HIV and injection drug use amongst First Nations in Vancouver: Outcomes of Care and Neglect

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Abstract

The purpose of this study was to examine First Nation's use of the hospital care from the point at which they were known to be HIV positive until death occurred. In British Columbia, First Nation's persons represent approximately 5% of the population. However, in 1997 First Nations made up 13.6% of new HIV diagnoses in BC. Because St. Paul's Hospital in Vancouver cares for the majority of persons with HIV/AIDS in BC, data were collected from a chart review of all HIV/AIDS related deaths occurring at St. Paul's and from the Drug Treatment Program of the British Columbia Centre for Excellence in HIV/AIDS. In 1997, once known to be HIV positive, First Nations persons were sicker earlier, with fewer days on antiretroviral therapy, shorter life from HIV diagnosis to death, more hospital admissions and hospital days per admission and less palliative care. Improved access to primary care, palliative care, housing and social support is needed to enhance the quality of living and dying.

Introduction

The purpose of this study was to examine First Nations use of the hospital care from the point at which they were first known to be HIV positive until death occurred. An examination of the patterns of use of hospital care provides insight into the experience of those receiving care and may suggest changes which need to be made to the delivery of care, or to the programs of care.

As with other epidemics, First Nations are suffering a disproportionate burden. In British Columbia, First Nations persons represent approximately 5% of the population. However, in 1997 First Nations made up 13.6% of new HIV diagnoses. Although prevention initiatives began in the late 1980's, it is only recently that the magnitude of the HIV/AIDS epidemic in First Nations has become apparent. Improvements to programs of prevention, health care, social services and housing will only be made on the basis of demonstrated deficiencies. This

paper is an early effort in documenting the impact of the HIV/AIDS epidemic on First Nations. As the epidemic evolves in British Columbia, the data presented here will provide a benchmark to measure the impact of new programs.

Background

Vancouver, British Columbia is an epicentre city in the HIV/AIDS epidemic in Canada (Health Canada, 1997). The first wave of the HIV pandemic infected predominantly white gay men. By the mid to late 1980's, First Nations gay men were also presenting with advanced HIV disease. These men instigated the founding of the first First Nations HIV/AIDS community based organization in BC: Healing Our Spirit--BC First Nations AIDS Society.

Despite significant and early initiatives in establishing an out-reach street nurse program (1989) (Rekart et al. 1989) and what is now the largest needle exchange in North America (1988) (Bardsley et al., 1990), Vancouver is in the midst of a dramatic outbreak of HIV and Hepatitis C in injection drug users (Strathdee et al., 1997; Patrick et al., 1998). Twenty-eight % of those infected are First Nations persons (Patrick et al., 1997). Much of this outbreak can be attributed to intravenous cocaine use with multiple injections daily (Patrick et al., 1997a). This outbreak appears to be leveling off due to saturation of the population at highest risk (Patrick et al., 1998).

The delivery of health care in British Columbia is undergoing substantial change as resources are shifted from an acute care hospital base to the community (Seaton et al., 1991). St. Paul's Hospital currently operates 460 beds (reduced by 100 beds since 1992), is a university affiliated hospital owned by the Sisters of Providence of Charity under Providence Health Care, and is one of four hospital boards operating under the new (1996) Vancouver/Richmond Regional Health Board. St. Paul's Hospital, which cares for 85% of the province's HIV/AIDS case load or 11% of Canada's caseload, has been funded by the B.C. Ministry of Health since 1986/7 to maintain 25 AIDS dedicated beds. Since 1989, seven of these beds have been located on the Palliative Care Unit (Goldstone et al., 1995). The acute care system is extremely pressured in attempting to respond to all those who present for care.

The British Columbia Centre for Excellence in HIV/AIDS was funded by the British Columbia Ministry of Health in 1992 to establish treatment guidelines (British Columbia Centre for Excellence in HIV/AIDS, 1999) and to distribute specific HIV/AIDS drugs across the province. The intention is to provide universal access to drug treatment to all British Columbians, including Status and Non-status persons. Pharmacare, a

department of the BC Ministry of Health, funds the program; thus, there is no direct cost to the individual. In addition, the Centre conducts viral and epidemiologic research and provides education to health care professionals. In the process of the Centre's work, a consultation process with First Nations HIV/AIDS community based organizations is maintained.

