.5% |
| Providing sex for money or drugs. | 58.3% | 43.6% | 60.7% | 62.5% |
| Paying money or drugs for sex. | 25.0% | 25.6% | 35.7% | 25.0% |
| Ever using heroin. | 29.2% | 41.0% | 53.6% | 25.0% |
| Ever injecting drugs recreationally. | 29.2% | 25.6% | 46.4% | 25.0% |
| Ever sharing needles. | 33.3% | 38.5% | 42.9% | 12.5% |
| Acquiring needles from friends. | 20.8% | 25.6% | 28.6% | 12.5% |
| Having sex under the influence of alcohol or drugs. | 66.7% | 51.3% | 67.9% | 50.0% |
| Daily alcohol usage. | 20.8% | 17.9% | 14.3% | 0.0% |

60.7% or those in the “other” ethnic group 62.5%. Hispanics were more likely to pay money or drugs for sex 35.7% than European Americans 25.0%, African Americans 25.6%, or those in the “other” ethnic group 25.0%.

With regard to drug usage, Hispanics were more likely to have used heroin 53.6% than African Americans 41.0%, who in turn were more likely than either European Americans 29.2% or those in the “other” ethnic group. Hispanics were also more likely to have injected drugs recreationally 46.4% than European Americans 29.2%, African Americans 25.6%, or those in the “other” ethnic group 25.0%. In addition, Hispanics were slightly more likely to share needles 42.9% than African Americans 38.5% or European Americans 33.3%, and much more likely to do so than those in the “other”

ethnic group 12.5%. Hispanics 28.6%, European Americans 20.8%, and African Americans 25.6% were more likely to acquire needles from friends than those in the “other” ethnic group 12.5%. European Americans 66.7% and Hispanics 67.9% were more likely than African Americans 51.3% or those in the “other” ethnic group to have sex under the influence of alcohol or drugs. Finally, European Americans 20.8%, African Americans 17.9%, and Hispanics 14.3% were more likely than those in the “other” ethnic group to use alcohol daily.

Sexual orientation and HIV risk. Finally, the HIV risk factors were examined as a function of sexual orientation, with results shown in Table 12. Homosexuals 21.4% and bisexuals 15.8% were found to have been much more likely to have had over 50 lifetime sexual partners than heterosexuals 2.1%. Homosexuals 35.7% and bisexuals 36.8% were also substantially more likely to have had five or more sexual partners in the past 12 months than heterosexuals 6.3%. Nearly all of the homosexuals 92.9% and bisexuals 94.7% reported not always using condoms compared with a lower percentage of heterosexuals 79.2% and those in the “other” sexual orientation category 55.6%. All of the homosexuals 100.0% and bisexuals 100.0% reported having anal sex, compared to 70.8% of heterosexuals and 77.8% of those in the “other” sexual orientation category (Table 12). Homosexuals 64.3% and bisexuals 78.9% were also more likely to have provided sex for money or drugs than heterosexuals 39.6%. However, only bisexuals 57.9% were more likely than heterosexuals 20.8% to have paid money or drugs for sex, with Homosexuals 21.4% resembling heterosexuals on this risk factor.

With regard to drug usage, bisexuals were also the group most likely to have used heroin 57.9% compared to heterosexuals 41.7% and homosexuals 14.3%, with 38.9% of those in the “other” sexual orientation group having used heroin. For the recreational injection of any drug, bisexuals 42.1%, heterosexuals 35.4%, and those in the “other” sexual orientation category were more likely to have responded affirmatively in relation to this risk factor than homosexuals 14.3%. Sharing needles was more commonly reported by bisexuals 42.1% and heterosexuals 35.4% compared to homosexuals 14.3%. Bisexuals were also more likely to acquire needles from friends 36.8% than heterosexuals 25.0%, homosexuals 14.3%, or those in the “other” sexual orientation group. In addition, a considerably higher percentage of bisexuals 84.2% than homosexuals 57.1% or heterosexuals 54.2% said that they have sex under the influence of drugs or alcohol, with those in the “other” sexual orientation group being least likely to do so. Finally, bisexuals were more likely to use alcohol daily 26.3% than heterosexuals 16.7%, homosexuals 14.3%, or those in the “other” sexual orientation group (Table 12).

Table 12

HIV Risk Factors as a Function of Sexual Orientation

(N=99)

| | Heterosexual (n = 48) | Homosexual (n = 14) | Bisexual (n = 19) | Other (n = 18) |
|---|--------------------------|------------------------|----------------------|-------------------|
| Having over 50 lifetime partners. | 2.1% | 21.4% | 15.8% | 5.6% |
| Having 5 or more sexual partners in the past 12 months. | 6.3% | 35.7% | 36.8% | 11.1% |
| Never using condoms or only sometimes using condoms. | 79.2% | 92.9% | 94.7% | 55.6% |
| Having anal sex. | 70.8% | 100.0% | 100.0% | 77.8% |
| Providing sex for money or drugs. | 39.6% | 64.3% | 78.9% | 55.6% |
| Paying money or drugs for sex. | 20.8% | 21.4% | 57.9% | 22.2% |
| Ever using heroin. | 41.7% | 14.3% | 57.9% | 38.9% |
| Ever injecting drugs recreationally. | 35.4% | 14.3% | 42.1% | 27.8% |
| Ever sharing needles. | 35.4% | 28.6% | 47.4% | 33.3% |
| Acquiring needles from friends. | 25.0% | 14.3% | 36.8% | 16.7% |
| Having sex under the influence of alcohol or drugs. | 54.2% | 57.1% | 84.2% | 50.0% |
| Daily alcohol usage. | 16.7% | 14.3% | 26.3% | 5.6% |

Note: Many of these high risks were identified by the assistance of DAC (Designated AIDS Center located at St. Barnabas Hospital).

Research Question 2: Health Care Practices

The interviews with health care workers aimed to explore whether there is any evidence to suggest that current health care practices in relation to older adults might be contributing to, or failing to tackle, the problem of HIV/AIDS among adults aged over 50. Using semistructured interviews, the researcher collected information on 17 health care workers' roles and socio-demographic characteristics as well as perceptions of high risk behaviors among older patients, and their practices with regard to discussing

HIV/AIDS risks with older patients and considering or testing for HIV/AIDS as a cause of symptoms. The interview data were coded and analyzed using content analysis.

Consideration of HIV/AIDS in Diagnosis of Older Adults

The majority 82.3% of respondents indicated that they were aware of an increase in HIV/AIDS among the older population. The reasons health care providers gave to account for this increase are shown in Table A4 (Appendix A). The most frequently cited responses were, in descending order of frequency: unprotected sex (9), longevity and improved treatment (4) and lack of information (3). Despite their high level of awareness of an increase in HIV/AIDS among older adults, only 58.8% of the health care professionals interviewed reported considering HIV/AIDS when diagnosing adults over the age of 50 years. In contrast, 88.2% reported considering HIV/AIDS when diagnosing adults aged 50 or below (Table 13).

Table 13
Awareness of and Consideration of HIV/AIDS in Diagnosis of Older Adults
(*n*=17)

| | Percentage |
|---|------------|
| Aware of increase in HIV in older adults | |
| Yes | 82.3 |
| No | 17.6 |
| When diagnosing adults >50, do you consider HIV | |
| Yes | 58.8 |
| No | 41.1 |
| When diagnosing adults <50, do you consider HIV | |
| Yes | 88.2 |
| No | 11.7 |

Table 14 shows the replies given by respondents when asked to indicate the circumstances in which they would consider a diagnosis of HIV/AIDS when treating an adult patient over 50 years old.

Having omitted a number of responses which were not directly relevant to the question, 12 usable responses remained, which can be divided between specific indicators and general context indicators. Specific indicators or symptoms that health care providers viewed as suggesting the need to rule out a diagnosis of HIV/AIDS in older adults included: presence of a viral URI syndrome; dementia, weakness, weight loss, frailty; symptoms that can mimic HIV/AIDS, such as menopause and diabetes; and lab results. General context indicators included: presentation and history, including past sexual behavior or drug use; symptoms that fit the age group; co-morbidity; demographic

Table 14

Circumstances Under Which Provider Considers a Diagnosis of HIV in Older Adults

Not often enough. Most people older than 50 tend to stick with one or two partners; sexual behaviors are not so high risk

Have viral URI syndrome

Dementia, weakness, weight loss, frailty

Based on the conversation I have with the patients. Sometimes they release information that would make me explore HIV/AIDS as a possible diagnosis

Depending on presentation & history

HIV/AIDS symptoms can mimic other medical conditions such as menopause, diabetes

Past sexual, drug activities or current activities; lab results

Depending on patient symptoms, presentation, work status, homelessness

Given the context of symptoms that usually fit the age group, or comorbidity

Older people come to hospital with other medical illness

In the Bronx, HIV is always considered. Everyone is HIV+ until proven not in the Bronx

It depends

characteristics such as work status or homelessness; and characteristics of the population in the geographic location of the study (“In the Bronx, HIV is always considered. Everyone is HIV+ until proven not in the Bronx”).

