

**HIV/AIDS AND THE OLDER ADULT:
AN EXPLORATORY STUDY OF THE AGE-RELATED DIFFERENCES IN
ACCESS TO MEDICAL AND SOCIAL SERVICES**

by

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**PROJECT SUBMITTED IN PARTIAL FULLFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF ARTS**

in the
Gerontology Program

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SIMON FRASER UNIVERISTY

August 2001

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An Exploratory Study of the Age Related Differences in Access
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**HIV/AIDS and the Older Adult:
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Abstract

This was an exploratory study investigating age-related differences in access to medical and social services among individuals infected with HIV/AIDS. Its primary purpose was to investigate the experiences that older adults with HIV/AIDS have had with accessing HIV/AIDS-related medical and social services and to compare their experiences to those of infected younger adults. The study also investigated the perceptions that younger and older adults have about the need to, or value of, providing specific medical and social services for older infected adults in order to understand current and future service needs and potential service accessibility issues.

Data were collected from 34 in-depth interviews and findings allowed for both quantitative and qualitative analysis. The Student's t-test was employed to evaluate age group differences in access and descriptive analyses were used to supplement and elaborate on the statistical analyses. The older adult's ability to access services was evaluated by addressing predisposing, enabling and need variables in addition to characteristics associated with the medical and social service systems.

The Student's t-test revealed that older adults accessed fewer medical services, health information sources and social organizations compared to younger aged adults. However, they accessed a similar number of social and emotional supports compared to younger aged adults, and reported fewer barriers to accessing services compared to younger adults. Descriptive analyses revealed that infected older adults had positive experiences accessing both health care professionals and organizations, and that they accessed a variety of HIV/AIDS-specific and non-specific social organizations. HIV/AIDS-related stereotypes held by the gay community limited the older adults' access to services to some degree. Younger adults however, experienced similar stereotypes.

Through qualitative analysis, three major themes explained the findings of this study: the older adults maintained an independent and forthright attitude about service access, had a comprehensive knowledge of their infection and available services and they resided in a service rich geographic area.

Key Words: older adult, service, attitude, gay community, knowledge base, HIV/AIDS

Dedication

This research is dedicated to infected older adults who are often seen but ignored, and whose voices are seldom heard. With their insight and an understanding of their everyday life experiences, we will be able to help them to improve their quality of life and to live long and prosperous lives.

This research is also dedicated to my father who offers his never-ending support in all of my pursuits.

Acknowledgement

I would like to thank and acknowledge the following individuals for their contribution to this project. Foremost, I would like to thank S.M. and other members of the Persons With AIDS Foundation whose wholehearted interest in promoting my research was valuable in recruiting participants. Additionally, I would like to thank K.L., C.C., L.C. and C.F. for posing challenging questions and offering their support and keen ears throughout each stage of the project.

I would also like to thank Dr. Yves Carrier, Dr. Michael MacLean, Dr. Gloria Gutman and Dr. Andrew Wister for their insightful suggestions and guidance in the completion of this personally fulfilling project. Dr. Carrier assisted in fine-tuning the direction and purpose of the research topic and Dr. MacLean offered his vested interest in the subject matter and assistance in understanding and interpreting qualitative data. Dr. Gutman was instrumental in bringing the project to life through careful and efficient review, organization and management and Dr. Wister encouraged a deep and precise analysis of findings.

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CHAPTER I

Introduction

Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) affect men and women of all ages. HIV/AIDS among the older adult population is more prevalent than typically thought and today, infected older adults comprise a special population not only within the general uninfected older adult population, but also within the HIV/AIDS population. Approximately one-tenth of all HIV-positive cases and 19.2% of all AIDS cases in Canada were reported among individuals aged 50 and older in 2000 (Health Canada, 2001). The number of cases will continue to rise as the proportion of older adults grows as a result of population aging. Further, advances in treatment options enabling infected individuals to live longer will also play a role in increasing the number of infected older adults (Avis & Smith, 1998; Bachus, 1998; Emler, 1998; Engle, 1998; Health Canada, 2001; Nocera, 1997; Ory & Mack, 1998; Wooten-Bielski, 1999).

Despite relatively consistent statistics describing infection rates among older adults, HIV/AIDS within this population is an under-acknowledged medical and social issue. Very few services exist among and within gerontological, mental health, physical health and AIDS-related programs and services that are directed towards this special population (Nazon & Levine-Perkell, 1996). There appears to be a lack of knowledge about aging among service personnel in AIDS service organizations and a lack of knowledge in aging-associated service systems about characteristics associated with HIV-infection and AIDS (Mellor, 1996). Services, both social and medical, designed and developed in the early years of recognition of the disease for younger infected gay men, may not meet the special needs of the different populations presenting with HIV-infection today (Siegel, Raveis & Karus, 1998), especially those of the older adult population. Further, many health and social service providers may not be prepared or equipped to manage the various special issues arising in the older age group (Mellor, 1996).

Studies investigating access to age-specific HIV/AIDS medical and social services for older adults have not been conducted. Instead, research has been mainly epidemiological and has targeted younger and minority populations who form the majority of those infected. It is presumed that factors affecting access to *medical services* are important predictors of HIV disease progression (Palacio, Shiboski, Yelin, Hessol & Greenblatt, 1999) and influence the older adult's ability to cope with being infected. It is also presumed that factors affecting access to *social systems* and supports are important

predictors of disease progression and ability to cope. The literature reviewed suggests that infected older adults face many personal, medical and social barriers that limit their ability to access these services.

A. Literature Review

1. Population Characteristics

In 2000, 10.9% of all new HIV-positive diagnoses and 19.2% of all new AIDS diagnoses documented in Canada were reported among individuals aged fifty years and older (Health Canada, 2001). Health Canada (2001) indicates that of adults aged 50 and older with AIDS, 54% were in the 50-54 age group, 22% were in the 55-59 age group and 24% were 60+.

The incidence of HIV-positive diagnoses remained relatively stable among older women and men between 1998, 1999 and 2000. Older women accounted for 6.3% of all female diagnoses in 1998 and 6.6% of all female cases in 1999 and 2000. Older men accounted for 11.5% of all male diagnoses in 1998, 11.4% in 1999 and 12.5% in 2000 (Health Canada, 2001). The incidence of AIDS diagnoses differs among older men and women. From 1998 to 1999 and 2000, the incidence of older adult females diagnosed with AIDS fluctuated from 7.2% to 11.9% to 7.1%. Among older men, the incidence of AIDS diagnoses steadily increased from 11.6% in 1998 to 16.7% in 1999 to 20.6% in 2000. The notable increase in older adult male incidence is likely the result of delays in reporting, the development of resistance to anti-retrovirals and the uncertain duration of the drug effects (Health Canada, 2001). The shift from HIV status to an AIDS status associated with reduced immunity and aging organs may also account for the increase in the number of new diagnoses among older people.

Crystal and Sambamoorthi (1998) describe the infected older adult population as living alone, of low income, uninsured, harbouring pre-existing barriers to health care and experiencing problems associated with poverty. Additionally, older adult women and men with HIV/AIDS are likely to have limited informal support systems and be functionally handicapped based on age-related co-morbidities. When comparing older and younger adult women with AIDS, Crystal and Sambamoorthi (1998), Nocera (1997) and Zablotsky (1998) noted the following differences: older adult women with HIV/AIDS were more likely to be widowed, separated or divorced, to live alone and to have less than 12 years of schooling.

These social and functional characteristics are limited in generalizability, however, because they have been drawn from small samples and surveillance data that focused primarily on disease rates and modes of disease acquisition. The actual number of older adults reported to be HIV-positive and the actual number of AIDS cases is likely to be higher than reported. Underestimation is due to a number of factors. First, AIDS-related symptoms often coincide with age-related or other disease-related symptoms and go undetected and unrecorded. Second, older adults do not consider or request HIV/AIDS testing and primary care physicians do not suggest testing due to the common misperception that older adults are not at risk for infection. Third, surveillance reports are subject to delays in HIV and AIDS diagnoses reporting and include only a fraction of the number of actual cases (Health Canada, 2001). Fourth, older adults with AIDS (in several cases undiagnosed) may live to normal life expectancy and die prior to demonstrating any AIDS-related symptoms (Nocera, 1997; Szirony, 1999).

2. Service Needs of Infected Older Adults

Infected older and younger adults have different illness-related medical and social service needs. Both age groups require medical care that addresses their illness onset, disease progression and treatment, and both groups require social support from family, friends, acquaintances and/or HIV/AIDS support groups and programs to help them cope with being infected. There are reasons to suspect that older and younger adults have different service needs. Crystal and Sambamoorthi (1998) point out that the two age groups differ in their social and economic circumstances, clinical course and rate of disease progression and survival, health care needs, medical co-morbidities, psychiatric co-morbidities, delays in diagnosis, access to medical care and patterns of service use.

Older adults with HIV/AIDS may require organized programming such as support groups, counseling and/or problem solving or coping programs which are aimed specifically towards their age group addressing issues such as how to accept their illness at an advanced age and how to communicate their condition to family members who may harbour false age and HIV/AIDS-related stereotypes (Nocera, 1997). Although research has not differentiated between older adults who acquired the disease in old age from those who grew into old age with the disease, it is plausible that the social needs of the newly diagnosed elder may be different from those of the older adult "survivor". Additionally, because older infected women typically have a higher incidence of psychiatric problems and

substance abuse than younger infected women, they may require unique counseling and treatment plans that can meet their specific social needs (Wooten-Bielski, 1999).

3. Barriers to Accessing Medical Services

The research literature concerning infected older adults suggests that they are unable, or limited in their ability to access HIV/AIDS-related medical services. First, they may self-limit access to medical services because of their preconceived thoughts about HIV-infection and AIDS. Second, their access may be limited by presumptions and stereotypes held by health care providers regarding aging and HIV/AIDS. Third, their access may be limited by the medical community's inability to provide age and disease appropriate medical services based on a lack of available research and information.

3.1 Older Adults and HIV/AIDS Stereotypes and Stigmas

HIV/AIDS-related stigmas and stereotypes are held by many older adults. Although persons over the age of fifty may have at least one risk factor for infection (Skiest & Keiser, 1997; Zelenetz & Epstein, 1998), many believe that they are not at risk (Wooten-Bielski, 1999). Instead they associate HIV and AIDS with certain social groups such as gay men, drug users, hemophiliacs and immigrants (Mueller, 1997). Because older adults do not perceive themselves to be at risk for infection, they do not request testing and therefore, do not access necessary care. Bachus (1998) points out that "older adults who have been tested have done so at the request of their physician, not because they themselves felt that they were at risk" (p.44). However, even when examined and found to be sero-positive, some older adults have not requested further medical attention because they feel healthy in which case their limited access is personally driven (NIA, 1999).

The perception of being 'at no risk' is a consequence of prevention and education messages and programs that target younger adults and gay men, traditionally deemed more susceptible to infection (Mueller, 1997). Not only are these messages not targeted directly to older adults, their non-existence for older adults may lead some older adults to believe that HIV and AIDS cannot, and does not, affect them or their age group.

3.2 Health Care Provider HIV/AIDS-Related Stereotypes and Ageism

Long-standing myths that older adults are not at risk for HIV-infection are also believed by many health care providers. Older adults are expected to be sexually inactive or if active, to be monogamous to heterosexual activity. They are not expected to be, or to have once been, intravenous drug users,

homosexual or bisexual (Engle, 1998; Mueller, 1997; Nocera, 1997). As a result, health care providers do not typically suspect that an older adult is at risk for infection and are not prepared or trained to acquire the information necessary to making the proper diagnosis. Informed care-related decisions and treatment modalities along with the provision of proper and necessary support are therefore compromised (Bachus, 1998; Nocera, 1997). Older women are at a disadvantage when compared to older men in accessing medical services because health care providers are even less likely to question them about their sexual or drug related history than they are to question men (Wooten-Bielski, 1999; McCormick & Wood, 1992).

3.3 Medical Awareness and Knowledge About HIV/AIDS and Aging

A lack of awareness, an incomplete knowledge base and under-developed skill sets among health care providers with respect to asking about HIV-infection as well as ageism reduces the likelihood of early detection and therefore access to health services (Wooten-Bielski, 1999; Bachus, 1998). The problem is compounded by older adults' reluctance to disclose details of their past and present recreational drug use and sexual preference or orientation to health care providers out of fear of being reproached and scorned (Mueller, 1997). As a result, health care providers do not necessarily recognize the risk factors associated with infection. Further, many health care providers were trained prior to HIV/AIDS becoming a prominent concern, and since completing their training, have had to manage only younger infected persons. As a result, many health care providers are inexperienced in working with the infected older population (Strombeck & Levy, 1998).

Health care providers are less likely to suspect an HIV/AIDS-diagnosis among older adults than among younger adults (Mueller, 1997). Skiest and Keiser (1997) along with Strombeck and Levy (1998), point out that primary care physicians have a narrow conception of the care issues surrounding the management of HIV/AIDS and the older adult. In their study, Skiest and Keiser (1998) questioned 330 Dallas primary care physicians about their practice characteristics and knowledge of HIV/AIDS and patients 50 and older. Of the fourteen questions, five addressed physician practice demographics, four addressed physician interactions with patients 50 and older, one targeted HIV/AIDS care for individuals younger than thirty and three addressed the physician's knowledge about HIV/AIDS and older adults. Physicians in the study were also asked to rank order the risk factors for infection among older adults. Findings indicated that these physicians were less likely to discuss HIV/AIDS-related issues with their older adult clients and that many had inaccurate knowledge about HIV/AIDS and older patients.

Patient difficulty in accessing knowledgeable health care providers is further compounded by the fear that some health care providers have about HIV/AIDS. Although the disease has been apparent for at least two decades, many health care providers continue to fear the illness and persons with it. Recognizing that HIV/AIDS is transmittable, some service providers still believe that in treating infected persons, they are putting themselves at risk (Emlet, 1993; Skiest & Keiser 1997). As a result, the number of physicians interested and available to provide care to older adults is limited.

3.4 Medical Specialty and Availability

Older adults require medical care from practitioners who appreciate that their physiological age-related changes and deteriorating health status can complicate diagnosis and treatment. For example, older adults show a more rapid rate of both disease progression and deterioration compared to younger adults, which is typically a result of reduced immunity associated with advanced age and delays in diagnosis (Crisologo, Campbell & Forte, 1996; Nocera, 1997).

Within the older adult group, there are also gender differences. Older men and women contend with different medical issues. For example, older women face complications of cervical carcinoma and pelvic inflammatory disease. These conditions are more common among infected older women than non-infected older women (Wooten-Bielski, 1999). Infected older adults of both genders could benefit from access to physicians familiar with both physiological aging and with HIV/AIDS, such as a geriatrician who is an expert in HIV/AIDS. Unfortunately, it is uncommon to find practitioners who are expert in both areas.

3.5 Health Care Provider Dedication and Treatment

Whenever groups of individuals such as homosexuals, people with sickle cell anemia, minority populations or older adults infected with HIV/AIDS are discriminated against, they become vulnerable to receiving less than equal treatment (Schmidt & Kenen, 1989). Although older adult AIDS cases have comprised at least 10% of all AIDS cases over the past ten years (Health Canada, 2001), treatment options and opportunities for improved health status have targeted the needs of younger persons (Bachus, 1998; Benjamin, 1999; Garvey, 1994). Ory and Mack (1998) and Siegel et al., (1998) suggest that health professionals set high goals when treating the young compared to modest goals for the old. According to Siegel et al. (1998), older adults "...also may receive different patterns of care (e.g. different treatments, less curative treatments) or be offered only selective treatment options or have treatments presented less enthusiastically, even after controlling for comorbidities" (p. 688). Upon interviewing 63

individuals between the ages of 60 and 68 with HIV/AIDS on the advantages and disadvantages of age among older HIV-infected adults, Siegel et al. (1998) noted that "...some participants expressed that they believed doctors were more motivated to try and restore younger people to "optimal" health than they might be with an older adult...Conversely, they felt physicians were likely to be less invested in attempting to maximize the functional performance or survival of older adults" (p. 703).

Access to medical services for the older adult is further limited by the amount of time health care providers dedicate to older adults with HIV/AIDS during medical visits. Siegel et al. (1998) indicate "that physicians may generally take less time with older patients during their encounters, even though older adults tend to have more medical problems and are less efficient in communicating information about their condition" (p. 688).

3.6 Medical Misdiagnosis and Treatment

Misdiagnosis limits access to age-appropriate HIV/AIDS medical care. Among the older adult population, HIV/AIDS has become known as the "great imitator" in that it goes undetected and misdiagnosed due to its low index of suspicion among health care providers (Nazon & Levine-Perkell, 1996; Strombeck & Levy, 1998). Diagnosis, and more particularly accurate diagnosis, is challenging for unsuspecting physicians who typically examine and relate symptoms such as weight loss, fatigue, memory loss, etc., associated with the infection to conditions associated with "normal" aging or illnesses such as pneumonia or Alzheimer's disease. It can be difficult for physicians to differentiate between the normal processes of aging and symptoms associated with HIV/AIDS as they mimic one another (Engle, 1998; Szirony, 1999). Furthermore, the treatment of infected older adults is challenging as health care providers must often manage other age-related morbidities such as diabetes, cardiovascular disease and arthritis (Crystal & Sambamoorthi, 1998).

Although the correct diagnosis may eventually be made, it is often when the older adult is in the later stages of the illness. A late diagnosis has been shown to reduce life expectancy, thus the older adult's survival time from diagnosis is shortened and typically, is less than that of the infected younger adult (Alder & Nagel, 1994; Chiao, Ries & Sande, 1999; Emler, 1993; Mueller, 1997). It is not uncommon for an older adult to die within the first month of an AIDS diagnosis (Alder & Nagel, 1994; Zelenetz & Epstein, 1998).

3.7 Participation in Medical Research

It is unclear whether or not infected older adults are limited in their access to participating in medical research which could potentially improve their overall access to medical care and services. Older adults are typically excluded from most clinical drug trials based on the likelihood that they will skew findings, potentially negating new drug benefits (for a younger population), or that they may complicate their own non-AIDS related medication regimens (Chiao et al., 1999). This limited access reduces the possible benefits older adults can obtain from experimental HIV-related drugs that may be superior to their current medications (Crystal & Sambamoorthi, 1998).

On the other hand, older adults may be under represented in drug trials because they may not be interested in participating in any type of research or drug-related experiment. Ory and Mack (1998) report anecdotal evidence that the use and effectiveness of aggressive treatments in the older population is questioned by both the patient and the doctor. Older adults may in fact fail to benefit from HIV/AIDS therapies because they may not be able to physiologically tolerate the treatments, may have several co-morbid conditions that complicate experimental medication regimens and have poorer immunologic reserves. However, if access to intervention trials and/or new medications is offered and/or improved, the question remains as to whether infected older adults will or will not achieve the same outcomes as infected younger adults (Justice & Weissman, 1998).