The Vancouver Native Health Society was founded in 1990 to provide culturally competent health care for inner city First Nations persons. Available data suggested that the seroprevalance among street involved First Nations was 6% (n = 28 persons) (Rekart, et al., 1991). In 1991, upon recognizing the need for formal liaison between St. Paul's Hospital, the position of a joint outreach social worker/AIDS Coordinator was funded (1993) by the British Columbia Ministry of Health (Tsang et al., 1991). Vancouver Native Health Society is now a major provider of primary care in the inner city, the Downtown Eastside.

St. Paul's Hospital and the AIDS Care Team at St. Paul's have been engaged in the process of adapting care to the needs of HIV infected drug users for several years. There has been a steady increase in the hospitalization of injection drug users, most commonly for the treatment of septicemia, endocarditis, cellulitis or community acquired pneumonia. Many are First Nations persons. Once the acute medical interventions have stabilized the individual, and managed the addiction, often with methadone, HIV testing and primary HIV care is offered. Many are found to be HIV positive. Some are responsive to the offer of residential recovery programs and/or maintenance on methadone. Others return to injection drug use (usually but not limited to cocaine, heroin or both), alcohol, the sex trade and life on the street or in single room occupancy hotels in the Downtown Eastside, the urban core. Drug treatment services are inadequate in quality and quantity, and the continuity of methadone maintenance is difficult. While increased and enhanced primary care services are now available in the Downtown Eastside, alcoholism, chronic mental illness, a history of head injury, injection drug use, HIV/AIDS, tuberculosis and extreme poverty co-exist in this community. As well, the gentrification of adjacent neighbourhoods has led to a concentration of urban decay. The withdrawal of federal support for social housing has compounded the loss of low income housing (O'Shaughnessy et al., 1998). Issues of safety, nutrition, shelter, addiction and social chaos dominate the lives of the citizens of this neighbourhood. Because the majority of HIV infected First Nations persons live in these circumstances, we were prompted to examine patterns of hospital utilization (number of admissions to hospital and length of stay) by First Nations persons with HIV/AIDS.

Methods

The population studied was first defined as all HIV positive persons known to both Vancouver Native Health Society and St. Paul's Hospital who died in 1997 (N = 128). Clinical staff of Vancouver Native Health Society and St. Paul's confirmed the ethnicity and location of these deaths. An internal clinical chart review of those deaths occurring at St. Paul's Hospital (N=62) was undertaken. Searching the St. Paul's Hospital medical records database identified charts for review. To enhance the internal consistency of the data collection and to ensure optimal use of the technology, a single individual collected data from the Medical Records Department. Data from the chart review were then linked with the BC Centre's Drug Treatment Program. Data were collected on demographic characteristics, disease progression, use of antiretroviral therapy and utilization patterns of acute hospital care and hospital based palliative care from the time an individual was known to be HIV positive to death. First samples were compared non-First Nations Nations and non-parametric tests between two medians. Proportions were compared using the chi-squared test. All reported P-values were two sided. Subjects with missing values were excluded from multivariate analysis. For insight into the meaning of the quantitative data, reference was made to qualitative studies by Schilder et al. (1998 (a), (b), (c)).

Results

Location of Deaths in 1998

Examining the location of death gives an insight into the quality of life of individuals immediately preceding and at the time of their death. For example, the relief of physical pain and other symptoms, access to social, emotional and spiritual support and the quality of shelter are key factors when evaluating the quality of living while dying.

In this study two levels of analysis were conducted. The first was an identification of the location of death for all deaths reported to the St. Paul's AIDS Care Team and Vancouver Native Health Society (128 deaths). The second level of analysis was a detailed review of those deaths, which occurred at St. Paul's Hospital in 1997, that is 62 of the 128.

Of the 128 persons with HIV/AIDS reported by St. Paul's AIDS Care Team and Vancouver Native Health Society, 19% (24) were First Nations persons (Table 1). Overall, the location of death for First Nations and non-First Nations persons was different (p=<0.001). While the percent dying in St. Paul's acute care beds or in other hospitals was similar, 17% (4) First Nations persons died in a hospital or community palliative

environment compared to 29% (30) non-First Nations persons. The degree of poverty and the fear of institutional care (both hospitals and community based palliative care) experienced by First Nations persons is illustrated by the fact that 25% (6) of First Nations persons died in a single room occupancy hotel (SRO) compared with <1% (1) non-First Nations person. In the authors' experience, this is related to residual impact of residential schools and the collective experience of abuse, rejection and abandonment.

