

First Nations People and AIDS: A Study of Social Work Knowledge in Northern Quebec

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Introduction

First Nations' people have experienced the greatest increase in the proportion of reported AIDS cases between 1989 and 1998 compared to all other ethnic groups in Canada (Health Canada, 1999). The proportion of reported AIDS cases among First Nations people jumped from 1.3% of the total reported cases in 1989 to 10.9 % in 1998 (Health Canada, 1999). This increase, in spite of the fact that First Nations people represent only 3.6% of the Canadian population (Statistics Canada, 1996), suggests that health and social service professionals working with First Nations people should increase their attention to issues such as AIDS prevention programs directed to First Nations' communities.

AIDS (Acquired Immune Deficiency Syndrome) is an example of a complex problem where scientific and psychological information continually modifies social work intervention. Furthermore, other related aspects of the disease regularly modify treatment dimensions. A recent example is the legal developments which allow AIDS sufferers to use marijuana for treatment purposes. This development demonstrates how quickly social and treatment issues may evolve. The question is whether the profession of social work is equipped to deal effectively with AIDS clients or those at risk of developing AIDS.

Purpose of the Study

This article reports on a study conducted on the level of knowledge of social workers in Northern Quebec with respect to HIV (Human Immune-deficiency Virus), and AIDS. Given that a large number of residents of Northern Quebec are Native, (more than 20,000: Statistics Canada, 1998), the results of this research are relevant for Native Social Work Educators, Native Health and Social Service Directors, as well as social work practitioners working with First Nations Communities. Social workers are often the first line of intervention in terms of education about safe sexual practices and substance abuse, as well as about discrimination

and social justice issues. What then is the level of knowledge of social workers and how prepared are they to deal with this serious problem both on an individual and community level? How much knowledge do they possess about medical issues, transmission of the disease, psychosocial aspects, and legal aspects? Are they able to deal with the discrimination that an HIV diagnosis can generate, and do they know how different ethnic communities are affected?

The results indicate a large proportion (22 out of 57) of social workers tested have little or no knowledge of the complexity of the problem. The Canadian Association of Schools of Social Work, the accrediting body for social programs in Canada, does insist on course content which provides for the integration of knowledge about AIDS /HIV as part of the regular curriculum but only since 1990 (CASSW,1995).

The goal of the research was the evaluation of the knowledge on the part of social workers of the Abitibi-Temiscamingue region of Quebec on HIV/AIDS . We chose to focus on the Abitibi-Temiscamingue region because of its large aboriginal population (over 20 000 people), mainly Algonquin, Cree, and Inuit. Our hypothesis was that social workers have little knowledge of AIDS and related issues, and consequently, they are poorly equipped to deal with the problem as well as provide preventative services.

The Problem

The transmission of HIV occurs in the majority of cases through unprotected sexual contact involving the exchange of sperm, vaginal fluid, or blood, with anal sexual contact being the most common form of HIV transmission and with the receiving partner being the most at risk (Steiner, 1995). There is a clear risk of infection through unprotected vaginal penetration, and it is important to note that vaginal mucous is more fragile and therefore more vulnerable to the virus in young women (Oliver, 1995).

Research demonstrates that intravenous drug users risk infection through soiled needles as well as through unprotected sexual relations (Quebec 1994). American and European studies demonstrate that 40% of intravenous drug users have unprotected sex with non-intravenous drug users, while 20% to 50% of people with psychiatric problems engage in high-risk behaviour (Grassi, 1996) One single unprotected act with an infected individual is enough to transmit the infection (Olivier, 1995). While HIV has been detected in saliva, kissing is seen by most as a low-risk behaviour (Patterson & Robichaud, 1996). There is still a scientific debate as to whether oral sex presents a risk of transmission.

