2001

AIDS in Ontario: An examination of mobility patterns and spatial variations (Immune deficiency)

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AIDS IN ONTARIO: AN EXAMINATION OF MOBILITY PATTERNS AND SPATIAL VARIATIONS

By

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Honours Bachelor of Arts Degree, Queen's University, 1997

THESIS

Submitted to the Department of Geography and Environmental Studies
in partial fulfillment of the requirements
for the Master of Arts degree
Wilfrid Laurier University
2000

ABSTRACT

The primary objective of this thesis is to examine mobility patterns of people with Acquired Immunodeficiency Syndrome (AIDS) in terms of where they go for testing, treatment and support. The secondary objective is to examine and describe spatial variations in the prevalence of AIDS among the forty-two Public Health Units (PHUs) of Ontario, and to explain the processes underlying these patterns. An assessment of the spatial perspective will be completed utilizing two contributors. The first employs the process of interviewing the AIDS Educators at the Ontario PHUs and capturing their impressions as to what is occurring within their areas regarding AIDS and other related issues with a focus on the mobility patterns of the AIDS patients. The second aspect is to examine and discuss the results of mapping the AIDS prevalence rates from 1990 to 1999, at the PHU level.

The major findings from the research are as follows. First, by conducting the interviews it was possible to examine the mobility patterns for people affected and infected by AIDS, in terms of where they go for testing, treatment and support. For the most part, people are leaving less urbanized areas to go to more urbanized areas for testing, treatment and support. Second, the research completed with the Educators allowed an examination of what processes are hindering and/or furthering the spread of AIDS within Ontario. There are great inconsistencies throughout the province contributing to and counteracting the spread of HIV/AIDS. A sense of invincibility appears to prevail in most areas of the province. Third, the mapping of the prevalence rates allowed general patterns and processes to be observed. The spatial variations of the prevalence rates showed areas with high prevalence rates attracting people from the surrounding areas. Mobility

patterns, the provision of support facilities and the relative location of PHUs in terms of how close they are to other PHUs with high prevalence rates also influenced the spatial variations of the prevalence rates.

ACKNOWLEDGMENTS

When one begins a work of this magnitude, where it will take you is never clear at the beginning, nor is the final "destination". What is put forward in initial proposals and what is found in the final product are not necessarily one and the same. In terms of where this research has taken me, I think that it is self evident in the work itself. I have learned not only about AIDS and its workings, both politically, and more importantly on a human level, but I have discovered a great deal about myself and my abilities. There have been many times throughout this research that I truly believed it would defeat me, I did not believe that I would reach completion. Had it not been for the support of a very dear friend in Toronto, and my family, this product would not exist. In addition, I would not have finished this work, had it not be for a certain professor at Wilfrid Laurier University who spent hours with me, encouraging and helping me to figure out where this research was going and what I should be looking and striving for. I received some wonderful advice, in that in research (and in life), it is not always the "bolts of lightning" that should be the all encompassing purpose(s), but the smaller facets are just as important and can be just as meaningful. Added together these facets can make a substantial and worthwhile contribution. This research is not a "bolt of lightning", nor is it the definitive word; instead it is a small part of a large puzzle that will hopefully make its own valuable contribution.

Acknowledgment must also be given to my two supervisors who challenged me and allowed me to grow in my academic endeavors and abilities. Finally, I would like to sincerely thank the AIDS Educators at the Ontario Public Health Units for their time and

honesty. Their responses are a fundamental part of this research, and without their impressions this research would be severely lacking.

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INTRODUCTION, RATIONALE & METHODOLOGIES

INTRODUCTION

The objective of this research is twofold: its primary intention is to examine mobility patterns of Acquired Immunodeficency Syndrome (AIDS) patients in terms of where they go for testing, treatment and support. The secondary intention is to examine and describe spatial variations in the prevalence of AIDS among the forty-two Public Health Units (PHUs) of Ontario, and to explain the processes underlying these patterns. The research will examine the influence of a number of factors as functions of the AIDS prevalence rates, with the most important, or most emphasized factor being the mobility patterns of those infected by AIDS. Other factors include the population of the PHUs, both relative to one another and their absolute numbers; the provision of support facilities; and prevention measures. This research provides a detailed spatial picture of AIDS in Ontario through the use of a mobility analysis and through the use of maps. To this author's knowledge, no one has looked at AIDS in Ontario from a spatial aspect before at the scale of the Ontario PHUs.

Examining and mapping the mobility patterns and prevalence rates of the past and present allows one to see any anomalies that cannot be seen in aspatial approaches, such as numerical charts. Further, we can break Ontario into manageable spatial units, the PHUs, where the disease can be examined in substantial detail, something that cannot be done by examining Ontario as an entire province, as has been the case with previous research attempts.

The first chapter of this research continues to focus on the rationale and methodologies for completing a study of this sort. The second chapter includes the necessary background information on Human Immunodeficiency Virus (HIV) and AIDS

that is needed to better understand the mobility patterns and prevalence rates. The third chapter is the Methods section and describes the interviewing of the Ontario PHUs, the use of Geographic Information Systems (GIS), and the making of the maps for this study. Chapter four is the Results chapter, and includes the answers and results of the interviewing process; and the mapping results, including distinctions that appear, as well as the anomalies. Further, Chapter four also discusses the extent that data issues limit one's ability to analyze and understand the spatial variations and patterns. Chapter five includes a summary discussion, concluding remarks and recommendations for future research attempt. Finally, the Appendices are included at the end of the report.

METHODOLOGIES & RATIONALE

Before a discussion of the rationale for completing this research is undertaken, it is important to explain the methodologies of this research. Methodology refers to the conceptual framework and the method(s) or tools used for a specific inquiry. In terms of this research the methodology will draw on Medical Geography and Epidemiology, and how these disciplines have dealt with the concepts of epidemics, the influence of space on health related issues, sexually transmitted diseases (STDs), mobility factors of infected people, and the process of diffusion. This section will also look at why studying the spread of AIDS is a spatial issue.

INTRODUCTION TO MEDICAL GEOGRAPHY AND EPIDEMIOLOGY

Medical geography is concerned with the geographic aspects of health, including diseases and health care systems. The use of medical geography is fundamental and very significant for any population, due to its capacity and ability to examine geographic

variation in health and to explore causal connections, whether they be ecological or epidemiological. To do this, it views subjects holistically and draws from the concepts and techniques of various other disciplines such as the social, cultural, physical, and biological sciences. By using medical geography we can map diseases and epidemics, and better determine where, when, and why they are spreading throughout a population. Medical geography attempts to provide a spatial distribution, location, diffusion and regionalization of health care resources, in terms of their locations relative to the population (Gesler, 1986: 963). Medical geography also seeks to provide a description of spatial patterns of mortality and morbidity, and the factors associated with these patterns, such as disease diffusion, or disease etiology (causes of diseases and illnesses).

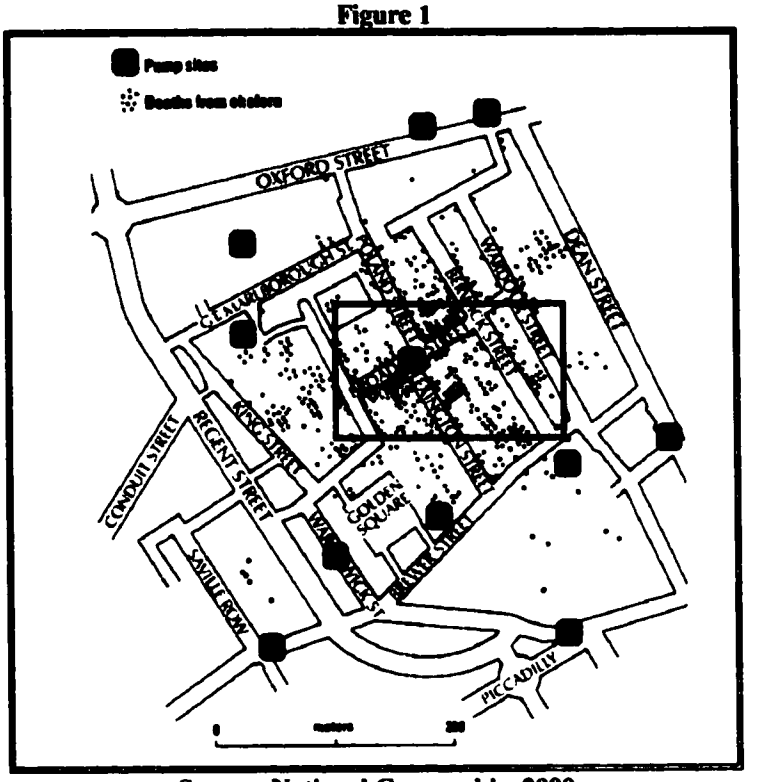
Central to the concept of diffusion or spread of a disease are the terms "epidemic" and "endemic". The word "epidemic" refers to a phenomenon spreading outward (epi) from a central point and moving through a population (demos). It is the structure of the geographic space, and the changing intensities of the connections, that are the crucial aspects of studying an epidemic (Gould, 1985: 231, 232). The characterization of an infectious disease as either an endemic or an epidemic is often inadequate. While it is true that sometimes a disease is previously nonexistent in an area, it can suddenly and often virulently arrive. However, it is more common for a disease to be already endemic in a population, and then develop into a health problem of epidemic proportions (Meade et al., 1988: 237). An epidemic is defined as an extensive outbreak of a disease affecting a large number of people simultaneously, usually spreading rapidly. Further, it can be a disease or other health-related event occurring suddenly in numbers clearly in excess of what is to be expected. An endemic can be native to a particular county, nation, or region. It is

constantly present in this particular area, but it may generally be under control. An endemic may occur at low levels, occasionally occurring at random, or it may occur with intense transmission. A disease, then, is said to be epidemic when it occurs at levels clearly beyond normal expectations and is derived from a common or propagated source (Meade et al., 1988: 11).

The idea that place and location can influence health is not a new concept; in fact it is a very old and familiar idea in Western medicine. In the time of Hippocrates, physicians observed that certain diseases would occur in some places, but not others. The process of disease diffusion across geographic space has been known for centuries, with the most famous discovery in 1854 by Dr. John Snow who demonstrated the usefulness of mapping disease outbreaks in Soho, a region of London, England. Snow mapped the distribution of cholera cases during an epidemic and discovered that the highest density of cases occurred in households which used the public pump on Broad Street as their water source. He was the first person to show the importance of spatial dynamics in the understanding of a disease, and how a disease spreads spatially and temporally. Dr. Snow made the hypothesis that cholera could be spread through infected water supplies. He used maps to demonstrate the spatial correlation between cholera deaths and contaminated water supplies (Loslier, 1999). Figure 1 shows the positions of the pump sites and the deaths from cholera. The blue square denotes the location of the Broad Street pump, where the majority of the cholera deaths occurred. Once the authorities removed the handle to the pump, making it unstable, the number of new cholera cases promptly declined.

Dr. Snow's Map of Cholera Deaths and Locations of Water Pumps, 1854

Figure 1



Source: National Geographic, 2000

Besides discussing and mapping acute infectious diseases, there can also be an examination of diseases that would be chronic in nature. A chronic disease usually lasts for a long period of time, or it can reoccur quite often, whereas an acute disease is often severe, but of short duration (Meade et al., 1988: 9). STDs are classified as chronic, as is AIDS. STDs and AIDS are also considered communicable diseases, in that infection can only be conveyed by contact with the infecting organism. The contact is of the intimate type, usually sexual intercourse, or sexual activity. With AIDS, contact can also occur with the sharing of an infected needle, or blood (Carruth, 1989: 951). When measuring chronic diseases, we refer to incidence and prevalence rates. Incidence is the degree or range of occurrence or effect, the extent of the influence. It refers to the number of new cases of a disease being diagnosed or reported for a population during a defined period of

time. Prevalence simply implies a widespread occurrence. It refers to the number of people in a population sick with a disease at a particular time, regardless of when the illness began; it is the total number of people who have the disease or illness. In the case of STDs, and AIDS, incidence and prevalence rates are measured as a per 100 000 rate. This rate simply tells us how many people per 100 000 within an area are infected.

Finally, with the "return" of infectious diseases like tuberculosis and declining health budgets in many areas, the significance of "space" in understanding health and disease is stronger than ever. The spatial component of medical geography can also be looked at in more detail by examining people's mobility. In the case of this research, emphasis is placed upon where people are moving for testing, treatment and support for HIV/AIDS. Sometimes when people become seriously ill, they often "respond spatially", by relocating either to an area with the appropriate services, or to where their family, friends, and support networks are. This issue of mobility is examined further in the mobility section of this chapter.

MAPS AND MEDICAL GEOGRAPHY

Medical geographers have traditionally used maps to analyze associations between space and disease. A modern operating system like Geographic Information Systems (GIS) is well suited for studying these associations because of its spatial analysis and display capabilities. Maps rarely provide definitive answers; instead they can help to generate interesting questions and observations. They do this by allowing our mind to visually see what is happening over space and through time. Maps guide the search for causes of ill health in specific populations by assisting in the generation of hypotheses about the causes of diseases. For instance, do a series of prevalence rate maps provide any

insight on the origin or progress of an epidemic? Does the epidemic spread in recognizable ways? Maps are also useful for monitoring changes in the health of specific populations and for monitoring the effects of efforts to improve health. Finally, maps can help us to understand why certain diseases seem to only occur in certain places and not others. Hopefully what one can learn from maps will help to indicate or delay the impact of an epidemic (Cliff et al., 1981: 3, 4).

Maps allow us to see what statistics cannot; maps can provide an instant visual impression of the relationship of the disease and its appropriate geographical position(s). Disease maps can reveal spatial variations and distribution patterns not previously discernible from something like a table of statistics (Howe, 1986: 54). Providing information in map form is the simplest, most elegant and informative way of presenting data which vary across a surface. A map enables a number of important spatial properties that were not initially measured to be isolated, such as the orientation of the phenomena, and most importantly, the relative location. Spatial patterns cannot likely be seen unless a map is produced. Maps are models of the real world made in order to facilitate our understanding (Unwin, 1981: 6). Finally, the provision of relevant health care information at something like the PHU level allows for a focus on local concerns in a manner that can highlight issues pertaining to the local community and can lessen the biases of the data being viewed from a provincial or federal perspective (Foster et al., 1992: 3, 4).

From the standpoint of education and prevention, good maps have always been acknowledged as an excellent means of communication. The AIDS epidemic is still literally "distant" to many people who believe that it is and always will be the problem of someone else, somewhere else. Those who feel this way need what experts in health

education have termed "a cue to action", something to make the disease appear nearby and of immediate and personal danger. Maps can effectively accomplish this by allowing a person to see the epidemic spreading and establish the realization that AIDS is indeed present in their county, city, or province. It is hoped that by "seeing" the disease there will be a vivid sense that the danger is close by, hopefully inducing a degree of self-reflection that will lead to behavioural change(s). By ignoring the geographic perspective of diseases and more specifically AIDS, a fundamental perspective with practical implications for educational intervention, and the planning of healthcare facilities is being ignored.

Data Issues For Medical Geography and Epidemiology

A discussion on Medical Geography and Epidemiology would not be complete without exploring the data issues related to completing a study of this sort. As will be discussed in greater detail in the next section, the reporting of HIV and AIDS is not straightforward. Because there are complexities with the reporting structure, the resultant data are limited in their descriptive and explanatory powers. Data for positive HIV tests are not published at the PHU level. One can know provincial numbers, including a breakdown of gender, and age cohorts, but this is as finite as the analysis goes. Given this circumstance, the focus of this research is to only discuss AIDS, since that is what is published at the PHU level. The objective is to examine AIDS from a detailed geographic perspective, something that cannot be done by examining the province as whole. However, this is not without its problems, as will be discussed in subsequent sections. It would not make sense at this point in the research to discuss which methodologies are appropriate, or can be used in this type of research without the reader first having a better

understanding of HIV/AIDS, most specifically, the reporting structures of HIV/AIDS. The remainder of this section will now focus on the rationale for completing this research, and will examine the AIDS disease in detail. In the "Results" section, the methodologies that can be employed for this type of research are considered.

RATIONALE

The rationale, or importance, for completing this research may at first seem straightforward, due to its subject matter. With a subject like AIDS, any research that is completed will hopefully contribute to prevention and education efforts. However, the rationale for this thesis is more than that. It attempts to achieve a deeper understanding of the disease patterns and processes. More specifically, it attempts to better understand and acknowledge the behavioural patterns, especially mobility patterns of people who become infected and affected by HIV/AIDS and where they are situated.

There have been more aggregated spatial studies of HIV/AIDS, but none at any scale on mobility behaviour. For example, in 1998 and 1999 Remis et al. completed Report on the HIV/AIDS Epidemic in Ontario 1981 - 1996 and Report on HIV/AIDS In Ontario 1997 - 1998, respectively. These reports focused on the province of Ontario, and only aggregated the province into five regions: Northern, South West, Central West, Central East, and Eastern Ontario. The 1999 report examines seven regions: Northern, Ottawa-Carleton, Eastern, Metro Toronto, Central East, Central West, and Southwest. By dividing Ontario into these vast regions it is extremely difficult to capture much detail, or to highlight any differences within the regions. A better approach may be to examine Ontario at the PHU level. Ontario is made up of forty-two PHUs. AIDS is a specific individual disease, in that very specific factors must be present before it will infect a given

individual. By reducing Ontario to five or seven large, unspecified regions much of the detail can be lost.

A second rationale for this work is that much of the emphasis in the Ontario reports has concentrated on the compilation of statistics, and not the mapping and analysis of the spread, and its impacts on people. Further, the reports do not look at where people are or are not moving for testing, treatment and support. This means that the reports have not fully examined the geographic perspective, such as a spatial view of the spread of AIDS, or the mobility patterns of people affected by HIV/AIDS. If we again refer to the 1998 and 1999 Remis et al. reports, we see that they contain graphs, charts, and a discussion of the general trends of the disease, but only one map exists in the entire one hundred page 1998 report, and no maps appear in the 1999 report. Further, no discussion of mobility patterns is included. The reports include statistics on the number of people who presently have AIDS, including age and gender breakdowns, the number of people who have died due to AIDS, the number of people in the major risk behaviour groups, and AIDS related illnesses and symptoms. What is missing from these reports is the "where", the spatial aspect. It would be valuable to move beyond pure statistics and look at more of a human and geographic dimension of AIDS. For example, we can know what PHUs have high prevalence rates by examining a numerical chart, but this does not tell us where the PHU is in relation to other PHUs with high rates. It is important to remember and consider that AIDS is about people, not statistics, thus we must keep the human aspect at the forefront. This research looks at what is occurring to people, and where it is occurring. It is extremely meaningful to look at the geography of the epidemic:

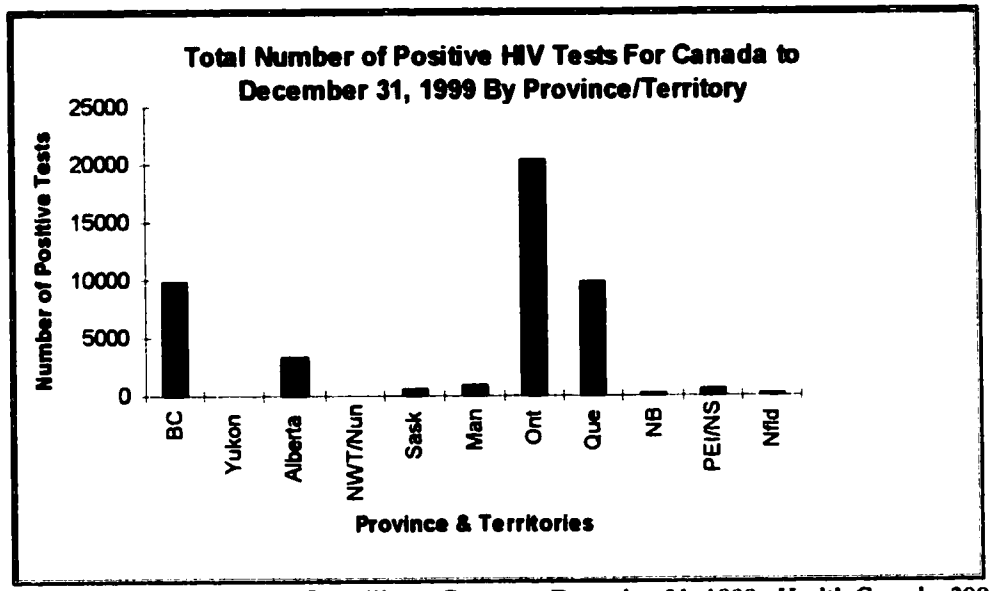
> If anyone had thought of looking at the geography of the epidemic, rather than simplistic numbers over time, we would not only have had a quite different and enormously valuable perspective on the explosive nature of the beast, but our thinking might have moved to ... using them [maps] as early warning signals (Gould, 1993: 113, 114).

The third rationale is that recent studies have clearly suggested that a cure for AIDS will not transpire for at least ten years; thus we must do all we can to lessen the impacts of the disease. World Health Organization (WHO), a normally cautious international body, predicted by the year 2000, forty million people would be infected with HIV or AIDS. WHO upgraded their prior estimates from five to ten million made in the middle and later 1980s. Forty million could still be an underestimation due to under- and late-reporting. Approximately 860 000 of these cases live in North America. To add some perspective to this, the worst world-wide disease previous to this one was that of influenza in 1918-1919; the number of people who died was an estimated thirty million. AIDS has the potential to be much worse (Gould, 1994: 101).

Further rationale for completing this study, is that since it is unlikely a cure will present itself in the near future, the concern regarding the cost of treatment to the health care system is paramount. Heather Kent's 1998 article in the Canadian Medical Association Journal asked "What does it cost to live with HIV?". "Costs" include expenses to partners, volunteers, and community agencies and support groups. Current direct costs per lifetime episode of AIDS are estimated as high as $180 000. Indirect costs and opportunity costs representing lost income because of death and debilitation may reach almost one million dollars per case (Kent, 1998). It is not only the cost to the individuals, but the cost to the health care system as well. Currently there are approximately 6 685 AIDS cases in Ontario, and if we use the $180 000 figure per life

episode of AIDS from the Kent article, this means an estimated one billion dollars for an already overburdened health care system. This figure only accounts for AIDS cases, not HIV cases. There are an estimated 20 349 positive HIV test reports in Ontario, as of December 31, 1999, as shown in Figure 2.

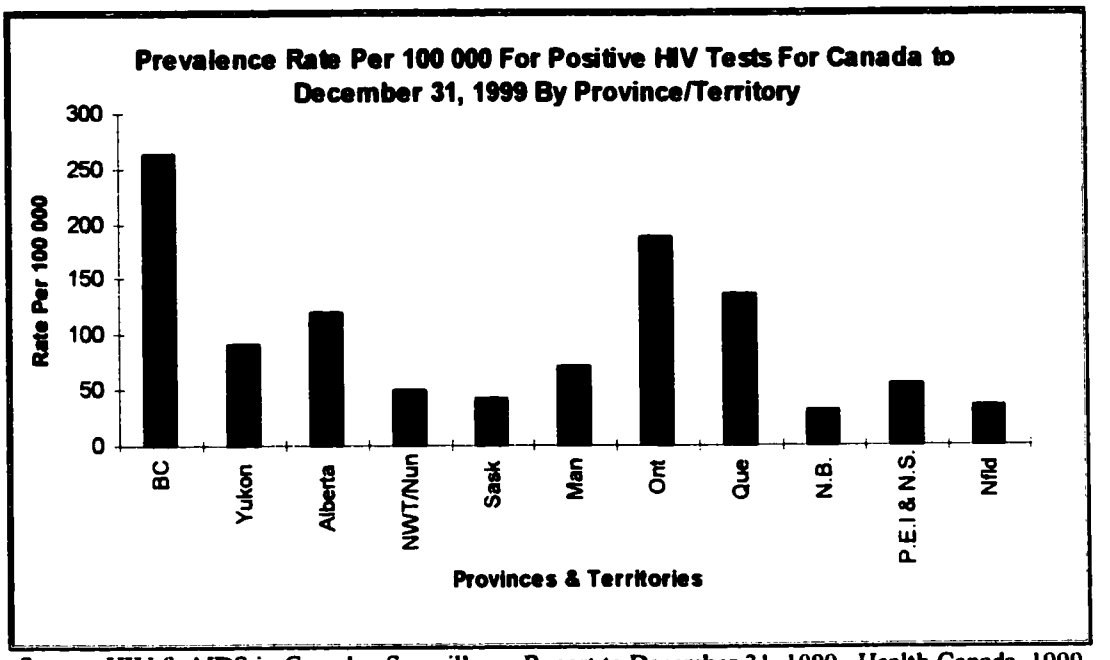
Figure 2



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000

Of greater concern, is the fact that the numbers displayed in the above Figure only account for the people who have been tested, and do not represent the total number of people that are infected with HIV in Ontario. Ontario has the most positive HIV test reports, at 45% of the total. When an HIV prevalence rate per 100 000 is examined, British Columbia, has the highest rate, with Ontario coming in second, as displayed in Figure 3. A prevalence rate is calculated by dividing the total number of cases for one area into that area's population, and then multiplying by 100 000.

Figure 3



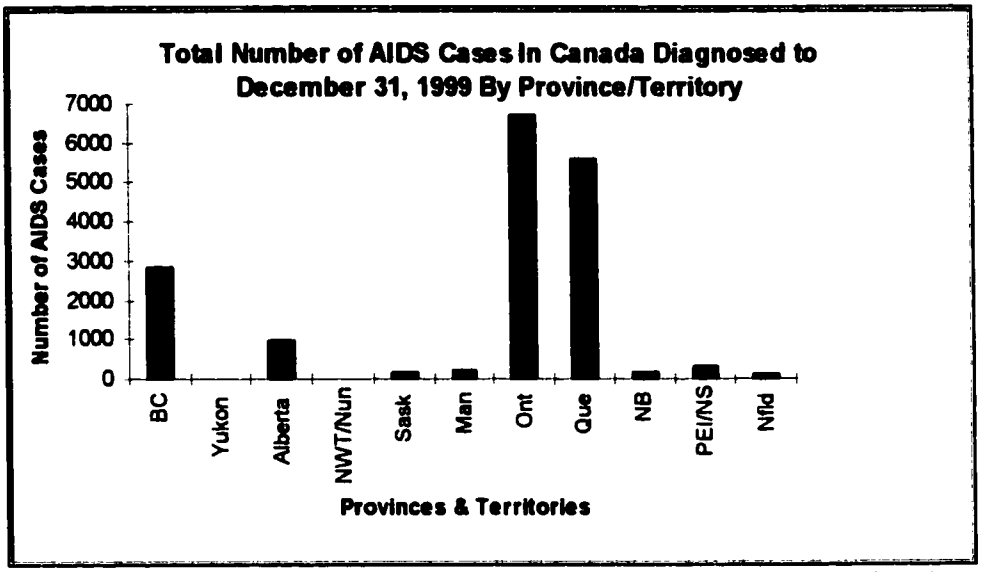
Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 1999

It is important to note, as aforementioned, that this research will focus primarily on AIDS, with only general remarks on HIV. One reason is that it is extremely difficult, if not impossible, to gather accurate data on HIV. Gathering accurate, up to date data on AIDS is also very challenging. However, AIDS is actually reported to the PHUs, and the Medical Officer of Health, whereas HIV data are not. This reporting component of HIV/AIDS will be discussed in further detail in subsequent sections. Suffice to say, that Figures 2 and 3 indicate the potential for growth of AIDS cases in Ontario

The final aspect of the rationale, and related to the previous discussion on the number of HIV positive test reports, is that Ontario presently has the most AIDS cases in Canada. There were 6 685 cases of AIDS in Ontario diagnosed as of December 31, 1999, as shown below in Figure 4. The province of Quebec has the next highest at 5 565. Ontario has approximately forty percent of the total 16 913 AIDS cases in Canada. One reason for the majority of the cases may be attributed to the fact that Ontario has the

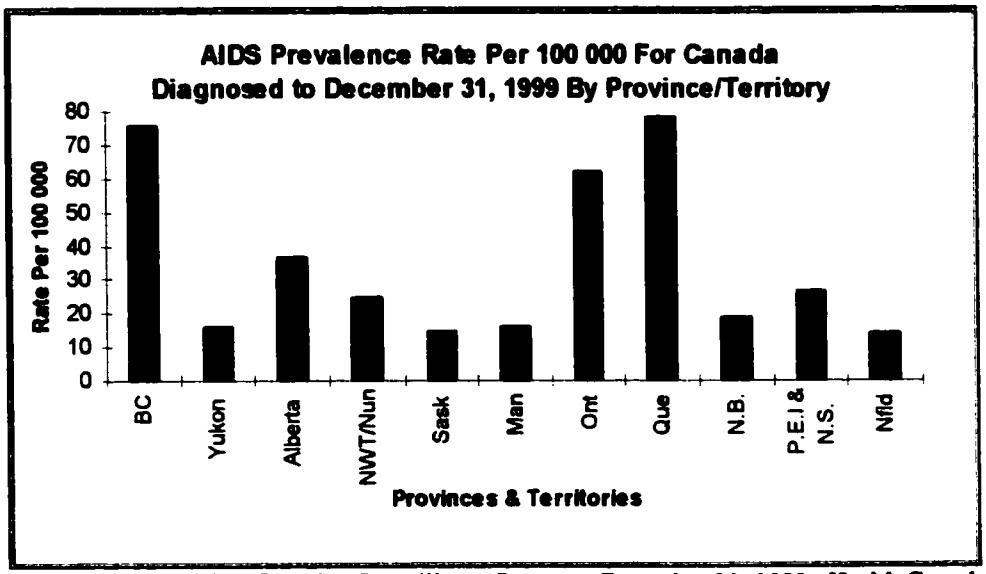
largest population. If we examine a prevalence rate per 100 000 people, we see that Ontario is third, behind Quebec and British Columbia, as shown in Figure 5. Ontario has 62 AIDS cases for every 100 000 people, Quebec has 77 and British Columbia has 76.

Figure 4



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000

Figure 5



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000

CHAPTER TWO

BACKGROUND INFORMATION ON HIV/AIDS

BACKGROUND INFORMATION ON HIV/AIDS

> That a hitherto unknown fatal infectious disease could appear and spread around the world, defy our best efforts to combat or even control it, is almost beyond belief given the technologically sophisticated societies that exist today. Our preoccupation with AIDS...is probably a reflection that we don't have nearly as many inevitably fatal or almost inevitably fatal diseases as we used to, and that helps makes this new one so frightening (Waugh, 1995).

Perhaps more than any other threat to public health in modern times, AIDS has entangled not only individuals, but families, friends, cultures, communities, cities and nations throughout the world. AIDS has no regard for race, ethnicity, class, education, age, religion, gender, or sexual orientation, only individual behaviour. AIDS is a devastating disease, in that at present, there is no known cure or vaccination. AIDS is not a single distinct disease; instead it is a disease that is characterized by a severe suppression of the immune system, after the development of HIV. It is the most severely and debilitating manifestation of the HIV infection and represents the final stage of an often prolonged period of disease development (Smallman - Raynor et al., 1992: 37). In order to better understand the mobility and prevalence patterns of this research it is necessary to comprehend the workings of the disease. This section of the research will examine all the necessary components for a better understanding of HIV/AIDS, including the workings of HIV; the spread of HIV; testing for HIV; AIDS terminology; exposure categories; reporting procedures; treatment; a controversial aspect of HIV/AIDS; methods to combat the spread of HIV/AIDS; and newly emerging risk groups. The components are examined from a Canadian point of view as well as from the Ontario perspective.

THE WORKINGS OF HIV

HIV belongs to a large group of viruses called the lenti-viruses, viruses that have the ability to enter cells without initially doing too much damage, lying there for long periods of time, and then starting their final and explosive burst of replication (Gould, 1993: 9). HIV is enormously complex, such that it can hide and protect itself in a number of different cells of the human body, and like all viruses has the propensity to mutate. The fact that HIV mutates makes it a difficult disease to track across space, or to model for prediction purposes. It is a virus that infects certain cells throughout the entire human body. Most importantly, HIV infects white blood cells of the immune system, especially T cells. The role of these T cells is to eliminate disease-causing substances from the body. Most AIDS related pathologies are caused by cancers or opportunistic infections from bacteria, viruses, fungi, protozoa, or other microbes that the body cannot fight because of its damaged immune system (Smith, 1998: 10).

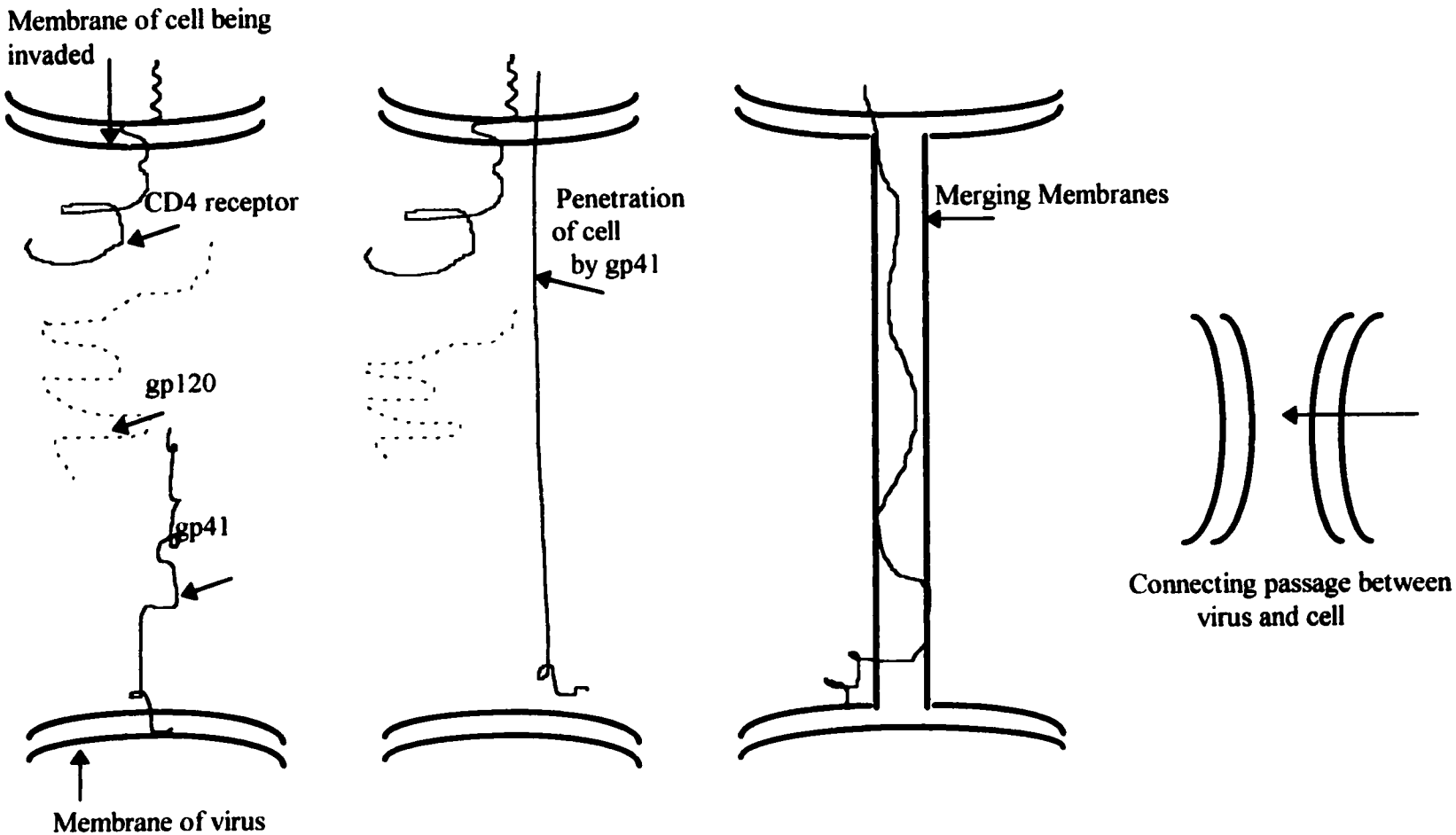
The actual form of HIV is a structure of genetic material. It has two strings of genes that are wrapped in several coats of fat and protein. The deadly nature of HIV lies in these strings and genes, together with an enzyme called reverse transcriptase. Penetrating out of the first layer of the virus are a series of small knobs each made up of a simple sugar protein called glycoprotein (gp120). The gp120 are attached to the outer membrane of the virus by another protein, gp41. It is the gp41 that actually penetrates the outer layer of the membrane of the cell. gp120 has a propensity to attach itself to molecules called CD4, which lie on the surface of a class of white blood cells called the T4 lymphocytes. The T4 cells are known as "helper cells" because they play a crucial part in the highly complex human immune system, in that they normally help the body to trigger a

response to all sorts of infections. However, these T4 cells can be ultimately destroyed by HIV. Further, any cells in the body with CD4 receptor molecules can be invaded by HIV, including two others in the first line of the immune system's defense: the monocytes and the macrophages. Monocytes roam around the body in the blood stream searching for ineffective agents to engulf and destroy. Macrophages locate in specific places and destroy infections specific to particular organs. The entrance of HIV into monocytes and macrophages is corrupting because neither are easily killed. They can harbour the HIV for a long time, and allow it to reproduce inside them, while simultaneously protecting the HIV from any immune response (Gould, 1993: 7).

Figure 6 demonstrates how HIV, with its sugar (glyco) proteins gp120 and gp41, penetrates a cell to provide a passage for the ribonucleic acid (RNA) and accompanying reverse transcriptase. When one of the gp120 "keys" protruding from the surface of the HIV locks onto a CD4 receptor of a lymphocyte, the anchoring root of gp41 follows and penetrates the membrane of the CD4 cell. It is along this line of penetration that the membranes of the virus and of the cell merge to form a connecting structure or passageway for the RNA and its accompanying reverse transcriptase, allowing movement from the virus to the cell. Once inside the cell, the reverse transcriptase "writes back" the RNA into a double helix of deoxyribonucleic acid (DNA), and it is this that works its way into the DNA of the cell's nucleus. The reverse transcriptase can then remain there for weeks, months, or even years. It is similar to a tiny template for a virus that remains until the lymphocyte is needed to fight some infection. When this happens the DNA begins to produce strands of RNA, each of which can become the core of new HIV. Other genetic information builds up the layers around it, until all it lacks is its own outer protective

Figure 6

Diagram of HIV



Source: The Slow Plague, 1993: 7

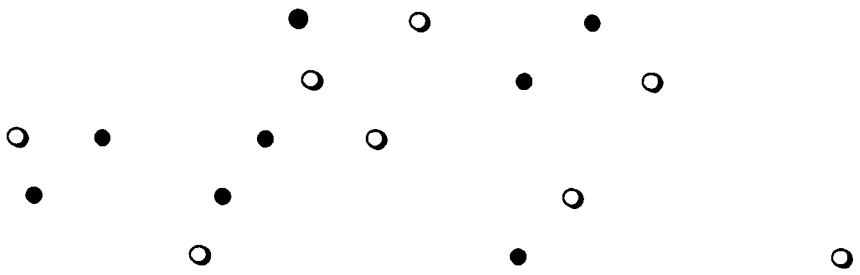
membrane. To manufacture the protective membrane, HIV uses chemicals in the membrane of its host cell as building materials. This forces a small protrusion or bud on the cell's surface. As a new and complete virus, it bursts through the membrane, and is then ready to find and lock onto a CD4 molecule on the surface of another T4 helper cell, where the process continues (Gould 1993: 7, 8).

Once HIV has attached itself to a CD4 molecule, the helper cells cannot perform their basic function of helping other lymphocytes to produce antibodies for a particular disease, nor can they produce interleukin. Interleukin is an important substance that stimulates the immune system to fight infection. As the HIV reproduces inside the helper cells, the cells also start to produce proteins on their surfaces that bind to each other. They remain uninfected cells until they form large clumps, called syncytia. Most of these conglomerations of cells die quite quickly, as do individual T4 cells. This is because their membranes are constantly ruptured by HIV buds, each of which leaves behind a tiny lesion. It does not take many of these lesions before a cell collapses. The monocytes and macrophages are more resistant, but they can still carry many HIVs inside themselves to all parts of the body, including the brain and the nervous system. HIV continues its deadly work, attacking the very cells that stimulate the immune system and using others that directly fight infection as carriers to all parts of the body. As the T4 helper cells decline, the body's immune response to infections normally kept at bay becomes weaker and weaker. Pneumonias and cancers that were once a rarity are now a way of identifying people with AIDS (Gould, 1993: 8). Thus, an appreciation of the physiology of this disease helps the researcher understand the lags between HIV and AIDS and the secondary infections used as markers for the disease.

THE SPREAD OF HIV

Understanding how HIV spreads through populations and across space and through time is necessary to better comprehend the mobility and prevalence patterns. While HIV moves literally through the human body, it also moves through areas of human life and the institutions that are a part of them. For example, if we look at a set of people, Figure 7, unstructured in any way by relations between them, HIV might live in one or two people in the set, perhaps transmitted by a blood transfusion, but could not be transmitted to others.

Figure 7

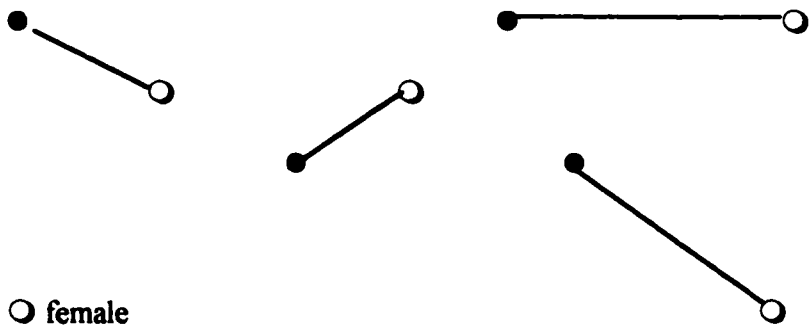


○ female

● male

However, if these same people were structured by a monogamous marriage relationship and if HIV existed on one or two people in the structure, Figure 8, HIV could only be transmitted to the marriage partner, and then disappear upon the death of both partners.

Figure 8

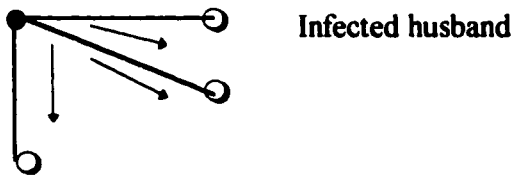


○ female

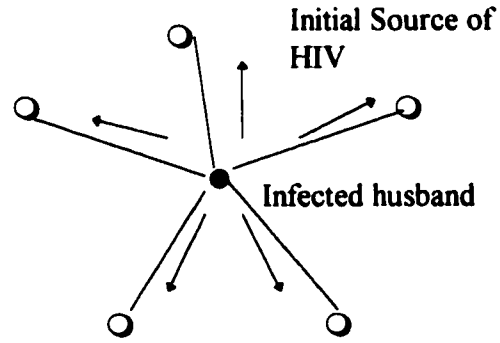
● male

Further, if we look at a set of people structured by the marriage rules and relationships of a polygamous society, Figure 9, the sexual connectivity allows for a much wider transmission of HIV.