In the absence of decent affordable housing, SROs become home for the most poverty stricken. SROs usually have minimal to hazardous facilities for basic hygiene, food storage and preparation, are day to day tenancy and are often not visited by home care nurses for reasons of physical safety. Thus, home based palliative care is virtually impossible. Despite this environment, some are able to gain a sense of sanctuary, in part because it is safer than the street and because there is some sense of security and comfort in a familiar community with family or family of attachment close at hand. Indeed the authors recognize that for some, the personal space of an SRO outweighs the unknowns of a hospital or community hospice.

Nevertheless, because SROs are substandard housing, Home and SRO were made distinct categories. Sixteen-percent (15) of non-First Nations died at Home; no First Nations person died in a Home that was not an SRO. Close follow-up of First Nations persons confirmed that violent death (unintentional overdose, assault and suicide by overdose and hanging) accounted for 4 (16.4%) deaths of First Nations persons compared with 10 (9.6%) deaths of non-First Nations persons. Eight (7%) of non-First Nations persons died in an unknown locations compared with 1 (<1%) First Nations person.

Table 1 - Location of all deaths reported to St. Paul's Hospital's AIDS

Care Team and Vancouver Native Health Society in 1997

N=128*

| Location of Death | First Nations Persons n = 24 (19%) | non-First Nations persons n = 104 (81%) | p value |
|---|---------------------------------------|---|---------|
| | | | <. 001 |
| St. Paul's, acute care units | 9 (36%) | 36 (35%) | |
| Unstable housing home in single room occupancy hotels | 6 (25%) | 1 (<1%) | |
| Other hospitals, acute care units | 4 (17%) | 13 (12.5%) | |
| Palliative environments: St. Paul's & community hospices | 4 (17%) | 30 (29%) | |
| Unknown | 1 (4%) | 8 (7%) | |
| Stable housing home | 0 | 16 (15%) | |

*62 Deaths Occurred At St. Paul's in Acute and Palliative Care

A detailed (second level) analysis of the 62 deaths occurring at St. Paul's Hospital was undertaken. These findings are reported below.

Demographic characteristics at terminal admission

Of the 62 persons identified by the chart review 55 were men, 6 were women, and one was transgendered. The median age at death was 42 years for men, 41 years for women and 27 years for the transgendered person. First Nations men (6) died at a median age of 36 (range 31-41) versus 43 years (range 27-71) for non-First Nations men (49). Thirty percent (3) of deaths of First Nations persons were women (median age 45, range 33-66) compared with 6% (3) non-First Nations women who died in 1997 (median age 39, range 34-43).

Transmission

Overall, as illustrated in Table 2, the route of transmission for First Nations and non-First Nations persons was different (p=<0.001). Eight (80%) First Nations persons attributed their HIV infection to injection drug use compared with 14 (27%) non-First Nations persons. Transmission via infected blood or blood products were similar in both groups. Injection drug use will drive the HIV epidemic in First Nations Peoples (Nguyen et al, 1998) and will have a particularly heavy impact on First Nations women.

Disease progression at terminal admission

The "CD4 count" and "plasma viral load" are two key markers of the degree of progression of HIV related disease. Without treatment, progression to AIDS occurs approximately 8-10 years after infection with HIV. Progression to AIDS can be slowed by timely treatment with antiretroviral therapy which reduces the viral load and enhances the ability of the immune system to protect the body from infection. Antiretroviral therapy should be considered once the viral load is greater than 5,000 copies and the CD4 count is below 500/mm3 (British Columbia Centre for Excellence in HIV/AIDS, 1999). Other drugs are used to prevent the occurrence of the Opportunistic Infections that mark the arrival of "AIDS". Without the use of antiretroviral therapy and drugs, which prevent Opportunistic Infections, infections diagnostic of AIDS usually occur once the CD4 count is below 200/mm3.