In contrast, Table 15 presents replies given by respondents when asked to indicate the circumstances in which they would consider a diagnosis of HIV/AIDS when treating an adult patient *under* 50 years old. Having excluded four responses that were not directly applicable to the question, nine usable responses were left, which can be divided between specific indicators and general context. Specific indicators or symptoms that health care providers viewed as suggesting the need to rule out a diagnosis of HIV/AIDS in younger adults included: dementia, weakness, weight loss, frailty, oral thrush; clinical symptoms that suggest HIV/AIDS; lab results. General indicators included drug usage, sexual behaviors (promiscuity, unprotected sex), presentation, job status, and elevated risk factors. With a few exceptions, such as job status, these indicators are similar to those interviewees listed for older adult patients.

Table 15

Circumstances under which Providers Consider a Diagnosis of HIV in Younger Adults

This population has higher incidence of STDs, have to consider HIV
 Dementia, weakness, weight loss, frailty, drug usage, sexual behaviors
 Patients with elevated risk factors, clinical symptoms suggest HIV
 Sexual activity, drug history, weight loss, oral thrush & other medical findings
 Sexual promiscuity, IV drug abuse, unprotected sex
 Based on significant lab results, sexual and drug history
 Also depends on patient's presentation & symptoms, job status, sexual practices, etc.
 Present/past sexual behavior
 Sexual history, drug history

Table 16 shows health care professionals' responses to the question of when an HIV/AIDS test is indicated. Many of the responses 43.7% included reference to specific risk factors, including: promiscuity, drug use, blood transfusions, and homosexuality. Notably, 37.5% of the responses included a call for routine HIV/AIDS testing. The findings thus indicate that the health care professionals in this sample either use patients' history to determine whether tests are needed or perform tests as a preventive measure (e.g. routine test).

Table 16
Circumstances in which an HIV Test is Indicated

Recommended as part of labs for annual physical
 Make it a routine test, part of annual checkup for everybody
 Promiscuity, IV drug use, prodromal symptoms
 History of risky behaviors, medical surgery related to HIV (TB, cough)
 All mothers who are pregnant or delivered, especially people 18-30 years. young females are not choosing mates carefully and they tend to be promiscuous... their men could be dating one or more people and may be involved in IV drug activity
 Age, risk factors (drug use, homosexual)
 To rule out a significant lab results that might indicate the patient has HIV/AIDS
 Patient's past sexual, blood transfusion, drug use, signs/surgeries physically, lab work
 Unusual weight loss, unexplained changes in medical condition
 Routine test for all patients. All factors, age, sexual behaviors, diagnoses
 Also depends on patient's presentation & symptoms, job status, sexual practices, etc
 In all circumstances, especially patients with IV drug use
 Everybody should be tested for HIV
 Sexually active
 All patients should have Orasure [HIV test] in this population
 Rape, unprotected sex, drug abuse

Perceptions of Older Adults' Awareness of and Views on the HIV/AIDS Risk

Health care professionals' responses regarding their perceptions of older adults' comfort with discussing sexuality, awareness of HIV/AIDS risk, and use of precautions revealed a range of opinions, with lack of certainty being an overall feature of their responses.

Only 29.4% of respondents indicated that they feel older adults are generally comfortable discussing sexuality, while 41.1% were of the view that older adults are not comfortable discussing sexuality, and the remainder felt that they are only sometimes comfortable doing so. Nearly half (47%) agreed that older adults are aware of their HIV/AIDS risk, while 35.2% believed these adults are not aware of the risk, with the remaining 17.6% not sure. While the largest percentage (41.4%) of respondents expressed a belief that at-risk adults over the age of 50 take adequate precautions against contracting HIV/AIDS, 35.2% believed that they do not, while 23.5% were unsure (Table 17).

The health care professionals were asked about their perceptions of risky behaviors in younger versus older adults. The results indicated that, according to respondents, between 10% and 60% of older adults practice risky behaviors ($M = 29.8\%$).

Table 17
Perceptions of Older Adults' Awareness of and Views on the HIV/AIDS Risk
 (N = 17)

| | Percentage |
|--|------------|
| Are adults > 50 comfortable discussing sexuality | |
| Yes | 29.4 |
| No | 41.1 |
| Sometimes | 29.4 |
| Are adults > 50 aware of their HIV risk | |
| No | 35.2 |
| Maybe | 17.6 |
| Do at-risk adults > 50 take adequate precautions | |
| Yes | 41.1 |
| No | 35.2 |
| Maybe | 23.5 |

Among those respondents who expressed the view that fewer older adults engage in risky behavior compared with younger adults, this was accounted for by factors such as younger adults have more partners and failing to consider the consequences of behavior. Among respondents who thought the rate of risky behavior was lower among the younger adult population, reasons given for this included older adults being more likely to have unprotected sex because they are past childbearing years or believing that they are exempt from STD and HIV/AIDS (see Table A6, Appendix A).

More than a third of the sample of health care professionals 35.2% indicated that they do not believe that adults aged 50 and above take enough preventive measures to avoid HIV/AIDS. When asked to compare older adults to younger adults, some health care professionals indicated that younger adults are more likely to have multiple partners, fail to consider the consequences of their behavior, and are generally less responsible. Of those who thought that older adults indulge more in risky behavior than younger adults, reasons given included the following: “older adults are less responsible because they are past the childbearing years,” “older adults may think they are exempt from STDs and

HIV/AIDS”, and younger adults are “more aware, afraid, and use protective sexual habits.”

When asked which subgroups of the older adult population were most at risk of HIV/AIDS, respondents mentioned drug users most frequently ($n = 9$), followed by people who are homosexual or bisexual ($n = 4$) and people with multiple partners (prostitutes, the promiscuous; $n = 4$). The full range of responses is shown in Table A7, Appendix A. These results reinforce previous findings that drugs, sexual orientation, and sexual practices are factors related to HIV/AIDS risk, from the perspective of the health care professionals who provide services to older adults.

Adequacy of Information on HIV/AIDS among Older Adults

Only 35.2% of the health care professionals agreed that sufficient information about HIV/AIDS is made available to at-risk adults aged over 50, and 47% indicated that not enough information is being provided to increase awareness among older adults. When asked whether they felt enough information is being made available to health care providers to increase their own awareness of the HIV/AIDS risk among older adults, 47% agreed that this is the case, while 29.4% expressed a view that inadequate information is being made available to health care providers (Table 18).

Table 18
Adequacy of Information about HIV/AIDS in Older Adults
($N=17$)

| | Percentage |
|--|------------|
| Is enough info made available to at-risk adults > 50 to increase awareness | |
| Yes | 35.2 |
| No | 47.0 |
| Maybe | 11.7 |
| No response | 5.8 |

| | Percentage |
|--|------------|
| Is enough info made available to providers to increase awareness of risk of HIV in adults > 50 | |
| Yes | 47.0 |
| No | 29.4 |
| No response | 23.5 |

Summary

This chapter presented the findings of the study in relation to the first three research questions. First, it set out the characteristics of both the sample of older adults and the sample of health care professionals. Then the survey results were used to identify twelve risk factors which appear to be associated with HIV/AIDS. These included, for example, having a large number of sexual partners over their lifetime or over the past six months, not using condoms regularly, having sex under the influence of alcohol or drugs, using shared needles when taking drugs and having anal sex. The percentages of respondents in different socio-demographic groups who had responded affirmatively in relation to each of these risk factors were then compared, in order to provide a fuller understanding on how the risk factors might operate in practice within social groups, in line with the social systems conceptual framework of the study. On the basis of these findings, it appears that respondents aged 58 or over, European Americans and Hispanics and Bisexuals are the sub-groups of the older adult population that may be at greater risk of contracting HIV/AIDS and should be particularly targeted in efforts to address the increase of the disease among older adults. In the next section of the chapter, the identified risk factors for older adults were compared with what is known from the literature regarding HIV/AIDS risk factors among younger adults, to identify any key differences. This comparison reveals health care professionals indicate that the difference

with older adults are having multiple partners, failing to consider consequences and even the stereotype of younger adults as being less responsible. For those who think that older adults have more risky behavior, their reasons include the following: older adults are less responsible, thinking they are past the childbearing years, they may think they are exempt from STD & HIV/AIDS while younger adults are “more aware, afraid and use protective sexual habits.” It can be concluded that each health care professional has his or her own beliefs and assumptions on how both younger and older adults are at risk for HIV/AIDS.