3.8 Other Factors Limiting Access to Medical Services

Infected older adults typically have limited access to informal medical care provided by friends, family members and/or significant others. As age increase, the number of significant others and friends diminishes due to illness-related death and parents, if alive, may be too frail to provide care. Infected older women are more likely than infected younger women to be without a partner or to have a partner who may be unable to provide adequate care (Nocera, 1997). Older women too may face additional problems in obtaining the care they need as "many are caregivers for family members and are reluctant to take time out to care for themselves. Low-income women may be especially unable to seek medical attention or get the adequate services" (Buttenwieser, 1994, p. 63).

AIDS-related research funding agencies often disregard older adults as being at risk for HIV/AIDS-infection. Research interests, finances and resources instead, are directed towards youth and men having sex with other men (AIDS Alert, 1999a). Due to the direction of AIDS research, there is little

movement to broaden the information and knowledge base concerning HIV/AIDS and the older adult and little incentive to understand the service needs and access issues experienced by infected older adults.

4. Barriers to Accessing Social Services and Supports

In order for infected older adults to remain alive and healthy within their community, access to social services and supports such as HIV/AIDS-related social programming and social networks is necessary. Based on research reviewed, it is apparent that certain barriers preclude the older adult from accessing these services including societal and personal aging and HIV/AIDS-related stigmas and the availability of HIV/AIDS-oriented social networks and age-specific programming offered through local social service organizations.

4.1 Societal and Personal Stigmas and Stereotyping

Infected older adults face a dual stigma or situation of double jeopardy that affects their ability to access social services (Mellor, 1996; Szirony, 1999). On the one hand, they must contend with the hostility and lack of acceptance associated with their illness and may fear being reproached and scorned by friends and family because of their diagnosis and the assumed precipitating lifestyle (Mueller, 1997). On the other hand, generally held assumptions about aging and older people create impediments to social service access. For example, many organizations have not designed their services and programs with older persons in mind. This is particularly true of AIDS-service organizations. It is noteworthy that with the proportional increase in the older population over the past years, ageism has weakened and will likely continue to weaken as the older population continues to grow in size. Unfortunately, those currently infected with HIV/AIDS entered into a society that tends to view its older people as second-class citizens (Mellor, 1996; Engle, 1998).

Older adults also must contend with their own personal views about being infected and aging, both of which they may consider negative. Although the predominant routes of infection among both older and younger adults is through sexual activity (hetero- and homosexual) and intravenous drug use, older adults continue to associate infection solely with homosexual activity. Despite many older adults, especially older women, not having been infected as a result of homosexual activity, they continue to make the association, and to perceive the activity and associated infection as socially unacceptable. As a result, many infected older adults become or remain closeted, limiting their own access to social support services including those which may be age-specific (Emlet, 1993; Kosberg & Kaye, 1997;

Zelenetz & Epstein, 1999). Siverson (1999) specifically notes that shame and isolation seem to play a role in keeping HIV-positive older women invisible and untreated.

4.2 Social Networks

The availability of social networks has been shown to influence the infected individual's ability to cope with the illness (Strombeck & Levy, 1998). Unfortunately, infected older adults are hindered in their ability to cope because their access to support networks such as family, friends and acquaintances deteriorates and diminishes as a result of diagnosis (Avis & Smith, 1998; Crisologo et al., 1996; Nocera, 1997; Szirony, 1999). Families are often unprepared for providing the specific care and support required in addition to dealing with the social and psychological issues associated with the illness (Benjamin, 1999). Older men especially, have been found to have difficulty coping with their illness because they have lost much of their age cohort and often their personal social network to the disease (Siegel et al., 1998).

As with accessing medical services, older adults, who are either geographically separated from family and friends or living in rural communities, face limitations in accessing appropriate support offered through these social networks. Separation created by distance leaves the infected older adult not only feeling isolated, closeted and unsupported, but also potentially at a loss for a secure family support system (Hinkle, 1991; Nocera, 1997).

4.3 HIV/AIDS-Specific and Other Social Service Organizations and Programs

Programming offered by HIV/AIDS-specific or other community social organizations is valuable in addressing some of the older adult's emotional and social needs. However, the older adult's ability to access these programs may be compromised by their lack of availability and the groups they target.

The size of a community and whether it is rural or urban will dictate the availability of HIV/AIDS-specific organizations and even more so the availability of HIV/AIDS organizations targeting the social needs of older adults. Smaller communities as compared to larger communities may not have the resources to meet the social needs of even the majority of individuals with HIV/AIDS, namely younger adults.

Avis and Smith (1998) and Johnson, Haight, Faan and Benedict (1998) note that programs addressing the social needs of the older adult with HIV/AIDS are either not routinely in-place, or that there are too few of them, or that there are too few of them in-place too late. Some programs may also be slow to respond to the social needs of the older adult as they have typically focused on the needs of

the younger gay male (AIDS Alert, 1999b; Engle, 1998; Garvey, 1994; Nocera, 1997; Siegel et al., 1998; Strombeck & Levy, 1998; Szirony, 1999). Additionally, some organizations contain a mix of ages making it difficult for the older adult to interact with other older adults because there are few of them. The older adult's needs cannot be adequately met through these avenues as many find it challenging to relate to the issues pertaining to the younger infected person. Furthermore, Nocera (1997) found that within some of the already developed social networks, older adults providing information are themselves not well informed threatening access to accurate information.

4.4 Older Adults' Attitude Toward Social Service Use

Access to age-appropriate social services such as local HIV/AIDS support groups, organizations or volunteer friendship or buddy programs is dependant not only on the availability of such services but also on the older adult's ability, preference and attitude towards using these services. Several factors may explain why infected older adults are less likely to take advantage of available community supports in coping with their illness. First, many feel that these services are primarily for younger populations (Szirony, 1999). Second, many experience diminished energy and fatigue as a result of the illness, which limits their ability to travel distances to utilize resources. Third, the stamina necessary to reveal their diagnosis hinders the older adult's desire to connect with community AIDS services (Avis & Smith, 1998; Szirony, 1999). Fourth, social factors such as the fear of being stigmatized, a sense of guilt, embarrassment and shame hinder the use of such services (Garvey, 1994; Szirony, 1999). Mueller (1997) for example notes that the older adult may resist being identified as an "AIDS patient" and so avoids accessing HIV/AIDS-related social supports and social organizations that could provide beneficial services. Fifth, many older adults lack experience in group settings such as support groups where they are expected to discuss issues they may not yet have come to terms with (Emler, 1993). In Emler's (1993) investigation, 55.2% of younger persons with AIDS utilized emotional support services offered through a local AIDS support group compared to only 10% of older adults. Those who do become actively involved do so because they hope to find a network of older adults facing similar issues with whom they can connect (Engle, 1998; Siegel et al., 1998).

In summary, the literature reviewed suggests that older adults with HIV/AIDS may face difficulties in accessing HIV/AIDS-related medical and social services, over and above those experienced by infected younger adults. Personal, societal and medical HIV/AIDS and ageist stigmas and stereotypes, limited medical knowledge, differential priorities in HIV/AIDS research and limited or

non-existing age-specific formal and informal medical and social services and supports potentially limit the older adult from accessing services necessary in coping with their illness.

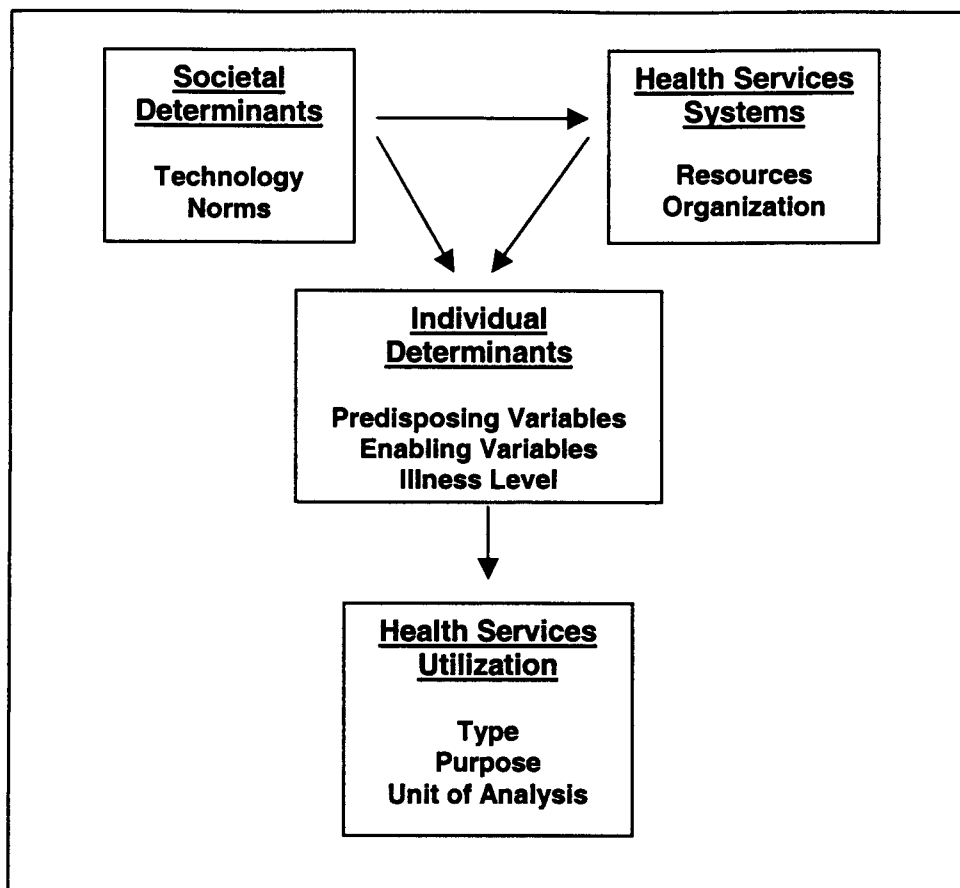
B. Investigative Framework

Access to medical and social services is investigated using the Medical and Social Services Access Model (**MSSAM**), which the researcher developed for this study based on the Health Services Utilization Model established by Andersen and Newman (1973).

1. Foundation of the Medical and Social Services Access Model: Health Services Utilization Model

The Health Service Utilization Model was established to examine, predict and explain the utilization of health services among individuals (Andersen, 1995). According to this model and as shown in Figure 1, health services utilization is viewed as a type of individual behavior that can be explained by examining three sets of determinants: societal determinants, individual determinants, and specifics of the health services system (Andersen & Newman, 1973). The Health Services Utilization Model will not be tested in this study. A cursory explanation of the original model is presented below.

Figure 1. Health Services Utilization Model



As shown in Figure 1, the Health Services Utilization Model predicts and explains health service utilization through relationships between three main components. Specifically, societal determinants affect individual determinants both directly and through the health services system. Individual determinants then influence the health services used by the individual (Andersen & Newman, 1973).

Societal determinants include “technology” and “norms”. Technology is defined as “a set of principles and techniques useful to bring about change towards desired ends” (Andersen & Newman, 1973, p. 100). Norms include what is normally expected (within society), how people ought to behave (in society), and how individuals must comply, in other words, laws implemented for society (Andersen & Newman, 1973).

Individual determinants encapsulate predisposing and enabling variables and one’s illness level. Predisposing variables, or characteristics that predispose a person to use a service, include: i) demographic characteristics such as age and sex, ii) social structures such as one’s status within society, level of education, race, ethnicity, religion, family size and residential mobility, and iii) health related attitudes or beliefs about physicians, care and disease. Enabling variables that facilitate the use

of, or enable one to use a service, include: i.) community characteristics such as one's geographic location and the ratio of community services to the population, and ii.) family characteristics such as income, health insurance, sources of care and accessibility of care. Illness level or perceived need reflects one's perception of his/her illness and associated symptoms, diagnosis and disability along with professional evaluated assessments of symptoms and associated diagnosis. A person's perceived illness level would determine his/her need to use services (Andersen & Newman, 1973).

Characteristics of the health services system influence one's utilization of the services and include resources and organization. Resources refer to the volume and distribution of services such as labour and capital and associated personnel, education and equipment necessary in providing care or support. Organization is defined according to the access and structure of the system and essentially, what the system does with its resources; the way in which medical personnel and facilities are coordinated and controlled in the process of providing services (Andersen & Newman, 1973).

To date, the full Health Services Utilization Model incorporating individual, societal and health services system characteristics has not been used to investigate service utilization among older HIV-infected individuals. However, some studies have used the Behavioral Model, a sub-component of the Health Services Utilization Model, which includes only individual determinants defined by the relationships between predisposing, enabling and illness variables, to investigate service use among older and/or HIV-infected individuals (Aday & Andersen, 1981; Bear, Sauer & Jentsch, 2000; Emlet, 1998; Fleishman, Hsia & Hellinger, 1994; Mitchell & Krout, 1998; Mor, Fleishman, Dresser & Piette, 1992; Palacio et al., 1999; Ward, 1977). Palacio et al. (1999) in their study Access to and Utilization of Primary Care Services Among HIV-Infected Women included characteristics of the health services system in addition to individual determinants.

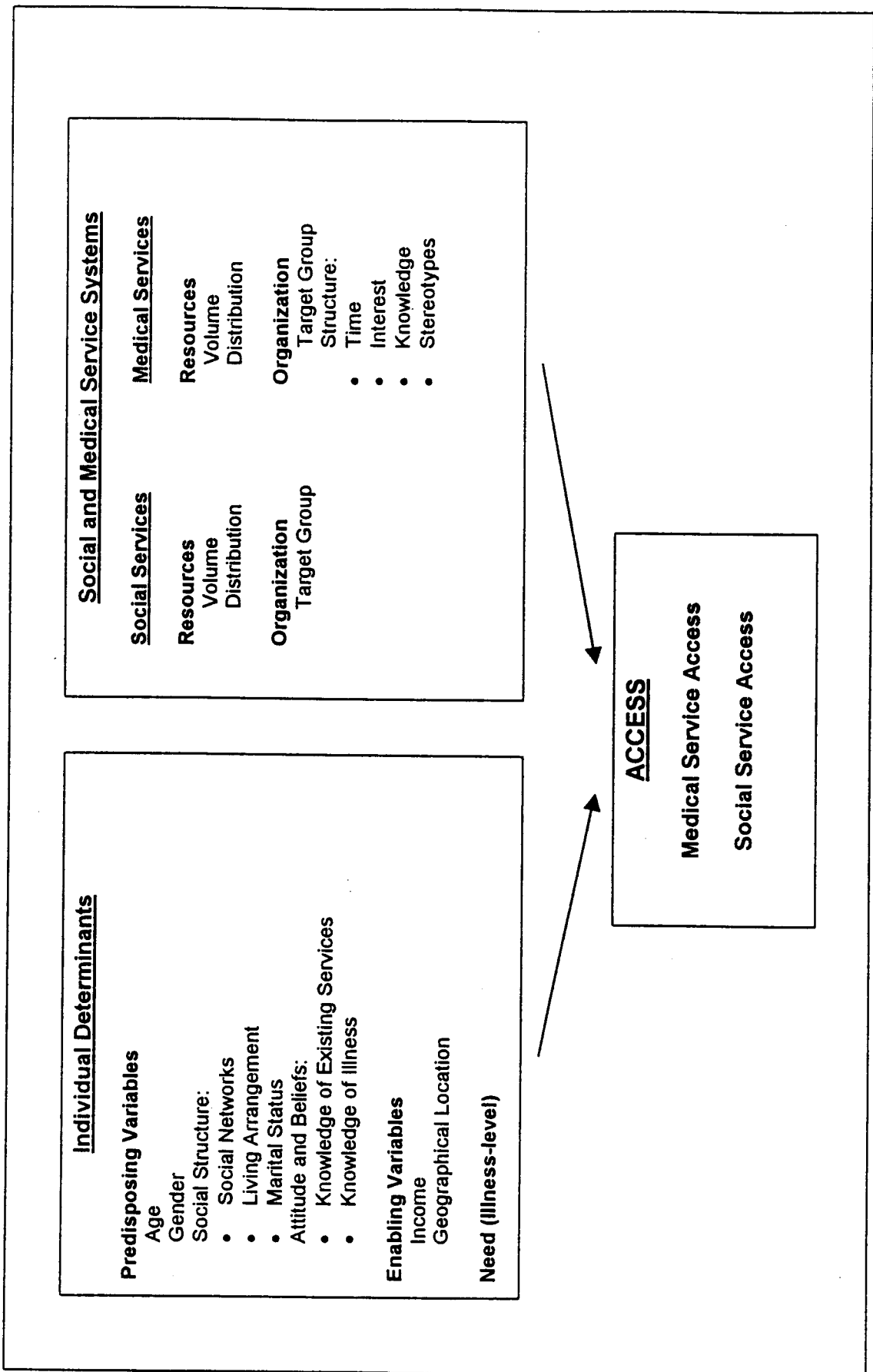
The Behavioral Model however, has been criticized for its inconsistency in measuring the strength of independent variables and in explaining the variance that predisposing, enabling or need variables contribute to a particular model. Upon a review of the literature, Andersen (1995) and Wister (1992) found that need, or health status, contributed the strongest correlation with medical use with predisposing and enabling variables establishing significant yet, weaker correlations. Further evaluation proposed that the Behavioral Model is more suitable for investigating informal health service use rather than investigating formal health service use.

2. Medical and Social Services Access Model (MSSAM)

The Medical and Social Services Access Model shown in Figure 2 was developed by this researcher to guide the investigation of both medical and social service access. While the model overall was not tested in the present study, some of its propositions were examined in a preliminary manner. For the purposes of this study, access to both medical and social services was defined as “the availability of services and personnel and/or having the opportunity to use, to make use of, or to reach a service, but not necessarily having gained entry to it or to have used it”.

It was felt that access to services could be influenced not only by individual determinants including predisposing, enabling and need variables, but also by characteristics of the systems providing services. As a result, the MSSAM adopted many of the Health Services Utilization Model's variables with some variation as these variables were perceived to be meaningful to investigating service access in addition to other variables discussed below.

Figure 2. Medical and Social Services Access Model (MSSAM)



As shown in Figure 2, two independent variable sets were used to investigate an individual's ability to access services: individual determinants and medical and social service systems determinants.

Individual determinants influencing access to services included predisposing, enabling and need variables. Age, gender, social structure including social networks, living arrangement and marital status in addition to health beliefs and attitudes which consisted of the knowledge people had about health and health services defined predisposing variables.

The Health Services Utilization model has been criticized for its lack of attention to social networks which fall within the concept of social structure (Andersen, 1995). It was assumed that one's social networks of friends and family could define the amount of social support one might have available to them. In Penning's (1995) literature review of health, social support and the utilization of health services among older adults, the effect social support has on the need for formal services was undetermined. Penning however, proposed that as social support decreases, formal service utilization increases. Social structure was therefore included as a predisposing variable that may influence one's ability to access services.

Income and geographical location defined enabling variables to accessing services and were retained in the MSSAM from the Health Services Utilization Model.

The actual need variable to access a service was retained from the Health Services Utilization Model. This need would stem from their perceived severity of illness.