Table 2 illustrates that the two groups in this study were remarkably similar with respect to disease progression at the time of death. Eight (80%) First Nations persons had a diagnosis of AIDS compared with 37 (71%) non- First Nations persons. Median CD4 counts, 50 (range 20-220) (First Nations persons) and 40 (range 10-490) (non-First Nations persons), were clinically similar; however, the upper limit of the range was clinically different. That is, those persons with a CD4 count above 200-250 were less likely to experience an illness diagnostic of AIDS and thus had a longer life expectancy. The viral load measurements, (both the median and the range) were clinically similar. Prescribed antiretroviral therapy (ART) was similar: 7 (70%) First Nations persons compared with 41 (79%) non-First Nations persons. However, the median duration of antiretroviral therapy, from the date prescribed to the date of death, for First Nations persons (n= 7) was significantly lower at 97 days (range 30-1416) and for non-First Nations persons (n=48) was 613 days (range 919-1479) (p=.014). No adherence data were available. No data were available on the use of drugs which prevent Opportunistic Infections. Clearly, there is an urgent need to make antiretroviral therapy and therapy which prevents Opportunistic Infections accessible to First Nations in a timely manner.

Table 2 – Disease progression for those who died at St. Paul's Hospital in 1997

| | First Nations Persons | non-First Nations | p – value |
|---|----------------------------|---------------------------------|-----------|
| | n=10 (%) | persons n=52 (%) | |
| Transmission | | | 0.023 |
| IDU | 8 (80%) | 14 (27%) | |
| Homosex/Bisexual | 0 | 24 (46%) | |
| IDU/Homo/Bisexual | 0 | 2 (4%) | |
| Transgendered | 1 (10%) | 0 | |
| Blood/Blood products | 1 (10%) | 4 (8%) | |
| Heterosexual | 0 | 1 (2%) | |
| Unknown | 0 | 7 (13%) | |
| Disease progression at terminal admission | | | |
| AIDS | 8 (80%) | 37 (71%) | 0.570 |
| Last reported: | 1 (00.1.) | | |
| CD4 count (median) | 50 (20-220) (n=8) | 40 (10-490) 0.73 (n=44) | |
| viral load (median) | 32,000 (22, -54, 000 (n=8) | 16,000 (20, -62, 000) (n=50) | |
| Ever received ART | 7 (70%) | 41 (79%) | 0.540 |
| Duration ART (median days) | 97 (30-1416) (n=7) | 613 (19-1479) (n=48) | 0.014 |
| Cause of Death | | | |
| Kaposi's Sarcoma | 0 | 2 (4%) | |
| Pneumocystis c. pneumonia | 0 | 4 (8%) | |
| Other Opport. Infections | 6 (60%) | 10 (19%) | |
| Other Malignancies | 1 (10%) | 19 (36.5%) | |
| HIV wasting | 0 | 5 (10%) | |
| HIV Encephalopathy | 0 | 1 (2%) | |
| Tuberculosis | 1 (10%) | 2 (4%) | |
| Overdose | 1 (10%) | 1 (2%) | |
| No AIDS defining illness | 1 (10%) | 8 (15%) | |

AIDS Defining Illnesses

The AIDS defining illnesses at terminal admission were the usual range of illnesses seen in advanced HIV disease. Other Opportunistic Infections in First Nations persons included 3 with recurrent bacterial pneumonia and 4 with infections of very advanced HIV disease; however,

no malignancies were reported. It is notable that 1 (10%) First Nations persons and 8 (15%) non-First Nations persons entered hospital for their terminal admission with no AIDS defining illness. This illustrates that HIV/AIDS is only one illness that causes death in persons with a poor health status.

Cause of Death

Table 2 illustrates the cause of death. Again, the illnesses represent the usual causes of death in persons with advanced HIV disease. Tuberculosis was present in both First Nations and non-First Nations persons. No First Nation person died of a malignancy or HIV encephalopathy, both of which are associated with prolonged survival with HIV/AIDS.

Length of Life, HIV and AIDS to Death

Table 3 illustrates length of life from the point at which an individual was known to be HIV positive, to AIDS and to death. For First Nations persons, the median length of life, from HIV diagnosis to death, was 854 days (range 189-4758), and from AIDS to death was 95 days (range 2-259) compared with 1672 days (30-5488) and 465 days (3-2255) for non- First Nations persons. Since the median period of antiretroviral therapy for First Nation was 97 days, this therapy was initiated upon diagnosis of AIDS, which is very late in the course of the HIV disease.

