

HIV/AIDS research priorities among aboriginal people in Canada¹

While the number of new AIDS cases reported has leveled off in Canada over the last decade, there are many indications that the disease's impact has continued growing among that country's aboriginal peoples. To address that situation and to better direct future research expenditures, the federal Health Canada system published a report in September 1998 outlining what is already known about HIV/AIDS and aboriginal people in Canada, the gaps in knowledge, and the directions that future research should take.

The report was prepared by the Northern Health Research Unit of the University of Manitoba. Funding for the study came from the Medical Services Branch (MSB), a Health Canada division that provides medical care for aboriginal people living on the reserve lands set aside exclusively for Indians, and also to the country's Inuit (Eskimo) people.

A literature review on HIV/AIDS and aboriginal people in Canada was done by searching in MEDLINE and other bibliographic databases, reviewing proceedings of meetings and symposia, and asking researchers about their ongoing projects that had not yet been completed or published.

The resulting information was organized into three sections: the burden of HIV/AIDS, determinants and risk factors, and interventions. Each of the sections described the research that had already been done, the results of those studies, additional research needed, and suggestions for a new research agenda.

The sections of the report on determinants and risk factors and on interventions contain a selection of annotations of key publications. The report also has an extensive listing of materials that were consulted. Since the document is intended to be a work-in-progress, it will be updated periodically to reflect additional research developments.

The burden of HIV/AIDS

By the end of 1997, the largest exposure category for male aboriginal AIDS cases was men who have sex with men (MSM), who made up 59.2% of the accumulated cases. Other exposure categories included intravenous drug users (IDUs) (18.8%), MSM/IDU (13.6%), heterosexual contact (4.2%), receiving blood/clotting factors (0.9%), and perinatal transmission (0.9%). Among aboriginal females, ex-

¹ Based on: University of Manitoba, Northern Health Research Unit. Research on HIV/AIDS in aboriginal people: a background paper. Health Canada, Medical Services Branch. Available from: <http://www.hc-sc.gc.ca/msb/fnihp/hivpaper.htm>. Accessed 26 February 1999.

posure categories included IDUs (47.6%), heterosexual contact (35.7%), receiving blood/clotting factors (9.5%), and perinatal transmission (4.8%). Adult aboriginal AIDS cases were much more likely to involve injection drug use than their non-aboriginal counterparts in Canada.

There are a number of reasons why aboriginal populations may face more risk from HIV than other population groups in Canada. Increased vulnerability may come from rates of sexually transmitted diseases (STDs) that are five to 10 times the national average. Other factors include substance abuse, including injection drug use, as well as other health and social issues. Aboriginal persons make up between 14% and 40% of the populations of the federal and provincial prisons. The movement of aboriginal persons from inner cities to reserves increases the risk of HIV in remote communities.

There are a number of gaps in the knowledge on the impact of HIV/AIDS among aboriginal populations. Ethnic information is frequently lacking for reported AIDS cases. Many of the studies of aboriginal HIV prevalence have been done with populations living in urban areas, making it difficult to generalize these results to the aboriginal population as a whole or to populations living on reserves.

One way to improve the understanding of the HIV/AIDS burden among aboriginal people would be to make certain that ethnic identifiers are used in voluntary seroprevalence studies. Such studies should include the gathering of data on risk behaviors. With a research study, the involved community needs to fully understand why it is being done, how the investigation will be carried out, who will own the data, and what will happen to the results.

Determinants and risk factors

There is a limited amount of literature on risk factors associated with HIV/AIDS in the aboriginal population. In addition, what research there is has generally focused on individual risk behaviors, knowledge, and attitudes, without dealing with such broader social concerns as poverty, discrimination, marginalization, migration between reserves and cities, changing employment opportunities, criminal activities, and housing availability. Some of those social and economic conditions may especially affect the self-esteem and social identity of aboriginal youth and lead to involvement in such high-risk activities as the sex trade and intravenous drug use.

Only limited research has been done on determinants of HIV/AIDS in on-reserve populations.

Nor is much known about the sexual behavior of aboriginal youth. Studies are needed on the social and cultural factors involved in condom and safer injection drug use. Research to date has suggested that homosexuality is generally viewed negatively in the aboriginal community in Canada. Nevertheless, more information is needed about other sexual issues, including attitudes towards multiple partners, early sexual experience, and the rights of women. More data are needed on the full extent of the epidemic, especially given the fact that epidemiological evidence indicates that intravenous drug use is becoming an increasingly important factor in HIV transmission among aboriginal persons.

Much can be done to address these research shortcomings. Investigators who have unanalyzed data on aboriginal subjects should be encouraged to complete their analyses and report their findings at meetings and in journals. Priority should go to studies on youth and on men who have sex with men, as well as identifying barriers to safer sex and prevention of injection drug use. Much needs to be done on attitudes and behaviors in areas that include condom use, STD control, sex education, circumcision, sex work, sexual orientation, sexual abuse, and the rights of women and homosexual persons. With youth, more knowledge is needed on self-esteem, identity, sexuality, peer influences, and generational relationships.

Interventions

Very little has been published on interventions specific to aboriginal communities. In addition, few of the aboriginally focused programs have been evaluated, so there are no objective indicators of either process or outcomes. Seroprevalence studies should continue, but they should be linked to prevention and treatment evaluations, or to analytical studies of risk behaviors.

There are many gaps in the knowledge on intervention. Some research indicates that aboriginal people with HIV/AIDS are experiencing less than ideal treatment protocols. Other research has pointed to obstacles arising from discriminatory attitudes and an absence of culture-based models for prevention and care. Little research has looked at which prevention programs have worked and which have not. Also lacking is research on the special needs of aboriginal people and their families living with HIV/AIDS, barriers to HIV testing, access to and compliance with combination therapies, and the palliative care needs of aboriginal people with AIDS living on reserves and elsewhere.

Also needing further study are cultural practices that may affect the design and delivery of interventions, including traditional aboriginal medicine and the role of elders. There are many lessons that could be learned from the experience of other countries, and a review of international programs and interventions in different ethnocultural environments may be useful in developing programs for aboriginal communities in Canada.

Research methods and ethics

Research on HIV/AIDS in the aboriginal community requires a community-based or participatory focus. Especially in the area of HIV prevention research, it is essential to involve research subjects so as to increase participation rates and make it more likely the research results will have an impact. More and more aboriginal communities are insisting that they be full partners in developing research and that there be strict protocols governing access to data and publication. Capacity building at the community level should also be a fundamental component of these efforts.

SINOPSIS

Investigaciones de prioridad sobre el VIH y el sida en los grupos aborígenes del Canadá

Aunque el número de casos de sida se ha nivelado en el Canadá en el último decenio, muchos factores indican que la enfermedad ha seguido teniendo un impacto creciente en las poblaciones aborígenes del país. Para hacer frente a la situación y adjudicar más adecuadamente los futuros gastos en investigación, el sistema federal Health Canada publicó un informe en septiembre de 1998 en el que se detallan los conocimientos actuales sobre la situación del VIH y sida en los aborígenes del Canadá, lo que aún se desconoce y la orientación que deben tener las investigaciones realizadas de ahora en adelante. Se hizo una revisión de la literatura en MEDLINE y otras bases de datos bibliográficas, se revisaron los informes de reuniones y simposios y se preguntó a los investigadores el estado de aquellos proyectos que aún no habían acabado o publicado. La información así obtenida se organizó en tres secciones: la carga de VIH y sida, los factores determinantes y de riesgo y las intervenciones. El documento está destinado a ser un trabajo en continuo desarrollo y se actualizará periódicamente para que abarque los resultados de investigaciones adicionales.
