SPECIAL EDITION
NATIVE SOCIAL WORK JOURNAL

HIV / AIDS : Issues Within Aboriginal Populations

Volume 3, September 2000

Circle represents the moon, the grandmother, the extended family.
Fire represents the sun, center of a family, warmth of a family.
Graphics represent light from the fire.
Lines from the mouth represent communication.

NISHNAABE KINOOMAADWIN NAADMAADWIN

Special Edition

NATIVE SOCIAL WORK JOURNAL

HIV/AIDS: Issues Within Aboriginal Populations

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NISHNAABE KINOOMAADWIN NAADMAADWIN

Canadian Strategy on HIV/AIDS
La Stratégie canadienne sur le VIH/sida

Health Canada provided funding for this project.

The views expressed herein are solely those of the authors and do not necessarily reflect the official policy of the Minister of Health Canada.

Prayer

Great Spirit, Creator of All

Please hear this prayer as it is meant to be heard from our heart and not our thoughts.

In our hours and days of fear, pain or isolation allow gentleness and kindness to touch us and guide us as we walk this journey. Help us to be kind to others and ourselves as we complete this circle and return to you.

Allow us to live our lives as a prayer in honour to you and all of creation.

Ho.

Ann Charter
Musteke Mahingan Isquew

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In Memoriam

Lena Odjig White Waabi-Ojiig
June 1, 1940 - January 28, 2000

Lena was a founding member of the Native Human Services Programme and an active advocate of furthering educational opportunities for Aboriginal people. She was recognized for her contributions as an educator in the preservation of Aboriginal languages.

In her life she accomplished much and was selfless in her sacrifices. Her strong relationship to her family, her quiet assurance and deep sense of commitment were indicative of her personal and professional beliefs that working together strengthens the Circle of Hope.

To the Spirit of Lena Odjig White (Waabi-Ojiig) we dedicate this Special Edition of the Native Social Work Journal

The staff, students, and community of the Native Human Services Programme.

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Native Human Services Programme

Established in 1988, the Native Human Services Programme utilized a regional consultation process involving 27 First Nations within the Robinson Huron Treaty area. The consultation formed the basis of the curriculum and distance education component of the programme.

The philosophy, content, techniques and strategies that characterize the curriculum model represent a specialization for obtaining the knowledge and skills necessary as a social work practitioner with Aboriginal populations. The cultural content, practice methods and specific competencies reflect distinct realities in self-determination, cultural preservation and community empowerment.

The primary method within the curriculum model utilizes an applied approach that focuses critical knowledge in exploring strengths derived from holistic healing approaches. Other curriculum areas include: community based participatory research, Native child welfare practice, sociocultural ecology theory in family and community systems and case management. A necessary component to the curriculum is the historic political legislative and policy relations, which have defined and continue to have impact upon current socio-economic and political rights of Aboriginal populations.

Important and unique as a teaching and learning method is the incorporation of interaction activities with cultural relevance. Holistic healing practices expose students to the role worldviews, values, beliefs, and practices play in cultural based strategies. Additional benefits to students are the insights provided by participating in a process that examines culturally related perceptions of psychological growth and wellness. Finally, such experiential based cultural practices create opportunities for students to explore their own self-cultural awareness. Particularly relevant to this process is that such cultural based practices act as a positive reinforcement in the development of cultural identity and serve to promote Aboriginal healing strategies as a source of interpretative balance, interpersonal renewal and community aspiration.

Field Education

The main objectives of Field Education are to impart to its graduates the ability to apply professional social work methods and approaches in a manner that is culturally appropriate to Aboriginal people.

Field education involves the establishment of field placement opportunities in native communities. A practicum setting provides the student an opportunity to apply the knowledge and skills learned in an actual practice setting. It is a planned and supervised learning experience for a 3rd-year or a 4th-year student, which fulfils the practicum requirements.

A Native Human Services Field Education Manual has been published to guide the student, the field instructor and the faculty consultants in the field practicum process. The manual is based on traditional Native teachings.

Distance Education

The Distance component of the Native Human Services Program is offered through ENVISION: Laurentian University's Distance Education Program on a part-time basis. This means that a student may take the first two years of the program on a full-time basis. Part-time status begins when a student reaches upper years of the program (3rd & 4th years). All NSWK courses are alternated each year and require professional year acceptance into the program.