Figure 9



Infected husband

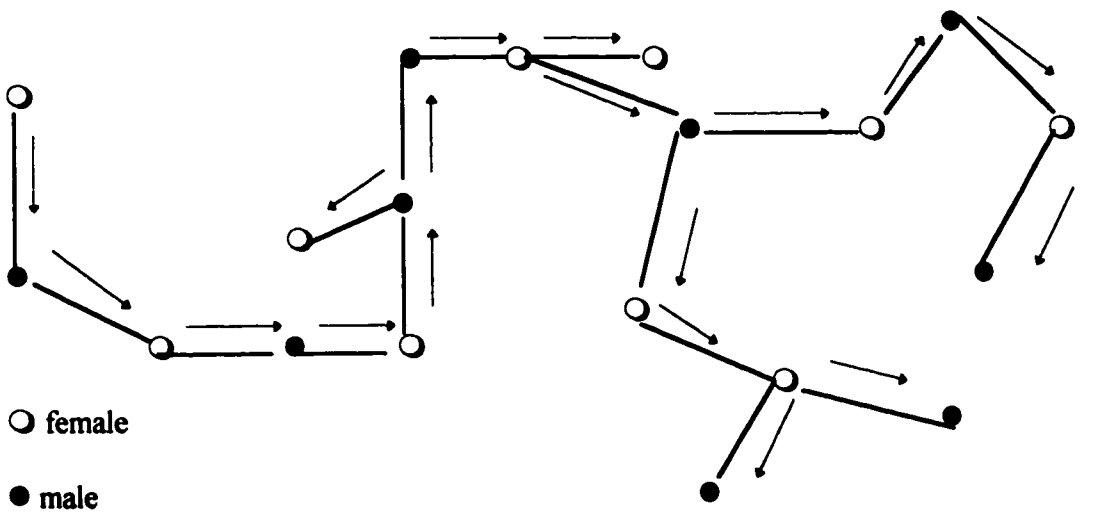


○ female

● male

Alternatively, we could have a set of people structured by multiple and unprotected sexual relations, Figure 10, allowing HIV to be transmitted over a tightly connected set of relationships.

Figure 10

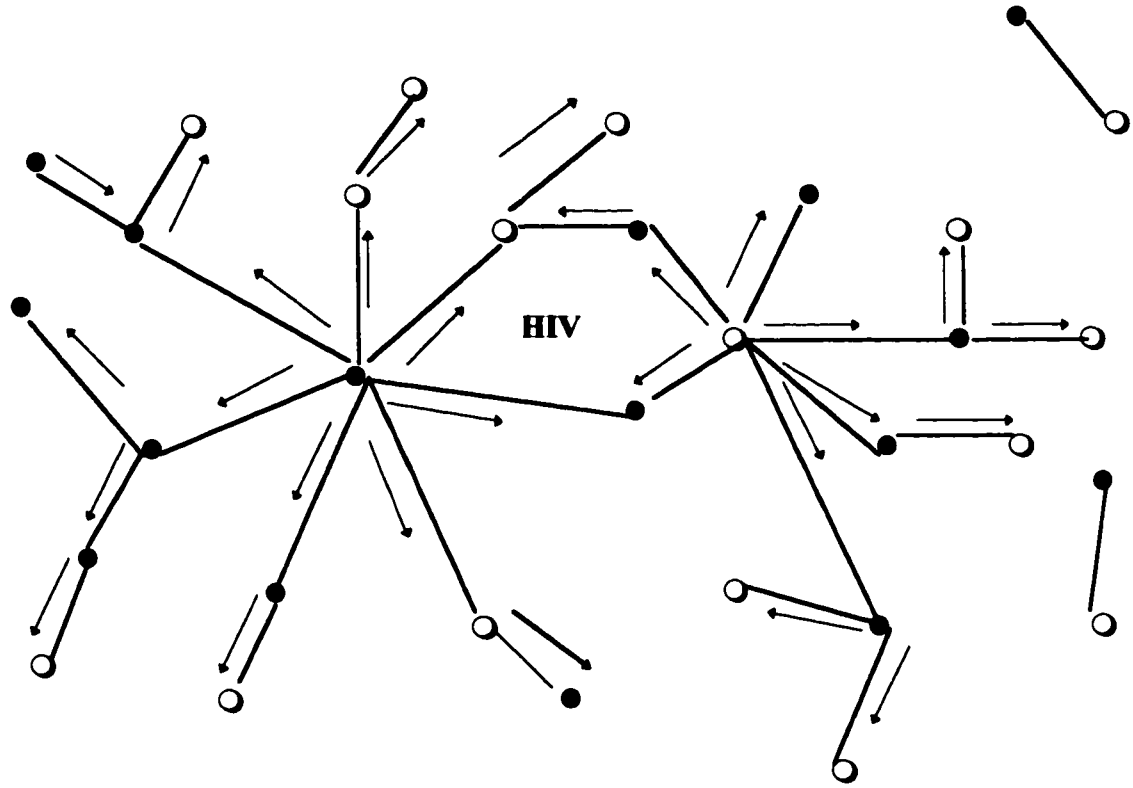


❍ female

● male

The final and most deadly structure is a set of people structured by multiple sexual relations, Figure 11, including males and females, both infected by HIV. The structure of this situation allows for rapid transmission of HIV unless structure breaking items like clean needles and condoms are used.

Figure 11



○ female

● male

If we continue to examine an even larger geographic scale we see that HIV can spread from scales that can range from the local geographies of certain districts to the national scale. In terms of a national or global scale, airline travel is a major connector of sets of countries into an international situation over which HIV can be transmitted. It should be of little surprise that there is a direct relationship between the number of international airline connections a county has and the spread of HIV. At the global scale airline travel virtually guarantees the rapid transmission of HIV. For example, in 1981 before HIV had actually been identified, the sexual contacts of forty men who had converted to AIDS were carefully traced. This led to the identification (probable) of

Patient Zero. He was later identified as an airline steward with international connections. The trail was carefully followed within the United States and it followed a series of connections that led from cities with major airports, like Los Angeles, New York, and San Francisco. Most of the men involved reported large numbers of sexual partners. Patient Zero is believed to have had approximately two hundred and fifty partners a year, in a five year time span. Patient Zero could only identify the names of seventy-two of the twelve hundred fifty contacts. Eight out of a sample of forty were infected by Patient Zero. Patient Zero is thought to have been infected in the early 1970s from homosexual relations around the world. It only takes one infected person to move from place to place, making the spatial extent of the spread of the virus limitless (Gould, 1993: 38, 39).

TESTING FOR HIV

Testing for HIV became available in Canada in 1985. The HIV antibody test is a blood test which tells an individual if they have been infected with HIV. Since the body produces antibodies to fight the HIV virus, the blood test will show if one has developed these antibodies. Most people develop antibodies to HIV within fourteen weeks after infection. Waiting fourteen weeks after a high risk activity to get tested will help ensure the test's accuracy. The knowledge of whether or not one is HIV positive can be useful for several reasons. First, if the person is found to be HIV infected consideration can be given regarding antiretoviral therapies. Second, counselling received at the time of HIV testing can provide information on how to reduce the risk of HIV infection to the individual if they are HIV negative, and to others if the individual is HIV positive.

It is important to note that laboratory data do not represent the number of individuals who are infected with HIV, but remain untested. It only provides information

on the tested population. Consequently, trends identified in HIV test data may only reflect changes in testing patterns, such as who comes forward for testing; improving duplicated removal processes; or improvement in reporting delays. Estimates suggest that approximately eleven to seventeen thousand Canadians are infected with HIV, but are unaware of the infection, as of the end of 1996. Encouraging individuals to be tested if they have engaged in "at risk" activities may not be appropriate for individuals who do not have any perception of risk. Focusing on "risks" may not be an effective prevention strategy for at least some groups or segments of the population (Jackson et al., 1997: 21, 22). Positive HIV test reports from anonymous testing sites are not included in analyses of test report data because of the implications of repeat testing and duplicate removal. The statistics represent the minimum number of positive HIV tests after removing duplicates to the highest degree possible (Health Canada, 1999).

Two reporting protocols were originally available for HIV testing: nominal and non-nominal testing. Nominal testing is a test report that includes the individual's name, and is placed in the physician's file. Ontario physicians are required by law to put the client's name on the requisition form that they send to the lab for HIV testing. If the physician chooses to use the patient's initials, this is considered non-nominal testing. Instead of a name, the form is given a code number and is then placed in the physician's file. However, the number can still be traced back to the patient. Non-nominal testing is not considered legal in Ontario, but more and more physicians are using this method. Even with the initials the physician is still legally required to report the name, address, date of birth and other personal information to the public health authorities if the client does test positive.

Since 1985 public awareness campaigns and other factors increased the need and demand for anonymous HIV antibody testing. A significant number of individuals with risk factors for HIV infection were hesitating to use HIV test services because of perceived risks to confidentiality. In 1992 the Ontario Ministry of Health introduced anonymous testing programs in designated sites under the direction of the Ministry of Health. The purpose of the anonymous testing sites was to encourage high risk individuals who feared being reported to come forward for appropriate HIV testing and counselling (Myers, 1998: 2). Anonymous testing can only occur at sites designated by the government. The site must submit a proposal to the government before obtaining approval. For the entire testing procedure, the person is known as a file number. Only the person's initials and date of birth are provided. Anonymous testing means the person being tested is the only one who can identify or receive the test result, and the individual must return to the site a week later for the results. Before the individual is tested, they must undergo intensive counselling. If the individual tests positive, it is suggested that they go and see their physician for a retest.

The HIV test is unlike any other diagnostic test, and must be done only with fully informed consent. The consequences of the test can challenge a person's identity, and is often a life altering event, thus quality counselling is designed to help inform the individual about the means of HIV transmission, and the significance of a positive or negative antibody test result. The Ontario Ministry of Health feels that counselling is more important than the test itself. The test is viewed as an effective method to help prevent HIV transmission and to help people who are infected identify the support and resources needed to live with and manage a positive test result. Counselling occurs during both the

pre- and post-testing sessions. Pre-test counselling includes reason(s) for being tested, transmission and risk assessment, prevention, interpretation of test results and reactions to a positive test result. During the post-test session, the results are given. For a positive result the procedure is to make sure the recipient is referred to appropriate treatment and counselling services and to provide support, care and information to enable the patient to manage the diagnosis. If the result is negative ways to prevent HIV transmission are reviewed (Myers et al., 1998: 2, 3).

In all Canadian provinces, HIV testing of pregnant women remains the choice of the woman. In January 1999, Ontario incorporated voluntary HIV testing of all pregnant women after informed consent as part of routine pregnancy care. This voluntary method was thought to avoid any sort of discrimination (PHERO, 1999: 174). HIV serotesting during pregnancy can provide the opportunity to offer antiretroviral treatment, such as Zidovudine (AZT) to the mother and infant. A full AZT protocol includes administering AZT to the mother during the second or third trimester, during labour and delivery, and after delivery to the infant for six weeks. Administering a full antiretroviral protocol can reduce the likelihood of transmission of HIV from mother to newborn by approximately sixty-six percent (Health Canada, 1998). Some have argued that prenatal testing is dangerous because it can produce erroneous results. The belief that they are HIV positive can persuade healthy women to start using antiviral drugs that can cause cancer and birth defects. One AIDS drug, which now carries a warning, has been linked to birth defects, and although there are concerns about some other AIDS drugs, none have been clearly linked to cancer (Nichols, 1999: 54).

Appendix A entitled "HIV Testing In Ontario", provides some samples of the literature that is used for HIV testing. The first item in this Appendix is the "Counsellor Check List for Evaluation Purposes Only". This form is for first time testers only at Anonymous Testing Sites. It collects information about gender, date of birth, place of residence, ethno-cultural identity, and country of birth. The site number of the anonymous site must also be recorded. The form asks the client reason(s) or motivation(s) for being anonymously tested at this time. It asks how the client found out about the service; completes a risk assessment, including the number of sexual partners, the use of condoms, the sharing of unclean needles, and the last possible exposure to HIV. Finally, it discusses partner notification and the post test visit.

The second item in Appendix A, is entitled "Counsellor Check List for Evaluation Purposes Only" and is similar to the first item, but this form is used for repeat testers only. Again, this form is only used for anonymous testing because no identifiers are used on the form. '95006' refers to the Ontario designated anonymous site number. Personal information is recorded such as gender, date of birth, date of visit, place of residence, ethno-cultural identity and country of birth. The form looks at the individual's previous test history, reason(s) or motivation(s) for being anonymously tested, and how the client found out about the service. A risk assessment is also completed for the client's past and current behaviour, including sexual and drug use, as well as the last possible exposure to HIV. Related information such as other STDs and other substance issues are also discussed. Partner notification is also mentioned at this time. The last section of the testing procedure includes what occurred at the post test visit and what sort of notification will occur for positive results. Many health officials comment that when they are

discussing these issues with a client, the health officials can provide the client with a relatively good idea of the final test result, based on the information that is gathered on these forms.

"Anonymous Testing HIV Serology" is the third item in Appendix A and is used for submitting anonymous HIV antibody tests. The client is only known by the number '061608'. The laboratory will only process the specimen with date of birth, sex and a risk assessment. The anonymous site's number must also appear on the form.

The fourth item is the "Seropositive Flow Sheet", for positive test results. It discusses with the client partner notification, how many partners the health department must notify, medical and social referrals that were made and which handouts were provided.

The final item in the this Appendix , "AIDS/HIV - RDIS Form" is the form used to transmit the information to the Reportable Disease Information System (RDIS). It includes information on demographics, residence, reporting source, case management, diagnostics, risk factors, diseases indicative of AIDS, and follow up data.

AIDS Terminology

When discussing a disease like HIV/AIDS, it is extremely important to clearly define the language and the terminology. The following is a list of terminology that is used throughout the research. This research uses the total annual reported AIDS cases by year of diagnosis from the PHU reports.

Table 1: AIDS Terminology and Definitions

TERM	DEFINITION
Cumulative AIDS Cases	The total number of all AIDS cases that have occurred in the population. This includes people who have died, but have not been reported since the beginning of the epidemic.
Cumulative Reported AIDS Cases	The total number of all AIDS cases that have occurred in the population. This includes those who have died since the beginning of the epidemic. The cumulative number of reported AIDS cases is only a proportion of the cumulative AIDS cases.
Canadian Surveillance Definition of AIDS	The standard inclusion/exclusion criterion to decide whether a case report is qualified to be entered into the AIDS surveillance database. It requires a positive HIV test and the onset of one or more specifically defined clinical diseases that characterize a weakened immune system.
Year/Month/Day of AIDS Diagnosis	The year/month/day of the earliest onset of the clinical disease.
Year/Month/Day of AIDS Reporting	The year/month/day when a diagnosed AIDS case is entered into the computerized AIDS surveillance database at the LCDC.
Reporting Delay of AIDS Cases	The difference between AIDS diagnosis and AIDS reporting. The ability for adjusting long reporting delays has recovered a significant proportion of the AIDS cases previously designated as underreported.
Unreported AIDS Cases	The total number of AIDS cases that have been diagnosed, but not yet reported.
Total Annual Reported AIDS Cases By Year of Diagnosis	The breakdown of the cumulative total of reported AIDS cases according to year of AIDS diagnosis.
Total Annual Reported AIDS Cases by Year of Report	The breakdown of the cumulative total of reported AIDS cases according to year of AIDS report. The greater the difference between the Annual Reported AIDS Cases by Year of Diagnosis and the Annual Reported AIDS Cases by Year of Report, the greater the problem in reporting delay.
Total Annual AIDS Cases by Year of Diagnosis Adjusted for Reporting Delay	By applying statistical analysis to the cumulative number of reported AIDS cases in Canada, measurements on the reporting delay can be made based on estimates of the number of AIDS cases diagnosed in each year that will be eventually be reported. This allows one to estimate the number of unreported AIDS cases and is important for trend interpretation. Trend interpretation is significant

TERM	DEFINITION
	because there may be changing diagnosis patterns from HIV diagnosis to AIDS diagnosis. AIDS cases diagnosed, but never reported cannot be recovered by this method.

Source: Health Canada, 1999.

EXPOSURE CATEGORY

HIV and AIDS cases are assigned to a single exposure category, or risk behaviour. This is done according to a hierarchy of modes of exposure. If more than one mode is reported for a case, the case is classified in the exposure category that is listed first in the hierarchy. For example, persons who are "injection drug users" may also be at risk of HIV infection through heterosexual activity. Injection drug use is accepted as the higher risk activity, thus this would be the documented exposure category. The only exception to this is "men who are reported to have sex with men" and have injected drugs. Such cases are classified in a combined exposure category. The following Table provides a listing of the exposure categories as defined by Health Canada, according to the hierarchy of modes of exposure.

Table 2: Major Risk Behaviours & Definitions for HIV/AIDS

EXPOSURE CATEGORY	DEFINITION
MSM	Men who report either homosexual or bisexual contact (MSM).
MSM & IDU	Men who report either homosexual or bisexual contact and who report using unclean needles (MSM/IDU).
IDU	Males and females who report using unclean needles (IDU).
Blood/Blood Products	This category is divided into two sections: those who were recipients of blood (Blood); and those who were recipients of clotting factors (Clotting).
Heterosexual Contact/Endemic	This category is divided into two sections. First,

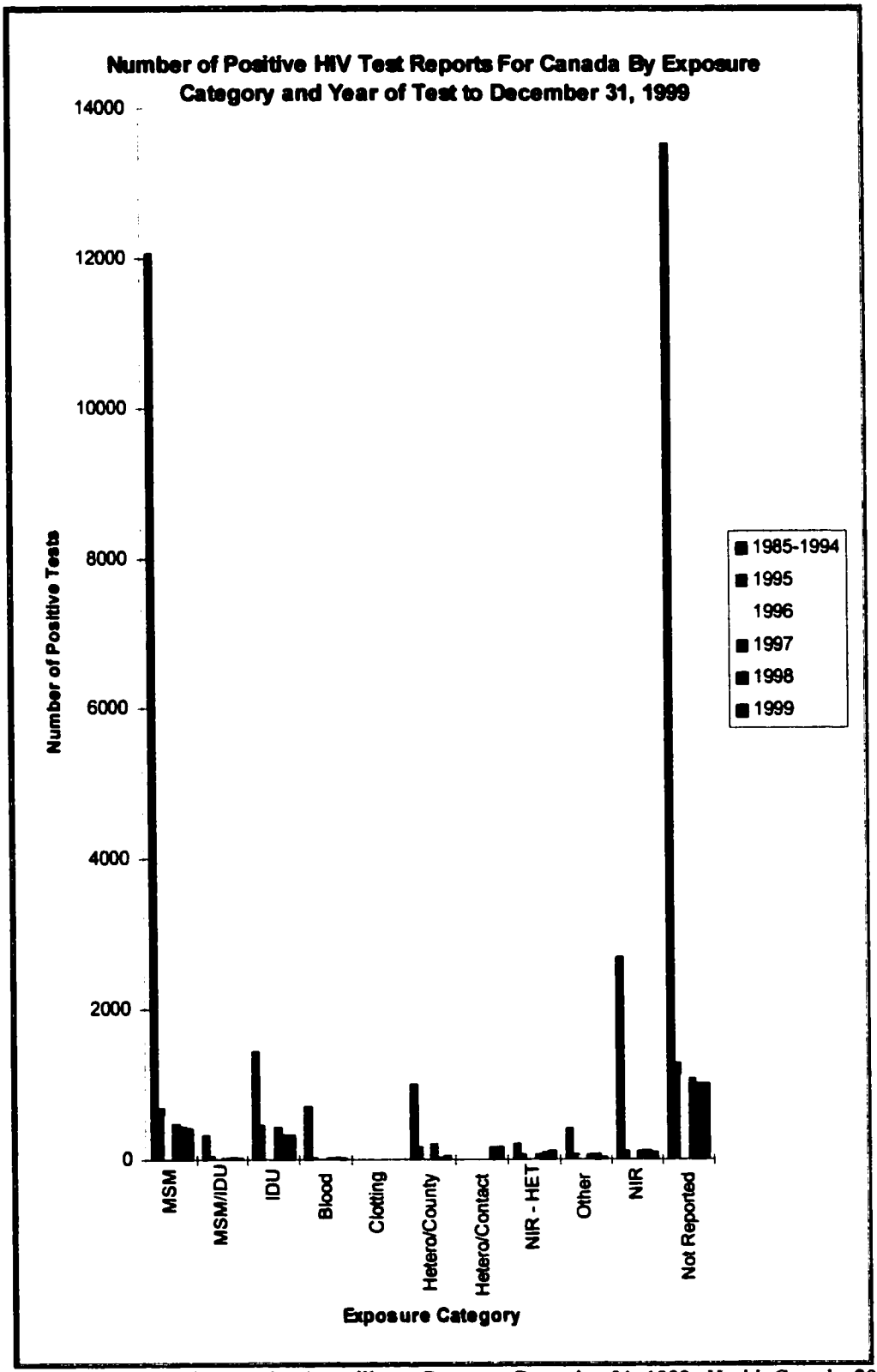
EXPOSURE CATEGORY	DEFINITION
	those whose origin is from a pattern II country (Hetero/Country). Pattern II countries are countries where the predominant means of transmission is heterosexual contact. The second category is for people who report heterosexual contact with a person who is either HIV infected or who is at increased risk for HIV infection(Hetero/Contact).
Occupational Exposure	This category may include occupational hazards, such as a health official sticking themselves with infected blood from a needle (Occupational).
Perinatal Transmission	Infection that is passed from an infected pregnant woman to her newborn child. Transmission can occur during gestation, delivery, when the fetus makes contact with maternal blood and mucous in the birth canal, or after delivery through breast milk. (Perinatal).
No identified Risk - Heterosexual	If heterosexual contact is the only risk factor, and nothing is known about the mode of exposure for the heterosexual partner (NIR-HET).
No identified Risk	This category is for persons for whom the history is unknown, or there is no reported history of exposure to HIV through any of the above modes of transmission. This category may include cases that are currently being followed by local health department officials; persons whose exposure history is incomplete because they died, or declined to be interviewed, or were lost to follow up (NIR).
Exposure Category Not Reported	The information on exposure categories of individuals who have tested positive for HIV is not available (Exposure).

In terms of occupational exposure, the Federal Government has issued standards for both health care workers and laboratories in the handling of blood, since 1985. This includes the principle that all blood should be considered infectious. The transmission of HIV through occupational accidents remains a rare cause of AIDS. As a result, occupational transmission may also be unsuspected; consequently, investigation of "No Identified Risk" cases may fail to adequately explore this possibility. People at risk for

occupation exposure include nurses, therapists/technicians, students/residents, laboratory technicians, and physicians. Means of transmission may occur through a needlestick, surgical instrument wounds, mucous membranes, or skin contact (Eves & Gemmill, 1992: 102, 103).

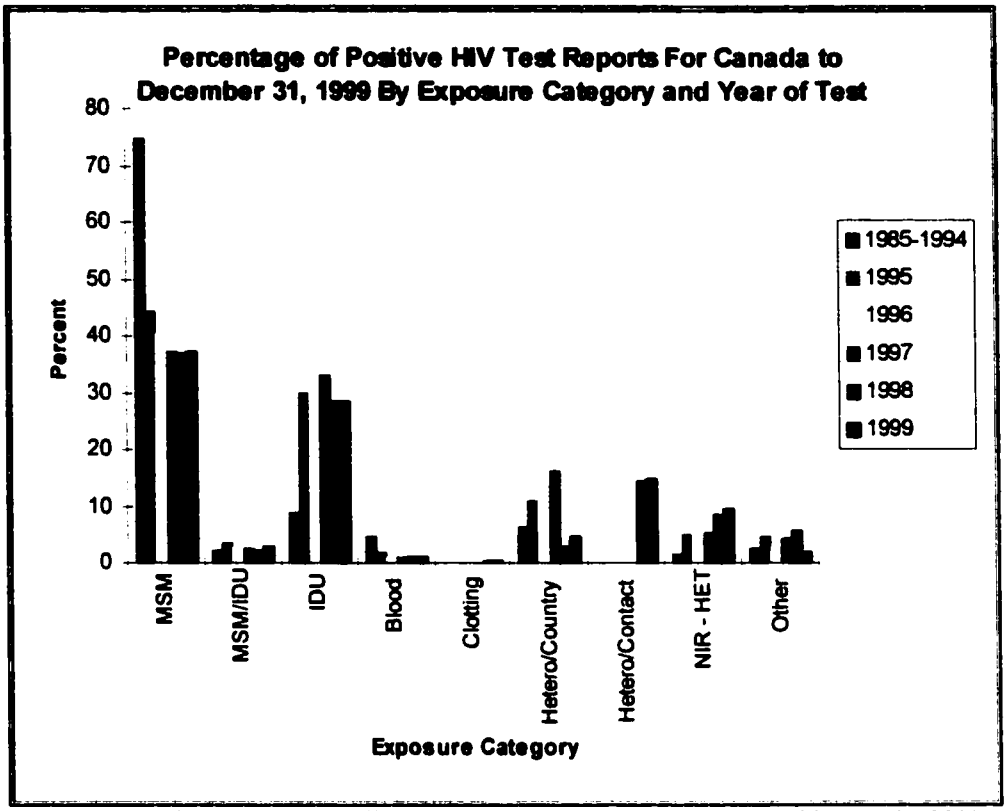
Figure 12 shows the number of positive HIV test reports by exposure category for Canada. Since the beginning of the epidemic to December 31, 1999, there have been 45 534 positive HIV tests reported to the Laboratory Centre for Disease Control (LCDC) at Health Canada. As shown by Figure 12, MSM is the largest reported category. When examining the percentages for positive test reports, Figure 13, MSM are followed by IDU. The labels on the y axis for both Figures 12 and 13 can be found in Table 2. Figure 14 looks at where the most positive tests results are occurring. Aside from not being reported, MSM are displaying the highest numbers in Ontario. However, IDU are again showing very high numbers, especially in British Columbia. The "Not Reported" category shows very high numbers in Figure 12 due to two factors. First, the HIV data for 1997 from Prince Edward Island are not available by exposure category. Therefore, these data are considered "Not Reported". Second, in Quebec, information on exposure categories of individuals who have tested positive for HIV is not available. The "No Identified Risk" and "Exposure Category Not Reported" categories do not appear on Figure 13, as the percentages are only calculated for the "known" exposure categories, not the "unknown" exposure categories. In summary, it is important that what constitutes a "case" in HIV/AIDS research, and its spatial designation, be carefully defined. In my research a "case" includes all the categories, even the "Not Reported" category.

Figure 12



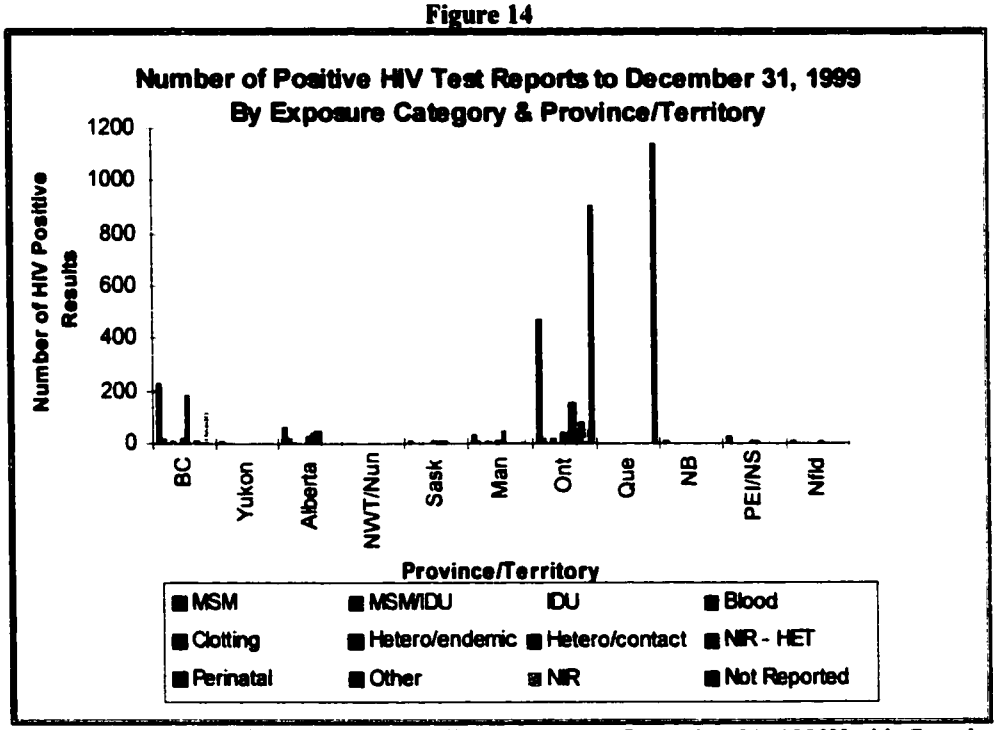
Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999 Health Canada, 2000.

Figure 13



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999Health Canada, 2000.

Figure 14



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999Health Canada, 2000.

REPORTING

In terms of reporting for HIV/AIDS, all Canadian provinces and territories participate in the AIDS Cases Reporting and Surveillance System. With the identification of AIDS in the United States in 1982, the Department of Health and Welfare Canada initiated the AIDS Case Reporting Surveillance System. The first AIDS case in Canada was diagnosed in 1979, and in 1985 the Federal Centre for AIDS (FCA) was established. It defined a case of AIDS as a person who has an illness characterized by the following:

1. One or more of the specified indicator diseases.
2. Either a positive test for HIV infection or an absence of specified causes of underlying immune deficiency (Health Canada, 1998: 35).

The AIDS case definition in Canada was revised in 1987. For those untested for HIV, the pre 1985 criteria was still to be used. The 1987 revision expanded the list of diseases to include extrapulmonary tuberculosis, HIV encephalopathy and HIV wasting. Between 1987 and 1992, the AIDS definition remained consistent and was uniformly adopted in the United States, Canada, the forty-eight countries of the WHO European Region, Australia and New Zealand. A consistent case definition enables an analysis of AIDS diagnosed cases over time.

As of July 1, 1993, the surveillance definition of AIDS in Canada was changed again. The AIDS defining illnesses of the previous case definition was retained in its entirety and three new clinical conditions were added:

1. Pulmonary tuberculosis
2. Recurrent bacterial pneumonia

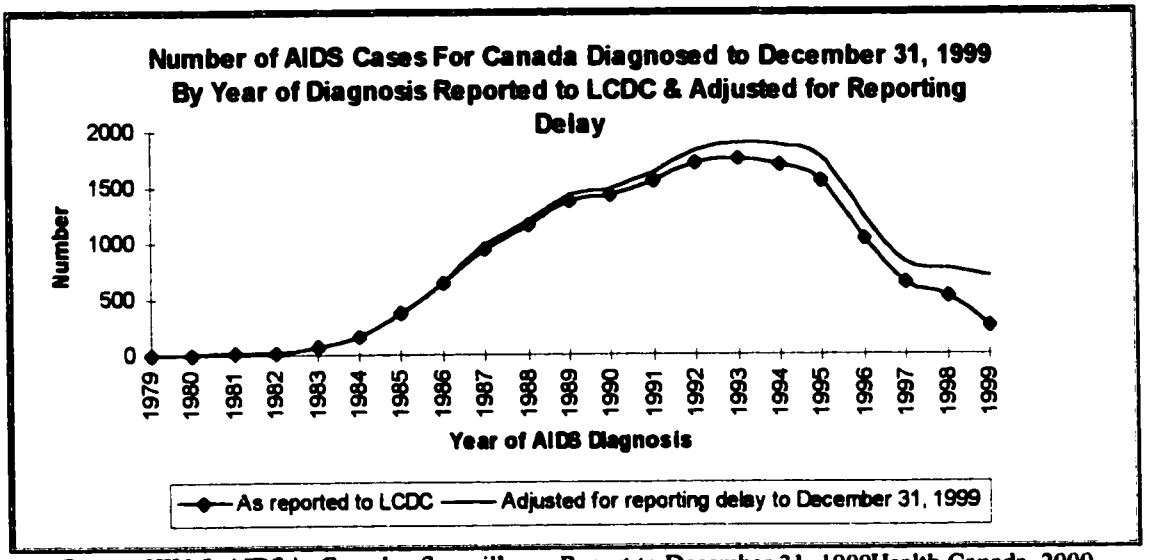
3. Invasive cervical cancer

Adding these three AIDS defining illnesses was supposed to assist in solving the concerns of under diagnosis of AIDS in women, and IDU.

After testing a client, physicians complete a standardized case report form, which is then forwarded to the respective local medical officer of health. AIDS cases in Ontario are reported to local PHUs and forwarded to the Public Health Branch, Ontario Ministry of Health. The Ministry of Health then forwards the information to the Division of HIV/AIDS Surveillance at the Laboratory Centre for Disease Control (LCDC) (Smith, 1998: 113). However, this is only done for AIDS cases, not for HIV. Data on reported cases of HIV are not available at the Ministry of Health, they are only collected at the PHU level. If a person tests positive for HIV the report only goes to the Medical Officer of Health, not to the Ministry of Health. AIDS data are managed through the Reportable Disease Information System (RDIS), which was implemented in 1990. RDIS provides for the organization of data on reportable diseases at the local PHU level and for electronic transfer to the Ministry of Health (Remis et al., 1998: 4). Physicians submit confidential case reports, including demographic, clinical and risk factor information, to their local health departments. The information is provided to the national surveillance program, the Bureau of Epidemiology and Surveillance, and the FCA. The FCA estimates that the median time between the date of diagnosis and the date of reporting is approximately three months (Calzvara et al., 1990: 38). Figure 15 show the difference between AIDS diagnosed cases reported and AIDS cases that have been adjusted for reporting delays. Reporting delay is measured as the lag time between the time of initial AIDS diagnosis, which occurs in physicians' offices, hospitals, or clinics, and the time when the case is

entered into the LCDC surveillance database. Because of reporting delays, those AIDS cases diagnosed in the recent past, for example, during the last year, will be less likely to be included in the data than those diagnosed perhaps as long as five years ago. This artifact produces unreliable trend information and substantial underreporting. Further, it makes it difficult to accurately analyze and map prevalence rates since the data are always somewhat "incomplete".

Figure 15



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999Health Canada, 2000.

Many factors affect the number of HIV or AIDS cases that will be reported in any given period. These factors include: variation in reporting delay patterns or in underreporting; current and historic HIV transmission patterns; patterns of HIV testing and access to care; the impact of therapy on the course of HIV diseases; variations in surveillance practices over time, as well as a number of factors that affect the interpretation of surveillance case report data. The failure of physicians to report all diagnosed cases of AIDS results in underestimates of the number of cases.

Underreporting leads to incorrect projections and modelling of the epidemic, which in turn may result in insufficient resources to deal with the problem. Delays in the reporting of cases may also affect the interpretation of growth rates and changes (Calzvara et al., 1990: 37).

TREATMENT

Treatment for HIV/AIDS has three dimensions. First, attacking the virus itself; second, strengthening the immune system; and third, controlling AIDS related cancers and opportunistic infections. Treatment for HIV/AIDS, or the drug "cocktails", help to reduce the incidence of opportunistic infections, to control infections previously refractory to therapy, to decrease rates of hospital admission, and to improve survival.

The new AIDS drugs have the potential to remove much of the HIV from the human body. However, researchers have long known that many copies of the virus lurk in white blood cells, ready to reactivate the deadly infection. Because only one surviving cell is needed to initiate a new infection, it can take a long time for the body to rid itself of cells that harbour HIV. If one infected cell lives in the body, it is able to pass the virus to newer cells, even at a slow rate; thus continuing the risk of AIDS. Eradicating HIV may be even more complicated if it turns out that the virus can lurk in the eyes, the testicles and the central nervous system. Many of the AIDS drugs may not be able to reach those areas. The New England Journal of Medicine (1999) has reported that the number of white blood cells that possess the HIV may slowly decline over time. Estimates suggest that it will take approximately seven to ten years of continuous, truly effective, therapy to eliminate the reservoir of HIV, and to actually consider a patient cured. It is difficult to maintain treatment for that length of time. Others have suggested that since HIV lingers

in the cells for so long, the virus cannot be eradicated with the current treatments because as older infected cells die, HIV may be infecting new white blood cells. The result is a continuously replenished supply of cells capable of reactivating AIDS once a patient stops taking medication. Others have suggested that it would take sixty years of treatment to eliminate the virus. Such long and uncertain time lags make it difficult to spatially predict the course of the disease.

The new drug "cocktails" have reduced the incidence of opportunistic infections and have helped to control infections that were previously refractory to therapy. Combination therapies such as AZT and lamivudine (3TC) have rendered monotheraphy essentially obsolete. The advent of protease inhibitors, which are designed to prevent HIV from proliferating in the human bloodstream has led to the development of triple drug combination regimes.

Many of the advances and improvements in treatments have been eclipsed by new reports of drug resistance, rising incidence in at-risk populations, and the fact that potent combinations of HIV therapies may remain too expensive and inaccessible to certain populations. These disadvantages allow the spread of AIDS to go unabated. AIDS experts also worry that the success of drug combinations known as antiretroviral treatments, are leading to a false sense of security among infected patients, as well as those most at risk of becoming infected. For example, infected individuals have thought they were cured and have behaved inappropriately. These are individuals who are taking risks in spite of the danger of infection because they mistakenly believe that there is a "cure" for AIDS. This behaviour and way of thinking only assists in the spread of AIDS. Some researchers fear that an AIDS vaccine could encourage risky behaviour. AIDSVax

is the first vaccine to receive Phase 3 testing, the final step before approval for general use. It is not being called a vaccine, only a clinical trial (Ha, 1999: A2).

Pill fatigue is another concern. Many regimens require as many as thirty-five pills a day, some with water, some without, others with meals. This has to be done for the rest of the patient's life. A growing number of patients taking the most common anti-AIDS drugs are developing severe fat problems, such as "buffalo humps" on their backs or increased girth known as "protease paunch". Side effects can also include an increased prevalence of premature heart disease, a serious form of obesity known as lipodystrophy, and liver disease. Further, the AIDS virus in some patients is already developing resistance to some of the most common antiretroviral drugs. One reason is that it is difficult to keep pace with new mutations of the virus, making it more difficult to manage the spread of AIDS. As long as the virus is given the smallest opportunity to replicate, it will do so (Mickleburgh, 1999: A1, A3).

In terms of looking at support for HIV/AIDS, there are a few options, such as hospices. A hospice is a concept of care; they are meant to help people with life threatening and terminal illnesses live at home, or in home-like settings, and to provide as much comfort as possible. Hospices focus on caring, not curing, and on life, not death. They also extend care to friends and family members. The services within a hospice are provided by an interdisciplinary care team that may include hospice volunteers, and staff, doctors, nurses, therapists, homemakers, counsellors and caregivers. The overall goal is to ensure that the emotional, spiritual, physical and practical needs of the client and family are met. The Hospice Association of Ontario has grown from eight hospice programs in 1989, to eighty in 1997. The general objective of the Association is to encourage, develop

and support the voluntary community hospice movement in Ontario. Most programs in Ontario care for people in their own homes. Hospice care spans all ages and provides services to clients with a multitude of life threatening and terminal illnesses, from cancer to AIDS (Hospice Association of Ontario, 1997).

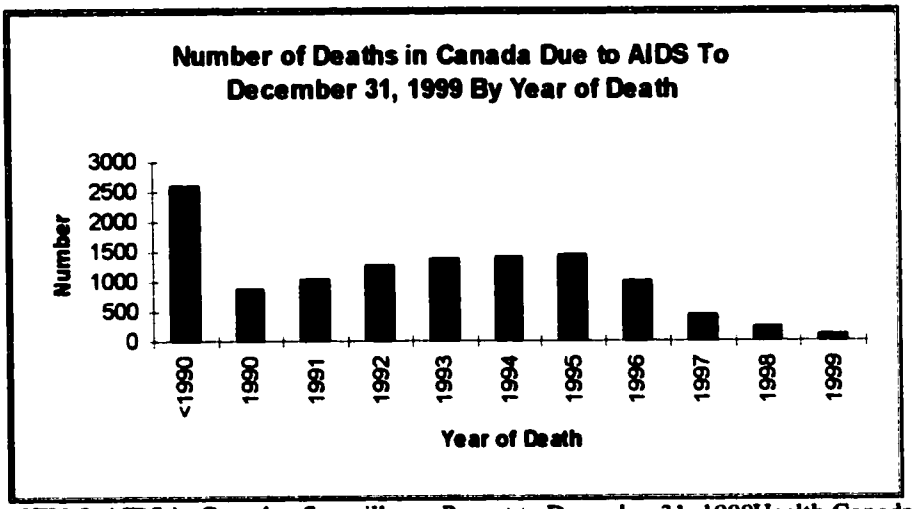
The AIDS Service Organization is another option for treatment and support. The Organization provides a number of different services to people living with HIV or AIDS. The services that are available in one community may or may not be available in another. All of the AIDS Service Organizations are members of the Ontario AIDS Network which is a provincial body of AIDS organizations. There is a strong belief and commitment to client support, confidentiality and educational services (AIDS Niagara, 1999). Appendix B, "Hospice Associations of Ontario and Ontario AIDS Service Organizations" shows a listing of the Hospice Associations of Ontario, and of the AIDS Service Organizations in Ontario at the PHU level.

One problem with many of the support groups, and this is especially true if it is a small area with only one support group, is that very few of the people who attend support groups have a lot in common with some of the other members. For example, an injection drug user and the parents of a HIV positive child may have very few of the same concerns, or needs. Other people may feel uncomfortable attending a group session. By having specific support groups, specific needs can be met, and there is the possibility that people will more open and honest.

Not all the news is negative. There has been some positive news concerning HIV/AIDS. For example, there have been significant advances in HIV therapies, as well as unprecedented reports of sharply declining death (mortality) rates. There have also

been reports of improved quality of life and extended survival for AIDS victims. People are managing the disease instead of simply dying from it. It is important to note that deaths among AIDS cases in Canada, as presented in Figure 16, may be undercounted. There are reporting delays and underreporting of deaths due to AIDS, just as there are for the reporting of AIDS cases. It is also possible that for people with HIV/AIDS, deaths due to causes other than AIDS are not reported to the LCDC. As well, in some situations, even though an attending physician may list AIDS as a cause of death, this may never be actually reported to the LCDC. The decreasing numbers may also show the impact of the treatments, or the fact that people are now managing the disease.