AIDS is not a single disease but rather a combination of symptoms of one or more diseases (Patterson & Robichaud, 1996). Eighty-eight

percent of deaths associated with HIV are related to opportunistic infections (Steiner, 1995). The opportunistic diseases (or secondary infections) are caused by bacteria or germs which would be harmless otherwise. However, since the immune system of the person living with HIV is weak, these germs are able to cause a fatal infection (Patterson & Robichaud, 1996).

One of these opportunistic diseases is tuberculosis which is a serious health risk because active tuberculosis can be transmitted by airborne bacteria (Canadian AIDS Society, 1996). In Canada, the co-infection of HIV and tuberculosis are more and more prevalent, and the incidence of tuberculosis is highest among the First Nations population as well as with intravenous drug users. This infection could be one of the first opportunistic infections affecting people living with AIDS (Canadian AIDS Society, 1996). The Canadian AIDS Society suggests in its brochure that individuals should consult a social worker to find out about the regulations concerning HIV and tuberculosis.

Research on psycho-neuro-immunology has shown that a correlation exists between the capacity of the individual to fight infections, his or her mental health, and the attitude of the individual (Weiser, 1996). A person living with HIV should consider various options in taking charge of the treatment, options which include both traditional medical treatment and/or alternative treatment (Whitehead & Patterson, 1993). The findings indicate that the reproduction process of HIV is complex and that the treatments used to slow down the progression of HIV within the organism are numerous and expensive (CATTE, 1995). Prevention, as opposed to the treatment, is therefore far more advisable.

As of December 31, 1998, there were 16, 236 persons with AIDS and 43, 347 persons infected with HIV in Canada. Furthermore, it is estimated that 11,000 to 17,000 recent cases of HIV have yet to be diagnosed (Health Canada, 1999). In 1998, Health Canada estimates that 87.4% of HIV cases were men and 12.6 % were women. In terms of AIDS cases, 7.4% were women, 92.5% were men and of these, 74.4% were gay or bisexual (Health Canada, 1998). As of 1998, 50.2% of new reported cases of AIDS are men who have had sexual relations with other men; 10.8% are related to perinatal transmission, 16% are related to intravenous drug use, 37.9% to heterosexual relations (where the virus is transmitted mainly from the man to the woman). The total comes to more than 100% since some individuals fit into more than one category as is the case with intravenous drug users and homosexual men.

Given the high incidence of other sexually transmitted diseases, the risk of infection is particularly great among First Nations people. (Health Canada, 1999). In 1985, there were only 2 reported cases of AIDS in the Native population, while in September of 1994, there were 110. In December of 1998, this figure climbed to 321. Today, First Nations people

represent more than 10% of all cases of AIDS in Canada (Health Canada, 1999). Health Canada estimates that there are between 11,000 to 17,000 undiagnosed cases.

Other characteristics of HIV/AIDS and First Nations people include the fact that infected individuals develop AIDS at a younger age than in the rest of the population; 31% will develop AIDS before 30 as opposed to 19% in total population. In the reported 321 infected cases, 263 are men while 58 are women. Native women then represent 18% of infected cases as opposed to 12% in the overall population. Of infected Native men, 57.4% are having sex with men, and 19.4% are intravenous drug users. For Native women, 53.4% are intravenous drug users, while 29.3% are infected through unprotected heterosexual relations. Of the 321 cases among First Nations' people, 151 live in Vancouver, the capital of intravenous drug use (Health Canada, May 1999).

Relevance to Social Work

According to the Canadian Association of Social Workers, "AIDS goes to the heart of our profession, of our competence and our possibilities" (CASW; 1996, 17). People living with HIV/AIDS and those who are part of the individual's support system present various psychosocial needs (Steiner, 1995). A study by Thompson et al. (1996) indicate that persons living with HIV are subject to numerous stresses as well as various levels of distress even before being diagnosed with AIDS. Social work should focus on these needs as well as education and prevention.

