Utilization Patterns of End-of-Life Services by Injection Drug Users who Have Died with HIV/AIDS

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in

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We accept this thesis as conforming to the required standard

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Abstract

Rationale: The changing demographics of HIV/AIDS have implications for the future use of health care resources.

Objective: To determine the location of death (hospital, community hospice, home) of HIV-infected injection drug users (IDU’s) and type of care (intensive, acute, palliative) at time of death; and to examine demographic, behavioral, and other variables in order to identify factors associated with receiving palliative care.

Methods: IDU’s who died with HIV/AIDS in Vancouver between 1991 and 1996 were identified through seven sources, including hospital data bases and direct services workers. Data collection consisted of a retrospective review of client records from Vancouver hospitals, community hospices, community organizations, and the Drug Treatment Program of BC Centre for Excellence in HIV/AIDS.

Results: There were 121 deaths documented that indicated that the individual was HIV positive and an IDU (92 were male, 24 were female, and 5 were transgendered). Median age at death was 35 years. Fifty-three percent were Aboriginal, and 61 percent lived in unstable housing. Sixty-one percent died in an acute care hospital setting, 27 percent died in a palliative care unit or in a community hospice, 11 percent died at home, and one percent on the street. Eleven of the thirteen home deaths were attributed to drug overdoses. AIDS was the most common cause of death (66%), followed by drug overdose (9%). Excluding deaths due to drug overdose, suicide or unknown causes, 71% of the IDU’s died while receiving some form of palliative treatment. However, the median length of palliative treatment was only two days. Having an AIDS diagnosis was
positively associated with receiving palliative care for more than two days, and with dying in a hospice or palliative care unit. Other variables, such as stable housing, being male and a period of longer than 36 months between HIV diagnosis and death were also positively associated with one of the three sets of criteria used for palliative care in this study. Multivariate analysis revealed that an AIDS diagnosis was independently associated with receipt of palliative care.

Conclusions: Analysis suggests that IDU’s are receiving palliative treatment, but for the majority, it is only for a very short period of time, and often when already bedridden or unconscious. Results should assist in planning future end-of-life services in light of changing demographics of HIV/AIDS in Vancouver, and in light of the moral and ethical imperative to provide compassionate care at the end of life.
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I. Introduction

The emerging AIDS epidemic among Vancouver's injection drug users means the coming years will see a dramatic increase in the number of deaths in this community. Social science and epidemiological research has explored treatment and prevention strategies among injection drug users with HIV/AIDS. However, palliative care or end-of-life issues have only recently been addressed. Some research suggests that injection drug users utilize the health care system erratically or sporadically, and that health care providers are not responsive to the unique conditions of injection drug users with HIV/AIDS. This situation may result in deficient or inappropriate health care utilization, including at the end of life.

Lack of current information, increasing demands in light of scarce health care resources, and the long-standing issues of poverty and marginalization, all make understanding access to palliative care services a paramount health issue for Vancouver's injection drug users with HIV/AIDS, as well as their health care providers.

The purpose of this study is to describe the utilization of end-of-life services by injection drug users who have died with HIV/AIDS in Vancouver. Injection drug users who died between 1991 and 1996 are examined in terms of location of death (home, hospital, hospice) and type of care at time of death (acute, intensive, or palliative). Associations between demographic, temporal and behavioral variables and utilization of palliative care are analyzed in the hope of identifying characteristics and factors which may contribute to appropriate and optimal health service utilization at the time of death.
2. Review of the Literature and Current Issues in Vancouver

2.1 HIV Infection and Injection Drug Use

2.1.1 HIV Incidence and Prevalence: Current Trends in Canada and Vancouver

As of December 31, 1996, there were 14,536 cases of AIDS reported in Canada and 2409 cases in British Columbia [1]. In spite of all that is known about prevention and treatment, AIDS continues to be the leading cause of premature death in adult males in Vancouver, Montreal, and Toronto [2].

Injection drug use is a major risk factor for acquiring HIV in western nations [3,4]. Transmission can occur when two or more people share syringes, water or other injecting equipment, which can transfer blood from one person to another. Studies on the infectivity of needle sharing estimate the probability of contracting HIV at one percent per exposure [5]. In British Columbia, injection drug use is currently the largest risk category for acquiring HIV, having surpassed the risk category of men-who-have-sex-with-men (MSM) in 1995 [6].

There are three sources of information on HIV prevalence in BC for injection drug users (IDU’s): BC Centre for Disease Control (BCCDC), BCCDC Study to enhance the HIV Surveillance System in BC, and the Vancouver Injection Drug User Study (VIDUS).

According to BC Centre for Disease Control [6], there have been 1552 HIV positive test results in British Columbia from people in the risk category of injection drug use, recorded from 1985 to 1996. (Number of test results does not equal number of individuals due to possibility of the same person requesting the test more than once.) The proportion of all
positive HIV tests that come from the category of injection drug use has been steadily growing, accounting for 35% of all positive tests in British Columbia in 1995 [7]. The proportion of HIV tests that are positive in 1996 for IDU’s is 8.8%, dramatically up from 1.7% in 1991 [6].

A second source of statistics on HIV infection rates comes from the BCCDC Study to Enhance the HIV Surveillance System in BC. The method of data collection for this study, carried out from January to December, 1996, eliminated duplicate tests. A total of 713 individuals were diagnosed with HIV for the first time during 1996 in British Columbia. Forty-four percent of these people reported injection drug use as their only risk factor [6]. When people who report multiple risk factors are included (e.g. MSM and IDU, or sex trade and IDU), the percentage of all individuals who were diagnosed with HIV in 1996 who fall into the risk category of IDU’s jumps to 55% [6].

The Vancouver Injection Drug User Study (VTDUS) examined current incidence and prevalence of HIV among Vancouver’s IDU’s. Begun in 1996, this prospective cohort study, which recruited IDU’s through self-referral and street outreach, revealed a baseline HIV prevalence of 23.2 percent [8]. A preliminary estimate of incidence was 18.6 per 100 person-years [8], higher than any other major city in North America [9].

It was once believed that the HIV epidemic among IDU’s in Vancouver was being curtailed with ambitious public health initiatives. Figures now point to a serious escalation in HIV infection rates, a trend that has been demonstrated earlier in other cities, where HIV prevalence among IDU’s doubled or tripled in a period as short as a year [10]. AIDS Vancouver, an agency that provides advocacy, counseling, support services and emergency
provisions, reports that 46 percent of their new clients in the second half of 1996 were current or past IDU's [11].

It is not clear why Vancouver is facing such a dramatic increase in HIV prevalence among its IDU's. However, it is speculated that the increased use of cocaine (which is associated with frequent injecting) and the development of a very geographically concentrated IDU community, which lends itself to the spread of HIV, may be contributing factors [9].

All of these figures point to a serious and ongoing HIV epidemic among Vancouver's IDU's, implying that IDU's will form the next wave of people who will eventually be dying from AIDS in this city. Such a trend has considerable implications for the allocation of future community and health care resources [12], including palliative care.

2.1.2 Demographics of IDU's

Chiswick et al [4] demonstrated that, in Edinburgh, IDU's were often unemployed, poorly educated, and lived in subsidized housing. In Vancouver, social determinants such as unstable housing were found to be independently associated with recent HIV seroconversion [8].

In British Columbia, IDU's with HIV/AIDS are more likely to be part of an ethnic minority than the general population [3,6]. For example, 19% of those reactive tests which reported an ethnicity were First Nations [6], whereas First Nations people only form 2.3 percent of the British Columbia population [13]. Strathdee et al also report that HIV positive IDU's in the VIDUS study were disproportionately of Native origin [8].

IDU's with HIV/AIDS are much more likely to be male, but overall in Canada, the proportion of HIV-positive IDU's that are female is rising [14]. Sixty-five percent of the
VIDUS study participants were male, but IDU’s testing HIV positive were more likely to be female [8]. Nationally, Aboriginal IDU’s with HIV/AIDS are, generally, more likely to be younger and female [14] than the general HIV positive IDU population.

2.1.3 Health Care Issues for IDU’s with HIV

Recent developments in pharmaceutical and other research has led to significant changes in the treatment and prognosis of AIDS. Many researchers and persons with HIV/AIDS are hopeful that the life span may now be dramatically increased, even to the point that AIDS may be managed as a chronic disease, as opposed to a terminal disease [15]. This new optimism is based on a medication regimen which requires a great deal of personal commitment and adherence to complex therapeutic regimens. As Hu points out, however, because IDU’s are more likely to be diagnosed with HIV late in disease progression or even at death, these new advances are rendered much less useful [16]. Berge and Hope add: “Antiretroviral agents can reduce viral load and decrease the risk of progression to AIDS and death. The high cost of these drugs together with the potential for low patient compliance and for the emergence of drug-resistant mutations of HIV represent obstacles to successful treatment” [17].

The costs for treating a person with HIV/AIDS are quite high, and increasing due to new pharmaceutical agents [17,18]. The costs for each case of HIV includes not only hospital and medical costs but also lost wages and personal suffering. Costs for AIDS in general and specifically in the last few months of life, are higher than other terminal conditions [19,20]. Health care at the end of life, regardless of disease, consumes 10-12 percent of the total American health care budget [21].
Stein reported that over the course of the disease, IDU's with AIDS had larger costs per hospitalization, longer lengths of stay, and had more frequent admissions than non-IDU's with AIDS in Rhode Island [22]. However, Twyman and Libbus disputed this in their study, which demonstrated that age, ethnicity, gender, cause of death, and AIDS risk factors such as injection drug use, were not associated with number of hospital days in the last six months of life [23].

The literature suggests that IDU's present unique situations to patient care in general. First of all, it is well-documented that health care professionals frequently have difficulty coping with IDU's, often due to patients' inability or unwillingness to comply with hospital routines [24,25], drug seeking behavior, and leaving against medical advice [26]. Conversely, a survey of injection drug users in Sweden reveals that many believe they are not treated well by the mainstream health care system, and therefore often do not trust health care workers [24]. Both situations may lead to disproportionate access to services, as evidenced in a study by Weisfuse et al [27] in New York, where 84% of men-who-have-sex-with-men received prophylactic drugs against opportunistic infections, contrasted with only 53% of IDU's.

In summary, as deaths amongst IDU's with HIV/AIDS increase in Vancouver, there will be a noticeable impact on the health care system. Addressing the economic, social and health services impact will need to be an ongoing priority.

2.1.4 Current HIV Prevention Strategies for IDU's

An understanding of non-medical drug use is essential. Drug use in its many forms has always been a part of society. Society's tolerance of non-medical drug use and the people
who engage in it has varied a great deal. For example, current societal values and laws reflect its intolerance for drug use such as cocaine and heroin, while other addictions, such as caffeine and alcohol are tolerated to a greater degree. HIV prevention strategies for IDUs cannot be examined outside the social and legal context of injection drug use.

The Netherlands has become well-known for its unique policies on drug use. The Dutch government has adopted a pragmatic or "nonmoralistic" approach to drug problems. Leuw and Marshall explain the Dutch philosophy as follows: "Prohibitionist policy assumes that drugs and addiction form an evil in itself, which can be purged from society by deterrence and by promoting total abstinence. Within the framework of Dutch drug policy, drug users are not held accountable for the social marginality, deterioration and degradation that accompanies deviant addiction. These adversities are understood as consequences of society's choice to prohibit the use of certain psychoactive substances" [28]. This pragmatic approach to the "problem of drugs" argues that the extent of a country's drug problems is a reflection of a society's moral priorities, the inequalities of its distribution of wealth among ethnic classes and the integrative inadequacies of its culture [28].

A core concept to the Dutch model and similar models dealing with drug use is harm reduction. The harm reduction approach tries to reduce problems associated with drug use and recognizes that abstinence may be neither a realistic nor desirable goal for some. Goals which reduce the harm of drug use, such as prevention of needle sharing to reduce the risk of HIV, are more immediate and pressing goals than abstinence [29]. In the Netherlands, harm reduction has meant extensive non-conditional methadone programs, social and medical assistance for drug users, large-scale free needle exchange programs and the acceptance of a
number of zones where the consumer drug market is left relatively undisturbed. Law enforcement is restricted to higher levels of the illegal drug trade [28].

Many harm reduction principles are now policy in Canada and Vancouver, including the use of methadone programs and needle exchange programs. The AIDS epidemic has been a catalyst for the incorporation of harm reduction strategies in North America [29]. However, a considerable amount of law enforcement resources are still used to fight the demand side of drugs, such as possession for individual use [30], making policies and practices in many Canadian cities seem contradictory. Alexander, a Vancouver researcher, adds to Leuw and Marshall’s analysis when he says “There is no good evidence that drugs cause any substantial part of the social pathology that is attributed to them. On the contrary, there is good evidence that social pathology causes destructive forms of drug use...Many historians believe that the war (on drugs) emerged primarily because drugs became a scapegoat for social problems” [30].

The importance of the concept of harm reduction in regards to HIV/AIDS becomes apparent in the face of evidence that harm reduction practices may lead to reduction in HIV infection rates. Studies from Great Britain show that HIV incidence among IDU’s in areas (e.g. Merseyside) where harm reduction practices (including the decriminalization of drugs for personal use) are similar to those in the Netherlands, is much lower than other British cities where harm reduction policies have not been instituted [29].

Harm reduction practices, such as needle exchange programs, have not been shown to lead to an increase in injection drug use [31,32,33]. It is interesting to note that marijuana
use has declined steadily in the Netherlands since its de facto legalization in the 1970's. Marijuana use in the Netherlands is now lower than use in Canada [30].

The lack of needle exchange programs in the United States may be associated with high HIV infection rates among IDU's in many American cities [34]. However, this does not explain why Vancouver, with a large needle exchange program, currently has the highest incidence rate of HIV infection among IDU's in North America. Strathdee et al suggest that needle exchange, in itself, is no longer adequate to curb the escalating prevalence of HIV in Vancouver. Additional harm reduction strategies need to be bolstered to reduce HIV transmission among IDU populations [8].

Methadone programs form another integral part of the harm reduction model. Methadone, a laboratory-made opiate, has the same chemical properties as heroin and produces relatively the same effects for the consumer [30]. Methadone is prescribed and monitored by a physician and is taken daily in an oral form. The availability of methadone can dramatically reduce the chaotic nature of a lifestyle that is dependent on getting unreliable drugs from an unreliable source requiring large amounts of money. “Thousands of addicts have reduced their reliance on illegal drugs, their participation in crime, their dependence on welfare payments and their ill-health when provided with a reliable supply of methadone through their doctor or a methadone clinic” [35]. Most importantly, methadone liberates the addicted person from having to use syringes, thereby greatly reducing the chances of contracting HIV [36]. Another advantage of methadone over street heroin is the avoidance of impurities. Alexander states that while there are no known irreversible side effects of
opiate drugs, impurities found in street opiates such as heroin have many potentially harmful side effects [30].

British Columbia is well-known for its methadone program. Eighty-five percent of Canada’s methadone clients live in British Columbia, which also was the first North American jurisdiction to use methadone in the 1950’s [31]. In 1996, the province-wide program had a registration of 1800 clients who were managed by 250 physicians [31]. However, access to methadone may still be a problem for some IDU’s, as only a handful of the 250 prescribing physicians practice in the vicinity of Vancouver’s Downtown Eastside [37], where most of Vancouver’s IDU’s are concentrated [8].