The medical services system component of the Health Services Utilization Model was enhanced for the purposes of this study to include characteristics of social services systems. The variables of resources and organization were retained in the MSSAM and applied to both service domains. "Access" as introduced from the Health Services Utilization Model, was replaced by "targeted groups", as the specific groups targeted by the organization could limit service access by other groups. Organizational structure included variables that investigate what happens to infected adults once they are interacting with service providers and applies only to medical services, specifically health care providers. These variables included the amount of time health care providers allocated to treat infected individuals, their interest in, and knowledge of treatment, and any stereotypes or stigmas health care providers harboured regarding aging and/or HIV/AIDS-infection.

Rather than focusing on specific types of outcomes such as the number of physician visits or hospital stays or support group participation and/or therapist visits which are traditionally investigated

with the Andersen and Newman Model (Andersen & Newman, 1973), the dependent variable in this study was access to medical and social services.

C. The Present Study

The primary purpose of this study was to investigate the experiences that older adults with HIV/AIDS have had accessing HIV/AIDS-related a) medical services, and b) social services and to compare their experiences to those of infected younger adults. Based on the literature review, it was thought that older adults would be limited in general to accessing necessary medical and social services and less able than younger adults to access necessary medical and social services. Further, it was expected that their experiences would be influenced by both ageist and HIV/AIDS-related stigmas and stereotypes. Two exploratory research questions arose out of the reviewed literature.

Research Question 1: Are infected older adults limited in their ability to access, or unable to access HIV/AIDS-related medical and social services necessary in coping with their disease?

Research Question 2: Are infected older adults less able to access HIV/AIDS-related medical and social services necessary in coping with their disease than infected younger adults?

As an aid to understanding the current and future service needs and potential service accessibility issues, the present study also investigated younger and older adults' perceptions about the need for, or value of, providing specific medical and social services for infected older adults.

CHAPTER II

Method

A. Study Population

This study explored the experiences of three adult groups infected with HIV or diagnosed with AIDS; older adults aged 50 and older, persons between age 40 and 49 and persons aged 30-39. Older adults were defined as those 50 and older in order to remain consistent with, and comparable to existing HIV/AIDS-related and aging-related research. To date, older adults have comprised a small percentage of the total number of individuals diagnosed with HIV and AIDS. As a result, until most recently, HIV/AIDS surveillance reports have grouped individuals 50 and older together. Additionally, 50 and older has been used to define the older adult in order to recognize that an infected individual's immune system ages quickly as a result of the infection, leaving it in an "older" and more fragile state, and that most infected individuals do not live into their fifth decade.

As shown in Table 1, a total of 34 individuals infected with HIV or diagnosed with AIDS participated in the study. Most (n=29; 85%) resided in the city of Toronto; the remaining five participants (15%) resided in the city of Hamilton. Of the 34 participants, 11 (32%) were aged 30 to 39 (mean=34.6 years), 11 (32%) were aged 40 to 49 (mean=43.8 years), and 12 (36%) were aged 50 to 65 (mean=56.0 years). The sample included 30 (88%) males and four females (12%). Most (n=23; 68%) of the participants acquired HIV through homosexual contact, three (9%) through heterosexual contact, three (9%) through intravenous drug use, one (3%) through a blood transfusion and the remaining four participants (12%) were unclear about how they became infected. The participants in this sample were infected with HIV for an average of 10.7 years. More than half of the sample (n=18; 53%) lived alone, four (12%) lived with a roommate and 12 (35%) lived with a significant other or spouse. Most of the participants (n=29; 85%) were single, four (12%) were married and one (3%) was involved in a common law relationship. Of the total sample, 13 (38%) participants had children. With an official diagnosis of HIV/AIDS, infected individuals were unable to be legally employed if they collected provincial subsidy assistance. None of the participants interviewed were employed and 32 participants (94%) collected income from the Ontario Disability Support Program and two participants (6%) collected income from private insurance.

Table 1. Socio-Demographic Characteristics of Study Participants

Socio-Demographic Characteristics	Age Group							
	30s n=11		40s n=11		50+ n=12		Total n=34	
	n	%	n	%	n	%	n	%
Age								
Mean (years)	34.6		43.8		56.0		44.8	
Standard Deviation (years)	3.3		2.2		4.7		9.4	
Gender								
Male	10	91	9	82	11	92	30	88
Female	1	9	2	18	1	8	4	12
Route of HIV Transmission								
Homosexual Contact	5	45	8	72	10	84	23	68
Heterosexual Contact	1	9	1	9	1	8	3	9
Intravenous Drug Use	3	27	0	0	0	0	3	9
Blood Transfusion	0	0	0	0	1	8	1	3
Unknown	2	19	2	19	0	0	4	12
Mean Length of Infection (years)	9.0		12.3		10.75		10.7	
Living Arrangement								
Lived Alone	2	18	7	64	9	75	18	53
Lived with Roommate	4	36	0	0	0	0	4	12
Lived with Partner	5	46	4	36	3	25	12	35
Marital Status								
Single	9	82	9	82	11	92	29	85
Married	2	18	1	9	1	8	4	12
Common Law	0	0	1	9	0	0	1	3
Have Children								
Yes	4	36	6	55	3	25	13	38
Income								
Ontario Disability Support Program	11	10	11	10	10	84	32	94
Private Insurance	0	0	0	0	2	16	2	6
		0		0				6

Age-Group Comparisons

There were four notable demographic differences between the three age groups. As can be seen in Table 1, as age increased, the primary route of infection was through homosexual contact. A greater proportion of older adults (n=10; 84%) became infected via homosexual contact than either the 40 to 49 (n=8; 72%) or the 30 to 39 (n=5; 45%) age groups. Participants in their forties however, had been infected for a longer period of time (12.3 years) compared to participants in their thirties (9 years) and those 50 and older (10.75 years). More of the older adults (n=9; 75%) lived alone compared to

those in their forties (n=7; 64%) and thirties (n=2; 18%). Few participants lived with a partner and age differences are minimal. Specifically, only three (25%) older adults compared to four (36%) adults aged 40 to 49 and five (46%) adults 30 to 39 lived with a partner. A greater proportion of participants in their forties (n=6; 55%) had children compared to participants in their thirties (n=4; 36%) and those 50 and older (n=3; 25%).

B. Sampling and Recruitment

Confidentiality mandates established within HIV/AIDS-service organizations prevented access to lists of infected individuals. As a result, this study employed non-random sampling in the recruitment of participants. Participants were recruited with the assistance of local HIV/AIDS-service organizations located in selected cities within Ontario. Each organization was sent an introductory letter indicating the purpose of the study and requesting assistance with the distribution of flyers and posters. Coffee shops, gay bars and community centers typically frequented by the gay or HIV/AIDS population were provided with posters indicating details of the study. Table 2 shows the targeted HIV/AIDS-service organizations in the specific cities. The organizations selected were located within close proximity to where the researcher lived in order to enable in-depth interviews rather than a mail back survey. Participants were offered a \$20.00 honorarium for their time and incidental expenses.

Table 2. HIV/AIDS Organizations Assisting With Participant Recruitment

Location	Organization
Toronto	AIDS Committee of Toronto (ACT) Persons with AIDS Foundation (PWA) Voices of Positive Women Community AIDS Treatment and Information Exchange (CATIE) Casey House Deaf Outreach Program Centre d'Accueil Heritage
Hamilton	Hamilton AIDS Network (HANDS)
Waterloo Region	AIDS Committee of Cambridge, Kitchener and Waterloo
Niagara	AIDS Niagara
Etobicoke	Etobicoke AIDS Committee
London	AIDS Committee of London Association of Iroquois and Allied Indians

Recognizing that older persons comprise only a small proportion of the infected population and that many infected older adults are closeted, snowballing was utilized to increase the response rate. Participants were asked “Do you know any older adults, those 50 and older, who are infected with HIV or AIDS who would be interested in participating in this study?” Participants who indicated that they did know of someone were given a flyer and asked to pass it on to the individual. Given that the HIV/AIDS population in general, and in particular the older population, is hesitant to come forward and discuss personal issues among potentially judgmental, uninfected and heterosexual individuals, it was necessary to accept all individuals who indicated an HIV/AIDS diagnosis and who fell within the pre-defined age groups. A total of 36 participants volunteered for the interview and 34 actually participated and completed the interview.

C. Data Collection and Recording

Data were collected from in-depth individual interviews that lasted between 0.5 and 1.5 hours. All but three interviews were audio taped (three participants did not feel comfortable being audio-taped). Participants were asked the following six open-ended questions intended to explore their experiences with accessing available medical and social services and their perceptions of service need. The probes shown below each question were used to acquire further detail when necessary.

1. Interview Questions

Demographics

1. Can you tell me a little bit about yourself, who you are, perhaps some history?

- Age
- Marital status (married, single, divorced, widowed)
- Children
- Living Arrangement (with children, spouse, relatives, other)

Medical Services

2. What have your experiences been with HIV/AIDS related medical services (such as walk in clinics, hospitals and reference resources like libraries)?

- Do you require regular HIV/AIDS related medical visits? Where do you typically go? How Often? Why there and not elsewhere?
- If you are looking for information about how to improve your health status, what resources do you look to (physician, support groups, local HIV/AIDS networks, naturopaths, internet)? Why have you chosen these resources over others?
- Are there any HIV/AIDS related medical services targeted to your age group (those over 50)?
- Do you use them? If no, why not?

3. What experiences have you had with HIV/AIDS related medical or health professionals (such as doctors, nurses)?

- Have your experiences with HIV/AIDS health care professionals been positive or negative and why?
- Have the HIV/AIDS health care professionals you've had experience with been knowledgeable or not knowledgeable about your illness?
- Have they or have they not taken special account of your age?
- Do you feel that it is or is not necessary to have health care providers who are knowledgeable in both HIV/AIDS and older people?
- In your opinion, are there enough or not enough health care professionals specializing in HIV/AIDS patients over the age of fifty? (both age group question)
- Are the health care professionals you interact with as interested, or not as interested in improving your health status, as they are for younger (or older) persons with HIV/AIDS?
- Do the HIV/AIDS related health care professionals you interact with allow enough time or not enough time during your visit to listen, understand and discuss your HIV/AIDS health related concerns?
- Have you ever participated in HIV/AIDS research or drug trials? If no, why, and if yes, how did you get involved in it?
- Do you think that existing stereotypes associated with having HIV/AIDS do or do not affect your ability to access the health care services you require?
- What about stereotypes about older people? Do you think they have any impact on your ability to access health care services you need to cope with HIV/AIDS?

Social Networks and Organizations

4. How have your relationships with family, significant others, friends and/or acquaintances helped you cope with having HIV/AIDS?

- Who provides you with the emotional or social support you need to cope with your illness?
- Since you have been diagnosed with HIV/AIDS have your relationships with family members or significant others changed or stayed the same?
- If yes, how have your relationships changed?
- Since you were diagnosed with HIV/AIDS have your relationships with friends changed or stayed the same? If they have changed, how have they changed?
- Do any of your friends provide you with emotional or social support that helps you cope with having HIV/AIDS?
- Do you in any way feel isolated from your friends, family or community as a result of having HIV/AIDS?

5. What have your experiences been with HIV/AIDS social support organizations?

- Are there any social organizations supporting individuals with HIV/AIDS within your community? (such as AIDS Action Committee of Toronto, Voices of Positive Women etc. – this would be location specific)
- Do you use or visit any of these organizations? Why or why not? What do they offer you/ not offer you?
- Do these organizations target their programs and support services to specific groups? If yes, what groups?
- If you feel isolated from your friends, family and/or community, does this play a factor in you not utilizing available services? What does?
- Is distance to HIV/AIDS related support networks or organizations a factor or not a factor in your access to, or use of services?

6. Are there any other comments you would like to make about your experiences with accessing medical and social services with respect to having HIV/AIDS?

- What other barriers if any, limit you from accessing the medical and social services you require to cope with having HIV/AIDS?
- What existing services are of little or no value to you and why?
- What services are not in place which you feel you could benefit from?
- What services are not accessible to you that you feel you could benefit from?

An inventory of available HIV/AIDS-services targeting individuals 50 and over was constructed for the geographical areas in which participants resided. This information was collected to assess the degree of local service availability in order to understand findings associated with participants' ability to access services.

D. Data Analysis

1. Quantitative Analysis

The Student's t-test was employed to analyze similarities between groups on variables upon which mean values were calculated (Spiegel & Stephens, 1999). Descriptive analyses were then used to supplement and elaborate on the statistical analyses. The correspondence rule for the comparison of groups was 25%.

2. Qualitative Interpretation

After each interview took place, all of the data recorded on audio-tape(s) were transcribed immediately in order to ensure that the information was consistent with the context within which it was communicated. As the purpose of the study was investigative rather than theory and network-building, qualitative-based software programs such as NUD*IST, ATLAS or HyperRESEARCH® (Crabtree & Miller, 1999; Huberman & Miles, 1994) were not considered necessary for the analysis. Further, the data collected were manageable and facilitated efficient organization without the need for text-based managers such as Folio View or ZyIndex, or code and retrieve software programs such as Ethnograph (Crabtree & Miller, 1999). Personally managing the transcripts assisted in ensuring that the researcher remained close to the context of the data. The transcripts were reviewed repeatedly and prominent observations were organized into categories and coded. Categories and associated codes were then re-

read for further interpretation and comprised the explanatory themes describing the older adults' ability to access services.

3. Medical and Social Services Access Model Assumptions

In order to appreciate the qualitative intention of this study and to investigate access to services using the Medical and Social Services Access Model, assumptions were established to facilitate the interpretation of the findings. Access to services was evaluated assuming that the variables associated with individual determinants and characteristics of the medical and social services systems had a direct influence on one's ability to access services. For example, if an infected adult had a significant other, was married or had strong social networks, some of their informal medical and social needs were expected to have been addressed through these avenues. As a result, the individual's ability to access services, specifically informal support services, would not have been limited. Similarly, living in a resource and service rich location would not limit access to services. However, having little time to discuss issues with health care providers or having non-knowledgeable health care providers would limit access to services. Although a direct independent and outcome variable relationship was assumed, it was understood that variables were capable of influencing one another and collectively, capable of influencing the older adults' overall ability to access services.

4. Variable Mutability

Andersen and Newman (1973) discuss the mutability of variables and their associated effectiveness in influencing the use of health services. Andersen (1995) commented "...to be useful in promoting access, a variable must also be considered mutable" (p. 5). Several variables associated with the Medical and Social Services Access Model were viewed as mutable as they could have potentially influenced the degree of accessibility to services for older adults. Mutable variables included marital status, health beliefs, income, living arrangement, geographic location, need and one's social structure. Characteristics of the medical and social services systems were also considered mutable as various levels of volume and the distribution of services along with the quality of services and service delivery could dictate the degree or amount of access an individual had. An alteration in the status of any one of these variables was thought to influence one's ability differentially to access services. This study

recognized the mutability of the above variables, however, the measurement of mutability and the degree to which the variable's mutability influenced access to services was not undertaken.

CHAPTER III

Quantitative Findings and Descriptive Analysis

Despite the qualitative nature and intention of this study, data collected from the interviews allowed findings to be quantified to some degree. These data are reported in this chapter. Chapter IV discusses the relationship of the quantitative data to the research questions and provides an explanation of the findings through qualitative analysis.

A. Existing HIV/AIDS-Related Medical and Social Service Inventory

An inventory of services geared to HIV-infected individuals was constructed for the geographic locations within which participants resided, namely Toronto and Hamilton. The following information details the type and focus of services provided in these locations.

1. City of Toronto

The city of Toronto was rich in its availability of medical and social services targeting individuals with HIV/AIDS. The services and programs offered in the city and more specifically in the gay community, addressed needs and issues surrounding counseling and advice, education and skill building, emergency contact, employment opportunities, financial, food and nutrition issues, health and wellness issues, housing issues, information and referral, insurance and benefits, legal and advocacy issues, medical and dental, practical assistance, recreational and social events, support groups and volunteer opportunities (ACT, 2000). Many of the HIV/AIDS medical and social organizations provided service in one or more of the areas listed above. Ethno-culturally specific services targeted Aboriginal, African, Asian, Black, Caribbean, French-speaking, Jewish, Portuguese-speaking, South Asian and Spanish-speaking backgrounds and communities (ACT, 2000). Additional services were in place for children, consumers of mental health services, the deaf or hard of hearing, drug users, families, hemophiliacs, homeless or street people, immigrants and newcomers, men, prisoners and ex-prisoners, program and service workers, refugees, sex workers, transsexuals or trans-gendered people, women and youth (ACT, 2000).

In comparison to those for the groups listed above, there were only a limited number of HIV-related medical or social services for older adults. There were only two programs in place addressing older adults' needs; one which catered to Francophone seniors and offered housing, information and referral, and practical assistance; and another, an "Aging with HIV/AIDS Support Group" hosted by the

AIDS Committee of Toronto which was offered infrequently. None of the older adult participants in the present study accessed either program.

EXTRA Magazine distributed within the community and specifically targeting gay, bisexual, transsexual and HIV-populations, provided information on upcoming community events. It listed specific social activities within the HIV/AIDS-service organizations and community. On occasion, the publication listed activities and social outings for older adults. However, these activities were not structured nor regularly offered. Participants in the older adult group did not mention accessing any of the publicized activities.

2. Hamilton

The city of Hamilton was not as service rich as the city of Toronto, however, it offered several medical and social resources to individuals infected with, and affected by HIV/AIDS. Services included financial and legal assistance, home support, information and referral and medical, social, specialized and support services (North Hamilton Community Health Centre, 1997). Hamilton also offered HIV/AIDS-services to different cultural groups such as African, Black, Asian, South Asian, First Nations and Spanish-speaking populations. Further, specialized medical and social services were available for children, youth, addicts, prisoners and ex-prisoners, hemophiliacs and women. There were no targeted services in Hamilton for infected older adults. Study participants residing in Hamilton (16%), indicated that they were not aware of any services that targeted the older adult. However, only one study participant from Hamilton was over the age of 50.

Many of the HIV/AIDS-related services listed in The Positive Living Guide, which provided detailed information on available medical and social services for people with, or affected by HIV/AIDS, who live within the Hamilton area, were services offered in Toronto (North Hamilton Community Health Center, 1997). All participants residing in Hamilton indicated that aside from accessing the Hamilton AIDS Network (HANDS), they frequented Toronto for its available services such as the AIDS Committee of Toronto Library, the Community Information and Treatment Information Exchange and Persons with AIDS Foundation.

B. Access to HIV/AIDS-Specific Medical Services

1. Medical Services/Organizations and Health Information Accessed

Participants were asked to comment on the various HIV-related medical services they were accessing at the time of the interview and where they went to obtain HIV-related health information. Many participants accessed more than one medical service and sought health information from more than one source.

As shown in Table 3, study participants accessed an average of 2.1 HIV-related medical services (range=1-4) and an average of 2.6 HIV-related health information sources (range=1-7).