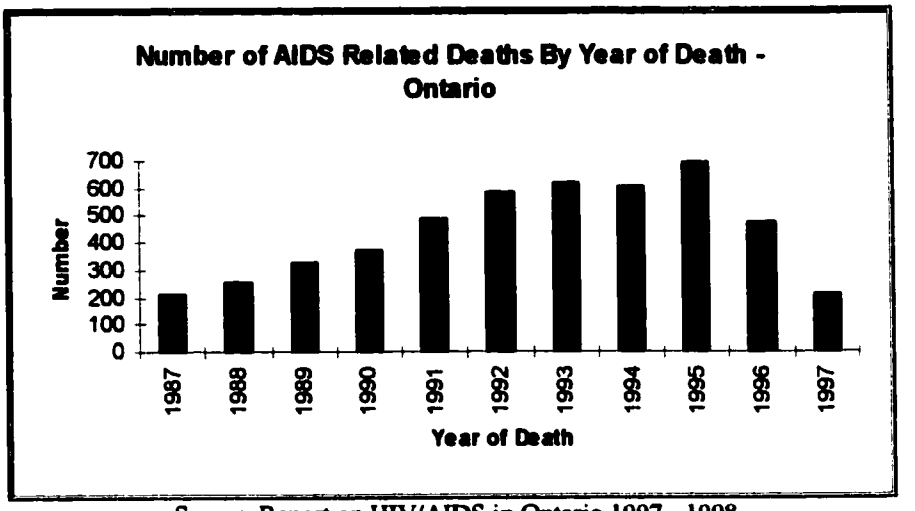
Figure 16



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999Health Canada, 2000.

Figure 17 demonstrates a similar situation at the provincial level. AIDS related mortality rates have declined steadily after 1995. However, data for 1997 are not complete.

Figure 17



Source: Report on HIV/AIDS in Ontario 1997 - 1998

A CONTROVERSIAL ASPECT OF HIV/AIDS

Like all complicated diseases there is still another side of HIV/AIDS to discuss. Some controversial research has suggested that HIV does not cause AIDS, and that AIDS is not a STD. Some researchers feel that other sexually transmitted agents are an integral part of the beginning of AIDS in some patients (Nichols, 1999: 53). There is a concern that some studies are demonstrating syphilis can trigger the process of immune system degradation. This is not easy to diagnose, and many patients become infected without knowing. Single, and especially multiple infection is very damaging to the immune system, and a strong predictor for AIDS in HIV positive people. They further argue that orthodox science has yet to explain how a difficult-to-isolate benign retrovirus can cause wreckage to the immune system and cause the devastating syndromes of AIDS. Some have suggested that this debate has been kept out of the public eye on the grounds that an open debate would undermine public health efforts. Some of this research has stemmed from the fact that many people who are HIV positive remain free of any symptoms. These

people attribute their lack of symptoms to the fact that they have never taken any of the powerful drugs (protease inhibitors) routinely prescribed for people with HIV. They believe that HIV is probably harmless and plays no part in the sickness and deaths attributed to AIDS. Further, they argue that physicians are blinded by the "HIV myth" and are harming patients by prescribing drugs that can themselves undermine the human immune system.

In this contrary view, AIDS does not actually exist. Instead, AIDS is a label placed on a group of conditions and diseases that include several types of cancer, pneumonia, tuberculosis and weight loss in people whose immune systems have been damaged by "lifestyle" factors, such as drug abuse, malnutrition, foreign proteins, antibiotics, intestinal and venereal pathogens and antiviral chemotherapies. Many dissenters claim that HIV is probably a harmless particle that may have been lodged in some families' genes for countless generations. Mainstream medical experts and AIDS organizations reject this, stating that there is a huge body of evidence that shows HIV is the cause of AIDS (Nichols, 1999: 53, 54).

There is also some concern that the dissenters could persuade people to refuse standard medical treatment, causing people to sicken and/or die prematurely as a result. For the mainstream researchers, the success of protease inhibitors is proof of the HIV-AIDS connection. Protease inhibitors are not a cure, but they can dramatically prolong the lives of AIDS victims. Health Canada attributed sixty deaths to AIDS in 1998, down from 1 419 in 1995, again suggesting that the new drugs are truly making a difference (Nichols, 1999: 53, 54). However, this could also be due to the fact that people are better managing the disease.

For those who are opposed to mainstream AIDS research, they suggest that they will need a lot more than a reduced rate of mortality to believe that HIV causes AIDS. As with the rest of the issues surrounding HIV/AIDS, politics are involved. How likely are thousands of researchers who have staked their reputations on the HIV-AIDS connection going to say that they were wrong, argue the dissenters. What is important to remember is that regardless of how the science world believes HIV/AIDS is contracted, we should be working toward the same common goals: a greater understanding of AIDS, especially in terms of prevention, and ultimately a cure. However, for many physicians who are battling AIDS, "an equally pressing concern is the harm that may be done by dissenters who seem intent on pressing their case, even at the possible cost of human lives" (Nichols, 1999: 54).

METHODS TO COMBAT THE SPREAD OF HIV/AIDS

With a better understanding of the workings of HIV/AIDS, and risk behaviours, it is time to examine what methods are available to defeat HIV/AIDS, or at the very least to reduce its spread. The success of prevention methods will have an influence upon the prevalence rates within an area. It must be noted that the methods mentioned in this section to reduce the spread of HIV/AIDS vary among the PHUs, in terms of the methods themselves, and to what degree each method is used. The variance in the use of these methods to eliminate or control the spread of HIV/AIDS may explain to some degree the spatial variation in the prevalence rates. Further, the effect or success of actions to halt the spread of HIV/AIDS depends on the epidemiologic environment within which transmission occurs. The epidemiological environment refers to the biological pattern, including infectivity and disease progression rates; behaviour patterns, such as contact

rates and patterns, sexual and drug injecting practices; and demographic features, such as birth, immigration, emigration and death rates (Kaplan & Brandeau, 1994: xxv, xxvi).

The extent and form of human interaction is critical for the spread of AIDS. Variables such as distance, intervening opportunities, and the distribution of attractions and facilities all influence the level of transmission. Diffusion is patterned by the configuration of the networks that encourage movement and barriers that discourage it. A major prerequisite of disease diffusion is the existence of a sufficiently large susceptible population. A sufficiently large immune population, or a sufficiently small susceptible population can serve as an effective barrier to disease transmission (Meade et al., 1988: 235). Further, a sufficiently protected population, in terms of sexual practices and injection drug use, is also an effective barrier to the transmission of HIV/AIDS. The next part of the discussion focuses on the elements that can act as effective barriers to the spread and transference of HIV/AIDS. At the end of the section a summary Table is included that encapsulates the methods to eliminate, or reduce the spread of HIV/AIDS.

EDUCATION

Education must target all parts of society because all humans are potentially at risk. AIDS education must have long term goals because short term changes in risk behaviours are not sufficient. There are only two effective and humane ways to combat the AIDS epidemic: education and planning. Many have argued that for the most part, education appears to be ineffective. A great number of people see HIV/AIDS as something vaguely "out there", far away and without personal immediacy. Many people may need to personally experience the reality of HIV/AIDS in order to see it as a threat. HIV/AIDS awareness has become so much a part of our culture, that for some it may be

barely noticeable. The results of how effective educational efforts have been at the provincial and PHU levels are discussed in the "Results" section of this research.

One problem with sexual education within HIV/AIDS education is that some adults or authorities are concerned that this information will promote experimentation and/or promiscuity. They further argue that open and free discussions among young people about sex and sexuality may be harmful to moral, cultural and family values. HIV/AIDS education must also deal with the notion of hedonism, a theory that suggests that people will always act in such a way as to seek pleasure and avoid pain. Everyone needs to hear the prevention message, and if the focus is only on those who participate in the major risk behaviours, education efforts will not be as effective because it may mean that many misinformed people were convinced that they were immune.

The most important facet concerning prevention and education is the message itself, and how that message is communicated. The ethnic diversity of a country like Canada, forces AIDS educators to use a variety of methods to deliver the message. If people cannot understand the message and/or internalize it, they are putting themselves at risk for HIV/AIDS by their own ignorance; thus stressing the importance of a message that relates to all people. Members of some cultural groups may feel excluded from mainstream HIV/AIDS education, treatment, and support services, because preventative information produced by mainstream service organizations can create resistance in ethically diverse communities. People may find it alienating or even offensive. Many ethnic communities are now establishing their own culturally specific AIDS education programs.

One of the biggest misconceptions that AIDS prevention and education programs must face is the idea that AIDS is a disease of "gay white men". For example, the Alliance for South Asian AIDS Prevention in Toronto found that South Asian people generally believed that AIDS could not happen to them. The unfortunate reality is that India will soon have one of the world's highest rates of HIV infection. People frequently travel back and forth between Canada and India, making Indian-Canadians at risk, even if they live a "traditional lifestyle". This "traditional lifestyle" means living according to the religious laws that govern the culture. It means that sex is rarely discussed, and sex outside of marriage and homosexuality are considered sinful; thus talking about the causes of HIV/AIDS goes well beyond the norms of decency. Moral and religious beliefs also hamper AIDS education among immigrants from Caribbean countries. Many have strong beliefs that AIDS is like a biblical plague, a retribution for doing something "bad". Many people believe that if they are "good" they will never contract HIV/AIDS. Cultural issues thus play a crucial role in the spread of the disease.

Another concern about the prevention message is its geographic location, in terms of where people must go to hear it. Sections of the Greater Toronto Area have many immigrants, often from designated endemic countries. Many of the support groups are located in downtown Toronto, and many of the infected women do not want to go downtown for fear of being recognized by someone else. Toronto's Department of Public Health funds the group Caribbean Women Against AIDS, and has tried to alleviate the location problem. Since women are reluctant to attend the support groups, the outreach workers visit grocery stores, laundromats, and hairdressing salons where they can get to know the women and offer them education on prevention and support (Lechky, 1997).

One reason to ensure that prevention messages are being heard and understood is that the AIDS rates among the black immigrant populations are far above the national average. For example, people coming from African and Caribbean countries account for twelve percent of Ontario's HIV cases (Bueckert, 2000: C8). A 1996 study found that seventy percent of HIV infected children at the Toronto Hospital for Sick Children were born to mothers of African descent. To make matters worse, Canada has not committed to mandatory AIDS testing of newborn infants. Mothers from countries where AIDS is endemic are informed about the risk and offered a test, but many women refuse due to fears that a positive test result would affect their prospects of being allowed to stay in Canada. AIDS endemic countries like Botswana, Namibia, Zimbabe have one fifth to one quarter of their populations infected with HIV/AIDS (Bueckert, 2000: C8).

NEEDLE EXCHANGE PROGRAMS

Needle exchange programs started in Canada in 1989 and have since become widespread. Needle exchange programs are important because they are a means of preventing HIV. IDU indicate that a common reason for sharing needles is the difficulty in obtaining clean equipment. The long term objective of a needle exchange program is to prevent HIV infection from the sharing of needles. The immediate objective is to minimize harm by reducing needle sharing through the provision of clean needles. Needle exchange programs reduce the risk of HIV infection with the use of the "circulation theory", by helping to decrease the amount of time that contaminated needles are in circulation.

However, there is conflicting evidence as to whether needle exchange programs increase either initiation into injection drug use, the frequency of injection, or prevailing

levels of drug use in a community. There is a great deal of evidence suggesting that needle exchange programs are cost effective and can help control the transmission of HIV among IDU (Hankins, 1997). However, there are still concerns that needle exchange programs may be less effective for people who inject cocaine, whose numbers are increasing. Cocaine users tend to inject as many as twenty times a day and the likelihood of them using a clean needle every time is slim. In addition, there is the worry that in attracting IDU, who are at high risk for HIV/AIDS, needle exchange programs in large metropolitan areas may be serving to foster new social networks. The programs may be bringing people together who otherwise might not meet, creating new social networks, which extends the number of susceptibles and the likelihood of the disease spreading. It also fosters the mixing that has been shown to increase HIV transmission. In addition, quotas on the number of needles that can be exchanged daily may exacerbate the situation and likely disadvantage cocaine injectors more than heroin users (Hankins, 1997).

Some of the concern results from the fact that rigorous evaluations of how effective needle exchange programs are at reducing the incidence of HIV infection have not been possible, due to ethical issues associated with experimental methods. There has also been difficulty in terms of follow-up in observational studies. It must also be noted that reliance cannot be on needle exchange programs alone; instead they must be integrated with a wide range of additional services that emphasize treatment and rehabilitation. In Hankins' 1997 article in the Canadian Medical Association Journal, she states that once the prevalence rate of HIV infection in a community of IDU has reached ten percent, it is difficult to control transmission. This is based on the experience of several cities in Europe and Asia. There is also considerable evidence that needle

exchange programs are having their intended effect of reducing incidence rates of HIV infection among IDU without increasing rates of drug use. In Canada federally funded evaluations of the early programs looked at the number of people who were being reached, the rates of needle and syringe exchange, demographic characteristics and behavioural factors, such as drug injection practices, and sexual activity. Reductions in needle sharing and the increased use of bleach to clean needles were clearly shown. Hankins' work further revealed that needle exchange participants are more likely to have paying sexual partners, to be MSM, and to have a higher HIV incidence rate than nonparticipants, clearly suggesting that needle exchange programs attract a higher risk clientele (Hankins, 1997).

In reference to the earlier comment about treatment and rehabilitation, a difficulty for IDU is that access to detoxification services and to appropriate treatment and rehabilitation programs is generally poor. Many of the programs have long waiting lists. It is interesting to note that four times more is spent on law enforcement for illicit drug use in Canada, than is spent on health care and treatment for users. Further, incarceration itself has been shown to constitute a risk for HIV infection. Inadequate and ill-adapted treatment programs contribute to maintaining the number of active drug users, with huge implications for HIV transmission. Finally, HIV among drug users may ultimately touch other lives, infecting and affecting many people who have never even used drugs (Hankins, 1997). For example, a study by Homberg in 1996, showed that as of 1995, 80% of HIV positive heterosexual men and women who had never used injection drugs had become infected through sexual contact with someone who did (Homberg, 1996).

In addition to providing clean needles, needle exchange programs are useful as a way of getting in touch with an otherwise hard to reach population in order to provide a variety of related harm reduction services to drug users, including substance abuse counselling and referral; anonymous HIV testing; hepatitis B vaccination; safer sex counselling, and the provision of condoms and dental dams. Needle exchange programs have evolved to provide primary health care to a marginalized, urban core population (Health Canada, 1998). An effective way of preventing HIV/AIDS in IDU is to establish trust on the street through the use of outreach workers. These workers use a non-judgmental approach, and are willing to go into shooting galleries. A shooting gallery is a place, such as an apartment, where addicts can prepare and inject illicit drugs. The necessary equipment is usually provided on the premises. Success in this type of prevention method can also be attributed to hiring a street worker who knows street life, and who has come from that background. What is paramount in this discussion is the fact that clean needles and condoms alone are not sufficient prevention efforts to tackle the social underpinnings of poverty and addiction. It is difficult for people to use clean needles if they cannot even supply themselves with the basic necessities of life, like food and shelter.

In summary, various studies on the effectiveness of needle exchange programs have yielded different results. Some studies, like Hankins, have shown that needle exchange programs attract IDU who are at a relatively high risk for HIV infection. A study completed in Montreal in 1998 found that frequent needle exchange programs attendees have lower incomes, less social support, and are more likely to attend shooting galleries or inject with a group of people (Health Canada, 1998). Another study in

Vancouver found that males who were frequent needle exchange program attendees reported higher cocaine use. Females who were frequent attendees injected more habitually, were more likely to have a non-legal source of income, and were more likely to inject at shooting galleries. However, there is also evidence that needle exchange programs prevent HIV infections among IDU and do not increase the number of IDU or lower the age of first injection. Some studies have found a reduced incidence of HIV among those who attend needle exchange programs (Health Canada, 1998). This topic continues to be spatially important because it discusses barriers to the spread of HIV/AIDS. If these barriers are effective it can mean that HIV/AIDS will no longer continue to spread throughout an area, thus affecting the prevalence rates.

PROTECTED SEXUAL ACTIVITY

When examining the effectiveness of condoms in terms of preventing HIV/AIDS, there are a variety of studies. First, Dahl et al. (1996) looked at the purchase and availability of condoms and found that highly specific targeted marketing approaches are necessary to overcome existing barriers to purchasing condoms. Dahl et al. completed their study at a Canadian University and found that the barriers to purchasing condoms are embarrassment, complexity of purchase (difficulty in choosing a brand), type of condom to purchase, and price (Dahl et al., 1996).

Another study by Guttmacher et al. in 1998 examined if access to condoms influenced adolescent sexual behaviour. They determined that condom availability had a modest, but significant effect on condom use at last intercourse, but did not increase rates of sexual activity. They found that many adolescents do not have the financial resources, the self confidence, or the foresight to obtain condoms at drug stores, or family planning

clinics. School based condom availability programs can reduce financial and psychological barriers and offer opportunities for discussing HIV/AIDS and other STDs, proper condom use and safer sex. Reported condom use at last intercourse varies by age, gender, ethnicity, age at first intercourse, number of sexual partners, frequency of sexual activity, self efficacy, peer risk taking, sense of control and presence of depression. Guttmacher et al. determined that most adolescents do not perceive themselves at risk for HIV/AIDS, despite the fact that they might engage in unprotected sex. Because of this misperception, HIV/AIDS education alone has been found to have little impact on behaviour. For example, classroom based programs have had limited success in delaying the onset of sexual activity, raising contraceptive or condom use, or lowering pregnancy or STD rates. Instead, programs that provide additional services such as comprehensive school based clinics or youth development services, have been somewhat more successful (Guttmacher et al., 1998). Condom usage and safer sex at the PHU level will be discussed further in the "Results" section.

Contact Tracing and Partner Notification

Contact tracing refers to the type of efforts conducted by various government agencies to identify any and all persons who might be at risk of contracting a particular disease from an affected person. Partner notification refers to information conveyed to spouses, sexual partners, needle sharers and any person that might be at risk of communicable diseases. Both of these actions are thought to help educate people about the risk of the disease, to hopefully reduce the number of new incidences of the disease, and to identify persons who might benefit from medical attention (Smith, 1998: 153).

All of the aforementioned prevention mechanisms are fighting the forces of denial, discrimination and scarcity. Prevention efforts can only achieve their desired success if efforts are made to prevent discrimination against those that are infected, or those who may be at risk. Prevention efforts should not be viewed as a one time action, but rather a continuous effort that extends for a long period of time, or until it is no longer necessary. Successful or effective education and prevention efforts can help to eliminate and/or reduce the spread of HIV/AIDS. Table 3 provides a summary of the methods to combat the spread of HIV/AIDS.

Table 3: Summary of Methods to Combat the Spread of HIV/AIDS

METHOD	PURPOSE	INFLUENCE
Education	• To openly discuss the means by which HIV/AIDS can be spread, or contracted, and ways to prevent this from happening.	• Education is only effective if it reaches every person who is sexually active or who participates in injection drug use. • Working against: barriers of ignorance; seeing HIV/AIDS as something without personal immediacy; and cultural differences. Many do not perceive themselves at risk, therefore education alone has little impact on behaviour.
Needle Exchange Programs	• To prevent HIV infection from the sharing of needles by reducing needle sharing through the provision of clean needles. • To decrease the amount of time that contaminated needles are in circulation. • To get in touch with a hard to reach population in order to provide a variety of related harm reduction services.	• Conflicting evidence regarding whether needle exchange programs increase either initiation into injection drug use, the frequency of injection, or prevailing levels of drug use in a community. • Needle exchange programs may also foster new social networks among injection drug users. • Needle exchange programs can be cost effective and can help control the transmission of HIV among injection drug users.
Protected Sexual Activity	• To use protective measures like condoms to reduce the likelihood of HIV/AIDS being contracted during sexual activity.	• Difficulties in purchasing condoms can influence the effectiveness of people using them. • Using a condom also depends on age, gender, ethnicity, age at first intercourse, number of sexual partners, frequency of sexual activity and self-efficacy.
Contact Tracing and Partner Notification	• To educate people about the risk of the disease, to reduce the number of new incidences of the disease, and to identify persons who might benefit from medical attention.	• Fighting the forces of denial and discrimination.

NEWLY EMERGING RISK GROUPS

Several social phenomena have combined to make this a particularly dangerous time for transmission of HIV infection in older adults. First and foremost, the demography of Canada is changing. Older adults comprise the most rapidly increasing population subgroup. These older adults are leading active, vigorous lives, in which sexuality plays a role. However, these "sexy seniors" often view themselves at low risk for HIV infection, possibly because they did not grow up thinking about AIDS and sexual activity in the same way that many young adults during the late 1980s and 1990s have done. Second, pregnancy is not a paramount issue when older adults engage in sexual activity; therefore protective measures are often discarded. Behavioural studies have shown that the elderly are the least likely to practice HIV preventative measures (High, 1998). This lack of awareness is heightened by the fact that AIDS preventative measures typically neglect older adults as targets for preventative education. Third, pharmacological interventions now make it possible for many older adults to increase their sexual activity. Most notably, the introduction of silbenafil (Viagara) may greatly enhance rates of successful intercourse in older men with erectile dysfunction. All of the enhanced sexual activity may not be confined to monogamous, low risk, or protected relationships (High, 1998). Again, without using the appropriate preventative measures, HIV/AIDS will continue to spread and pose a threat to all populations.

The background information on HIV and AIDS is necessary to accomplish the objectives of this research, examining mobility patterns and prevalence rates. The workings of the disease, the testing procedures, the reporting structures, how it is treated, and the prevention methods, all impact how the disease will spread, and how people will

react and be affected. How the disease spreads and people's reactions all influence mobility patterns and prevalence rates. This concludes the section pertaining to background information on HIV/AIDS. The next sections will discuss the Methods and Results of the research.

CHAPTER THREE

METHODS

INTERVIEWING THE ONTARIO PUBLIC HEALTH UNITS

THE PURPOSE OF THE INTERVIEWING PROCESS

This section will continue to provide the necessary background information that will allow an examination of the mobility patterns of AIDS patients. The original idea of mapping the spread, or prevalence of AIDS in Ontario originated from the work of Professor Peter Gould at The Pennsylvania State University. Gould's work sought to map the spread of AIDS throughout the state of Ohio. However, there is one important difference between this study in the United States and in Canada. In the United States, the reporting of AIDS is done according to place of residence; that is regardless of where one tests for HIV, the test results reflect that person's place of residence. In Canada, and more specifically, Ontario, the system is slightly different.

Reporting of AIDS in Ontario is done according to place of diagnosis. This may not cause difficulty if a person is undergoing a nominal or non-nominal testing procedure, since they are likely going to a physician's office within their area of residence. However, if the client wants an anonymous test and there is not a designated site within his/her area they will have to go elsewhere, meaning that if they test positive their number will go to the area where they were anonymously tested. This restricts the questions one can ask about the spread of HIV/AIDS. For example, the area of Toronto displays very high numbers of AIDS cases. However, these numbers do not necessarily reflect all the cases simply within the area of Toronto. Many people from the surrounding areas may go to Toronto to the anonymous sites for testing. There are further implications of this. People may test positive in Toronto, but return to their own area to use the services and

resources, even though they would not be reflected in their area's statistics. To gain a better understanding of where people were or were not moving for either testing, or treatment, or support of HIV/AIDS, the decision was made to interview those people in charge of HIV/AIDS at the forty-two PHUs of Ontario. By better understanding the degree or likelihood of mobility, it would hopefully be easier to examine and draw some conclusions about the spatial patterns and variations of the disease, the accuracy of the existing statistics, and to alleviate some of the problems resulting from the place of residence versus place of diagnosis testing issue.

Population mobility is considered to be a key factor influencing the geographic spread of human diseases, especially those with direct human-to-human transmission, like HIV/AIDS. Daily patterns of activity, such as commuting to and from work, visiting relatives and friends for short periods, and holiday travel, are the kinds of activities that are most relevant for infectious disease transmission. According to Sattenspiel, what is needed most for models of the geographic spread of infectious diseases, including AIDS, is detailed data on daily activities. These data should include questions on where, when and how people travel within and among regions and how long they stay at their destination. "Without knowing the answers to these questions, it will be difficult to gain more than a minimal understanding of the mechanism by which infectious diseases spread across time and space" (Sattenspiel, 1994: 511). This research will only focus on one aspect of mobility behaviour, that of the likelihood of movement to sites near or far from place of residence for testing, treatment and support.

THE INTERVIEW PROCESS

All forty-two of the AIDS Educators at the Ontario PHUs were successfully interviewed. Approximately one third of the Educators were interviewed in person. This meant travelling to the PHU and meeting with the AIDS Educator. In one instance the interview was conducted during a team meeting. The meeting involved approximately ten people from different aspects of the PHU; thus a greater perspective of the area and HIV/AIDS was obtained. The interviews usually lasted approximately one hour. For the remaining Educators, a telephone interview was conducted. Again, each interview lasted for about an hour, and the same questions were posed. Every Educator was extremely helpful and very interested in this research. Initially, the intention was to only ask about the mobility issues. However, it seemed to make sense to ask the Educators for their impressions on other aspects of HIV/AIDS, such as the politics behind the disease, reporting issues, prevention, major risk behaviours in their respective areas, testing issues, support, and overall impressions. In many instances the questions simply acted as a starting point for the discussion. One question could create lengthy debates about other related issues and topics. However, at no time were individual cases discussed; no breach of confidentiality was possible as each PHU has more than one case, as displayed by Table 4. The primary questions were on general patterns of mobility, not on individuals. The interview process started on June 3, 1999 and finished on September 29, 1999. Approximately two to three interviews were completed each week during the time period.

Table 4: Total Number of AIDS Cases Per Public Health Unit 1990 - 1999

PUBLIC HEALTH UNIT	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
Algoma	5	6	9	8	8	10	8	10	13	13
Brant	12	17	18	27	29	31	31	30	31	31
Bruce, Grey-Owen Sound	10	10	12	14	16	21	21	25	26	27
Durham	17	28	37	50	60	74	87	98	101	102
East York	43	47	63	83	91	107	107	117	125	126
Eastern Ontario	6	10	15	16	22	25	26	28	28	29
Elgin-St. Thomas	3	4	6	7	7	8	8	9	11	13
Etobicoke	36	52	68	91	101	115	137	141	151	156
Haldimand	4	11	12	12	14	15	15	16	16	16
Haliburton-Kawartha	2	2	4	7	10	13	14	16	18	18
Halton Region	29	29	43	55	66	75	79	86	92	93
Hamilton-Wentworth	38	51	64	88	117	135	147	163	180	181
Hastings-Prince Edward	12	15	20	25	27	39	42	45	45	45
Huron	4	4	4	5	6	6	8	10	10	11
Kent-Chatham	2	4	4	10	12	15	17	17	17	19
Kingston-Frontenac	17	19	20	36	39	45	53	58	60	62
Lambton	8	9	10	14	14	18	19	19	20	20
Leeds-Grenville	6	8	9	11	15	16	21	25	27	27
Middlesex-London	65	87	113	130	158	182	193	205	216	220
Muskoka-Parry Sound	2	3	4	5	6	8	13	11	14	14
Niagara	25	42	55	71	82	94	109	115	122	127
North Bay	5	8	12	15	20	22	22	23	23	24
North York	71	89	114	149	168	196	213	225	228	235
Northwestern	2	2	2	2	2	3	4	5	6	6
Ottawa-Carleton	162	220	267	304	426	441	464	487	527	544
Oxford	2	4	4	10	13	18	18	15	17	17

PUBLIC HEALTH UNIT	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999
Peel	47	85	105	127	143	176	191	208	221	226
Perth	7	10	10	13	14	16	17	17	17	17
Peterborough	8	8	11	16	23	26	31	32	32	33
Porcupine	3	7	7	8	9	9	8	8	10	10
Renfrew	8	9	11	11	11	13	13	13	13	14
Scarborough	52	73	100	136	168	181	193	206	215	222
Simcoe County	17	27	33	49	52	59	60	68	71	73
Sudbury	7	12	18	24	43	49	55	56	59	60
Thunder Bay	11	11	13	13	18	26	28	28	29	29
Timiskaming	1	1	2	6	6	8	8	8	8	9
Toronto City	1018	1208	1594	2007	2260	2682	2944	3073	3163	3233
Waterloo	13	25	31	41	46	57	70	71	72	76
Wellington-Dufferin-Guelph	14	25	24	32	37	43	48	49	50	50
Windsor-Essex	70	100	113	132	151	165	166	172	188	189
York City	27	34	44	61	76	87	94	108	114	114
York Region	44	48	54	66	85	88	97	112	116	118

Only one catch arose out of the entire interviewing process. One individual believed that since the Greater Toronto Area (Etobicoke, East York, North York, Scarborough, Toronto City and York City) is now one political unit, the six PHUs within the Greater Toronto Area should provide a unified response. However, this was not actualized for a number of reasons. First, when the suggestion was made for a unified response, five of the six Educators had already been interviewed. Further, the Greater Toronto Area may geopolitically exist as one area, but by examining it as one entity a great deal of detail for the six areas would be lost. Within each area of the Greater Toronto Area there are a number of differences in terms of what is or is not happening with respect to mobility patterns and the spread of HIV/AIDS. The concerned individual agreed with this reasoning, and all six areas within the Greater Toronto Area provided their own answers and impressions.

There are three main reasons for using the AIDS Educators at the Ontario PHUs for this research. First, there are a workable number of AIDS Educators with which to collect and present the information and impressions. To interview people affiliated with HIV/AIDS related facilities or people directly associated with HIV/AIDS would mean that there would be countless organizations and people to consider, a task far beyond the scope of this research. Further the AIDS Educators are highly trained and focused on HIV/AIDS. The majority of the Educators have been involved with HIV/AIDS for a lengthy period of time, some had close to a decade worth of experience. It must be noted that since the Educators had different amounts of experience working with HIV/AIDS, their "impressions" are based on their experience thus far into their career. The second reason for using the AIDS Educators is that they are dealing firsthand with people affected

by and affected with HIV/AIDS. This firsthand knowledge is very valuable because it provides a unique perspective that other sources cannot. Finally, interviewing the AIDS Educators is a first step in attempting to better understand the mobility patterns for testing, treatment and support. Future research attempts could consider interviewing people associated with HIV/AIDS since it would provide a large sampling frame from which to choose subjects from. In addition, by interviewing these people one could obtain a much different impression of the disease. As such, the interviews with the AIDS Educators were simply meant to provide an impression of spatial patterns, not a direct analysis of individuals and processes producing the patterns.

The first set of questions asked the AIDS Educators to assess the degree of mobility of individuals in their catchment areas in terms of testing for HIV, treating HIV/AIDS, and receiving support for people with HIV/AIDS. The second set of questions examined the sorts of events that were occurring in the Educator's areas that were either contributing to, or counteracting the spread of AIDS in Ontario. The third set of questions were meant to better understand the major risk behaviour groups in each of the PHUs, and to gain an overall impression of HIV/AIDS in each of the PHUs. The answers and discussions regarding all of these questions appear in the "Results" section.

1. MOBILITY QUESTIONS:
   - Do you have the impression that people are leaving the area to be tested for HIV; or do you feel that they are remaining in the area to be tested for HIV?
   - Where is the closest Anonymous Testing Site, if there is not one within your catchment area?
   - Do you have the impression that people are leaving the area for treatment and support for HIV/AIDS; or do you feel that they are remaining within the area for treatment and support for HIV/AIDS?

- Do you have the impression that people who are in the final stages of AIDS are returning to their area of origin to die, if they have left the area?

- To what degree do you think people who are living in one area use the services and resources of another area? In other words, do you feel your catchment area is supporting HIV/AIDS cases that are not necessarily reflected in your numbers and statistics?

2. QUESTIONS REGARDING FACTORS THAT CONTRIBUTE TO, OR PREVENT THE SPREAD OF AIDS IN ONTARIO:
   - Based on your working relationship with physicians in your area, do you feel that there is a great deal of late and/or under reporting? Further, do you feel that necessary follow-up procedures, like partner tracing and partner notification, are occurring in your area?

   - Is there a needle exchange program in your area?

   - Do you think the safer sex message is reaching the appropriate people, for example, young people? If the message is reaching people, are people responding suitably and appropriately with their behaviour?

   - In some areas there have been "right wing groups", "family coalition groups" or "fundamentalist groups" who have opposed what the PHUs are doing in terms of prevention and education. Has this been a concern in your area?

3. QUESTIONS CONCERNING MAJOR RISK BEHAVIOURS AND OVERALL IMPRESSIONS OF HIV/AIDS IN THE ONTARIO PHUS
   - In your opinion, what is the major risk behaviour for HIV/AIDS in your area? Do you see this changing in the next five to ten years?

   - In terms of testing, are you seeing any major risk behaviour group testing more than another? Are you seeing any particular age group testing more than another? Are you testing equal numbers of males and females?

   - What is your overall impression of HIV/AIDS in your area? Do you feel that progress is being made in terms of prevention, and individuals changing their behaviour(s)? Are you optimistic or pessimistic about HIV/AIDS for the future?

THE ONTARIO PUBLIC HEALTH UNITS

Public Health Units have been an important part of Ontario's health care delivery systems for more than fifty years. A Public Health Agency Unit is an official health agency

established by a group of urban and rural municipalities to provide a more efficient community health program. Health units administer health promotion and disease prevention programs to inform the public about healthy lifestyles. This includes, but is not limited to, information about controlling communicable diseases, including education about STDs/HIV/AIDS; immunization; food premises inspection; healthy growth and development, including parenting education; health education for all age groups; and selected screening services.

The pattern of local public health services administration for Ontario was established in 1833 when the Legislature of Upper Canada passed an Act allowing local municipalities "to establish Boards of Health to guard against the introduction of malignant, contagious and infectious disease" (Association of Local Public Health Agencies, 1999). This delegation of public health responsibility to the local level has persisted to the present day. In 1884 Dr. Peter B. Bryce prepared a more comprehensive Public Health Act. It established the position of the medical officer of health and a relationship with the board of health. Since 1890 the Ontario Ministry of Health's Laboratories Branch has provided public health laboratory services to citizens of the province when it established the first public health laboratory in North America. The branch now operates the Central Public Health Laboratory in Toronto and several regional laboratories throughout the province, including Ottawa, London, Kingston, Thunder Bay and Windsor. The Central Public Health Laboratory also provides specialized diagnostic and reference services in microbiology on a provincial and national basis. A major portion of the work, almost two million tests annually, is directly related to public health, through

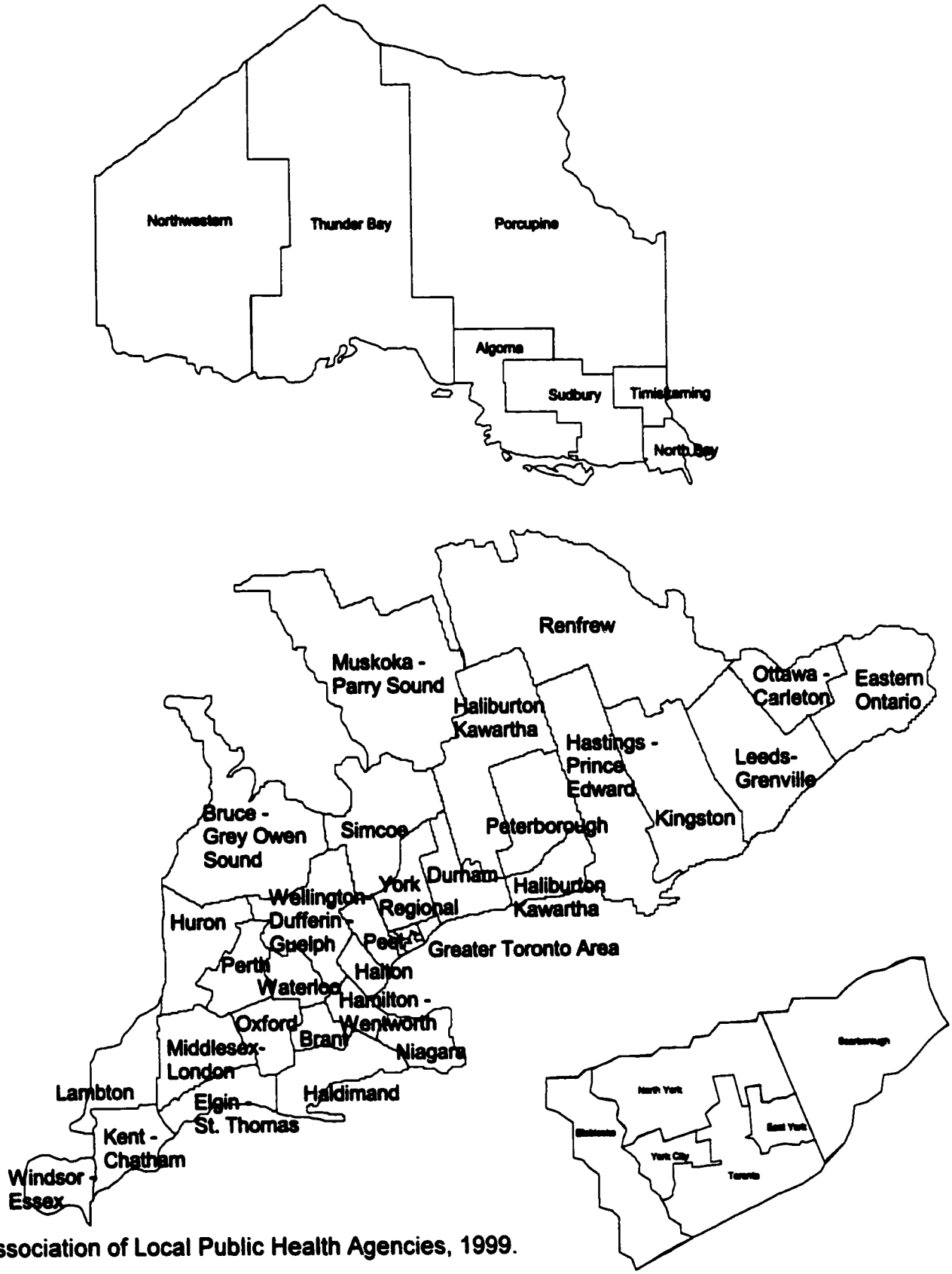
the assistance of physicians, medical officers of health and epidemiologists for the control of infectious diseases (Ontario Ministry of Health, 1999).

In 1912 the Public Health Act was amended so that health units could be established on a county basis. The Public Health Act was further amended in 1967 so that organized municipalities were required to provide full time public health services. The district health unit concept was introduced based on the collective experience of operational health units in Ontario. Economies of scale concepts were introduced and suggested optimum population sizes for health unit catchment areas. The province encouraged health units to regroup on a multi-county basis to become more efficient. In 1998 the municipalities in Ontario assumed full funding of public health services. The forty-two PHUs break down into twenty-seven county-district health units; nine regional health departments and one single municipality (Greater Toronto Area), formerly six distinct units (Association of Local Public Health Agencies, 1999). Figure 18 shows the forty-two PHUs of Ontario.

PUBLIC HEALTH UNITS AND HIV/AIDS

The Ontario PHUs are mandated to reduce the incidence of and complications arising from all STDs, including HIV/AIDS. All positive laboratory tests for HIV are to be reported to the local medical officer of health, who in turn enters the information into RDIS. Only when the client has contracted AIDS is the information sent to the Public Health Branch of the Ontario Ministry of Health. The Ontario Ministry of Health then collects the information from all the PHUs and reports the incidence of all notifiable diseases in an annual summary which is distributed to all PHUs. Monthly information on the notifiable diseases is published in the Public Health Epidemiology Reports of Ontario

Figure 18: The Ontario Public Health Units



Source: Association of Local Public Health Agencies, 1999.

(PHERO). PHERO publishes the number of AIDS cases per PHU on a monthly, and quarterly basis, and provides an annual total. The publication also includes HIV/AIDS information on gender, major risk behaviours and leading causes of death due to an AIDS defining illness.

USING GEOGRAPHICAL INFORMATION SYSTEMS (GIS) AS A TOOL FOR HEALTH & DISEASE RELATED RESEARCH

The maps for this research were digitized on-screen using Environmental Systems Research Institute's (ESRI) ArcView version 3.1. ArcView is one of the most popular desktop GIS software programs. Like any other GIS program, it links information to location. By linking information to location, it allows one to see and analyze data in different and useful ways.

WHAT ARE GIS?

GIS are a type of integrated system used for the collection, storage, manipulation and presentation of geographical data. There is great potential for the use of GIS within the management and analysis of health and health care related issues. A well conceived GIS combines description, analysis, and provides the opportunity and potential to uncover more in the way of understanding and explanation of health related issues and diseases. The spatial modelling capacities offered by GIS can also aid in the understanding of spatial variation in the incidence of disease, and its covariation with environmental factors. The capabilities of GIS only help to increase the range of questions that can be addressed, as well as increasing the speed at which they can be answered. With the ability to perform endless "what if" scenarios, GIS may be used as a powerful planning and analysis tool.

The database is central to the GIS and contains two types of data. The first, is spatial data that contains a locational component. For this research the locational component is the forty-two Ontario PHUs. Locational data describe the geography of the earth's surface. The second type, attribute data, contain certain characteristics of the spatial features. Attribute data are stored in a relational database management system. In terms of this research, population, the crude number of AIDS cases, and the prevalence rate per 100 000 all represent the attribute data. The database management system of the GIS is used for the creation, maintenance and accessing of the database. The system incorporates traditional relational database management system functions, as well as a variety of other utilities to manage geographic data. This management system makes it possible to pose complex queries, and to produce statistical summaries, and tabular reports of attribute data, all of which can be mapped (Loslier, 1999). The relational database manager allows searching, reordering, and selecting on the basis of a feature's attributes and values.

GIS AND HEALTH AND DISEASE

GIS can be useful for health related issues because these issues are affected by a variety of lifestyle and environmental factors. Further, health and health related issues have spatial dimensions, both in terms of where people live, but also where they seek treatment and support. In addition, with respect to a disease like HIV/AIDS, there is also the spatial aspect of where people are being tested. According to Kabel:

> ... the spatial distribution of AIDS can contribute to both educational intervention and the planning of health care delivery systems. Mapping can play an important role in both areas as it is an excellent means of communication. In order to be of use to resource planners... AIDS should include a spatial component (Kabel, 1990).

The use of the maps showing AIDS rates, cross referenced with demographic and socio-economic data is a powerful medium. The ability to easily examine the relationship between location, population and the availability of health care facilities is of great benefit when determining and allocating health care related resources.

GIS should be seen as improving the set of tools to promote public health. Good epidemiological science and good geographic information science should work together (Clarke, 1999). Health care needs timely information on the course of diseases and other health related events in order to implement appropriate and effective actions. Most epidemiological data have a location and time reference. Knowledge of the new information offered by spatial and temporal analysis will increase the potential for public health action. Further, by tracking the sources of diseases and the movements of contagions, agencies can respond more effectively and efficiently to outbreaks of disease by identifying at risk populations, targeting intervention and providing support. In the increasingly information intensive environment of the future's health care, "the role of GIS will have greater importance due to its abilities to integrate a wide range of data sources, from legacy systems to image data, and to make complex data more quickly and easily understood" (Davenhall, 1999: 24). The use of GIS for health and health related issues will continue to rise in prominence with the recognition that health surveillance practices and health service allocations need to become more sensitive to the needs of people in local geographic areas.