Another form of drug therapy for people addicted to drugs is treatment programs. Unlike a methadone program, a treatment program, utilizing behavior modification, behavior modeling and/or counseling practices [38] usually aims for complete and permanent abstinence. Such rehabilitation programs are not part of the harm reduction model. Treatment programs are costly and subsidized by government; however, whether or not they are able to rehabilitate the client is a matter of debate. The strategies of conventional drug treatment programs have come under scrutiny due to their alleged ineffectiveness. Several well-controlled studies have reported that recovery rates for people addicted to heroin are generally no better than the rates of natural recovery without professional treatment [39, 40]. Some of the more non-traditional rehabilitation programs may have better success rates, but they are usually so expensive and impractical on a large scale, that they could never play any significant part in the amelioration of widespread addiction [30].
There are various options for an IDU in Vancouver seeking drug treatment with the intention of abstinence. These include outpatient counseling services, residential treatment programs, and support groups such as Narcotics Anonymous or Cocaine Anonymous.

There are two outpatient counseling services (but no residential treatment programs) in Vancouver which are culturally specific to Aboriginal people, and two residential treatment programs which are specific to women. Waiting lists for residential treatment programs vary from two weeks to several months [38]. Participation in any of the forms of treatment may be via self-referral or medical referral or may be a condition of parole [38].

2.1.5 Drug Use

It is estimated that there are between 10,000 and 15,000 injection drugs users in British Columbia [31]. Heroin and cocaine are the drugs of choice, and are sometimes mixed together to form what is called a speedball [31]. Strathdee et al found that in Vancouver’s Downtown Eastside, 64% of IDU’s reported cocaine as drug of choice, compared to 25% for heroin [8]. Cocaine is the drug of choice in other Canadian cities, such as Toronto and Montreal [9].

In recent years, the number of overdoses has risen significantly in Vancouver, due to a rise in the potency of street heroin. For example, In February, 1996 alone, twelve IDU’s in Vancouver died of overdoses related to a particularly powerful batch of heroin [31]. In his report into illicit overdose deaths in British Columbia, the provincial coroner recommended that, in light of the failure of the war on drugs and the vast human costs associated with drug
overdoses, amendments to legislation governing controls over illicit drugs should be made [41]. However, none have been made to date.

The medical model has often been used to explain drug addiction. The medical model stresses that addiction is a disease, and may have biological and genetic factors. While the medical model may be helpful in that it takes the blame away from the afflicted individual, it still attributes many social problems to the addiction [30].

An alternative model is called the Adaptive Model. According to this model, negative addiction is seen as a way people adapt to serious problems if they can find no better solution. In other words, the cause of the addiction is not a drug, but a situation so dire that addiction is the most adaptive response a person can muster [30]. Understanding that addiction is not a disease of the individual is an integral part of the harm reduction model [28]. And while many researchers assert that addictions are found in all socioeconomic groups, the fact cannot be escaped that addictions are much more common among the poor and disenfranchised [28]. It is clear that educational, economic and social realities may limit coping choices.

The percentage of IDU’s in Vancouver who are infected with HIV who continue to use injected drugs until the time of death is not known. It is also unknown how using injected drugs until time of death might be associated with location of death or access to end-of-life services. It was demonstrated in Edinburgh, however, that 50% of HIV patients infected through sharing injection equipment were no longer using drugs by the time of death [42].
2.1.6 HIV Illness and IDU’s

Evidence suggests that IDU’s generally do not live as long as other groups with HIV/AIDS, and that IDU’s die prematurely from many causes that are not directly associated with HIV. In a study by van Haastrecht et al in Amsterdam [43], a comparison was done between AIDS deaths among HIV-positive IDU’s and HIV-positive gay men. The results showed that while 20 percent of the IDU’s died before an AIDS diagnosis was made, only 0.7 percent of gay men died before an AIDS diagnosis.

Small reports that poverty appears to have an impact on both the rates of infection and its speed of progression [44]. However, Chaisson et al found that in Baltimore, there was no relation between disease progression and injection drug use. Slower disease progression was associated, however, with use of antiretroviral therapy, age, and having a job at time of HIV diagnosis [45].

Van Haastrecht et al found that only 38 percent of deaths of IDU’s infected with HIV occurred after an AIDS diagnosis was made [46]. In other words, the majority died of unrelated causes. Their study also revealed that being HIV positive was associated with an increased risk of death for IDU’s from all causes, including suicide and overdose. Similar results were found in Italy, where Goedert et al reported that in a cohort of 253 HIV positive IDU’s, only 60 percent died of AIDS-related causes [47]. About 25 percent died of drug overdoses and 15 percent died from trauma. They found that mortality was increased for causes such as trauma, overdose, bacterial infections, hepatitis and cirrhosis for HIV positive IDU’s, compared to HIV negative IDU’s. Zaccarelli et al’s results correspond, as they also found higher death rates due to overdose and endocarditis in HIV positive IDU’s [48].
In another Italian study involving a cohort of IDU’s followed from 1980 to 1991, it was reported that overdose was the number one cause of death, followed by AIDS [49]. Robertson et al found that the pattern of deaths changed as the AIDS epidemic progressed. It was noted in Edinburgh, that overdose was the main cause of death in the early 1980’s, but it shifted to AIDS by the late 1980’s [50].

Comparisons of HIV illness between male and female IDU’s have been reported in several studies. Cozzi et al found little evidence for appreciable differences in HIV progression between men and women [51]. Similar results were found by Brettle et al in Edinburgh [52]. Some of the studies cited suggest that HIV disease can affect the outcome of unrelated diseases, such as hepatitis and endocarditis. However, more research is needed in this area. Mai et al studied a cohort of gay men to determine whether HIV status or HIV treatments affected the progression of hepatitis B disease. However, they found no difference between HIV positive and negative subjects [53].

Bell et al found that HIV encephalitis rates were much higher in IDU’s than in gay men (59% versus 15%) [54]. Encephalitis resulted in cognitive impairment for 88 percent of the patients. It was also reported that prolonged zidovudine treatment was associated with decreased incidence of HIV encephalitis [54].

Another cause of death common among HIV positive IDU’s is suicide. Higher suicide rates transcend HIV risk category [55] and are associated with other terminal illnesses, such as cancer [56]. Mancoske et al’s study in Louisiana found that people suffering from AIDS (from all risk categories) had a suicide rate of 175 per 10,000, compared to the general population rate of 1.3 per 10,000 [57].
Starace acknowledges that suicide seems to be more frequent among people with HIV/AIDS than in the general population, but cautions on any interpretation because an increased risk of suicide has been found in high risk categories such as gay men and IDU's regardless of HIV infection [58]. However, van Haastrecht's study, cited earlier, seems to show that for IDU's, at least, being HIV-positive is associated with a higher risk for suicide [46].

The reasons that HIV positive IDU's commit suicide are varied. They may include inability to cope with changes associated with terminal disease, such as pain, isolation, or loss of independence. The act may be a planned peaceful event or spontaneous; carried out in isolation, or with the help and support of friends.

Assisted suicide among gay men dying with AIDS in Vancouver was documented by Ogden [59]. Ogden interviewed individuals who had participated in or were witness to assisted suicides. In the hope of alleviating the pain and suffering of a friend or partner, many individuals performed euthanasia in the face of legal ramifications, lack of social and professional support, and without knowledge and experience in assisting someone to die. In light of these conditions, many of the deaths were not peaceful at all, but led to protracted suffering of the person with AIDS, and the lack of opportunity for the assistant to talk about the incident or receive emotional support after it was over.

Ogden summarized the characteristics of an individual who might seek out an assisted suicide: a clear understanding of HIV disease progression and the limits of therapy, careful monitoring of drug therapies and treatment of opportunistic infections, strong social support,
and knowledge of and access to lethal drug combinations [59]. These characteristics are in contrast with the often chaotic lifestyle of the IDU [4, 7].

Mental illness and HIV/AIDS is another issue which has warranted study. Research from the United States and Brazil indicates that psychiatric conditions are associated with increased risk behavior for acquiring HIV [61, 62, 63] and increased HIV prevalence [64, 65]. Psychiatric illness was also associated with poorer disease prognosis among HIV positive individuals [55].

2.2 Palliative Care

2.2.1 Overview

"Where death takes place and how it is handled reflect societal values and priorities" [66]. Location and circumstances of death have changed dramatically in our society during the twentieth century. In response to many medical and social changes, palliative medicine has emerged as a unique branch of health care.

Palliative care is that branch of health care devoted to the terminal period of life. Palliative care shifts the overall management of a patient from cure to comfort and quality of life. The Canadian Palliative Care Association has defined it as “the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with, or dying from, a progressive life threatening illness, or who are bereaved [67]. The World Health Organization envisions palliative care to affirm life and regard dying as a
normal process, to neither hasten nor postpone death, to integrate psychosocial and spiritual aspects into patient care, and to provide relief from pain and other distressing symptoms [68].

The BC Hospice/Palliative Care Association describes the various components of palliative care as follows: pain and other symptom control, spiritual care, bereavement, education, evaluation/research, and volunteer involvement [69]. Palliative care philosophy recognizes that treatment can be delivered in a variety of settings, but that creating a “home” environment is necessary for proper care [70].

Palliative care may be viewed by some as “anti-technology”. It may also be viewed by those with a limited understanding of conventional health services, due to language, cultural or educational barriers, as a push to less expensive care, or as an indication of “giving up on a person” [71]. Problems arise when both care provider and recipient might interpret the conclusion that “nothing more can be done about the disease” as “nothing more can be done for the patient” [72]. Even health care professionals may view palliative care as a failure of active care [73]. In reality, palliative treatment may occasionally use high technology to help manage a patient’s pain or symptoms, and palliative care knowledge is considered a specialty in both medicine and nursing.

The premise of palliative care has been practiced throughout the centuries and in many different cultures. However, in Western conventional medicine, it only experienced a rebirth with the groundbreaking work of Dr. Elisabeth Kubler-Ross and Dr. Cicely Saunders [74]. Palliative care was officially reborn in the western world with the opening of St. Christopher’s Hospice in London, England in 1967, founded by Saunders [44]. The first official palliative care centres opened in Canada in 1975, as special units in hospitals in
Winnipeg and Montreal [75]. Since this time, there has been an upsurge in the awareness of and response to the needs of the terminally ill [70].

In Vancouver, palliative care services are offered in a variety of settings, including two free-standing hospices (May's Place and Normandy House), two palliative care units (PCU's) at each of two hospitals (St. Paul's Hospital and Vancouver General Hospital), and at home, through Vancouver/Richmond Health Board's home care program.

Palliative services may also be offered in an acute care setting, such as a hospital medical ward. Due to waiting lists for hospice or PCU placement, this is often the only option. Whether or not palliative services offered on an acute medical ward can achieve the optimal "home" environment, or are equivalent to those in a hospice or PCU is a matter of debate. A hospice or PCU is generally considered to be more flexible than an acute medical ward, and offers the terminally ill individual more autonomy [76], and a more home-like setting [77]. The expertise of specially trained medical and nursing staff ideally contributes to superior pain and other symptom management.

Population surveys consistently show that people faced with terminal illness prefer to die at home [77, 78] or in a home-like environment, such as a PCU or hospice [79]. In reality, the majority of Canadians with terminal illnesses die in hospital without palliative care services. Only ten percent of Canadians with cancer receive palliative care [75], and less than five percent of Canadians with all terminal illnesses receive palliative care. Although it is difficult to compare different studies because of inconsistent definitions, the Canadian rates compare poorly with Great Britain, where 25 percent of cancer patients receive palliative care.
Per capita, Canada has only 40 percent of the palliative care beds that Great Britain has.

Palliative care may be advantageous for people with terminal conditions not only because it offers improved care, but also because of associated health care cost savings, which may be as high as 25 to 40 percent in the last month of life [21].

2.2.2 AIDS and Palliative Care

Currently AIDS is still considered a terminal disease [81], and therefore palliative care should be an integral part of the overall health services for a person with AIDS.

In comparison to other people with other terminal conditions, people with AIDS present unique challenges and require specific care when it comes to palliative services [82, 83, 84]. Betrutti states: “The problem of pain and suffering in the terminal phase of illness such as AIDS has not received adequate attention and has not been given valid solutions” [85]. Small goes further by saying that the style and nature of hospice regimes may have to respond to IDU’s, as their numbers will continue to grow [44].

AIDS care challenges the traditional trajectory of palliative care developed for individuals with cancer, where, in the past, a distinct separation existed between active, aggressive care and the shift to palliative care. The division between acute and palliative care for an individual with AIDS is much less distinct, as preparation for dying might begin with HIV diagnosis, and acute invasive medicine (e.g. TPN or total parenteral nutrition) may occur at or near time of death [86]. The Canadian Expert Working Group on palliative care and AIDS believes that palliative aims must begin at diagnosis and be integrated with aggressive aims to provide optimal care [69].
The location where a person with AIDS dies can depend on the availability of health services, support systems, personal attitudes and preferences, and nature and course of the illness. From 1987-1991 in Vancouver, the proportion of people with AIDS (from all risk categories) dying at home was 25 to 32 percent. This percentage steadily dropped afterwards, reaching 11 percent in 1993 [79]. The proportion of people who preferred to die at home, however, remained constant at 40% [79]. In comparison, a study from Seattle indicated that the proportion of people with AIDS (from all risk categories) dying at home increased significantly from 1984 to 1988, from 11% to 28% [87]. According to the authors, the increase appeared to be related to a corresponding expansion of community-based health and social services, which allowed more people with AIDS to die at home.

The trend towards increasing numbers of individuals with HIV/AIDS dying in hospital in Vancouver, as opposed to home, needs further exploration. It is not known how IDU’s fit into this trend. It may be, as suggested by the Seattle study, that community resources do not match current needs. Canadian experts have identified that community services, such as home care, to assist people with AIDS to die at home may be lacking [88]. It may be related to the fact that conditions surrounding the individuals who are dying with AIDS are different now than they were ten years ago. Factors suggested by Goldstone et al, such as loss of partners due to HIV/AIDS, longer life span with difficult symptom management, exhaustion of caregivers, and confidence in the hospital palliative care units may all be contributing to the shift in location of death for people with HIV/AIDS [79].

Another suggestion to explain the trend towards hospital-based versus home-based deaths is the changing demographics of AIDS, from an essentially middle-class gay disease to a
disease of the poor and marginalized. A study in England and Wales revealed that by the end of 1987, 18 percent of gay and bisexual men had died at home, compared with 9 percent of IDU’s [89]. Many palliative care experts are currently addressing the concern that palliative services appear to be utilized almost exclusively by middle class people [75, 76]. If, in fact, AIDS is becoming a disease of poverty, an understandable trend away from palliative services may be taking place. Van Bommel adds that the majority of the professional caregivers and volunteers are also white and middle class, which may add to the alienation [75].

An additional explanation might be that many IDU’s are not dying with end-stage AIDS, as is suggested by studies mentioned earlier, but rather with other acute conditions such as trauma, suicide, or infections related to other illnesses secondary to non-sterile injection practices, as opposed to decreased immunity. The number of cases of AIDS in IDU’s reported to BCCDC for the entire province has dropped from 22 in 1994 to only 8 in 1996, in spite of the fact that other evidence points to a worsening of the epidemic [6]. This might be explained by underreporting or a lag time in reporting, or it may be due to the fact that HIV positive IDU’s are dying before advancing to the stage of AIDS.