Table 3. Mean Number of Medical Service/Organizations and Health Information Sources Accessed, by Age Group

Medical Services and Information	Age Group			
	30s (n=11)	40s (n=11)	50+ (n=12)	Total (n=34)
Mean Number of HIV-Related Medical Services/Orgs Accessed	2.3	2.2	1.8	2.1
Range of HIV-Related Medical Services/Orgs Accessed	1-4	1-4	1-3	1-4
Mean Number of HIV-Related Health Information Sources Accessed	2.7	2.8	2.0	2.6
Range of HIV-Related Health Information Sources Accessed	1-7	2-4	1-3	1-7

As shown in Table 3, as age increased there was a difference in the number of medical services/organizations accessed between groups. Compared to participants in their thirties and forties, older adults accessed the fewest number of HIV-related medical services/organizations with a mean of 1.8 organizations and a range of 1-3 organizations. Participants aged 30 to 39 accessed the greatest number of services with a mean of 2.3 services/organizations and participants aged 40 to 49 accessed slightly fewer services than those aged 30 to 39 (mean= 2.2 services/organizations). Both of the younger age groups accessed a range of 1 to 4 services. As shown in Table 4, there was a statistically significant difference in the number of medical services accessed between the 50+ group and those between 30 and 39 ($t=1.67$, $df=21$, $p<.10$).

Table 4: Student's t-test for Between Age Group Access to Medical Services/Organizations and Health Information

Variable	Age Group	Student's t-test	
		t-score	df
Medical Services/Organizations Accessed	50+; 30-39	1.67 *	21
	50+; 40-49	1.19 (ns)	21
HIV/AIDS-Related Health Information Sources Accessed	50+; 30-39	.88 (ns)	21
	50+; 40-49	1.87 *	21

* $p < .05$, + $p < .10$

As shown in Table 3, older adults accessed the fewest number of HIV-related health information sources (2.0 sources) compared to participants aged 30 to 39 (2.7 sources) and participants aged 40 to 49 (2.8 sources). A difference in the number of sources accessed was also reflected in the range as older adults accessed 1 to 3 sources whereas participants in their thirties accessed 1 to 7 sources and participants in their forties accessed 2 to 4 sources. As shown in Table 4, there was a statistically significant difference in the number of HIV/AIDS-related health information sources accessed between older adults and those in their forties ($t=1.87$, $df=21$, $p < .05$).

Information describing the specific types of medical services and health information sources accessed by each age group is found in Table 5 and 6.

1.1 Medical Services/Organizations Accessed

Participants were asked to describe the medical services/organizations they accessed. Information collected was divided into two groups: (1) personal medical care or services provided through one-on-one contact and (2) medical care provided by different people within an organization. Findings are described in Table 5.

Table 5. Types of Medical Services/Organizations Accessed

Medical Services/Organizations*	Age Group							
	30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
	n	%	n	%	n	%	n	%
Personal Medical Care								
Primary Health Care Provider	11	100	11	100	12	100	34	100
Psychiatrist	2	18	0	0	2	17	4	12
Chiropractor/Massage Therapist	1	9	1	9	0	0	2	6
Casey/Fife House Nurse	0	0	1	9	2	18	3	9
Persons with AIDS Foundation (PWA) (Treatment Advisor)	0	0	3	27	0	0	3	9
Organizational Medical Care								
Community Health Centre	1	9	2	18	0	0	3	9
HIV-clinic (Hospital)**	6	55	4	36	8	67	18	53
HIV-clinic (410 Sherbourne Clinic)	4	36	1	9	0	0	5	15
Community AIDS Treatment and Information Exchange (CATIE)	0	0	3	27	3	25	6	18

* Multiple responses were permitted.

**Hospitals included Toronto General Hospital, Wellesley Hospital, Mount. Sinai Hospital; Clinic for HIV-Related Concerns, St. Michael's Hospital and Hamilton General SIS Hospital.

All study participants accessed the medical services of a primary health care provider (which included either a general practitioner or HIV-specialist), four (12%) participants also accessed the services of a psychiatrist, two (6%) the services of a chiropractor or massage therapist, three (9%) accessed the Casey or Fife House nurse and three (9%) accessed the treatment advisor at the PWA Foundation.

Of the organizational medical services accessed, more than half (n=18; 53%) of the sample accessed an HIV-clinic located within a hospital setting whereas fewer participants (n=5; 15%) accessed the designated HIV-clinic of 410 Sherbourne, three (9%) participants accessed services from the local community health center and six participants (18%) accessed the services of the CATIE staff.

There were two notable between-group differences in the proportion that accessed various organizational medical care services. A greater proportion of older adults (n=8; 67%) accessed an HIV-clinic within a hospital setting than either participants in their forties or thirties (n=4; 35% and n=6; 55% respectively). Further, as age increased a smaller proportion of participants in each age group accessed

the designated HIV-clinic at 410 Sherbourne. Specifically, none of the older adults accessed this clinic compared to four (36%) participants in their thirties and one (9%) participant in their forties.

There was also a notable difference in the variety of personal and organizational medical care services accessed. Participants in their forties accessed a greater variety of services compared to participants in their thirties, and those 50 and older accessed the smallest variety.

1.2 Sources of Health Information Accessed

Table 6 describes the various types of health information sources accessed and is divided into four categories: Individuals who provided health information, HIV-Related Health Organizations that provided health information, HIV-specific Groups from which infected participants obtained information and Other-HIV-Information Sources from which participants actively sought information.

Table 6. Sources of Health Information Accessed

Health Information Sources*	Age Group							
	30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
	n	%	n	%	n	%	n	%
Individuals								
Primary Health Care Provider	3	27	7	64	5	42	15	44
Partner/Friend	2	18	0	0	1	8	3	9
HIV-Related Health Organizations								
Persons with AIDS Foundation (PWA)	6	55	4	36	0	0	10	29
HIV-clinic (Hospital)	1	9	2	18	1	8	4	12
Hamilton AIDS Network (HANDS)	1	9	2	18	1	8	4	12
Community Health Centre	0	0	1	9	1	8	2	6
Community AIDS Treatment Information Exchange (CATIE)	1	9	3	27	4	33	8	24
HIV-Specific Groups								
Ontario AIDS Network	0	0	1	9	0	0	1	3
Prisoners with HIV/AIDS Support Action Network	2	18	0	0	0	0	2	6
Positive Straight Men	1	9	0	0	0	0	1	3
Native Groups**	1	9	0	0	0	0	1	3
Voices of Positive Women	0	0	0	0	1	8	1	3
Alliance for South Asian AIDS Prevention	1	9	0	0	0	0	1	3
Other HIV-Information Sources								
AIDS Committee of Toronto Library (ACT)	5	45	5	45	8	67	18	53
Internet	1	9	4	36	4	33	9	26
Magazine (POZ and EXTRA)	1	9	2	18	4	33	7	21

* Multiple responses were permitted.

**Native Groups include: Two Spirited People, Black Top and Spirit of the People

As can be seen in Table 6, more than one-half of all participants (n=18; 53%) accessed information from the ACT Library and slightly less than one-half of the sample (n=15; 44%) accessed information from their primary health care provider. Other frequently accessed information sources included the PWA Foundation (n=10; 29%), internet (n=9; 26%), CATIE (n=7; 24%) and gay-related magazines (n=7; 21%). HIV-Specific Groups were accessed by the fewest number of participants whereas all age groups accessed the Other HIV-Information Sources.

There was a noticeable difference in the proportion of infected adults who accessed information from their primary health care provider. Specifically, a greater proportion (n=7; 64%) of participants aged 40 to 49 accessed their primary health care provider for information compared to participants aged 30 to 39 and those 50 and older (n=3; 27% and n=5; 42% respectively).

There were two notable differences in participants' access to HIV-Related Health Organizations. First, as age increased, fewer participants accessed health information from the PWA Foundation. None of the older adults accessed information from this source compared to more than one-half (n=6; 56%) of those aged 30 to 39 and more than one-third (n=4; 36%) of those 40 to 49. Second, as age increased, the proportion of participants in each age group accessing information from CATIE increased. Four (33%) participants over the age of 50 compared to three (27%) participants aged 40 to 49 and one (9%) participant aged 30 to 39 accessed CATIE's services.

There were no notable differences in the proportion of each age group accessing any of the HIV-specific Groups.

It is notable that as age increased, a greater proportion of participants in each age group accessed health information from gay-related magazines. One-third of the older adults accessed information from gay-related HIV magazines compared to only two (18%) participants in their forties and one (9%) participant in their thirties. There was consensus among study participants that they were interested in ensuring that they had the most current and correct HIV-related information and that they were well informed. As a result, study participants accessed sources such as the internet and various gay and HIV-oriented magazines to update themselves and authenticate what they learned from other sources such as ACT, PWA and their primary health care provider. Participants felt that they did not have difficulty obtaining health information and that they would not allow themselves to be misinformed or uneducated. Much of the participants' health research centered on HIV-medication and reviews of subsequent side effects.

There was also a notable difference in the diversity of information sources accessed by each group. Participants aged 30 to 39 accessed the greatest variety of information sources compared to participants aged 40 to 49 and those 50 and over.

2. Experiences Accessing Medical Services and Personnel

Participants were asked to describe their experiences with accessing medical services, particularly, their experiences with health professionals and organizations and their perception of the effect aging and HIV/AIDS stereotypes had on their ability to access medical services.

As shown in Table 7, 28 (82%) participants reported positive experiences accessing HIV-related medical services or organizations. Reasons for negative experiences included organizational problems and cutbacks to the scope of medical services offered, refusal to serve by some organizations and a lack of centrally coordinated services.

Table 7. Experiences Accessing Medical Services

Medical Service Experiences	Age Group							
	30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
	n	%	n	%	n	%	n	%
Positive Experiences w/ Medical Services/Organizations	9	82	9	82	10	83	28	82
Positive Experiences w/ Health Care Providers (HCP)	10	91	11	100	12	100	33	97
Knowledgeable HCP	10	91	11	100	12	100	33	97
HCP Interested In Promoting Their Health	11	100	10	91	12	100	33	97
HCP Interested In Promoting Older Person's Health	10	91	10	91	11	92	32	91
HIV-specialist	5	45	5	45	8	67	18	53
Enough Time with HCP	10	91	9	82	9	75	28	82
Participated in Drug Trials	3	27	2	18	6	50	11	32
Participated in Research Studies	5	45	6	55	8	67	19	56
HIV-stereotypes Limit their Access	2	18	5	45	4	33	11	32
Aging-stereotypes Limit Access for Older People	4	36	5	45	NA		NA	
Aging-stereotypes Limit Their Access	NA		NA		2	17	NA	

The majority of participants (n=33; 97%) reported positive experiences with their health care provider. Similarly, the majority (n=33; 97%) of participants felt both that their health care provider was knowledgeable about the disease and that their health care provider was interested in promoting their health. Most (n=32; 91%) of the participants felt that their primary health care provider was just as interested in promoting the health of an older adult as they were in promoting the health of a younger adult. More than one-half of the participants (n=18, 53%) indicated that their health care provider was an HIV-specialist. Further, 28 (82%) participants reported that they felt that they had enough time with their health care provider at the time of their visit.

When asked about participation in HIV-related drug trials and research studies, more than one-quarter of the sample (n=11; 32%) indicated current or past involvement in experimental drug trials. More than one-half of the participants (n=19; 56%) had been involved in other types of HIV-related research studies.

With respect to the impact of stereotypes on accessing medical care, almost one-third of the sample (n=11; 32%) indicated that HIV-stereotypes limited their ability to access medical services.

There were no notable differences in the experiences of the three age groups in accessing medical services or organizations and health care providers.

There were no notable differences between the proportion of each age group who felt that their health care provider was knowledgeable with respect to their illness nor were there any notable differences with respect to the degree to which each age group felt that their primary health care provider was interested in promoting their health and in promoting the health of an older adult.

As age increased there was a decline in the proportion of participants who felt that they had enough time with their primary care provider. Among participants in their thirties, one expressed the view that time with their primary care provider was like "Assembly Line Medicine" in that at times, they felt rushed in and out of the office because there were so many clients requiring care. Participants in their forties expressed similar concerns indicating long lineups and a felt sense of being rushed and cheated out of time with their provider because their provider was extremely busy. Participants understood that such waits were unavoidable particularly during flu season. One older adult indicated experiences with the assembly line phenomenon while another felt that because of high patient load their

physician simply did not have the time and subsequent interest in addressing the mental, social and psychological aspects of the disease and medications, only the physiological aspects.

It is notable that a greater proportion of older adults than younger adults had been involved in experimental drug trials: specifically, six (50%) older aged participants compared to three (27%) participants in their thirties and two (18%) participants in their forties. Two of the six older adults were currently participating in one. Younger participants became involved on the recommendation of their physician in addition to accepting the medications because they were free of charge. Four of the six older adults who had accepted drug trial opportunities did so in the early days of the disease when new cocktail combinations first came to the pharmaceutical market. They chose not to participate in drug trials in their later years indicating that the medications age the body quickly and that although they may prolong life, they reduce quality of life.

As age increased, a greater proportion of participants in each age group indicated that they were involved in HIV-related research other than drug trials. Five (46%) participants aged 30 to 39 who had participated in other research, explained that they did so for the monetary gain. The six (55%) participants aged 40 to 49 who had participated in other research also did so for monetary reasons. Of the older adult group, eight participants (67%) indicated that in the past they had been involved in other HIV-related studies not only for the monetary incentive but also because they felt that it was important to do more research because not enough was being done with respect to infection among the older age group.

There was a notable difference in the proportion of participants in each age group who felt that HIV-stereotypes limited their access to medical care: 2 (18%) in the 30-39 age group, 5 (45%) in the 40 to 49 age group and 4 (33%) in the 50 and over age group. Participants aged 40 to 49 stated that one could look wasted or sick because of the different medications and various stages of the disease and that looking wasted in a healthy, young, attractive and predominantly HIV-negative community discouraged infected people from going out in public and getting to services. Among the older adults, four (33%) felt that HIV-related stereotypes limited their access to medical services for reasons similar to those provided by those in their forties. Specifically, two participants were concerned about the effects the medications and various disease stages could have on their physiology and “external façade” with one stating:

Oh my god, does it show yet...there are certain signs to look for and people recognize people who are lesioned, bloated and wasted, they differentiate people...when people are like this they don't want to go out into the open to services...they don't want to go outside and this leads them to depression and people are ashamed of the way they look.

Some participants from the 40 to 49 and 50 and older age groups felt that there was still a "skiddishness" within hospital settings among care providers in treating infected individuals.

There was a notable difference between the proportion of participants in each age group who thought that aging-related stereotypes would limit an older person's access to medical care. Unexpectedly, a greater proportion of participants in their thirties (n=4; 36%) and forties (n=5; 45%) felt that being older and infected would limit a person's access to medical services whereas a smaller proportion of older adults (n=2; 17%) felt and experienced this. Participants in their thirties felt that aging-stereotypes would limit an older person's access noting physical disabilities associated with aging, that medical services were for younger aged individuals, that doctors and nurses weren't used to the infected older adult, and that specific treatments designed for younger persons may be toxic to the older person limiting their access to necessary treatments. Participants in their forties thought that physicians would not want to accept an infected older client due to the complications associated with aging and HIV-infection and that the health care profession had not yet accepted the fact that some older people could become, and were already, infected with HIV. One participant commented that being an infected older adult and requiring nursing home care would be problematic because nursing home staff were not experienced in caring for infected patients. Another added that HIV/AIDS medical specialties such as pediatric and youth AIDS had been established whereas the specialty of geriatric AIDS was non-existent and instead, like any other minority or "non-mainstream" population, older adults infected with HIV/AIDS would be pigeonholed and as a result, limited in their ability to access services. Typical physical disabilities associated with aging such as difficulties walking were also thought to limit an older adult's ability to get out and access services. Older adults who felt that aging-stereotypes limited their access to medical care commented that:

When you are older, medical people don't think that you have too long to live and push you aside and make way for younger people.

If you are aging you are dismissed more...you are getting older so this is part of the aging process...it is nothing to worry about.

3. HIV-Specialist or Aging-Specialist: Which is More Important?

The literature reviewed indicated a lack of knowledge on the part of health care providers about aging and HIV that translated into potentially limiting access to medical services for older adults. To further investigate access to services, participants' perceptions regarding the importance of primary health care providers having an aging or HIV-specialty for treating infected older adults were collected.

As shown in Table 8, most (n=23; 68%) of the sample indicated that it was more important for health care providers to have a knowledge of aging-related issues rather than a specialty in aging or solely a specialty in HIV. One participant in the older adult group did not express an opinion.

Table 8. Necessary Medical Specialty

Medical Specialty	Age Group							
	30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
	n	%	n	%	n	%	n	%
HIV-specialty	5	45	0	0	0	0	5	15
Aging-specialty	1	9	2	18	2	17	5	15
Aging-related Knowledge	5	45	9	82	9	75	23	68
Do Not Know	0	0	0	0	1	9	1	3

As can be seen in Table 8, only participants aged 30 to 39 felt that it was important to have an HIV-specialty. These five participants thought that age did not make a difference when treating HIV although one noted that it was more important to focus on the treatment of younger adults. However, the remaining six participants in their thirties who indicated that there was a need for physicians to have aging-related knowledge identified three reasons they felt this way. Firstly, they wanted someone to care for them when they were old. Secondly, they found that they could not answer older adults' medically related questions because they have not had experience with the same issues. Thirdly, they thought that long-term survivors faced different medical problems than individuals who had been infected for shorter periods of time and would need a different type of care.

Although there was little difference in the proportion of participants aged 40 to 49 and 50+ who felt that an aging specialization or an aging-knowledge was important, their comments were notably different. Those aged 40 to 49 indicated that health care providers needed to deal with older adults differently than younger adults because older adults had different life experiences and require certain

sensitivity when providing care. Further, they felt that older adults faced many other medical concerns such as tooth loss, arthritis, diabetes and other common age-associated ailments that HIV-physicians have not yet had to address and treat because in the past, infected populations had not lived so long. Appreciating that infected people are living longer and that they themselves expected to live into their fifties, participants aged 40 to 49 wanted someone there to care for them when they were older. Participants 50 and older felt that there was value in having a health care provider knowledgeable in aging-related issues first because they felt that the issues facing infected older adults were different than those faced by younger adults. For example, medication toxicities and tolerances and social and emotional feelings of shame and guilt are different between age groups and can affect health care issues. Older adults indicated that:

Eventually infected older adults would be the majority.

The demographic is getting bigger and physicians need to understand what is aging and what is HIV and currently, physicians do not know that much about aging and HIV.

HIV/AIDS is going into its 30th year so all those diagnosed in the early epidemic, if not dead, are old...there is a different attitude and dialogue with older people.

Second, four older participants felt that there was a link between HIV and aging that was not yet established with physicians lacking the knowledge necessary in caring for them. Specifically, one older adult indicated that:

Physicians have this idea that you are aging and what your problem is, is related to aging, they don't know if your problem is related to HIV or aging or both.