For specific information on the Native Human Services Program, contact the Native Human Services Bachelor of Social Work Program at:

(705) 675-1151 ext. 5082,
FAX: (705) 675-4817
or visit our website at www.laurentian.ca/www/nhs/

Foreword

As the year 2000 unfolds before us, HIV/AIDS continues to be a major public health and social problem, infecting more than 30 million people world-wide and affecting countless others. The impact on families and communities is nothing short of devastating and catastrophic. No culture, including the vast mosaic of Canada's Aboriginal peoples, has been immune to the ravages of HIV, the virus that causes AIDS.

As of December 1998, 321 AIDS cases in the Aboriginal community had been reported to the Laboratory Centre for Disease Control. However, these numbers do not reflect the true number of Aboriginal people who are infected with HIV, which is probably much higher, nor do they reflect the families and communities affected. Most of the people diagnosed with AIDS are two-spirited men, followed by women, in particular, those who have engaged in injection drug use or have had unprotected sex with an infected partner. Although it seems that most people living with HIV/AIDS are two-spirited men, recent data suggest that the bulk of new HIV infections are primarily due to injection drug use, which is the principle cause of infection in heterosexual men.

The facts reveal only the surface of what is a much more complex problem. In many Aboriginal communities, health and social inequities that are generations old seem to have grown and multiplied. Homophobia and the disempowerment of women have resulted in the loss of significant members of the circle. Youth are engaging in high risk behaviours, and occasionally, they are killing themselves as though to repel or vanquish the horrors which surround them. In the face of such widespread tragedy, it is easy to lose yourself and feel powerless, like a shaman suddenly bereft of power.

Today, Aboriginal traditions, which were once vilified by governments and even by some Aboriginal people, have emerged as fundamental in the urgent need to address these human tragedies. Knowledge has been instrumental in empowering people and communities to reclaim their rightful place within the great family. And, the immutable spirit that courses through countless individuals has become a true source of inspiration, as evidenced in the diverse articles in this journal.

From the provocative discussion on injection drug use and youth, to the poignant stories of First Nations women living with HIV/AIDS, these articles are the evidence that people and their actions matter. Although these words may seem empty to some, it is important to remember that small steps do count.

In the end, change will come from the efforts of people and communities. Like the seeds sewn in springtime, however, the true fruits of our collective labour will be visible only with the passing of time. As a Metis who has been involved in the Aboriginal AIDS movement for several years now, I can attest to the value of individual and community action. For individuals are changing the landscape. Individuals are changing the face of HIV/AIDS.

Marcel J. DuBois, B.A., MSc

Foreword

This special edition of the Native Social Work Journal on "HIV and Social Work" provides a forum for academic and community-based articles on social work with Aboriginal populations. The intent is to expand the literature base of Aboriginal social work practice and to provide practical and up-to-date information to social workers and other practitioners working in Aboriginal settings.

In the following Introduction, the Editor provides a precis of the 15 articles contained in this special issue. These articles are wide ranging and provide new perspectives in the following areas: care, treatment and support; community development and prevention; HIV/AIDS research in social work; and legal, ethical and human rights issues.

The social and cultural construct of HIV within the aboriginal context is well presented and shared by the authors in the published articles. The proactive and nurturing approach taken by the Editor and his committee have inspired and stimulated a number of new authors. The Call for Papers in June 1999 was published in the second edition of the Native Social Work Journal as well as in four other Aboriginal newspapers: the Anishnabek News, the Manitoba Aboriginal News, the Native Journal and the Maliseet Times. As well, the call for papers was sent to all First Nation, Inuit and Metis Health Units and to rural and urban /aboriginal health organizations and agencies.

Extensive consultations followed and subsequent networking partnerships developed. In particular, acknowledgement of appreciation is extended to the Canadian Aboriginal AIDS Network (CAAN) and Aboriginal HIV/AIDS Organizations as well as to the 39 Selection and Review Committee members. Writing assistance was made available to those who requested it and this was provided to 15 groups or individuals. The Journal provided funding for this assistance. Out of the 20 articles submitted, 15 have been published for publication

The collective contributions of the authors in this special issue have addressed concerns of First Nation, Metis and Inuit communities. In addition to the results of studies presented, several of the authors shared their own experiences in their HIV journey which in many ways demonstrated the respect for, honoring of traditional values and beliefs, and ways of coping which will help social work practitioners and other professionals understand the holistic day-to-day approaches within the Aboriginal communities.