The social justice issues related to HIV/AIDS are also numerous (discrimination is the first question which arises). In spite of having a public health system in Canada, Patterson and Robichaud (1996) explain that many of the treatments are expensive and that the level of health care varies from region to region. The authors also point out that treatment facilities are scant in First Nations' communities and even more in remote areas. Even if private insurance companies help to fill the financial gaps, the majority of insurance companies will not take on HIV positive clients if they are not already insured. (Patterson & Robichaud, 1995). CASW (1995) states that:

AIDS is added to an already long list of social problems which "increases the complexity of intervention and the necessity of collaboration." The problem related to psychosocial functioning existing before the diagnosis is worsened by poverty issues from an economic perspective and from the perspective of life opportunities (p. 14).

For social workers, lack of knowledge in the area of HIV/AIDS creates an obstacle to working effectively with clients. It is essential to overcome the irrational fears associated with the cause of infection. Understanding the epidemiology of AIDS is also vital to overcome the long term effects of prejudice against persons whose behaviour puts them at risk.

Legal Aspects

It was only ten years ago that Americans gripped by panic proposed to the Senate compulsory testing of health care personnel (CASW, 1992). In Canada, during this period, the Canadian AIDS Society took an official position against compulsory testing of health care staff. This position was based on the abundant medical information available about the transmission of HIV/AIDS. The Canadian AIDS Society concluded that the risk of infection was so slight that it was thought better to promote measures that would prevent transmitting the infection. For the Canadian AIDS Society, the slight risk of infection in this context did not justify the cost, the infringement of individual rights and the right to privacy (1992).

Most provincial and federal laws prevent discrimination based on a handicap; however, certain provincial human rights commissions do not cover persons living with HIV/AIDS within their definition (Germaise, 1993). The Canadian Charter of Rights and Freedoms states, in article 15, (contrary to the rights of the person) that all individuals have the right "to the same protection and benefits under the law" without discrimination (Patterson & Robichaud, 1996). However, the recourse to these "rights" can be long (around 2 years) and expensive (Patterson & Robichaud, 1996).

Prevention: Some Specific Points

Social workers are in a position to help their clients learn about these prevention methods, regardless of where these social workers practice: schools, agencies, child welfare or child protection, hospitals, mental health centres, or community organizations (Leonard & Holtz, 1996). However, certain authors caution us against the use of inaccurate or unclear language in dealing with prevention of infection. Advice about prevention concerning safe sex should be based on accurate bio-social information, since the use of language that is inaccurate could have devastating results. As an example, there is a difference in the use of organic versus latex condoms since organic condoms, while offering protection against unwanted pregnancy, offer no protection at all from infection of HIV (Patterson & Robichaud, 1996).

In terms of prevention of the transmission of HIV/AIDS, using specific language does not seem to be enough. For example, issues such as

low self-esteem, social isolation, social rejection and guilt on the part of survivors, should also be addressed in promoting prevention (CAS, 1995). According to Rotheram-Borus et al. (1995): "AIDS prevention programs must be tailored to consider stereotypic sex roles, gay youths' sexual orientation, and substance abuse" (320).

Social Workers and Specific Knowledge about HIV/AIDS

According to Leiyu et al. (1993), the majority of studies show that social workers generally lack knowledge about HIV/AIDS, the use of drugs, managing terminal diseases and prevention (Leiu Shi et al. 1993). However, little is known about the impact of social work knowledge in this area. The study by Peterson (1992) provided some insight in a global sense as well as more specifically on social work knowledge about HIV/AIDS. In 1988, a study was carried out on 500 social workers who were members of the National Association of Social Workers. According to Peterson, "a national survey of (...) members to assess social workers' knowledge about AIDS, found that the average respondent correctly answered less than half of 45 questions" (118). Other important conclusions of this survey revealed that the knowledge of those social workers indicating having personal or professional experience with HIV/AIDS was significantly higher than those without (Peterson, 1992).