4. The Need to Target Medical Services to Older Adults

In order to assess limitations in access and whether or not there was a need to target medical services specifically to older adults, participants were asked if they thought existing HIV/AIDS-medical services targeted any group(s) in particular and if there was a need to target medical services to older adults.

Participants in each age group indicated HIV/AIDS medical services and organizations targeted several groups including: everyone, youth, those between 19 and 24 years of age, gay men, women and HIV-infected individuals. None of the participants indicated that medical services specifically targeted older adults.

As shown in Table 9, half of the sample (n=17; 50%) felt that there was a need to specifically target medical services to infected older adults, slightly less than one-half of the sample (n=15; 44%) felt that there was not a need and two (17%) participants were unsure.

Table 9. Is There a Need to Target Medical Services to Older Adults?

Need to Target Older Adults	Age Group							
	30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
	n	%	n	%	n	%	n	%
Yes	5	45	5	45	7	58	17	50
No	6	55	6	55	3	25	15	44
Not Sure	0	0	0	0	2	17	2	6

Participants in their thirties who felt that there was no need to target older adults felt that services should target everybody equally, or with no particular emphasis on one group or another. Others felt that "HIV was HIV" for any age group and that age was not an issue in treating older adults as their medical concerns would be the same as any other individual. One thirty-four year old indicated that there was no need to target medical services to older adults indicating that it was his age group that was dying and that needed the help; older people were lucky if they were still alive. Alternately, participants in their thirties who felt that medical services should target older adults did so because they felt that older people, who for example are single, and who live alone, are unable to access personal informal medical care. One participant stated that he had infected friends over the age of fifty who were asking him medically related questions that he could not answer and as a result, he felt that that there was a need for services that could address these issues. While participants aged 40 to 49 shared similar views to those in their thirties, they also commented that common medications taken by all ages, such as protease inhibitors which prolong life, are known to be toxic to one's body and more particularly, an older person's body. One participant indicated that:

Because older people have by nature older bodies and organs, specific medications could be toxic and the medications prescribed for a twenty-four year old may not be appropriate for a fifty-four year old.

Participants felt that there was a need for medical services to understand the connection between treatment and aging associated issues and thus a need for medical services to be targeted to older people.

Older adults felt that it was important to have specific medical services for their age group because:

Not all people diagnosed in the early years of the epidemic are dead and instead people are living longer and there will be long term chronic illnesses such as dementia, cancer and pneumonia which seem to hit older people faster.

You are dealing with people with older organs who are living longer.

There is an empty void of services to older people.

There is, and will be, a need for medical care staff who treat and care for infected individuals who require catheterization, tube feeding, intravenous and other medical assistance commonly associated with aging but not necessarily associated with nursing home or formal placement. The needs among those who are 50 and older are so diversified that it is necessary to have something in place to help meet and address them.

As time goes on, doctors will have to deal with geriatrics and the HIV-specialist should have some competence in aging.

In addressing a link between informal and formal care and support, one older adult indicated that:

Single older adults who live alone and/or who have lost their partner to the disease will need someone to help them with their own care. Older infected individuals within a couples type relationship are in a better position as they have one another to depend upon and to receive informal medical support from whereas once the relationship ends or fails to exist, the older adult is left alone and to care for themselves. There is a need therefore for medical professionals to not only care for them but to address and understand their unique issues that occur as a result of the loss.

C. Access to HIV/AIDS-Specific Social Supports and Social Organizations

1. Social and Emotional Support Accessed

Participants were asked to identify the sources from which they accessed a) social or emotional support, and b) organizations which offered HIV/AIDS-related social services and programming.

As shown in Table 10, the total sample accessed an average 1.8 social and emotional supports to help cope with being infected (range = 0-5 supports).

Table 10. Mean Number of Social Supports and Social Services Accessed

Number of Social Supports and Services	Age Group			
	30s (n=11)	40s (n=11)	50+ (n=12)	Total (n=34)
Mean Number of Social Supports Accessed Range of Social Supports Accessed	1.6 0-4	1.9 1-4	1.9 0-5	1.8 0-5
Mean Number of Social Organizations Accessed Range of Social Organizations Accessed	2.6 1-6	2.5 1-4	2.1 1-4	2.4 1-6

Table 10 indicates that older adults accessed a similar average number of social and emotional supports as those aged 40 to 49 and a greater average number of social and emotional supports than those 30 to 39. Individuals aged 30 to 39 accessed the fewest number of social and emotional supports with an mean of 1.6 supports (range = 0-4) whereas participants aged 40 to 49 and those 50 and older accessed an equal number of emotional and social supports (mean=1.9, range = 1-4 and 0-5 respectively). Table 11 indicates that there were no statistically significant differences between the groups in the number of social and emotional supports accessed.

Table 10 depicts the number of social organizations accessed by each age group. Individuals aged 30 to 39 accessed the most social organizations with an mean of 2.6 organizations (range = 1-6) whereas participants aged 40 to 49 accessed an average of 2.5 organizations (range=1-4) and those 50 and older accessed an average of 2.1 organizations (range=1-4). The sample accessed an average of 2.4 social organizations with a range of 1 to 6. As shown in Table 11, there was a statistically significant difference in the number of social organizations accessed between the 50 and older group and those 30 to 39 ($t=1.35$, $df=21$, $p<.10$).

Table 11: Student's t-test for Between Age Group Access to Social/Emotional Support and Social Organizations

Variables	Age Group	Student's t-test	
		t-score	df
Social/Emotional Supports Accessed	50+; 30-39	.94 (ns)	21
	50+; 40-49	.21 (ns)	21
Social Organizations Accessed	50+; 30-39	1.35 *	21
	50+; 40-49	1.1 (ns)	21

* $p<.10$

Social and emotional supports are shown in Table 12 and are classified into the four categories shown in order to examine the type accessed (organized, unorganized, macro and micro) by age group. Unorganized micro-supports included support of an informal nature provided by partners, family and friends, whereas organized micro-supports included supports from organized or formal entities such as one's health care provider, therapist or support groups. Organized macro-supports included established formal organizations that mandated support or services for infected individuals as a whole, while unorganized macro-supports catered to infected and non-infected individuals and were not formalized or mandated.

Table 12. Social and Emotional Support Accessed

Category	Support Source*	Age Group							
		30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
		n	%	n	%	n	%	n	%
Unorganized Micro-Support	Partner/Significant Other	3	27	4	36	4	33	11	32
	Friends/Roommates	6	55	5	45	5	42	16	47
	Family	2	18	4	36	4	33	10	29
	Loner (Nobody)	4	36	0	0	1	8	5	15
	Prescription Drugs	0	0	1	9	0	0	1	3
Organized Micro-Support	Health Care Provider	1	9	0	0	0	0	1	3
	Psychiatrist/Psychologist or Social Worker	3	27	0	0	2	17	5	15
	Occupational Therapist	1	9	0	0	0	0	1	3
	Support Groups	0	0	0	0	1	8	1	3
Organized Macro-Support	Fife or McEwan House	0	0	1	9	1	8	2	6
	Casey House	0	0	1	9	1	8	2	6
	YMCA	0	0	0	0	1	8	1	3
	Persons with AIDS Foundation (PWA)	0	0	4	36	2	17	6	18
	AIDS Committee of Toronto (ACT)	0	0	3	27	1	8	4	12
	Church	0	0	0	0	1	8	1	3
Unorganized Macro-Support	Gay Community	1	9	0	0	2	17	3	9

* Multiple responses were permitted.

As shown in Table 12, a greater number of study participants accessed unorganized micro-supports than organized micro-supports or organized and unorganized macro-supports. Just under one-

half of the sample (n=16; 47%) accessed social and emotional support from their friends or roommates. Other highly accessed social and emotional supports included family (n=10; 29%) and partners or significant others (n=11; 32%). All three age groups accessed some form of unorganized micro-support whereas not all age groups accessed the remaining three support categories.

There was a notable difference in the proportion of adults age 30 to 39 who were loners and who accessed a psychiatrist compared to other age groups. A greater proportion of those in the youngest age group than the other two age groups, were loners and sought support from a psychiatrist. Also notable was the greater proportion of participants aged 40 to 49 than the other two age groups who accessed PWA and ACT.

There were notable differences amongst the three age groups in the overall type or category of social and emotional support accessed. Participants aged 30 to 39 predominantly accessed unorganized and organized micro and unorganized macro-support services whereas participants aged 40 to 49 predominantly accessed unorganized micro and organized macro social and emotional supports. Participants 50 and older exhibited the greatest diversity of social and emotional supports compared to each of the younger aged groups accessing services within each category.

2. Social Organizations Accessed

Participants were asked to indicate what social service organizations they accessed which helped them cope with being HIV-positive. Findings are presented Table 13. Organizations were divided into two major categories; HIV/AIDS-Service Organizations and Community Based Non-HIV/AIDS Specific Organizations.

Table 13. Social Service Organizations Accessed

Category	Organization*	Age Group							
		30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
		N	%	n	%	n	%	n	%
HIV/AIDS-Service Organizations Everyone	Persons with AIDS Foundation (PWA)	10	91	7	64	7	58	24	71
	AIDS Committee of Toronto (ACT)	6	55	7	64	7	58	20	59
	Hamilton AIDS Network (HANDS)	1	9	3	27	1	8	5	15
	Casey House	1	9	1	9	1	8	3	9
	Fife/McEwan House	0	0	3	27	2	17	4	12
	HIV & AIDS Legal Clinic (Ontario)	1	9	1	9	2	17	4	12
Families	Teresa Group	2	18	1	9	0	0	3	9
Men Only	Positive Straight Men	1	9	0	0	0	0	1	3
Women Only	Voices of Positive Women	1	9	0	0	1	8	2	6
Ethnic Groups	2 Spirited People of the 1st Nation	1	9	0	0	0	0	1	3
	PASAN	2	18	0	0	0	0	2	6
	ASAP	1	9	0	0	0	0	1	3
	Black Cap	1	9	0	0	0	0	1	3
Community Based Non-HIV/AIDS Specific Organizations	Community Centre	0	0	0	0	1	8	1	3
	YMCA	0	0	0	0	3	25	3	9
	Social Clubs	0	0	0	0	2	18	2	6
	Churches	0	0	2	18	1	8	3	9

* Multiple responses were permitted.

As shown in Table 13, participants accessed more HIV/AIDS-social service organizations than non-HIV/AIDS-specific organizations. The predominant service organizations accessed were PWA which almost three-quarters of the sample (n=24; 71%) accessed and ACT which was accessed by more than one-half (n=20, 59%) of the sample. Both were well known and comprehensive HIV/AIDS-service organizations within Toronto.

There was a notable difference between the range and types of social service organizations the three age groups accessed. Participants age 30 to 39 accessed the greatest variety of HIV/AIDS-service organizations. Participants age 40 to 49 accessed the least variety of HIV/AIDS-service organizations.

Older adults accessed HIV/AIDS-service organizations providing services to everyone and women only in addition to community based non-HIV/AIDS-specific organizations.

As age increased there was a notable decrease in the number of participants who accessed PWA. Almost all (n=10; 91%) participants aged 30 to 39 accessed PWA compared to just over one-half of both those aged 40 to 49 (n=7; 64%) and those 50 and older (n=7; 58%).

There were no notable differences between age groups in their access of gendered or ethnic HIV/AIDS-service organizations. However, there was a notable difference in the proportion of each age group that accessed the YMCA with 3 (25%) of the older adults accessing this service compared to none of the 30 to 39 and 40 to 49 year old adults.

3. Social and Emotional Relationships

To further investigate access to social services, namely informal services or social/emotional supports, participants were asked how their relationships with friends and family had changed since they had been diagnosed. It was hoped that the responses would provide additional information pertaining to the social structure maintained by infected individuals.

As shown in Table 14, more than one-third of the total sample (n=12; 35%) indicated that their relationship with their family had improved since diagnosis, just under one-half (n=14; 41%) indicated that their relationships had remained the same and less than one-quarter (n=6; 18%) indicated that their relationships with family had diminished since diagnosis. Two participants indicated that relationships had both improved and diminished with family since diagnosis.

Table 14. Changes in Personal Relationships Since Diagnosis

Category	Relationship Status	Age Group							
		30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
		n	%	n	%	n	%	n	%
Family	Improved	3	27	5	45	4	33	12	35
	Remained the Same	2	18	5	45	7	58	14	41
	Diminished	4	36	1	9	1	8	6	18
	Improved and Diminished	2	18	0	0	0	0	2	6
Friends	Improved	0	0	3	27	NA		NA	
	Remained the Same	4	36	2	18	NA		NA	
	Diminished	3	27	3	27	NA		NA	
	Improved and Diminished	4	36	3	27	NA		NA	

There was a notable increase with increasing age in the proportion of participants reporting that relationships with family remained the same since diagnosis. More than one-half of those 50 and older (n=7; 59%) gave this answer compared to five (45%) of those aged 40 to 49 and two (18%) of those 30 to 39. Participants in the 30 to 39 age group, were more likely to report a diminished relationship with family.

Table 14 provides information about relationships with friends since diagnosis for the 30 to 39 and 40 to 49 age groups. Information pertaining to the older adults' relationship with friends could not be quantified and instead is described below.

Unlike infected younger adults, older adults were unable to provide clear responses about how their relationships with friends changed after having been diagnosed with HIV. Instead, they indicated that it was difficult to make friends and get close to other people for several reasons. First, infected older adults tended to associate with other infected older adults. However, infected adults died which became more noticeable as one grew older and subsequently became a survivor. One participant indicated that at older ages it was difficult to cope because more and more people in the gay community were dying and the number of potential friends diminishes. Second, older adults commented that despite wanting to make friends, it was difficult for HIV-positive and HIV-negative people to become friends for the following reasons:

Gay men are difficult to get to know.

Due to a lack of understanding, HIV-negative gay men want nothing to do with HIV-positive gay men.

You need complete understanding...it becomes painful for both, understanding is difficult.

The latter comment referred to the knowledge and level of sympathy and comfort HIV-negative men had with HIV-positive status and infected individuals, particularly intimately. The difficulty in friendship development between HIV-positive and HIV-negative adults was further supported by a 65 year old female who did not know any other older infected women. She was only able to socialize with older infected gay men and younger infected women. Third, older participants felt that it was difficult to break into a younger age strata and get to know people as an older person because the gay community was one of youth. Fourth, the issue of long-time friendships arose as participants indicated that they had lost friends due to the disease and felt that:

It is difficult to make friends in your own age group because you don't have a history with them.

4. Isolation

Study participants were asked if they felt isolated and the reasons for their isolation in order to determine if and how isolation related to accessing services. If someone felt isolated, it was expected that they would have had difficulty accessing the services they required to cope with being infected.

As shown in Table 15, more than one-half of the sample (n=20; 59%) indicated that they felt isolated. As age increased, the proportion of participants who felt isolated decreased. Almost three-quarters of those aged 30 to 39 (n=8; 73%) felt isolated compared to seven (64%) of those aged 40 to 49 and five (42%) of those 50 and older.

Table 15. Felt Sense of Isolation

Feel Isolated	Age Group							
	30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
	n	%	n	%	n	%	n	%
Yes	8	73	7	64	5	42	20	59
No	3	27	4	36	7	58	14	41

As shown in Table 16, the twenty study participants who felt a sense of isolation indicated six reasons why they felt this way. Personal reasons leading to isolation were noted by eight (40%) of the participants, whereas five participants (25%) felt isolated from friends, four (20%) felt isolated from the gay community, two (10%) felt isolated from educational opportunities and one (5%) each felt isolated from family and social programs.

Table 16. Causes of Isolation

Isolation*	Age Group							
	30s (n=8)		40s (n=7)		50+ (n=5)		Total (n=20)	
	n	%	n	%	n	%	n	%
Friends	3	38	1	14	1	20	5	25
Family	1	13	0	0	0	0	1	5
Gay Community	0	0	1	14	3	60	4	20
Social Programs	0	0	1	14	0	0	1	5
Personal Reasons	2	25	4	57	2	40	8	40
Education	2	25	0	0	0	0	2	10

* Multiple responses were permitted.

There was a notable difference in the proportion of participants in each age group who felt isolated from the gay community. A greater proportion of older adults (three) felt isolated because of characteristics associated with the gay community than did younger adults. Older adults indicated that fatigue, wasting and bloating commonly associated with recurring illness and medication cocktails discouraged them from going out in public. Further, these older adults felt that when they told others about their HIV-positive status, even individuals in the gay community did not want to be associated with them. Two participants felt that due to a lack of illness related education, there would always be judgment against older adults, even in the gay community, as having made a bad decision and subsequently acquired HIV at such an advanced age.

5. The “Gay Community”, Isolation and Service Access

Although not addressed during the interview, characteristics of the gay community in Toronto were described which were considered to have a potential impact on participants’ ability to access services.

As age increased, there was an increase in the proportion of participants who mentioned that characteristics of the gay community limited their access to services or were in some way isolating. All older adults commenting on the gay community felt that it was a community based on youth, beauty and HIV-negative status; anything different was socially unacceptable. Comments from three older adults included:

There is lots of ageism...suddenly you feel you are a non-person because you are older.

You feel older than everyone else because the community is young, blond and blue eyed...you feel old in the community.

There is discrimination within the HIV and gay population and there is discrimination with age...the older people are not treated as well as the younger people.

Some older participants stated that there was a stigma and a fear of unacceptance even within the gay community with being HIV-positive and because the gay community is knowledgeable about symptoms associated with infection such as looking thin, lesioned, bloated or wasted, one is stereotyped. These participants stated that:

The community is not an HIV-community, only a gay-community where people with HIV live. Some people in the gay community will isolate you because of the way you look...you always want to look your best and if you don’t, you don’t go out to the gay community.

HIV is a death sentence...nobody in the community wants to talk to you, even in the gay community if you are HIV-positive.

The community is not educated enough and you don’t tell people within the community about your status because of the stigma, they will think you are a bad person, similar to the stigma associated with being an alcoholic; you are a bad person because you are an alcoholic... you feel pushed back from people.

Your peers will look at you and say...you stupid fool, how could you at your age? You should know better.

Alternately however, some infected older adults felt comfort within the gay community indicating that it was an ideal place to live. Connection and involvement with the gay community was viewed as helpful because:

The community is composed of a tightly knit group of individuals and people can belong to many different groups.

It is not necessary to be young to be a part of a young group, or old to fit in with an old group. Individuals could find their way into different social groups if they wanted to.

One participant indicated that he didn't know what he would do if he wasn't a part of, or connected to the gay community because being connected allowed him not to feel left out. Another older adult added that infected individuals living in rural areas would have difficulty accepting and dealing with an HIV-positive status. The likelihood of being connected to a cohesive group like the gay community in Toronto is less, particularly if one was heterosexual and part of an established family.

Two participants aged 40 to 49 supported comments offered by the older adults with respect to the gay community being one of youth, beauty and HIV-negative status adding that people in the community treat older people poorly, viewing them as "trolls" and unwanted.

Everybody in the "culture" is 22 or 24 and homosexual. Anything over the age of thirty is old...the culture is about youth – pretty boys, and dictates an older person as 30.