By engaging Aboriginal social workers, ASO's and other health care givers, this Special Edition has contributed to the creation of an extensive network of academics and practitioners in the field of HIV/AIDS among Aboriginal communities. I would like to thank the Native Human Services Programme, School of Social Work, Laurentian University; in particular, Professor Schuyler Webster, Journal Editor, members of the Steering and Review Committees and the authors for their unique and valuable contributions.

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Acknowledgements

We are indebted to all whom were collaborators in making this endeavor a success.

Our gratitude extends to the following: the Aboriginal community of HIV/AIDS organizations, agencies, and advocates for their article submissions; the Canadian Aboriginal AIDS Network (CAAN) which allowed us to draw upon their expertise and organizational resources; the Editorial Advisory Committee for reading and thoughtfully evaluating manuscripts; Nena Nera, Senior Social Services Advisor, Health Canada for her contribution to the Forward and her expertise and guidance throughout all phases of the project; Laura Commanda, Health Canada for her timely consultation and networking assistance; Dr. Geoffrey Tesson and Dr. Joan Mount, Laurentian University for their continued support of the Journal; Ann Charter, University of Manitoba for serving as our Traditional Resource Person and offering spiritual guidance; Sandra Ladouceur, Project Manager for her organizational abilities; Jennifer Lister, Project Assistant for coordinating the final phases of the editorial process; the Editorial Board of the Native Social Work Journal, for their ongoing involvement; the Native Human Services faculty and staff, Herbert Nabigon, Barbara Waterfall, Cheryle Partridge, Sheila Hardy, Sharon Corbiere-Johnston and Freda Recollet for providing support resources and serving as Associate Editors to the project; Elizabeth MacDougal and Cheryle Partridge for their much needed skills as Copy Editors; Ruth Reyno, for her excellent work in proposal development; Julian Cote for his technical skills in computer design and layout; Jennifer Keck and Richard Carriere, School of Social Work, Laurentian University for their helpful suggestions and support; Angela Recollet, Manager for the Laurentian University Native Education Council (LUNEC) for providing institutional support for the Journal; Marcel J. Dubois for lending his knowledge and eloquence in the Foreword; Pat Mills, for her work in writing the Press Release; Vicki Kett, Health Access Aids and Ghislaine Goudreau, Shawenekezhik Health Centre for their contribution and participation on the Planning Committee; Carl Orr, HIV/AIDS Prevention Coordinator, Union of Ontario Chiefs, for information and dissemination support; Paul de la Riva, Media Relations Officer, Public Affairs Laurentian University for assisting in media coverage; Laurentian Press, for publishing and technical services; Jonathon Waiwia and Elaine Bembamkwe, student assistants, in the Native Human Services Programme for providing office and activity support; the National AIDS Clearinghouse for distribution of the Special Edition; Leland Bell, for the artwork; and finally, many thanks to the authors who devoted their time and knowledge in the preparation of articles.

Introduction

This Special Edition: HIV/AIDS Issues Within Aboriginal Populations focuses upon one of the most pressing concerns today in First Nations, Metis', and Inuit communities. The information in this publication seeks to expand our understanding of the health status of Aboriginal populations as they confront the challenges of HIV/AIDS.

Current knowledge with new information derived from a diverse range of topics characterizes the breadth of analysis by the authors. It is hoped that this volume will help inform individuals, families, communities, practitioners, programmers, research, and policy advocates in building the partnerships necessary to overcome the barriers created by the HIV/AIDS health care crisis. The authors present important issues and perspectives, which may provide critical guidance in the development of effective health promotion and prevention strategies for Aboriginal communities in Canada.

This Special Edition is organized into six (6) Sections. Each section contains information which reflects distinct perspectives and emergent practice issues: Section 1) The Healing Journey: Aboriginal Persons Living With AIDS; Section 2) Aboriginal Women's Experience; Section 3) Community Development, Section 4) Research; Section 5) Two-Spirited People; and, Section 6) Legal Issues.

In section 1) The Healing Journey: Aboriginal Persons Living With AIDS, each story presented is a poignant and passionate testament to the courage the human spirit plays in raising awareness and understanding in the campaign against AIDS. The authors focus attention upon the relationship between perceived control and health behaviours, the stress-mediating role of social cultural supports, cultural constructs of illness, and coping with illness induced stress. The implications for health care, treatment, and support highlight the need for future study of stress, coping, and health among Aboriginal populations. "Living with HIV: Frequently Asked Questions" by Archie explores the physical, mental, social, and spiritual dimensions of Living with HIV. The author recounts in vivid detail the impact of and his subsequent reactions to being diagnosed with HIV. This personal account, told with courage and humour, describes a journey of healing and growth in overcoming fear and uncertainty. The author utilizes a series of question and answers which help illuminate the private and public dimension of Aboriginal People Living with HIV.