Only 25% of the social workers in the sample mentioned have professional reasons for knowing about HIV/AIDS, which concerned the author, since all social workers have a professional responsibility to know about AIDS (Peterson, 1992). It is worth noting that of the population in the study, 83.6% had a Masters of Social Work (MSW) (Peterson, 1992). Eight categories of knowledge were identified in developing the questionnaire: transmission, the diagnosis, impact, social policy, resources, feminine reality, minority reality, and gay reality. Knowledge on the part of those respondents having professional reasons to know about the HIV/AIDS transmission and diagnosis was significantly higher in all other areas of knowledge (66.4% and 51.4% accuracy for these categories) (Peterson, 1992)

The purpose of the study by Leiyu Shi et al. (1993) was "[Y] to test the hypothesis that knowledge and skill are significantly associated with improving attitudes" (269). The same study concluded, "Findings show that AIDS related knowledge and skill were significantly associated with improving the general attitudes of social workers toward HIV/AIDS clients" (268). According to Leiyu Shi, of five-hundred and fifty-two (n=552) social workers from North Carolina who were contacted.,

[Y] the 383 respondents identified several skill areas in which they needed improvement. The most frequently identified skills were the ability to deal with clients in crisis (84.9 percent), knowledge about HIV transmission (84.3 percent), the ability to overcome support staff resistance to working with people with HIV/AIDS (73.6 percent) [Y]. (p. 272).

A third study, a Canadian survey, was done on 438 social workers selected because of their work with people living with HIV/AIDS across the country (CASW, 1995). The goal of this survey was to gather information from social workers working in this area in order to develop a guide for members of the Canadian Association of Social Workers (1995). The study reveals that 83% of participants have clients who live in poverty and may be victims of segregation, while 74% have witnessed social dysfunction before the HIV diagnosis (CASW, 1995).

A review of the literature does not indicate the existence of research data specifically related to the realities of social workers working with HIV/AIDS in northern regions. The Canadian study by CASW (1995), which had as its purpose the surveying of workers working in the area of HIV/AIDS, did not include a single social worker from Northern Quebec. This absence is explained by the fact that the majority of populations affected by HIV/AIDS are situated in major urban areas.

Methodology

To answer our questions about social work knowledge, a questionnaire dealing with personal demographic information, and a stamped self-addressed envelope was mailed to 138 social workers. The participants were members of the Order of Social Workers of Quebec (OSWQ) and who are registered with the 08/10 administrative region of the Order (Abitibi-Temiscamingue, James Bay, and Nunavik). The packages were sent to the members from the offices of OSWQ. There were specific First Nations communities included in this region are: Algonkin, Cree and Inuit. A period of one month was given to complete the questionnaire. Financial constraints did not allow for a follow-up mailing as is customary in this type of research. This fact was explained in the introductory letter.

Survey Instrument

The main survey instrument, which was developed by Jean Peterson, D.S.W. from the University of Kansas, was adapted to account for the realities of Northern Quebec. For example, the questions in the

instrument developed by Peterson dealing with Hispanic and African-American minorities were modified to include First Nations' populations. We elected to keep the general structure of the instrument, which consisted of questions which could be answered by the categories True or False or Do Not Know. We chose to keep the DNK category of responses to identify a lack of knowledge and to make the respondent aware of the need for information.

The new questionnaire addressed areas of knowledge relating to general, legal, medical, preventive, psychosocial, discrimination (stereotypes), and the transmission aspect of the virus.