Finally, the main findings of the interviews with health care professionals were presented, in order to identify any ways in which health care practices may be contributing to, or failing to tackle the problem of HIV/AIDS among adults aged 50 and over. Although the majority of the health care professionals were aware of the increase in HIV/AIDS among the older adult population, less than two thirds said that they generally considered HIV/AIDS when diagnosing older adults, considerably less than the 88% who considered HIV/AIDS when diagnosing younger adults. Despite this, the types of reasons for considering HIV/AIDS were similar whether diagnosing older or younger adults. The health care professionals exhibited a high level of uncertainty regarding older adults’ level of comfort in discussing sexuality; their perceptions of the risk and precautions taken. Similarly, the wide variation in responses regarding the propensity of older adults to engage in risky behavior indicated that health care professionals, overall, have relatively poor knowledge about the views and behavior of older adults. The interview findings provided support for the argument that insufficient information is being made available on the risks of HIV/AIDS among people aged 50 or over, with nearly half of the

interviewees indicating that they feel insufficient information is being provided to older adults and nearly a third indicating that health care providers are not receiving enough information on this issue.

In chapter 5, these results are discussed further and their implications highlighted. This final chapter directly addresses Research Question 4 by using the research findings to examine how health education and health care practice in relation to older people can be modified to help reduce the growing problem of HIV/AIDS among this group, and improve health outcomes for those diagnosed with the infection. Recommendations are made for future policy and practice in this area.

Chapter 5: Discussion, Conclusions, and Recommendations

Within behavioral and social science, there have been a number of studies of high-risk groups and people already diagnosed with HIV in order to understand the factors associated with its transmission, and to provide direction for possible interventions to help reduce the spread of the disease. However, older people with HIV, and the older population as a possible high-risk group, have largely been neglected in this body of research. In order to address this gap, the present study focused on the problem of the steady increase in HIV/AIDS diagnoses for older adults, defined as those aged 50 years and above. It used a systems theory conceptual framework to gather and interpret empirical evidence regarding factors that contribute to the transmission of HIV/AIDS among older adults, including their own behavioral characteristics and health care professionals' practices. This framework acknowledged that the problem may be attributable to the behavior of both patients and health care professionals, and the aim of the study was to determine what specific behavioral factors on the part of patients and health care professionals may be contributing. These findings can be used to formulate interventions to target the lack of awareness among patients and health care workers, as well as the lack of attention given to older adult HIV/AIDS patients.

Previous chapters of the study discussed the research problem and its significance, reviewed the relevant research, described the methods used to collect and analyze data, and presented the results of the analysis in relation to the first three research questions:

1. Among a sample of older patients with HIV or AIDS, what common factors can be identified which are likely to have contributed to their infection?
2. Based on qualitative research with a small sample of health care providers, is there any evidence to suggest that current health care practices in relation to older adults might be contributing to, or failing to tackle, the problem of HIV/AIDS among adults aged 50 and over?

In this chapter, the empirical research findings and their implications are discussed in the context of the broader literature in this area. The main findings are reviewed and their significance is discussed, focusing first on Research Questions 1 to 2. The overall key conclusions are then identified and recommendations are made on the basis of these for future policy and practice.

HIV/AIDS Risk Factors among Older Adults

Since the study was not based on a representative sample of older patients with HIV or AIDS, it was not possible to generate firm evidence on the relationship between particular socio-economic or behavioral factors and being diagnosed with HIV/AIDS, nor can the findings be generalized to all older adults with HIV/AIDS. However, from the survey evidence, based on a sample of older adults with HIV/AIDS drawn from a nursing home in The Bronx, New York, a number of factors could be identified which appear to be associated with HIV/AIDS in older people and may therefore be contributing to the increase in HIV/AIDS among this group. These findings should be regarded as indicative

rather than conclusive, but do constitute useful information which can be used to inform interventions, policies, and campaigns to help address the increasing problem of HIV/AIDS among older people.

Socio-demographic Factors

The main socio-demographic variables that appeared to be possible HIV/AIDS risk factors were African American ethnicity, male gender, and heterosexuality or bisexuality, as indicated by the relatively large percentages of our sample which fell into these socio-demographic categories. The survey findings also indicated that people with an annual household income of less than \$100,000 and those with only a high school education may be over-represented among older adults living with HIV/AIDS than those in higher income groups or with higher levels of education. Additionally, among the sample of HIV/AIDS patients aged 50 or over, the majority fell within the 50-57 age category rather than older age categories.

These findings must be interpreted with caution, however, as they may simply reflect the socio-economic characteristics of the area in which the nursing home is located. In particular, the population of this area includes a high percentage of African Americans, low-income people and those with low levels of education, so it is unsurprising that these groups are over-represented among the HIV/AIDS patients in the sample. Similarly, the lower proportion of older adults in our sample may reflect high mortality rates among HIV/AIDS patients, with relatively few surviving into their sixties or above.

Some of these results, however, do corroborate the findings of other studies. For example, males were overrepresented among respondents to this survey and, compared with females in the sample, were found to be more likely to use drugs and engage in regular sexual activity. This corroborates the findings of another recent study of 260 HIV-positive older adults who have unprotected sex, of which the majority were males (University of Ohio, 2007), and lends support to the argument that the disease is more likely to be obtained from males. This suggests that there may be a need to design information and education campaigns which are specifically targeted at older men, regardless of their sexual orientation.

Similarly, other studies (e.g. National Institute on Aging, 1999) have observed a rapidly increasing number of African American and Hispanic HIV/AIDS patients. Within the population of older Americans, the rapidly growing rate of HIV infection among African American and Hispanic people is of particular concern, as this represents the fastest growing number of reported cases in this age group (Department of Health and Human Services (2001). It may be that cultural and religious influences are impeding certain ethnicities from receiving the proper education and treatment, as reported by the Department of Health and Human Services (2001).

The current study also revealed some findings that cannot be regarded as conclusive, but are worthy of further investigation in order to improve understanding of the risk factors associated with HIV/AIDS among particular socio-economic groups. For example, more than half 53.4% of all the research participants said that they have engaged in sexual intercourse for money or drugs. Since most of the participants fell into

the “annual household income of less than \$10,000” category, it may be that they are in need of extra income and providing sexual services in exchange for money or drugs is one of their important sources, but one which left them vulnerable to infection with the HIV/AIDS virus.

The results also imply that the bisexual orientation may be related to an increased risk of contracting HIV/AIDS. This provides support for Coleman’s (2003) explanation that HIV/AIDS is related to risk factors such as drug injection and sexual orientation. Overall, ethnicity and sexual orientation appeared to be more strongly correlated with HIV risk factors than gender and age. This supports data from the American Civil Liberties Union (2002) and Coleman (2003) regarding the importance of culture and sexual orientation respectively.

Behavioral Factors

Testing and preventative health. According to the literature, the greatest potential for further spread of HIV infection among late middle-aged or older Americans derives from sexual behavior (Entwhistle, n.d.) It has been argued that high-risk older individuals are less likely to have adopted AIDS prevention strategies, including use of condoms and regular HIV testing, than younger high-risk individuals (e.g. Stall & Catania, 1994). One factor to which this has been attributed is the reported reluctance of many older patients to discuss sexuality with their primary health care providers, due to embarrassment or a perception that younger people, including their health care providers, will expect them to know more about protection than they really do (Zablotsky, 2003).

The present study generated mixed findings in relation to HIV testing among the sample of older adults. It was found that 61.6% of the participants had not had regular check-ups before being diagnosed as HIV positive, a measure which might have led to earlier detection or even prevention of the disease. The most common reason for seeking out HIV testing was “upon a doctor’s request,” indicating that older adults with HIV/AIDS were not likely to take the initiative in seeking a diagnosis. Only 17.2% had been tested as part of a regular check-up. This provides strong evidence of a need for information campaigns promoting regular health checks and HIV testing among older adults, especially among high-risk groups.