"Teacher, Helper: My Relationship with HIV" by Jenkins recounts the challenges encountered by the realization of contracting HIV. Through a personal narrative the author reveals the cultural construction of illness and its meaning within an traditional context. Physical disease within Aboriginal cultures undergoes an explanatory or interpretative process that often departs markedly from mainstream medical labelling theory. The author explores the cross-cultural dimensions of HIV and effectively promotes the concept that traditional beliefs and healing practices are effective mediators in explaining and coping with illness. Given the increased influence of traditional healing practices within Aboriginal communities the introduction of health care strategies, which incorporate social and cultural variables, appears to merit further exploration.

"Confronting HIV and AIDS: a personal account of spiritual awakening" by Boucher and Timpson reminds us that, as depressing as social and economic conditions may be, those who believe they have some control over their lives have hope. Overcoming the labelling process and stigmatization associated with HIV/AIDS requires community support and acceptance. The authors document the changes brought on by the devastating consequences of AIDS and the deep sense of purpose found in giving back to the community the lessons of survival and spiritual renewal. Boucher and Timpson identify fears, prejudices, and barriers which prevent many Aboriginal Persons Living With HIV/AIDS from disclosing their illness. The internalization of rejection is explored as a primary barrier which affects one's own self-perception, self-concept, and the concept others have of those living with AIDS. The authors report through an open and honest dialogue on those issues which link improved health outcomes for Aboriginal Persons Living With HIV/AIDS with those of community awareness and understanding.

Section 2), Aboriginal Women's Experience. "HIV, Sexual Violence and Aboriginal Women" by Neron and Roffey examines the impact HIV/AIDS has in the lives of Aboriginal women. Increased incidence of HIV/AIDS indicates a disturbing trend among Aboriginal women. A profile of risk factors are presented which point out gender issues among Aboriginal populations which require more critical analysis, such as sexual violence and HIV/AIDS. Included in the article are concrete steps which can be taken by health care organizations and policy advocates in overcoming barriers in the development of appropriate and relevant support, prevention, and treatment strategies for Aboriginal women. The role Aboriginal women are playing in advocating for improved services has implications for expanding resources which are more responsive to gender-based needs.

"It's Hard To Be A Woman," First Nations Women Living with HIV/AIDS by Ship and Norton explores the historic and current issues related to Aboriginal women and HIV/AIDS. The authors report the results from an exploratory qualitative study, which indicates gender discrimination, racism, and socio-economic factors contributing to multiple barriers for Aboriginal women living with AIDS. Included in the analysis is a critique describing the status of Aboriginal women and the general exclusion of gender specific issues related to HIV/AIDS. The authors provide information and recommendations, which address the under-representation of Aboriginal women's issues in the areas of support, direct services, research, and policy development.

Section 3): Community Development: "Point of Death," HIV/AIDS and IV Drug Use: Youth Awareness Video Project by Adkins describes the success of a community development initiative designed to increase awareness and knowledge in the prevention of HIV/AIDS. By using an empowerment approach responsive to the needs of northern youth, the Fort Smith Metis' Council sanctioned a health education project which involved creative and innovative strategies in building community participation. A health promotion video project developed by the youth of the community has garnered recognition for its success in using media technology in HIV/AIDS prevention. The authors make a strong case for prevention methods, which provide information, resources, and opportunities for skill and knowledge development.

"Dynamics of the 1999 AIDS Walk in 31 First Nations Communities: The Community Within the Community" by Saulnier and Masching addresses an ambitious undertaking by the Atlantic First Nations AIDS Task Force to raise awareness and increase knowledge about HIV/AIDS among 31 Aboriginal communities of the Atlantic Coast region. A chronological series of events and activities that helped to shape and define the goals and complex tasks of developing health promotion and prevention activities are described. By engaging in a process of critical reflection, more culturally congruent strategies, which improve community-based partnerships, emerged. The lessons learned from *the community-within-the-community* approach hold promise for building effective partnerships in the prevention of HIV/AIDS. The authors report that the Atlantic Coast Mi'kmaq communities have made significant gains in raising awareness and contributing their support for important events such as the National AIDS Walk.