2.2.3 Death, Palliative Care and Society

It is pertinent to consider possible explanations of why, first of all, palliative care came about so recently, and second of all, why more people with terminal conditions such as AIDS do not seem to access adequate palliative care. Two ideas will be explored.

The first area which needs to be examined is our societal view of death. Death has become the great taboo subject of our age [44]. Aries argues that western civilization has come to conceal death like Victorian England concealed sex [90]. Talk of death is seen to be
morbid. When Elisabeth Kubler-Ross began a project in the late 1960’s which involved discussing death with people who were dying in hospital wards, she was unable to get the cooperation of the doctors and nurses. Her requests were taken as extremely odd, unprofessional and unethical by staff, but patients cooperated overwhelmingly, with less than 2% of the questioned patients refusing to participate [91]. One of Kubler-Ross’ most valuable lessons from her extensive research in death and dying is summed up as follows: “We have learned that for the patient, death itself is not the problem, but dying is feared because of the accompanying sense of hopelessness, helplessness, and isolation” [92].

Ernest Becker, a philosopher and sociologist, discusses the subject in his book Denial of Death. He writes: “Of all things that move man, one of the principle things is his terror of death” [92]. Becker argues that this fear is inherent and universal and is the tragic result of being the only creature on earth that is consciously aware of his/her own mortality. Humans are unique in that they are able to tower above the rest of nature, yet inevitably return to it as “food for worms” [92]. The result of this fear is denial, which manifests itself in many areas of life, including the delivery of health care, and the refusal to acknowledge that one’s condition is terminal. Kubler-Ross talks much of the various stages of death and dying, one of them being denial [91]. Many patients are unable to move beyond this stage. She also noticed that terminal patients showed the greatest confidence in the doctors who allowed for hope for a cure, regardless of how dire their condition was [91].

Ahmedzai, a physician, reflects that it has become less common to say that an elderly person has died of old age. “Nearly always we identify a medical diagnosis, and the assumption is that the person has died from a disease, despite medical intervention” [93].
The second area of consideration is the medicalization of death, which stems from the exponential rise of technology in western medicine. Technology has dramatically changed the delivery of health care in western countries such as Canada, and has positively contributed to our significantly improved life expectancy. However, one of the spin-offs of burgeoning technology is that terminally ill people who are severely disabled can be kept alive long after they would have died otherwise. The point of death is now often difficult to determine. "The more we are making advancements in science, the more we seem to fear and deny the reality of death." [91]. In addition, another one of the dilemmas of our high-cost, medical-model health care system is that people increasingly receive more and more services simply because these services exist [75]. Konigova writes: "Advances in medicine have brought immense possibilities in therapy but at a price including tremendous financial costs and also protracted human suffering" [94].

Kubler-Ross argues that one of the most devastating results of increased technology is the way people are dying: in lonely, dehumanized and mechanical environments, away from anything familiar and comfortable [91].

In spite of Kubler-Ross's exploration of denial as a stage in terminal illness, she also reports the following: "We have seen several patients who were depressed and morbidly uncommunicative until we spoke with them about the terminal stage of their illness. Their spirits were lightened, they began to eat again, and a few of them were discharged once more, much to the surprise of their families and the medical staff. I am convinced that we do more harm by avoiding the issue than by using time to sit, listen, and share" [91].
The societal views of death and the use of expensive life-prolonging technology in the care of terminally ill individuals have not gone unchallenged. The AIDS epidemic, in addition to bringing to light many human rights issues, has exposed numerous problems with the care of the terminally ill. Russel Ogden’s exposure of the desperate and often unsuccessful attempts of persons with AIDS to achieve a peaceful and dignified death revealed the lack of adequate services and support offered to them by the mainstream health care system. The 1990’s witnessed numerous challenges to society’s views of and treatment of terminal illness, including the nationally highlighted case of Sue Rodriguez, who brought her struggles for the right to assisted suicide to the Supreme Court of Canada [93]. This culminated in the Special Senate Committee on Euthanasia and Assisted Suicide, a response to the ongoing issue of an individual’s right to be in control of their lives, including their death, and to be guaranteed dignity and the ability to refuse treatment. Locally, the BC Persons with AIDS Society ratified a position statement in 1994 calling for the legalization of assisted suicide, in order to provide real choices for persons with AIDS facing death, and as a necessary alternative to the “backstreet euthanasia”, which people were practicing out of desperation. [96].

The evolution of palliative care in Canada has been shaped by the numerous issues in the preceding discussion. The delivery of palliative care has fallen short of the goals set out by Higginson: effectiveness, acceptability, accessibility and efficiency [97]. Today, palliative care is facing a new challenge: IDU’s dying with HIV/AIDS. Insight is needed into how IDU’s might utilize existing palliative care services and how those services might be modified to respond to the unique needs of IDU’s.
The future of palliative care for IDU’s with HIV/AIDS remains unknown and uncertain. Small believes that the style and nature of hospice or palliative care need to respond to IDU’s [44]. Higginson adds that because people who are imminently dying cannot complain about poor care, and because time is limited for testing care or postponing care “perhaps more than in any other aspect of health or social care, quality of care for people who are dying must be a priority” [97].

2.3 Conclusion

A review of the literature and the current situation in Vancouver regarding IDU’s and AIDS has raised many important issues concerning the provision of end-of-life services. To summarize, the coming years in Vancouver will see a dramatic increase in IDU’s dying with HIV/AIDS, and therefore requiring end-of-life or palliative services. Provision of these services may be complicated by lack of harmony between health care services and IDU’s needs, by society’s difficulty in dealing appropriately with terminal illness and death, and by the lack of understanding of the unique patterns of end-of-life service utilization by IDU’s. Additional issues include the increasing costs associated with treating HIV disease as well as the poverty and marginalization experienced by the IDU community.

It is within this context that the following study is placed. The literature and current situation in Vancouver form the basis for a descriptive analysis of the utilization patterns of end-of-life services of IDU’s who died with HIV/AIDS in Vancouver. This study will primarily look at where IDU’s with HIV/AIDS are dying, and what type of services they are
utilizing at the end of life. Secondly, the study will examine aspects such as demographic data, utilization of community and hospital services once HIV-positive, and drug use at time of death. A third aspect of the study is a "testing out" of the methodological tools (such as hospital and community data bases) utilized. No data base on deaths of IDU’s with HIV/AIDS in Vancouver existed prior to this study. The exercise of creating one, by utilizing and comparing a number of distinct and varied information sources will, consequently, be an assessment of the information sources themselves.

In conclusion, an effort to determine where IDU’s with HIV/AIDS are dying in Vancouver would be important. The study would help determine the health services utilization patterns of this subgroup, the effectiveness of community-based health services, and the need to design and implement future palliative care services for IDU’s. Because the spread of HIV/AIDS among IDU’s will likely continue, it is necessary, both financially and ethically, to understand and to plan for the adjustments in the health care needs of people in this unique subgroup.
3. Methodology

This study is a descriptive, retrospective chart review. Utilizing this approach has the advantages of accessing a large volume of valuable information with minimal risk to subjects [98], and being able to identify specific areas of concern or focus [99]. This study lends itself to hypothesis generation rather than hypothesis testing.

3.1 Setting

The setting for the study is the city of Vancouver. The city of Vancouver and its suburbs account for 78 percent of British Columbia’s AIDS cases [6]. While precise figures are not available, Vancouver’s Downtown Eastside probably holds British Columbia’s largest concentration of IDU’s. Sixty-five percent of participants of the Vancouver Injection Drug Use Study reported this neighborhood as home [9]. Vancouver’s needle exchange program is the largest one in North America in terms of volume of needles exchanged [8].

The IDU community in Vancouver is in the midst of an AIDS epidemic [8] and is experiencing changing patterns of injection drug use (i.e. more cocaine use), and worsening poverty and homelessness [100].

3.2 Time Frame and Sample Size

Before data collection began, it was hoped that documentation of death could be found for at least 100 IDU’s who died with HIV/AIDS. A sample size of this magnitude would allow one to determine estimates about the characteristics of this population with a reasonable degree of statistical confidence.
Because no accurate information existed as to how many IDU’s with HIV/AIDS died in Vancouver in recent years, it was impossible to pre-determine how long a time frame was necessary to provide at least 100 IDU deaths. In order to gain a slightly better estimation of the number of deaths, a preliminary search at St. Paul’s Hospital was done. A list of deaths, cross-matching ICD-9 coding on hospital death summaries for drug abuse/dependence (304.0, 304.7, 305.5, 305.6) and being HIV positive (042.0 - 042.9) [101], generated a list of 40 IDU’s with HIV/AIDS who died at St. Paul’s Hospital from 1990 to 1996. Based on this finding, it was estimated that approximately 100 deaths of IDU’s with HIV/AIDS in the entire city of Vancouver could be located between the years of 1991 to 1996. (1990 was dropped because there was only one death identified during this year).

3.3 Ethical and Academic Screening

Prior to data collection, the study proposal went through two review processes. The first process was the Thesis Screening Panel, where the study proposal was presented and defended before a panel of researchers from the department of Health Care and Epidemiology at University of British Columbia. The purpose of the process was to ensure the research was carried out with sound scientific and methodological principles. Recommendations from the panel were considered and incorporated into the proposal by the researcher and the researcher’s thesis committee.

The second process was University of British Columbia’s Ethical Review Board. The thesis proposal was reviewed in order to ensure that ethical principles, such as
confidentiality, were not violated. Ethical approval was also applied for and granted by St. Paul's Hospital and Vancouver General Hospital Research Committees.

3.4 Data Collection

Two separate groups of data sources were utilized. The first group of data sources, presented in Table 1, was used to locate the IDU's who died with HIV/AIDS in Vancouver from 1991-1996. The result of the first step in data collection was the creation of a complete data base for all deaths of IDU's in the study years, consisting of 121 individuals. The second group of data sources, presented in Table 2, was used to collect data on the demographic, behavioural, health care utilization and end-of-life variables for the 121 IDU's. A detailed description of the two data sources and data collection components are described below.

All information from the various sources was collected by the researcher, except for data from Vancouver/Richmond Health Board.

3.4.1 Part One: Creation of a Data Base for IDU Deaths

No central data base for HIV/AIDS deaths in IDU's existed in Vancouver. An important methodological consideration, therefore, was to determine how to locate all IDU's who died in Vancouver from 1991 to 1996. Missing a significant portion could have easily biased the study sample. Of special consideration was the potential to miss IDU's who were significantly street-entrenched and did not seek health care at any of the conventional locations. Street-entrenched individuals may not have sought health care for a variety of reasons, including mistrust of authority figures, denial of symptoms, or chaotic
lifestyle. However, based on informal interviews with a convenience sample of front-line health care and community workers involved with street entrenched IDU’s, there was consensus that at some point in the course of being HIV positive, most IDU’s did make contact with the health care system and therefore would be located through the study’s data sources. The adaptation of health care services in Vancouver, such as utilizing street outreach nurses, to meet the health care needs and of IDU’s has most likely significantly increased contact.

Seven different data sources were utilized in the creation of the IDU death registry (see Table 1), including hospital data bases, community organization records, and front-line workers. It was anticipated that a sizable degree of overlap of cases among the seven sources would occur. Significant overlap of identified cases might have indicated that most IDU’s were, in fact, being identified. It was believed that utilizing seven different sources would decrease the probability that IDU’s who died with HIV/AIDS would be missed.

Table 1 displays the number of IDU’s that were located through each data source. St. Paul’s Hospital Medical Records and AIDS Care Rounds (defined next page) were the major sources. The table also reveals that there was a substantial amount of overlap among the various sources. For example, all the IDU’s that were identified through the AIDS social worker at Vancouver Hospital had already been identified through other sources.
Data Sources for Creating IDU Data Base

The method for collecting the 121 cases consisted of several different forms. The various methods are described below.

**St. Paul's and Vancouver General Hospitals.** Medical Records personnel carried out computer searches matching ICD-9 (International Coding for Diseases) codes for drug abuse and HIV disease. Two searches were completed. The first one used death summaries for matching HIV and drug abuse ICD codes. The second computer search used discharge summaries (where the patient was discharged from hospital alive), and the ICD codes. Patients whose discharge summaries were found to have ICD codes for both HIV disease and drug abuse were then checked (via medical records computer search) to see whether they had since died.

**May's Place.** May's Place is a community hospice in Vancouver's Downtown Eastside. Direct service workers who were familiar with past residents of the hospice identified IDU's who died with HIV/AIDS.

**AIDS Care Rounds.** AIDS Care Rounds is a weekly gathering of St. Paul's Hospital physicians, community physicians, and other professionals working with individuals with HIV/AIDS, to review and coordinate care. Patients who have died with HIV/AIDS are usually discussed. The researcher reviewed the weekly written summaries for the entire time period under study.

**Vancouver Native Health Society.** This medical and outreach clinic in the Downtown Eastside provides care to a number of IDU's. The researcher met with the outreach nurse,
who reviewed the death record of NHS clients, and, from her documentation, identified
which clients were IDU’s who died with HIV/AIDS.

**AIDS Vancouver.** AIDS Vancouver is a community advocacy organization for people
with HIV/AIDS. Its services include education, counseling, support, and emergency food
and financial aid. The researcher reviewed client intake records, which included
information on an individual’s risk factors.

**Vancouver General Hospital AIDS Social Worker.** The AIDS social worker has the
mandate to work with all people with AIDS who were either admitted to the hospital or
who visited the emergency department. Her personal records were reviewed by the
researcher in order to locate IDU’s with HIV/AIDS.

Not all seven sources for locating IDU’s who died with HIV/AIDS had information
available for the entire study period (1991 to 1996). For example, the computer search at
St. Paul’s Hospital extended only to November, 1996, and the search at Vancouver
General Hospital extended only to October, 1996. Because of the delay of record
inputting into the computer systems, these limitations were inevitable, as data collection
was carried out in the early months of 1997. Also, information from Vancouver Native
Health Society dated back only to May, 1995, when the current outreach nurse’s
employment began. The information from the AIDS social worker at Vancouver Hospital
was also limited by her length of employment, which began in June, 1995. The other three
sources covered the entire period from January 1, 1991 to December 31, 1996.
Inclusion Criteria

There were four criteria used to determine whether an individual was to be included in the IDU death registry for the study: past or present injection drug use, diagnosis of being HIV positive, having died in the city of Vancouver, and having died between 1991 and 1996.

The first inclusion criterion to include a death in the data base was injection drug use. Since this study examined retrospective material that was recorded by other people, the definition, in essence, depended on those who recorded the material. For example, an individual was included if a physician, nurse, social worker, or intake worker defined that person as an IDU in their chart or medical record. Defining someone as an IDU was usually only done after the individual disclosed his/her drug use to a health care worker, but an individual could also have been defined as an IDU by evidence such as needle marks on the arms or legs, or by finding syringes on a person who also showed signs of drug intoxication.

For the definition of injection drug use, the following methods were used to include/exclude an individual. From the seven sources mentioned above, 158 potential IDU’s were identified. These 158 cases were placed into one of two categories: confirmed IDU’s (n=91) and suspected IDU’s (n=67). In Part 2 (gathering data on the variables) more detailed information was examined in order to determine whether suspected IDU’s were, in fact, IDU’s.
Confirmed IDU’s. A Confirmed IDU was an individual who was explicitly defined by at least one of the above seven sources as an IDU, whether or not their medical records made mention of injection drug use.

There was only one individual who was explicitly identified as an IDU by two sources, but denied having ever used injection drugs according to his hospital chart. This person was still included because two of the seven sources, including one direct service worker, confirmed this individual was an IDU.