In order to be a part of the gay community one participant indicated that it was necessary to fit into a certain social group such as a "butch" [*plaid wearing male*], a "queen" [*male behaving like a flamboyant female*], or a "twink" [*also known as a pretty boy*]. Older adults may have experienced difficulty in fitting in with these groups as they were modern social classifications typically attributed to younger gay men.

6. The Need to Target Social Services to Older Adults

Participants were asked if they thought that organizations providing social services to infected individuals targeted any specific group and whether they felt that there was a need to provide HIV/AIDS-related social services and programs specifically to infected older adults. It was expected that the former question would give insight into any gaps within social service provision whereas the latter question would investigate the perceptions different age groups had about the service needs of older people.

There was consensus among the three age groups that the HIV/AIDS-related service organizations and programs did not target any groups in particular other than youth. As shown in Table 17, more than three-quarters of the sample (n=26; 76%) felt that there was a need to provide social services that included support groups and activities for infected older adults. Further, more than one-half of each age group felt that there was a need to provide social programs specifically for the older person.

Table 17. Is There A Need to Provide Specific Social Services for Older Adults?

Age Group

Need to Provide Specific Services	30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
	n	%	n	%	n	%	n	%
Yes	7	64	9	82	10	83	26	76
No	4	36	2	18	2	17	8	24

As age increased there was a slight increase in the proportion of participants who felt that there was a need to provide specific social programs for older adults. Reasons were as follows. First, they felt that:

There are not enough social activities for us, instead services are geared to younger people who have the disease.

It is getting to the point where it may be necessary to provide social programs for older people because as time goes on, more people will be living longer and there will be a need to provide targeted services. Services now are geared to the young-this is a normal social barrier.

Second, there were sub-groups that were currently left out or forgotten about by social services such as those who were single and those who were still economically contributing members of society. One participant indicated that services within Toronto were geared to those living in the city, who were collecting income assistance and who had acquired HIV through homosexual activity, lived in subsidized housing and were unable to work. Infected older adults still employed, living outside of Toronto, whether heterosexual or homosexual, were not able to access the same services as those provided to similar aged and infected adults living in Toronto. Also, older adults who did not have a significant other to count on and look to for support were at a disadvantage and required supportive or social services to help them cope. Older adult couples were thought to be at an advantage when compared to single older adults because they would have one another to turn to. It was commented that:

With increasing age, social networks diminish and friends and significant others begin to die, and progressively with HIV/AIDS. Older adults in a single situation will need the extra help.

Third, infected older adults had different social needs than younger infected adults and therefore needed different social services. These older adults proposed that:

There is a different lifestyle with older people, they were brought up differently, with stigma and shame around sexual behaviors and HIV. They grew up with a different philosophy.

Older people tend to be more serious and exhibit greater responsibility than younger adults and as a result, require different social services.

Older people need social activity oriented services more so than support oriented services such as leisure and recreational outings.

Basic social events, things that keep older people occupied are lacking, for example, when you join groups like a reading group put out by_____, I am the granddaddy of the group.

It was felt that basic social events, activities and services were missing from the existing range of social services offered and would have a positive effect on older adults' ability to cope compared to support group settings where discussions revolved solely around disease.

Fourth, older participants felt that there was value in providing social services that catered to older adults only, rather than to a mix of age groups. Particularly, they indicated that people like to stay within their own age group and that there was a need to separate older and younger people because their issues were different. On the other hand, one older adult suggested that it would be valuable to have a mixture of ages within social services and programs so that the young and the old could learn from one another.

Participants aged 40 to 49 echoed many of the older adults' views. These individuals commented that with aging, there was a normal a loss of friends and that with HIV/AIDS, the loss accelerates. Older people required assistance in coping with loss because if there were no specific services that could address the older person's needs, older people would become isolated and shut-ins. It was also felt that there was a need for more recreational and social activities to be offered to older people because although there were services that could meet the counseling needs of older adults such as support groups geared to all ages, recreational activities were infused with, and tended to target younger adults. Having recreational and social outings for older adults was considered beneficial because older adults could feel comfortable amongst their own age group. One participant noted that his age group was not dying and that there would be many more long living infected older adults and that social services would need to be available for older adults in the future. Another suggested that many gay men believe that life ends at fifty and one's ability to meet new people diminishes; servicing the older adult group would change their perception.

Participants aged 40 to 49 also believed that older adults could benefit from targeted social service programming because they had a different attitude about the disease. Typically, older adults

have come to terms with being infected because they have already lived most of their life, accomplished many of the things they had intended to accomplish and had lived long enough with the disease to learn to appreciate life. Younger adults on the other hand, upon being diagnosed, believed that life was over and that they were going to die right away. Also, older adults would have already experienced many of the issues that the younger person was experiencing and in situations where the support group members were younger, they noticed frustration among older adults in revisiting issues they had already experienced.

Of the small proportion of study participants aged 30 to 39 who felt that older adults should have specific social services targeted to their age group, three reasons were provided. First, infected older adults were viewed as more fragile, physically and mentally, compared to younger adults who were viewed as stronger and healthier. Second, it was felt that older adults and younger adults dealt with separate issues. Many older adults for example, had so many friends and loved one's die that they needed the extra social support. Third, one participant felt that older adults experienced HIV-burnout and became complacent. Although stating that specific social services were required for older adults, participants indicated that these services should not be all that different from those provided to younger adults because essentially "HIV was HIV" for everyone at any age.

The remainder in this age group did not feel that there was a need for social services specifically for older adults. Instead, they felt service provision should be based on need and that if the need was there, then so should the service be. Further, they felt that it would be more beneficial to integrate infected older and younger adults within social services. That way, younger adults could learn from older adults who were perceived as wiser, more mature and open to sharing and who had more common sense and a better perspective on life.

D. Barriers to Accessing Medical and Social Services

Participants were asked to indicate barriers that affected their ability to access medical and/or social services. As shown in Table 18, the sample reported an average of 1.4 barriers (range=0-5) to accessing services.

Table 18. Mean Number of Barriers to Accessing Services

Number of Barriers to Accessing Services	Age Group			
	30s (n=11)	40s (n=11)	50+ (n=12)	Total (n=34)
Mean Number of Barriers Reported	1.5	1.5	1.25	1.4
Range of Barriers Reported	0-5	0-4	0-4	0-5

Table 18 indicates that the older adult group compared reported fewer barriers (1.25, range=0-4) to accessing services than either those age 30 and 39 and those age 40 to 49 (1.5, range=0-5 and range=0-4 respectively). As shown in Table 19, there were no statistically significant differences in the number of barriers reported between the older and younger aged groups.

Table 19. Student's t-test for Between Age Group Barriers to Accessing Services

Variable	Student's t-test		
	Age Group	t-score	df
Barriers to Accessing Services Reported	50+; 30-39	.44 (ns)	21
	50+; 40-49	.65 (ns)	21

Barriers to accessing services were categorized into organizational, individual, societal and informational and are shown in Table 20. Almost one-half of the sample (n=15, 44%) considered a lack of income to be a barrier to service access. Participants commented that although income assistance from the provincial disability program was sufficient to pay monthly bills and necessary expenses, it was not sufficient to allow participants to enjoy small pleasures or benefits such as a cup of coffee at the local coffee shop, tickets to various functions and/or alternative and complementary therapies, therapists, vitamins and other nutritional supplements they perceived as necessary for their health status. Almost one-third of the sample (n=10, 29%) indicated that they did not experience any barriers to accessing services. Approximately one-quarter of the sample (n=8; 24%) indicated that a lack of available information, existing misinformation, uncoordinated information or a lack of education about how, where and what services to access limited, or could limit one's access to services.

Table 20. Barriers to Accessing Services

Category	Barrier*	Age Group							
		30s (n=11)		40s (n=11)		50+ (n=12)		Total (n=34)	
		n	%	n	%	n	%	n	%
Organizational	Lack of Service	1	9	0	0	1	8	2	6
	Physician/Hospital Questions	0	0	0	0	2	16	2	6
	Operation Hours	3	27	1	9	1	8	5	15
	Service Location	1	9	1	9	1	8	3	9
	Ethnic Target/Others Attending	2	18	0	0	0	0	2	6
Individual	Illness/Fatigue/Personal Reasons	2	18	2	18	1	8	5	15
	Lack of Income	3	27	6	55	6	50	15	44
	Transportation	3	27	2	18	1	8	6	18
	No Barrier	5	45	2	18	3	25	10	29
Societal	Gay Community Judgment	0	0	1	9	1	8	2	6
Informational	Lack of Information/Education	1	9	2	18	5	42	8	24

*Multiple responses were permitted.

There were no notable differences between the proportion of participants in each age group with respect to experiencing organizational and societal barriers that could limit one's ability to access services.

There was a notable difference in the proportion of participants in each age group who reported characteristics associated with available information as barriers to accessing services. A greater proportion of older adults mentioned a lack of available and coordinated information about HIV, existing misinformation and a lack of education in knowing how, what and from where to access information compared to participants aged 30 to 39 and 40 to 49. However, older adults explained that this did not necessarily limit their own access to services but it limited access for people in general.

CHAPTER IV

Qualitative Analysis

Access to HIV/AIDS-related medical and social care and services was investigated and two exploratory research questions were investigated with the assistance of the Medical and Social Services Access Model framework. The model proposed that individual determinants and characteristics of the medical and social services systems servicing infected individuals would influence their ability to access necessary services required to cope with being infected. The following summarizes the older adults' ability to access medical and social services as it relates to the research questions and explains the outcome through qualitative interpretation.

A. Research Question 1:

Are infected older adults limited in their ability to access, or unable to access HIV/AIDS-related medical and social services necessary in coping with their disease?

1. Individual Determinants

It was expected that infected older adults who lived alone and who were single would be limited in their ability to access informal medical and social care and services because at advanced ages, available family and friends capable of providing the support tend to diminish (Mitchell & Krout, 1998; Nocera, 1997). In this study, older adults had a social structure that facilitated access to informal social and medical services. Although all the older adults were single and three-quarters lived alone, they had relationships with family members that mostly remained the same and for some improved since diagnosis. Additionally, they accessed a variety of social and emotional supports to help them cope with their disease. Older adults did however, have difficulty developing friendship-relationships due to their own fears of losing another friend to the disease and an HIV-positive phobia, and focus on youth within the gay community. Further, some older adults reported feeling isolated but related this isolation to characteristics associated with the gay community, which to some degree, compromised their desire to go out in public to access services. The isolation was, however, not a result of an inability to access services.

Older adults in this study did not experience limitations in accessing health-related information. They were knowledgeable about their illness and knew exactly where to obtain services. They accessed a variety of personal and organized medical services and obtained health information from several dedicated and non-dedicated HIV/AIDS-avenues such as physicians and clinics, the internet and gay magazines. All older adults accessed services and information sources which were well known, respected, multi-faceted and focal points of service delivery, such as the AIDS Committee of Toronto and the Persons with AIDS Foundation which act as an information and service clearinghouse for infected individuals.

Income was highlighted as a barrier that limited access but only to secondary medical and social services. Specifically, all older adults receiving income assistance from the Ontario Disability Support Program and the two participants collecting private insurance were able to access primary medical services including a necessary health care provider, an HIV-specialist, hospital and/or clinic. Further, all medications required in managing the illness were covered by the provincial drug plan and therefore, were available at no expense to the infected older adult. Medical services of a secondary nature such as massage therapy, chiropractors, vitamins and supplements and psychiatrists were more difficult to access because the associated fees were not covered by the provincial program. However, volunteer massage therapy, chiropractic services and vitamin disbursement were regularly provided by local HIV/AIDS-service organizations at no cost to individuals. Lack of income did at times limit access to social programs and services. However, some activities requiring small fees such as those offered by the local YMCA and social clubs were accessed by the older adults.

Access to medical and social services was not limited by geographic location. All but one of the participants lived within the gay community of Toronto that harbours a concentration of the medical and social services required by infected individuals. The one older adult living in Hamilton knew where the services within both Hamilton and Toronto were located and accessed them easily and at no cost as most services had a 1-800 number. Despite the fact that Toronto and Hamilton had few services specifically for older adults, older adults in this study accessed a variety of services geared to persons of all ages, ethnic groups and both genders.

The need for services determined the older adults' access to service. Older adults indicated that if they needed a service they would access it and assumed responsibility for doing so. In general, they

accessed what they felt they needed and should there have been services available that were perhaps more difficult for them to access, the older adults indicated that they would find a way to access them.

2. Societal Determinants

Societal determinants although part of the Health Services Utilization Model (Andersen & Newman, 1973), but excluded from the Medical and Social Services Access Model due to inappropriate defining characteristics, proved to be valuable in assessing the older adults' ability to access services. Instead of utilizing the Health Services Utilization Model's "norms" and "technology", the norms and stereotypes associated with aging and HIV-status held by the gay community were most important. These norms and stereotypes limited, or in some way threatened some of the older adults' ability to access services. According to the study participants, the gay community accepts young, healthy and HIV-negative people but discriminates against those who are older and HIV-positive. Some of the older adults were apprehensive about going out in the community because they felt old and ashamed of their HIV-positive status but their apprehension did not limit their ability to access the services they needed. Further, older adults in this study indicated that the gay community was knowledgeable about the symptoms associated with HIV-infection and was unwelcoming to those who exhibited infection-related characteristics. Most older adults in this study as a result, felt the dual stigma of aging and HIV/AIDS referred to in the literature review. However, some did not experience these feelings and felt well connected to the gay community.

3. Social and Medical Service Systems Characteristics

With respect to addressing components of the service systems included within the Medical and Social Services Access Model, older adults were able to access both the medical and social services they needed to cope with their illness. First, within Toronto and to some degree Hamilton, there were many HIV/AIDS-related medical and social services. Older adults accessed a host of these despite the fact that there were very few specifically targeted to infected older adults.

Second, all older adults reported positive experiences with accessing medical service organizations and health care professionals. Specifically, more than three-quarters of the older adults in this study felt that their health care provider was knowledgeable about their illness and interested in promoting their health. Further, they felt that for the most part, they had enough time with their health

care provider except during cold or flu seasons when many people became ill and required medical attention.

Based on the literature reviewed, it was expected that aging-related stereotypes held by physicians would limit the older adults' access to medical services. Some of the older adults expressed concern that some physicians maintained some of these stereotypes and that they were unable to accurately differentiate symptoms associated with aging and HIV. However, despite their concern, they did not feel limited in accessing medical services.

In summary, older adults in this study were able to access the medical and social services they needed to cope with their disease. They were not limited in their access to necessary services by individual determinants such as income, social structure, and geographic location nor by characteristics of the services systems such as service availability, volume, distribution and quality which included physician knowledge, interest and time. However, to some degree, some older adults felt limited in their ability to access medical and social services due to aging and HIV-related stereotypes held by the gay community within which most of the older adults lived.

B. Research Question 2:

Are infected older adults less able to access HIV/AIDS-related medical and social services necessary in coping with their illness disease than infected younger adults?

1. Medical Services

Like younger aged participants, older adults in this study accessed both personal medical care services provided by primary health care providers and therapists and organized medical care offered through medical clinics. Further, they accessed several of the same medical and health information sources accessed by the younger age groups and were active in conducting their own health information research through libraries, research literature and the internet. Older adults in this study however, accessed on average, fewer medical and health information sources than younger aged adults.

Older adults were as able to access both medical organizations and health care professionals as younger adults. Most, if not all of the older adults reported positive experiences in accessing medical organizations and health care professionals and more older adults than younger aged adults had an HIV-specialist. Further, similar to the younger adults, the older adults felt that their health care providers

were knowledgeable and interested in promoting their health. In comparison to younger adults however, a greater proportion of older adults felt that their health care provider was as interested in promoting their health as they would be a younger person's health. All three age groups indicated that there were occasions when they felt that did not have enough time to interact with their health care provider. More older adults than younger adults reported this experience but the older adults were more understanding given that these instances occurred during flu outbreaks when there was a greater demand for medical attention.

More older adults than younger adults in this study had participated in experimental drug trials and two were doing so currently. Findings from this study showed that older adults were more involved, or had participated in HIV/AIDS-related research other than drug trial research compared to the younger aged adults.

It was anticipated that aging and HIV/AIDS-related stereotypes held by the medical community would limit an older adult's access to medical services more so than for infected younger adults. However, older adults in this study were no more, nor no less likely to report HIV-stereotypes limiting their access to medical services than younger aged adults. Some older adults however, did feel that aging-stereotypes limited their access to services but based this upon the gay community's affection for youth and its lack of regard for older people.

2. Social Services/Organizations and Supports

Infected older adults overall, had access to, and accessed the same types of social and emotional supports as infected younger adults. Further, older adults accessed the same number if not more social and emotional supports than younger age adults but fewer social organizations. The types of organizations accessed were also similar across age groups: all age groups accessed both organized and unorganized micro or individual-related social supports, and organized and unorganized macro or community based supports. In comparison to the younger age groups, older adults accessed a greater variety of social and emotional supports. Older adults had access to informal social and emotional supports such as friends and family and many had existing and improved relationships with family members since diagnosis. The reviewed literature indicated that older adults report feeling isolated and closeted as a result of being HIV-positive and it was therefore expected that if they felt isolated, their access to services would be limited or they simply would not access services. Findings from this study

indicated otherwise in that fewer older adults than younger adults reported feeling isolated and isolation was not a function of limited access to services.

It was expected that older adults would not be able to access social organizations as effectively as younger adults because of a lack of available services and programs targeted to the older age group. When compared to younger adults, older adults did access fewer social organizations but they accessed both HIV/AIDS-service organizations mandated to serve all age and ethnic groups and non-HIV/AIDS-specific organizations which offered services for HIV-positive individuals such as the YMCA, social clubs and churches; the younger age groups did not access the latter services.

3. Barriers to Access

Older adults reported similar although on average fewer barriers to accessing services than younger adults. Barriers associated with HIV-related information, specifically a lack of information, misinformation and uncoordinated information were prominent barriers to access reported by the older adults. However, of the three groups interviewed, older adults appeared to be the most proactive in their quest for information as a greater proportion of them accessed several key and well-known information sources such as the AIDS Committee of Toronto and the Community AIDS Treatment and Information Exchange anonymous hotline compared to younger adults. Further, they accessed additional sources of information from the internet and magazines to corroborate the information they obtained.

Overall, infected older adults in this study were no less able to access HIV/AIDS-related medical and social services than infected younger adults. Although in some cases they accessed fewer overall services than younger adults, they accessed similar services and in some cases, a greater variety of services.

C. Qualitative Interpretation

Through the qualitative analysis of the older adults' data, four major themes emerged, three of which assist in explaining their experiences with being HIV-positive and accessing medical and social services. The themes focus on the older adults' attitude towards accessing services, their knowledge of HIV-infection and understanding of the increasing infected older population and its needs, and the gay community's positive and negative impact on service access. Various sub-themes emerged from these

major themes. The remaining theme addresses the older adults' perception of necessary changes to both the health care system and social service provision.