ERROR AND UNCERTAINTY IN GIS

The use of GIS for environment and health applications nevertheless carries with it serious dangers for GIS are influential and persuasive instruments. It is all too easy to use

them to promote false conclusions, especially through the naïve or simplistic use of maps and mapping techniques. Great care needs to be taken in terms of the quality of the data used in GIS. Once in the form of maps the quality of the data can be easily overlooked (Briggs & Elliot, 1992: 92). It is widely known that geographical information, like any other information, is subject to error and uncertainty. This applies to the map base data, and the associated attribute information. This section has only acknowledged the general problems associated with using GIS. It is beyond the scope of this research to discuss in great detail the issues and difficulties in utilizing GIS. However, in the "Results" section, the research will examine data issues in greater detail in terms of how data may limit our ability to analyze and understand the spatial patterns and variations of the AIDS prevalence rates.

MAKING THE MAPS FOR THIS STUDY

The Association of Local Public Health Agencies has published a map of all the Ontario PHUs on a web site, including a map of the southern section, and a map of the northern section (Association of Local Public Health Agencies, 1999). Both images are graphics interchange format (GIF) images. This is a highly compressed graphics format that allows one to download and view graphics very quickly. Since ArcView will not read a GIF image the images were saved as Joint Photographic Experts Group (JPEG) images. A JPEG is a graphic image created by choosing from a range of compression qualities. In order for ArcView to be able to read the JPEG image, the JPEG Image Processor Extension had to be activated in ArcView. Once the extension was activated the JPEG image was brought into ArcView as a Theme. Then, using the polygon drawing tool the polygons of the Units were simply digitized while the JPEG image was still on the screen.

Once the images were fully digitized the JPEG image was turned off as a Theme leaving only the linework.

The reason behind creating two maps and not one complete map of the province is to capture as much detail in the southern section of the province as possible. In addition, the two images were not originally created at an equal scale, and so combining the two images with a high degree of accuracy would have been quite difficult, and a great deal of detail in the southern section of the province would have been lost. It should also be noted that the Greater Toronto Area was displayed as one unit on the original image from the web site. To accommodate the detail for the Greater Toronto Area the boundaries of the six areas were simply digitized in, based on an older 1995 map from the Directory of Public Health Agencies.

Once the two images were digitized, an accompanying attribute table was created that included information for each PHU. This included population numbers, crude AIDS numbers, and AIDS prevalence rates. Some of the maps in this paper also show qualitative data from the interview process. When these impressions were mapped each impression was given a unique value, meaning that ArcView coloured each Unit according to the impression that was provided by the AIDS Educator.

In summary, the research used two types of data. The first type includes primary and secondary data, primary data from reports that have already been published, and secondary rates that were complied and then mapped. The second type of data is anecdotal data from the interviews.

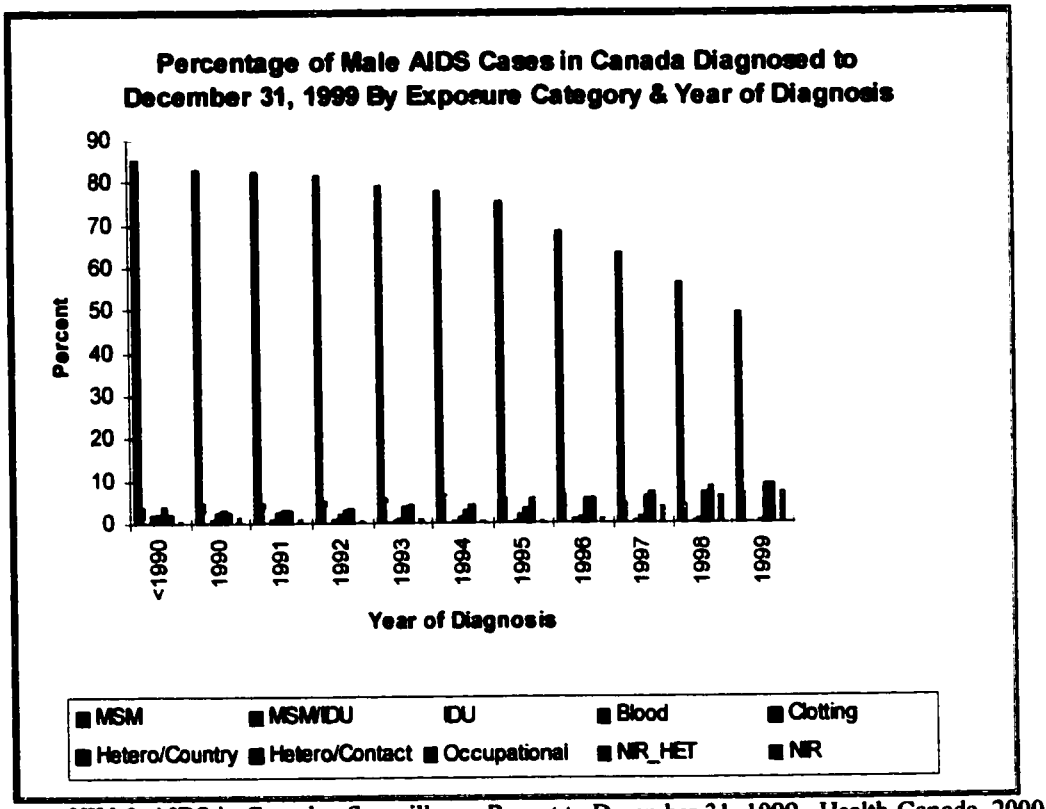
CHAPTER FOUR

RESULTS

AIDS IN CANADA AND ONTARIO

This section provides a breakdown of AIDS in Canada and Ontario. It discusses exposure categories; year of AIDS diagnosis, age cohorts; and place of diagnosis. The section attempts to provide a basic description of AIDS cases in Canada, and more specifically in Ontario. Once an understanding of the cases in Ontario is complete one can move forward and look at the mobility patterns of the affected people, and to look at the spatial patterns and variations of the AIDS throughout Ontario at the PHU level. The source of the Canadian HIV/AIDS statistics is from the Division of HIV/AIDS Surveillance of the Bureau of HIV/AIDS, STD and TB at the LCDC, Health Canada. The combined report of HIV and AIDS is published semi-annually, covering the periods January to June and July to December.

Figure 19



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000.

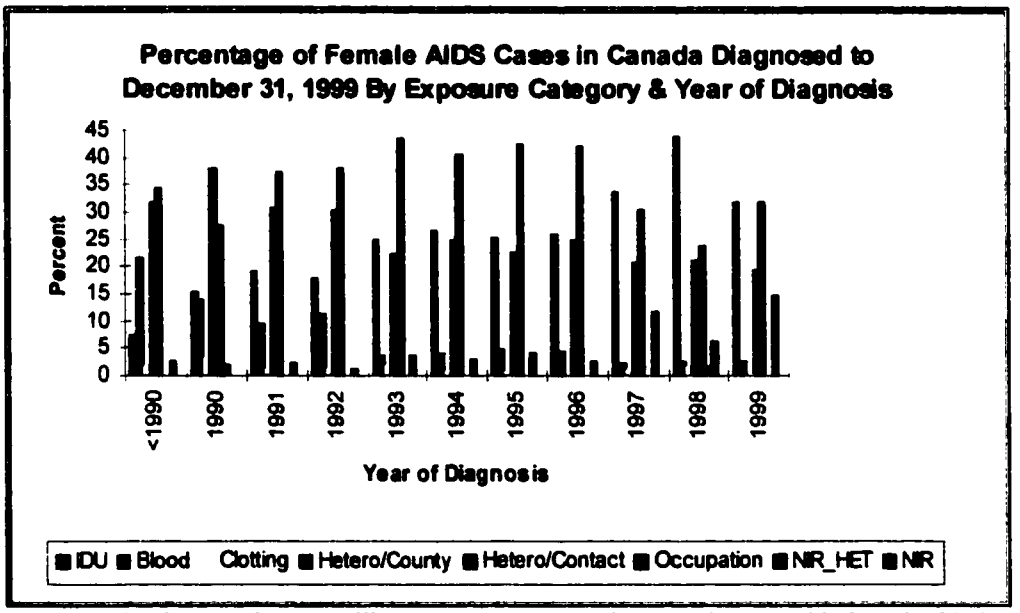
When examining the percentages for exposure categories for males, Figure 19, we see that the MSM category has remained as the highest percentage. However, what is most noticeable on Figure 19 is the increasing rate of injection drug use. Prior to 1990, injection drug use accounted for 1.1% of AIDS cases for men. By 1990 it was 2.2%, 1993 it rose to 4.5%, 1996 it was 10.1% and finally in 1999 it was 18.5%. The information in this Figure also corresponds to what is displayed in the HIV testing patterns; the number of IDU who are getting tested is increasing, thus it only makes sense that the number of AIDS cases would also be increasing.

Questions arise as to why the epidemic is evolving around IDU. One reason might be that drug consumption patterns are changing. Increased injection of cocaine is being reported by many communities across Canada. Heroin users may inject two or three times a day, often alone or with one other person, whereas cocaine injectors may do so twenty or more times a day and often in large groups. These conditions make it very difficult to keep track of one's needles, meaning that infection due to unclean needles is more likely to occur (Hankins, 1997). Injection drug use is also a concern among street youth and prisoners. Injection drug use is a much more common method of transmission in females than in males (Health Canada, 1998). Given the geographic mobility of IDU and their social and sexual interaction with non-users, the dual problem of injection drug use and HIV infection is one that ultimately affects all of Canadian society, as population interaction is a fundamental parameter in the propagation of most human infectious diseases.

When looking at the female perspective for the exposure categories, Figure 20, there appears to be more variance throughout the categories. Prior to 1990 data show a

high percentage of heterosexual contacts from endemic counties, but as we move forward in time, it appears to be declining. Heterosexual contact experienced rising proportions until 1993, when it too seems to have levelled off. Like the data on males, we are seeing a steady increase in the injection drug use percentage rates. For instance, the percentage of female IDU is 7.3% prior to 1990. By 1990 that rate has more than doubled to 15.5%. It continues to rise and by 1999 it is at 31.7%. The remaining categories appear to remain relatively evenly distributed throughout the time period, with the exception of the blood category which has drastically dropped from its pre 1990 levels, due to improved testing methods for blood donation purposes.

Figure 20

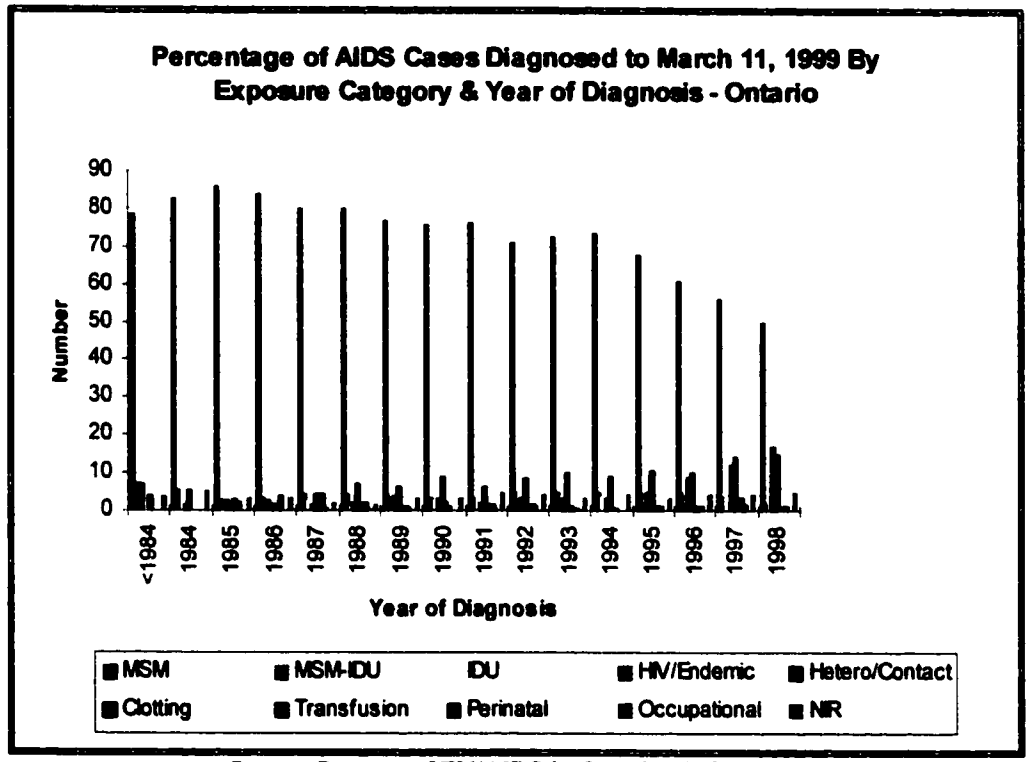


Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000.

Any decrease in the number of AIDS cases may be attributed to a number of factors, such as improving antiretroviral treatments and drug prophylaxis that delay the onset of the clinical presentations defining AIDS. In addition, it could be attributed to under and/or late reporting by physicians and health care workers (Health Canada, 1998).

If we use the same criteria, exposure category and year of diagnosis, and look at the Ontario percentages in greater detail, (Figure 21), we see that MSM again dominate the graph for all of the years, with the proportion decreasing slightly over time. Cases of infection from heterosexual contact from endemic countries has increased, as has heterosexual contact and injection drug use. These Ontario results are very similar to the Canadian results.

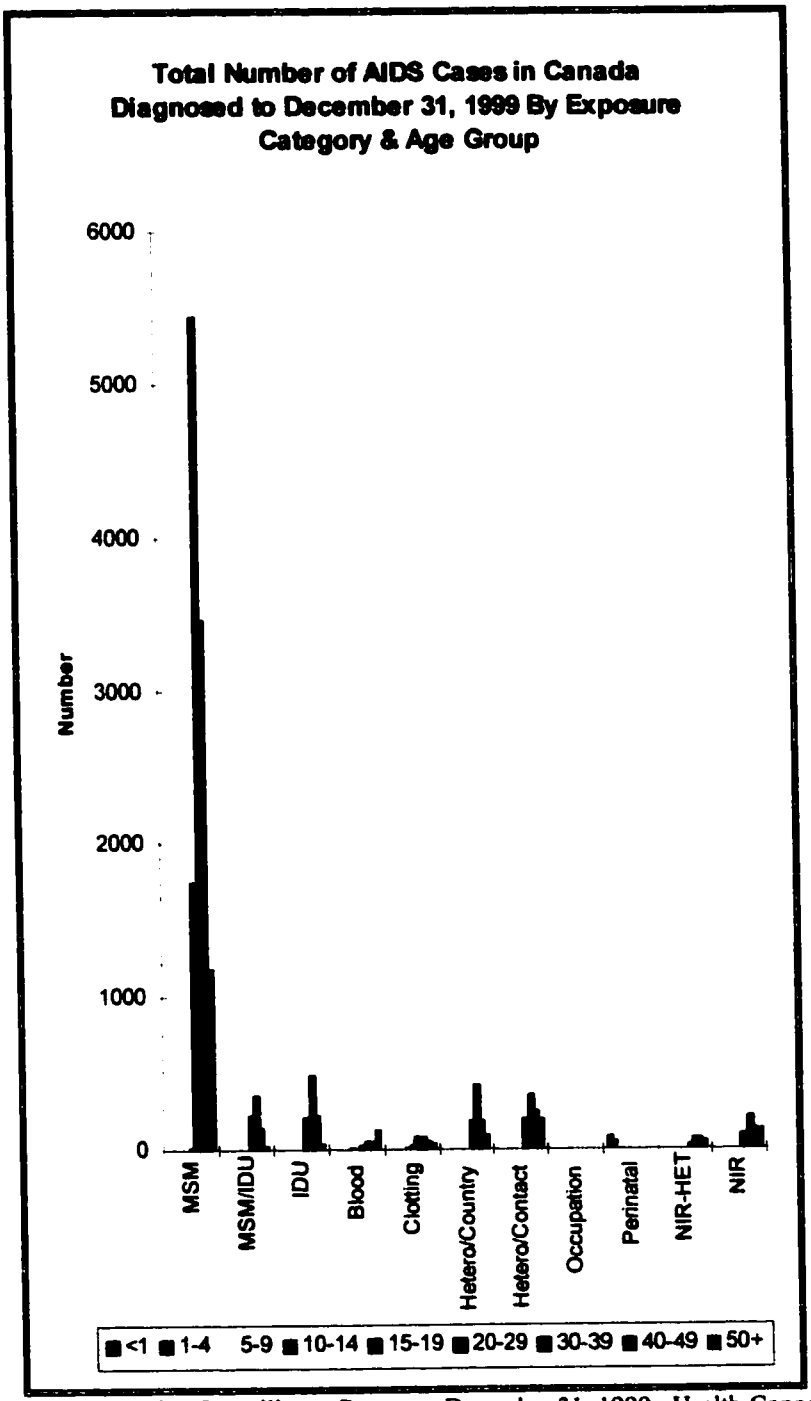
Figure 21



Source: Report on HIV/AIDS in Ontario 1997 - 1998.

When using age cohorts, Figure 22, we see an overwhelming number in the MSM exposure category. The majority are in the 30 - 39 age group, followed by those aged 40 - 49 years. From what has been displayed by the previous Figures we are continuing to see the IDU, heterosexual contact and heterosexual contact from endemic countries as the emerging exposure categories in Canada.

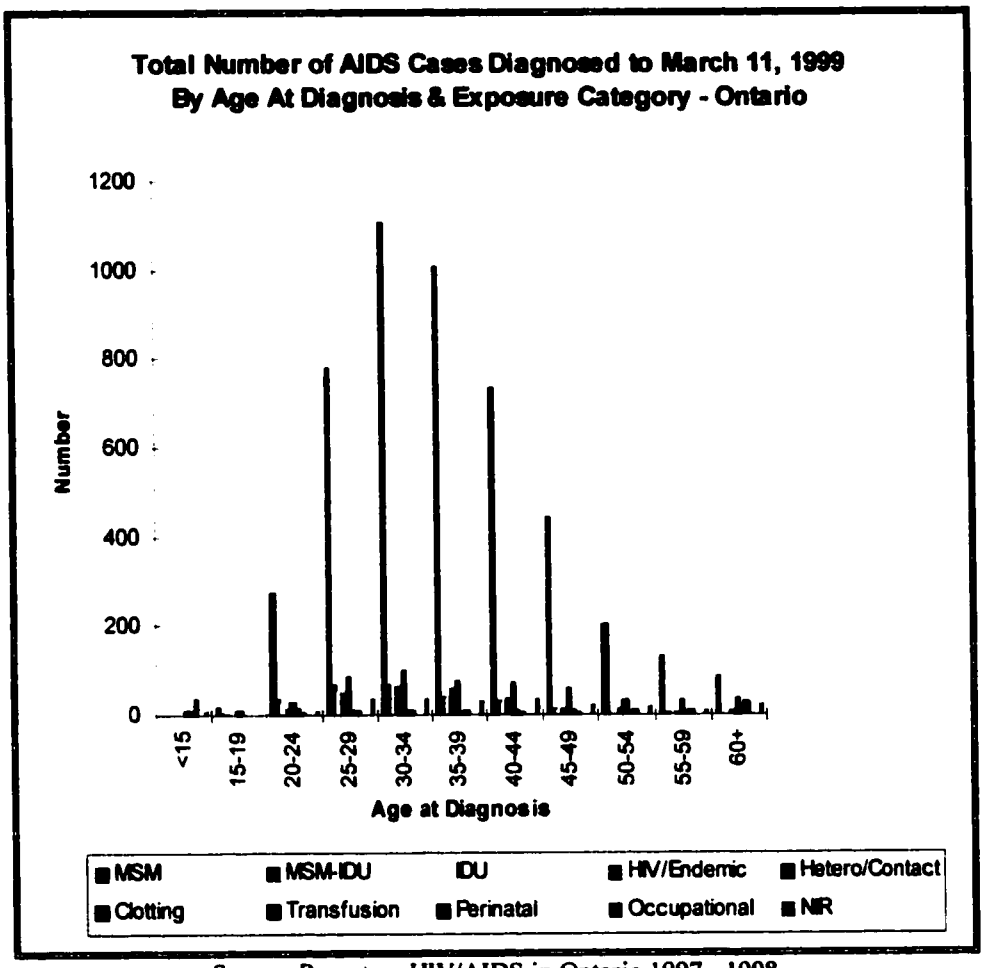
Figure 22



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000.

When examining the number of AIDS cases by age at diagnosis and exposure category for Ontario, Figure 23, we see that the majority of the cases occur between the ages of 25 and 44 years of age, again very similar to the Canadian results.

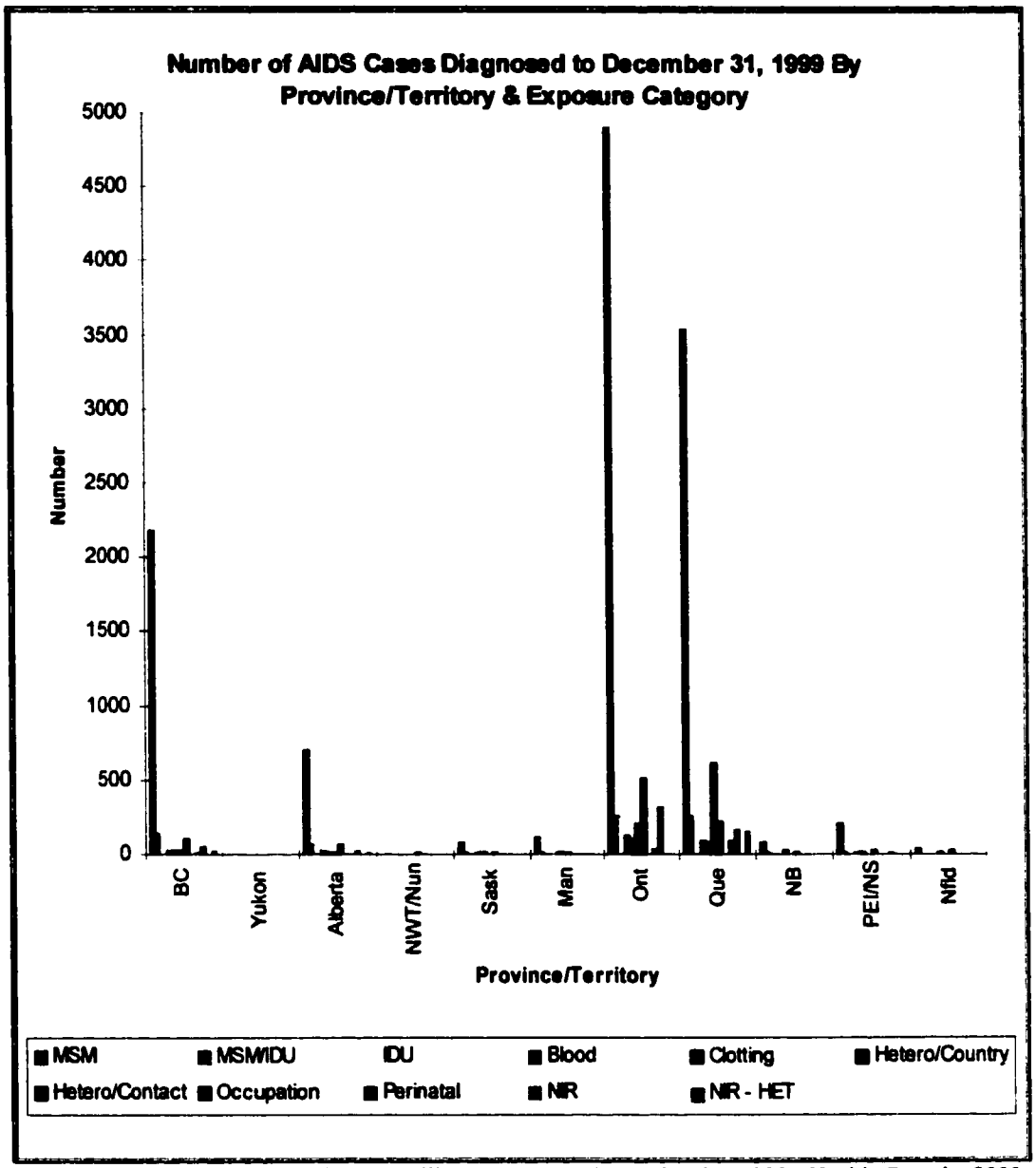
Figure 23



Source: Report on HIV/AIDS in Ontario 1997 - 1998.

When looking at the AIDS cases in terms of where they occur in Canada, Ontario, Quebec and British Columbia stand out as having the most cases, especially Ontario, as displayed in Figure 24. Ontario and Quebec also have proportionately much higher numbers of MSM. Heterosexual contact stands out for Ontario and heterosexual contact from an endemic country stands out for Quebec. It should be noted that on some of the graphs, like Figure 24, some of the categories are not that visible. This is due to the fact that some of the categories like "Occupation" and "Perinatal" have very few, if any, cases. As well, certain geographical areas like the Yukon and Nunavut/Northwest Territories have very few cases.

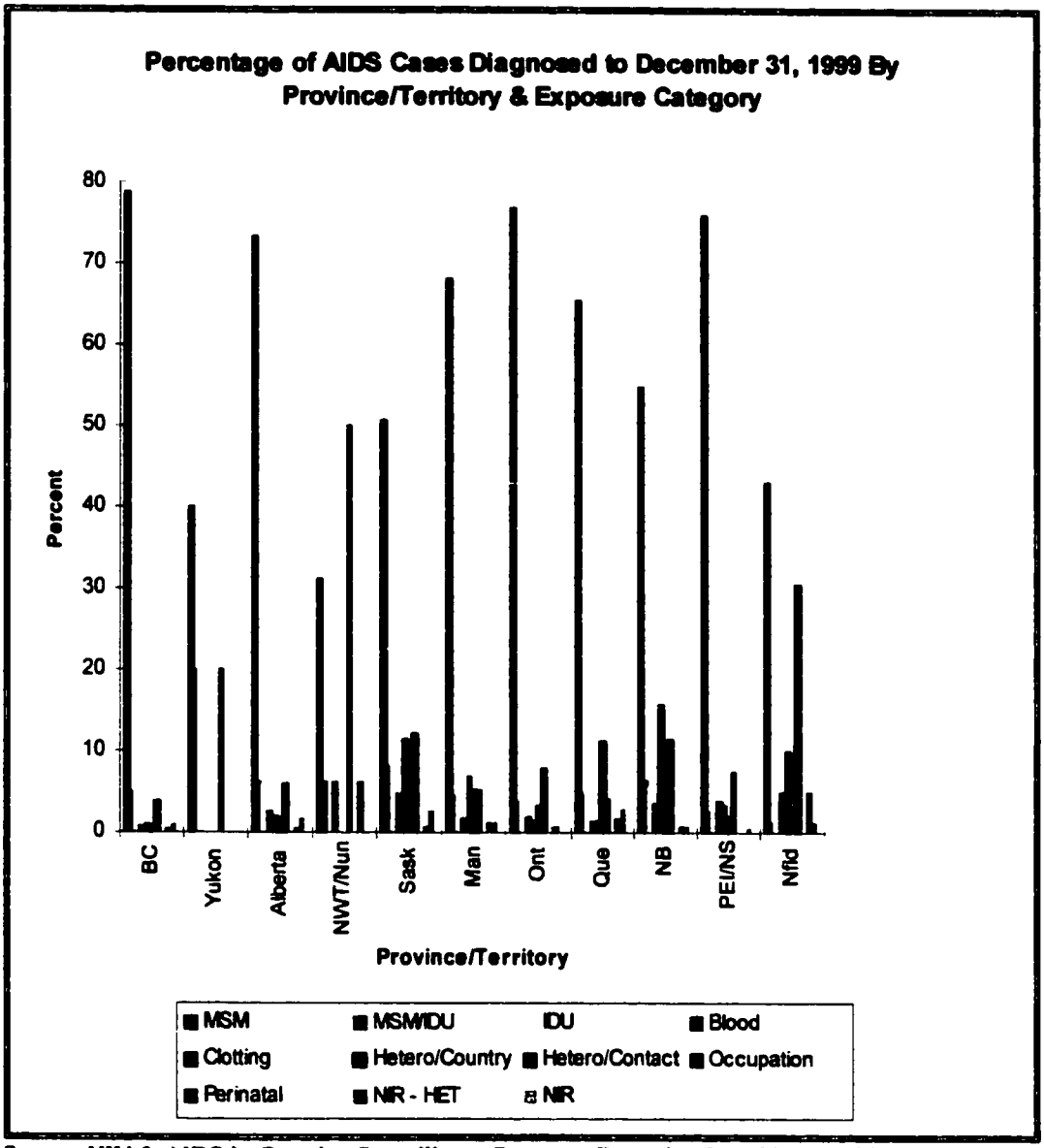
Figure 24



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000.

Figure 25 still shows a dominance of the MSM exposure category. For all of the provinces except the Northwest Territories, MSM make up the greatest percentage. In the Northwest Territories and in Newfoundland there is a high percentage of heterosexual contact. As with the male and female graphs, the IDU category is making itself known, especially in the Yukon territories.

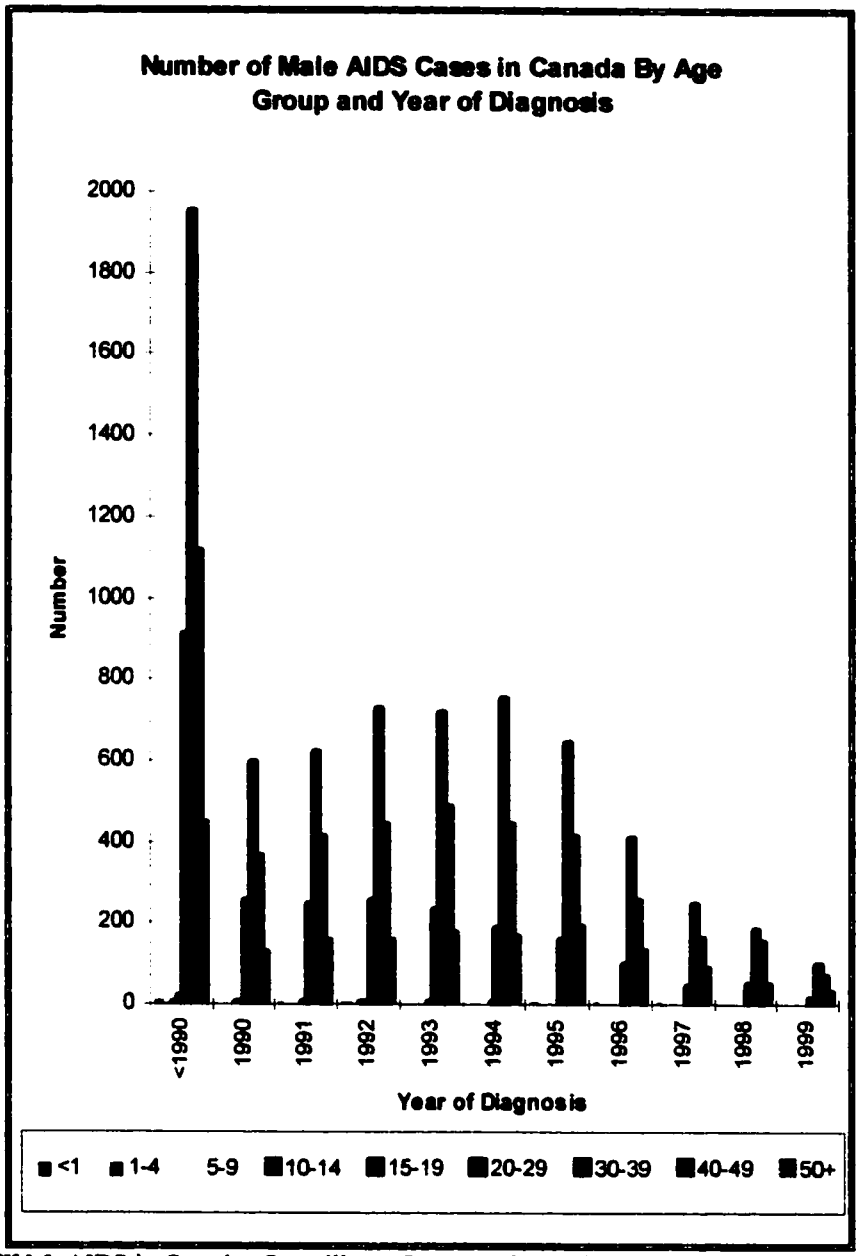
Figure 25



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000.

When looking at exposure categories in terms of age cohorts, prior to 1988, we see a large number of males aged 30 - 39, Figure 26. If it takes an average of ten years to contract AIDS from initial HIV infection, this would mean that these men became infected in the late 1970s and the early 1980s, while they were in their twenties. According to the literature many of the homosexual men with large numbers of partners would have been in their twenties during the 1980s.

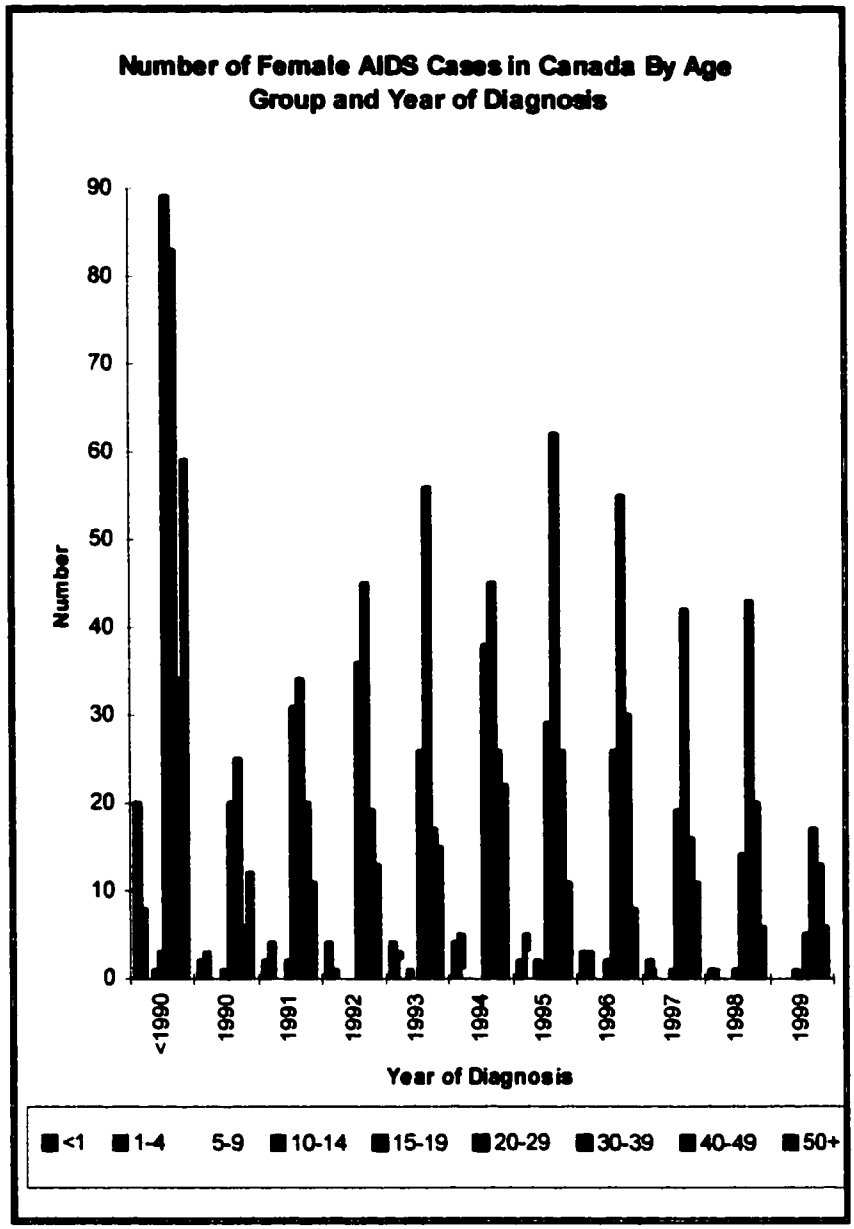
Figure 26



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000.

With the graph of female data, Figure 27, we see a high number of people aged 20 - 29 and 30 -39 prior to 1988. The high numbers prior to 1988 for both males and females may be aggregated by the fact that this temporal category is taking into consideration a number of years, while the other years are only looking at one year.

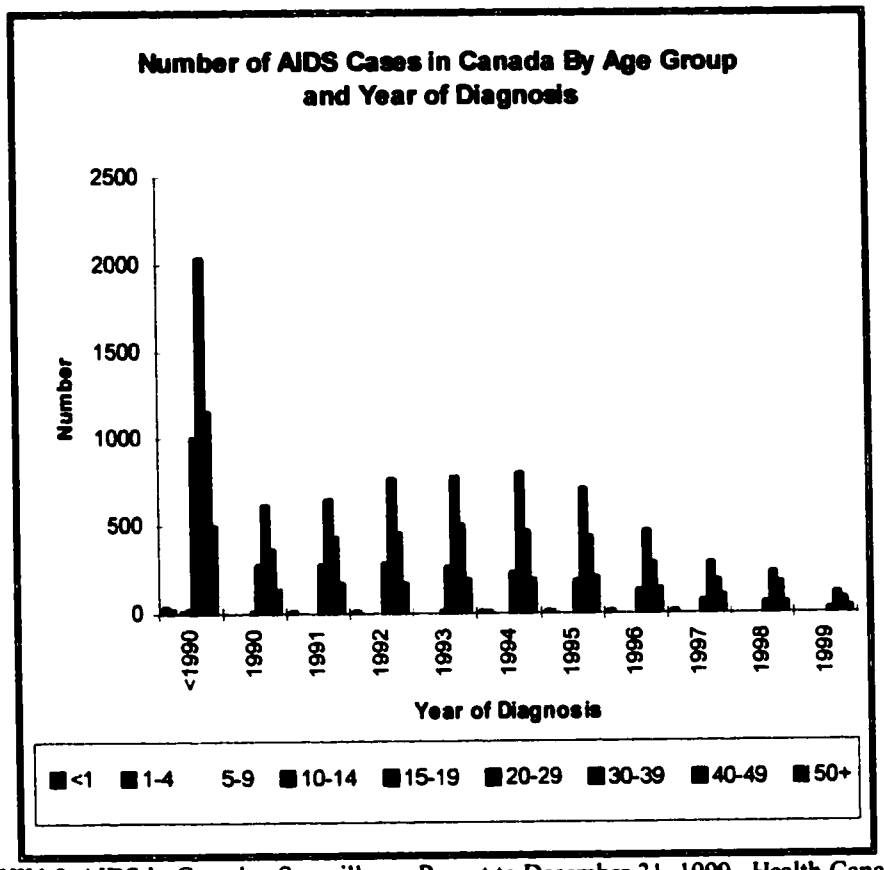
Figure 27



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000.

In the combined graph, Figure 28, for males and females, we again see the highest numbers of people age 30 - 39, followed by those aged from 40 - 49. The very few cases in 1997 for all of the aforementioned graphs may suggest two things. First, it could be due to late and under reporting. Second, it could be attributed to the fact that with the new treatments, people are taking longer to develop an AIDS defining illness.

Figure 28



Source: HIV & AIDS in Canada. Surveillance Report to December 31, 1999. Health Canada, 2000.

In summary, this section has shown AIDS cases according to gender, age cohorts and geographical location. This is important information to know because it provides one with the required background information to better understand the disease in terms of who is infected and affected. Injection drug use is of definite concern, as is heterosexual contact. The majority of the people infected are thirty to thirty-nine years of age, meaning that they were likely infected with HIV during their twenties. Ontario, Quebec, and British Columbia stand out as geographical areas with the highest number of cases. In terms of gender, males still make up approximately ninety percent of all AIDS cases in Canada and Ontario. However, the proportion comprised by females has steadily increased throughout the course of the disease.

RESULTS AND DISCUSSION FROM THE INTERVIEWING PROCESS

INTRODUCTION

The first section of the Results will include the outcomes from the interview process. The second section of the Results will focus on the mapping component of the thesis, specifically examining the spatial patterns and variations of the prevalence rates. The second section also explores to what extent the data used by this research limits our ability to analyze and understand the spatial patterns and variations. When information from the interview process helps to explain a pattern demonstrated by one of the maps, that information will also be included in the mapping section.

Normally when conducting research of this kind, one first describes a pattern and then looks for explanations or processes at work. However, the different aspects of the Results, the interviewing, and the mapping, work together to provide a more complete picture, and therefore will be integrated with one another. Another explanation for the way in which the Results are laid out has to do with the method of research. The mobility interviews were one of the first components of the thesis to be completed; thus to some extent it seems logical to make them the first part of the Results. Further, the information gathered from interviewing the AIDS Educators is necessary to better understand the patterns of spatial variation in the prevalence rates. When looking at the spatial variations, one will be relying to a certain degree on the information provided by the interviews. Although some of the information from the interview process may be better suited with the mapping component, all the interview results were kept together in order to keep the

interview process as a continuous entity. A summary of the results will be done in the last section of the thesis.

MOBILITY QUESTIONS

The most important questions asked of the AIDS Educators at the PHUs concerned the mobility of individuals in their respective areas, and the provision of support facilities. The first question was: **"Do you have the impression that people are leaving the area to be tested for HIV; or do you feel that they are remaining in the area to be tested for HIV?"** This was a meaningful question to ask because if a person tests positive during a testing procedure their count goes to the place of diagnosis, not their place of residence. With nominal or non-nominal testing procedures it can be assumed that individuals are being tested within the catchment area where they reside. This assumption can be made because if they are going for this sort of testing they are more than likely going to their family physician, according to the majority of the Educators. If an individual must leave their area for an anonymous test at a designated Anonymous Testing Site, their count is still recorded at the place where they tested positive. Table 5 shows which PHUs have Anonymous Testing Sites within their catchment areas. Where a person tests is a concern because when examining the PHU's AIDS statistics there is no way of telling if the numbers reflect the people who reside in the area, or if the numbers reflect people coming in from other areas, or a combination of the two. By attempting to examine where people are moving to for testing, one can better ascertain levels of mobility. In addition, one can also hopefully see what areas are drawing people and what areas are seeing people leave.