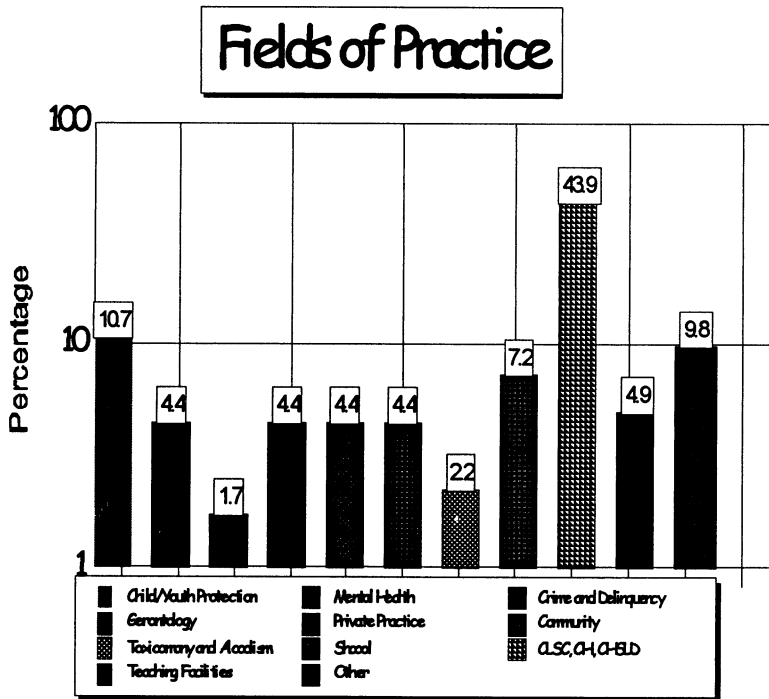
Analysis of the Data

Demographic Data

There were 79 social workers who returned the completed questionnaires, a response rate of 58% of the population of social workers for this region. Of these, 22 (or 28% of the sample) confirmed having personal or professional reasons for knowing about HIV/AIDS, while 57 (72%) admitted having no such reason. Histogram 1 describes the distribution of social workers and their professional areas of practice.

Fifty-four of the social workers who responded to the questionnaire (68% of the sample) indicated that they work in direct practice, 13 (16%) provide indirect practice, and 9 (11%) are involved in other practice areas. In terms of education, 66 (83%) hold a Bachelor of Social Work, 11 (13%) have a Masters' degree, and 2 (2%) have a doctorate. Eighteen (22%) were between 20 and 30 years of age, 18 (22%) between 31 and 40, 30 (38%) between 41 and 50, and 11 (14%) were between 51 and 60.

Histogram 1



Overall Results

In the sample, 47.8% of the questions were answered correctly by the majority of the respondents. The rate of correct responses varied between 50.6% to 89.9%.

Interpretation by specific variables

The questions on general information seemed to have presented an important degree of difficulty. Question 26 makes specific references to information related to First Nations people. The rate of questions with the answers Do Not Know (DNK) was, in a way, reassuring since participants identified these as important shortcomings in their knowledge. Nevertheless, the high rate of DNK answers indicates a serious lack of

knowledge on the part of social workers. All Quebec social workers should know about the existence of AIDS in their area of work (the government implemented a program, "Sida en milieu de travail", to that effect). More encouraging is the rate of correct responses to question 12, but this rate could be related to the fact that there has been a lot of public education on this question.

Q 12: In 1996, in Canada, more people will die from cancer than from Aids.

Q 26: Canadian First Nation leaders declared that the number of HIV-positive First Nation people is increasing at an alarming rate risking the annihilation of their people.

Table 1

question	Right		wrong		dont know	
	N	%	N	%	N	%
12	41	51.9	11	13.9	27	34.2
26	19	24.1	5	6.3	55	69.6

Legal

In the section testing knowledge about legal aspects related to HIV/AIDS, only questions 23 and 37 seemed to have presented some difficulty for respondents. The importance of knowing about insurance companies paying some part of life insurance to an infected person before death is clear in terms of direct intervention, since the individual can present the alternatives available for persons living with HIV/AIDS. With respect to question 37, which deals with ethical issues, a majority believe that doctors should divulge cases of HIV or AIDS to those responsible for monitoring infectious diseases when such information is gained confidentially. As many as 68.4% of respondents were able to identify compulsory identification of HIV/AIDS as being illegal in Quebec. Nevertheless, 17.7% incorrectly answered this question.

Q 23: Private companies which offer money in exchange for being beneficiaries of life insurance policies are legal in Quebec.