Suspected IDU’s. A suspected IDU was an individual who was not explicitly identified but rather suspected. For example, the computer searches of hospital medical records using ICD codes identified all individuals with drug abuse in general. This could (and did) include drug abuse such as alcoholism. Therefore, individuals identified in this manner were categorized only as suspect and their injection drug use had to be verified by the individual’s medical chart. Therefore, unlike a certain IDU, if an individual was suspected as an IDU, but their medical records made no mention of injection drug use, the individual was excluded.

Another example of a suspected IDU was an individual whom a direct service worker suspected (but was not certain) of being an IDU. Again, if the individual’s injection drug use was not verified by their medical records, he/she was excluded.

A second inclusion criterion was being HIV positive. All deaths of HIV positive IDU’s were included in the study, including, but not limited to those who died of AIDS.
A third inclusion criterion for the study was that all HIV positive IDU’s had to have died in the city of Vancouver. IDU’s who lived in Vancouver but eventually went back to their home towns to die were not included because it was not feasible to collect information from other geographic locations.

In summary, 121 of the original 158 potential IDU’s were included in the study. Thirty seven individuals were excluded for the following reasons:

- 8 individuals died outside Vancouver
- 25 individuals were classified as non-IDU’s
- 4 were excluded because no information on them could be found.

The four individuals who were excluded because of lack of information were identified through AIDS Care Rounds. However, aside from their name and date of death, searches of records from hospitals, Vancouver Health Board, Coroner’s office, and all other sources could not locate any other information.

3.4.2 Part 2: Gathering Data on the Variables

Information such as demographics, location of death and utilization of palliative care, was collected by the researcher using a data collection tool (See Appendix 1). The tool consisted of 25 questions, under the topics of Demographics, HIV/AIDS, Conditions of Death, Service Utilization and Drug Use.

Pretesting was carried out on several hospital charts at St. Paul’s Hospital to assess the tool’s effectiveness. Modifications were made and the tool was then reviewed by several staff members at the BC Centre for Excellence in HIV/AIDS who had expertise in creating data collection tools in the area of HIV/AIDS.
All the data were collected by the researcher using the data collection tool. An exception to this was data from the Vancouver/Richmond Health Board (home care). The Vancouver/Richmond Health Board (VRHB) had a policy that only health department staff could access their medical records, which made using a second data collector (VRHB staff member) necessary. The data collection tool used for all other institutions was not used for VRHB data. A new tool, with only 17 questions was developed. The new tool was made much shorter and simpler as questions which were more subjective in value were removed to prevent problems with inter-rater reliability. In other words, because the VRHB data collector was not intimately familiar with the study and the data, it was decided to sacrifice information on less important variables for the sake of accuracy on the most important variables. In addition, because there were only six cases where information was collected from the VRHB, the smaller tool did not sacrifice much information. A copy of the data collection tool used for VRHB data can be found in Appendix 2.

Data Sources for Gathering Information on the Variables

The nine different information sources for collecting information on the 121 IDU’s who died with HIV/AIDS are listed in Table 2. The sources include records from hospitals, community hospices, Vancouver/Richmond Health Board Home Care, coroner’s office death summaries and the BC Centre for Excellence in HIV/AIDS Drug Treatment Program’s data base. A tenth anticipated source of information was the BC Methadone Treatment Program Data Base. However, access to this information was denied on the basis of confidentiality. Information from an eleventh source, the BC Linked Health Data
Base, which contained information on hospital and home care utilization, was not available by the time data analysis was completed.

Following completion of data collection, a number of variables, including intended place of death, education level, housing amenities and treatment for a psychiatric condition, were discarded as documentation was inadequate. Methadone use and hospital and home care utilization were also dropped because information, for aforementioned reasons, was not available.

Defining the Variables

Univariate, bivariate and multivariate analyses were carried out using the variables listed in Table 3. The following paragraphs describe the variables' operational definitions.

Injection drug use, as previously mentioned, included past or present use. An individual was defined as an IDU primarily by self-disclosure.

Categories for ethnicity/race were taken from Statistics Canada definitions [13] and included Aboriginal, Caucasian, Black and Hispanic.

For sex, it was necessary to include the category of “transgendered”. A person was defined as transgendered only if they defined themselves as such.

Housing was divided into five categories: single detached house, apartment/condo, hotel/rooming house, no fixed address, and prison. These were then collapsed into two broad categories: stable and unstable housing. Unstable housing was defined as not meeting basic shelter needs, such as cooking facilities and safety needs, and included hotel/rooming house and no fixed address.
For injection drug use at time of death, an attempt was made to categorize drug use by utilizing Alexander’s trajectory: abstinence, circumstantial use, recreational use, drug dependence and drug addiction [30]. However, during pretesting of the data collection tool, it became evident that the data sources did not provide adequate information to break down the variable into so many values. In the end, injection drug use at time of death was defined as a dichotomous variable: abstinent or not abstinent.

Living arrangements were defined as to whether an individual was living alone or with others, and were included as an indicator of social support.

Registration with AIDS Vancouver and the BC Centre for Excellence Drug Treatment Program were included as indicators of accessing community health resources. Utilization of home care services was to be included, but the data were unavailable.

Length of time between HIV diagnosis and death, and AIDS diagnosis and death were recorded as continuous variables, in number of months.

Location of death was broken down as hospital (not including PCU), community hospice and PCU, home, and other. Palliative Care Unit was included with hospice rather than hospital because the philosophy, environment and care in a PCU is more similar to the former.

The criteria for type of treatment was taken from the St. Paul’s Hospital AIDS Care Team [102] which is divided into three different possibilities:

1) Aggressive treatment with resuscitation as an option.

2) Aggressive therapy with a No-Code order written.
3) Palliative Care in which a No-Code order has been written and an order for palliative management has been written.

"No-Code" refers to the decision not to resuscitate a patient if cardiac arrest occurs. The decision to identify a person as a "No-Code" is usually based on the severity of the patient’s condition and his/her medical prognosis [93, 103]. The order is written by the physician, usually after consulting with the patient, family, and other members of the health care team. Unless the "No-Code order is explicitly written by the physician, an attempt to resuscitate the hospitalized patient is automatically made.

Cause of death was an open-ended variable. Following collection of the data, the variable was categorized into the following values: AIDS, overdose, liver disease, sepsis, trauma, suicide and other. One case trauma, and one case of drug overdose were classified separately as suicides, based on information from the data sources, and due to their importance to the study. Although other cases of drug overdose and trauma may have been suicides as well, information was inadequate to classify them as such.

For the purposes of analyzing associations between prognostic factors and accessing palliative care, the criteria for having received palliative care were defined in three different ways: receiving palliative treatment as defined by McLeod (i.e. a "No Code" order written and an order written for palliative care [102]); dying in a hospice or palliative care unit; and receiving palliative treatment (as defined by McLeod) for more than two days. Dying in a hospice or palliative care unit was utilized because of the literature's discussion on the qualitative differences between palliative care received in acute and palliative settings. Receiving palliative treatment for more than two days was
utilized in order to separate out those individuals who received palliative treatment for a very short period of time. A length of two days was chosen because it was the median length of palliative care received in the study sample.

3.5 Statistical Analysis

The descriptions and analyses were completed using SPSS (Statistical Package for the Social Sciences) computer software. The Chi-squared Test and Wilcoxon Sum Rank Test were used for the bivariate analyses.

In order to determine whether a variable independently predicted outcome, multiple logistic regression was used to explore the relationship between the receipt of palliative care and prognostic factors, using the three sets of criteria for palliative care. The only variables included were those that achieved a p-value less than .10 on univariate analysis. This criterion was used because of the relatively small number of cases and the frequency of missing data. Cases would not be included in the analysis if there were even a single missing variable.

The regression analyses were run two ways. In the first, backward regression was used whereby a full model was fit and variables were removed one at a time until only statistically significant variables remained. In the second approach, forward stepwise regression was used.
Table 1  Data Sources for Identifying Injection Drug Users (N=121)

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<th>SOURCE</th>
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</tr>
</thead>
<tbody>
<tr>
<td>1) St. Paul’s Hospital Medical Records</td>
<td>57</td>
<td>32</td>
</tr>
<tr>
<td>3) May’s Place</td>
<td>18</td>
<td>11</td>
</tr>
<tr>
<td>4) St. Paul’s Hosp. AIDS Care Rounds</td>
<td>48</td>
<td>20</td>
</tr>
<tr>
<td>5) Vancouver Native Health Society</td>
<td>20</td>
<td>5</td>
</tr>
<tr>
<td>6) AIDS Vancouver</td>
<td>19</td>
<td>7</td>
</tr>
<tr>
<td>7) Vancouver Gen. Hosp. Social Worker</td>
<td>7</td>
<td>0</td>
</tr>
</tbody>
</table>

*This column adds up to more than 121 because of the overlap of cases found at the various locations.

**This column adds up to less than 121 because those cases which were found in more than one location do not appear in this column.
Table 2 Data Sources for Gathering Information on the Variables

1) St. Paul's Hospital: Medical Records
2) Vancouver General Hospital: Medical Records
3) May's Place: Client Records
4) Normandy Hospital Special Care Unit: Client Records
5) BC Coroner's Office: Death Summaries
6) Vancouver/Richmond Health Board: Client Records
7) AIDS Vancouver: Client Records
8) Vancouver General Hospital AIDS Social Worker: Client Records
9) BC Centre for Excellence in HIV/AIDS: Drug Treatment Program Data Base
Table 3  Summary of the Variables for Univariate and Bivariate Analysis

I. Univariate Analysis

A. Demographics
   Age
   Sex
   Race/Ethnicity
   Housing
   Living arrangements
   Income source
   Risk factors in addition to injection drug use
   Type of injection drug use
   Membership in AIDS Vancouver
   Use of antiretroviral therapy
   Use of a family physician

B. Summary of Deaths
   Year of death
   Location of death
   Type of care at death
   Cause of death
   Injection drug use at time of death
   AIDS diagnosis by time and death
   Length between HIV diagnosis and death
   Length between AIDS diagnosis and death

II. Bivariate Analysis

A. Demographics
   1. Sex and:
      i) Age
      ii) Abstinence from injection drug use
      iii) Cause of death
      iv) Race/Ethnicity

   2. Age and
      i) Race/Ethnicity
Table 3 Summary of the Variables (cont’d)

B. Comparison of IDU’s with and without AIDS Diagnosis and Location of Death

C. Comparison of Prognostic Factors and Receipt of Palliative Care
   i) Receiving palliative care
   ii) Dying in a hospice or PCU
   iii) Receiving palliative care for longer than two days
       and:
       i) AIDS diagnosis
       ii) IV drug abstinence at death
       iii) HIV diagnosis to death greater than 36 months
       iv) Receiving antiretroviral therapy
       v) Unstable housing
       vi) Sex
       vii) Race/Ethnicity
       viii) Year of death
       ix) living alone
       x) having additional risk factors for HIV
4. Results

A total of 121 deaths of IDU's with HIV/AIDS were located in Vancouver from January 1, 1991 to December 31, 1996.

4.1 Univariate Analysis

4.1.1 Demographics

A summary of the demographics of the IDU’s at time of death can be found in Table 4. The median age at death was 35 years (mean = 36.43; 95% CI: 35.05-37.81). Age at death ranged from 23 to 59 years.

The study identified 92 males, 24 females and 5 transgendered individuals.

Aboriginal individuals made up the largest ethnic or racial category, comprising 53 percent of individuals for which ethnicity/race was identified (n=75; 95% CI: 41.7-64.3%). Only four individuals were neither Caucasian nor Aboriginal.

The majority of the IDU’s lived in unstable housing (61%; 95% CI: 51.5-70.5%) at time of death, which included single room occupancy hotels, rooming houses, or shelters (52%), and “No fixed address” (9%).

Sixty IDU’s (59%) who died with HIV/AIDS lived alone at the time of death (95% CI: 49.5-68.5%) For those individuals who lived with others, the most common arrangement was with their spouse or partner (55%), followed by other family member(s) (24%), and, lastly, with friends (21%). Only two individuals reported living with dependent children.

The overwhelming majority (n=99; 91%) of individuals relied on social assistance (95% CI: 85.6-96.4%). Only three individuals (3%) were employed prior to terminal admission.
Risk factors for acquiring HIV, in addition to injection drug use, were reported in the information sources. Forty men (including the 5 transgendered individuals, all of whom were male at birth) reported having sex with other men, meaning there was substantial overlap between the two risk categories. Reporting of other risk factors was minimal. Medical histories in hospital charts seldom explored this information. In total, 52 individuals or 43% of the sample reported risk factors in addition to injection drug use.

Information on type of injection drug use was not consistently documented in the information sources. Type of drug use, as described in Table 1, was collected on both past and present injection drug users. However, type of drug was less likely to be documented for past users.

The majority of IDU's injected cocaine (83%, n=63) and a sizable number injected heroin (53%, n=40). Thirty-five (46%) injected both cocaine and heroin. Reporting of other injection drug use was minimal, and included morphine (n=3), talwin and ritalin (n=1) and valium (n=1).

Alcohol use was also substantial among the IDU's. Of the 66 IDU's for which information was available, 37 or 56% reported alcohol use. The distinction between social and addictive alcohol consumption was not consistently apparent from reviewing the medical charts.

Fifty-five percent of the IDU's were registered with AIDS Vancouver (n=67). Forty-four percent utilized the BC Centre for Excellence in HIV/AIDS Drug Treatment Program, which offers antiretroviral therapy to HIV positive individuals (n=111). Eighty-four percent (n=87) reported use of family physician.
4.1.2 Summary of Deaths

Table 5 summarizes the deaths of the IDU's according to pertinent variables. The data clearly show a dramatic rise over time in the number of deaths of IDU's with HIV/AIDS. Each succeeding year shows an increase in number of deaths. For example, only 3 deaths were recorded in 1991 compared to 47 deaths recorded in 1996. In fact, 1995 and 1996 alone comprised 71% of all the deaths.

The majority of IDU's with HIV/AIDS died in hospital, accounting for 79 (66%; 95% CI: 57.4-74.6%) of all deaths, including those deaths in palliative care units (PCU's). Of the 79 hospital deaths, 73 (92%) occurred at St. Paul's Hospital and 6 (8%) occurred at Vancouver General Hospital. The median length of terminal admission to hospital or community hospice was ten days (mean = 35.8 days, n=107). Median length of terminal stay on an acute medical ward was nine days (mean = 13.3 days, n=47).

In total, 31 (27%, n=116) died either in a palliative care unit or in a community hospice. Of these 31, 17 (55%) IDU's died at May's Place, a community hospice in Vancouver's Downtown East Side. Another six (19%) died at Normandy House, an AIDS hospice adjacent to a private hospital. The remaining eight (26%) died in a PCU either at St. Paul's Hospital (n=7) or Vancouver General Hospital (n=1).

The location of death was unknown for five IDU's, who did not die at any of the aforementioned locations.

Table 6 displays a breakdown, by ward, of in-hospital deaths. Of the 79 hospital deaths recorded, more than half (58%; 95% CI: 43.8-72.2%) of the in-hospital deaths occurred on acute medical wards. More than twice as many deaths of IDU's with
HIV/AIDS occurred in an intensive care unit compared to a palliative care unit (17 versus 8).