Table 3 - Hospital utilization for those who died at St. Paul's Hospital in 1997 n=62

| | First Nations n=10 | Non-First Nations persons n=52 | p – value |
|--|-----------------------|-----------------------------------|-----------|
| Length of Life-Days | | | |
| HIV to Death (median) | 854 (189-4758) | 1672 (30-5488) | .326 |
| AIDS to Death (median) | 95 (2-259) | 463 (3-2255) | .060 |
| Hospital Admissions | | | |
| HIV to Death (median) | 5 (4-12) | 3 (1-12) | .005 |
| AIDS to Death (median) | 3 (1-9) | 3 (1-8) | .394 |
| Hospital Days | | | |
| HIV to Death (median) | 46 (2-123 | 27 (2-130) | .300 |
| AIDS to Death (median) | 24 (2-70) | 27 (3—126) | .855 |
| ICU: HIV to Death (median) | 1.5 (1-18), (n=6) | 3.5 (1-33), (n=12) | .62 |
| Palliative Modality HIV to Death – Days | | | |
| median | 0 (0-3) | 0 (0-67) | .331 |
| mean | .6 | 7.5 | .331 |
| Pallative Care Unit | 3 (3-3), (n=2) | 11.5 (1-67), (n=22) | .331 |

Hospital Utilization

As shown in Table 3, First Nations persons had more hospital admissions HIV to death than non First Nations (5, range 4-12, compared with 3 (range 1-12) (p = .005) for non-First Nations persons). additional hospitalizations, 2, occurred in the period preceding an AIDS diagnosis. Hospital admissions, AIDS to death, were 3 for First Nations persons (range 1-9) and 3 for non-First Nations persons (range 1-8). The median hospital days, HIV to death, for First Nations persons, were 46 days (range 2-123), compared with the same period for non-First Nations persons were 27 (range 2-130). It is interesting to note that the median days used for hospital care, AIDS to death (24 [range 2-70) compared with 27 [range 3-126]) are similar. Note that for the intensive care unit, 6 (60%) First Nations persons experienced a median of 1.5 days (range 1-18) while 12 (23%) of non-First Nations persons experienced a median of 3.5 days (range 1-33). This means that First Nations persons were more likely to experience an acute and devastating illness leading to death rather than a slower decline ultimately leading to death.

While AIDS is now perceived to be a treatable chronic illness, no cure is yet available. Inevitably, HIV/AIDS will shorten life expectancy. Even in the well ordered life, insufficient attention is given to consideration of how one would like to live out ones final days. In an earlier study of AIDS patients in Vancouver, 95% preferred to die in a palliative environment (Goldstone et al., 1995). Palliative environments included

home, a community based palliative facility or a hospital based palliative care unit. In this study, two (20%) First Nations persons received a median of 3 days of care on the palliative care unit compared with 22 (82.6%) non-First Nations persons who received a median of 11.5 days (range 1-65).

Discussion

Injection Drug Use, HIV and the Health of First Nations Persons in British Columbia

Historically vulnerable to the epidemics of migrating European populations which decimated First Nations populations in North America (Johansson, 1982; Dickason, 1996) and profoundly affected by multiple abuses experienced at residential schools (Millar, 1996; Wiwchar, 1998). Canada's First Nations Peoples are confronted with the epidemics of injection drug use, HIV, Hepatitis B and C, and persistently high levels of tuberculosis. Injection drug use is the route of transmission in half or more of new HIV infections in First Nations Peoples and will thus drive the HIV epidemic (Nguyen et al, 1998). In British Columbia, First Nations Peoples represent approximately 5% of the population (Health Canada, 1995), but in 1997 they represented 13.6% (Wong et al., 1997) of new HIV diagnoses. In an open cohort study of injection drug users in Vancouver, 27% of participants were First Nations persons (Schechter et al., 1998), while in a review (1991-1996) of deaths in Vancouver due to HIV/AIDS in injection drug users in Vancouver, 33% were First Nations persons (Janzen et al., 1997). Other evidence suggests that among First Nations, IDUs, although very knowledgeable about HIV/AIDS, were not well educated, were living in poverty and in unstable housing, and came from a background of abuse, domestic violence and alcohol use (Canadian Aboriginal AIDS Network harm reduction model, 1998).