Table 5: Public Health Units With Anonymous Testing Sites

PUBLIC HEALTH UNIT	ANONYMOUS TESTING SITE WITHIN AREA	NO ANONYMOUS TESTING SITE WITHIN AREA
Algoma	✓	
Brant		✓
Bruce-Grey-Owen Sound		✓
Durham		✓
East York		✓
Eastern Ontario		✓
Elgin-St. Thomas	✓	
Etobicoke	✓	
Haldimand-Norfolk		✓
Haliburton-Kawartha		✓
Halton		✓
Hamilton-Wentworth	✓	
Hastings-Prince Edward		✓
Kent-Chatham		✓
Huron		✓
Kingston-Frontenac	✓	
Lambton		✓
Leeds-Grenville		✓
Middlesex-London	✓	
Muskoka-Parry Sound		✓
Niagara	✓	
North Bay		✓
North York	✓	
Northwestern		✓
Ottawa-Carleton	✓	
Oxford		✓
Peel	✓	
Perth		✓
Peterborough		✓
Porcupine		✓
Renfrew		✓
Scarborough		✓
Simcoe	✓	
Sudbury	✓	

PUBLIC HEALTH UNIT	ANONYMOUS TESTING SITE WITHIN AREA	NO ANONYMOUS TESTING SITE WITHIN AREA
Thunder Bay	✓	
Timiskaming		✓
Toronto	✓	
Waterloo	✓	
Wellington-Dufferin-Guelph	✓	
Windsor-Essex	✓	
York	✓	
York Region		✓

19 of the 42 AIDS Educators (45%) believed the people in their area were going elsewhere to be tested, as listed below. A (✓) means that there is an Anonymous Testing Site within each PHU's catchment area.

Bruce-Grey-Owen Sound	Durham	Eastern Ontario
Haliburton-Kawartha	Halton	Hastings-Prince Edward
Kent-Chatham	Huron	Lambton
North Bay	Oxford	Peel (✓)
Perth	Renfrew	Timiskaming
East York	Etobicoke (✓)	York Region
Waterloo (✓)		

16 of these 19 PHUs do not have Anonymous Testing Sites in their area, so it makes sense that if people are concerned about confidentiality, they would go to an Anonymous Testing Site, meaning they would have to leave their area and go elsewhere. It is interesting to note that one AIDS Educator stated that people are leaving the area for testing even though there is an Anonymous Testing Site within their region. However, the Anonymous Testing Site is located at the PHU and people may be concerned about

anonymity; they may know someone who works at the Unit, for example. This may be one reason why a person would choose to leave their area for testing. According to the AIDS Educator people leave the area to go to large urban areas like Toronto for testing. If it is a close community people may worry about confidentiality. Another AIDS Educator believed that people were leaving the area because of a physician shortage even though there are a number of Anonymous Testing Sites within the area.

16 of the 42 AIDS Educators (35%) thought that people in their area were remaining in the area to be tested, as listed below. A (✓) denotes an Anonymous Testing Site within the catchment area.

Algoma (✓)	Haldimand-Norfolk	Hamilton-Wentworth (✓)
Leeds-Grenville	Middlesex-London (✓)	Ottawa-Carleton (✓)
Peterborough	Porcupine	Simcoe (✓)
Sudbury (✓)	Thunder Bay (✓)	North York (✓)
Toronto (✓)	Wellington-Dufferin-Guelph (✓)	
Windsor-Essex (✓)	York (✓)	

12 of these 16 PHUs do have an Anonymous Testing Site within their area. This means that for the most part, people who are remaining within their areas are doing so in areas that have Anonymous Testing Sites. In some cases people appear to feel comfortable enough using their family physician for nominal and non-nominal testing and do not feel the need to go to one of the Anonymous Testing Sites in the surrounding areas. In other cases, people who live there were originally leaving the area to be tested. However, more people are now staying in the area and are going to their family physician

for nominal and non-nominal testing. According to many of the Educators, people are increasingly staying within their area to be tested even if there is not an Anonymous Testing Site within the area.

7 of the 42 AIDS Educators (19%) were unsure what people were doing in terms of testing. A (✓) means that there is an Anonymous Testing Site within each PHU's catchment area. These PHUs include:

Brant	Elgin-St. Thomas (✓)	Kingston-Frontenac (✓)
Scarborough	Northwestern	Niagara (✓)
Muskoka-Parry Sound		

For the Educators that were unsure about where people were going for testing, there are almost equal numbers of PHUs with and without Anonymous Testing Sites. Most of these Educators believed that people were doing a combination of things in terms of testing; some were leaving the area, others were staying, but no clear distinction could be made one way or the other. The other PHUs simply did not know what people were doing in terms of testing.

Of the 35 Educators that could provide an answer to this testing question, 54% believed that people were going elsewhere, thus suggesting some degree of mobility.

Based on what was said during the interview process, the following can be determined about where people go for HIV testing. If an area has an Anonymous Testing Site, people will likely remain in the area to be tested. A great number of the people that did leave the area where they resided were going to areas which had Anonymous Testing Sites. Many of the respondents who are located in close proximity to the Greater Toronto Area stated that many of their clients were going to the Hassle Free Clinics in Toronto.

The Hassle Free Clinics are large Anonymous Testing centres in Toronto. Most of the larger urban centres do have Anonymous Testing Sites, such as Toronto, Ottawa, Hamilton, London, Windsor, Sudbury, and Thunder Bay. These centres attract people from the surrounding areas that do not have Anonymous Testing Sites. If there is not an Anonymous Testing Site within an area, people will go to their own physician for testing if they feel comfortable enough, or if they feel they have "nothing to hide". If there are concerns about anonymity people will likely leave the area. In addition, if the testing site is located in a hospital, for example, people may be reluctant to go for fear they may know someone visiting or working in the hospital.

Some have suggested that issues concerning mobility and testing are not valid. They argue that if people do test positive at an Anonymous Testing Site, they will return to their family physician to be retested for confirmation purposes. This is a huge assumption to be making for two reasons. First, people are often in denial about their results, especially if the results are positive, and may not seek medical attention for a retest for a long period of time. Second, we do not know that the physician they will see will be within their area of residence. An assumption was made earlier in this section that if someone was undergoing nominal or non-nominal testing they would be doing so within their area of residence. As per the opinion of the various AIDS Educators this is likely the case. If an individual was going out of their area for testing, they would likely seek an Anonymous Testing Site, not another physician's office. However, another point needs to be made that with Ontario facing a physician shortage, people may in fact be seeking physicians outside of their area of residence, or they could be seeking or using a physician in an area in which they formerly lived.

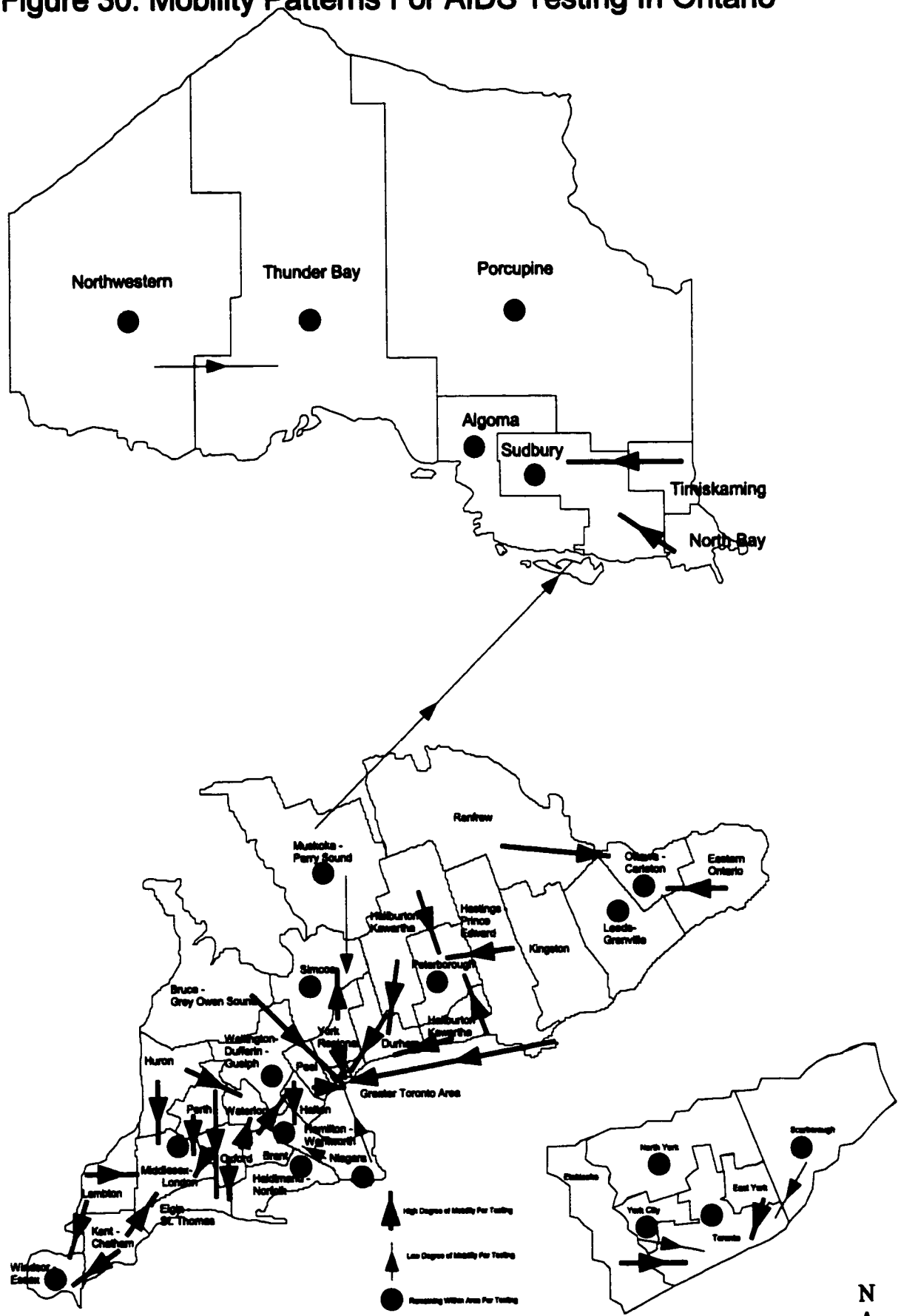
From these mobility testing results and numbers, an assumption can be made that the AIDS numbers for a city like Toronto reflect what is also occurring in the surrounding areas. Toronto has very large numbers of AIDS cases, but these numbers do not necessarily reflect the reality of the situation. Even within the Greater Toronto Area a great many Educators thought that people were travelling from areas like Scarborough to Toronto for testing.

The following map, Figure 29, displays the mobility patterns of HIV testing in Ontario at the PHU level. The second map, Figure 30, shows where individuals are going for testing. If we look at what areas people are leaving for testing, we see that in southern Ontario, (Figure 29) these areas are less urbanized, like Bruce-Grey-Owen Sound, and Oxford for instance. In terms of areas that have people remaining, we see that they are the larger urban areas. They are interspersed throughout the province as focal points; points where the surrounding areas can come to. A majority of these areas have Anonymous Testing Sites, as denoted by the yellow circles on Figure 29. An educated guess can be made as to where people who leave their areas for testing are going, based on where the Anonymous Testing Sites are located. For example, it is likely that people from Kent-Chatham are going to Windsor-Essex, or to Middlesex-London. If we look at the second map (Figure 30) we see that this is true, based on what was stated by the AIDS Educator in the interview process. Another example, Halton is likely going to Wellington-Dufferin-Guelph or to Hamilton-Wentworth for anonymous testing, and again this is confirmed by the AIDS Educator, and displayed in Figure 30. The thin arrows on Figure 30 represent

Figure 29: Mobility Patterns For AIDS Testing In Ontario

Source: Ontario Public Health Unit AIDS Educators, 1999.

Figure 30: Mobility Patterns For AIDS Testing In Ontario



Source: Ontario Public Health Unit AIDS Educators, 1999.

areas that have some people moving out for testing, and a circle represents those who remain within the area. The thicker arrow denotes areas whereby the majority of the people leave for testing. The length of the arrow is not significant. If we look at northern Ontario, we see that for the most part people are remaining in their areas, with the exception of Timiskaming and North Bay. One would assume that both of these areas would go to Sudbury for testing. This is confirmed by Figure 30, based on what was said by the AIDS Educator.

This exercise in mapping and discussing where people go for HIV testing can definitely help to bring about some clarity surrounding the issues of mobility. We know for the most part what areas have people leaving them, and what areas have people staying within them for testing. If people are leaving the area we can make fairly accurate predictions about where they are going based on where the Anonymous Testing Sites are located. Later in the paper when discussing AIDS prevalence rates, reference is made back to this testing mobility analysis. For example, if an area has a very high prevalence rate and a relatively small population, we could look at these maps and see if the area's contiguous neighbours were leaving their own areas for anonymous testing and coming to the area displaying the high prevalence rate.

The next question concerning mobility was: **"Do you have the impression that people are leaving the area for treatment and support for HIV/AIDS; or do you feel that they are remaining within the area for treatment and support for HIV/AIDS?"**

25 of the 42 AIDS Educators (59%) believed that people were going outside of their area to be treated. These PHUs include:

Algoma	Brant	Bruce-Grey-Owen Sound
Durham	Eastern Ontario	Haldimand-Norfolk
Halton Region	Kent Chatham	Huron County
Lambton	Leeds-Grenville	North Bay
Oxford	Peel	Perth
Porcupine	Renfrew	Simcoe
Timiskaming	East York	Etobicoke
Waterloo	York Region	York
Northwestern		

10 of the 42 AIDS Educators (24%) thought that people were remaining within the area for treatment. These PHUs include:

Hastings-Prince Edward	Kingston-Frontenac	Middlesex-London
Ottawa-Carleton	Peterborough	Sudbury
Thunder Bay	North York	Toronto
Windsor-Essex		

9 of the 42 AIDS Educators (17%) were unsure as to what people were doing in terms of treatment. The PHUs include:

Elgin-St. Thomas	Haliburton-Kawartha	Hamilton-Wentworth
Wellington-Dufferin-Guelph	Scarborough	Niagara
Muskoka-Parry Sound		

Of the 35 Educators that could provide an answer to this question, 71% believed that people were going elsewhere for treatment. Reasons for not providing an answer are that the AIDS Educator simply did not know if people were staying or leaving the area for

treatment. Unsure answers also include responses whereby the AIDS Educator believed that people were staying and leaving, thus no definite pattern of mobility could be determined.

71% believe there is a large percentage of mobility, which suggests two things. First, the areas where there are HIV/AIDS related facilities are supporting a great many people from the surrounding areas. Second, in terms of resource planning this means there are two options. One, augment existing resources so as to compensate for supporting the surrounding areas. Or alternatively, by looking at which areas are seeing their clients leave, improve the support and resources in these areas. However, by examining the results, there are a great many more areas where people are leaving and thus it may be more effective and efficient to augment and to continue to support the existing facilities in other areas. Support for such areas could include transportation services to the surrounding areas, for example.

Based on what was said during the interview process, the following can be determined about where people go for HIV/AIDS treatment. Some of the mobility could be due to normal residential mobility patterns. For example, Hays et al. completed a study in 1990 on the "Spatial Patterns of Attendance At General Practitioner Services". Geographical theory suggests that consumers will travel to the centre nearest to their residence which offers a particular service. The spatial pattern of utilization is a product of the location of the service used and the frequency with which each patient uses it. Central place theory suggests that general practitioners (or medical services) will be situated in the most conveniently located outlet in a market large enough for the service to be viably offered. Customers seek to minimize the cost and effort expended in obtaining a service,

and will normally travel to the nearest centre. Such behaviour relies upon the consumer making decisions based upon full knowledge of the costs and alternatives involved. The explicit assumption is that for a particular level and type of service the consumer will attend the nearest centre offering such a service (Hays et al., 1990: 773).

According to Hays et al. three ideas have been influential in hypothesizing the patterns of attendance at health services. These are distance decay, socioeconomic status of patients as it relates to mobility, and relic behaviour patterns. With respect to distance decay, an area with near or above average provisions of (general practitioner) services, will service more than eighty percent of the population. While distance tends to confine use of the services to those located within a narrow radius of the patients' homes, higher socioeconomic groups were able to consult doctors further away, thus allowing for greater personal mobility. Hays et al. found that with visits to hospital emergency rooms, obstetric admissions, and abortions, travel distance did not seem to be a barrier for higher status patients because such patients would travel a long distance to their preferred hospital environment. Mobility levels were assumed to be the influential factor. The third proposed influence on attendance patterns is pre-established patterns of utilization, which can be explained largely in terms of relic patterns of travel. The current place of medical attendance was related to the respondent's previous residential area (Hays et al., 1990: 773, 774).

Hays et al. concluded that if patients choose to travel further than necessary to receive medical care, it lessens the need for policies to correct any maldistribution of general practitioners, although the effects of lower socioeconomic groups must be recognized (Hays et al., 1990: 780).

The AIDS Educators confirmed much of what Hays et al. stated. In most cases people living in smaller urban areas, or outside of larger urban areas will travel to larger centres for treatment. Many of the Educators mentioned the HIV specialists in Toronto, St. Thomas, Niagara and Windsor, the London HIV Treatment Centre, or the Haven Clinic in Sudbury. Again with the treatment question, we see a similar response to that of the testing question. It only makes sense that people will travel to areas with many resources and the appropriate support facilities, again supporting what Hays et al. determined. This travel or mobility will only occur if people have the economic means to do so. There are obvious advantages for individuals with HIV/AIDS if they live near large medical and social service centres, or if they have the means to travel to their preferred medical facility. For example, if a community has formed to respond to the needs of persons with HIV/AIDS, additional support is often available on the basis of the person's close proximity to the community of interest. In many cases service delivery is more efficient as there are shorter distances to be covered for both the caregiver and the person seeking care (Willms, 1992: 267). After the onset of full blown AIDS individuals are likely to go through a number of acute episodes needing in-patient treatment interspersed with periods in which they may be relatively well and able to live outside the hospital with suitable support. HIV/AIDS patients therefore are liable to draw on resources from across the gamut of hospital and community based health services, and services provided by local government and voluntary agencies.

These results truly reflect the fact that the AIDS numbers may not resonate reality, making it extremely difficult to allocate precious health care resources. For example, a smaller urban area may see a great number of their people being tested in Toronto at Anonymous Testing Sites. If they do test positive Toronto receives the numbers and the

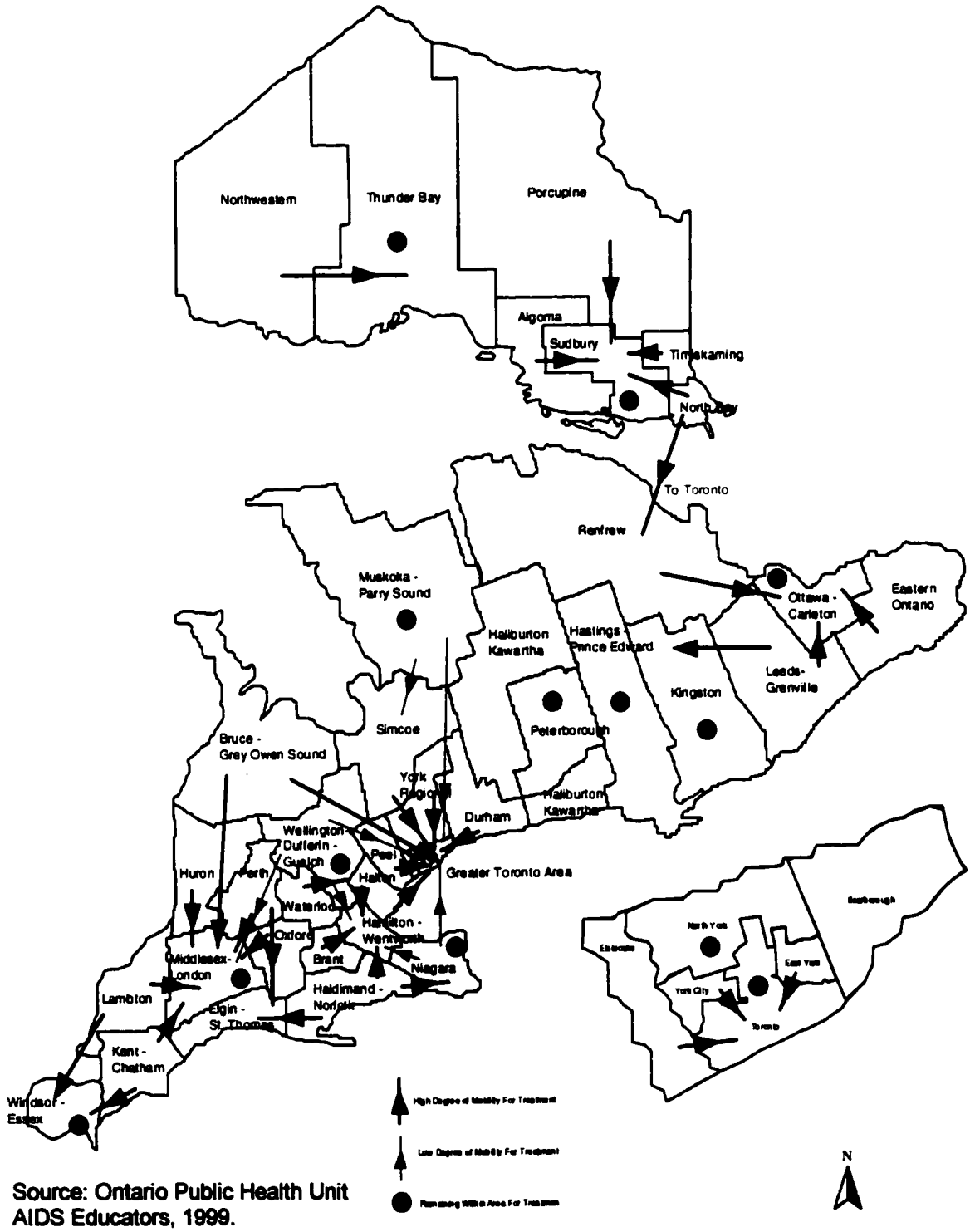
potential resources will then go to the larger centres because they have larger numbers of AIDS cases. The concern is that the client may return to the smaller centre after their positive test and use the services and resources of the smaller centre, even though their case is not being reflected in the smaller area's statistics. However, that same person may continue to go to the larger centre for support and treatment. Either way it is difficult to truly know how many people are actually being reflected by an area's AIDS statistics.

When we examine the map of where people go for treatment, Figure 31, we see a very similar pattern to that of the testing mobility patterns. Again there are areas that stand out as locations where people are remaining for treatment and support, surrounded by areas where people are coming from for treatment and support. When looking at Figure 31 we see that the majority of the areas are coloured red, meaning that people remaining within these areas for treatment and support, are also the areas that are attracting people from other areas, as is displayed by the second map, Figure 32. By just looking at Figure 31 we can guess where people are going and confirm our guesses with Figure 32. The data used for Figure 32 were obtained by asking the Educators where they thought people would be moving to for treatment if they were in fact leaving the area. A high degree of mobility means that a great number of people are leaving the area. A low degree of mobility means that only a few people are leaving the area for treatment. The length of the line has no meaning, it only shows where the people are moving to. Many of the red areas on the map also correspond to where the HIV specialists are located. Further, we know that an area like Kingston has people who remain in the area with few people coming from the adjoining areas.

Figure 31: Mobility Patterns For Treatment of AIDS In Ontario

Source: Ontario Public Health Unit AIDS Educators, 1999.

Figure 32: Mobility Patterns for HIV/AIDS Treatment In Ontario



Source: Ontario Public Health Unit AIDS Educators, 1999.

The next question concerning mobility and treatment was, **"Do you have the impression that people who are in the final or late stages of AIDS are returning to their area of origin to die if they have left the area?".** The reasoning behind this question was to hopefully gain some more information about the degree of mobility. For instance, if people are returning to their area of origin this could suggest that they were living elsewhere and using the services and support of another area. However, this question is problematic in that if the person was living elsewhere did this mean that they were tested elsewhere as well? If this is the case, then the numbers and support for that area will work out; they were tested elsewhere, but they were also treated and supported elsewhere. However, now that the person is returning to their original area they will now be using the resources of this area, and again this area's numbers would not reflect reality, if the person was not tested there. In addition, support is not just needed for the person infected with HIV/AIDS, but support is also needed for the friends and family affected by HIV/AIDS.

26 of the 42 AIDS Educators (61%) believed that if people were living elsewhere they were returning to the original area in the later stages of the disease. These PHUs include:

Elgin-St. Thomas	Timiskaming	Halton
Brant	Waterloo	Muskoka-Parry Sound
Porcupine	Peterborough	Leeds-Grenville
Etobicoke	Peel Region	Perth
Huron	East York	Eastern Ontario

Haliburton-Kawartha	Hastings-Prince Edward	Lambton
Middlesex-London	Oxford	Renfrew
Simcoe	Sudbury	Thunder Bay
Toronto	Wellington-Dufferin-Guelph	

11 of the 42 AIDS Educators (26%) thought that people were not returning to the area after living elsewhere. These PHUs include:

North Bay	Kent-Chatham	Niagara
Northwestern	Haldimand-Norfolk	York
Ottawa-Carleton	Algoma	North York
York Region	Bruce-Grey-Owen Sound	

5 of the 42 AIDS Educators (11%) were unsure of the situation. These PHUs include:

Kingston-Frontenac	Scarborough	Durham
Hamilton-Wentworth	Windsor-Essex	

Many of the Educators mentioned that people are now managing HIV/AIDS, and so there is less talk of dying, making this a difficult question for which to receive a definitive answer. Not returning home can also mean that there was no need to leave in the first place, that there was enough support within the original area. Of the 37 Educators that did provide an answer to this question 70% believed that if people had lived elsewhere for the duration of their disease, they were in fact returning to the area where they had first lived. Reasons for not providing an answer were numerous especially since it is difficult to know what individuals are or are not doing. However, some generalizations can be made.

The Educators believed that patients would not return to their original area unless they had a partner, friends, family or some sort of support system to come to. Further, if there was a hospice in the area the chances were greater that a patient would return. For example, the Casey Hospice in Toronto attracts a great deal of people.

If we examine the map, Figure 33, we see that very few places have patients who are not returning to their area of origin. This suggests two things. First, there may not be the necessary support systems to come to. Second, there may have not been a need to leave in the first place; there was adequate support and treatment systems and few concerns about confidentiality, if this was an issue. It is not surprising that an area like Toronto would have people living there because of the numerous support systems. However, the Toronto AIDS Educator believed that people were possibly leaving the province during the early stages of the disease and then returning. One would think that Toronto would be like Ottawa, in that people would not be returning to the area, but just remaining there. In an area like Timiskaming people are returning because the cost of living is lower. Many of the Educators mentioned that people really are managing, not dying. Another difficulty in answering this question is that it is hard to know what people are doing in terms of what type of support they are receiving, or where they are going to receive the necessary support. The PHUs do not have adequate statistics to know what support people are receiving or where they are receiving it unless they contact a support agency like Homecare. In addition, according to many of the AIDS Educators there is less fear and ignorance surrounding HIV/AIDS, as compared to five years ago, meaning that people do feel more comfortable about returning to smaller urban areas. Nevertheless, many of the AIDS

Figure 33: Mobility Patterns For AIDS Patients

Source: Ontario Public Health Unit AIDS Educators, 1999.

Educators still believe that HIV/AIDS is an "underground disease" and people still move around a lot, making it increasingly difficult to really know what people are doing. In addition, how attractive the hospice is, or the actual concept of a hospice, may also determine one's mobility.

It is important to remember that with this issue of mobility we are only looking at general patterns and impressions. What are people generally doing who have AIDS? Where are they receiving support? Are they moving around a lot? By answering some of these questions we can better assess where resources and support should be provided; we can estimate where a need is. In addition, by obtaining some mobility impressions we can hopefully gain a better understanding of what we are seeing in the maps of the spatial patterns and variations of AIDS in Ontario at the PHU level.

The final question concerning mobility and related to the previous question was: **"To what degree do you think people who are living in one area are using the services and resources of another area? In other words, do you feel your catchment area is supporting HIV/AIDS cases that are not necessarily reflected in your numbers and statistics?"** The reasoning for asking this question concerns RDIS. When a person contracts AIDS the information is transmitted to RDIS, based on where that person was confirmed to have an AIDS defining illness and a positive HIV test. RDIS is not updated from the time of an AIDS diagnosis to reflect any changes in one's place of residence, or where one is receiving treatment and support.

13 of the 42 AIDS Educators (31%) believed that they were supporting AIDS cases from outside of their area. The PHUs include:

Elgin-St. Thomas	Haliburton-Kawartha	Halton
Lambton	Middlesex-London	Ottawa-Carleton
Simcoe	Thunder Bay	East York
North York	Toronto	Wellington-Dufferin-Guelph
York Region		

19 of the 42 AIDS Educators (45%) thought that they were not supporting AIDS cases from outside of their area. These PHUs include:

Brant	Bruce-Grey-Owen Sound	Durham
Eastern Ontario	Haldimand-Norfolk	Hastings-Prince Edward
Huron	Leeds-Grenville	North Bay
Oxford	Perth	Peterborough
Porcupine	Renfrew	Timiskaming
Waterloo	Windsor-Essex	York
Northwestern		

10 of the 42 AIDS Educators (24%) were unsure. These PHUs include:

Algoma	Hamilton-Wentworth	Kent-Chatham
Kingston-Frontenac	Peel	Sudbury
Etobicoke	Scarborough	Niagara
Muskoka-Parry Sound		

Of the 32 Educators that could provide an answer to this question, 41% believed that they were supporting cases that were not reflected in their numbers. 59% believed that they were not supporting cases outside of what their AIDS numbers reflected. The

following provides some more insight into these numbers, and also provides reasons as to why a substantial proportion (23%) of the Educators could not answer the question.

When attempting to answer this question (and many others included in the interview process), many people thought that the numbers and data relating to AIDS statistics are extremely misleading, making it difficult to make sense of any of the trends. However, some commonalties were established. As aforementioned, people who live in smaller urban areas tend to move to larger urban areas for support. For the majority of PHUs that were supporting cases beyond what their numbers reflected, they were larger urban centres. Areas that have correction facilities, or facilities such as the addictions hospital in St. Thomas, were more likely to be supporting cases from other areas. People from Toronto come to St. Thomas to the addictions hospital. Many of the Educators stated that for a great deal of other diseases we know where people are, they do not seem to move around to the same degree. However, it seems like the complete opposite is true for HIV/AIDS. It was restated that people are very mobile.

A great number of the Educators had difficulty answering this question. One reason is that the only way a PHU would know if a person tested outside of their area, and is now living and using the services and facilities of their area, is if that person seeks out the services of the PHU. For example, unless people are being tested and/or treated with an agency like Homecare, the PHU is not aware that they are even in the area. A few of the PHUs attempt to conduct updates by asking the physicians. However in some cases, the client was no longer with that specific physician. For that reason many of the PHUs have stopped doing the updates. There is still the possibility that if the patient remains in the area, the PHU may receive an update. In some cases, the patient may be returning to the

area as many as five years later. In large areas like Toronto where there are so many cases, it is impossible to review every case, or to know what people are doing.

As one can see from the number of observations, thus far, completing this informal study with the AIDS Educators at the Ontario PHUs was extremely beneficial. Along with the informal study, mapping these occurrences is also very useful. If we look at Figure 34, we see that once again there are pockets of the phenomenon. A large proportion of the Greater Toronto Area is supporting cases, likely from the surrounding areas. It is not surprising that Toronto is supporting a great many cases because there are so many support services in the area. Some PHUs estimate that there are as many people reported as not reported in their area. Wellington-Dufferin-Guelph falls into this category and from looking at the map it is easy to see why. Bruce-Grey-Owen Sound, Huron, Perth and Waterloo areas all report that they are not supporting people from other areas, potentially leaving Wellington-Dufferin-Guelph to do so. For example, from speaking with the AIDS Educator in Bruce-Grey-Owen Sound, it is known that no official AIDS Committee exists to offer support for this area. York Region also feels that they are supporting a lot of cases from Toronto because they are a less expensive city to live in and they have a great deal of inexpensive housing. It appears to be according to the AIDS Educators, a "bedroom" city for Toronto. With its close proximity to Toronto, it can easily be accommodating. If we look at northern Ontario, Thunder Bay is considered the "Toronto" of northwestern Ontario. People from Winnipeg also come to Thunder Bay for support and treatment.

If we compare Figure 34 showing what areas are and are not supporting cases from other areas and refer back to where people stay or go for treatment, Figure 32, we can see some similarities. For example, in Eastern Ontario people are leaving the area for treatment

Figure 34: Mobility Patterns For AIDS Support In Ontario

Source: Ontario Public Health Unit AIDS Educators, 1999.

and support, according to Figure 32, and so it would make sense that this area is not supporting cases from other areas. The same holds true for Ottawa-Carleton. People remain in Ottawa-Carleton for treatment and support, thus suggesting that there is sufficient support in the area, and we can also see that this area is supporting patients from other areas. Leeds-Grenville and Renfrew display the same sort of pattern as Eastern Ontario. Hastings-Prince Edward is an anomaly. People are remaining in the area for support and treatment, but this area is not supporting other cases. One reason for this is that people may be going to the Haliburton-Kawartha area for treatment, since this area is supporting other areas. Peterborough is displaying the same sort of trend as Hastings-Prince Edward. It is interesting to note that Haliburton-Kawartha was unsure if people were remaining in the area for treatment and support, but at the same time they felt that they were supporting people from other areas. As we move across southern Ontario, we see places like Durham, Bruce-Grey-Owen Sound, Huron, Perth, Waterloo, Oxford, Brant, and Haldimand-Norfolk all showing trends of patients leaving the area for treatment and support and simultaneously not supporting other areas. Interesting areas are Simcoe, Lambton, York Region and Halton because they show their patients leaving the area for support, but simultaneously supporting patients from other areas. Middlesex-London seems to make sense in that people are remaining in the area, and the area is supporting other cases. Finally, patients in Windsor-Essex remain in the area for treatment and they do not appear to be supporting any other areas.

If we look at northern Ontario we see that Northwestern, Porcupine, Timiskaming and North Bay are areas whereby people are moving elsewhere for support, and they are

not supporting any other areas. Thunder Bay shows that people are remaining in the area and that they are also supporting people from other areas.

Finally, as the vast majority of AIDS Educators state that they are not supporting cases reflected in their numbers, or were generally unsure, this variable is something that needs more study before any conclusions can be made.

The literature seems to support what was found in the informal mobility study, but not at such an aggregated level. For example, Hogg et al. completed a study of HIV/AIDS and mobility patterns in Canada in 1997. Their study sought to characterize migration patterns of people with AIDS in Canada, from the onset of AIDS diagnosis to death. Their analysis revealed that only a small proportion of people changed their residence between AIDS diagnosis and death. They also found that geographic mobility was the greatest among people with AIDS residing outside of areas where the overwhelming majority of people with AIDS reside in Canada. In other words, people likely live where they can receive the support that they need. This coincides with what the AIDS Educators stated. Comparing place of AIDS diagnosis with place of death is an important method for measuring the mobility of persons with AIDS. From this two way classification, Hogg et al. state that estimates can be made of in and out migration rates for a specific region or province. Again coinciding with this informal study, Hogg et al.'s study determined that metropolitan centres like Vancouver, Toronto, and Montreal have large gay and bisexual communities. Research has shown that gay and bisexual men are attracted to these larger metropolitan centres from smaller cities and rural areas. This pattern is usually only in one direction and may be attributable to these men becoming more economically and socially

independent (Hogg, 1997). In addition, depending on what stage of the disease one is at will determine one's degree of mobility. This is likely a big factor.

The mobility for all HIV/AIDS patients, or their motives for mobility may not be as obvious. People with HIV/AIDS are a heterogeneous population, each with different circumstances, and motivated by different factors. People with AIDS may change location in order to be closer to social support systems or to be near family and friends. Mobility may also be motivated by a need for access to health care or tertiary facilities. Hogg et al. also cautions that the interpretation of these results must be done with prudence, as with the results from this more informal study. Using data based on AIDS diagnosis is disadvantageous because one is uncertain about the date of arrival or length of stay at that location, or about previous migration. There is also concern about people who were not diagnosed at their usual place of residence (Hogg et al., 1997).

The findings from this section of the chapter are as follows:

- If people are worried about confidentiality they will go to an Anonymous Testing Site, even if it means leaving the area in which they reside.
- Larger urban centres attract people from smaller urban centres for both testing and treatment procedures.
- If people do leave an area we can make fairly accurate predictions about where they are going based on where the Anonymous Testing Sites are located.
- AIDS statistics in large areas likely reflect the fact that people are moving there to be tested and to receive support. However, this is difficult to absolutely prove without devising a new research design.

- How attractive a support facility is, or the actual concept of a facility like a hospice, or the location of the facility may also determine one's mobility. Further, people likely live where they can receive the support that they need, if they have the means to do so.
- AIDS is still considered an "underground disease" which can create large amounts of mobility.

QUESTIONS REGARDING FACTORS THAT CONTRIBUTE TO OR PREVENT THE SPREAD OF AIDS IN ONTARIO

This section will discuss the factors that contribute or prevent the spread of AIDS in Ontario, at the PHU level. The information from this section will go towards forming a more complete and conclusive picture of AIDS in Ontario. It is a well documented fact that there is a great deal of late and under reporting when dealing with HIV/AIDS. Inaccurate numbers cannot provide one with an factual picture of the degree of the severity of the situation; nor can it allow for accurate mapping of prevalence rates. In order to assess how much late and under reporting is occurring in Ontario at the PHU level, the question was posed to the AIDS Educators: **"Based on your working relationship with physicians in your area, do you feel that there is a great deal of late and/or under reporting? Further, do you feel that necessary follow-up procedures, like partner tracing and partner notification, are occurring in your area?".** This question was not meant to impose blame on the physicians of Ontario, or on anyone else in the medical field; instead, it was simply meant to get a sense of to what degree late reporting is occurring, and to get a sense of how often pre and post counselling procedures are being carried out. As mentioned in the "Background Information on HIV/AIDS Section", partner tracing and

partner notification are important and effective measures to stopping and/or eliminating the spread of AIDS.

8 of the 42 AIDS Educators (19%) believed that physicians were doing a conscientious job of reporting, counselling and notification. 17 of the 42 AIDS Educators (40%) thought that physicians in their area were not doing a conscientious job of reporting, counselling and notification. 17 of the 42 AIDS Educators (40%) were unsure of how conscientious physicians were being in terms of reporting, counselling, and notification. Of the 25 Educators that could provide an answer to this question, 32% believed that physicians were doing a conscientious job of reporting, counselling, and notification, while 68% believed that physicians were not doing a conscientious job. However, a very large proportion of the PHUs, 40%, were not sure one way or another. Based on what was compiled during the interview process, the following can be determined about testing, reporting, counselling, and partner notification in Ontario.

One concern that was expressed by the Educators was that many physicians are not conducting prenatal testing even though there have been many campaigns to promote this. The chances of a woman receiving prenatal testing were higher if the woman was seeing a gynecologist. Another concern was that quality counselling does not always occur with nominal and non-nominal testing. Many of the Educators claimed that a high number of physicians do not feel comfortable testing and/or providing the counselling. Many physicians have expressed low comfort levels with HIV/AIDS, others treat it like a routine blood test. The reasons for physicians not feeling comfortable range from feeling that they do not have enough information, judging their patients from a moral standpoint, or having large case loads. Physicians with large geographical areas can have very large case loads,

spread out over a great area. Some physicians may be judgmental about high risk clients and this bias may come though in the counselling procedures. There are other instances whereby the patient did not know they were being tested, nor did they know what being HIV positive really meant.

Low comfort levels for physicians who are conducting testing may stem from inexperience. The PHUs are very good at counselling and testing because they have a lot of experience with the procedures and their ramifications. As well, in many instances they can be more supportive because they can take the time (or have the time) to fully explain the procedures and the results. In cases when the physician will not, or cannot offer, pre and post counselling and contact tracing, the PHU will do so.

Finally, there are instances whereby physicians provide little or no counselling and simply forward the results to the PHU. Some Educators commented that some physicians felt that they were not being paid to complete all of the necessary paper work for reporting. On the other hand, some physicians are on "top of things", and simply use the PHU as a resource and support mechanism. There are great inconsistencies; some physician are very keen and want to provide the best support, others want nothing, or very little to do with HIV/AIDS.

Many Educators felt that counselling has improved from what it once was. Others felt that under and late reporting were issues that also needed attention. There have been cases whereby the reporting is not completed if the physician is trying to protect their client. In some cases the patient has died before the PHU knew about the status of the patient. There are also instances of duplication if the patient has been diagnosed in more than one place. There have also been cases whereby the physician will not test a client, even if the

client requests it. The physician may feel that in their opinion the client is not in a high risk behaviour group and therefore does not need to be tested, regardless of what the patient may really need and/or want. Finally, for others there were not enough positive cases in the area for the Educator to get a sense of how conscientious the physicians were being.

Finally, if there is a HIV specialist in the area, generally speaking, the procedures are followed more accurately and completely. Areas where there is a specialized care centre, like the Specialized Immunization Services in Hamilton, create a different situation. The same thing occurs in the Greater Toronto Area whereby many of the physicians in the outlying areas will work with the HIV specialists. Other physicians will "bulk" their case loads, meaning that the physicians who feel more comfortable working with HIV/AIDS will take on patients from physicians who for whatever reason do not want to handle the case. One general conclusion is that there appears to be little continuity across the province in terms of reporting, counselling, and partner notification.

Another method to reduce the spread of AIDS in an area is the use of needle exchange programs. The Educators were asked, **Is there a needle exchange program in your area?** Sixty four percent of the PHUs have some sort of needle exchange program. The majority of the remaining few Units are working on one. For the most part the needle exchange programs have been very well received. Some of the needle exchange programs are mobile, meaning that they will go to where the users are. Some of the needle exchange programs also provide HIV testing. One reason some of the Units do not have a needle exchange program is due to budgetary concerns. Another reason is that some feel that the drug of choice in the area is marijuana, which does not require the use of needles. Most of

the Educators stressed that they are working towards harm reduction, not necessarily abstinence.

An additional question concerning prevention was posed: **"Do you think the safer sex message is reaching the appropriate people, for example, young people? If the message is reaching people, are people responding suitably and appropriately with their behaviour?"** By using the term "safer sex message", the meaning is that when people are engaging in sexual intercourse or activity, they are protecting themselves with a condom, or they are abstaining. By responding to the safer sex message the idea is that people are hearing the message, internalizing it, and acting in an appropriate manner; they are using the necessary protection, and are being tested after engaging in risky behaviour(s). This was an important question to pose in order to provide some insight as to how effective prevention and education programs are in Ontario, especially at the PHU level. Young people were chosen as the age group of interest because they are ones most likely to be receiving the safer sex message in an educational environment. People who are not in school are less likely to be receiving this sort of message, although some information may be received from the media and other similar sources.

The age at which at person becomes sexually active and their number of sexual partners are well established risk factors for contracting STDs. According to the Ontario Ministry of Health, multiple sexual partners are more common among young people than other age groups and highest among young males. Forty-five percent of males and thirty-three percent of females aged sixteen to nineteen report having had two or more sexual partners in the twelve months before the survey conducted by the Ministry of Health was completed. Eighty-eight percent of all males and ninety-three percent of all females report

only one or no sexual partners in the past year. The use of condoms is important in the prevention of STDs and HIV/AIDS. However, for the majority of those reporting two to four sexual partners in the past year, seventy-two percent, and of those with five or more partners, sixty-three percent, use condoms only infrequently or never (Ontario Ministry of Health, 1992: 33, 34).