The most common cause of death among the IDU’s was AIDS, comprising 66 percent of all deaths (95% CI: 57.4-74.6%). Drug overdose was the second most common cause of death (9%) followed by liver disease and sepsis (5% each). There were only two documented cases of suicide (2%) among the sample of IDU’s, and three cases of death due to trauma (3%).

Neither person who committed suicide had advanced to the stage of AIDS. One IDU committed suicide shortly after discovering his child was infected with HIV, and the other IDU committed suicide shortly after her child died of AIDS. In both cases, the reason for the suicide was attributed to their child’s affliction with HIV.

It is possible that some of the other drug overdoses and deaths due to trauma were actually successful suicide attempts, but the data could not confirm this. None of the IDU’s who died of drug overdoses (n=11) had progressed to the stage of AIDS.

Type of care at death was divided into three different possibilities: 1) aggressive care with resuscitation as an option, 2) aggressive care with a “No Code” order written, and 3) palliative care, in which a “No Code” order has been written, palliative care orders have been written, and where there is no aggressive treatment [102]. Twelve cases were excluded because they were brought to hospital when already dead (n=12: 2 suicides and 10 overdoses).

More IDU’s died while receiving palliative treatment than any other type of care (71%, 95% CI = 62.3-79.7%). However, length of palliative treatment varied greatly, ranging
from less than one hour to over 500 days. Median length (n=101) was only two days. Median length of palliative care on an acute medical ward was zero days (n=47).

Twenty percent of the 76 IDU’s who died after having progressed to the stage of AIDS (n=15) received no palliative care.

For those IDU’s who died while undergoing aggressive therapy (n=30), a “No Code” order had been written for 25 (83%) of them. Five individuals died with resuscitation as an option, and, in fact, resuscitation efforts were attempted on only four of them. None of the resuscitation efforts was successful.

By the time of death (that is, prior to terminal admission to hospital or hospice) 49 (42%, n=116; 95% CI = 33-51%) of the IDU’s were no longer using injection drugs.

The median length of HIV illness (n=101) was 36 months (mean = 50.7 months; 95% CI = 42.3-59.1 months; range = 0 to 180 months). The length for males (mean =53.5 months) was longer than for females. Four IDU’s died within one month of being diagnosed with HIV, having received the diagnosis during their terminal admission to hospital.

Eighty-three, or 72 percent of the study sample had progressed to the stage of AIDS by the time of death (95% CI: 63.8-80.2%). The median length from AIDS diagnosis to death (n=63) was only six months (mean = 12.3 months; 95% CI = 8.0-16.6 months; range = 0 to 84 months). Nineteen IDU’s (30%) died within one month of being diagnosed with AIDS.
4.2 Bivariate Analysis

4.2.1 Demographics

There were numerous differences between male and female IDU’s. Females were younger (Wilcoxon p = .006, see Table 7), were less likely to be abstinent from injection drug use at time of death (Chi squared p = .01, see Table 8), received less palliative care (Wilcoxon p < .001), and were less likely to die of AIDS (Chi squared p = .04, see Table 9) than males.

The results for the transgendered individuals are found in Tables 7 to 9. Their numbers were excluded from the above analysis due to their small numbers (n=5).

There was little difference in the average ages of Caucasian and Aboriginal IDU’s (means: 37.8 and 36.2 respectively). Similarly, the association between being female and Aboriginal was not statistically significant (p=.20).

4.2.2 Comparison of IDU’s with and without AIDS Diagnosis and Location of Death

Roughly the same percentage of IDU’s died in hospital (excluding PCU), whether the illness had progressed to the stage of AIDS (58%, n=83) or not (69%, n=32). All individuals who died in a PCU or hospice had an AIDS diagnosis (n=31).

4.2.3 Characteristics Associated with Receiving Palliative Care

The association between patient characteristics and the receipt of palliative care was evaluated with the Chi squared test of association. Those deaths attributed to suicide, drug overdose, or of unknown origin were excluded from the analysis.

Tables 10 to 12 outline the results of the analysis. Three different sets of criteria for palliative care are used:
Patients in unstable housing and a shorter time since diagnosis of HIV were less likely to receive palliative treatment, according to McLeod’s criteria.

Patients were more likely to die in a hospice or palliative care unit if they were male or had an AIDS diagnosis.

Patients with an AIDS diagnosis, a long period between HIV diagnosis and death, and who received antiretroviral therapy were more likely to receive palliative treatment for more than two days (according to McLeod’s criteria).

No factor was associated with all three sets of criteria for palliative care, although the direction of the effect was consistent across all three sets for any factor that was statistically significant on at least one analysis.

4.3 Multivariate Analysis

Logistic regression analyses were performed to determine whether any of the prognostic factors were independent predictors of receiving palliative care.

Stable housing was only marginally independently associated (p = .057) with receiving any form of palliative treatment. Having an AIDS diagnosis was independently associated with dying in a hospice of palliative care unit (p < .001), as well as receiving two or more days of palliative treatment (p < .001). Being male fell slightly short of statistical
significance as an independent predictor for dying in a hospice or palliative care unit (p=.13). A length greater than 36 months from HIV diagnosis to death was independently associated with receiving two or more days of palliative care (p < .05).

4.3 Summary

A detailed description of the IDU’s who died with HIV/AIDS in Vancouver between 1991 and 1996 was carried out. The results described a population of which the majority was male, lived in unstable housing, lived alone and received social assistance as the primary source of income. Aboriginal people made up the largest ethnic group for which data were available. The majority of the IDU’s died of AIDS, with drug overdoses being the second leading cause of death.

A hospital was the most common location of death. All the deaths which occurred in a hospice or palliative care unit were of IDU’s who had progressed to the stage of AIDS. Only two IDU’s died at home with palliative care services.

Excluding deaths attributed to suicide, drug overdose, or unknown causes, 71 percent of the IDU’s received some form of palliative treatment at time of death, although the median length was only two days. The median length of palliative care for those who died in a hospice or palliative care unit was 72 days.

Multivariate analysis revealed that having an AIDS diagnosis was independently associated with dying in a hospice or PCU, as well as two days or more of palliative treatment. A length greater than 36 months from HIV diagnosis to death was independently associated with receiving two or more days of palliative treatment.
Table 4: Demographics of IDU’s at time of death

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age (n=119)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>mean: 36.4 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>median: 35 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Sex (n=121)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>92</td>
<td>76%</td>
</tr>
<tr>
<td>Female</td>
<td>24</td>
<td>20%</td>
</tr>
<tr>
<td>Transgendered</td>
<td>5</td>
<td>4%</td>
</tr>
<tr>
<td>3. Race (n=75)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal</td>
<td>40</td>
<td>53%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>31</td>
<td>41%</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>5%</td>
</tr>
<tr>
<td>4. Housing (n=102)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hotel/Rooming house</td>
<td>53</td>
<td>52%</td>
</tr>
<tr>
<td>Apartment/Condo</td>
<td>34</td>
<td>33%</td>
</tr>
<tr>
<td>No fixed address</td>
<td>9</td>
<td>9%</td>
</tr>
<tr>
<td>House</td>
<td>4</td>
<td>4%</td>
</tr>
<tr>
<td>Prison</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>5. Living Arrangements (n=102)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>60</td>
<td>59%</td>
</tr>
<tr>
<td>Living with others</td>
<td>42</td>
<td>41%</td>
</tr>
<tr>
<td>6. Income Source (n=108)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social assistance</td>
<td>99</td>
<td>91%</td>
</tr>
<tr>
<td>Employment</td>
<td>3</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>6%</td>
</tr>
<tr>
<td>7. Risk Factors in addition to injection drug use (n=121)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MSM (n=97*)</td>
<td>40</td>
<td>41%</td>
</tr>
<tr>
<td>Sex trade</td>
<td>11</td>
<td>9%</td>
</tr>
<tr>
<td>Multiple sex partners</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Blood product recipient</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>None reported**</td>
<td>69</td>
<td>57%</td>
</tr>
<tr>
<td>8. Type of injection drug use (n=76)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cocaine</td>
<td>63</td>
<td>83%</td>
</tr>
<tr>
<td>Heroin</td>
<td>40</td>
<td>53%</td>
</tr>
<tr>
<td>Morphine</td>
<td>3</td>
<td>4%</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>3%</td>
</tr>
<tr>
<td>9. Membership in AIDS Vancouver (n=121)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>67</td>
<td>55%</td>
</tr>
<tr>
<td>No</td>
<td>54</td>
<td>45%</td>
</tr>
<tr>
<td>10. Use of antiretroviral therapy through BCCE Drug Program (n=111)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>49</td>
<td>44%</td>
</tr>
<tr>
<td>No</td>
<td>62</td>
<td>56%</td>
</tr>
<tr>
<td>11. Use of a family physician (n=104)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>87</td>
<td>84%</td>
</tr>
<tr>
<td>No</td>
<td>17</td>
<td>16%</td>
</tr>
</tbody>
</table>

*Only males and transgendered are included

**due to limited quality of information, there is probable underreporting of additional risk factors
Table 5: Summary of Deaths

<table>
<thead>
<tr>
<th>Variable</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Year of death (n=121)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>91</td>
<td>3</td>
<td>2%</td>
</tr>
<tr>
<td>92</td>
<td>7</td>
<td>6%</td>
</tr>
<tr>
<td>93</td>
<td>11</td>
<td>9%</td>
</tr>
<tr>
<td>94</td>
<td>14</td>
<td>12%</td>
</tr>
<tr>
<td>95</td>
<td>39</td>
<td>32%</td>
</tr>
<tr>
<td>96</td>
<td>47</td>
<td>39%</td>
</tr>
<tr>
<td>2. Location of death (n=116)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital (excluding PCU)</td>
<td>71</td>
<td>61%</td>
</tr>
<tr>
<td>PCU</td>
<td>8</td>
<td>7%</td>
</tr>
<tr>
<td>Community hospice</td>
<td>23</td>
<td>20%</td>
</tr>
<tr>
<td>Home</td>
<td>13</td>
<td>11%</td>
</tr>
<tr>
<td>On the street</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>3. Type of care at death* (n=104**)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aggressive care with resuscitation</td>
<td>5</td>
<td>5%</td>
</tr>
<tr>
<td>Aggressive care with “No Code”</td>
<td>25</td>
<td>24%</td>
</tr>
<tr>
<td>Palliative care</td>
<td>74</td>
<td>71%</td>
</tr>
<tr>
<td>4. Cause of death (n=116)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AIDS</td>
<td>76</td>
<td>66%</td>
</tr>
<tr>
<td>Overdose</td>
<td>11</td>
<td>9%</td>
</tr>
<tr>
<td>Liver disease</td>
<td>6</td>
<td>5%</td>
</tr>
<tr>
<td>Sepsis</td>
<td>6</td>
<td>5%</td>
</tr>
<tr>
<td>Trauma</td>
<td>3</td>
<td>3%</td>
</tr>
<tr>
<td>Suicide</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>10%</td>
</tr>
<tr>
<td>5. Injection drug use at time of death (n=116)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abstinent</td>
<td>49</td>
<td>42%</td>
</tr>
<tr>
<td>Not abstinent</td>
<td>67</td>
<td>58%</td>
</tr>
<tr>
<td>6. Progression to AIDS by time of death (n=115)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>83</td>
<td>72%</td>
</tr>
<tr>
<td>No</td>
<td>32</td>
<td>28%</td>
</tr>
<tr>
<td>7. Time between HIV diagnosis and death (n=101)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>median:</td>
<td>36 months</td>
<td></td>
</tr>
<tr>
<td>mean:</td>
<td>50.7 months</td>
<td></td>
</tr>
<tr>
<td>8. Time between AIDS diagnosis and death (n=63)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>median:</td>
<td>6 months</td>
<td></td>
</tr>
<tr>
<td>mean:</td>
<td>12.3 months</td>
<td></td>
</tr>
</tbody>
</table>

* Values as defined by McLeod (1990)
**twelve cases were excluded because they arrived at a hospital already deceased. Therefore, whether or not they accessed palliative care was not applicable.
Table 6: Breakdown by Ward of In-Hospital Deaths (n=79)

<table>
<thead>
<tr>
<th>Ward</th>
<th>Number of Deaths</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Medical Ward</td>
<td>47</td>
<td>59%</td>
</tr>
<tr>
<td>Intensive Care Unit</td>
<td>17</td>
<td>22%</td>
</tr>
<tr>
<td>Palliative Care Unit (PCU)</td>
<td>8</td>
<td>10%</td>
</tr>
<tr>
<td>Emergency Department</td>
<td>7</td>
<td>9%</td>
</tr>
<tr>
<td>Total</td>
<td>79</td>
<td>100%</td>
</tr>
</tbody>
</table>
Table 7: Summary of Gender and Age at Death (N=121)

<table>
<thead>
<tr>
<th>Age</th>
<th>Male</th>
<th>Female</th>
<th>Transgendered</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29</td>
<td>11 (12%)</td>
<td>9 (37%)</td>
<td>1 (20%)</td>
<td>21 (18%)</td>
</tr>
<tr>
<td>30-39</td>
<td>45 (50%)</td>
<td>10 (42%)</td>
<td>4 (80%)</td>
<td>59 (49%)</td>
</tr>
<tr>
<td>40-49</td>
<td>29 (32%)</td>
<td>4 (17%)</td>
<td>0</td>
<td>33 (28%)</td>
</tr>
<tr>
<td>50-59</td>
<td>5 (6%)</td>
<td>1 (4%)</td>
<td>0</td>
<td>6 (5%)</td>
</tr>
<tr>
<td>Total</td>
<td>90 (100%)</td>
<td>24 (100%)</td>
<td>5 (100%)</td>
<td>119 (100%)</td>
</tr>
</tbody>
</table>
Table 8: Abstinence at Time of Death According to Sex (n=116)

<table>
<thead>
<tr>
<th>Sex</th>
<th>Total</th>
<th>Number</th>
<th>Number Abstinent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>90</td>
<td>44</td>
<td>44 (49%)</td>
</tr>
<tr>
<td>Female</td>
<td>22</td>
<td>3</td>
<td>3 (14%)</td>
</tr>
<tr>
<td>Transgendered</td>
<td>4</td>
<td>2</td>
<td>2 (50%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>116</td>
<td>67</td>
<td>67 (58%)</td>
</tr>
</tbody>
</table>
Table 9: Primary Cause of Death According to Sex (n=116)