Such education campaigns might focus on the importance of using condoms, since the results of this study revealed that a high number of the research participants had used condoms inconsistently. Other studies have shown that postmenopausal adult women are less likely to take safety precautions (e.g. condoms and contraceptives) knowing that they will not get pregnant, but tears and small abrasions in the vaginal area as a result of dryness and thinning in the menopausal stage make the spread of HIV/AIDS easier among this group (Center for Women Policy Studies, 1994; NIA, 1999; Vlahov, 2003; Wallace, Paauw & Spauch, 1993).

Precautions taken before being diagnosed as HIV/AIDS positive were also explored in the survey. Most of the participants (65.7%) reported the use of condoms, 32.3% reported putting a limit on the number of partners and 17.2% reported lessening the frequency of sexual activity. Overall, these represent a relatively low level of preventative measures taken to prevent the risk of HIV/AIDSs, a finding which reinforces

the need for more education and information to be targeted at this group, and illuminates the types of issues which the content of such campaigns might cover.

Sexual history. The survey collected information on the sexual history and sexual practices of the research participants in order to identify any particular risk factors that appear to be particularly associated with HIV/AIDS infection. The results revealed that, of the 99 adults in the sample, 50.5% had only male sexual partners over the last 5 years while 20.2% had only female partners. This supports the contention that HIV/AIDS is contracted more often from male partners than from female partners. The survey evidence also suggests that becoming sexually active at a young age and having a relatively high number of sexual partners over time may represent HIV/AIDS risk factors. More than 50% of the sample had had intercourse before the age of 18 and the average number of lifetime sexual partners ranged between 11 and 50 for 44.4% of the participants. The implication of this finding is that a long-term health education strategy is needed to arrest the future increase in HIV/AIDS among older people, by raising awareness of the risks among youths and young adults who are just becoming sexually active.

However, the study did not provide evidence in support of the commonly argued view that the use of sexual enhancement drugs such as Viagra have resulted in higher rates of HIV/AIDS among older adults by promoting more sexual activity in this age group. In the survey sample, only a very small percentage of the participants reported being users of sexual enhancement drugs such as Viagra (10.1%), Levitra (2.0%) or

Cialis (1.0%), even though the majority of the survey respondents reported currently being sexually active.

Alcohol and drug use. The majority 59.6 % of patients in the sample had engaged in sexual activity under the influence of drugs and alcohol in the past five years. Overall, there were found to be high levels of drug usage among the research respondents; for example, 42% reported that they had used cocaine by itself during their lifetime, while 28% reported using heroin by itself and 32% said they had used cocaine together with heroin. More than a third of the sample was still using cocaine by itself every week, while just fewer than 20% in each case were either using heroin along or heroin with cocaine. These results suggest that drug use or excessive alcohol consumption may be HIV/AIDS risk factors since these practices impair judgment and lead people to indulge in risky practices.

Drug usage also represents an HIV/AIDS risk factor in its own right if needles are shared. Sharing needles was found to be a common practice among the sample, with 36.4% stating they have used shared needles and 33.3% that they have been doing so within the past five years. The very practice of sharing needles itself involves high risk, and even more so if the source of the needles is unknown.

Identifying High-Risk Subgroups

In order to understand more fully the social contexts within which the rise in HIV/AIDS among older adults is occurring, so that effective interventions and information campaigns can be designed, the researcher compared the percentages of various socio-demographic groups that indicated that they had engaged in each of twelve

identified risk factors. This analysis demonstrated which of the sub-groups in the sample of adults with HIV/AIDS, defined by gender, age, ethnicity and sexual orientation, can be defined as high risk in terms of the identified factors, so that these groups in the wider population might be targeted by health campaigns and interventions. Even though the sample only included older adults who already have HIV/AIDS, and cannot be generalized to the general population of older adults, the findings are likely to be valuable in helping health care professionals to identify categories of individuals who might be defined as high risk, and ensure that adequate preventative health care advice as well as appropriate diagnostic procedures are targeted at these groups.

With regard to gender, the males in this sample were found to be significantly more likely than the females to have engaged in risky behavior. A higher number of males (38.9%) indicated paying money or drugs for sexual activity compared to females 15.6%. Furthermore, the number of males' 48.1% using heroin were higher than the number of females 31.1%. Additionally, 22.2% of the males indicated having five or more sexual partners in the past 12 months while only 11.1% of the females did so.

It terms of ethnicity, even though African Americans were over-represented among the sample as a whole, this group was found to engage considerably less in risky sexual and health-related behavior than the European Americans and Hispanics in the sample. For example, European Americans were the ethnic group most likely to have had five or more sexual partners within the past year 29.2%, followed by Hispanics, and European Americans also ranked the highest with regard to having anal sex 85.7%. Hispanics were found to be the ethnic group most likely to engage in sex for payment and

make use of shared needles 35.7%. It could be inferred, at least within the sample population, that sexual and health practices among European Americans could be related to disease acquisition, while Hispanics may be more likely to acquire the disease through sex as a paid service. There is also a high possibility that Hispanics acquired the disease through unsterile needles which are needed for their drug usage. Both European Americans (66.7%) and Hispanics 67.9% were found to rank considerably higher than other ethnic groups with regard to engaging in sexual activity under the influence of drugs or alcohol, though with regard to daily alcohol consumption, European Americans and African Americans were found to rank the highest.

The relationship between sexual orientation and HIV risk was also analyzed. Bisexuals were found to be more likely to use heroin and to share needles with friends. They were also the group most likely to engage in sexual activity under the influence of drugs or alcohol, and ranked highest in daily alcohol consumption. It can be inferred that daily alcohol use is likely to be a major cause of irresponsible sexual behavior and practices, which may result in infection.

Finally, both bisexuals and homosexuals were ranked more highly than heterosexuals in relation to many of the sexual history and practices risk factors. For example, having over 50 lifetime sexual partners was more prevalent in homosexuals 21.4% and bisexuals 15.8% compared to heterosexuals 2.1%, and homosexuals 35.7% and bisexuals 36.8% also ranked the highest in having five or more sexual partners within past 12 months. A large percentage of the homosexuals 92.9% indicated they do not regularly use condoms during intercourse. All of the participants (100.0%) from the

homosexual and bisexual (100.0%) groups indicate practicing anal sex. Though this might be highly expected in the first place due to biological characteristics, (especially for intercourse between two males) it could also be inferred that the lack of condom usage and engaging in anal sex could be significant factors of obtaining HIV/AIDS.

Bisexuals in particular were found to be more inclined to engage in risky behavior than either heterosexuals or homosexuals. For example, bisexuals indicated that they were more likely to pay drugs or money for sex. Bisexuals also ranked the highest in relation to recreational heroin use, and sharing needles from friends, and were more likely than those of other sexual orientations to indicate that they engaged in sexual activity while intoxicated with drugs or alcohol. Lastly, bisexuals rank highest in daily alcohol consumption.

Overall, the findings indicated that sexual orientation and ethnicity were more strongly associated with multiple HIV risk factors than age or gender. It might be inferred that the kind of behavior that can be expected from sexual orientation and the culture of a specific ethnicity is especially linked to the risk of contracting the disease. HIV risk factors were higher for Hispanics and European Americans compared to African Americans and the “other” sexual orientation group, and for bisexuals compared with other sexual orientation groups. Other sub-groups, such as women, African Americans, homosexuals and heterosexuals have a high risk only in relation to specific HIV risk factors, which may suggest that for these groups in the wider population of older adults, the overall level of risk may be lower.

Differences in HIV/AIDS Risk Factors between Older and Younger Adults

The second research question was, Do these differ from the factors known to be associated with HIV/AIDS among younger people and if so, what are the differences?

The results suggest that there are few differences between younger and older adults. The difference in diagnosis rates, therefore, much be explained by other factors. For example, older adults in this sample indicated they were most likely to receive HIV testing upon a doctor's request. This result clearly shows that there is a lack of initiative among older adults to undergo testing at their own discretions. Older adults in general are less inclined to be open about their sexual history (National Institute on Aging, 2003) and behavior, rather than a difference in behavior, may be a cause of inaccurate diagnosis.

Among older adults, those aged 58 and older were more likely to engage in sex in exchange for money or drugs and were more likely to use shared needles for drugs than adults aged 50-57. This suggests that those in the "younger" group of 50–57-year-olds are better informed on how to prevent HIV/AIDS infection. HIV/AIDS educators, therefore, may not be giving enough attention to the increasing population of older adult HIV/AIDS patients (National Institute on Aging, 2003).