Vancouver's Downtown Eastside has a stable population but also a pattern of in-and-out migration within British Columbia and across Canada. This pattern of migration includes the movement of First Nations to and from rural reserves, some of whom migrate to Vancouver prior to their AIDS diagnosis in search of HIV/AIDS-related programs, health care resources and HIV- experienced physicians (Wood et al., 1998). However, because of inherent inequities, First Nations persons face great challenges in accessing and adhering to antiretroviral therapy (Heath et al., 1999). A lesser virologic response to antiretroviral therapy has been reported in injection drug users and has been attributed to residual non-adherence. The difficulty in accessing and adhering to a complex antiretroviral treatment represents a threat to the health of the individual injector as well as to the health of the sexual and injection partners (Palepu, et al., 1998).

At the time of writing (the fall of 1999), an outbreak of hepatitis A is occurring in the urban core of Vancouver. This outbreak will undoubtedly have an impact across the province. With respect to hepatitis B, it is important to note that by 1990, British Columbia's rate was almost three times the national average and has been attributed, in part, to injection drug use. A provincial-wide immunization program starting with sixth graders in 1992/93 along with an increased effort to target risk groups is expected to result in a progressive decline in the rate of new cases, but hepatitis B is expected to remain a problem for several years to come. Of the newly identified hepatitis C cases, an estimated 80% are related to injection drug use. To date, British Columbia has accounted for more than half of all hepatitis C cases reported in Canada with a rate that is currently more than four times the national average. This rate is attributed to a higher rate of injection drug use, as well as to more complete reporting in BC than in other provinces (Millar, 1998). In 1997, baseline hepatitis C prevalence in a Vancouver cohort of injection drug users, of whom 28% were First Nations, was 85% (Patrick et al., 1998a). There are no data on the prevalence of hepatitis C in our sample. However, because 80% of First Nations in this study were injection drug users, we must assume they were also hepatitis C positive.

Although an overall downward trend of tuberculosis in First Nations persons living both on and off reserve in British Columbia has been reported, the rates for those living on reserve are approximately five times that of the overall provincial rate (8.7/100,000 in 1991). As early as 1993, a number of cases of tuberculosis related to HIV and injection drug use in First Nations and non-First Nations residents of Vancouver's inner city had been reported (Health Canada, 1995). This trend continues (Patrick, et al., 1999).

Accessing Health Care

The over-representation of First Nations persons in our sample correlates with a qualitative study of street involved gay, bisexual and transgendered persons in Vancouver by Schilder et al. (1998 (a), (b), (c)). Schilder reported high rates of injection drug use in this population and found that First Nations persons reported little experience with primary care, avoided seeking health care until catastrophic illness forced the issue, and tended to present to the emergency room with addiction related disease rather than symptoms of HIV. First Nations persons reported that as children, sexual and physical assault and poverty were common as were histories of running away and survival prostitution. Literacy levels were low. Life as an adult included prison experience, poverty, injection drug use and unstable housing. This population had impaired self-help and

self-care skills were less likely to accept antiretroviral therapy, and when this was prescribed, reported poor adherence to therapy.

Health practice seeks to improve an individual's control over their health. For First Nations persons, managing their health is compromised by social conditions and legislation which does not permit First Nations Peoples full control over the determinants impacting their health status. In Canada, the federal government is responsible for medical and health services provided to First Nations persons living on reservations while the provinces are responsible for the delivery of health care to the general population and off reserve First Nations persons. Participants in this study sought care within the context of provincially funded health care services. Existing services are often not reflective of their cultures and are further compromised by the need for management of addiction and HIV care. The absence of these services on reservations triggers migration to urban settings.