Q 37: A doctor must report an individual diagnosed confidentially (but not anonymously) with HIV or AIDS to the authorities responsible for infectious diseases.

Table 2

question	Right		wrong		dont know	
	N	%	N	%	N	%
23	9	11.4	21	26.6	49	62.0
37	14	17.7	44	55.7	21	26.6

Medical

Questions 4, 24, 25, 31, 33, and 39 raise concerns with the evaluation of knowledge. Question 4, which makes the distinction between HIV and AIDS, demonstrates the lack of specific knowledge and which applies to question 24 as well since it deals with different types of HIV.

The issues raised in these questions comprise basic information, which is lacking on the part of social workers. The results of question 25, dealing with the various medications available to slow the progress of neuro-degenerative problems, are not surprising and underscore the limit of knowledge about the medical realities of people living with HIV/AIDS. Questions 31 and 33 deal with an important fact about the Northern Quebec population, that co-infection of HIV and tuberculosis is quite frequent with the First Nations people. The rate of (DNK), while surprising, points to a wide gap in knowledge concerning prevention and health issues of First Nations people.

Questions 6, 18, 22, 41, 43, and 45, where higher scores were recorded, may be related to increased public knowledge by print and media.

- Q 4: The diagnosis of AIDS is associated with HIV infection and requires the presence of one of the opportunistic diseases listed by the laboratory for the fight against the disease.
- Q 24: The medical profession now speaks about different types of HIV.
- Q 25: Haldol, Ritalin and Valium are used to inhibit the progression of neuro-degenerative problems related to AIDS.
- Q 31: The co-infection of HIV and tuberculosis is widespread in the world of persons living with HIV and AIDS.
- Q 33: In Canada, First Nations people living with HIV and AIDS present a higher risk for co-infection of HIV and tuberculosis
- Q 39: A new test on viral quantity is helping to determine the quantity of HIV virus in the person's body.

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Table 3

Question	right		wrong		dont know	
	N	%	N	%	N	%
4	30	38.0	8	10.1	41	51.9
24	32	40.5	4	5.1	43	54.4
25	2	2.5	18	22.8	59	74.7
31	23	29.1	9	11.4	47	59.5
33	15	19.0	3	3.8	61	77.2
39	13	16.5	3	3.8	63	79.7

Prevention

Astonishingly, 55.7% of social workers believe that latex condoms eliminate the risk of contracting HIV. Naturally, this fact is essential in dealing with prevention because latex reduces without eliminating the risk of transmission. Question 36, dealing with heterosexism and homophobia, was responded to mostly with Do Not Know, showing the lack of awareness of the realities of sexual minorities. The 53.2% correct response rate to question 17 is surprising since popular belief contradicts this response. In fact, it is justified to recommend safe sexual activity with reduced risk between two HIV partners, even if the two are monogamous. In terms of practice, this reality relates to the mutation of the virus and mutual reinfection.

- Q 17: Recommending safe sex practices is not justified in cases where two HIV positive partners are monogamous.
- Q 21: Use of latex condoms or vaginal dams (ex. Dam'z) eliminates the risk of contracting HIV as a result of homosexual or heterosexual relations.
- Q 36: In order to better respond to the problem of HIV and AIDS, different methods of conquering heterosexism and homophobia are being proposed.

Table 4

question	right		wrong		dont know	
	N	%	N	%	N	%
17	42	53.2	13	16.5	24	30.4
12	26	32.9	44	55.7	9	11.4
36	20	25.3	18	22.8	41	51.9

Psychosocial

In examining the psychosocial dimension, questions 5, 7, and 15 produced favourable results. This response should not be surprising since general social work knowledge should be sufficient to respond adequately to these questions.