"Celebrating Community Knowledge: Encouraging involvement, achieving ownership and building confidence through comprehensive community consultation" by Armstrong reports on an Inuit initiative which sought to develop educational materials in HIV/AIDS prevention which would assist communities in coming to grips with HIV/AIDS. The story of the first Inuk woman diagnosed with HIV and the subsequent reactions of fear and uncertainty, spurred efforts to mobilize a community consultation process which helped to articulate the challenges posed by the threat of HIV/AIDS. Constructing empowering relationships requires a cultural-networking approach, which focuses on respect, strengths and diversity within cultures a sine qua non for HIV/AIDS prevention. Capacity building and sustainability emerge as important principles in expanding community resources. Community input and involvement assisted immensely in the success of this initiative. By encouraging community ownership the Inuit voice has emerged as a vital force with respect to the development of effective health promotion materials which are culturally appropriate and linguistically sensitive.

"A Community-based Approach to Reducing HIV/AIDS Infection in the Wikwemikong Unceded Indian Reserve" by Cooper, Maar, and Peltier reports on the human health issues raised by the increased incidence of HIV/AIDS in a Northeastern Aboriginal community. The article depicts the relative absence of HIV/AIDS information within the federal health transfer initiative as having serious implications for communities addressing the consequences of HIV/AIDS. The authors contend that distinct health programming is needed at the community level in order to turn back the tide of HIV/AIDS. In order to develop effective prevention initiatives adequate funding, specialized resources, and trained personnel are identified as critical resources. Confronting community denial and increasing support for Aboriginal communities impacted by AIDS is described as a priority in reversing the trend of HIV/AIDS. Ascertaining the risk factors at the community level creates dilemmas for health planners due to a lack of reliable data. The state of long-term planning and programming is viewed as critical in addressing the multiple and complex needs of HIV/AIDS within Aboriginal communities. Information from a community dealing with the increased incidence of HIV/AIDS lends important insights regarding needed resources in the continuum of care, treatment, and support.

"Honouring and Caring for Aboriginal People and Communities in the Fight Against HIV/AIDS" by Marsden, Clement, and Schneider presents information relevant for community-based services. By describing the organizational history and evolving activities of Healing Our Spirit the authors document the organization's progressive role in developing care, treatment, and support for Aboriginal persons impacted by HIV/AIDS. Recruitment and hiring policies reflect the inclusion of Aboriginal People Living with HIV/AIDS within the organizations service structure. A Holistic approach is applied in building community outreach initiatives and treatment resources. Multiple levels of service development characterize the evolving role Healing Our Spirit plays in expanding the healing resources for British Columbia's Aboriginal communities. As a model of community-based organizational development Healing Our Spirit shares its resources and expertise to assist many Aboriginal communities in the fight against HIV/AIDS.

Section 4) Research begins with "HIV and injection drug use amongst First Nations in Vancouver" by Goldstone, Albert, Churchill, Schilder, Perry, Markowski, Hogg, and McLeod. This article provides outcome data from a sample study, which holds significant implications for the care, treatment, and support of Aboriginal people infected with HIV/AIDS. Among the most troubling aspects of the research results are the distressingly lower rates at which Aboriginal injection drug users access health care resources compared to that of their non-Aboriginal counterparts. The authors present information, which is critical to addressing barriers to health care, treatment, and support. The study results indicate treatment interventions and outcomes are influenced by a variety of risk factors which often result in an accumulation of burdens and "failed connections" for those most in need of acute care, treatment, palliative services, adequate housing, and social cultural supports.

"First Nations People and AIDS: A Study of Social Work Knowledge in Northern Quebec" by Rouillier, Boudreau, and van de Sande reports on the results of a study conducted to determine the level of knowledge (pertaining to HIV/AIDS) of social work practitioners. The target population for the study were social work practitioners residing within the Abitibi-Temiscamingue region of Quebec. A large Aboriginal population of Algonquin, Cree, and Inuit are located within the area where many social workers' professional practices are located. The study sought to understand the acquisition of knowledge of HIV/AIDS within the professional human service sector as an important determinant in social worker's attitudes, preparedness, and general understanding. While social workers employed in the medical service sector were more likely to be informed about HIV/AIDS, a serious deficit of knowledge currently exists among the ranks of many social workers outside the medical services field. The implications for professional preparedness for working with populations impacted by HIV/AIDS pose significant issues for educators, human service organizations, and northern communities.