Health Care Practices in Relation to Older Adults

The rising incidence of HIV/AIDS among older people may reflect the fact that they are not often targeted by health care workers and educators for HIV education, and may be less likely to talk about their sex lives in general (National Institute on Aging,

2003). The factors that this has been attributed to in the literature include erroneous perceptions on the part of health care providers, caregivers, and educators that older people are not sexually active or unlikely to participate in high-risk behaviors (e.g. Zablotsky, 2003). Moreover, some of the symptoms of the AIDS virus replicate those of normal ageing processes, thereby making it more difficult to make an accurate diagnosis (NIA, 2003).

The interview results indeed provided evidence that some health care providers perceive that older adults in general are more responsible and less likely to engage in risky behavior. The health care providers in the study sample were found to be more likely to consider a diagnosis of HIV/AIDS when examining a younger patient as opposed to an older patient, and were more likely to view their older patients as sufficiently informed about the disease. Some health care providers indicated a belief that HIV/AIDS was not common among older patients, a finding that suggests insufficient awareness of the disease among some practitioners. It is very likely that these types of views could contribute to late diagnosis or misdiagnosis in older adults infected with HIV/AIDS.

Although considerable numbers of interviewees did indicate that they thought inadequate information was being provided about the risk of HIV/AIDS among older adults when asked about this directly, a lack of information or awareness were only cited spontaneously by a small number of respondents as a factor contributing to the rise of the illness within this age group. In contrast, more of the respondents cited factors relating to the behavior of older adults, such as being sexually active and having unprotected sex

(see Tables A5 and A6). This apparent tendency for health care profession to focus on behavioral factors rather than a lack of information as the main reasons for the increase in HIV/AIDS among older adults, may lead to the development of misguided, ineffective policies and strategies which aim to change behavior among this age group rather than educating people of all ages about how to best protect themselves from the disease. The results of this study have shown that risky behavior and practices over the course of a lifetime appear to be risk factors for HIV/AIDS, and that these may be linked to social and cultural contexts relevant to particular socio-economic groups.

Recommendations

Policy Recommendations

This section of the study addresses Research Question 4, which asks how health education and health care practice in relation to older people can be modified to help reduce the growing problem of HIV/AIDS among this group, and to improve health outcomes for those diagnosed with the infection.

First, disseminating the results of studies such as this one to the general public, with a focus on informing older adults, would accomplish this goal. Such information would be useful to both the patients and the health care professionals. It will be important, however, to translate the findings into language and communication styles which are accessible to the various subgroups of the target population, including people with relatively low levels of education, and to disseminate this information using appropriate media, such as TV or radio advertising, or in magazines and newspapers known to be popular with older adults or sub-groups of this population.

Based on the results of this study, it is recommended that a nationwide dissemination of information for HIV/AIDS be undertaken, with an emphasis on older adults. Such a measure would have the benefit of educating health care professionals, HIV/AIDS patients, and the general public. It would aim to raise awareness of the risk of HIV/AIDS and how to reduce this among all age groups, so that the prevalence of the disease is gradually reduced among the cohorts reaching older ages.

It is also recommended that education and training programs should be designed and implemented for health care professionals, especially doctors and other primary care providers, to educate them about the risks of HIV/AIDS among older adults and the importance of considering the possibility of this disease when making diagnoses. This study has provided evidence that some health care professionals do not generally consider the possibility of HIV/AIDS when diagnosing older adults unless the patient's background or history strongly suggests a risk, or if they have specific types of symptoms associated with HIV/AIDS. Similarly, education and training are needed for other health care system workers whose main responsibilities are preventative health, in order to ensure that appropriate and effective publicity campaigns are developed to tackle the problem of HIV/AIDS among older adults generally, and those in specific sub-groups at high risk, such as Hispanics and bisexuals.

Research Recommendations

It is also recommended that further research is conducted to provide more robust information on HIV/AIDS risk factors among older adults. This study has been exploratory and has been valuable in highlighting the types of factors associated with an

increased risk of HIV/AIDS among older adults. However, quantitative research is urgently needed to explore the associations between these variables and HIV/AIDS in the older adult population more generally, and to identify in particular which of the factors identified in this study have played a role in delaying diagnosis.

Further qualitative research would be useful to build on the findings of this study regarding the sub-groups and cultures within the older adult population which appear to be at particularly high risk of HIV/AIDS. In-depth interviews with members of these groups or cultures, including those already diagnosed with HIV/AIDS, could provide further insights, for example, into the ways in which HIV/AIDS is most commonly transmitted and the reasons why victims of the disease engage in such behaviors. Additionally, further research with these groups could inform education and awareness campaigns, by illuminating the types of messages and language that the groups would be receptive to, as well as the communications channels that might be used.

Relevance of the Conceptual Framework

Following systems theory, this research has been able to show how many different aspects of society contribute to the HIV/AIDS problem our world currently faces. As Laszlo (1972) explained, systems theory shows how different levels of society (e.g., family, community, nation), when examined from a macro perspective, could be seen as a whole. This was shown to be true among the survey sample, with the different factors associated with HIV/AIDS such as sexual orientation, annual household income, and ethnicity being highlighted. These factors are important elements of the social system, as are the health care professionals whose perceptions and beliefs directly affect

how accurately or inaccurately they diagnose their patients and thus impact on the whole system of the HIV/AIDS phenomenon.

Kadushin's (2004) social network theory explains that the relationship between people in society is of more significant impact than the behavior or characteristics of the people themselves. Furthermore, it explains that the weak ties between specific groups of people (e.g. patients and health care professionals) could be the cause of isolation of information within a specific group. This study included health care professionals who, because of their own perceptions and lack of awareness might fail to disseminate relevant information to at-risk patients, resulting in uninformed older adults.

Social network theory can also be used to demonstrate how the effectiveness of public information campaigns would likely to gain momentum over time in line with the "threshold" or "tipping point" concept (Granovetter & Soong 1983). According to this, certain types of behavior tend to spread to all members of a network once they have been adopted by a certain number of members (Granovetter & Soong, 1983). It can be assumed on the basis of the theory that changing the behavior of a certain proportion of older people through health education is likely to have positive knock-on effects to the wider population.

Summary and Conclusion

This chapter has drawn together the main findings of both stages of the research, discussed their significance, and made recommendations for policy and future research on the basis of the research results.

Although exploratory and illustrative in nature, the study results are a valuable addition to the limited field of knowledge about factors associated with the rise in HIV/AIDS among older adults. It has highlighted, in particular, a number of risk factors some of which relate to lifelong behavior and practices, and which must therefore be tackled among adults of all ages, not just older adults. It has also identified apparently strong associations between particular socio-demographic groups and the likelihood of contracting HIV/AIDS, such as Hispanics and bisexuals, which suggest that interventions and awareness campaigns should be targeted and tailored to these sub-groups of the older adult population. Importantly, it has also provided evidence that some health care professionals are failing to consider HIV/AIDS when diagnosing older patients, and that there is a need for more information about the risks faced by this group, targeted at health care professionals as well as the general population of older adults and those in high-risk groups.

Implications for Social Change

The increasing rate of HIV/AIDS among older adults (50 years old and above) calls for further study on the causes of this problem. Once determined, the root of the problem could be addressed. As explained in the first part of this research, HIV/AIDS patients who are diagnosed at an early enough stage have the advantage of time and

medicinal technology. However, for older aged adults with a more progressed stage of HIV/AIDS, it may be too late. The research findings show that there are indeed certain behaviors and perceptions among health care professionals that should be corrected in order to improve accuracy and timeliness of HIV/AIDS diagnosis among older adults.