1. Older Adults' Attitude

Older adults in this study were independent, proactive, forthright, determined and directive about their service needs. Although they indicated that there were plenty of services available to them, which were not necessarily age, gender or ethnic specific, actual access to the services differed between participants according to their unique situations. Older adults accessed what they felt they needed or wanted and most accessed only what they felt was necessary. Some indicated that they did not want to access any specific medical and social services and that if they did want to, they would do so. These older adults took control over their health status, social situations and service needs and ensured that they could access and receive what they needed regardless of potential barriers.

Accompanying their determined attitude towards accessing services, some older adults expressed a positive and "survivor" type attitude towards promoting their quality of life. They expected to live for many years, many more than typically expected with HIV-infection. When the time came for them to die, they were adamant about either dying from the disease and not the side effects of the illness-related medications such as lung cancer, or they would die of natural age-related causes at night in their sleep.

There are two possible explanations behind the older adults' confident attitude towards service access. First, their access to services may have reflected their existing health status. Most of the older adults indicated that they felt healthy; some were exercising and some were "cocktail" or medication free. In the past, they had experienced good and bad times with the illness but at the time of the interview all felt well. Their health status may not have required that they access any medical services other than their primary health care provider or HIV-specialist. Further, the older adults' social structure may have been such that they did not need to access outside social supports and organizations because they already had a strong support network that met their social needs.

Second, the attitude towards service access may also be explained by established coping strategies. The older adults in this study had been infected with HIV for an average of 10.75 years (range from 4 to 18 years). It is possible that over this period of time, they had developed coping strategies that eliminated the need to access a large quantity of informal and formal medical and social

services. As discussed below, older adults highlighted advantages of being older and infected as compared to younger and infected. Many it seemed, had come to terms with being infected and were comfortable with the services available to them.

A sub-theme that emerged from the older adults' attitude towards accessing services focused on their perception of self-responsibility. Many indicated that the medical and social services, organized and unorganized, were out there for everyone to access. There was not a service shortage and services were easily determined and located. These older adults felt that it was the responsibility of infected individuals to locate the services they needed. They did not perceive the responsibility to fall on the shoulders of service organizations to locate infected older adults and determine what their specific needs were and service them. The same viewpoint was held for collecting health-related information and HIV/AIDS-related information. Older adults perceived that it was their responsibility to make sure that they either had, or could locate a source for information.

A second sub-theme that emerged was the advantage older adults perceived in being older and infected versus being young and infected. Some noted that the collection of a pension associated with older age was advantageous. Collecting a pension meant a greater monthly income than what was available solely from income assistance provided by the provincial disability program. For some, this meant having more money to access services such as those for example of a psychiatrist. Further, there was less shame they felt in collecting a pension income than collecting a disability income.

More importantly however, the older adults felt that age helped them to recognize the value of life. In similarity to Siegel et al's (1998) study of older adult's beliefs with respect to being infected at an advanced age, were the views expressed that with age came wisdom and the opportunity to have accomplished life goals prior to infection. Older adults in this study expressed the view that the disease was a big wake-up call that forced one to grow up quickly. Many felt that they had lived long enough to appreciate life and to not take it for granted; they had developed a new perspective on life.

...life became more meaningful to me...time became more precious...and I gained spirituality...you want to enjoy life even on a limited income and be happy.

The older adults' focus had changed from their younger infected days and they felt at peace at their age.

Being old and diagnosed has its advantages because you have lived through everything such as wanting to have children and meeting other men. But if you are younger and diagnosed it is more difficult.

Also in similarity to Siegel et al's (1998) findings was a sense of patience and contentment among these older adults. Issues that had concerned them in the past were no longer of concern. Some had found themselves, and some suggested that older adults were more tolerant than younger adults who were still contending with the possibility of not being able to achieve their life goals because of their disease. Older adults had lived through many of the issues infected younger adults were facing and as a result, could lead a more peaceful life. Additionally, because they had lived through many events, both social and medical, they no longer needed to access specific services in order to cope.

2. Knowledge Base

A second common theme emerging from the data was the comprehensive knowledge these older adults had about the disease, medications associated with it and the side effects, available services and the emerging growth in the infected older population. Older adults in this study understood the health related-issues associated with infection such as the various disease stages and the effects that HIV-specific medications had on the body and their accompanying side effects. Because the older adults were knowledgeable, they understood their own needs and accessed the services they knew could help them meet their needs. Specifically, they were aware of their own medical condition and took active roles with their primary health care providers in their treatment regimens.

These older adults were resourceful in locating information. They looked to key individuals such as physicians, key community based HIV/AIDS and non-HIV/AIDS-service organizations and conducted their own active searches for information via the internet and library or publication sources. It was common for these older adults to locate as much information as they could about a health or related HIV-issues and cross-reference the information to ensure that it was current and correct. Many believed that there was a need for further research about medication and treatment issues for older adults. The infected older adults were also familiar with the social and health care issues and service provision limitations infected older adults living outside of the community and in rural areas faced, expressing concern for their potentially isolating situations.

Within the theme of having a solid knowledge base, a sub-theme emerged relating to the older adults' understanding of the current and future infected older population and its service needs. Older adults were especially cognizant of the medical service needs.

There is a new thing coming up, people are living longer all the time, we are getting more long term chronic diseases like cancer what not, and they seem to hit older people faster. We are now going into our 30th year...we need to target the older ones.

Older adults felt the approach to service provision should be proactive rather than reactive and that there should be integration between aging and HIV-service provision.

There is a correlation between the two...this particular demographic is going to be with us, we are noticing it even more now that people are living longer than they used to thus Gerontology will be integral within the HIV-community by virtue of the pharmaceuticals that are out there. There is a tendency to separate the two; if there are aging-problems speak with someone in the aging field, if you have HIV-problems speak to someone in the HIV-field, but to integrate the two is a new horizon.

Many of the older adults perceived value in professionals and organizations that had knowledge of aging issues providing medical services to infected older adults. It was important they thought for health care providers of infected older adults to have knowledge of aging issues that could complement their practice either as a general practitioner or an HIV-specialist. These views stemmed from concerns that older people have issues that are different than younger people and that aging bodies and organs cannot tolerate medications often prescribed for HIV/AIDS treatment as they can be toxic and have emotional and psychological effects in addition to physiological effects.

Older people have other things that may not be related to HIV. Because we are slowing down, arthritis, rheumatism, diabetes, cancer – all these things could be attributed to the way we feel, where the younger person wouldn't have that.

It was important to the older adults that health care providers understood these issues and how they relate to treatment and outcome success. More specifically, older adults valued quality of life more than increased length of life facilitated by the use of medications. It was presumed that health care providers' knowledgeability about aging issues would acknowledge their expectations.

3. Gay Community

A third major theme emerging from the interviews addressed characteristics of the "gay community" and the positive and negative impact the gay community has on one's ability to access services. The gay community by nature of its location within the city of Toronto, was viewed by the older adults as resource rich in its service provision to HIV/AIDS infected individuals. It was considered a "one-stop shop" where everything was central, well organized and accessible. Older adults compared the services provided in the gay community of Toronto to those of the United States and to outlying areas. There was consensus that the services provided within the gay community were more

comprehensive and better overall. Some participants felt lucky to live in this service rich area and expressed concern for infected older individuals who did not live in, or close to the community. One stated that he

...could not see how an older person diagnosed with HIV or AIDS in their sixties would have a problem accessing services or support groups because they would live in the community-they would have access...but those with HIV and not in the gay community may not be able to access social organizations and support.

Older adults felt that equitable access to services in outlying and rural areas would not be possible.

Relating back to the theme of the older adults' comprehensive knowledge regarding services one older adult felt that:

HIV medicine is becoming so complex that anyone who does not have a downtown HIV-doctor is not getting the best medical treatment possible.

Despite living in the gay community, some older adults felt uncomfortable in, and disconnected from it viewing it as discriminatory, ageist, uneducated and an entity that catered to, and promoted youth, beauty and HIV-negative status.

In the gay community, older people carry two loads with them. First, they no longer have their exterior physical beauty which in the gay community is very, very promoted. Second, they have HIV. As soon as you tell somebody you are HIV, its Speedy Gonzales, they couldn't get out quick enough. The stigma is even worse in the gay culture, it is shameful in a certain way.

It was felt that the community isolated those who were old and who looked different than the mainstream young, HIV-negative gay male. Some older adults felt old in the community because everyone was young, male, HIV-negative, blond and blue eyed and older age was viewed as affecting one's exterior appearance and therefore, excluded them from the general acceptable and attractive population. Further to this, older adults felt that the gay community was well versed in the symptoms associated with HIV-infection and could spot those who were infected, creating a discriminating environment and situation. The gay community was not viewed as kind to those who were older and infected as many infected older adults found it difficult to develop new friends in the community. As a result, for some there was apprehension in going out into the community to access services.

Instead of feeling alienated and disassociated from the community, some older adults in the sample felt that the gay community was a close knit community. Some felt lucky to live in the gay community; that they were in the right community. Unlike those who felt disconnected from the community, these older adults had many friends within the community who were younger and who formed the basis of their social and emotional network.

4. Changes in Service/Program Provision

The fourth theme that emerged from the interviews involved the older adults' perception of changes that were necessary to the medical care and social service systems in order for older adults to cope with their situation. First, nursing-home access was highlighted as a necessary future medical issue requiring attention. It was felt that HIV is, and will be an added dimension or process associated with aging and that it can be considered a chronic illness similar to high blood pressure, diabetes and hypertension. As a result, the older adults felt that it was necessary to have people in place today to meet the future older persons' needs and to have a "gay old age home". This old age home would provide medical programs and services to the early baby boomers whose needs will be diversified and include catheterization, intravenous feeding and Alzheimer's disease for example. Concerns were raised with respect to existing nursing homes and their ability to deal with infected older adults especially when staff and residents are not familiar with caring for, and interacting with, this infected older population. These older adults wanted to have a place to go and someone to care for them when they were even older and in the last stages of the disease.

Second, these older adults indicated that changes were needed to make social services more meaningful for them. Although some recognized the value in support groups and the discussion of HIV-related issues, most did not see the value in age-mixed groups. Instead, they preferred age-segregated groups as they had already dealt with many of the issues younger adults were dealing with.

There should be a specific organization for older people, that way it would make them feel more comfortable rather than the young being near and you have to compete with them, where you could discuss matters of people that are older.

These older adults wished that existing support groups would focus on coping with the everyday life issues everybody faced rather than dealing with issues associated with the disease which only served to remind them that they were infected. They did not feel that support groups were empowering, rather, they mainly provided an opportunity for infected individuals to complain about the disease.

There was great interest in improving socialization among older people and in providing more social programs. More importantly, they perceived a need for activity-oriented groups.

There are not enough social activities available to us, those over fifty...seems to be geared to younger people who have the disease...things to keep older people occupied are lacking.

This comment is particularly important as infected people of all ages who are collecting income assistance are not permitted legal employment. In such situations, older adults have a great deal of free time available.

In summary, three themes explain why older adults in this study were not limited in their access to services. First, their attitude towards service access was forthright and determined; they were adamant about accessing whatever services they needed. Second, their knowledge of the illness, the changing demographics and the associated service needs empowered them to remain up-to date with current illness-related information, participate in their own illness management and be aware of their own specific health and service needs. Third, the fact that these older adults lived in a community that was rich in resources for individuals infected with HIV/AIDS reduced their limitations in accessing necessary services.

CHAPTER V

Discussion and Conclusions

The present study set out to investigate access to medical and social services for older adults infected with HIV/AIDS and to compare their experiences to those of younger infected adults. The two research questions posed were sufficiently answered with the assistance of the descriptive analyses, student's t-test and a qualitative analysis of the data, which provided an in-depth explanation of the findings. In summary, infected older adults were not limited in their ability to access necessary medical and social services and were as able to access services as younger infected adults. The overall outcome of this research however, opens itself to further discussion.

Findings from this study with respect to the lack of available services for older adults concur with those of Avis and Smith (1998) and Johnson et al. (1998). However, despite the fact that there were no age-specific medical services or organizations targeted to the older adults living in Toronto or Hamilton, older adults in this study accessed a variety of medical services similar to those accessed by younger adults. Older adults in this case however, accessed on average, a fewer number of services. Specific individual group characteristics may have contributed to the difference in the lower number of services accessed. Older adults for example, may have experienced various health and aging-related problems and associated issues over time which may have been both HIV/AIDS and non-HIV/AIDS-specific. As a result, they may have developed personal coping strategies for managing and dealing with their medical needs thus reducing their overall need to access formalized services. Findings from this study also found that older adults were resourceful. It is possible therefore, that they may have located a small group, or single source, of medical care that addressed most, or all of their medical and health-related needs. Younger adults may not have been as resourceful in obtaining available service-related information and as a result, were unable to locate a single or small group of medical care providers who could address all of their needs. In turn, they may have had to access several sources accounting for the greater number of organizations accessed. Further, younger adults may not yet have come to terms with being infected and perhaps may not have developed coping strategies to manage the disease more independently necessitating additional services.

Although accessing a variety of health information sources, older adults also accessed on average, fewer health information sources compared to younger adults. Even though they accessed

fewer sources, they were sufficiently knowledgeable about the disease. This outcome suggests again, that there are unique age group differences. Because older adults were so knowledgeable about the disease and what services were available to them in addition to being resourceful, they may have been more efficient and specific about where they obtained information reducing the overall number of required sources. They accessed for example, two key, one-stop, all-information sources, the AIDS Committee of Toronto library and the Community AIDS and Treatment Information Exchange that allowed for various questions to be answered and issues to be addressed through one distinct avenue. Younger adults were perhaps less efficient and specific about where they obtained information as they accessed more sources, predominantly, the Persons with AIDS Foundation. Although a key service resource, this organization was not as well organized in one-stop information dissemination as its primary mandate was to refer individuals to other organizations and individuals for further information. As a result, younger individuals may have had to access more sources to obtain the necessary information.

Avis and Smith (1998) and Johnson et al. (1998) found that social programs capable of addressing the infected older adults' social needs were scant. As a result, it was expected that a lack of available age-specific social organizations would limit the older adults' access to necessary support services. In reviewing the social services both in Toronto and in Hamilton, there were only two specific services targeted to the older aged group. The lack of available age-specific social services however, did not prevent the older adults from accessing both HIV/AIDS-specific and non-specific social services and from perhaps addressing their social needs. Rather, they accessed a variety of services and maintained a determined attitude towards accessing any service that they felt they needed.

Upon evaluating the older adults' access to social organizations, findings suggested that the older and younger adult groups were also different in their access to social organizations and supports. Older adults accessed on average, fewer social organizations than did younger adults but unlike younger adults, sought social interaction within both HIV/AIDS-specific and non-specific organizations such as the Persons with AIDS Foundation, YMCA and social clubs. Because older adults accessed these non-HIV/AIDS specific services whereas younger aged adults did not, the findings of Garvey (1994) and Szirony (1999) indicating that shame, guilt and embarrassment hinder access to services, in this case, cannot be supported. Their access to such services is possibly due to the fact that with non-HIV/AIDS specific services such as the YMCA, the older adult is not assumed to be infected or perhaps even gay

reducing any opportunities for stigmas or stereotyping. In turn, the older adult can interact comfortably with others. Older adults in this study may have accessed fewer social services because those in place were not necessarily meeting their social needs as they were frequented by younger adults and lacked personal meaning and purpose. As a result, older adults may have removed themselves from existing social programs to find other social alternatives that could offer recreational and leisure activities where they could interact with others their own age. This outcome coincides with the findings of Engle (1998) and Siegel et al. (1998) who indicated that older adults who do become actively involved in social programs do so because they hope to find a network of older adults facing similar issues with whom they can connect. Possibly contending with the stigma of being old and infected, older adults may have been selective in the social organizations they accessed limiting them in number to those within which they felt most comfortable. It is noteworthy that although most older adults lived alone and were single, they had social structures that were supportive. As a result, they may have accessed fewer social organizations because they may have been able to obtain some of the social interaction from those who were providing them with social and emotional support.

Avis and Smith (1998), Crisologo et al. (1996), Nocera (1997), Siegel et al. (1998) and Szirony (1999) indicated that with increasing age there is a decline in the number of social and emotional supports available to infected older adults. Despite the fact that most of the older adults in this study lived alone and were single, findings from this study both disputed and supported the case for diminished social networks and supports. On the one hand, older adults accessed a similar number of social and emotional supports when compared to younger aged adults. They accessed a variety of organized and unorganized supports such as friends, physicians, YMCA and the AIDS Committee of Toronto, and had relationships with family members, all of which may have acted as mechanisms for informal support. Further, many of the family relationships described by the older adults had not changed since diagnosis and many were in frequent contact with family members. On the other hand, older adults in this study found friendship-development and initiation challenging and more so as they grew older. Friendship development was difficult because of the discomfort HIV-negative men had with HIV-positive status within the gay community and fears infected older adults had about the loss of more friends to the disease which became increasingly difficult to cope with.

In further investigating the older adults' ability to access services and to compare their access to that of younger adults, this study addressed additional barriers infected individuals perceived and

experienced with accessing services. Unexpectedly, infected older adults indicated on average, fewer barriers to accessing services than did younger aged adults, specifically reporting parameters associated with information. Older adults indicated that information was lacking, misinforming or uncoordinated. This barrier however, did not preclude the older adults from accessing services as they continued to access similar services, both medical and social, to those of younger adults. As discussed, it is possible that older adults accessed fewer medical and social organizations and services than younger adults because they were knowledgeable and specific about what they needed and what was available. Specifically in this case, older adults were experienced with the service systems which in addition to their determined attitude towards service access, may have enabled them to avoid existing or potential barriers to accessing services. Younger adults in this study did not appear to be as resourceful as older adults, or feel a sense of responsibility for locating and accessing services. Furthermore, they did not appear to share the same sense of determination towards accessing available services. As a result, they may have perceived more barriers to access than did older adults because they may not have known what was available and how to access it.

With respect to the older adults' evident preference in accessing medical clinics for care and services, Garvey (1994) and Szirony (1999) found that older adults were less likely to take advantage of available services because of the shame and embarrassment associated with being infected. In the present study, the shame and embarrassment may have hindered access to medical services, specifically, the HIV/AIDS-designated medical clinic in Toronto. None of the older adults accessed this clinic whereas younger adults did. Instead, they accessed clinics in local hospital settings. It is plausible that the older adults' perception and accompanying discomfort with being amongst an ageist-younger infected group that frequents the HIV/AIDS-specific clinic in addition to their own personal stigmas and shame associated with being infected at an advanced age, discouraged their access to this resource. A hospital setting where many people of all ages and various ailments frequent may have been more welcoming, unassuming, and less personally threatening and as a result, encouraging access.