<table>
<thead>
<tr>
<th>Cause</th>
<th>Males</th>
<th>Females</th>
<th>Transgendered</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>63 (70.8%)</td>
<td>10 (43.4%)</td>
<td>3 (75%)</td>
<td>76 (66%)</td>
</tr>
<tr>
<td>Overdose</td>
<td>9 (10.1%)</td>
<td>2 (8.7%)</td>
<td>0</td>
<td>11 (9%)</td>
</tr>
<tr>
<td>Liver Disease</td>
<td>4 (4.5%)</td>
<td>2 (8.7%)</td>
<td>0</td>
<td>6 (5%)</td>
</tr>
<tr>
<td>Sepsis</td>
<td>2 (2.2%)</td>
<td>4 (17.4%)</td>
<td>0</td>
<td>6 (5%)</td>
</tr>
<tr>
<td>Trauma</td>
<td>1 (1.1%)</td>
<td>1 (4.4%)</td>
<td>1 (25%)</td>
<td>3 (3%)</td>
</tr>
<tr>
<td>Suicide</td>
<td>1 (1.1%)</td>
<td>1 (4.4%)</td>
<td>0</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (10.1%)</td>
<td>3 (13.0%)</td>
<td>0</td>
<td>12 (10%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>89</td>
<td>23</td>
<td>4</td>
<td>116</td>
</tr>
</tbody>
</table>
Table 10: Characteristics Associated with Receiving Palliative Treatment (as defined by McLeod, 1990)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Died with Palliative Treatment</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. AIDS diagnosis (n=81)</td>
<td>61 (75%)</td>
<td>.10</td>
</tr>
<tr>
<td>No AIDS diagnosis (n=21)</td>
<td>12 (57%)</td>
<td></td>
</tr>
<tr>
<td>2. HIV diagnosis-death &gt;36 months (n=43)</td>
<td>36 (84%)</td>
<td>.02*</td>
</tr>
<tr>
<td>HIV diagnosis-death &lt;36 months (n=45)</td>
<td>28 (62%)</td>
<td></td>
</tr>
<tr>
<td>3. Unstable housing (n=54)</td>
<td>34 (63%)</td>
<td>.01*</td>
</tr>
<tr>
<td>Stable housing (n=32)</td>
<td>28 (88%)</td>
<td></td>
</tr>
<tr>
<td>4. Male (n=89)</td>
<td>58 (65%)</td>
<td>.44</td>
</tr>
<tr>
<td>Female (n=23)</td>
<td>13 (57%)</td>
<td></td>
</tr>
<tr>
<td>5. IV drug abstinence at death (n=48)</td>
<td>37 (77%)</td>
<td>.20</td>
</tr>
<tr>
<td>Not abstinent at death (n=55)</td>
<td>36 (65%)</td>
<td></td>
</tr>
<tr>
<td>6. Received antiretroviral therapy (n=45)</td>
<td>35 (78%)</td>
<td>.19</td>
</tr>
<tr>
<td>No antiretroviral therapy (n=59)</td>
<td>39 (66%)</td>
<td></td>
</tr>
<tr>
<td>7. Ethnicity (Aboriginal) (n=33)</td>
<td>22 (67%)</td>
<td>.92</td>
</tr>
<tr>
<td>Other (n=26)</td>
<td>17 (65%)</td>
<td></td>
</tr>
<tr>
<td>8. Year of death: 1995 and 1996 (n=69)</td>
<td>46 (67%)</td>
<td>.10</td>
</tr>
<tr>
<td>Year of death: 1991-1994 (n=34)</td>
<td>28 (82%)</td>
<td></td>
</tr>
<tr>
<td>9. Living alone (n=52)</td>
<td>38 (73%)</td>
<td>.84</td>
</tr>
<tr>
<td>Living with others (n=36)</td>
<td>27 (75%)</td>
<td></td>
</tr>
<tr>
<td>10. Having additional risk factors for HIV (n=43)</td>
<td>32 (74%)</td>
<td>.54</td>
</tr>
<tr>
<td>No additional risk factors for HIV (n=61)</td>
<td>42 (69%)</td>
<td></td>
</tr>
</tbody>
</table>

* Statistically significant
Table 11: Characteristics Associated with Dying in a Hospice or Palliative Care Unit (PCU)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Died in Hospice/PCU</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. AIDS diagnosis (n=82)</td>
<td>31 (38%)</td>
<td>.0007*</td>
</tr>
<tr>
<td>No AIDS diagnosis (n=20)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>2. HIV diagnosis-death &gt;36 months (n=43)</td>
<td>15 (35%)</td>
<td>.28</td>
</tr>
<tr>
<td>HIV diagnosis-death &lt;36 months (n=46)</td>
<td>11 (24%)</td>
<td></td>
</tr>
<tr>
<td>3. Unstable housing (n=53)</td>
<td>16 (30%)</td>
<td>.65</td>
</tr>
<tr>
<td>Stable housing (n=33)</td>
<td>11 (33%)</td>
<td></td>
</tr>
<tr>
<td>4. Male (n=92)</td>
<td>27 (29%)</td>
<td>.03*</td>
</tr>
<tr>
<td>Female (n=24)</td>
<td>2 (8%)</td>
<td></td>
</tr>
<tr>
<td>5. IV drug abstinence at death (n=48)</td>
<td>18 (38%)</td>
<td>.11</td>
</tr>
<tr>
<td>Not abstinent at death (n=54)</td>
<td>13 (24%)</td>
<td></td>
</tr>
<tr>
<td>6. Received antiretroviral therapy (n=45)</td>
<td>16 (36%)</td>
<td>.29</td>
</tr>
<tr>
<td>No antiretroviral therapy (n=8)</td>
<td>15 (26%)</td>
<td></td>
</tr>
<tr>
<td>7. Ethnicity (Aboriginal) (n=33)</td>
<td>8 (24%)</td>
<td>.92</td>
</tr>
<tr>
<td>Other (n=26)</td>
<td>6 (23%)</td>
<td></td>
</tr>
<tr>
<td>8. Year of death: 1995 and 1996 (n=69)</td>
<td>21 (30%)</td>
<td>.92</td>
</tr>
<tr>
<td>Year of death (n=34)</td>
<td>10 (29%)</td>
<td></td>
</tr>
<tr>
<td>9. Living alone (n=52)</td>
<td>16 (31%)</td>
<td>.98</td>
</tr>
<tr>
<td>Living with others (n=36)</td>
<td>11 (31%)</td>
<td></td>
</tr>
<tr>
<td>10. Having additional risk factors for HIV (n=42)</td>
<td>11 (26%)</td>
<td>.40</td>
</tr>
<tr>
<td>No additional risk factors for HIV (n=61)</td>
<td>20 (33%)</td>
<td></td>
</tr>
</tbody>
</table>

* Statistically significant
Table 12: Characteristics Associated with Receiving Palliative Treatment for More than 2 Days.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Palliative treatment &gt;2 Days</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. AIDS diagnosis (n=79)</td>
<td>43 (54%)</td>
<td>.00005*</td>
</tr>
<tr>
<td>No AIDS diagnosis (n=21)</td>
<td>1 (5%)</td>
<td></td>
</tr>
<tr>
<td>2. HIV diagnosis-death &gt;36 months (n=41)</td>
<td>24 (59%)</td>
<td>.01*</td>
</tr>
<tr>
<td>HIV diagnosis-death &lt;36 months (n=45)</td>
<td>14 (31%)</td>
<td></td>
</tr>
<tr>
<td>3. Unstable housing (n=54)</td>
<td>20 (37%)</td>
<td>.08</td>
</tr>
<tr>
<td>Stable housing (n=30)</td>
<td>17 (56%)</td>
<td></td>
</tr>
<tr>
<td>4. Male (n=78)</td>
<td>37 (47%)</td>
<td>.10</td>
</tr>
<tr>
<td>Female (n=19)</td>
<td>5 (26%)</td>
<td></td>
</tr>
<tr>
<td>5. IV drug abstinence at death (n=46)</td>
<td>24 (52%)</td>
<td>.11</td>
</tr>
<tr>
<td>Not abstinent at death (n=55)</td>
<td>20 (36%)</td>
<td></td>
</tr>
<tr>
<td>6. Received antiretroviral therapy (n=44)</td>
<td>24 (55%)</td>
<td>.05*</td>
</tr>
<tr>
<td>No antiretroviral therapy (n=57)</td>
<td>20 (35%)</td>
<td></td>
</tr>
<tr>
<td>7. Ethnicity (Aboriginal) (n=33)</td>
<td>11 (33%)</td>
<td>.41</td>
</tr>
<tr>
<td>Other (n=25)</td>
<td>11 (44%)</td>
<td></td>
</tr>
<tr>
<td>8. Year of death: 1995 and 1996 (n=68)</td>
<td>28 (41%)</td>
<td>.49</td>
</tr>
<tr>
<td>Year of death: 1991-1994 (n=33)</td>
<td>16 (48%)</td>
<td></td>
</tr>
<tr>
<td>9. Living alone (n=52)</td>
<td>22 (42%)</td>
<td>.56</td>
</tr>
<tr>
<td>Living with others (n=35)</td>
<td>17 (49%)</td>
<td></td>
</tr>
<tr>
<td>10. Having additional risk factors for HIV (n=43)</td>
<td>18 (42%)</td>
<td>.77</td>
</tr>
<tr>
<td>No additional risk factors for HIV (n=58)</td>
<td>26 (45%)</td>
<td></td>
</tr>
</tbody>
</table>

* Statistically significant
5. Discussion

In this retrospective study on IDU's who died with HIV/AIDS, a number of important issues arose which warrant further discussion.

5.1 Demographics

The majority of IDU's who died with HIV/AIDS were male, as has been described in other IDU studies in Vancouver [6, 8]. Females were, on average, younger than the males.

The proportion of individuals who were Aboriginal was higher than proportions reported in other literature on IDU's in Vancouver [6, 8]. The reason for this was probably due to the large number of individuals for whom race/ethnicity was not available (38%). It was likely that most of these were Caucasian, as recorders were probably less likely to record race/ethnicity for a Caucasian individual than for a Black or Aboriginal individual.

It is also not surprising that the majority of IDU's who died with HIV/AIDS lived alone, in hotels, and utilized social assistance as their main source of income. Unstable housing, reliance on social assistance, and poverty are characteristics of this population previously described in Vancouver [8, 100] and elsewhere [4, 44].

The findings of this study did not support the findings of other studies which found a greater proportion of women and ethnic minorities among younger IDU's [14, 104, 105].

5.2 Risk Factors in Addition to Injection Drug Use

Thirty-five men and five transgendered individuals reported having sex with other men, meaning there was substantial overlap between this risk category and injection drug use.
Reporting of other risk factors was minimal. It is assumed that risk factors in addition to injection drug use and MSM might have been under-reported in the information sources, due to: a) not being addressed by the physicians conducting the medical histories in hospital charts, and b) potential reluctance on the part of the IDU’s to report other risk factors such as involvement in sex trade and multiple sex partners. In total, 52 individuals (43%) of the sample reported risk factors in addition to injection drug use. Taking into account the probable under-reporting of risk factors, it is probable that many of these individuals were at significant risk for acquiring HIV. It is also probable that, given multiple risk factors, it would be quite difficult to determine actual mode of HIV transmission.

5.3 Location of Death

An assumption of this study is that a hospice, palliative care unit or home with palliative services in place represented a preferred location of death over an acute care ward in a hospital, even if palliative services were in place on the acute care ward. This assumption is based on the literature [76, 77, 79]. The disparity between the median length of palliative care in a hospice/palliative care unit and an acute care ward (72 days versus 0 days) found in this study demonstrates an important issue.

The majority of the IDU’s with HIV/AIDS died in hospital, excluding palliative care units. Patients with an AIDS diagnosis were as likely as those with an AIDS diagnosis to die in hospital. Sixty-nine percent of the HIV positive IDU’s without an AIDS diagnosis died in hospital compared to 58 percent of those with an AIDS diagnosis.
Twenty-six percent (n=31) of the IDU's died in a palliative care unit or hospice. (All of the 31 individuals had progressed to the stage of AIDS). A total of 40 percent (n=33) of IDU's who progressed to the stage of AIDS died in a palliative care unit, a hospice, or with palliative care services provided in the home. Although the numbers could be higher, the fact that 40 percent of IDU's with AIDS died in locations where the emphasis was on dying with comfort and dignity does offer some reason for hope and optimism.

A significant reason why a large percentage of IDU's were able to die in a preferred location is the establishment of May's Place. A community hospice located in the heart of Vancouver's injection drug using community, May's Place was initiated by St. James Social Service Society (Anglican Church) and has provided care for many IDU's with AIDS (17 during the study period). It is a reasonable hypothesis that many other cities in Canada do not have such accessible palliative care services for IDU's and that without May's Place, the percentage of IDU’s dying with specialized palliative care in Vancouver would be much lower.

The optimism expressed in the above discussion must, however, be placed within a larger context. For instance, it could be argued that a number of the HTV positive IDU's who did not have an AIDS diagnosis should have been eligible for placement in a hospice or palliative care unit. An argument could be made that an HIV positive IDU dying with terminal liver disease (but not AIDS) would be a suitable candidate for placement in a hospice or palliative care unit, or for palliative care services to be available in the home. Six individuals in this study died of liver disease, and they all died either on an acute medical ward or in an emergency department.
Another issue that must be addressed is the fact that 58 percent of IDU’s with an AIDS diagnosis died in an acute care setting, including nine (11%) individuals with AIDS who died in an intensive care unit. In other words, the same number of IDU’s with AIDS (n=9) who died in a hospital palliative care unit also died in a hospital intensive care unit. Another 34 (41%) died on an acute care ward. The median length of palliative care was zero days in the intensive care ward for IDU’s who died after progressing to the stage of AIDS and two days on an acute care ward for those IDU’s who died after progression to AIDS.

A better understanding of why some IDU’s with AIDS were transferred to a hospice or palliative care unit and others were not, would be valuable. From this study it is not clear what variables had an impact on this decision. An investigation into the referral procedures might reveal, for instance, that those IDU’s who were managed by home care services or certain physicians were more likely to get referred to a hospice or palliative care unit. Waiting lists may have been another issue.

While the literature speaks of dying at home with palliative care services in place as optimal, only two IDU’s in the study managed to achieve this option. The reasons for this are not clear. Although Vancouver Health Board home care services does have an official palliative care program, resources and other circumstances do not allow for the provision of home services until the time of death in an unstable housing situation. Many IDU’s did receive home care services in the course of their HIV disease, but most of them were either transferred to hospice or hospital. Reasons for why individuals with AIDS (including all risk categories) were not dying at home in Vancouver were explored by
Goldstone et al [79]. Factors such as complex medical treatments were cited as reasons which prevented the potential for dying at home.

For IDU’s in particular, unstable housing and lack of social support might be additional factors. Both persons in this study, for instance, who died at home with palliative services lived in stable housing. For the majority of IDU’s, though, dying at home would have been a challenge due to housing conditions. The majority also lived alone, pointing to limited social support.

5.4 Cause of Death.

Sixty-six percent of the study’s IDU’s died from AIDS. This is the same percentage that Goedert et al reported in the study on IDU’s in Italy [47], but higher than Van Haastricht et al’s study [46] in Amsterdam (38%). This study’s results fit into the trend shown in the literature that a greater percentage of HIV positive IDU’s are dying from AIDS than ten years ago.

5.5 Length of Palliative Care

The overall median length of palliative care (as defined by McLeod), when overdoses, suicides and unknown deaths are excluded, was two days. The median length of terminal admission to hospital or hospice was ten days. This implies that, on average, an IDU dying with HIV/AIDS had only two days prior to death which were free from intrusive procedures (such as bronchoscopies, investigative bloodwork) and in which the health care team formally acknowledged that death was imminent. Prior to this, it might be said that medical investigations took priority over patient comfort. Particularly for palliative care delivered in an acute care environment, palliative care was often only delivered after a
period of acute or intensive treatment, when the patient was already unconscious, and
after death was determined to be imminent.

These results are a grim reminder of the acute nature of hospital inpatient care for
people with terminal illnesses. Reasons for this may include those topics discussed in a
previous section, such as growth of technology in medicine, fear/denial of death by
hospital staff and by the patients themselves.

However, the length of palliative care received is more complex than this, and may be
associated with certain patterns of hospital use. Goldstone et al describe a pattern of
health care utilization by people with HIV/AIDS which they refer to as “crashing” [19].
This occurs when an individual presents him/herself to a hospital emergency department
when acutely ill, which likely leads to a period of acute or intensive treatment, including
numerous investigative and diagnostic procedures. Unless the person with HIV/AIDS
articulates his/her desire for palliative care, the health care team will attempt acute or
intensive treatments in an effort not to “give up on a person”.