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Appendix A: Additional Tables

Table A 1

Descriptive Statistics for Sample Demographic and Background Characteristics
(N = 99)

| | Percentage |
|-------------------------|------------|
| Gender | |
| Male | 54.5 |
| Female | 45.5 |
| Age Group | |
| 50 through 57 | 52.5 |
| 58 or older | 47.5 |
| Ethnicity | |
| White | 24.2 |
| African American | 39.4 |
| Hispanic | 28.3 |
| Asian | 6.1 |
| Other | 2.0 |
| Sexual Identity | |
| Heterosexual | 48.5 |
| Transgender | 10.1 |
| Homosexual | 14.1 |
| Bisexual | 19.2 |
| Not sure | 3.0 |
| Other | 1.0 |
| Missing | 4.0 |
| Gender Identity | |
| Male | 46.5 |
| Female | 48.5 |
| Transgender | 3.0 |
| Missing | 2.0 |
| Circumcised | |
| Yes | 38.4 |
| No | 14.1 |
| N/A | 47.5 |
| Annual Household Income | |
| Less than \$10K | 51.5 |
| Between \$10K and \$19K | 31.3 |
| Between \$20K and \$29K | 11.1 |
| Between \$30K and \$39K | 4.0 |
| Between \$40K and \$49K | 0.0 |
| Over \$50K | 2.0 |
| Education | |
| Less than 12 years | 22.2 |

| | Percentage |
|---------------------------------------|------------|
| 12 years but no diploma | 12.1 |
| GED | 14.1 |
| High school diploma | 27.3 |
| Some college | 17.2 |
| Bachelor's degree | 7.1 |
| Employment Status | |
| Full time | 14.1 |
| Part time | 14.1 |
| Student | 2.0 |
| Employment Status | |
| Homemaker | 3.0 |
| Retired | 12.1 |
| Medically unfit | 29.3 |
| Unemployed | 25.3 |
| Reside in a Senior Environment | |
| Yes | 27.3 |
| No | 67.7 |
| Missing | 5.1 |
| Proximity to Nursing Home | |
| In nursing home | 25.3 |
| Within 30 minutes | 35.4 |
| Between 30 minutes and 1 hour | 31.3 |
| Between 1 hour and 2 hours | 7.1 |
| Over 2 hours | 1.0 |
| Traveled in the Past 12 months | |
| Yes | 36.4 |
| No | 60.6 |
| Missing | 3.0 |

Table A 2
Descriptive Statistics for Sexual History and Practices Variables
(N = 99)

| | Percentage |
|---|------------|
| Sexually Active | |
| Yes | 60.6 |
| No | 36.4 |
| Missing | 3.0 |
| Sexually Active in Past Five Years | |
| Yes | 89.9 |
| No | 8.1 |
| Missing | 2.0 |
| Gender of Sexual Partners in Past Five Years | |

| | Percentage |
|--------------------------------------|------------|
| Male | 50.5 |
| Female | 20.2 |
| Both | 24.2 |
| Missing | 5.1 |
| Age of First Sex | |
| Under 18 | 54.5 |
| 18 to 21 | 34.3 |
| 22 to 24 | 7.1 |
| 25 to 30 | 1.0 |
| Over 30 | 1.0 |
| Missing | 2.0 |
| Number of Lifetime Sexual Partners | |
| One | 6.1 |
| Less than 5 | 11.1 |
| Between 5 and 10 | 27.3 |
| Between 11 and 50 | 44.4 |
| Over 50 | 8.1 |
| Missing | 3.0 |
| Number of Lifetime Male Partners | |
| One | 4.0 |
| Less than 5 | 10.1 |
| Between 5 and 10 | 31.3 |
| Between 11 and 50 | 26.3 |
| Over 50 | 7.1 |
| Missing | 21.2 |
| Number of Lifetime Female Partners | |
| One | 15.2 |
| Less than 5 | 14.1 |
| Between 5 and 10 | 18.2 |
| Between 11 and 50 | 19.2 |
| Over 50 | 2.0 |
| Missing | 31.3 |
| Currently Have a Main Partner | |
| Yes | 52.5 |
| No | 40.4 |
| Missing | 7.1 |
| Number of Partners in Last 12 Months | |
| One | 33.3 |
| Less than 5 | 34.3 |
| Between 5 and 10 | 7.1 |
| More than 10 | 10.1 |
| Missing | 15.2 |
| Sexual Practices* | |
| Vaginal | 75.5 |
| Oral | 86.9 |

| | Percentage |
|--|------------|
| Anal | 81.8 |
| Role in Sexual Practices* | |
| Vaginal receptive | 40.4 |
| Vaginal insertion | 34.3 |
| Oral receptive | 63.6 |
| Oral insertion | 14.1 |
| Anal receptive | 61.6 |
| Anal insertion | 42.4 |
| Sexual Practices with Regular Partners Once Per Month* | |
| Vaginal | 55.6 |
| Oral | 61.6 |
| Anal | 62.6 |
| Condom Usage | |
| Always | 9.1 |
| Sometimes | 61.6 |
| Never | 18.2 |
| N/A | 11.1 |
| Type of Condom Used | |
| Latex | 69.7 |
| Female | 2.0 |
| Other | 2.0 |
| Missing | 26.3 |
| Livitra | 2.0 |
| Cialis | 1.0 |
| Ever Sexually Abused | |
| Yes | 29.3 |
| No | 66.7 |
| Missing | 4.0 |
| Type of Abuse* | |
| Looking | 8.1 |
| Touching | 12.1 |
| Genital contact | 15.2 |
| Penetration | 15.2 |

*Multiple responses allowed.

Table A 3

Descriptive Statistics for Categorical Demographic and Background Variables (Health care Professionals)

(n=17)

| | Percentage |
|--------|------------|
| Gender | |
| Male | 35.2 |
| Female | 64.7 |

| | | Percentage |
|--------------------|---|------------|
| Age | | |
| > 25 | 0 | 0 |
| 26-35 | 6 | 35.2 |
| 36-45 | 2 | 11.7 |
| >46 | 8 | 47.0 |
| Ethnicity | | |
| European American | 5 | 29.4 |
| African American | 7 | 41.1 |
| Hispanic | 1 | 5.8 |
| Asian | 4 | 23.5 |
| Job Title/Degree | | |
| MD | 8 | 47.0 |
| Intern | 1 | 5.8 |
| RN | 5 | 29.4 |
| Nurse Practitioner | 1 | 5.8 |
| Social Worker | 1 | 5.8 |
| Other | 1 | 5.8 |

Table A 4
Descriptive Statistics for Continuous Demographic and Background Variables (Health care Professionals)
 (n=17)

| | Min. | Max. | M | SD |
|---|------|------|------|-------|
| Years in current job | 0 | 33 | 9.8 | 9.09 |
| Years in profession | 0 | 35 | 12.7 | 12.15 |
| Percent of patients > 50 years | 0 | 90 | 56.6 | 4.8 |
| Percent of patients HIV+ | 1 | 80 | 34.7 | 29.2 |
| Percent of patients > 50 HIV+ | 0 | 50 | 20.1 | 22.6 |
| Percent of patients > 50 practicing risky behaviors | 10 | 60 | 25 | 19.3 |

Table A 5
Factors cited by Health care Professionals as Contributing to the Rise of HIV among Older Adults

Spouses are dying, leaving the other spouse to find new mates; not using protection

Not properly informed educators

Living longer, OA more sexually active, unprotected sex

Lack of information & education

HIV medications & proper tx of acute illnesses

People are not protecting themselves anymore

HIV/AIDS patients are living longer with the diagnosis

Unprotected sex, younger men + older women, older men + younger women
 Older people think HIV is a disease of young people
 Previously undiagnosed
 Decreased awareness, lack of barriers during sexual activity
 Drug use, unprotected sex
 Lack of contraception/protection
 General population increasing in age, incidence, prevalence; treatment improves longevity
 Unprotected sex, IV drug abuse
 Unprotected sex

Table A 6
Health care Professionals' Perceptions of Risky Behaviors in Younger versus Older Adults

| % of Older Adults Practicing Risky Behaviors | How Does This Compare With Younger People? |
|--|---|
| 15 | Less in older people--about 35-40% in adults <50, based on my patient population |
| 10 | Risky behavior, multiple partners |
| 20 | Same |
| 20 | 30 percent in younger people |
| 10 | Young people do not think of the outcomes of their actions. They involve themselves in risky behaviors too often. This is based on the increasing number of teen pregnancies and teen to early 20s females with HIV, herpes, other STDs |
| - | IV drug use, homosexuality |
| 20 | Compared to younger patients of at least 40-60% higher. Unprotected sex due to no longer childrearing |
| 60 | Older adults are having unprotected sex, no risk for pregnancy. Older adults believe they are exempt from STD & HIV/AIDS |
| 55 | Same |
| - | Not sure |
| 50 | Much less in younger population. They re more aware, afraid, and use protective sexual habits |
| 60 | - |
| 20 | Same |
| 33 | Lower risk based on my own stereotypes (younger people less responsible, etc.) |
| 15 | Younger people are higher (30% +). Older feel they are no longer having children and are exempt from STDs |