Findings from this research relating to health care professional dedication and attention in providing care both contrast and support previous investigations. For example, Siegel et al (1998), Bachus (1998) and Nocera (1997) found that infected older adults were under-served by the medical community in that they received lower standards of care and were treated with less enthusiasm than younger adults. Findings presented by Wooten-Bielski (1999) suggested that health care providers are

not well informed or knowledgeable about treating older people leaving them to manage alone. Older adults in the present study were able to access services and were not under-served. Further, they were selective in what they chose to access both with respect to formal medical services and information sources and took an active role in their own illness management. Older adults reported positive experiences with their health care providers and health or medical-related organizations and felt confident that their health care providers were capable of providing them with quality care and that they were interested in promoting their health. Some older adults however, reported that at times they did not have enough time with their health care providers but expressed that this was acceptable because during these times, there was an increased demand for medical attention due to flu outbreaks. It is likely that the older adults' determined attitude in accessing services, their motivation to ensure that they obtained the services they needed and their possible efficiency in locating services of most value may have contributed to their overall positive outcome in accessing medical services.

Forecasting needs according to comprehensive illness and demography-related knowledge, older adults in this study felt that there was significant value in integrating traditional age-related medical issues with medical issues associated with HIV-infection. Infected older adults felt that it was crucial to have HIV-health care providers who had a solid knowledge of aging issues. Similar to the findings presented by Engle (1998) and Szirony (1999), this preference stemmed from the perception that some physicians still maintain some confusion over what ailments are age-related and which are HIV-related.

Older adults in addition to some younger adults expressed that nursing home care would be a necessary service for those at any age who were in the later stages of disease and managing multiple health conditions. Older adults felt that current nursing homes were not prepared to care for older gay people let alone older HIV-infected people who presented with other chronic illnesses. Their perceptions were similar to those reported by Crisologo et al. (1996) who contend that nursing homes will face challenges in integrating AIDS patients as they have typically served one age, or age-related illness group. Younger adults were more concerned however, about where they would obtain care in their later years and who would be providing it rather than realizing or understanding that HIV/AIDS is, and will continue to be a chronic disease.

Chiao et al. (1999) reported that older adults tend to be excluded from experimental drug trials. It was expected that this exclusion would limit access to necessary and effective pharmacological treatments. Ory and Mack (1998) however, reported that older adults in fact question the value of

participating in such trials. More older adults in this study than expected had either once participated, or were currently participating in drug trials. Further, they perceived both advantages and disadvantages in such participation. Those who were currently involved in the trials did so because they were interested in trying something new that could potentially improve their HIV and health-status. Others who had participated in drug trials in the past felt that the trialed medications aged them and that instead of being beneficial, they were toxic to the older organs and aging bodies. Older adults in this study were more concerned with leading a life of quality rather than a longer life associated with certain HIV-related drugs.

Older adults in this study expressed the need to modify supportive and social services. Rather than providing traditional-style support programs/groups where older adults could discuss their HIV-related concerns, there was greater interest in support groups that could address everyday life issues related to being older. The older adults no longer wished to discuss issues relating solely to infection which only functioned to re-enforce that they were infected. Further, they were partial to age-segregated support groups not necessarily because they experienced difficulty interacting with younger individuals as suggested by Engle (1998) and Siegel et al. (1998), but more so because they wanted a different group direction and to achieve a greater benefit from the group dynamic. Although some of the older adults did see value in having age-mixed support groups, they preferred age-segregated groups where they could be with others their own age. In this regard, they could avoid listening to, and dealing with the issues infected younger adults faced.

Isolation as a consequence of the shame, guilt and deteriorating social networks associated with being infected, was expected to limit the older adult's access to services as proposed by Kosberg and Kaye (1996) and Zelenetz and Epstein (1998). Older adults in this study instead, reported little sense of isolation and in fact, less sense of isolation than younger aged adults. It is plausible that the infected older adults in this study may have come to terms with their disease and after having lived with it for several years and after having experienced various life and specific social and medical events, they knew how to manage their needs and where to go to address their concerns reducing opportunities for isolation. Furthermore, the variety of social and emotional supports accessed by the older adult group may have contributed to reducing their sense of overall isolation. As mentioned, younger adults may not have yet come to terms with being infected and may have experienced situations which they were unable to manage, or know who to turn to for help leaving them feeling isolated.

A prominent issue that arose throughout the study was the influence the gay community had on the older adults' ability to access services. Given that the community was resource rich facilitating access to various medical and social services, it became evident that specific characteristics of the gay community hindered access. It was expected that the gay community would welcome individuals of all ages, orientations and ethnic backgrounds yet unexpectedly, older adults felt that the community was ageist and discriminatory to those who were older and infected with HIV. Although older adults felt this way, they did not necessarily allow their feelings to isolate them and avoid accessing services. This however, was dependent upon how they were visually perceived by the community. Should they have exhibited any signs of infection such as bloating or lesions, they would not have ventured out into the community to access services. The gay community was experienced in recognizing those who showed the signs of infection and once recognized, older adults felt disregarded.

This study also set out to investigate the perceptions younger and older adults had about the need to provide age-specific medical and social services to older adults. There was a greater overall consensus among the three age groups that the need to provide age-specific social programming was greater than the need for age-specific medical care. Further, the perception that both medical and social age-specific services for older adults were necessary grew with each older age group. The preference for social services may have been driven by the fact that all necessary medical services are provided free of charge to infected adults through coverage offered by a provincial health program. As a result, all medical needs were met with this coverage. Most social services however, were not provided free of charge, particularly those offering a recreational and leisure component. Appreciating that infected adults received limited monthly income assistance, they were often unable to afford social activities with associated fees compromising their ability to meet some of their social needs. Further, there was consensus among the age groups that older individuals contend with different social issues associated with infection at an older age than do younger individuals and as a result, require different social programming. For example, participants indicated that older adults contend with the personal stigmas of being both infected and older, fears of explaining personal lifestyle preferences, shame and guilt which is consistent with the findings reported by Szirony (1999), Mueller (1997) and Mellor (1996). Additionally, social support programs in place include mostly younger adults dealing with younger age-related issues. As a result, the overall perception indicated a need to provide different services that could address the different social needs older adults had.

A larger proportion of older adults compared to younger adults perceived the need for age-specific medical and social services. Younger adults were perhaps less inclined to feel the need for services for older adults due to limited personal experience. They were more likely to feel that HIV was HIV regardless of age and that medical and social services for older adults need not be any different than those for younger adults. Because younger adults may not have yet experienced some of the age-related medical and social issues older adults experienced, they may not have been able to relate to any specific needs.

Finally, this study considered the possible influence aging and HIV-related stereotypes had on the older adults' ability to access necessary medical and social services. It was expected that both aging and HIV/AIDS stereotypes would limit access to services. Older adults in this study perceived age and HIV-related stereotypes to be held by medical professionals and the gay community but only those held by the gay community were capable of limiting their access to services. Presumptions on the part of the older adults that some physicians still were unclear about the distinctions between aging and HIV-related symptoms, led them to believe that aging-stereotypes prevailed and that some physicians were more likely to misclassify ailments as aging-related than HIV-related which is consistent with the findings of Nazon and Perkeil-Levine (1996) and Strombeck and Levy (1998). It is important to highlight the attitude the older adults in this study had about their service needs and accessing services. These older adults were not precluded from accessing medical services because they would not allow potential stereotypes held by care or service providers to limit their access. However, age and HIV-related stigmas and stereotypes held by the gay community were powerful in their ability to limit access at times causing fear in entering the community.

Usefulness of the Medical and Social Services Access Model

The Medical and Social Services Access Model was developed by the researcher for this specific study and was formulated according to the Health Services Utilization Model (Andersen & Newman, 1973). Its purpose was not to be tested but instead, to provide a framework useful in specifically investigating access to services for an older population infected with HIV/AIDS as it related to the reviewed literature and research questions. Overall, the model was deemed valuable in addressing the research questions and addressing the study purpose.

Although the sample size limited opportunities for measuring the impact that specific variables could have on access, most variables used in this model were considered to be valuable in investigating access. The analyzed predisposing variables thought to be useful in influencing access were social networks, and attitude and beliefs including knowledge of illness and services. Social networks appeared to assist older adults in their access to informal services such as social and emotional supports. Additionally, knowledge of their illness status and available services promoted the older adults' awareness of their needs and their defined access to necessary services. Gender was not analyzed with respect to access as only a small percentage (12%) of participants were female. Further, living arrangement and marital status were not directly evaluated in their impact on access but are considered as they relate to social networks and subsequent access to social organizations and social and emotional supports.

Enabling variables including geographic location and income were considered to have a mixed influence on access with geographic location being more meaningful. It is logical to assume that residing in a city center that is service rich would facilitate service access. Older adults in this study lived in a resource rich community and did not have difficulty accessing services because they felt there were numerous services to access if the need prevailed. However, they indicated that infected older adults living in rural communities would have difficulty accessing services because the likelihood of these areas offering services for infected individuals in general would be minimal. Some of the older adults had infected friends living in rural areas and others had once lived in city centers less, or not at all resourced.

Income was felt to have a questionable influence on social service access. Social services were not routinely funded and as a result, recreational activities and supportive services not offered through mandated AIDS service organizations required a fee for service. The limited monthly income infected adults received was not enough to afford various social activities. In such as case, income limited access to specific social services. It is questionable however, whether or not infected older adults would actually access social services as discussed by Strombeck and Levy (1998) should age-specific services have been available. Income did not influence the older adults' ability to access medical services because health care was funded by a provincial health plan. Infected individuals could obtain the medical services they required free of charge. Maintaining income as an investigative variable for future research using this model should be reviewed.

The need variable, based on the qualitative interpretation of the data, proved to have a meaningful influence on access to services and in this study, was thought to be informally linked to attitude towards illness and knowledge of services. Older adults were adamant about accessing the services they needed and knew where to go to get them. However, older adults did not need too many services likely because their health status was formidable, they were efficient in locating services and they had a supportive social structure reducing their overall need to access them.

Incorporating specific characteristics of the medical and social services system proved useful in investigating access to services. Volume and distribution in addition to groups targeted, are logical variables associated with accessibility. In this study, the services available to the older adult, even though not age-specific, were numerous, centrally located and did not necessarily target one group over others. These factors clearly assisted in the older adults' ability to access services. Furthermore, the structure of the organization namely medical services, in terms of its capability through knowledge and interest in providing care to older infected adults valuably influenced access. Health care professional stereotypes pertaining to aging and HIV status were viewed as somewhat valuable in influencing access but offset by attitude. Because older adults' maintained a determined attitude towards service access and were knowledgeable about their disease, it became evident that even if health care providers harboured these stereotypes, older adults in this study would find a way to access services regardless. In studies where older adults are not as confident or informed, such stereotypes may limit access.

In the early stages of planning this project, it was felt that societal determinants defined as "norms" and "technology" in the Health Services Utilization Model (Andersen & Newman, 1973) were non-contributory to investigating access to services. However, upon viewing societal determinants more broadly, unexpected findings from this study indicated that stereotypes and stigmas held by the gay community specifically, could limit access to services. Variables associated with societal determinants if clearly defined, would be valuable in investigating service access particularly for populations affected by stereotypes and prejudice.

Both the Medical and Social Services Access Model and the Health Services Utilization Model neglect to consider the length of time an individual has been ill or infected and how this influences access to services. It is possible that individuals who have been infected for long periods of time may not require as many medical or social services as someone who is newly diagnosed because they may have developed strategies for coping with their situation. Alternately, depending on the disease

progression, individuals infected for longer periods of time may need to access more medical and social services to manage the increased severity of their situation. Including a variable that address the length of time an individual is infected with a specific disease(s) would be valuable in investigating access to services.

Limitations of This Study

The non-random sampling and the snowballing techniques used in recruiting participants for this study limits the generalizability of the findings. It is possible for example, that older adults who had access to the service organizations, coffee shops and bars where posters were displayed, were different from those who did not access or have access to these establishments. Also, many participants were recruited through word of mouth from those who had already participated in the study. It is possible that participants assisting in recruitment selected some individuals over others whose experiences may not have provided as positive views as those interviewed.

Most of the older adults in this study were healthy, ambulatory, exercised, gay and acquired HIV primarily through homosexual contact. Their experiences may not parallel those of infected older adults who are heterosexual, illness stricken, who acquired HIV through other routes and/or who are not ambulatory. Further, older adults in this study were well informed and proactive in their quest for information and service. Infected older adults who are not as informed or independent may have different experiences with accessing services.

Despite the fact that older adults comprised 36% of this sample which exceeds the older adult representation amongst infected individuals in Canada (Health Canada, 2001), the sample size was not numerically large enough to assume global HIV/AIDS population representation. It may however, represent infected older adult populations in other major city centers.

Analytically, the small sample size introduces further limitations in the application of the student's t-test. Although the test was useful in assessing similarities, or in this study, differences between variables influencing access, the small sample size of each age group may have compromised a true and conclusive comparison.

Further, the geographic location in which the study was conducted also limits generalizability. The catchment area within which 92% of the older adult sample lived was Toronto which is rich in service

provision and medical specialization to infected individuals. Infected older adults living in rural areas or areas not geared to the HIV/AIDS population may not have the same experiences accessing services.

One final limitation of this study is the newness of the Medical and Social Services Access Model and its utility with respect to investigating access. As this model has not yet been tested and the sample size for this study was small, it is difficult to determine the influence specific variables had on one's ability to access services.

In summary, the research findings of this study are more applicable to infected older adults who are well informed, healthy and active, and who live in a service rich geographic location.

Future Research Directions

Future research in the area of HIV/AIDS and aging is required. Rather than addressing the epidemiology of HIV/AIDS among older adults upon which most studies focus, there is a need to undertake further studies that specifically address access to services, both medical and social.

Findings from this study indicated that older and younger adults accessed similar services and that there were numerous services available to everyone regardless of age. However, this study involved only a small number of older adults who lived in a resource rich community. Future investigations must address larger and more diverse older and younger adult groups from areas that are not necessarily saturated with services. Such populations would include ethnic and rural communities.

The majority of participants in this study were gay and male. Access to services for infected groups other than gay men such as heterosexual women and men, intravenous drug users and transsexuals also requires investigation. Furthermore, this study did not address the individual impact that living arrangement and marital status had on access other than combining them into social structure. Future research should address the influence of these variables.

Research investigating the experiences infected older adults living in other metropolitan cities such as Vancouver, San Diego and New York would be fruitful, specifically in addressing this study's generalizability. Further, to complement a closer population and city comparison, further access-related studies should be conducted with other countries with large HIV/AIDS population centers such as Africa, Asia and European communities.

The study investigated service access among older adults who had been infected for an average of ten years. It is possible that access to medical and social services even within a resource rich

community would be different for older adults who are newly diagnosed. Future research should investigate the accessibility of services to newly diagnosed older adults and compare it to those who have aged with the disease.

Although the purpose of this study was not to specifically investigate the medical and social differences between age groups as they related to accessing services, the descriptive analyses and student t-test suggested that possible differences between age groups influenced ability to access services. Further specific research should address the differences between age groups as they pertain to accessing both social and medical services.

Finally, the Medical and Social Services Access Model was felt to be a potentially useful tool in investigating access related issues. However, appreciating its newness and undetermined utility, it requires further evaluation and testing particularly on larger samples. In future applications of this model, specific societal determinants such as underlying stereotypes as they relate to specific characteristics of the population should be included. Future studies involving this model should also consider the length of time an individual has been infected by the illness.

Study Contribution

Although the sample size in this study was small limiting the generalizability of the findings, this research is thought to be beneficial and contributory for several reasons. First, the study addresses two research areas that are under-investigated in existing HIV and gerontological research: older adults infected with HIV/AIDS and access to medical and social services for infected older adults. Second, the information collected provides an understanding of the experiences infected older adults have with accessing services in a resource rich community, despite resources not being targeted specifically to the older age group. Existing studies highlight concern over limited resources in city centers and the subsequent inability to access necessary services. Third, the study highlights the true experiences of infected older adults living in a gay community that is focused on youth, beauty and HIV-negative status which itself, was once the target of prejudice and non-acceptance. Fourth, findings from this study signify the valuable contribution infected older adults can make to program and policy planning with respect to current and future service requirements. Infected older adults tend not to be questioned about their needs and instead, are assumed to have the same needs as infected younger adults. This research although indicating that younger and older adults access similar services, found that older

adults have different needs, specifically social needs, which cannot necessarily be effectively addressed and met with the social services currently in place. Overall, this study formulates the preliminary groundwork for future research and acts as a comparison for other infected older populations.

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November 7, 2000

Ms. Teresa Fritsch
Graduate Student
Gerontology
Simon Fraser University

Dear Ms. Fritsch:

Re: HIV/AIDS and the Older Adult: Access to Medical and Social Services

I am pleased to inform you that the above referenced Request for Ethical Approval of Research has been approved on behalf of the University Research Ethics Review Committee. This approval is in effect for twenty-four months from the above date. Any changes in the procedures affecting interaction with human subjects should be reported to the University Research Ethics Review Committee. Significant changes will require the submission of a revised Request for Ethical Approval of Research. This approval is in effect only while you are a registered SFU student.

Best wishes for success in this research.

Sincerely,

Dr. James, R.P. Ogloff, Chair
University Research Ethics Review Committee

c: G. Gutman, Supervisor

/bjr

APPENDIX B – Organizational Letter

November 6, 2000

**Stephen Mueller
Benefits & Assistance Program Coordinator
Toronto Persons with AIDS Foundation
399 Church Street, 2nd Floor
Toronto, Ontario
M5B 2J6**

Dear Mr. Mueller,

My name is Teresa Fritsch and I am a Masters student in the Gerontology Program at Simon Fraser University. I am conducting a research study in Ontario investigating the experiences adults with HIV/AIDS have with accessing medical and social services. The project is supervised by Dr. Gloria Gutman, from Simon Fraser University, and Dr. Michael MacLean, from the University of Regina.

I am requesting your assistance in locating 20 participants with HIV or AIDS aged 50+ and 20 participants between 20 and 49 who are willing to share their thoughts and experiences about accessing services. I plan to interview study participants at a convenient time and location for them. The interview will last no longer than 1.5 hours. A \$20.00 honorarium will be given to each participant for their time or donated to a charity of their choice. Furthermore, I have included information and contact flyers and posters should you wish to distribute this information to individuals visiting your organization. The interview will address the following questions:

- Experiences with HIV/AIDS medical care and services.
- Experiences with HIV/AIDS health professionals.
- Supportive relationships the participant has which helps them cope with their illness.
- Experiences with HIV/AIDS social support groups or organizations.
- Comments on barriers that prevent service use.

No identifying information will appear in any report. The anonymity and confidentiality of each participant will be fully respected. Information describing the interview and participant will be destroyed upon study completion.

This study has been approved by the Simon Fraser University Ethics Committee. A copy of the research proposal and interview questions are available upon request. If you have any questions you can contact me at (905) 333-0561 in the evenings or by email at queentess2@yahoo.com. Call collect if necessary. Please call or email me as soon as possible with your interest in helping out with this project as I would like to complete the study before December 20, 2000.

Thank you for your consideration.

Sincerely,

Teresa Fritsch
(B.Sc. Kin., Dip. Gerontology, MA-In Progress)