28 of the 42 AIDS Educators (66%) believed that the safer sex message was reaching young people. 3 of the 42 AIDS Educators (7%) did not think the message was reaching young people. 11 of the 42 AIDS Educators (26%) were unsure. Of the 31 AIDS Educators that could provide an answer to this question, 90% believed that young people were receiving the safer sex message. The Educators based their answers on the work that they have completed while in the school systems.

In terms of responding to the safer sex message, 7 of the 42 AIDS Educators (16%) believed that young people were responding appropriately. 12 of the 42 AIDS Educators (28%) believed that young people were not responding to the message. 23 of the 42 AIDS Educators (54%) were unsure. Of the 19 AIDS Educators that could provide an answer to this question, 36% believed that young people were in fact responding to the safer sex message.

Reasons for not providing an answer included responses whereby the Educator simply did not know what people were or were not doing. As well, for the second question, responding to the safer sex message, some Educators felt that a few people were responding, and others were not. These responses were grouped into the "Not Sure" category since no clear distinction was made by the AIDS Educator. Based on what was

said during the interview process the following are indicators about young people receiving and responding to the safer sex message.

Most of the PHUs stated that condoms were available in the public high schools, but not in the separate high schools. The separate schools are becoming more progressive with condoms, and homosexuality in terms of acceptance levels, and what is taught and discussed in the classroom setting. Many teachers are uncomfortable discussing some of the issues surrounding HIV/AIDS, such as anal sex and drug use. Schools that do not provide condoms may offer them in supervised clinical services, either within the high school, or at the PHU. It was also determined that more females than males go to birth control clinics for counselling and protection. Many Educators felt that students were accessing the condoms, if they were available. It was again reiterated that the people who were most at risk were not using protection. Some of the Educators estimated that approximately fifty to sixty percent of young people are still not using condoms. One reason according to many young people is that condoms are expensive. Access to condoms and birth control on the weekends when the free birth control is not available is a barrier for some youths; they claim that economics is a barrier to practicing safer sex. Another deterrent to some is that using condoms may make young women feel "bad", having "planned" to have sex, regardless if this is safer sex. In some areas where there is a large rural population, gaining access to birth control clinics may be difficult, especially if the youth wishes to remain anonymous. Some of the AIDS Educators mentioned that they would personally see that these youths could be given the service and support that they needed.

Durham Regional Health Unit completed a survey in 1999 to examine condom usage in young people aged thirteen to nineteen years of age. Their findings are as follows:

- Males: 44% reported using condoms; 9% reported using condoms and oral contraceptives.
- Females: 43% reported using condoms; 13% reporting using condoms and oral contraceptives.
- These numbers have increased since 1998 when 43.5% reported that they were using condoms; and 1995/96 when 35.5% reported that they were using condoms.

Better data is needed on condom sales in terms of who is buying them, for example. The youth of today are better protected than the youth of ten to fifteen years ago, and for the most part they are more careful. However, a great number of young people commit risky acts and worry about the consequences later. They "live for the moment". In addition, the birth control pill is a barrier to safer sex, and a leading cause of STDs and HIV/AIDS, meaning that pregnancy may be of greater concern than HIV/AIDS. The students are being taught the information and many are aware of the risks, but their behaviour does not always reflect what they know, nor is it always consistent. There are certain subpopulations within young people that need specific attention, such as young gay men and high risk youth. Concerning the term "risk", there are three different types. The first type is taking a risk, knowing the odds, but believing that one can beat the odds. The second type of risk is uncertainty, not knowing the odds, but still being willing to take the risk. The final type of risk is ignorance, not knowing the odds, or the facts surrounding the issue. According to the Educators, many of the young people do know how HIV/AIDS is contracted, and they know the odds of contracting HIV/AIDS; yet they are still willing to take the risk, they are not internalizing the message. It should be reiterated that adults are

not necessarily consistent with their actions either; young people just happen to be the ones used for this discussion to assess prevention efforts and concerns.

For the most part Public Health nurses and the Educators are no longer in the schools. Instead they act as consultants and resources to teachers and students; or they may come to the schools on an invitational basis. In many instances it is the whole community working together to teach sexuality, not just the school teachers. Many Health Units provide health fairs throughout the school year, with some of the emphasis on safer sex and sexuality. Most felt it was too soon to tell how effective the fairs have been. There is concern from many of the AIDS Educators that sexuality is not taught as a developmental task. Instead, much of the focus has been on the mechanics of sexual intercourse, not on sexuality itself: the way we think, feel and behave concerning sexual issues.

Presenting the safer sex message is never easy. Many young people are facing safer sex fatigue; they have heard the message so often that they are no longer listening. In addition, many moralists see abstinence as the best method and feel that young people should be offered all of the choices, not just the "safer" ones. The message needs to be broadened to not just include the high risk behaviours because many young people feel that they do not belong to a high risk behaviour group. Many of the AIDS Educators in the Greater Toronto Area feel that there are not adequate campaigns to address some of the cultural and ethnic issues that arise in an area full of ethnic diversity and a variety of cultural backgrounds.

A final challenge for prevention is that the three "i's still apply to many young people. They feel that they are "Invincible, Immortal and Infertile". Many young people believe that it is "not going to happen to them". Or they may believe that they are not

sexually active, "it just happened". Some feel that the AIDS cocktails can cure HIV/AIDS and so there is no need to take precautions. In the 1980s HIV was a prominent part of the curriculum and of the discussions, now it is a smaller part with more attention being given to hepatitis. Some people feel that the risk for HIV is over because they are only looking at the number of AIDS cases. Alcohol also plays a role in inconsistent condom usage. Safer sex is a self-esteem issue and is like any other risky behaviour, such as smoking, drinking, or drinking and driving. Self-worth and self-esteem is determined a long time before decisions to have sex are made. A challenge for many Educators to overcome is to gain the trust of young people. The media also plays a large role in young people's perceptions and interpretations of sexuality. For example, the AIDS Educators explained that it is extremely rare to see a condom being used or discussed in most of the pop culture that is viewed by young people.

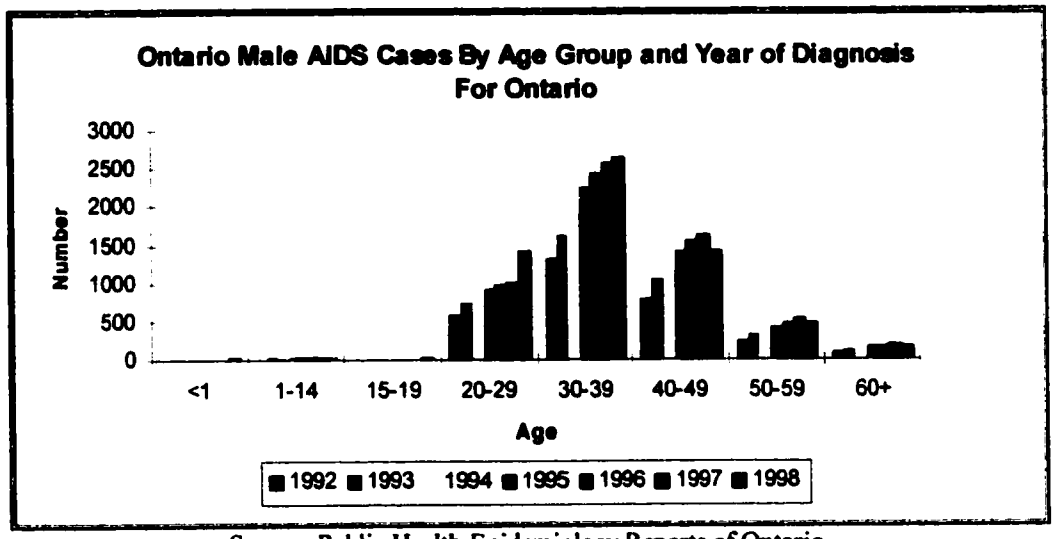
In terms of education and support, in 1997 the public school board servicing the County of Northumberland and the Municipality of Clarington and the Haliburton, Kawartha Pine Ridge District Health Unit and the Regional Municipality of Durham Health Department asked their students and their parents to comment on sexual health education. Parents of students in junior kindergarten to grade thirteen were asked to comment on the importance of certain sexual health topics. Parents in 6 833 families returned complete questionnaires. Students in grades 5 to 13 were asked about the importance of sexual health topics to themselves, how they preferred to be taught, and what they thought made for a good sexual health teacher. 8 784 students completed questionnaires.

Ninety-eight percent of parents agreed or strongly agreed that learning how to prevent infection from STDs including HIV/AIDS is important. Ninety-four percent of

male and female students believed that preventing STDs and AIDS is an important or very important topic. This was the topic that students rated as most important. How to get testing and treatment for STDs was rated as the second most important topic overall.

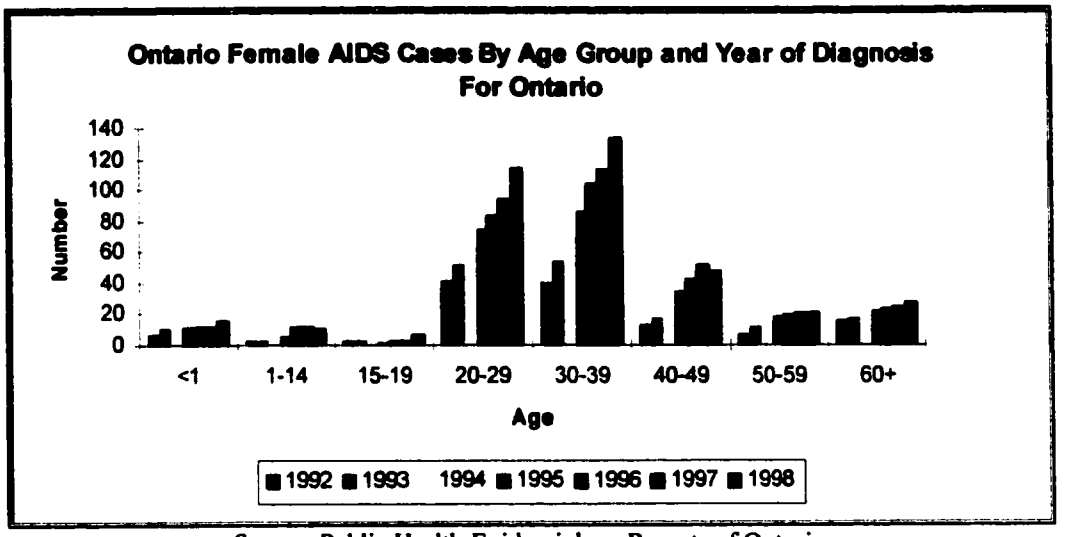
The literature seems to support much of what the Educators stated. For example, the Association of Local Public Health Agencies has suggested that half of the youth population is sexually active by grade eleven. Further, the number of cases of AIDS in Ontario in the twenty to twenty-nine year age group is increasing and has been doing so over time, as shown in the following figures, Figure 35 and Figure 36.

Figure 35



Source: Public Health Epidemiology Reports of Ontario.

Figure 36



Source: Public Health Epidemiology Reports of Ontario.

Since the time it takes to develop AIDS is approximately ten years, the twenty to twenty-nine year olds were likely infected as young people. Other sources have suggested that the campaign to promote safe sex among young people and to prevent the spread of HIV/AIDS is not working. Approximately a dozen Canadians become infected with HIV every day and among homosexuals, the median age of infection has dropped from over thirty to less than twenty-five (Bueckert, 1998).

Prevention is not simply an effort between the PHUs, the schools and the students. It also needs the support of the community in which these people live. A question regarding this community support was posed to the AIDS Educators. The question was, **"In some areas there have been "right wing groups", "family coalition groups", or "fundamentalist groups" who have opposed what the PHUs are doing in terms of prevention and education. Has this been a concern in your area?"** This was an important question to ask because it can provide some insight as to how prevention and

education programs in Ontario are being perceived and more importantly how they are being supported by the community at large.

13 of the 42 AIDS Educators (31%) believed that "right wing groups" were an issue in their area. 23 of the 42 AIDS Educators (54%) believed that it was not an issue. 6 of the 42 AIDS Educators (14%) were unsure if it was an issue. Of the 36 AIDS Educators that were able to provide an answer to this question, 63% did not see "right wing groups" as an issue in their area, in terms of supporting or not supporting their prevention efforts. Reasons for not providing an answer included responses whereby the Educator simply did not know if it was an issue or not. Based on what was said during the interview process, the following can be determined about the issue of "right wing groups" and prevention efforts in Ontario.

Most areas have only experienced a few letters to the editor in the local paper. Some have protested the school board, others have provided skewed sexual information to their children. They have argued that their children are not sexually active and therefore do not need education or prevention messages on STDS and/or HIV/AIDS. For example, some "right wing" parents would rather have their teenage daughter come to them pregnant than to know that she was practicing safe sex. Sometimes these groups can simply act as a slowing down mechanism and as an interference. Some of the challenges faced by the PHUs from these groups have been concerning accessibility and availability to condoms. Some groups have ensured that condoms would not be made available in the high schools. Some have also expressed their concern over needle exchange programs. However, for the most part, the PHUs have had the support of the "silent majority".

"Right wing groups" can be seen in a positive light as well. They have helped with the sexuality message, by strongly advocating for abstinence. This is an important part of the sexuality message. Their presence has promoted an interest in presenting a more balanced picture.

One concern expressed by many of the AIDS Educators was that as aforementioned, the media glamorizes sex, causing many young people to believe that protection may not be necessary. Another "mental issue" to contend with is that some young women believe that by having a baby they will "fit in" and be accepted. By being a parent, they can be "good at something". For others, they feel that there is "nothing to do", in terms of social activities, and so they will engage in sexual activity and protection may not be used or even considered. Areas that are economically depressed expressed that young people in their area see few options, in terms of their future prospects, and so they become pregnant, or they do not have the self-esteem to be in healthy relationships and to negotiate safer sex. In areas like Muskoka and Parry Sound, where there is a large cottage industry, sex "takes off" in the summer months and protection is not a consideration. Some of the females in these areas see the males "from the city" as more "sophisticated". Finally, with improved testing methods for STDs the numbers have and will increase.

The findings from this section of the chapter are as follows:

- In terms of preventing the spread of HIV/AIDS there are great inconsistencies throughout the province. For example, some Educators felt that people were using the appropriate protection for sexual activity, others were not.
- Some areas provide adequate counselling and partner notification procedures, other areas do not.

- (Young) people with numerous sexual partners who are not using appropriate protection are of great concern. A sense of invincibility appears to prevail in most areas of the province.
- Eliminating or preventing the spread of AIDS is a community responsibility. For the most part communities are working together to reduce the diffusion of HIV/AIDS.

MAJOR RISK BEHAVIOURS AND OVERALL IMPRESSIONS OF HIV/AIDS IN THE ONTARIO PUBLIC HEALTH UNITS:

This final section of the interview questions attempts to understand the major risk behaviour groups and to gain an overall impression of HIV/AIDS in Ontario at the PHU level. Regarding the major risk behaviours for AIDS, the Educators were asked: **"In your opinion, what is the major risk behaviour for HIV/AIDS in your area? Do you see this changing in the next five to ten years?"** The break down of their responses is as follows:

- MSM: 16 of the 42 AIDS Educators (38%)
- Unprotected heterosexual activity: 14.5 of the 42 AIDS Educators (34%)
- IDU: 8.5 of the 42 AIDS Educators (20%)
- Substance Abuse: 1 of the 42 AIDS Educators (2%)
- Ignorance surrounding prevention issues: 1 of the 42 AIDS Educators (2%)
- Unsure: 1 of 42 AIDS Educators (2%)

Only one AIDS Educator did not provide an answer this question. Some of the AIDS Educators defined two major risk behaviours. To accommodate this each risk behaviour was given a weight of 0.5 so that the overall total would still remain forty-two. Based on

what was said during the interview process the following can be determined about major risk behaviours for HIV/AIDS. As per the Figures below, Figure 37 and Figure 38, we can see that what is published in PHERO and what was said by the Educators coincides very well for the major risk behaviours.

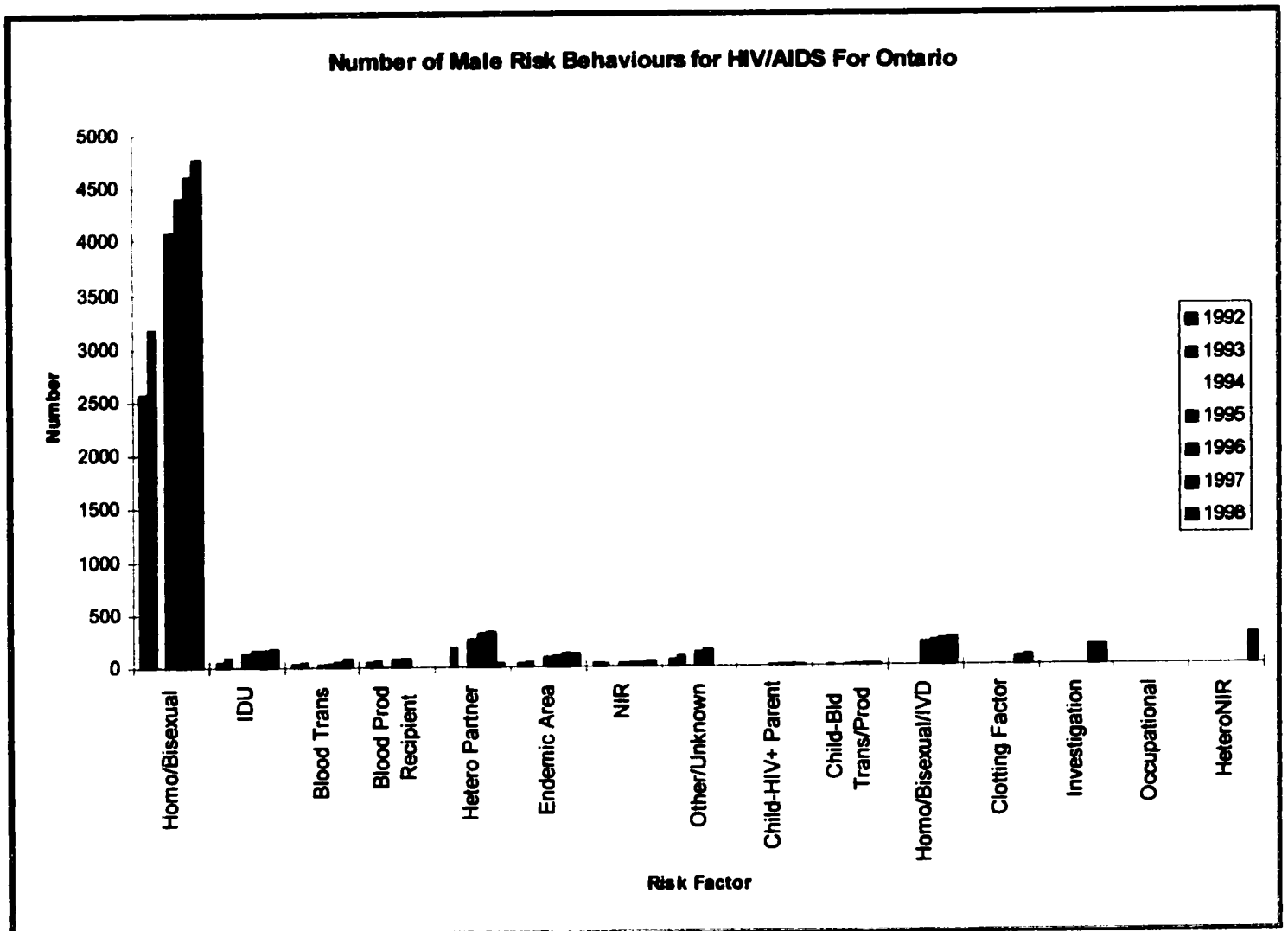
In terms of predicting risk behaviours for the next five years a good number of Educators felt that unprotected heterosexual activity was a concern, especially for women and their unborn children, as shown in Figure 38. Injection drug users are also seen as a concern in the next five years. This coincides with what Health Canada has predicted in their HIV and AIDS in Canada 1999 report. It was also noted that all risk behaviours come and go in waves. Finally, as confirmed by the mobility analysis, many people in small urban areas are going to larger urban areas to practice risky behaviours.

An additional question concerning risky behaviours and testing was: **"In terms of testing, are you seeing any major risk behaviour group testing more than another? Are you seeing any particular age group testing more than another? Are you testing equal numbers of males and females?"** In terms of testing the major risk behaviours, the following groups were mentioned:

- "Worried Well": 20 of the 42 AIDS Educators (47%)
- Unprotected Intercourse: 4.5 of the 42 AIDS Educators (10%)
- Engaging in high risk activities: 1 of the 42 AIDS Educators (2%)
- Men who have sex with men: 1 of the 42 AIDS Educators (2%)
- Injection Drug Users: 0.5 of the 42 AIDS Educators (1%)

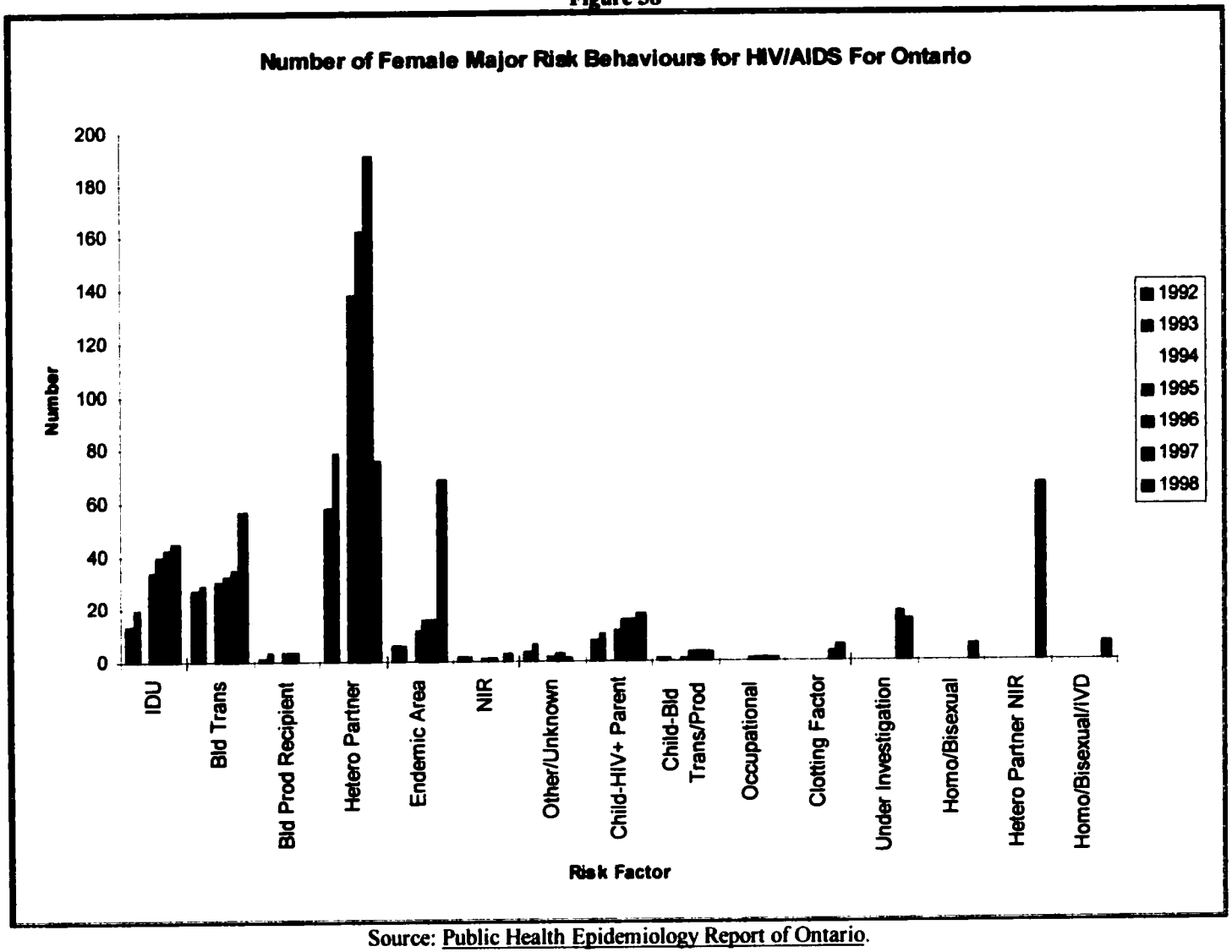
In terms of testing for any particular age group, the following can be noted:

Figure 37



Source: Public Health Epidemiology Report of Ontario.

Figure 38



Source: Public Health Epidemiology Report of Ontario.

- Older than eighteen years of age: 1 of the 42 AIDS Educators (2%)
- Young people in general were also distinguished: 2 of the 42 AIDS Educators (4%)
- Not Sure: 12 of the 42 AIDS Educators (28%)

Of the thirty Educators that did answer this question, two thirds believed that the majority of people being tested within their areas were the "worried well". The "worried well" are well informed about HIV/AIDS in terms of transmission of the disease, and prevention methods. In many instances these are people starting new relationships and would like a "clean bill of health". Again, some of the Educators defined two groups and to accommodate this each risk behaviour was given 0.5 so that the overall total would still remain forty-two.

The Educators stated that young people will go for testing if they have been with someone who is considered "dirty", in other words, someone who has had unprotected sex. Unfortunately in many instances, young people feel that if they have been tested, they can somehow be issued a "clean bill of health", regardless of their previous activities, or the protection methods used. They view testing as a cure. However, most teens are never tested so surveillance estimates are inadequate and conservative.

More women than men are being tested. This may be attributed to the fact that women have traditionally undergone more health examinations than do men. As well, during pregnancy women may get tested. What is unfortunate is that many Educators believed that the people who were most at risk are not being tested. This again confirms what Health Canada has stated about people who are HIV positive, but have not been

tested. Finally, this can be a difficult question to answer because many times when people are being tested they will not correctly identify their true risk behaviour group.

The final question posed to the AIDS Educators was, **"What is your overall impression of HIV/AIDS in your area? Do you feel that progress is being made in terms of prevention, are individuals changing their behaviour(s)? Are you optimistic or pessimistic about HIV/AIDS for the future?"** Based on what was discussed during the interview process, the following summaries can be made. The summaries only help to underline the importance of completing this research.

There needs to be more of an emphasis on healthy relationships for young people. This would mean an emphasis on skill development, such as refusing sexual relationships. Alcohol also appears to play a large role in this development, and in the decision making process.

There are low levels of concern for HIV/AIDS in the smaller urban areas. There is a sense of apathy because there are so few visible cases. People feel that it is a "big city" disease and one that they do not have to worry about. This attitude only changes when it happens to them, or to someone they know. This is a major misconception that definitely needs to be addressed.

Further, AIDS has become a chronic infection; there is more managing and less dying. This may be causing people to not view HIV/AIDS as such a serious disease because there is less death associated with it. For example, some of the treatments, such as the AIDS cocktails have created a backlash. People feel that they can do whatever they want because all they have to do is take a few pills, and they will be fine. Some feel that to make any headway people must be encouraged to practice to stay negative. The difficulty

is that media has made it look like there is a cure. For example, Magic Johnson has shown very few symptoms, and has a very low viral count. People do not fully understand this and think he is cured. There is no cure for HIV/AIDS, but some people feel that there is. For some people the fear of the disease has left; the tragedy of AIDS is that it is not as visible because people are not seeing as much death.

There have been improvements in the mainstream, "middle of the road" population in terms of prevention and education. However, there are increasingly fewer services to the high risk, fringe groups. For example, there are needle exchange issues in many correction facilities. Correctional institutions have the highest HIV prevalence of any institutional setting in Canada. Condoms are available with varying accessibility in all federal and some provincial institutions. Bleach provision and needle exchange programs could be instituted without modifying disciplinary status.

Sexuality and addictions are topics that not all people understand, and may be hesitant to support, due to emotions and fear. Imposing blame on people will make them less likely to change. Drugs and other sorts of addictions are seen as "black and white" issues to many people. They become very emotional issues, as do sexual issues. Because the face of HIV/AIDS has changed there is a need to look at other determinants of health, such as housing, food and mental health issues. Support needs to exist where people are, not where we think they "ought" to be. Many people are abused and there are a lot of underlying factors for those suffering from addictions. How can we expect people to use clean needles and condoms when they do not have a place to live, or they cannot feed themselves. We must remember that these are health issues, not moral or ethical issues.

The challenge is to keep the prevention message fresh. People are more aware than they were five years ago, and more people are getting tested. However, there are new people every five years who need to be educated. Education is an ongoing effort for everyone. The message for HIV/AIDS needs to suit the people who are receiving it. This is an ongoing battle. There are different methods of getting the message out, not just the traditional techniques. As well, females and males experience different levels of vulnerability in terms of sexuality. They need access to services, to condoms and to testing. There is so much diversity in Ontario that no one message applies to everyone. "AIDS 101" never disappears as there is always a new generation to educate. The younger people are more aware, but we have to look at the world the way they see it; they are prone to taking risks.

Finally, HIV/AIDS is a political disease in that has received more stigma than any other disease. Because of this stigma health authorities may sometimes behave in dubious ways. On the one hand we want information on sexuality and sexual activity in the community, but at the same time there are concerns about confidentiality, making it quite difficult to know what is happening in terms of infection rates, both spatially and temporally. Because of the reporting structure of HIV/AIDS many PHUs feel that they do not have an accurate picture of what is going on. There are not the accurate statistics on HIV to provide the "portholes" needed to see what is going on with the disease. This issue will be discussed in greater detail in the next section of the "Results".

The answers and impressions from the final set of interview questions provide a overall view of AIDS in Ontario at the PHU level. The following concluding remarks can

be made both about the last section of interview questions, and for the entire interview process.

- In terms of major risk behaviours, what was discussed at the PHU level coincides very well with what is represented at the federal level. Unprotected heterosexual activity and injection drug use are continuing to rise in terms of which risk behaviour group is displaying the most AIDS cases. MSM are still quite prominent at the PHU level.
- The "worried well" display the highest numbers in terms of who is being tested. Again, as was stated at the Canadian level, those who are in the highest risk groups are not being tested.
- In terms of the overall view of AIDS in Ontario, developing healthy relationships are a fundamental concern.
- AIDS is still seen as a disease that only occurs in the larger urban centres, creating a sense of apathy in smaller urban areas because the disease is less visible.
- People who are developing AIDS are managing the disease a lot better, resulting in a lower death rate. The improved AIDS "cocktails" have also helped to improve the situation.
- Finally, because HIV/AIDS is contracted by individual behaviour(s), it is hard to truly know what is going on. The statistics are not too indicative of reality, thus again establishing a need for the informal mobility study to see where people are going to and from.

This concludes the first component of the Results Section. The information gathered in this section will be used in the subsequent section to augment the data provided by the mapping of the prevalence rates, and the spatial patterns and variations that emerge.

Spatial Variations and Data Issues with the Prevalence of AIDS In Ontario

The second section of the Results begins by focusing on the product of the secondary objective of the research, to examine the spatial variations and patterns of AIDS prevalence rates throughout Ontario at the PHU level. Further, this secondary objective also explains to a degree, some of the functions that could explain the prevalence rates. This section of the Results is divided in two. The first section examines the mapping aspect of the prevalence rates and examines the variations and patterns. The second segment returns to the subject of methodologies, and looks at what methodologies could be employed in this type of research now that the background information has been supplied on the mobility of AIDS patients, and the mapping of the prevalence rates. Further, it examines to what extent the data issues limit our ability to analyze and understand the underlying processes, or functions of the spatial patterns and variations. Finally, the second section returns the focus to the primary objective, to examine the mobility patterns of AIDS patients, and to what degree mobility determines the methodologies that will be employed.

The first aspect of this section of the Results is to examine and describe the spatial variations in the prevalence rates of AIDS in Ontario at the PHU level, through the use of maps. Crude rates are not mapped as this would provide very little information, simply where the most cases are. However, crude rates are vital for PHUs as they describe the

magnitude of the number of cases and how much staff will be needed. In the case of AIDS this would likely follow the population hierarchy, in that cities with the highest population would likely have the greatest number of AIDS cases. As aforementioned, the prevalence rate is a per 100 000 rate. This rate simply tells us the total number of people per 100 000 within an area that have AIDS. The prevalence rate for this research is calculated on an annual basis using population figures from 1991, 1992, and 1996. From what we know of AIDS, a higher population number is likely going to mean a high AIDS prevalence rate, as compared to a low population level, with a low prevalence rate. The more people an area has the greater likelihood that some of those people will participate in risky behaviours. Further, for areas with many people the greater is the possibility that they will come in contact with someone who is infected. Finally, as was demonstrated in the mobility analysis, large urban areas have the propensity to attract people from surrounding smaller urban areas. HIV/AIDS needs humans and their cells to exist, therefore it moves where people move.

It should be noted that only four maps are discussed: 1990, 1993, 1995, 1998. These four maps were chosen because they displayed the greatest, or most noticeable changes from year to year; other years such as 1994 did not show any changes from 1993. These maps are sufficient to show the basic patterns and variations for the entire time period, and to use every map would be redundant and unnecessary. In addition to the maps, a Table is included showing the population and prevalence rates for each of the four years. The first Table for 1990 used the 1991 population figures because that is what was published with the 1990 data. The population changes again in 1992 and in 1996. These changes are according to what was published in PHERO. The reason for using population

figures is to examine the effect population can have on prevalence rates. The next section begins with Table 6 displaying the 1990 data, followed by a discussion of what is displayed by the map. Tables for the subsequent years are included in Appendix C entitled: "Population and Prevalence Rates".

Table 6: 1990 Population and Prevalence Rates

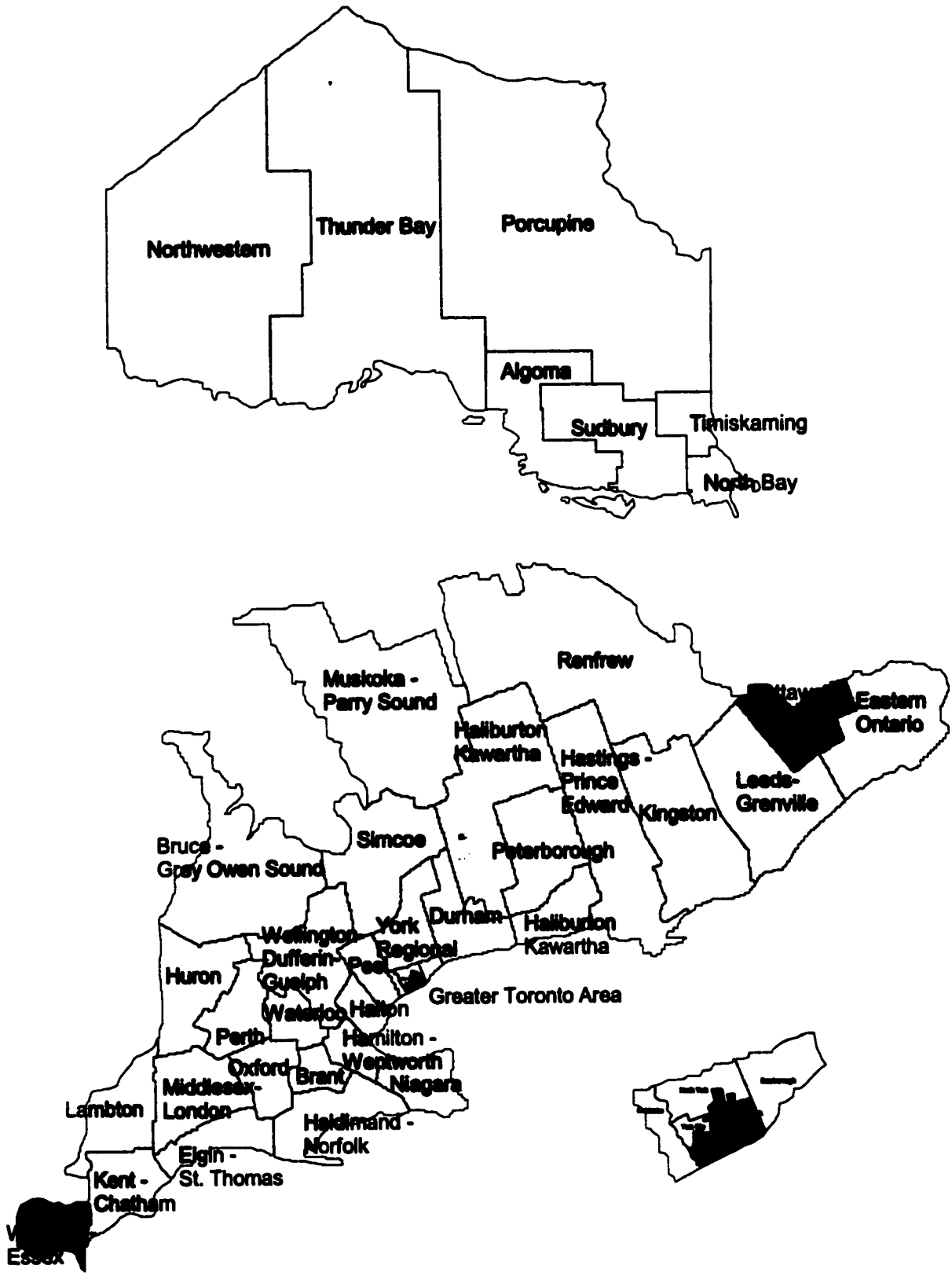
PUBLIC HEALTH UNIT	1991 POPULATION	PREVALENCE RATE
Peel	732798	6
Ottawa-Carleton	678147	23
Toronto	635395	160
North York	562564	12
Scarborough	524598	9
York Region	504981	8
Hamilton-Wentworth	451665	8
Durham	409090	4
Niagara	393936	6
Waterloo	377762	3
Middlesex-London	372274	17
Windsor-Essex	327365	21
Halton	313136	9
Etobicoke	309993	11
Simcoe	288684	5
Wellington-Dufferin-Guelph	199506	7
Sudbury	198580	3
Eastern Ontario	175024	3
Kingston-Frontenac	166332	10
Thunder Bay	158810	6
Haliburton-Kawartha	155977	1
Bruce-Grey-Owen Sound	149339	6
Leeds-Grenville	145038	4
York	140525	20
Hastings-Prince Edward	140197	8
Lambton	128943	6
Algoma	127267	3
Peterborough	119992	6
Brant	110806	10
Kent-Chatham	109943	1
East York	102696	41
Haldimand-Norfolk	98707	4

PUBLIC HEALTH UNIT	1991 POPULATION	PREVALENCE RATE
Porcupine	93917	3
Oxford	92888	2
Renfrew	91685	8
Muskoka-Parry Sound	86428	2
North Bay	84723	5
Northwestern	81745	2
Elgin-St. Thomas	75423	3
Perth	69976	10
Huron	69065	6
Timiskaming	38983	2

The first map, Figure 39, shows four areas that display the first signs of relatively high prevalence rates: Windsor-Essex, Toronto, East York, and Ottawa-Carleton. It should be noted that all of the Units have some AIDS cases throughout the time period, starting in 1990. Only two of the aforementioned areas, Toronto and Ottawa-Carleton have relatively high populations. Peel, North York and Scarborough also have high populations, but their AIDS prevalence rates are much lower. This would seem to suggest that we cannot rely solely on population figures when examining our expectations for how high the AIDS prevalence rates will be. What is most surprising in 1990 is East York. It has a relatively small population, yet a high prevalence rate.

If we look at what was said during the interview process and what we have seen thus far on the maps, the results are even more surprising. We know from the interviews that people leave the East York area for HIV testing. However, according to the AIDS Educator in the area, East York's numbers do not necessarily reflect reality, as they are likely supporting cases that are not reflected in their numbers. East York has a prevalence rate almost double that of Ottawa-Carleton, but when we compare their populations,

Figure 39: AIDS Prevalence Rates For Ontario 1990

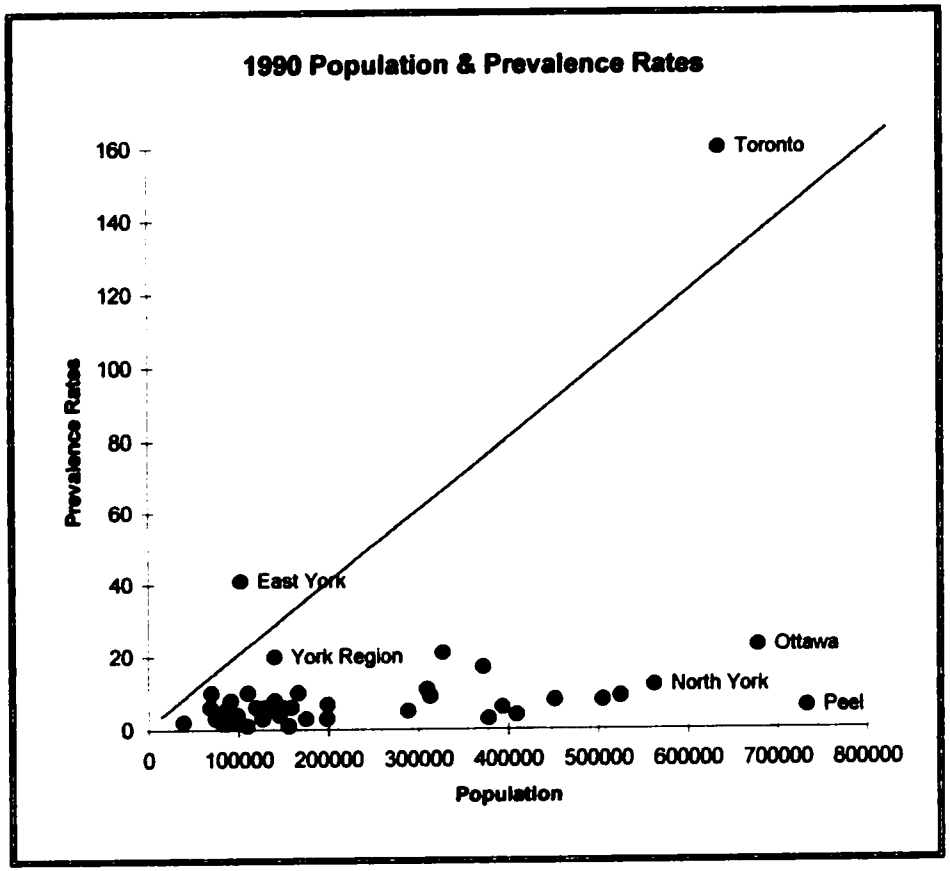


Source: Public Health Epidemiology Report of Ontario, 1990.

Ottawa-Carleton has a population six times that of East York. This would seem to suggest that population is not the only factor or function influencing the AIDS prevalence rates. Further, Windsor-Essex, Toronto and Ottawa-Carleton all have Anonymous Testing Sites, meaning that people are likely coming to the areas for anonymous testing if their area does not offer anonymous testing. East York appears to be somewhat of an anomaly. As of 1990 the four aforementioned places are the only ones that really seem to draw our attention on the map. It is important when trying to examine AIDS in Ontario to look at both the statistics, as well as what is displayed on the map. From the map, it looks like these four areas are where high AIDS prevalence rates really started into the province. The only areas that are contiguous to one another are East York and Toronto.