Table A 7
Health care Professionals' Perceptions of Risk of HIV in Older Adults

| Older Adults Most at Risk | Reasons |
|--|--|
| Females in poverty, Blacks, Hispanics | Based on the population I work with |
| People with multiple partners | - |
| Don't use protection, iv drug users, homeless | - |
| Older gay men, drug usage (needle sharing) | Lack of education, lack of condom use |
| IV drug users, alcoholics | When under the influence they do not think about what they are doing |
| IV drug users | - |
| Gays, bisexuals, older men with younger women | - |
| Bisexuals, homosexuals, iv drug users, younger man + older woman & vice versa, prostitutes | - |
| Homosexual males, IV drug abusers, bisexual males & females | - |
| IV drug abusers, prostitutes, quiet housewives | - |
| IV drug users, sexual promiscuity, single/divorced | - |
| Over 40yrs old | - |
| Adolescent age | - |
| Abuse substances, live in shelters, prostitutes | - |
| Low SES, low health literacy | - |

Appendix B: Letter of Explanation

To All Participants:

Study Purpose:

You are invited to take part in a research to study whether Doctors and Patients communication can improve medical condition and treatment between people age 50 and over with HIV/AIDS and do they test people over 50 for HIV/AIDS. The reason for the study is to gather information that can be use to help make a diagnosis for people with HIV/AIDS as early as possible. The study will include people who are over 50 and HIV/AIDS positive. Information will be use to gather numbers to develop information on HIV/AIDS campaigns, teachings, prevention programs and medical treatment options. Your information is very important.

You qualify to take part in this study because you were diagnose with HIV/AIDS and resides in St. Barnabas Nursing Home, you are currently admitted in St. Barnabas Hospital or you are seen in St. Barnabas Clinic. You were chosen because being a part of this study may be helpful in improving treatment among health care workers and early testing and diagnosis of HIV/AIDS among people age 50 and older. The study will take place in your room or a private room for privacy. Please read this form and ask any questions you have before agreeing to be part of the study.

This study is being conducted by a researcher named Lorraine C. Barnett, LMSW, ACSW who is a doctoral student at Walden University. Ms. Barnett is a License Masters Social Worker (LMSW) for over 10 years who provides clinical services to patient admitted to St. Barnabas Hospital.

Study Procedure

If you decide to participate you will be given a list of questions for which you will read and answer all information. There is no risk and you can refuse at anytime and all information will be kept strictly top secret. You were either referred to the study by your medical doctor, admitted to St. Barnabas Nursing home or hospital. The questions should take about 30 minutes to 1 hour (time varies). All information will be kept locked in a file cabinet.

Study Risks

Your participation in this study involves no risk. There are no dangers, side effects or future harm to you in this study.

Study Benefits

You may or may not benefit personally from this study. Benefits to you may include the ability to share your personal experiences in order to assist and improve the health outcome of other patients.

Alternatives

The only choice to this study is simply not to participate.

Costs/Compensation

You will not receive any payment for this study.

Confidentiality

Any information received in this study and identified with you will remain private. You will not be known to this study at all. No personal information (name, social security numbers, address) will be used in the study. Even though full anonymity and

confidentiality will be guaranteed, we will obtain your full consent in reporting any of your personal data. You should be aware that St. Barnabas Hospital *will not* stand to benefit any money from the results of this study.

Participation is Voluntary

Your participation in this study is completely voluntary. You can refuse to participate, or withdraw at any time. If you refuse or withdraw from the study your medical care will not be affected, now or in the future. Signing this form does not give up any legal rights. There are no consequences for early withdrawals.

Questions

If you have any questions, please ask, and we will do our best to answer them. If you have additional questions in the future, you can reach Lorraine C. Barnett, LMSW, ACSW at 718-960-9204 or 877-314-3750.

I have discussed this study with Ms. Lorraine C. Barnett, *LMSW, ACSW* to my satisfaction. I understand that my participation is voluntary and that I can withdraw from the study at any time without prejudice. I have read the above and agree to enter this research study.

I have been informed that if I receive any injury as a result of participating in this study, I may contact Lorraine C. Barnett, LMSW, ACSW at 718-960-9204. I understand that I will receive a copy of this consent form.

***PLEASE ALSO NOTE THAT THERE WILL BE SOME PERSONAL,
DELICATE AND SENSITIVE QUESTIONS.***

Appendix C: Survey of HIV-Positive Older Adults

(Possible responses also printed on show cards for easy reference by respondent)

1. Gender Male
Female
2. Please could you tell me your date of birth? _____
3. Which of these ethnic groups do you belong to?
European American
African American
Hispanic
Asian
Other (pls specify)
.....
4. How close do you live to the nursing home at which you are a patient?
I live in the nursing home
Within 1 mile
Within 2-5 miles
Within 6-10 miles
More than 10 miles

I am now going to ask some general questions about your background:

5. What is your highest level of education?
Lower than 12th grade
12th grade – no diploma
High school graduate
Some college education
Bachelor's degree or higher
6. What is your current employment status:
Full-time employed/self EMP
Part-time employed/self EMP
Student
Homemaker
Retired

Medically unfit to work
 Unemployed

7. What is your annual household income?
- Less than \$10,000
 - \$10,000-19,999
 - \$20,000-29,999
 - \$30,000-39,999
 - \$40,000-59,999
 - \$60,000 or more

8. Have you been on vacation in the last 12 months?
- Yes
 - No

9. If yes, please indicate where you went on vacation (Country or U.S. State).

The next set of questions relate to your medical history in relation to HIV.

10. When did you, personally, first think that you were HIV positive (month and year – or approximate date)

11. And when were you first formally diagnosed as HIV positive? (Month and year)

12. Why did you take an HIV/AIDS test? (don't prompt unless necessary)

Part of regular health care regime
 Concerned might have been at risk
 Asked to by doctor
 Other (please specify)

13. Were you having regular health checks (at least annual) before being diagnosed as HIV positive?

Yes
 No

14. Have you ever been diagnosed with a sexually transmitted disease, other than HIV/AIDS (e.g. gonorrhea, Chlamydia, syphilis, herpes)

Yes
 No

15. If yes, how old were you when you were first diagnosed with a STD?

I am now going to ask you a series of questions about your sexual history. Please be assured that all responses will be treated in complete confidence and anonymity.

16. First, do you think of yourself as (read out answers in turn and stop when a positive response given)?

Heterosexual (straight)?
 Homosexual (gay)?
 Bisexual
 Not sure
 Other (please specify)

17. When you had sex for the first time, how old were you? (Read out answers in turn and stop when a positive response given)?

Under 18
 18-21
 22-24
 25-30
 Over 30

18. During your lifetime, how many people would you say you have had sex with? Would it be ...? (Read out answers in turn and stop when a positive response given)?

- One
- Less than 5
- Between 5 and 10
- More than 10 but less than 50
- 50 or more

19. During your lifetime, how many men have you had sex with (read out answers in turn and stop when a positive response given)?

- One
- Less than 5
- Between 5 and 10
- More than 10 but less than 50
- 50 or more

20. During your lifetime, how many women have you had sex with (read out answers in turn and stop when a positive response given)??

- One
- Less than 5
- Between 5 and 10
- More than 10 but less than 50
- 50 or more

21. Do you have a main partner, defined as someone who is your spouse, regular lover or anyone else you feel committed to or have a special relationship with?

- Yes
- No

22. During the last 12 months, how many people would you say you have had sex with (read out answers in turn and stop when a positive response given)??

- One
- Less than 5
- Between 5 and 10
- More than 10

23. When having sex, how often do you or your partner use a condom?

- Always
- Sometimes
- Never

24. Which of the following sexual practices have you ever performed with a partner?

- | | Yes | No |
|-------------|--------------------------|--------------------------|
| Vaginal sex | <input type="checkbox"/> | <input type="checkbox"/> |
| Oral sex | <input type="checkbox"/> | <input type="checkbox"/> |
| Anal sex | <input type="checkbox"/> | <input type="checkbox"/> |

25. Which of the following sexual practices do you perform with a partner regularly (more than once a month)?

- | | Yes | No |
|-------------|--------------------------|--------------------------|
| Vaginal sex | <input type="checkbox"/> | <input type="checkbox"/> |
| Oral sex | <input type="checkbox"/> | <input type="checkbox"/> |
| Anal sex | <input type="checkbox"/> | <input type="checkbox"/> |

26. Have you ever had oral, anal, or vaginal sex in exchange for money or drugs?

- Yes
- No

27. Have you ever paid someone else or given them drugs in exchange for oral, anal, or vaginal sex?

- Yes
- No

28. Before being diagnosed as HIV-positive, had you taken any special precautions to avoid catching AIDS? (don't prompt unless necessary)

- Less frequent sex
- Avoided oral sex
- Avoided anal sex
- Avoided prostitutes
- Avoided homosexual sex
- Avoided kissing
- Limited number of partners

- Monogamy
 Abstinence
 Used condoms
 Only HIV-negative partners'
 Other (please specify)
-

Finally, I'd like to ask about your experiences of taking recreational drugs.