- Q 5: A person living with AIDS may encounter more difficulty in meeting his or her needs than a person living with HIV. It is believed that this is due to the psychosocial factor.
- Q 7: The results of blood analysis [ex. Lower levels of lymphocytes CD4 +(4) or CD8+(8), etc] could provoke a fear of death and be a source of anxiety for person living with HIV or AIDS.
- Q 15: Persons living with HIV and AIDS sometimes experience organically based neuro-degenerative problems or cognitive abnormalities which should not be confused with depression or memory loss.

Table 5

question	right		wrong		dont know	
	N	%	N	%	N	%
5	64	81.0	11	13.9	4	5.1
7	46	58.2	3	3.8	30	38.0
15	46	58.2	2	2.5	31	39.2

Discrimination (stereotyping)

In the section, Question 16 indicates the lack of knowledge on the part of social workers about the incidence of HIV/AIDS in First Nations' communities of the Abitibi-Temiscamingue. Questions 35 and 42 underline, in our opinion, the major aspects of information programs on HIV/AIDS. It is nevertheless surprising to see such a high rate of correct responses for question 35. Popular belief seems to reinforce the stereotype in terms of sexual-homosexual relations and that the known methods of transmission do not necessarily refer to *cunnilingus* (oral sex) between women as a high-risk behaviour for the transmission of HIV.

Q 16: In Canada, there is little data on the rate of HIV infection among First Nations people.

Q 35: Women can contract HIV as a result of homosexual relations.

Q 42: In Canada, the majority of haemophiliacs are HIV positive.

Table 6

question	right		wrong		dont know	
	N	%	N	%	N	%
16	35	44.3	3	3.8	41	51.9
35	48	60.8	12	15.2	19	24.1
42	40	50.6	9	11.4	30	38.0

Transmission

A substantial proportion (73.4%) answered question 2 incorrectly. This question, which seems simplistic, refers to the fragility of the virus since Javel water destroys HIV. This notion is also important in the fight against HIV since the virus is quickly destroyed outside of the human body. Here again, the correct responses seemed specific to information sharing strategies.

- Q 2: Domestic javel water (ex. Javex) can destroy HIV.
 Q 19: In Canada, use of intravenous drugs is the principal cause of the spread of HIV among heterosexuals.

Table 7

question	right		wrong		dont know	
	N	%	N	%	N	%
2	16	20.3	58	73.4	5	6.3
19	41	51.9	17	21.5	21	26.6

Conclusion

According to the *Code of Ethics* (1998), social workers are expected to assist individuals, families, groups, and communities ameliorate social problems. Social injustices related to HIV/AIDS, as is shown in recent literature, are still very much in evidence. It is therefore incumbent upon social workers to become familiar with this issue. Article 3.01.05 of the Code of Ethics of the Social Workers of Quebec (1997) states;

The social worker should not carry out an assessment of the client’s situation nor to intervene unless he or she has sufficient knowledge to make informed clear judgements about the client’s situation and to act in the client’s best interests (1).

Unfortunately, the results of our research indicate social workers generally lack knowledge about the problem of HIV/AIDS. The results are similar to those reported by Peterson (1992) which indicate less than 50% of respondents were able to correctly answer questions related HIV/AIDS (47.8%). While social workers in the medical field tend to be more familiar with the bio-psycho-social dimension of HIV/AIDS, there is a serious knowledge gap concerning the threat HIV/AIDS poses to northern First Nation communities.

Social workers involved with First Nation communities should therefore focus their intervention strategies on increasing awareness of high-risk behaviour and knowledge concerning transmission. Of major concern is the extensive mobility of the First Nation populations from inner

city areas to rural communities, a fact which may increase the rate of infection in isolated rural communities

If the pandemic effects of AIDS persist and the rate of infection continues to increase among First Nation people, social workers will need to take a leadership role as providers of service, as researchers, and as policy planners. Social workers will need to become more proactive in understanding the issues of HIV/AIDS and its relevance in combating homophobia, racism, classism, sexuality and death, to mention a few. The importance of training social workers with a more informed knowledge of HIV/AIDS is imperative if prevention strategies are to be effective for northern communities.

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