Another interesting method to examine the prevalence rates and population rates is to create a scatter plot. A scatter plot of the 1990 population and prevalence rates was completed, Figure 40. A scatter plot helps to show the relationship, if any, between population and prevalence rates, and graphically displays the outliers. The red line on the graph indicates where a direct relationship between population and prevalence would occur. None of the PHUs are on this line. East York and Toronto are both above the line, indicating that their prevalence is above what is to be "expected", if using population as a function of prevalence rates. What is interesting to note is that population increases towards the 800 000 mark, but the prevalence rates do not increase in the same manner. For example, larger places like Peel, Ottawa-Carleton, North York, and York Region all have large populations, but low prevalence rates. This would suggest that some other factors are influencing the prevalence rates, mobility factors, for example.

Figure 40

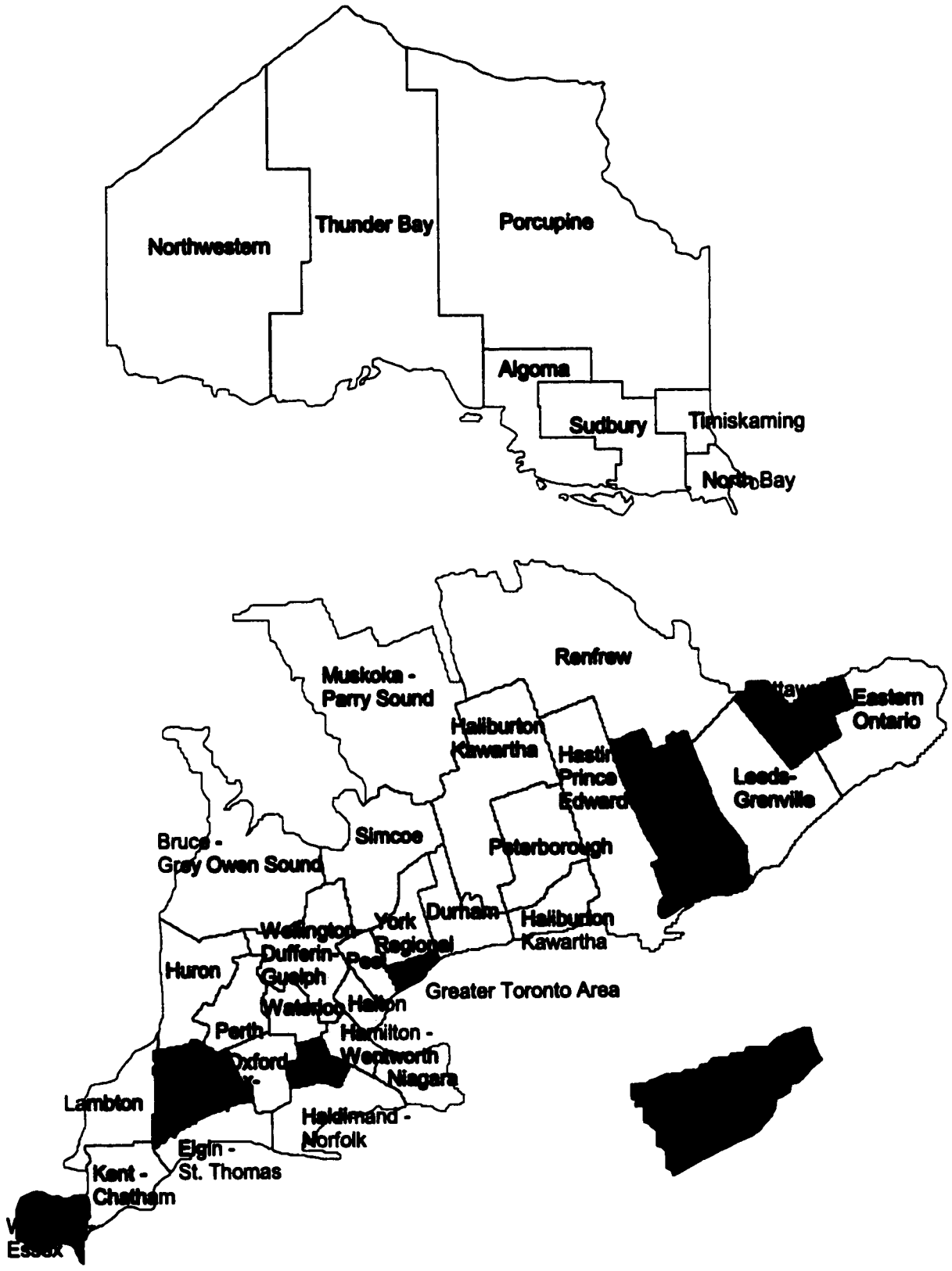


1993, Figure 41, shows the emergence of Kingston, Brant, and Middlesex-London. As well, all of the Greater Toronto Area now shows higher prevalence rates. Toronto, Ottawa-Carleton, North York and Middlesex-London are the only areas that are exhibiting prevalence rates one would expect given their population sizes. Areas like East York, York City, and Brant all have smaller populations, but high prevalence rates. We could likely explain East York and York City's high rates and low population figures due to their close proximity to Toronto. However, Brant seems to be standing out as an anomaly.

This pattern that we are seeing, areas with high populations that do not have high AIDS prevalence rates, may be demonstrating some other phenomena. Both York City and East York have relatively small populations, but the fact that they each border Toronto, whose prevalence rates are extremely high may have something to do with their high prevalence rates. This realization could not be made as easily without the use of the maps, again underlining the importance of not just using statistics, but using statistics and maps simultaneously. From the interviews we know that people come to York City for testing and that there is an Anonymous Testing Site there. We also know from the previous mapping section that York City is not likely supporting cases from other areas. In fact, according to the AIDS Educators in the area, people with AIDS actually move out of the York City area. Because there is an Anonymous Testing Site here, it may be adding to York City's numbers, if people are testing positive.

Further, AIDS has really begun to show up in the Greater Toronto Area. From the literature and the classical diffusion theory we know that AIDS moves out from an initial

Figure 41: AIDS Prevalence Rates For Ontario 1993



Source: Public Health Epidemiology Report of Ontario, 1993.

source of infection with the time of arrival at the surrounding communities, or areas, dependent upon distance from the initial source and the number of people in the surrounding area. This means that nearby individuals have a greater likelihood of contact than do more remote individuals. Toronto, in this case, likely acts as the initial source, with the surrounding areas being subsequently affected. We know from the previous discussion that this is a function of distance, more so than a function of population, as displayed by East York and York City.

Brant seems to display quite high AIDS numbers, in relation to its population size. What is more puzzling is that one would think that areas like Hamilton-Wentworth and Peel, which are closer to the Greater Toronto Area would be impacted before Brant, and to a greater degree, both because of their distance from the Greater Toronto Area and because of their population sizes. Brant appears to be functioning as one of the more noticeable anomalies. It is not closely surrounded by other areas with high prevalence rates. The closest areas are Middlesex-London and the Greater Toronto Area. If we look at this in terms of distance, for the major cities in each area, Brantford is approximately eighty-five kilometres from London and one hundred from Toronto. Brant is an almost equal distance from the two large centres, both with relatively high prevalence rates. What is interesting to note is that the places in-between Brant and Middlesex-London and Brant and the Greater Toronto Area do not display noticeable prevalence rates at this point in time. If population was the only function influencing AIDS we would not see an area like Brant showing high prevalence rates before an area with a larger population, like Hamilton-Wentworth. As of the 1992 population numbers, Hamilton had 469 100 people, while Brant had 120 700, meaning that as of 1992, Hamilton had approximately three and

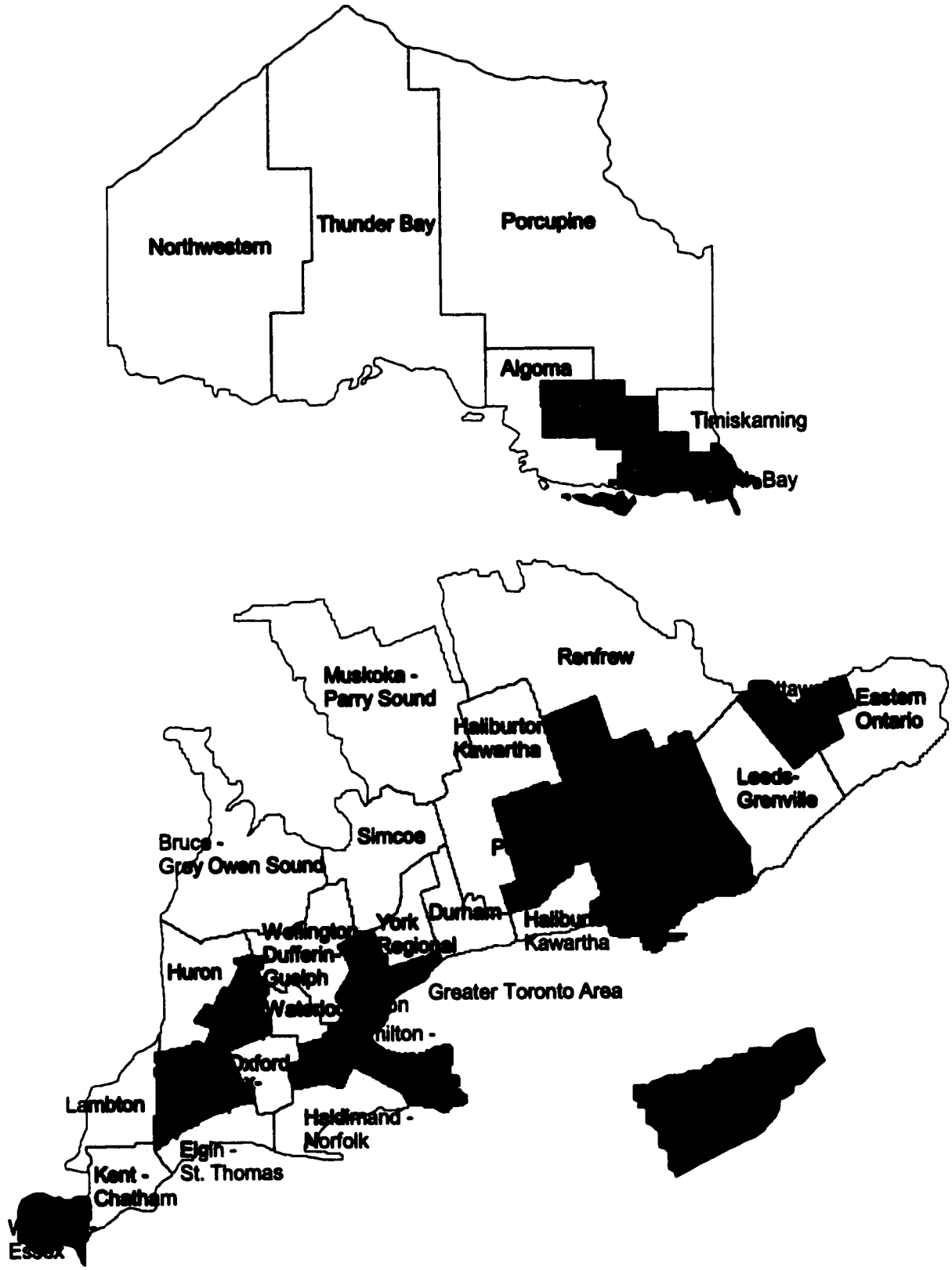
a half times as many people as Brant, yet Brant has the prevalence higher rate. However, it is important to note that one is always subject to the vagaries of the data. This also stresses the importance of mapping so that we actually see where the places are and where they are in relation to one another. Further, Hamilton-Wentworth is closer in proximity to Greater Toronto Area, so one would think the Greater Toronto Area could influence Hamilton-Wentworth before Brant.

Brant, according to the AIDS Educators in this part of the province, has high rates of young pregnancies. The AIDS Educator felt that there were high levels of unprotected sex occurring in this area because many of the young people feel that there is "nothing to do", and so sexual activity becomes an option. This may partially explain Brant's high AIDS prevalence rate.

The map displaying 1995, Figure 42 shows quite a different picture from previous years. First, a great many more areas are now appearing. Hastings-Prince Edward, Peterborough, Peel, Halton, Niagara and Perth now emerge as areas with high AIDS prevalence rates. Most of the areas surrounding Lake Ontario now display high AIDS prevalence rates; Brant is also grouped into this. There are also some other noticeable patterns in 1995. First, in eastern Ontario we seeing a grouping of areas, Peterborough, Hastings-Prince Edward and Kingston, along with Ottawa-Carleton, but Ottawa-Carleton is not part of the contiguous grouping. Leeds-Grenville has maintained low rates even though it is surrounded by areas with higher rates.

In Figure 42, Hamilton-Wentworth also appears, and as discussed previously, this is perhaps a little strange. It is a relatively large city, and yet we are many years into the disease (in terms of reporting and publishing), and it is just appearing now with higher

Figure 42: AIDS Prevalence Rates For Ontario 1995



Source: Public Health Epidemiology Report of Ontario, 1995.

rates. We could be seeing something like hierarchical diffusion here from Toronto to Hamilton-Wentworth, or it could be a function of population. Hamilton has a large population; it is simply surprising, or unexpected that it took this long to appear on the map as an area with a relatively high prevalence rate.

Perth is another anomaly, in that it has a very low population, but it is showing up before an area like Waterloo. Waterloo has a population of 398 600 and Perth's is 73 100, meaning that Waterloo's population is five times the size of Perth's. Perth is also interesting because it may be experiencing some effects from Middlesex-London. The distance between Stratford and London is only sixty kilometres, making contact between the two quite accessible. Or it could be the influence from Brant, Hamilton-Wentworth or Halton. Stratford to Brantford is approximately eighty-five kilometres, to Hamilton-Wentworth is approximately one hundred and five kilometres and to Oakville is approximately one hundred and fifty-four kilometres, all easily allowing for personal contact.

East York, York City, Brant, North Bay and Perth all stand out as irregularities. In addition, Peel is the largest area in terms of the population figures, and yet its AIDS prevalence rate not that high. One would expect that the area with the most people would demonstrate relatively high AIDS prevalence rates. Further, it is contiguous with the Greater Toronto Area; one would think that Toronto could have a substantial impact on Peel, in terms of people coming in contact with one another. If the impact was not felt from Toronto, then one would expect the rest of the Greater Toronto Area would have had some sort of influence.

In addition, all of the Greater Toronto Area now shows higher prevalence rates. Toronto and North York are the only areas that are exhibiting prevalence rates one would expect given their population sizes. We can likely devote some of the explanation of East York and York City's high rates and low population figures due to their close proximity to Toronto.

There is also the case of Sudbury and North Bay. It is not surprising to see Sudbury since it has the largest population in northern Ontario, so one would expect to see Sudbury displaying high prevalence rates at this point in time. However, what is unexpected is North Bay. Sudbury is twice the population size of North Bay (208 800 versus 88 900), yet North Bay has a higher prevalence rate. According to the AIDS Educators in the area there are some youth pregnancy issues. In addition, some of the young people feel that this area is "hopeless" in terms of employment and future opportunities, and many lack a "life plan" for the long term. For many, completing a post secondary education is difficult and starting a family may seem like a good option. Issues of self-esteem and socio-economic factors become important indicators.

East York and York City are especially worrisome areas because they have such high prevalence rates but relatively low populations. We see that Toronto surrounds each of the areas on two sides, making both of them very susceptible to its influence. According to the AIDS Educator in East York, they believed that most of their people were being tested and treated in Toronto, meaning that the number would be going toward Toronto's total, and that East York may have numbers not reflected in their statistics. The East York AIDS Educator also said that many people were returning to the area in the later stages of their illness because they did not want to live in Toronto

(downtown). This worsens the situation because it means that East York is likely supporting cases that were being counted in Toronto. The majority of the cases in this area are made up from MSM, followed by "women from endemic countries" and IDU. The AIDS Educator felt that it would be men and women from endemic countries and injection drug users who would make up the majority of the cases in the years to come. In addition, because there is so much ethnic diversity in an area like East York, communicating the HIV/AIDS message can be difficult.

The situation for York City is very similar. Most people go to Toronto for testing and treatment. The AIDS Educator felt that this area was not supporting a lot of cases that were not being accounted for. This area also has the highest proportion of chlamydia (also a highly infectious STD) in the Greater Toronto Area, meaning that there must be a great deal of unprotected sex occurring. In addition, there is a large immigrant and ethnic community, again making it potentially difficult to communicate a mainstream HIV/AIDS message. This area has many marginalized, poor communities who are dealing with housing issues and issues of poverty. As aforementioned, these factors can make it difficult for people to use the appropriate means of protection, like clean needles and condoms.

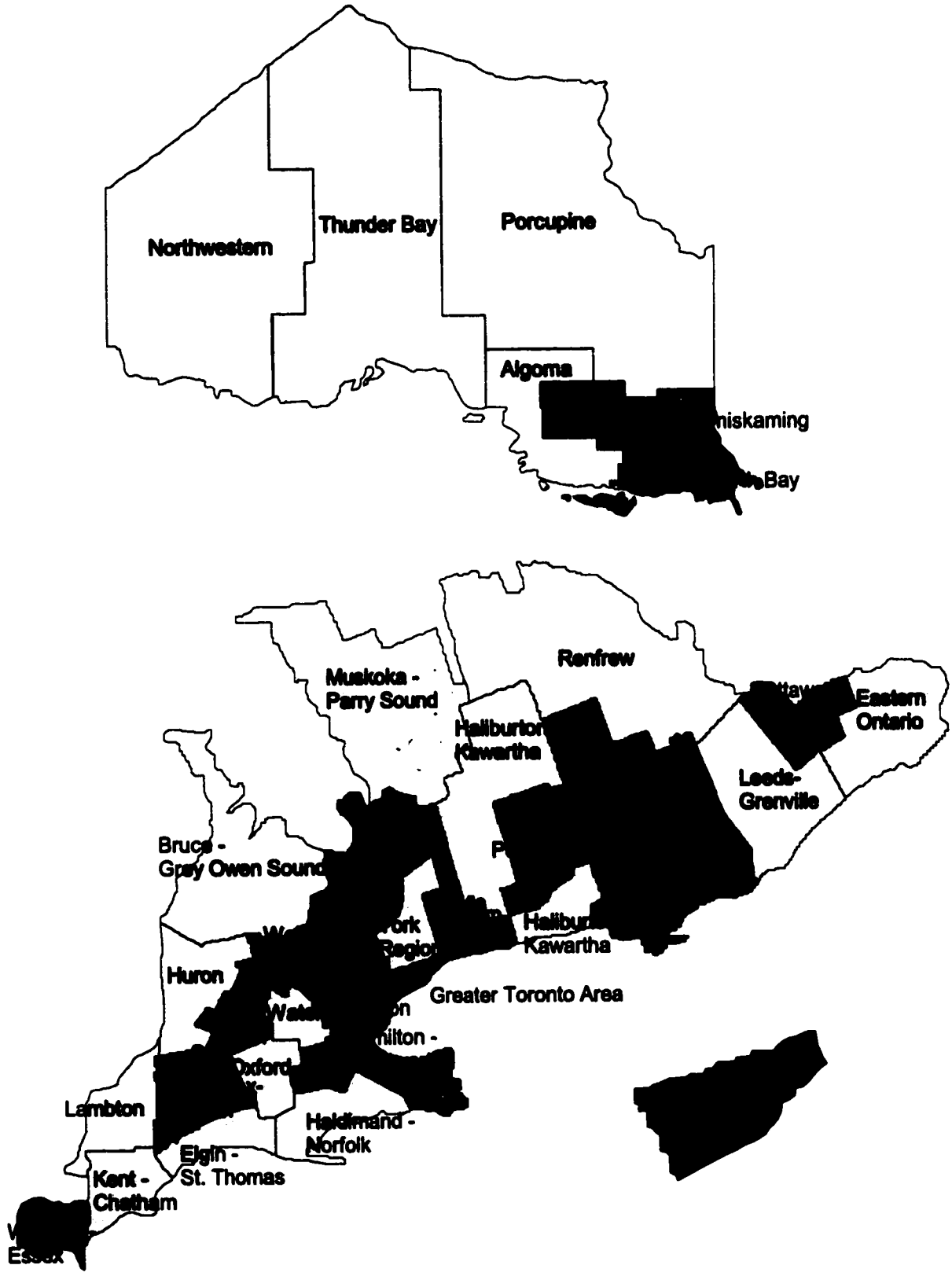
It is important to reiterate that AIDS does not infect like other diseases in its contagious components. Very specific factors must be present before one would be susceptible to HIV/AIDS. However, people do travel and do move around a lot, especially from areas of lower urban densities to areas of higher urban densities, as was evidenced by the mobility study. Because there is this movement and because people interact with other people outside their own areas there is the propensity for one to

become susceptible to HIV/AIDS, especially if they are participating in risky behaviours. AIDS needs people in order to survive and to move through a population.

If we look at the map for 1998, Figure 43, we can see how through time, some areas, like the Greater Toronto Area have gradually become quite saturated in terms of higher prevalence rates. Wellington-Dufferin-Guelph appears as an area with a high AIDS prevalence rate. If we look at the map we see that a ring has formed around the Waterloo and Oxford areas, spreading out from the Lake Ontario area. Further, a similar situation is occurring around York Region, and the southern part of Haliburton-Kawartha, areas being surrounded by areas with higher prevalence rates. Timiskaming has now reached similar prevalence levels to that of Sudbury and North Bay. What is really unexpected about this is that Timiskaming is the smallest area in terms of population. It is likely showing higher prevalence rates because of its close proximity to Sudbury and perhaps North Bay. North Bay is likely influenced by its close proximity to Sudbury, the area that has the highest prevalence rate in northern Ontario.

From the aforementioned discussions about York City and East York, we know that high population figures do not necessarily mean high AIDS prevalence rates and vice versa. Therefore, this would suggest that something else is going on, perhaps higher mobility, where people are leaving their area for whatever reason and becoming infected elsewhere and either staying in that area, or returning to their original area. From speaking with the AIDS Educators we know that young gay men, for example, will leave smaller urban areas for larger urban areas, practice risky behaviours, become infected, and return to their original areas, potentially bringing with them HIV/AIDS. We also know from the mobility study that people will go to the larger urban areas for testing, which can

Figure 43: AIDS Prevalence Rates For Ontario 1998

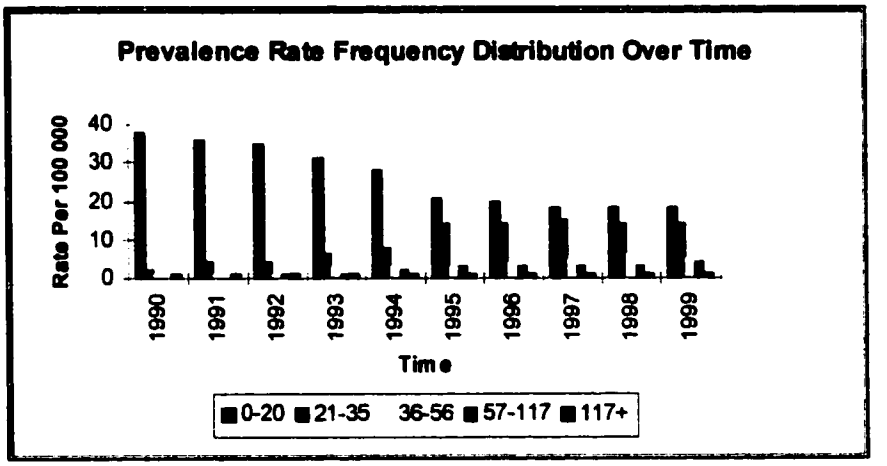


Source: Public Health Epidemiology Report of Ontario, 1998.

contribute to larger urban areas demonstrating higher numbers, due to the place of diagnosis versus place of testing issue.

Figure 44 displays the AIDS prevalence rates frequency distribution from 1990 to 1999. The rate in the 21 - 35 per 100 000 category rose steadily until 1997 and then began to level off. The rate in the lowest category, 0 - 20 per 100 000, declined in 1997, when it levelled off. The 57 - 117 per 100 000 category is the only category that continues to increase. The highest category, 117 per 100 000 or more, has only one unit in it throughout the time span. It is not encouraging to think that the 57 - 117 category is increasing. The fact that this category is increasing means that prevalence rates are increasing, meaning that the number of AIDS cases is increasing, since the population numbers are not increasing too substantially.

Figure 44



A mobility perspective does not answer all our questions and observations. Based on what was displayed in the mapping sequences, AIDS appears to be a mixture of population functions, where an area is located in relation to other areas, and the processes of people moving into and out of areas for either testing purposes, or to practice risky behaviours. For example, how do we explain how Peel has relatively low rates and such a

high population; or how do we explain areas like Brant, Timiskaming, East York, York City and Perth with low populations, but high prevalence rates? People must be moving about, testing elsewhere and having their numbers counted elsewhere, and coming into contact with infected people from outside their area. Again, population is not the only function to consider. These questions underlie the importance and value of conducting the interviews, and mapping the anecdotal data. Although the interviews cannot provide all the answers, and although the AIDS Educators can only provide some impressions as to what is happening in their respective areas, it is a beginning. Further, by having these rates mapped out we can see where these places are in relation to one another, and how they change over time. Charts, and numbers cannot give us this picture, this spatial perspective. By using charts, numbers, and maps, we can obtain a much better impression of the situation.

In summary, we can see from this section that population is not the only determinant of AIDS prevalence rates. Mobility factors, the provision of support facilities, the relative location of PHUs in terms of how close they are to other PHUs with high prevalence rates can also be influential. Throughout the time period, the maps demonstrated AIDS spreading from the original areas of high prevalence rates: Toronto, East York, Ottawa-Carleton and Windsor-Essex. A great deal of time did not pass until higher prevalence rates were appearing throughout the province.

This concludes the Results section of the research. The next chapter will focus on a summary discussion, conclusions and recommendations for future research.

CHAPTER FIVE

SUMMARY DISCUSSION, CONCLUSION AND RECOMMENDATIONS

SUMMARY DISCUSSION

This section will summarize and assemble the findings from the research. As stated in the "Introduction", the primary objective of this research was to examine the mobility patterns of AIDS patients. Further, the research also looked at the spatial patterns and variations of the prevalence of AIDS in Ontario at the PHU level. The objectives were accomplished by completing a mobility study to see where people were moving for testing, treatment and support, and by mapping the prevalence rates over time.

From interviewing the AIDS Educators we know that there appears to be a great deal of mobility occurring at the PHU level. We do know that people will move to other areas for testing if there are concerns about confidentiality. Larger urban areas attract people from the surrounding areas for testing, treatment and support. Further, people will live in, or move to areas where they can receive the necessary support. If a person does leave an area one can make fairly accurate predictions about where they are going based on the location of the Anonymous Testing Sites. The degree of mobility occurring in Ontario makes it difficult to know how accurate the statistics are because of the fact that the reporting of numbers is done according to place of diagnosis, not place of residence. The fact that many of the Educators believe that people move around a lot only further complicates the issue.

We also know that there are great inconsistencies in terms of preventing the spread of AIDS in Ontario. Some prevention procedures like partner notification are being carried out, others like consistent condom usage are not. Ontario communities are working together to eliminate and/or reduce the spreading of AIDS.

In terms of major risk behaviours, what is most prevalent at the federal and provincial levels, is also what is most prevalent at the PHU level. Unprotected heterosexual activity and injection drug use are behaviours that are continuing to rise in numbers and are contributing to the spread of AIDS. An appropriate way to summarize what the PHU interviews indicated would be to state that because of the way in which HIV is transmitted from one person to another, at the most intimate, or personal level, it really is difficult to know what is occurring. The mobility study has aided us in understanding individual behaviour and how it contributes, or does not contribute to the spread of AIDS throughout Ontario.

From the mapping work we know a number of things. When looking at the prevalence rates using population as an influential factor a number of processes were evident. Throughout the time period we saw areas of low population displaying high prevalence rates and vice versa. This may suggest that people are moving around and going to certain areas for testing, and/or people are moving to certain areas to practice risky behaviours, both of which were confirmed by the AIDS Educators. People moving around allows HIV/AIDS to spread from one area to the next, which was likely indicated by the maps. AIDS appears to spread by starting out in a centre, intensifying and then moving out to the outlying areas. This was displayed by the Greater Toronto Area where prevalence rates initiated, intensified, and spread to nearby areas. This pattern was only noticeable when the Greater Toronto Area was disaggregated into the six Units. Finally, we know that by using PHU level data, one can only make general remarks about the spatial patterns and variations, due to the place of diagnosis versus place of residence issue. Further, individual PHU level AIDS data do not include any information about the

patient, such as gender, age cohort, or major risk behaviour. Without this type of information any advanced spatial analysis cannot be completed because the data cannot be standardized.

As mentioned in the introductory section there was to be a return to the subject of methodologies. Now that we have mapped the prevalence rates and have somewhat of an idea of where people are moving for testing, treatment and support, one needs to move forward and analyze the spatial patterns and variations. Some of the methodologies used in previous research attempts in Medical Geography and Epidemiology have used methods such as evaluation of diffusion patterns, or a further examine the data and patterns. Before one can attempt to look at diffusion rates, or any other pattern, it is important to standardize the rates for age and sex. However, when dealing with AIDS data at the individual PHU level there are some serious data problems. First, there is the place of diagnosis versus place of residence. In order to overcome this, AIDS Educators had to be interviewed. Although it is purely impressionistic data it still provides some insight into people's degree of mobility. A second problem with AIDS data at this level is that it does not contain any details such as gender, age, or major risk behaviours; we simply have crude AIDS and population numbers. Standardized information is available at the provincial level, but as discussed in previous sections, this level is not disaggregated to be spatially meaningful. For example, we would not be able to tell which areas of the province have especially high levels, or where those areas are in relation one to another. In a sense it is like trading one level of detail for another. We can create a detailed spatial approach, or detailed information about the numbers, but unfortunately not

simultaneously. Since the objective was to examine AIDS in Ontario from a spatial perspective, the PHU level data is used since it provides more spatial detail.

Given that we know very little about the individual PHU AIDS data, completing a predictive model of future AIDS cases for an area or province is difficult for a number of reasons. Most of these models demand certain characteristics be present in the data, such as age cohorts, major risk behaviours, or other demographic data. Most models will not work well with only crude population and AIDS numbers. Even if the model will work its predictive powers may be quite limited, due to the constraints of the data.

Finally, the question arises as to whether or not detailed data about AIDS are sufficient. AIDS is the final stage of the disease. In terms of prevention and education efforts it would be far more beneficial to have detailed information about HIV at the PHU level. Instead this information is only available at the provincial and federal levels. It is at the individual level, but it is considered confidential.

There are so many policy issues surrounding how much information should be available on people with HIV/AIDS. In Ontario we do not even know exactly where the numbers are coming from, in that people test outside their area of residence. Further, we know nothing about the data at the individual PHU level. Much of the detailed information about AIDS data, such as where the person resides, their age, gender or major risk behaviour could be provided, allowing substantial insight into the disease. For example, the Ontario government has released road accident data, which could be of a confidential nature. However, the confidentiality issue is part of the stigma with HIV/AIDS and we are left with making general comments about the spatial patterns at the PHU level. We know from the literature on HIV testing in Ontario that demographic and

residential data are collected, and then passed on to the provincial and federal levels. These would be helpful geographic data in that we would know something about the person, their gender, age, and where they resided. Geographers could use this data without compromising any issues of confidentiality. The data can be "disguised" by referring anonymously to the patient's identity, while simultaneously using the demographic and residential data to its full extent. By knowing more about people and where they live at a spatially disaggregated level like the PHU would allow far better prevention, planning and education programs that are difficult to ascertain from the aggregated provincial and federal data.

Even though there are data issues this does not mean that the primary objective of the thesis, to examine the mobility patterns of AIDS patients, cannot be realized. The secondary objective, examining the spatial patterns and variations, although rudimentary, complimented the mobility study. The social and political limitations of AIDS geography are nowhere better illustrated than in trying to map the disease. No matter what method one uses to map AIDS we still need to understand and acknowledge the social and cultural contexts of places, or areas that have been thoroughly changed by HIV/AIDS. Therefore by mapping where people are moving to and from, by mapping their behaviour, we are mapping people, not the virus. Given that AIDS should be about people, this is very important. At the same time spatial exercises, like this one of mapping the prevalence rates can play a role in education, prevention, and planning efforts (Brown, 1995: 168).

CONCLUSION

With a topic like HIV/AIDS concluding thoughts should be along the lines of working towards a cure, and continuing with prevention and educational efforts. The primary intention of this research was to examine mobility patterns and to map prevalence rates. With the impressions of the AIDS Educators we now have an improved understanding of where people are moving to, and the reasons behind the mobility. Any mobility conclusions can only be based on generalizations, but nonetheless, some understanding is better than none at all. The impressions also helped to explain the patterns and processes displayed by the prevalence rate maps.

Professor Gould has been a major inspiration for this research. The major contribution of his AIDS research is that maps can tell us so much, so much more than can a table of statistics. By ignoring the spatial component of HIV/AIDS we are compromising our understanding of the disease. Medical geography, and more specifically the mapping of diseases, has come a long way since the days when Doctor Snow was mapping cholera. However, the same philosophy and spirit still continue.

Mapping and spatial analyses are helpful in that they differ from the perspective of many other disciplines, such as history and anthropology. Maps rarely provide definitive answers; instead they can help to generate interesting questions and observations. Maps can help us to understand why certain diseases seem to only occur in particular places and not others. They provide an instant visual impression of the relationship of the disease and its appropriate geographical position(s). Providing information in map form is the simplest, most elegant and informative way of presenting data which vary across a surface. Further, the ability to easily examine the relationship between location, population and the

availability of health care facilities is of great benefit when determining and allocating health care related resources. Geographic study is beneficial because it brings to the forefront the issues of spatiality, the location of areas with high prevalence rates in an absolute sense and relative to other areas. Geography allows us to examine mobility patterns, how people or a phenomena are moving across space and through time. Finally it permits distance to be examined. Seeing how people and phenomena play out in space is important and should not ignored.

Likely one of the more unique factors about HIV/AIDS is its ability to teach us about the importance of socioeconomic and cultural factors in health. HIV/AIDS has not turned out to be a disease that science can simply control or alleviate. This is why Medical Geography and its holistic approach is so helpful. A vaccine or a cure do not presently exist, nor will for some time. Another difficulty with AIDS is its present disproportionate focus on individuals and communities that are already facing other health, social and economic challenges. The question arises, for example, of how we can insist that people use clean needles and condoms when they cannot afford housing, food or any of the other basics of survival. These other determinants of health are of great significance. Support needs to be where people are at the moment, not where we think they should be, or ought to be. AIDS is a health issue, not a moral or ethical issue. Further, the face of AIDS has dramatically changed. When AIDS was first discovered, it was primarily homosexual men who were contracting it. The homosexual community bonded together and used their influence; they lobbied and made policies happen. For example, they are part of the reason HIV is not reportable/published in the same manner that AIDS is. The poor, or the new victims of AIDS, are not as well connected, nor as empowered.

Finally, HIV/AIDS research never really concludes; it just keeps moving forward. It will not conclude until there is a cure, or no more infection. It is important to keep furthering our understanding so that at some point in the future HIV/AIDS will be eliminated. This work is not the definite word; it is simply a different way of examining mobility patterns of AIDS patients, the spread of AIDS in Ontario, and the spatial variations therein. It provides a new way of looking at the disease, and its spatial aspects. With all infections diseases we are always on the defensive as new strains and viruses will emerge. What we can learn is how to respond to the disease.

Completing AIDS research can be quite circular, in that in attempting to better understand its spatial perspectives one develops a certain research design. That design allows exploration and a greater understanding of AIDS, but always returns to the question of what research design would allow us an even greater understanding or comprehension, given what we now know. Now that we have some idea about the mobility patterns of AIDS patients, the question of future direction arises.

RECOMMENDATIONS

This final section will examine recommendations for future research, given what we now know about mobility patterns of AIDS patients and the spatial patterns and variations of the spread of AIDS.

One of the questions that this research raises is that of what other factors could be influencing the prevalence rates? One could employ an explanatory model to explain how prevalence rates could be examined as a function of a number of factors. The factors could be placed into a regression model with each factor receiving a different weighting. Many of the factors could have several variables for measuring its influence. For example,

one factor could be population size, population density or an area's position in the urban hierarchy. Population size was discussed in this research, but future attempts could examine population density or a PHU's position in the urban hierarchy. Population influences prevalence rates. For example, from the interview process we know that there are low levels of concern for HIV/AIDS in less urbanized areas; there is a sense of apathy because there are so few visible cases. In addition, larger urban areas have the propensity to attract people from smaller urban areas. Population variables could be given different weights within the model.

Prevalence rates could also be a function of social demographics, such as the age or gender of the people within an area. For example, certain age groups like senior citizens (over seventy-five) are less likely to contract HIV/AIDS. If an area was composed of this type of demographic then one might expect lower prevalence rates. Alternatively, the gender breakdown of an area could also influence the prevalence rates. Women's rates are increasing and they are comprising a greater number of the total number of AIDS cases. For example, in 1990 women comprised four percent of the total number of reported AIDS cases. Eight years later in 1998, women accounted for sixteen percent of the total number of reported AIDS cases. Further, this is only accounting for the number of cases that are actually reported; this does not account for the population that has not been tested. Part of this could be explained by the fact that more women than men are being tested. The fact that the rates for women are increasing so dramatically only stresses the fact that research of this type must deal with women separately from men. Women face different issues in terms of HIV/AIDS, such as not holding the power

in relationships, suffering abuse, and having their own health issues. They should have their own research design in order to effectively deal with their issues.

Prevalence rates could also be a function of the social economic composition of the population, more specifically income levels, or education levels. From the literature it is well documented that HIV/AIDS is now concentrated among the disadvantaged, those that cannot afford appropriate housing, or the other basic necessities of life. This means that appropriate protection methods like condoms and clean needles are not always used. The literature also emphasized the fact that higher socioeconomic groups are able to consult physicians or facilities further away, thus allowing for greater personal mobility and the opportunity to go to their preferred medical location. The disadvantaged do not have the same opportunities.

A fourth function of prevalence could be mobility factors, as has already been discussed throughout the research. Mobility factors could influence the transmission of the disease, and appear to be influential in terms of people moving to clinics for testing, treatment or support. These mobility factors need further refinement and testing. One way to do this is to have peer groups interviewing each other about mobility issues and their own policy.

The presence or absence of diagnostic or support facilities could also have a bearing on the prevalence rates. As was displayed by the mobility analysis certain areas will attract people for testing, treatment and/or support. Because of the place of diagnosis versus place of residence issue in Ontario, the location of diagnostic facilities can be a substantial factor for prevalence rates. If an area has a well known diagnostic facility it will attract people and will also contribute to that area's prevalence rates. Further the

history of the facility is also influential. The introduction of an Anonymous Testing Site in an area could suddenly create a rise in prevalence rates if people in the area were previously going elsewhere for testing.

Another possible function to explain prevalence rates could be the success or failure of prevention methods within an area. If people are following through with the appropriate prevention methods this could mean a lower prevalence rate as compared to an area where the appropriate prevention methods are not being followed through. In addition, if educational efforts within an area are highly effective this will also affect the prevalence rates. Studies then on outcome measures would be helpful.

Another function of prevalence rates are local and cultural attitudes. As was discussed throughout the literature review, how people perceive the HIV/AIDS prevention message depends to a large extent on their cultural background and perceptions. In some cultures it is not appropriate to discuss such sexual issues. For various cultural reasons meaning that prevention measures may not be used, or risky behaviours may be practiced. Further, cultural issues may also mean that people do not seek appropriate testing and counselling services if they have participated in a risky behaviour.

A final factor for an explanatory model could be pre-established risky behaviours within an area. For example, if an area has a large injection drug culture, the prevalence rates may reflect this. From the literature we know that in many instances injection drug users infect their partners who are not injection drug users themselves.

In summary, the explanatory model looks to a number of functions as possible explanatory factors for the prevalence rates within an area. From the research we know that no one function, or factor can explain the prevalence rates.

The second question to raise about future research interests concerns data issues is operationalizing the model. It has been documented that the data at the PHU level is not standardized by age or gender. Once this acknowledgment has been made the question for future research attempts becomes a matter of what could be done if the data were standardized. Or alternatively, the question becomes a matter of what other types of data could be used. Using the data at the PHU level and the impressions of the AIDS Educators is a starting point. Using individual data, or the experiences of those directly affected or infected with HIV/AIDS is also possible. For some the issue of confidentiality arises, but this does not have to be the case. One is only perpetuating the myth of confidentiality by not using individual data. For example, in 1994 Brown conducted collected the oral histories of one hundred and twenty people who were involved in Vancouver's AIDS politics. His research revealed a complex set of responses to HIV/AIDS across the state, the voluntary sector and the family (Brown, 1994: 169). According to many of Brown's interviewees, confidentiality was a means of erasure. They did not want to be simply known as the statistics on a chart, a vector of the illness. By not interviewing people directly affected with and by HIV/AIDS, much of the pain, suffering and struggles can be ignored or misrepresented by statistical figures. The interviewees wanted their stories recorded and by refusing to participate they would be contributing to erasure (Brown, 1994: 176). By not seeing HIV/AIDS data as "confidential" one can gain individual insight into the disease by those most affected by it. This is one way to deal

with the data issues in the operationalizing model; not allowing confidentiality to be a barrier, but considering the importance of affected individuals and their perspectives.

Using the PHU data and AIDS Educators was a workable examination of the AIDS in Ontario. An alternative research design might be to complete all of the interviews in person. The benefits of this are threefold. First, a personal interview is often more effective, in that one can read body language, and communication is usually more favourable in person. Second, by visiting each Unit one can get a better sense of the area in terms of economics and social demographics. Thirdly, other members of the Unit could be included in the interview such as physicians.

Further issues in operationalizing the model could include the necessary components for GIS modelling. Many of the models for AIDS predictions require assumptions and/or the measurement of a broad range of variables. Some of the variables could include the present and future prevalence of condom use; STD rates; the rate of exchange of sexual partners in subpopulations; or other demographic information. Models must incorporate information on spatial and temporal interactions if reasonable projections are to be produced. Even the simplest models rely on parameters about which little is known, such as transmission and exposure rates. Other models use data that focus on the major risk behaviours within an area. For this type of modelling data comes from sources such as specific studies of at risk persons; information taken from reported AIDS cases in each area; STD clinics, counselling and testing sites, and drug treatment centres. Certain criteria are used for each of the major risk behaviours. Modelling must also account for the population known to be at risk and those members of the population who do not seek help. This group of people is almost never targeted for study.