29. Which of the following types of drugs have you ever taken for recreational purposes? (read out each in turn):

- | | Yes | No |
|----------------------------|--------------------------|--------------------------|
| Cocaine by itself | <input type="checkbox"/> | <input type="checkbox"/> |
| Heroin by itself | <input type="checkbox"/> | <input type="checkbox"/> |
| Heroin & Cocaine mixed | <input type="checkbox"/> | <input type="checkbox"/> |
| Demerol, Codeine, Dilaudid | <input type="checkbox"/> | <input type="checkbox"/> |
| Speed, Methamphetamine | <input type="checkbox"/> | <input type="checkbox"/> |
| Viagra or similar | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (pls specify) | <input type="checkbox"/> | <input type="checkbox"/> |

28. Which of the following types of drugs do you take for recreational purposes at least? Once a month?

- | | Yes | No |
|----------------------------|--------------------------|--------------------------|
| Cocaine by itself | <input type="checkbox"/> | <input type="checkbox"/> |
| Heroin by itself | <input type="checkbox"/> | <input type="checkbox"/> |
| Heroin & Cocaine mixed | <input type="checkbox"/> | <input type="checkbox"/> |
| Demerol, Codeine, Dilaudid | <input type="checkbox"/> | <input type="checkbox"/> |
| Speed, Methamphetamine | <input type="checkbox"/> | <input type="checkbox"/> |
| Viagra or similar | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (pls specify) | <input type="checkbox"/> | <input type="checkbox"/> |

THANK YOU VERY MUCH FOR TAKING PART IN THE RESEARCH

Appendix D

Topic Guide For Semistructured Interviews with Health Professionals

| | |
|-----------------------------|---|
| Gender | Male Female |
| Ethnicity: | European American <input type="checkbox"/> African American <input type="checkbox"/> Hispanic <input type="checkbox"/> Asian <input type="checkbox"/> Other (pls specify) <input type="checkbox"/> ----- |
| Age group | Under 25 26 – 35 36 – 45 46 or over |
| Employer/place of practice: | _____ |

1. First, please could you tell me your job title and give a brief description of your specialist background and your current work.
2. How long have you been employed in your current job?
3. How long have you worked as a (give job title)?
4. Roughly what percentage of the patients you deal with is aged over 50?
5. Roughly what percentage of the patients you deal with are HIV positive?
6. Roughly what percentage of the patients you deal with are aged over 50 and HIV positive?
7. Are you aware of the increase in HIV/AIDS diagnoses in older people? What factors do you think may be contributing to this increase?
8. When diagnosing medical symptoms in older adults, do you generally consider the possibility of HIV/AIDS as a cause? Please explain your answer. (Probe: In what circumstances? If not, why not?)

9. When diagnosing medical symptoms in younger people aged under 50, do you generally consider the possibility of HIV/AIDS as a cause? Please explain your answer. (Probe: In what circumstances? If not, why not?)
10. Under what circumstances would you recommend an HIV/AIDS test for a patient? What factors do you take into account in deciding whether to recommend this?
11. In your own view, roughly what percentage of adults aged over 50 are likely to be practicing behaviors that might put them at risk of HIV/AIDS or other sexually transmitted diseases? How does this compare with prevalence of high-risk sexual behavior among younger people? (Probe: Why do you say this? What do you base this estimate on?)
12. Among older adults, which types of people would you say are most at risk of contracting HIV/AIDS? Why do you say this?
13. Do you think that older people, aged over 50, are generally comfortable discussing their sexual behavior with their health professional? Why do you say this? Are there differences within this population in their willingness to discuss their sexual behavior? Please clarify.
14. Do you think that older people are generally aware of the risks of their getting HIV/AIDS? Please expand on your answer.
15. Do you think that older people who might be at risk of contracting HIV/AIDS generally take steps to protect themselves from the virus? Please clarify (probe: different groups, why/why not?)
16. In your view, is enough information provided to older people to increase their awareness of HIV/AIDS and what they can do to protect themselves from the virus. Please expand on your answer. What do you think should be done, if anything, to raise awareness of HIV/AIDS among this population?
17. In your view, is enough information provided to health professionals to increase their awareness of the risk of HIV/AIDS among older people? Please expand on your answer. What do you think should be done, if anything, to raise awareness among health professionals of the risks of HIV/AIDS in older adults?
18. Is there anything else you would like to add, on the subject of HIV/AIDS and older people?

THANK YOU FOR TAKING PART IN THIS RESEARCH

Curriculum Vitae

Lorraine C. Barnett

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Bronx, NY 10466

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Email: lbarnett2002@yahoo.com

Education:

- | | |
|----------------|--|
| 9/02 – Present | Walden University Baltimore, MD PhD Candidate |
| 9/95 – 6/97 | Columbia University School of Social Work New York, New York Master of Science in Social Work-M.S.W |
| 9/90 – 6/93 | Herbert H. Lehman College Bronx, New York Bachelors of Arts in Social Work- B.S.W |
| 9/87 – 6/90 | Borough of Manhattan Community College New York, New York Associates of Arts- A.A |

Experience:

- | | |
|----------------|--|
| 4/99 – Present | <u>St. Barnabas Hospital</u> Bronx, New York Geriatrics Social Worker |
|----------------|--|

Responsibilities:

- Supervise Masters level students from Columbia University
- Interview patients and families as to ascertain appropriate discharge plans
- Provide supportive counseling/Palliative care on Death and Dying
- Counsel patients and families regarding affects and illness
- Refer patients and families to appropriate facilities such as Nursing Home
- Contact community agencies to provide services to clients returning to their home
- Maintain communication with patient's physician to discuss patient's condition and discharge plans

- Document social work/discharge planning activities in patient's medical records
- Participate in inter-disciplinary staff conference and supervisory meetings
- Attend professional conferences outside of hospital to enhance social work skills.
- Participate in hospital wide educational programs
- Provide patient/families with appropriate information, resources and support in obtaining financial resources
- Provide professional quality care by adhering to "PATIENTS RIGHTS"
- Facilitate Discharge Planning Rounds for assigned units on a weekly basis
- Perform other related functions/duties at the request of the Director or the Administrator
- Perform the above duties on all patients ranging from adolescent to Geriatrics
- Maintain departmental statistics

2/95 – 4/99 Union Hospital
 Bronx, New York
 Social worker

Responsibilities:

- HIV Case Manager
- Provide Pre and Post HIV testing and counseling
- Complete biopsychosocial assessments and implements short-term treatment
- Conduct family outreach, interventions and psycho education
- Communicate and refer cases to the Agency for Children Services
- Act as a liaison for hospital and community agencies
- Write Statistical reports.

8/94 – 1/95 Family Support Children and Family Services
 Bronx, New York
 Social worker

Responsibilities:

- Provide individual and family counseling
- Co-facilitate parenting classes
- Provide support groups for women of substance abuse
- Serve as an advocate, case manager and referral source for families whose children are in foster care or "at risk" for placement
- Conduct home visits
- Acts as an advocate for long and short term rehabilitation programs

9/92 – 7/95 Cardinal McCloskey Children and Family Services
Bronx, New York
Social worker

Responsibilities:

- Provide mediation, counseling and social casework interventions to adolescents and their families referred by court or other agencies
- Conducts regular home visits to complete and update family needs assessments
- Facilitate group activities in after school programs for “at risk” adolescents
- Acts as liaison for Agency for Children Services
- Attend court hearings
- Write monthly statistical reports

Professional Affiliations: National Association of Social Workers
American Geriatrics Society (AGS)

Certificates: HIV/AIDS Counselor
Mandated Child Abuse Reporter
Domestic Violence in Households Affected by HIV/AIDS

References available upon request.