It was not possible to determine from the data collected for this study how often the
“crashing” phenomenon occurred, and if so, whether or not the subsequent acute or
intensive care was appropriate. What is known is that the Expert Panel on Palliative
Care’s recommendation that palliative care aims be integrated at all stages of treatment
[69] was not addressed. Clearly, more information is needed regarding this phenomenon.
Patient expectations [79] and hospital emergency department protocols need to be
reexamined to prevent unnecessary and inappropriate acute or intensive treatment.
In contrast to deaths in acute care settings, the length of palliative care in palliative care units and hospices was long (median: 72 days). Based on the literature reviewed in a previous section, several implications can be discussed. First of all, the IDU’s who died in this environment were less ill when the focus of treatment shifted from acute to palliative care, as compared to those who died in an acute care setting. Implicit in this shift is that the patient and the health care team most likely dealt directly with the physical, psychological and spiritual issues of dying with HIV/AIDS. In contrast, when the health care team’s focus of care shifted to palliation only hours before death, as was the case for 13 hospital deaths, the patient perhaps dealt with the issues of dying, either in isolation from his/her care providers, or not at all.

5.6 Rising Number of Deaths

A dramatic rise in the number of deaths of IDU’s with HIV/AIDS in Vancouver is reported in this study. Information from other sources indicate, as incidence is continuing to rise [8], that the number of deaths has not yet reached its peak. Each of the coming years will most likely see continued increases in the number of deaths of IDU’s with HIV/AIDS.

5.7 Drug Abstinence at Time of Death

Forty-two percent of the IDU’s were no longer injecting drugs by the time of terminal admission to hospital or hospice. This figure is close to Brettle’s for Edinburgh, where 50 percent of IDU’s were abstinent at time of death [40]. Reasons for this are not clear, but may reflect the fact that not all IDU’s inject drugs daily. On the contrary, many inject only
periodically [30]. It may also reflect the decreased access to drugs close to time of death due to deteriorating health.

5.8 Gender Differences

The results of the study revealed a number of differences between the male and female IDU’s. The discussion here is limited to the differences between male and female. Although there were five transgendered IDU’s, their small numbers made meaningful comparison unreliable. As already mentioned, the vast majority (76%) of the IDU’s in the study were male, and females died an average of 6.5 years younger than the males.

More females than males reported being involved in the sex trade, although there might have been underreporting for both genders.

Males were significantly more likely to die in a hospice or palliative care unit than females, although one of the reasons for this difference was that males were more likely than females to have an AIDS diagnosis at death.

Another disparity between males and females was the length of palliative care received. For those females who received palliative care, the median length was two days. For males, the median length was 15 days. Again, a possible explanation for this is the different likelihood in dying from AIDS.

The reason why fewer females died from AIDS than males is also perplexing. The mean length from HIV diagnosis to death for females was shorter than for males (mean length = 35.7 months and 53.5 months, respectively), although this difference was not
statistically significant. This difference, while offering explanation why fewer females died from AIDS, raises the question of why women had less time from HIV diagnosis to death. One possibility is the female IDU’s are at greater risk of death than male IDU’s independent of HIV for a variety of social reasons.

Results regarding abstinence from injection drugs at the time of death showed that males were significantly more likely to attain abstinence than females. A possible explanation for this would be that the two populations were intrinsically different, that the female population was more “street entrenched” and that many of the males were only recreational drug users. A possible reason for exploring this factor is that 35 (38%) of the males also fell into the category of men-who-have-sex-with-men (MSM). The cause, possibly, for becoming HIV positive was not their “street entrenched” injection drug use but rather sexual activity. However, the difference between MSM males and non-MSM males and their rate of abstinence was not statistically significant.

Another reason for the disparity in abstinence rates at death may related to the fact that more women died earlier in HIV disease progression (i.e. less likelihood of progressing to the stage of AIDS), which may be significant in light of the previously mentioned notion that worsening health may be associated with decreased access to and craving for injecting drugs.

The literature is lacking in comparisons between male and female IDU’s with HIV/AIDS. Cozzi et al did not find any gender differences in the natural course of HIV infection among IDU’s in Italy [51].
5.9 Accessing Community Services

Less than half of the IDU's accessed antiretroviral therapy. It is not known how this percentage compares with other risk groups such as gay and bisexual men, or whether IDU's in Vancouver access preventive programs less than other groups, as was demonstrated by Weisfuse et al [27] in New York.

It would be interesting to perform a more in-depth analysis, to see whether degree of compliance to the therapy was associated with receiving palliative care as well. Accessing antiretroviral therapy is associated with slower progression of HIV disease in IDU's [45] and might also be an indicator of a less chaotic lifestyle, which may place an IDU at greater chance for improved health care utilization in general.

Forty-nine percent of IDU's who died in 1996 accessed antiretroviral therapy, compared to 41% who died in 1995 or earlier. While this difference is not statistically significant, it may indicate that IDU's are accessing more services as the HIV epidemic among this population grows. Reports indicate that number of individuals in British Columbia accessing antiretroviral therapy is rapidly increasing, and almost doubled in the first ten months of 1996 [106]. Individuals from this study may have died too early to be a part of this trend, but the coming years may see a greater proportion of IDU's in Vancouver accessing antiretroviral therapies.

There was little difference between 1996 and pre-1996 percentages of IDU’s who accessed services at AIDS Vancouver (57% and 54% respectively).

Eighty-four percent of the sample reported use of a family physician. It is not known whether having a family physician is an indicator of a less chaotic lifestyle, or whether
utilization of a family physician might facilitate improved access to health services, such as palliative care. IDU's might utilize their family doctors quite differently, with varying frequency. Qualitative methods may be useful in gaining a better understanding of physician use and may shed more light on what role a family physician might have with assisting an IDU to receive palliative care.

5.10 Type of Care at Time of Death

Goldstone et al [79] examined type of care at time of death in their study on AIDS deaths at St. Paul’s Hospital in Vancouver for the year 1992. Because their study included all persons with AIDS from all risk categories, a comparison of this study and their results can offer some insight into how IDU’s might differ from other AIDS risk categories.

Goldstone et al used the same criteria for aggressive therapy and palliative care [102]. However, only 42 percent of the individuals with advanced HIV disease died with some form of palliative care, compared to 71 percent of the IDU’s in this study. It is important to note Goldstone et al’s study did not include hospice deaths. However, when only this study’s St. Paul’s Hospital deaths are analyzed, the result is still higher (62%) than the result from Goldstone et al (42%). Conversely, 19 percent of the subjects in Goldstone et al’s study died during aggressive therapy (with resuscitation as an option) while only four percent of this study’s subject did. The reason for the differences between the two studies might be due to evolving palliative care practices at St. Paul’s hospital (as most of the deaths in this study occurred in 1995 and 1996, compared to 1992), or it might reflect the fact that IDU’s receive better end-of-life care than gay men (who made up most of the
cases in Goldstone et al's study). This implies, however, that when a decision is made to no longer use aggressive therapy with resuscitation, that the patient (IDU) is involved in the decision or, at least, informed of it. Unfortunately, this is often not the case [103, 107]. The opposite might be true then - that physicians are more quick to discontinue aggressive therapy for IDU's, but without involving them in the decision. A third explanation might be that the differences in the two studies are the result of different interpretation of the palliative and aggressive care criteria during data collection.

Studies on access to palliative care cited in the literature review reported that only five percent of Canadians with terminal illness [75] and 25 percent of terminally ill cancer patients in England die with palliative care services [80]. Even if the criteria used for palliative care is stringently defined as dying in a palliative care unit, a hospice or at home with palliative care services, 28 percent of the IDU's with HIV/AIDS in this study died with palliative care services. There are at least two ways of interpreting these results. First, IDU's in Vancouver are receiving relatively good end-of-life care; and second, that terminally ill people in general, for whatever reason, receive grossly inadequate palliative care at the end of life.

5.11 Length of Time from AIDS Diagnosis to death

Median length of time from AIDS diagnosis to death was fourteen months in Goldstone et al's study, and only six months in this one. This difference suggests that IDU's with HIV/AIDS might have a shorter life span than individuals from other risk categories, or that their diagnosis is delayed.
5.12 AIDS and Suicide.

There were two documented suicides in the study. However, this figure is probably an underestimation because some of the drug overdoses and motor vehicle accidents (categorized under trauma) may have been successful suicide attempts. There was no evidence to suggest that any of the IDU's in this sample died by way of assisted suicide. Considering Ogden's [59] assertion that most individuals with AIDS who died by assisted suicide had strong social support and a strong understanding of HIV disease and therapy, it seems unlikely that any IDU's in this study were recipients of euthanasia. Both suicides seemed to come out of pain, loss and guilt (i.e. the loss of a child to AIDS) rather than a carefully planned action to die peacefully and with dignity.

5.13 Methodology.

It is difficult to ascertain whether the methodology was successful in identifying all the IDU's who died with HIV/AIDS between 1991 and 1996. Comparing the number of AIDS cases in this sample with the number collected by the provincial health registry between 1991 and 1996 may offer some substantiation. While the number of AIDS cases in IDU's between 1991 and 1996 for the city of Vancouver is not available, 88 cases were reported for the entire province [7]. Considering Vancouver (excluding suburbs) comprises 70 percent of the provincial AIDS cases [7], one could speculate that between 60 and 65 of these IDU's were from Vancouver. (The figure may be higher due to the probability of IDU concentration in Vancouver). The fact that, between 1991 and 1996, this study identified 83 AIDS deaths among IDU's, where the provincial registry identified approximately 65 AIDS cases among IDU's suggests that perhaps this study was
successful in identifying the majority of IDU deaths with HIV/AIDS. Taking into account that underreporting in the provincial registry may have been as high as 18 to 24 percent [108, 109] and the fact that not all AIDS cases in the registry would have died by the end of 1996 make an accurate comparison difficult. Nonetheless, the figures suggest that this study identified all (and perhaps more) of the AIDS cases documented in the provincial registry.

### 5.14 Study Limitations

There are a number of limitations to this study, as outlined in the following discussion.

**Nature of Study.** As set out in the objectives, the purpose of this study was descriptive and not hypothesis testing. Therefore, caution must be taken before inferring causal relationships between any of the variables.

**Generalizability.** This study examined IDU deaths in Vancouver only. Therefore, generalizing results to other locations, to other risk categories for HIV, or to other terminal illnesses requiring palliative care must be placed within its context.

**Sample Size.** A total of 121 IDU’s were located who died between 1991 and 1996 in Vancouver. However, because many of the cases had missing data on some of the variables, many of the descriptions and analyses were performed using relatively small numbers. Comparing gender differences is an example, as there was a maximum of 24 female cases (and often less) available for any statistical comparison.

**Data Sources.** Hospital medical records presented several problems and limitations. The quality of the data was subject to the fact that the information was collected by numerous and varying members of the health care team, and often over a long time span. Therefore,
occasionally the issue of reliability was a concern. For example, in a number of patient charts, there were several conflicting entries as to the date of a patient’s HIV diagnosis. It was unclear why this was the case, except to speculate that the patient gave conflicting information. This may have been due to a poorly worded question, or due to the patient being unsure, ill, or under the influence of drugs at the time of the interview. In the case of such a discrepancy, the earlier date was used.

The use of the terms HIV and AIDS interchangeably was another source of confusion. Occasionally, the term AIDS would be used in a patient’s chart when no diagnosis of AIDS had been made. This might have been due to carelessness, or due to the confusion around the definition of AIDS - namely, whether the physician was using the Canadian definition (based on the presence of an AIDS-defining illness) or the American definition (based on CD4 counts) [110]. For this reason, it was sometimes difficult to determine if and when an AIDS diagnosis had been made for a specific individual.

The quantity of information in a patient’s hospital chart varied a great deal. The initial complete history and physical examination was usually a source of much information. However, it varied substantially according to the admitting physician. Many physicians did not inquire into social health issues, such as housing, risk factors for HIV, drug use and social support.

The coding of hospital discharge and death summaries using ICD codes presented another problem in trying to locate all the IDU’s who died with HIV/AIDS. Every discharge and death in the hospital was summarized by the physician according to disease process, and then assigned codes, according to ICD manual, and entered into the hospital
medical records data base. However, like any other human endeavour, this process was limited by the accuracy and the completeness of the physician’s and the medical coder’s work. During Part One of data collection (locating IDU’s who died with HIV/AIDS), the limitations of the coding system became apparent. For example, while 73 IDU’s with HIV/AIDS died at St. Paul’s Hospital, the Medical Records computer search of death summaries revealed only 40. The other 33 deaths at St. Paul’s Hospital were identified by other sources.

Another example of the inaccuracy of hospital data bases was that a number of IDU’s determined to have died at St. Paul’s Hospital showed up in the hospital’s data base as still being alive. Their deaths, however, were confirmed upon reviewing their personal medical charts.

A third limitation of the data sources was that four of them did not span the entire study period. This could have lead to a number of problems, including underestimation of the number of IDU deaths in Vancouver. For example, the data bases for the two hospitals, St. Paul’s and Vancouver General Hospital, only extended to November, 1996 and October, 1996 respectively, potentially resulting in missed cases. For example, only one death from the study sample was documented for December, 1996. Considering there was an average of four deaths per month in 1996, it should be acknowledged that the incomplete information for December may have resulted in missing some IDU deaths. In addition, information from Vancouver Native Health Society and the AIDS social worker at Vancouver General Hospital was only available from 1995 onwards. However, the AIDS social worker believed this was not a problem. as IDU’s with HIV/AIDS essentially
only started receiving care at Vancouver General Hospital in 1995 [111]. While the potential for missing IDU’s from these incomplete sources existed, it was hoped that using the multiple sources compensated for a deficiency in any single source.

In addition to being subject to the accuracy of the recorder, information in medical and client records was also subject to the accuracy and completeness of self-disclosure by the IDU. While this potential limitation cannot be ignored, a study by Goldstein et al [112] determined that self-reporting by IDU’s in New York was reliable and accurate.

**Length (in days) as a Measurement of Quality of Palliative Care.** An important consideration in interpreting the results of this study is that length of palliative care is only one measure of its quality. Further research is needed to expand on this important, but limited measure of palliative care.

Another limitation is the division of palliative and aggressive therapy into two mutually exclusive categories. As Kuhl [86] suggests, ideally these two forms of therapy overlap in the care of an individual with HIV/AIDS.

**Potential for Selection Bias.** It may be possible that sources used in identifying IDU’s biased the study results. For example, IDU’s who did not access the usual health care services for individuals with HIV/AIDS would not have been included. This might imply that many IDU’s who died without any form of palliative care were not included.

Methods for locating IDU’s from the seven different sources were not all the same, which may have led to potential bias. For example, identifying IDU deaths through talking with direct service workers at May’s place might have been more exhaustive and complete.
than the hospital medical records searches. If true, this would have biased the sample towards IDU’s who died in a hospice.

Information Collection. Initially, the plan for data collection called for the researcher to complete all data collection. Unfortunately, Vancouver/Richmond Health Board would not allow the author access to patient files, which necessitated the use of a second data collector. Therefore, inter-rater reliability is a concern. In order to address this potential problem, a second, less complex collection tool was utilized by the Vancouver/Richmond Health Board data collector. Only information on concrete, or more objective variables was gathered.
6. Conclusions

Although this study is a descriptive one with the aim of generating (and not testing or confirming) hypotheses, there are a number of important generalizations that can be gleaned from this study about health care delivery for HIV-positive IDU's in Vancouver. Ten conclusions and recommendations are noted below.