Social, Cultural and Spiritual Identity

Schilder et al. (1998 (a), (b), (c)) in studying HIV positive person in Vancouver, found that First Nations persons often viewed themselves through their traditional cultural belief systems, which include acceptance of variations in the expression of human sexual identity referred to as a "berdache" (Katz, 1976) or "two-spirit persons" (Jacobs et al., 1997). As a First Nations bisexual man explained. "In my language, we call them 'contrary people'. They've always been there because that's just a part of life. [They] are always considered special people." In this study, one First Nations person self identified as transgendered. First Nations participants believed these were unique human beings imbued with special spiritual qualities for the benefit of the community. Schilder also reported that First Nations participants held cultural beliefs, personal spirituality and values that were intrinsic to their social identity. They reported that the health care system did not affirm their self-concept or acknowledge cultural beliefs in ways that could engage them in a care-giving relationship. First Nations participants made reference to healing customs such as the medicine circle, herbal medicine, smudging, and the sweat lodge ceremony. First Nations participants were aware of the validity of their cultures and strongly stated fears of being victimized by religious persons and institutions. These fears are consistent with Albert's (1997) findings in his study on HIV positive First Nations men with addictions living in the downtown core of Vancouver.

Accessing Palliative Care

The low rate of access to palliative care and the very short duration of palliative care are consistent with Janzen, et al.'s (1997) findings in injection drug users in the same community using the same resources. In part, this consistency can be explained by the desire to treat aggressively apparently reversible illnesses associated with injection drug use or HIV/AIDS (Goldstone, et al., 1995). The relative newness of HIV/AIDS, the constant change in available therapies and the optimism surrounding these therapies are undoubtedly influencing factors in this process. Particularly in the hospital setting, health care providers continue to have difficulty in recognizing and implementing a timely and appropriate transition from aggressive therapy to palliative care (The Support Principal Investigators, 1995; Miller & Finns, 1996). This practice will not necessarily be a healing approach for the individual who is dying nor for their immediate family, friends and community and raises the question of the role of advance directives in a marginalized population (Angoff et al., 1998). Advance directives are documents which state the type of care one wishes to receive in advance of serious illness. The legal status of advance directives varies from province to province. Nevertheless, the document serves as a statement which health care providers have an ethical obligation to consider

As an Elder is quoted "Death is not the end, it is a new beginning. It's in a different realm. When you walk into the light, there's unconditional love. Just walk into the light its love. There are no ugly things there." (Vanderhoef, 1998).

Limitations

There are a number of limitations to this study. The sample size is small and thus all P-values must be interpreted as "suggestive" only. The findings in this study are not representative of the whole population of persons living with advanced HIV disease in Vancouver. Note that the 62 deaths reported in this study represent 48% of the deaths reported to St. Paul's Hospital's AIDS Care Team and to the Vancouver Native Health Society for 1997. The limitations also include that data were collected retrospectively and are limited by the information available in the chart.

Conclusion

Once diagnosed with HIV infection, First Nations persons were sicker earlier, had shorter survival, less antiretroviral therapy, more admissions and hospital days and less palliative treatment than non-First

Nations persons. Our results suggest that a number of interventions are needed to mitigate the disaster HIV, the hepitides, tuberculosis and injection drug use represent to First Nations. These interventions include affirming traditional culture, providing improved and earlier access to primary care, developing and implementing innovative drug prevention programs, enhancing access to culturally sensitive alcohol and drug treatment programs, ensuring the provision of safe, stable housing, food and community life, providing social support for adherence to care and therapies, and providing enhanced access to palliative care through education about palliation for providers and HIV-positive persons and their families on and off Reserve.

Acknowledgements

The British Columbia Centre funded this study for Excellence in HIV/AIDS and the Vancouver Native Health Society. The authors are indebted to colleagues at the British Columbia Centre for Excellence in HIV/AIDS, Kevin J. P. Craib for his assistance in the design and statistical analysis, and Dr. M. V. O'Shaughnessy for moral and financial support; to colleagues in the AIDS Care Team, St. Paul's Hospital and Vancouver Native Health Society; Dr. David Patrick, British Columbia Centre for Disease Control Society and Mai Nguyen, Health Canada.

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Special Edition

NATIVE SOCIAL WORK JOURNAL

HIV/AIDS: Issues Within Aboriginal Populations

The Native Social Work Journal is a member of the Canadian Association of Learned Journals

Volume 3, Number 1, September 2000

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Published by the Native Social Work Journal Laurentian University Sudbury, Ontario www.laurentian.ca/www/nhs/

Printed by the Laurentian University Press Sudbury, Ontario

Cover Artwork by Leland Bell

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