A future operationalizing model also allows for the evolution of data problems. As aforementioned, one knows the limitations of the data at the individual PHU level. One answer is to use census tract data at the provincial level. Although the boundaries of the census tracts and the PHUs do not exactly coincide, once implemented into a GIS the boundaries of each could be amalgamated. Using census data allows access to many of the socio-demographic and social economic factors that are missing from the PHU level. By using census data along with the prevalence rates one can ascertain if high prevalence rates are a function of poverty levels, for example. This relates back to the explanatory model and the number of functions that could be used to explain prevalence rates.

Once one can answer the above questions, the making of effective policies becomes much easier. By knowing the makeup of the population, what factors, or functions are affecting the prevalence rates within an area allows one to establish what methods need to occur in order to better counteract the spread of HIV/AIDS.

APPENDIX A. HIV TESTING IN ONTARIO

Counsellor Check List for Evaluation Purposes *Only*

*Short Form – **First time testers Only***

Please remember to inform clients about the evaluation component of anonymous testing.
No identifiers are to be used on this form – do not link to requisition or client chart information.
Please use red, green, or blue ink only. Return completed forms to HIV lab.

☐ first time testing ever ☐ repeat testing *(please use long form 1905–62)*

*Check **all** appropriate boxes*

Sex ☐ male ☐ female	Date of Birth *(yy/mm/dd)*	Site number 950006	Date of visit *(yy/mm/dd)*

Place of residence
☐ Ontario ☐ Canada ☐ USA ☐ Other *(specify)* _____

Health Unit where client resides *(city or town if unknown)*

Ethno cultural identity *(self identification – see instructions)*
☐ white ☐ black ☐ hispanic ☐ asian ☐ indo asian ☐ aboriginal ☐ other *(specify)* _____

Country of Birth ☐ Canada ☐ other *(specify)*	Date of arrival in Canada *(yy/mm/dd)*	

1. **Reasons/motivation for being anonymously tested at this time** *(unprompted, client's perspective)* (*check **all** appropriate boxes*)

a) ☐ client chose anonymous testing over confidential/nominal

b) ☐ assurance of negative results *(client considers self to be low risk)*

c) ☐ not feeling well

d) ☐ notified by partner who is HIV positive *(sexual or needle sharing)*
- ☐ partner tested anonymously
- ☐ partner tested at a regular clinic
- ☐ don't know how partner tested

e) ☐ perceived benefit if positive (e.g. early treatment)

f) ☐ partner has requested client be tested

g) ☐ suspected exposure to HIV *(client perspective – suspects previous or current partner to be at risk for HIV or other exposure; e.g. work-related, tattoo)*

h) ☐ physician/dentist recommended testing

i) ☐ work-related accidental exposure to blood or body fluid

j) ☐ concerned about a blood transfusion

k) ☐ received notice from hospital about a blood transfusion

l) ☐ sexual assualt

m) ☐ other *(specify)* _____

2. **How did client find out about the service ?**

a) ☐ has been to this clinic before

b) ☐ testing publicity campaign
- ☐ pamphlet ☐ poster ☐ newspaper ad

c) ☐ word of mouth *(referral from friend)*

d) ☐ general media attention to AIDS *(radio, television, newspaper)*

e) ☐ provincial AIDS hotline *(1–800–numbers)*

f) ☐ local community AIDS group

g) ☐ local health unit

h) ☐ GP referred

i) ☐ other *(specify)* _____

3. Risk assessment *(past and current)* *(check all appropriate boxes)*

		within last 10 yrs	within last 6 months (safe)	within last 6 months (unsafe)
a)	Needle use	☐ yes ☐ no	☐ yes ☐ no	☐ yes ☐ no

b) Transfusion/product recipient ☐ yes ☐ no ☐ maybe

If *yes*

a) ☐ blood product ☐ before 1985 ☐ after 1985

b) ☐ blood transfusion ☐ before 1985 ☐ after 1985

c) Other risks

☐ tattoos ☐ work-related exposure ☐ sex or drug partner at risk

☐ endemic area ☐ suspect current or past sex or drug partner at risk for HIV ☐ no identifiable risk

☐ other *(specify)* _____

d) Total sexual behaviour (experience)

	more than 10 years ago	within last 10 years	within last 6 months
a) sex with men	☐	☐	☐
b) sex with women	☐	☐	☐
c) no sexual activity	☐	☐ (go to 7)	☐

e) Type of sexual activity

		within last 10 yrs	within last 6 months (safe)	within last 6 months (unsafe)
i)	oral sex	☐ yes ☐ no	☐ yes ☐ no	☐ yes ☐ no
ii)	vaginal sex	☐ yes ☐ no	☐ yes ☐ no	☐ yes ☐ no
iii)	anal sex	☐ yes ☐ no	☐ yes ☐ no	☐ yes ☐ no

4. Sexual partners *(over last year)*

a) number of regular partners *(safe & unsafe activities)* ☐ 1 ☐ 2 ☐ 3–5 ☐ 6–10 ☐ >10 _____

b) number of casual partners *(safe & unsafe activities)* ☐ 1 ☐ 2 ☐ 3–5 ☐ 6–10 ☐ >10 _____

5. Condom use *(last 6 months)*

a) Is client currently using condoms for anal/vaginal intercourse with regular partners? *(check the most appropriate box)*

☐ 0% ☐ 25% ☐ 50% ☐ 75% ☐ 100%

b) Is client currently using condoms for anal/vaginal intercourse with casual partners? *(check the most appropriate box)*

☐ 0% ☐ 25% ☐ 50% ☐ 75% ☐ 100%

6. Number of drug use episodes sharing unclean needles within last 6 months *(e.g. client used someone else's needle without cleanin*

☐ 0 ☐ 1 ☐ 2 ☐ 3–5 ☐ 6–10 ☐ >10 _____

7. a) Last possible exposure to HIV

date _____ *(yy/mm/dd)*

b) Risk of exposure is:

☐ ongoing

☐ within last 3 months

☐ within last 6 months

c) ☐ risk assessment minimal *(counsellor's assessment)*

7. *(continuous)*

d) Type of exposure *(check all appropriate boxes)*

i) ☐ sexual *(unprotected anal/vaginal with person potentially at risk)* specify _____

ii) ☐ needles *(shared)*

iii) ☐ blood product/transfusion *(prior to 1985)*

iv) ☐ tattoos

v) ☐ endemic area

vi) ☐ work-related exposure

vii) ☐ artificial insemination

viii) ☐ no identifiable risk

ix) ☐ sexual assault

x) ☐ other *(specify)* _____

8. Partner notification – discuss at pre-test visit with *all* clients

a) How many partners could be identified? _____

b) How many partners could not be identified? _____

c) Will client notify partners? ☐ yes ☐ no ☐ not sure

d) How many partners will client notify? ☐ all ☐ some _____%

9. Post-test visit

a) Client picked up results ☐ yes ☐ no date of pick up *(yy/mm/dd)* _____

Result ☐ positive ☐ negative

b) Referrals (recommendations and information given)

☐ community–based AIDS group

☐ HIV/AIDS outpatient clinic

☐ primary care physician

☐ self–help/peer group

☐ alcohol/drug treatment

☐ other *(specify)* _____

_____

10. Positive clients only

Partner notification *(sexual & drug)*

a) Will client notify partners ❑ yes ❑ no ❑ not sure ❑ client unable to respond *(go to e)*

b) How many partners will client notify? ❑ all ❑ some _____%

c) Who else will do partner notification?

- ❑ anonymous test location
- ❑ public health
- ❑ other *(specify)* _____

d) How will partner notification be done?

- ❑ client face-to-face or telephone
- ❑ client send anonymous letter
- ❑ clinic send letter
- ❑ other *(specify)* _____

e) Is client intending to go into health care system? ❑ yes ❑ no ❑ not sure ❑ client unable to respond

f) If yes

When _____

Where _____

g) If no, reasons: _____

_____

_____

_____

_____

Counsellor Check List for Evaluation Purposes *Only*

Long Form – Repeat Testers Only

Please remember to inform clients about the evaluation component of anonymous testing.
No identifiers are to be used on this form – do not link to requisition or client chart information.
Please use red, green or blue ink only. Return completed forms to HIV lab.

Previous HIV tests? ☐ yes ☐ no *(if no, use short form 2455–62)*

Check all appropriate boxes

Sex	Date of Birth *(yy/mm/dd)*	Site number	Date of visit *(yy/mm/dd)*
☐ male ☐ female		95006	

Place of residence
☐ Ontario ☐ Canada ☐ USA ☐ Other *(specify)* _____

Health Unit where client resides *(city or town if unknown)*

Ethno cultural identity *(self identification – see instructions)*
☐ white ☐ black ☐ hispanic ☐ asian ☐ indo asian ☐ aboriginal ☐ other *(specify)* _____

Country of Birth	Date of arrival in Canada *(yy/mm/dd)*
☐ Canada ☐ other *(specify)*	

1. Previous test history

a) Number of HIV tests since 1985 _____

b) Most recent test done ☐ anonymous ☐ confidential ☐ don't know
(yy/mm/dd)

c) Date of last test _____

d) If anonymous, was it done in a ***designated*** anonymous test clinic (since January 1992) ☐ yes ☐ no ☐ don't know

e) Where was test done ☐ Ontario ☐ elsewhere

result ☐ positive *(go to f)* ☐ negative *(go to i)* ☐ indeterminate *(go to 2)*

f) ☐ if previously **positive**, were partners notified? ☐ yes ☐ no ☐ don't know

☐ if *yes*, how many? ☐ all ☐ some _____%

g) If previously **positive**, is client under a doctor's care? ☐ yes ☐ no
if no, why not? _____

h) If previously ***positive***, retest reasons
- ☐ might be mistake
- ☐ monitoring disease progression *(not available through anonymous testing)*
- ☐ other, specify _____

i) If previously **negative**, in general, has risk behaviour changed since last test for HIV?
☐ riskier ☐ less risky ☐ about the same

j) If previously ***negative***, retest reasons *(check all appropriate boxes)*
- ☐ was in window period at last test *(within 14 weeks of exposure)*
- ☐ episode of unsafe sex behaviour
- ☐ ongoing unsafe sexual behaviour
- ☐ episode of unsafe needle use
- ☐ ongoing unsafe needle use
- ☐ reassurance of negative *(safe sex with known HIV+ partner)*
- ☐ reassurance – no risk
- ☐ other *(specify)* _____

1905–62 (95/01)

2. Other reasons/motivation for being anonymously tested at this time *(unprompted, client's perspective) – check all appropriate boxes*

a) ☐ client chose anonymous testing over confidential/nominal

b) ☐ assurance of negative results *(client considers self to be low risk)*

c) ☐ not feeling well

d) ☐ notified by partner who is HIV positive *(sexual or needle sharing)*
- ☐ partner tested anonymously
- ☐ partner tested at a regular clinic
- ☐ don't know how partner tested

e) ☐ perceived benefit if positive *(e.g. early treatment)*

f) ☐ partner has requested client be tested

g) ☐ suspected exposure to HIV *(client perspective – suspects previous or current partner to be at risk for HIV or other exposure; e.g. work-related, tattoo,*

h) ☐ physician/dentist recommended testing

i) ☐ work-related accidental exposure to blood or body fluid

j) ☐ concerned about a blood transfusion

k) ☐ received notice from hospital about a blood transfusion

l) ☐ sexual assault

m) ☐ other *(specify)* _____

3. How did client find out about the service ?

a) ☐ has been to this clinic before

b) ☐ testing publicity campaign
☐ pamphlet ☐ poster ☐ newspaper ad

c) ☐ word of mouth *(referral from friend)*

d) ☐ general media attention to AIDS *(radio, television, newspaper)*

e) ☐ provincial AIDS hotline *(1-800-numbers)*

f) ☐ local community AIDS group

g) ☐ local health unit

h) ☐ GP referred

i) ☐ other *(specify)* _____

4. Risk assessment *(past and current)* (*check all appropriate boxes*)

		within last 10 yrs	within last 6 months (safe)	within last 6 months (unsafe)
a)	Needle use	☐ yes ☐ no	☐ yes ☐ no	☐ yes ☐ no

b) Transfusion/product recipient ☐ yes ☐ no ☐ maybe

If *yes*

a) ☐ blood product ☐ before 1985 ☐ 1985 or later

b) ☐ blood transfusion ☐ before 1985 ☐ 1985 or later

c) Other risks

☐ tattoos ☐ work-related exposure ☐ sex or drug partner at risk

☐ endemic area ☐ suspect current or past sex or drug partner at risk for HIV ☐ no identifiable risk

☐ other *(specify)* _____

4. Risk assessment *(past and current)* **(check all appropriate boxes)**

d) Total sexual behaviour (experience)

	more than 10 years ago	within last 10 years	within last 6 months
i) sex with men	☐	☐	☐
ii) sex with women	☐	☐	☐
iii) no sexual activity	☐	☐ (go to 7)	☐

e) Type of sexual activity

	within last 10 yrs	within last 6 months (safe)	within last 6 months (unsafe)
a) oral sex	☐ yes ☐ no	☐ yes ☐ no	☐ yes ☐ no
b) vaginal sex	☐ yes ☐ no	☐ yes ☐ no	☐ yes ☐ no
c) anal sex	☐ yes ☐ no	☐ yes ☐ no	☐ yes ☐ no

5. Sexual partners *(over last year)*

a) number of regular partners *(safe & unsafe activities)* ☐ 1 ☐ 2 ☐ 3–5 ☐ 6–10 ☐ >10 _____

b) number of casual partners *(safe & unsafe activities)* ☐ 1 ☐ 2 ☐ 3–5 ☐ 6–10 ☐ >10 _____

6. Condom use *(last 6 months)*

a) Percentage of time client is currently using condoms for anal/vaginal intercourse with regular partners *(check the most appropriate box)*

☐ 0% ☐ 25% ☐ 50% ☐ 75% ☐ 100%

b) Percentage of time client is currently using condoms for anal/vaginal intercourse with casual partners *(check the most appropriate box)*

☐ 0% ☐ 25% ☐ 50% ☐ 75% ☐ 100%

c) Have they ever failed *(broken, leaked or slipped off during intercourse)?*

☐ yes ☐ no ☐ don't know Number of known failures _____ *(within the last 6 months)*

d) Reasons for not using condoms – last unprotected anal/vaginal intercourse

☐ knew partner was HIV negative
☐ partner said he/she was HIV negative
☐ client doesn't like condoms
☐ partner wouldn't use/doesn't like condoms
☐ got carried away
☐ assumed partner was HIV negative
☐ no condoms available
☐ doesn't understand HIV transmission
☐ influence of alcohol/drugs
☐ other *(specify)* _____

7. Number of drug use episodes using needles within last 6 months *(e.g. client used someone else's needle without cleaning)*

☐ 0 ☐ 1 ☐ 2 ☐ 3–5 ☐ 6–10 ☐ >10 _____

8. a) Last possible exposure to HIV

i) date _____ *(yy/mm/dd)*

ii) exposure since last test? ☐ yes ☐ no

iii) exposure prior to last test? ☐ yes ☐ no

b) Risk of exposure is:

☐ ongoing
☐ within last 3 months
☐ within last 6 months

1905–62 (95/01)

8. *(continuous)*

c) Risk assessment minimal *(counsellor's assessment)*

d) Type of exposure *(check all appropriate boxes)*

i) ☐ sexual *(unprotected anal/vaginal with person potentially at risk)* specify _____

ii) ☐ needles *(shared)*

iii) ☐ blood product/transfusion *(prior to 1985)*

iv) ☐ tattoos

v) ☐ endemic area

vi) ☐ work-related exposure

vii) ☐ artificial insemination

viii) ☐ no identifiable risk

ix) ☐ sexual assault

x) ☐ other *(specify)* _____

9. **Related information** *(check all appropriate boxes)*

a) ☐ History of STDs ☐ yes ☐ no ☐ unsure

if yes

How many episodes *(last 6 months)* _____

Types: ☐ herpes ☐ chlamydia ☐ GC ☐ syphilis ☐ NSU ☐ HPV (genital warts) ☐ trichomonas

☐ hepatitis A ☐ hepatitis B ☐ hepatitis C ☐ other *(specify)* _____

b) Last episode *(date)* _____
(yy/mm/dd)

c) Does client currently identify a problem with:

alcohol	☐ yes	☐ no
cannibis	☐ yes	☐ no
cocaine	☐ yes	☐ no
crack	☐ yes	☐ no
heroin	☐ yes	☐ no
poppers	☐ yes	☐ no

other *(specify)* _____

d) Does counsellor identify that client has mental health problems ☐ yes ☐ no

10. **Partner notification – discuss at pre-test visit with *all* clients**

a) How many partners could be identified? _____

b) How many partners could not be identified? _____

c) Will client notify partners? ☐ yes ☐ no ☐ not sure

d) How many partners will client notify? ☐ all ☐ some _____%

11. Post-test visit

a) Client picked up results ☐ yes ☐ no date of pick up _____ *(yy/mm/dd)*

Result ☐ positive ☐ negative ☐ indeterminate

b) Referrals (recommendations and information given)

- ☐ community–based AIDS group
- ☐ HIV/AIDS outpatient clinic
- ☐ primary care physician
- ☐ self-help/peer group
- ☐ alcohol/drug treatment
- ☐ other *(specify)* _____

12. Positive clients only

Partner notification *(sexual & drug)*

a) Will client notify partners ☐ yes ☐ no ☐ not sure ☐ client unable to respond *(go to e)*

b) How many partners will client notify? ☐ all ☐ some _____%

c) Who else will do partner notification?

- ☐ anonymous test location
- ☐ public health
- ☐ other *(specify)*

d) How will partner notification be done?

- ☐ client face-to-face or telephone
- ☐ client send anonymous letter
- ☐ clinic send letter
- ☐ other *(specify)*

e) Is client intending to go into health care system? ☐ yes ☐ no ☐ not sure ☐ client unable to respond

f) If yes

When _____

Where _____

g) If no, reasons: _____

Ministry of Health Laboratory Services Branch
Ontario

ANONYMOUS HIV SEROLOGY

Date Rec'd PHL No.

Patient Identification	Is this 1st test?	If NO, was previous result
061608	☐ YES ☐ NO	☐ + or ☐ −

Date of Birth	Sex	Date Specimen Collected	Last anonymous test code
yy / mm / dd	☐ M ☐ F	yy / mm / dd	

Please print/stamp doctor's name & address clearly and firmly on all copies. Include postal Code.

95006 M - 96 - N
ELGIN - ST. THOMAS HEALTH UNIT
M.O.H. PHONE: 631-9971
99 EDWARD STREET
ST. THOMAS, ONTARIO N5P 1Y8

CONFIDENTIAL WHEN COMPLETED

PATIENT'S SYMPTOMS/DIAGNOSIS

- ☐ None
- ☐ Fever
- ☐ Fatique
- ☐ Diarrhea
- ☐ Skin Rash
- ☐ Weight Loss
- ☐ Night Sweats
- ☐ Decreased helper cell number
- ☐ Recurrent oral candidiasis
- ☐ Kaposi's Sarcoma
- ☐ Generalized Lymphadenopathy
- ☐ PCP
- ☐ ARC/Pre-AIDS
- ☐ AIDS

Other (Specify) _____

Date of Onset

PATIENT RISK (check all applicable boxes)

- ☐ M has had sex with men
- ☐ W has had sex with women
- ☐ I needle use
- ☐ H sex partner of HIV + person
- ☐ R sex partner of person(s) at risk for HIV
- ☐ B recipient of blood products before 1/11/85
- ☐ T recipient of blood transfusion before 1/11/85
- ☐ E endemic area immigrant/traveller
- ☐ C offspring of HIV + mother
- ☐ N no identifiable risk
- ☐ O Other (Specify) _____

LABORATORY USE ONLY

SCREENING TEST (ELISA)

REMARKS

CONFIRMATORY TEST

☐ Immuno Blot (IB)

☐ No ID on sample tube
☐ Further report to follow

Date Reported _____

1210-44A (91/11)

SEE OVER FOR INFORMATION

061608 061608

SEROPOSITIVE FLOW SHEET

DATE NOTIFIED OF POSITIVE RESULTS: _____

1. PARTNER NOTIFICATION:
   - _____ Client already notified all
   - _____ Client will notify all
   - _____ Health dept will notify all
   - _____ Dept/client to notify
   - _____ Client refuses to cooperate
   - _____ No locatable partners

2. NUMBER OF PARTNERS HEALTH DEPT. TO NOTIFY:
   - _____ Sexual
   - _____ Needle-sharing

3. MEDICAL/SOCIAL REFERRALS MADE?
   - _____ Yes _____ No
   - _____ HIV Program _____ AIDS Committee

   Other: _____

4. HANDOUTS GIVEN:
   - _____ HIV + What You Should Know
   - _____ Advice For People Who Are HIV Positive
   - _____ Being HIV Positive

Post-test Counsellor _____ Date: _____

Additional Information

CONTACTS:

Name	Sex	Address	Result of Investigation

CORRESPONDENCE:

Date		Response/Date
	Letter ( ) Telephone ( )	
	Letter ( ) Telephone ( )	
	Letter ( ) Telephone ( )	

OTHER DATA: _____

ELGIN-ST. THOMAS HEALTH UNIT

AIDS/HIV - RDIS FORM

NOTICE OF COLLECTION:

_____ _____
Date Initials

Inputed to RDIS: _____
Edited: _____
Closed: _____

Episode Date: _____ **Type:** 1 - Onset of Symptoms; 2 - Clinic Visit or Specimen Collection; 3 - Treatment Date; 5 - Lab Report Date; 97 - Estimate

Disease: 128 - AIDS/HIV **Agent/Organism:** 723 - HIV

Subtype: 120 - Type 1; 131 - Type 2

Classification: 1 - Case; 2 - Carrier; 99 - Undetermined

Demographics 1

Name: _____ **D.O.B.:** _____ (Year/Month/Day) **Age:** ____ **Sex:** M F U

Marital Status: ☐ S ☐ M ☐ W ☐ D ☐ Sep ☐ C/L ☐ U

Language: 1 - English; 6 - German; 15 - Vietnamese; 98 - Other _____

Origin: 1 - Born in Canada; 3 - Born Outside Canada; 4 - Registered Indian; 5 - Inuit; 6 - Unregistered Indian; 98 - Unspecified; 99 - Unknown **County of Birth:** _____

Current Address

Address: _____ **City:** _____
P.C.: _____ **Home Phone:** _____ **Work Phone:** _____

Demographics 2

Physician's Name: _____ **Phone:** _____
Other Physician: _____ **Phone:** _____

Employer/Institution/School

Name: _____ **Phone:** _____
Address: _____
P.C.: _____ **Job Title:** _____

Parent/Guardian

Name: _____ **Phone:** _____
Address: _____ **P.C.:** _____

Reporting Source

Reporting Agency: 50 - MOH Labs; 01 - STEGH; 20 - MDS Labs; Other _____

Date of Report: _____ **Date Received:** _____

Reporting Physician: _____ **Other Report Source:** _____

Inter-Health Unit Communication

Referred From: _____ **Date Referred:** _____

Forwarded To: _____ **Date Forwarded:** _____

Case Management

Investigator: _____

Type of Interviewer: 1 - Physician; 2 - Own Health Unit Staff; 6 - Health Unit, Areas of Residence

Responsible Health Unit: ESTHU or Other _____

Physician's Health Unit: _____ **Date of Initial Interview:** _____

Case Disposition: 1 - Successful Treatment; 2 - Ongoing Treatment; 5 - Deceased; 50 - Untraceable; 53 - Lost to Followup; 54 - Referred; 57 - Eligible for Vaccine; 58 - Vaccinated; 59 - Treated; 60 - Symptomatic; 61 - Saw M.D.; 63 - Put on Prophylaxis; 99 - Unknown

Date Dispositioned: _____

Diagnostic Information

Date of Onset: _____ **Date of Diagnosis:** _____
(if unknown use Episode Date)

Date Type: 1 - Date positive specimen collected; 2 - Specimen received by lab; 3 - Clinical diagnosis; 4 - As reported by client; 5 - Report received by Health Unit; 98 - Other; 99 - Unknown

Method of Diagnosis: 2 - Lab Report HIV Positive; 100 - AIDS Case Definition Met; 98 - Other _____

Method of Detection: 1 - Symptoms; 2 - Contract Tracing; 3 - Routine Screening; 4 - Post Mortem; 6 - Immigration Screening; 98 - Other; 99 - Unknown

Pregnant: Y N/A **L.M.P.:** _____

Symptoms: 1 - Asymptomatic; 2 - Symptomatic; 3 - Abdominal Pain; 6 - Cough; 9 - Diarrhea loose sto
10 - Diarrhea Watery; 11 - Diarrhea bloody; 12 - Discharge; 14 - Sore Throat 15 - Dysuria; 18 - Fev
24 - Malaise; 27 - Nausea/Vomiting; 30 - Diaphoresis; 33 - Skin Change; 36 - Weight Loss; 40 Cram
43 - Fatigue; 44 - Chills; 45 - Weakness; 52 - Anorexia; 98 - Other

Name and Date of Birth: _____

Laboratory

Type of Test	Site	Result	Date
302 - Virus Isolation	1 - Blood		
603 - Elisa	1 - Blood		
604 - Western Blot	1 - Blood		
605 - p24 Antigen			
606 - PCR (Polymercase Chain Reaction) - diagnostic			
607 - PCR - prognostic (put results in comment field)			
608 - CD4 Count			
98 - Other			

Sites: 1 - Blood; 2 - CSF
Results: 1 - Positive; 2- Negative; 3 - Reactive; 4 - Non-reactive; 99 - Unknown; 98 - Other _____
{*p24:* **25** - Strong; **26** - Weak} {*PCR - Prognostic:* enter results in comment field} {*CD4 Count:* **32** - equal or greater than 500 cells/micro litre; **33** - 200 to 499 cells/micro litre; **34** - less than 200 cells/micro litre}

Treatment History

Treat/Type Prescribed	Date Started	Date Ending	Status
52 - AZT			
53 - ddI			
55 - ddC			
77 - Pentamadine			
82 - 3TC			

Current Treatment Status: 2 - In Progress; 4 - Not Initiated
Antibody Resistance: ☐ Y ☐ N ☐ U **Type (Name Drug):** _____
Drug Sensitivities/Allergies: _____

Outcomes

Complications: _____

Clinical Progress: 1 - Improving; 2 - Stable; 3 - Deteriorating; 4 - Deceased; 99 - Unknown; 98 - Other _____
Deceased? ☐ Y ☐ N **Cause of Death:** 1 - Related to this disease; 2 - This disease contributed; 3 - Not related to this disease

Date of Death: _____
Hospitalized: 1 - In Patient; 2 - Out Patient; 3 - No; 99 - Unknown
Where: _____

Named Contacts

Contact Name	Relationship	Disposition

Contact Relationship: 1 - Parent; 2 - Sibling; 3 - Co-worker; 4 - Companion; 5 - Sexual; 6 - Spouse; 8 - Child; 10 - Co-occupant; 12 - Relative; 99 - Unknown; 98 - Other _____

Contact Disposition: 50 - Untraceable; 51 - Traced; 53 - Lost to Followup; 54 - Referred; 56 - Became a Case; 61 - Saw M.D.

Number of Contacts Not Named: _____ **Number of Contacts Named:** _____
Refused to Name Contacts? ☐ Y ☐ N
Type of Interviewer: 1 - Physician; 2 - Own Health Unit Staff; 3 - Physician/Health Unit Staff

Social and Risk Factors

After 1978 and preceding the diagnosis of AIDS, the client had the following risk factors:

10 - Partner opposite sex; 20 - Partner same sex; 30 - Uses needles; 41 - Coagulation disorder - blood product **before** November 1985; 42 - Coagulation disorder - blood product **after** November 1985; 43 - Coagulation disorder - blood product date unknown; 51 - Transfusion **before** November 1985; 52 - Transfusion **after** November 1985; 53 - Transfusion date unknown; 60 - Lived/travel endemic area; 70 - Occupational Exposure (specify); 80 - Infant of Infected Mother; 400 - Other medical procedure exposure; 410 - Non-medical, Non occupational exposure; 420 - Donated blood, tissue, semen, etc.; 97 - No Identifiable Risks; 98 - Other _____

Exposure Category - Use same code numbers as Risk Factors _____

Ethnic Background: 10 - White; 20 - Black; 30 - Asian; 35 - South Asian; 45 - Arab/West Asian; 50 - Latin American; 60 - Native Indian; 70 - Inuit; 80 - Metes; 99 - Unknown; 98 - Other _____
Ethnicity Comments: _____
Endemic Area: _____

If Client has TB Disease:
TB-PPD Test: ☐ Y ☐ N ☐ Unknown
If Yes - TB-PPD Size _____
If ↓ 10 mm - TB Anergy Test: ☐ Y ☐ N ☐ Unknown
TB Sites Positive: ☐ Y ☐ N ☐ Unknown

AIDS (client) - Case Comments _____

Risk Factors of Sexual Partners

Risk factors of sexual partners include:

5 - Partner has HIV/AIDS; 10 - IV Drug User; 60 - Born/Resident County where heterosexual transmission predominant; 100 - Bisexual Male; 110 - Homosexual Male; 140 - Coagulation Disorder; 150 - Positive transfusion recipient; 99 - Unknown; 98 - Other _____

Endemic Area: _____

Diseases Indicative of AIDS

Diagnosis Code: 1 - Definitive; 2 - Presumptive; 99 - Unknown

Disease	Earliest Date	Diagnosis Code
10 - Candidiasis, Bronchi, Trachea, or Lungs		
20 - Candidiasis, Esophageal		
30 - Coccidioidomycosis		
40 - Cryptosporidiosis - Extrapulmonary		
50 - Crytosporidiosis - Chronic Intestinal		
60 - CMV - other than in liver, spleen or nodes		
70 - CMV - Retinitis		
80 - HIV - Encephalopathy		
90 - Herpes Simplex: Chronic Ulcer(s) (> 1 month duration) or Bronch, Pneum O/EO		
100 - Histopasmosis, disseminated or extrapulmonary		
110 - Isosporiasis, Chronic Intestinal (> 1 month duration)		
120 - Kaposi's Sarcoma		
130 - Lymphoma, Burkitt's (or Equivalent Term)		
140 - Lymphoma, Immunoblastic (or Equivalent Term)		
150 - Lymphoma (Primary in Brain)		
160 - M. Avium Complex or M. Kansasii Dissem. Extrapulmonary		
170 - Tuberculosis, Disseminated or Expulmonary		
180 - Mycobacterium of other species or unidentified, Diss/Expulmonary		
190 - Pneumocystis Carinii Pneumonia		
200 - Progressive Multifocal Leukoencephalopathy		
210 - (P) Bacterial Infections, Multiple or Recurrent (including Salmonellasept)		
220 - Toxoplasmosis of Brain		

230 - Wasting Syndrome due to HIV		
240 - Salmonella Septicemia, recurrent		
250 - (P) Lymphoid Interstitial Pneumonia and/or Pulmonary		
260 - Pulmonary TB		
270 - Recurrent Bacterial Pneumonia		
280 - Invasive Cervical Cancer		
98 - Other (HIV carriers only):_____		
99 - Unknown		
999 - AIDS disease unknown		

Follow-up Information

Received Pre-Test Counselling? ☐ Y ☐ N ☐ U Specify: _____

Patient Informed of Results? ☐ Y ☐ N ☐ U

Received Post Test Counselling? ☐ Y ☐ N ☐ U Specify: _____

Requires Ongoing Counselling? ☐ Y ☐ N ☐ U

Partner Notification

Can Identify Sexual/Needle Sharing Partners? ☐ Y ☐ N ☐ U

Who will obtain information about Partners? _____ Completed ☐ Y ☐ N ☐ U

Who will counsel Partners? _____ Completed ☐ Y ☐ N ☐ U

Episode Status

Episode Status: 1 - Pending Confirmation; 2 - Meets case definition; 3 - Does not meet case definition

Date Confirmed: _____ **Transmit to Ministry:** ☐ Y ☐ N

Signature: _____ **Date:** _____

EHU 587A (96/10)

APPENDIX B. HOSPICE ASSOCIATIONS OF ONTARIO AND ONTARIO AIDS SERVICE ORGANIZATIONS

Hospice Associations of Ontario & Ontario AIDS Service Organizations

PUBLIC HEALTH UNIT	HOSPICE ASSOCIATION OF ONTARIO	AIDS SERVICE ORGANIZATION OF ONTARIO
Algoma	1. Elliot Lake Palliative Care Program 2. Hospice Volunteer Visiting Program VON-Algoma Branch	1. Algoma AIDS Network
Brant		
Bruce-Grey-Owen Sound	1. Grey Bruce Palliative Care/Hospice Association 2. Bruce Peninsula Hospice	
Durham	1. Hospice Durham 2. North Durham Hospice	1. AIDS Committee of Durham Region
East York		
Eastern Ontario	1. VON Palliative Care Volunteer Eastern Counties Branch 2. Dundas County Hospice	
Elgin-St. Thomas		
Etobicoke	1. The Dorothy Ley Hospice	
Haldimand-Norfolk	1. Haldimand-Norfolk Community Senior Support Services	
Haliburton-Kawartha	1. Campbellford & District Palliative Care Service 2. Northumberland Lakeshore Hospice 3. SIRCH Community Hospice for Haliburton County 4. Palliative Care Victoria	
Halton	1. Ian Anderson House	1. Miriam Child & Family Support Services
Hamilton-Wentworth	1. VON Palliative Volunteer Visiting Program Hamilton-Wentworth Branch 2. Good Shepherd Centres 3. Dr. Bob Kemp Hospice Foundation	1. Hamilton AIDS Network
Hastings	1. North Hastings Palliative Support	

PUBLIC HEALTH UNIT	HOSPICE ASSOCIATION OF ONTARIO	AIDS SERVICE ORGANIZATION OF ONTARIO
	2. Hospice Quinte 3. The Heart of Hastings Hospice 4. COPE A Community Resource for Palliative & Bereavement Support	
Huron	1. Huron Hospice Volunteer Service 2. Wingham & Area Palliative Care Services	1. Huron County HIV/AIDS Network
Kent-Chatham	1. VON Palliative Care Volunteer Service/Geranium House	
Kingston-Frontenac	1. Hospice Kingston 2. Hospice Lennox and Addington 3. Land O'Lakes Palliative Care Volunteer Program	1. HIV/AIDS Region Service
Lambton		1. AIDS Support Committee of Sarnia-Lambton
Leeds-Grenville	1. St. Vincent De Paul Hospital Palliative Care Service 2. North Grenville Community Hospice 3. Perth & Smiths Falls District Hospital Palliative Care Services	
Middlesex-London	1. Hospice of London 2. Charis House Hospice	1. AIDS Committee of London 2. John Gordon Home
Muskoka-Parry Sound	1. Hospice Muskoka, Almaguin Palliative Care Team 2. Hospice Huntsville 3. Hospice West Parry Sound	1. Parry Sound-Muskoka AIDS Committee
Niagara	1. Palliative Care Services of Greater Fort Erie 2. West Niagara Palliative Care Service 3. Niagara-on-the-Lake Community Palliative Care	1. AIDS Niagara

PUBLIC HEALTH UNIT	HOSPICE ASSOCIATION OF ONTARIO	AIDS SERVICE ORGANIZATION OF ONTARIO
	Service 4. Hospice Niagara	
North Bay	1. Near North Palliative Care Network 2. VON-North Bay	2. AIDS Committee of North Bay and Area
North York	1. Downsview Services to Seniors 2. Bayview Community Hospice	
Northwestern		
Ottawa-Carleton	1. Sylvia House Hospice-Home Hospice Service	1. AIDS Committee of Ottawa-Comite du sida d'Ottawa 2. Bruce House
Oxford	1. Woodstock & District Hospice	
Peel	1. Hospice Caledon 2. Hospice of Peel	1. Peel HIV/AIDS Network
Perth	1. North Perth Community Hospice 2. Hospice Services/Family Services Perth Huron	1. AIDS Action Committee of Perth County
Peterborough	1. Hospice Peterborough	1. Peterborough AIDS Resource Network
Porcupine		
Renfrew	1. VON Volunteer Palliative Care Program, Pembroke Branch	
Scarborough	1. Hospice Scarborough	
Simcoe	1. Hospice Simcoe 2. Collingwood Community Hospice 3. Hospice Orillia 4. Hospice Huronia	1. AIDS Committee of Simcoe County
Sudbury	1. VON Espanola Hospice Volunteer Visiting Program 2. Sudbury Region Palliative Care	1. AIDS Committee of Sudbury-Comite du sida de Sudbury
Thunder Bay	1. Via Vitae Community Palliative Care Volunteers	1. AIDS Committee of Thunder Bay
Timiskaming	1. Timiskaming Palliative Care Network	

PUBLIC HEALTH UNIT	HOSPICE ASSOCIATION OF ONTARIO	AIDS SERVICE ORGANIZATION OF ONTARIO
Toronto	1. White Light Hospice Foundation 2. Casey House Hospice 3. Trinity Home Hospice 4. Palliative Care Information Centre of Toronto 5. L'Hospice des Centres d'Accueil Heritage 6. Fife House Foundation 7. The Phillip Aziz Centre 8. MCC Toronto Community Care/AIDS Care 9. Hazel Burns Hospice	1. Community AIDS Treatment Information Exchange 2. HIV/AIDS Legal Clinic of Ontario 3. HIV-T Group 4. Hemophilia Ontario 5. Prisoners HIV/AIDS Support Action Network (PASAN) 6. The Teresa Group 7. Voices of Positive Women 8. Black Coalition for AIDS Prevention 9. Casey House Hospice 10. Fife House Foundation 11. Ontario Aboriginal HIV/AIDS Strategy 12. Positive Straight Men 13. Positive Youth Outreach 14. 127 Isabella Non-Profit Residence 15. 2-Spirited People of the First Nations 16. Africans in Partnership Against AIDS 17. Africans Untied to Control AIDS 18. AIDS Action Now! 19. AIDS Committee of Toronto 20. Alliance for South Asian AIDS Prevention 21. Asian Community AIDS Services 22. Community Research Initiative of Toronto 23. David Kelly Lesbian and Gay Community Counselling Program 24. Prostitutes' Safe Sex Project 25. Toronto PWA Foundation
Waterloo	1. Hospice of Waterloo Region 2. Woolwich Hospice	1. AIDS Committee of Cambridge, Kitchener/Waterloo and Area
Wellington-Dufferin-	1. Hospice Wellington	1. AIDS Committee of Guelph and

PUBLIC HEALTH UNIT	HOSPICE ASSOCIATION OF ONTARIO	AIDS SERVICE ORGANIZATION OF ONTARIO
Guelph	2. Hospice Dufferin	Wellington County
Windsor-Essex	1. Hospice of Windsor	1. AIDS Committee of Windsor
York City		
York Region	1. Hospice King 2. Evergreen Hospice of Markham-Stouffville 3. VON-Toronto Volunteer Resources 4. Hospice Newmarket 5. Hospice Richmond Hill 6. Hospice Georgina 7. Hospice Thornhill 8. Jewish Hospice Program 9. Hospice Vaughan	

APPENDIX C. POPULATION AND PREVALENCE RATES

1993 Population and Prevalence Rates

PUBLIC HEALTH UNIT	1992 POPULATION	PREVALENCE RATE
Peel	788100	16
Ottawa-Carleton	717700	42
Toronto	655300	306
North York	579300	25
York Region	547100	12
Scarborough	540200	25
Hamilton-Wentworth	469100	18
Durham	437300	11
Niagara	411800	17
Waterloo	398600	10
Middlesex-London	392800	33
Windsor-Essex	342600	38
Halton	331500	16
Etobicoke	319300	28
Simcoe	309700	15
Wellington-Dufferin-Guelph	210800	15
Sudbury	208800	11
Eastern Ontario	186400	8
Kingston-Frontenac	174600	20
Thunder Bay	165600	7
Haliburton-Kawartha	164600	4
Bruce-Grey-Owen Sound	157000	8
Leeds-Grenville	153300	7
Hastings-Prince Edward	148600	16
York	144900	42
Lambton	135400	10
Algoma	133300	6
Peterborough	125400	12
Brant	120700	22
Kent-Chatham	114300	8
East York	105900	78
Haldimand-Norfolk	104100	11
Renfrew	98200	11
Oxford	97800	10
Porcupine	97000	8
Muskoka-Parry Sound	91100	5
North Bay	88900	16
Northwestern	88600	2
Elgin-St. Thomas	78900	8
Perth	73100	17
Huron	61400	8
Timiskaming	40600	14

1995 Population and Prevalence Rates

PUBLIC HEALTH UNIT	1992 POPULATION	PREVALENCE RATE
Peel	788100	22
Ottawa-Carleton	717700	61
Toronto	655300	409
North York	579300	34
York Region	547100	16
Scarborough	540200	34
Hamilton-Wentworth	469100	29
Durham	437300	17
Niagara	411800	23
Waterloo	398600	14
Middlesex-London	392800	36
Windsor-Essex	342600	48
Halton	331500	23
Etobicoke	319300	36
Simcoe	309700	19
Wellington-Dufferin-Guelph	210800	20
Sudbury	208800	23
Eastern Ontario	186400	13
Kingston-Frontenac	174600	26
Thunder Bay	165600	16
Haliburton-Kawartha	164600	8
Bruce-Grey-Owen Sound	157000	13
Leeds-Grenville	153300	10
Hastings-Prince Edward	148600	26
York	144900	60
Lambton	135400	13
Algoma	133300	8
Peterborough	125400	21
Brant	120700	26
Kent-Chatham	114300	13
East York	105900	101
Haldimand-Norfolk	104100	14
Renfrew	98200	13
Oxford	97800	18
Porcupine	97000	9
Muskoka-Parry Sound	91100	9
North Bay	88900	25
Northwestern	88600	3
Elgin-St. Thomas	78900	10
Perth	73100	22
Huron	61400	10
Timiskaming	40600	20

1998 Population and Prevalence Rates

PUBLIC HEALTH UNIT	1996 POPULATION	PREVALENCE RATE
Peel	852526	26
Ottawa-Carleton	721136	73
Toronto	653734	484
York Region	592445	20
North York	589653	39
Scarborough	558960	38
Hamilton-Wentworth	467799	38
Durham	458616	22
Waterloo	405435	18
Niagara	403504	30
Middlesex-London	389616	55
Windsor-Essex	350329	54
Halton	339875	27
Simcoe	329865	22
Etobicoke	328718	46
Wellington-Dufferin-Guelph	217052	23
Sudbury	201154	29
Eastern Ontario	185314	15
Kingston-Frontenac	175568	34
Haliburton-Kawartha	165039	11
Thunder Bay	161187	18
Leeds-Grenville	156129	17
Bruce-Grey-Owen Sound	153312	17
York City	146534	78
Hastings-Prince Edward	143790	31
Lambton	128975	16
Algoma	123953	10
Peterborough	123448	26
Brant	114564	27
Kent-Chatham	109650	16
East York	107822	116
Haldimand-Norfolk	102575	16
Renfrew	97634	13
Porcupine	97437	10
Oxford	97142	18
North Bay	93841	25
Northwestern	80235	7
Elgin-St. Thomas	79159	14
Muskoka-Parry Sound	78675	18
Perth	72106	24
Huron	60220	17
Timiskaming	38847	21

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