1. The epidemic of HIV/AIDS among IDU's is getting worse

While this conclusion is by no means unique to this study, the number of deaths of IDU's with HIV/AIDS per year show an alarming increase from 1991 to 1996. The actual number of HIV-infected IDU's in Vancouver is not known, but recent studies confirm [6, 8] that the trend points to a sharp increase in prevalence. Using deaths of HIV-infected IDU's as an outcome measure has merely supported what other studies have shown.

The current overall trend in Vancouver for AIDS-related deaths, for all risk categories, shows a noticeable decrease, attributed primarily to new antiretroviral therapies. However, considering the relatively short span from HIV diagnosis to death for IDU's in Vancouver, and given that less than half of the IDU's in this study accessed antiretroviral therapy, the marked decrease in overall AIDS deaths may soon be reversed. An important concern, then, is developing strategies to include IDU's in the use of antiretroviral therapy.

The implications of this trend are enormous, and go far beyond the scope of palliative care services. In keeping with the focus of this paper, however, it is imperative to stress
that planning for health care delivery at the end of life must acknowledge this trend in order to adequately prepare for it.

2. There is a need to agree upon a common operational definition of palliative care.

For the sake of future research in palliative care services, an agreed-upon definition would allow for comparison of results from various studies and locations. The comparison of statistics on palliative care among various countries revealed highly varied utilization of palliative care services, depending on the criteria used. The disparity of utilization leads to the inevitable conclusion that palliative care was defined in various ways.

This study utilized three different sets of criteria for palliative care as a form of sensitivity analysis, due to the lack of a standard definition. In addition to McLeod’s criteria [102] of having a “No Code” order written, palliative care orders written and no aggressive therapy, analysis using: 1) palliative care for longer than two days and 2) dying in a hospice or palliative care unit, were included. The problems with McLeod’s definition have already been discussed. However, its straightforwardness does offer the advantages of drawing a distinct line between the often blurred division between acute and palliative care.

3. If palliative care is to be part of the health services offered to IDU’s with HIV/AIDS in Vancouver, the provision and appropriateness of acute, intensive and palliative care needs to be reexamined.
Dying in an intensive care unit with a terminal illness such as AIDS is, in most cases, inappropriate. Dying on an acute care ward with less than two days of palliative treatment is not much of an improvement.

In order for optimal care delivery at the end of life, health care providers for IDU’s need to reexamine priorities when an individual enters a hospital, albeit acutely ill, but dying with a terminal illness. Coordination of service delivery between hospital and community is important in order to introduce (and carry through) the concept of palliation well before an individual becomes very ill. Strategies aimed at educating both patients and health care providers might assist in dealing with an IDU who is dying, and presents him/herself to an emergency department acutely ill, so that the push for acute or intensive care may be cushioned by a greater awareness of and sensitivity to the needs of a terminally ill person.

More effort must be made to provide appropriate palliative care services to people dying on acute care wards in hospitals. Due to limited space and availability, not every IDU has the opportunity to spend his/her last days in a palliative care unit or hospice. It is, therefore, necessary that palliative services be provided for individuals, regardless of location of death.

4. Palliative care resources in Vancouver for IDU’s need to be assessed.

As the number of deaths of IDU’s with HIV/AIDS increases, a corresponding increase in palliative services needs to occur. It is important to determine whether or not current resources are adequate. Currently, a new community hospice is being planned, as an
expansion of the services of St. James Social Service Society (the organization which runs May’s Place). This new facility, to be called Cottage Hospice, will open in 1998, and will provide care for up to ten people at a time.

A second issue for current and future palliative care services is their ability to accommodate the unique needs Vancouver’s IDU’s. As Small (1993) states, openness to accepting IDU’s is going to be a major challenge for future palliative care services. One important issue of accessibility is geographic location. Close proximity to the IDU’s community (e.g. Downtown Eastside) would allow friends and relatives to continue to visit and be involved, especially since many members in this community do not own vehicles. May’s Place, located in the middle of Vancouver’s Downtown Eastside, exemplifies this. Normandy House, however, is located quite a distance from Vancouver’s downtown.

Another issue of accessibility is the sensitivity to the social and behavioral aspects of injection drug use. For example, palliative care ideally could incorporate a harm reduction philosophy in a way that drug use which did not severely compromise the IDU’s, staff’s or other patients’ health or safety might be tolerated. Actual injection drug use in a health care facility may be considered be too risky; nonetheless, the issue of compromise between the needs of an IDU and the policies of a health care facility must be addressed.

5. Guidelines are needed for determining when the care of an IDU with HIV/AIDS should move from acute to palliative treatment.
This task is difficult, as acknowledged in previous discussion, because the line between acute and palliative care is not always obvious, especially for AIDS. However, the disparity among the care of IDU’s with HIV/AIDS at the end of life, as demonstrated in this study, calls for some form of standardization. Guidelines would have to remain flexible, but would perhaps assist members of the health care team in decision making. Input from a multidisciplinary health team would be needed, and would have to include input from IDU’s themselves.

6. Future studies on IDU’s with HIV/AIDS need to measure palliative care in more diverse ways.

Length of palliative care utilization is an important component in describing and evaluating end-of-life care for IDU’s with HIV/AIDS. Nonetheless, it is one-dimensional. Future study initiatives could expand the concept by analyzing such factors as patient and family satisfaction, control of pain and other disease symptoms, and cost-effectiveness. An economic analysis comparing location (e.g. home, hospice and hospital) and type of care (e.g. palliative versus acute and intensive) would be quite relevant.

7. End-of-Life Service utilization by IDU’s with HIV/AIDS needs to be included in current and future prospective research.

Due to the limited perspective of a retrospective study such as this one, an alternative study design such as a prospective cohort study, could approach the issue with a different,
more complete perspective. IDU cohort studies currently underway may be able to 
incorporate palliative care utilization into their framework.

A prospective study would also lend itself to looking at additional aspects of palliative 
care (e.g. cost-effectiveness).

8. Due to the short time period between HIV diagnosis and death for IDU’s in 
Vancouver, earlier planning and intervention regarding end-of-life services is necessary.

The median length from HIV diagnosis to death for this study was 36 months, or just 
three years, and the median length from AIDS diagnosis to death was only six months.
This implies that the total amount of contact with health care services is less than for the 
average HIV positive individual. Less contact means less discussion and less planning for 
both IDU and health care provider. It may seem inappropriate to start talking about 
preparing for death soon after an HIV diagnosis, but implementation of palliative services 
at an early stage, integrated with aggressive and preventive therapies, may be a key to 
improved services at the end of life.

A shorter length of time between HIV diagnosis and death may be due to several 
factors, including late screening, inadequate treatment, and chaotic and unhealthy lifestyle. 
Efforts must be made to investigate the impact of these potential factors and strategies in 
which to address them.
9. Further exploration into the gender differences of access to hospice care, drug abstinence at time of death, and progression to AIDS among IDU’s in Vancouver should be made a research priority.

Information on the differences between male and female injection drug users in the literature is lacking. Answers to the disparities mentioned above can only be subject to speculation. It is not immediately clear why female IDU’s were much more likely than males to die from causes other than AIDS.

10. An evaluation of the reliability of established data bases is imperative.

Much of the information collected on the IDU’s with HIV/AIDS came from hospital medical records data bases. Numerous examples of the inaccuracy of this information source have already been discussed, such as the low percentage of IDU deaths at St. Paul’s Hospital which were generated by the Medical Records computer search. This shortfall was exposed by the cross-checking with other data sources. However, other shortfalls of the data sources may not have been uncovered.

This study attempted to address the issue of incomplete data by utilizing a number of different and overlapping information sources. However, issues of reliability and completeness have implications for retrospective studies which rely entirely on one data source.

In conclusion, a major accomplishment of this study was the creation of a data base of all HIV-positive IDU deaths in Vancouver from 1991 to 1996. This data base has
provided better insight into the beginning stages of the emerging AIDS epidemic among Vancouver’s IDU’s, which will be necessary in order to plan for future policies and services. In addition, the examination of end-of-life or palliative service utilization by IDU’s with HIV/AIDS is a much needed contribution to a research topic that has been largely ignored in Canada.

The results are both promising and disappointing depending on one’s emphasis. The majority of IDU’s died in acute care wards following only a short period of palliative care, if any. However, a substantial minority died in either a hospice or palliative care unit, following a lengthy period of palliative care, in an environment specializing in providing comfort and dignity to individuals dying with a terminal illness.
7. References


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and followed up for up to nine years from seroconversion. (Italian Seroconversion Study). British Medical Journal, 1994; 309: 1537-42.


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Appendix 1: Data Collection Tool

I.D.# St. Paul’s Hospital
      May’s Place
      Normandy Hospital
      Vancouver Health Department
      Vancouver Hospital
      Downtown Community Health Centre
      Portland Hotel
      Native Health Services

Name_____________________________________________________(first, middle, last)

Address

Postal Code __ __ __

A. DEMOGRAPHICS

1. Gender __ (male, female, transgendered)

2. Birth date __ __ __ (day, month, year)

3. Education
   a) grade school, number of years __ (0 to 13, or unknown)
   b) post secondary, number of years __ (0 to 10, or unknown)
   c) degrees, diplomas, etc __ (undergraduate degree, graduate degree,
                              college diploma, trades certificate,
                              unknown)

4. Race/Ethnicity __ (Aboriginal, Caucasian,
                       other ____________, unknown)

5. Living Conditions at time of death
   a) housing __ (apt/condo, single detached house,
                  hotel/rooming house, shelter/hostel, no
                  fixed address, other, unknown)
   b) housing amenities: bath __ (private, shared, none, unknown)
      kitchen __ (private, shared, none, unknown)
      telephone __ (private, public, unknown)
   c) living arrangement: __ (living alone, with friend(s), with
                              spouse/partner, with parent(s)/
                              sibling(s)/adult child(ren))
   d) living with dependent children __ (yes, no , unknown)
6. Main income source at time of death __ (paid employment, pension, savings/loans/gifts, community agencies, unemployment insurance, social assistance, other, unknown)

7. Other risk categories __ (prostitute, MSM, unknown, none)

**B. HIV/AIDS**

1. Date known HIV positive __ __ __ (day, month, year, if known)

2. AIDS diagnosis made __ (yes, no, unknown)
   - if yes:
     a) Date of AIDS diagnosis __ __ __ (day, month, year, if known)
     b) AIDS defining illness
     c) Number of days from AIDS dx to death __ (number of days)

**C. DEATH**

1. Date of death __ __ __ (day, month, year)

2. Place of death __ (St. Paul’s Hospital, Vancouver Hospital, Home, May’s Place, Normandy Hospital, other, unknown)
   - if in hospital:
     a) type of ward __ (emergency, emergency- DOA, family practice, Clinical teaching unit, palliative care unit, ICU, other, unknown)
     b) length of terminal admission __ (length in days, if known)

3. Intended place of death __ (St. Paul’s Hospital, Vancouver Hospital, Home, May’s Place, Normandy Hospital, other, unknown)
   - if in hospital:
     a) type of ward: __ (Palliative care unit, other, unknown)
4. Cause(s) of death

(as listed in death summary)

5. Is death HIV/AIDS related
   _ _ (directly, indirectly, no, unknown)

6. Is death from suicide
   _ _ (yes, no, unknown)
   if yes:
     a) was it a planned, peaceful event
        _ _ (yes, no, unknown)

D. SERVICE UTILIZATION

1. Type of care at death
   _ _ (aggressive therapy with resuscitation as an option in therapy, aggressive therapy with a no resuscitation order written, palliative care in which orders for no resuscitation and for palliative care had been written, other, unknown)

2. Palliative Care
   _ _ (yes, no, unknown)
   if yes:
     a) date palliative care initiated
        _ _ _ _ (day, month, year, if known)
     b) total length of palliative care
        _ _ (number of days, 0 if less than one day)

3. Number of hospitalizations since HIV dx
   _ _ (number of hospitalizations)

<table>
<thead>
<tr>
<th>HOSPITALIZATIONS:</th>
<th>Reason(s)</th>
<th>Lgth of hosp. (in days)</th>
<th>Date of admission</th>
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<tbody>
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<td>1.</td>
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4. Number of E.R. Visits since HIV dx (number of visits)

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<tr>
<th>E.R. VISITS:</th>
<th>Reason(s)</th>
<th>Date</th>
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5. Source of primary care (IDC, CHC, private GP, NHS, other, unknown)

6. Treatment for a psychiatric condition since HIV dx (yes, no, unknown)

7. Community services accessed since HIV dx (homemaker, home nursing, AIDS Vancouver, methadone program, other, none, unknown)

8. Anteretroviral therapy (yes, no, unknown)

**E. DRUG USE**
1. Drug use at time of death/ up to final admission  
   if drug use:  
   a) type(s) of drug  
   if abstinent:  
   date of last drug use  

2. Using methadone

<table>
<thead>
<tr>
<th>1. Drug use at time of death/ up to final admission</th>
<th></th>
<th></th>
<th>(abstinence, circumstantial, recreational, addiction, unknown)</th>
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</thead>
<tbody>
<tr>
<td>if drug use:</td>
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<tr>
<td>a) type(s) of drug</td>
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<tr>
<td>if abstinent:</td>
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<td></td>
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<tr>
<td>date of last drug use</td>
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<td>(date of last drug use, if known)</td>
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<tr>
<td>2. Using methadone</td>
<td></td>
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<td>(yes, no, unknown)</td>
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### Appendix 2: Data Collection Tool for Vancouver Health Board

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<tbody>
<tr>
<td>1. Name</td>
<td>____________________________</td>
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<td>2. PHN</td>
<td>____________________________</td>
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<tr>
<td>3. Date of Birth</td>
<td>____________________________</td>
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<tr>
<td>4. Date of Death</td>
<td>____________________________</td>
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<tr>
<td>5. Gender</td>
<td>____________________________</td>
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<tr>
<td>6. Race</td>
<td>____________________________ (Caucasian, Aboriginal, Hispanic, African/Caribbean, unknown)</td>
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<tr>
<td>7. Housing</td>
<td>____________________________ (apt/condo, house, hotel/rooming house, no fixed address, unknown)</td>
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<tr>
<td>8. Income source</td>
<td>____________________________ (employment, pension, UI, social assistance, unknown)</td>
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<tr>
<td>9. Date known HIV positive</td>
<td>____________________________</td>
</tr>
<tr>
<td>10. Has AIDS dx been made?</td>
<td>____________________________ (yes or no)</td>
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<tr>
<td>11. Date of AIDS dx, if known</td>
<td>____________________________</td>
</tr>
<tr>
<td>12. AIDS defining illness, if known</td>
<td>____________________________</td>
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<tr>
<td>13. Location of death</td>
<td>____________________________ (home, hospital, street, unknown)</td>
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<tr>
<td>14. Cause of death</td>
<td>____________________________</td>
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<tr>
<td>15. Was client in palliative care program or officially receiving palliative care?</td>
<td>____________________________ (yes or no)</td>
</tr>
<tr>
<td>16. Was client using injection drugs at (or near) time of death?</td>
<td>____________________________ (yes or no)</td>
</tr>
<tr>
<td>17. Type(s) of drugs used (includes street drugs and alcohol)</td>
<td>____________________________</td>
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</table>