"Attitudes and Beliefs Towards HIV and AIDS Among Aboriginal Peoples Living in British Columbia" by Schnieder, Marsden, Copley, Skaling, and Nowgesic continues a line of inquiry which addresses differences in perceptions about HIV/AIDS. The study indicates that while community education efforts can play a significant role in reversing negative perceptions and attitudes about HIV/AIDS, locations of community, age, and gender differences require further attention. The authors point out that limited knowledge exists within most Aboriginal communities about HIV/AIDS. The need for more specialized education initiatives designed for rural and remote communities was also cited as critical for improving health outcomes through community acceptance, understanding, and support.

In Section 5) Two Spirited People, the article "An Historic Overview of Two Spirited People" by Le Duigou effectively documents the historic and current profile of Two Spirited People within the context of Aboriginal cultures. The author provides examples of ethnographic profiles of homosexuality within the pre-contact periods. Gender roles and social status possessed by *"Winkte"* within some Aboriginal cultural traditions are documented. The author contends that the intrusion of colonialism and the influence of various religious movements have contributed to a pervasive erosion of gender roles and status occupied by *Winkte* within many Aboriginal cultures. While a great deal of rejection and misunderstanding remains, inroads are being made in respecting gender-based identity issues in the development of effective health care strategies for this segment of the Aboriginal population. The author suggests that informed social workers could be an effective ally in advocating for more responsive care, treatment, and support resources at the community level.

In Section 6) Legal Issues, the article Working Together: The CHALN/CAAN Project on Legal Issues, Aboriginal People and HIV/AIDS" by Matiation reports on a joint partnership endeavour by the Canadian HIV/AIDS Legal Network (CHALN) and the Canadian Aboriginal AIDS Network (CAAN) which examines discrimination and human rights, jurisdiction and funding, and testing and confidentiality issues specific to Aboriginal populations. The author effectively explores the tensions and processes which necessitated reforming Social Policy Discussion Initiatives so that consultation and input be representative of Aboriginal perspectives concerning legal issues and HIV/AIDS. By reporting on these often sensitive issues the author illuminates the restructuring efforts utilized by CHALN and CAAN to identify areas of divergent and common interests in policy development which reflect the needs of Aboriginal populations impacted by HIV/AIDS. The result of this joint partnership has contributed to a policy document, which is inclusive of Aboriginal issues and offers important information for Aboriginal and non-Aboriginal policy advocates.

The convergence of themes and topics provide a vision of what can be accomplished in the fight against HIV/AIDS. The first step has been made by many communities, organizations, and advocates in promoting greater recognition and understanding of the HIV/AIDS crisis within Aboriginal populations. There is good reason to believe that we possess the knowledge for what is needed and what works from the contributions contained in this Special Edition.

Miigwich,

Schuyler Webster, MSW
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Section 1

The Healing Journey: Aboriginal Persons Living With AIDS

Living with HIV: Frequently Asked Questions

Alex Archie

What was the first thing you did when you found out that you were HIV positive?

I was in a combination of shock and denial. If it weren't for the mixed emotions, I would have probably cried. I believe that I did cry eventually. I had been sitting in this nurse's office waiting for a while, thinking that it shouldn't be taking this long. Then, I realized that I already knew that I was HIV positive. The nurse who took my blood two weeks before came into the small office, said hello without looking at me and sat at the desk. He put my file on the desk, sat in the swivel chair and turned to face me. He smiled; I smiled. I could tell from the way he was acting that he wasn't going to tell me anything that I didn't already know. Finally, after listening to his well-rehearsed lines about sex, safer sex, my limited treatment options (in November of 1990), and whether or not I had any questions, I was in a daze. So, the first thing I did when I found out that I was HIV positive was walk out of the walk-in clinic.

The next task was to find my way home. After waiting tables during the lunch rush I wanted to get home and take a nice hot shower. I was thinking that the nurse could smell me as soon as he walked into the tiny room. Looking back on it now, I suspect that he probably thought it was best not to say how bad I smelled because he had some pretty bad news. My day was filled with enough devastation, but the dogs that lived on the streets leading back to my apartment didn't know that. They still smacked their jowls and barked, jumping up and down on the fence. Pizza! They wanted me because I smelled like pizza.

My best friend/roommate was home. I told him. He said he could tell by the look in my eyes. It must have been the desperate, scared, hurt, far away stare that I had on my face. The second thing that I did was take a hot shower, almost believing that I could wash this away, that maybe I'd wake up in the shower, and this would all be just a dream.

The feeling of denial was the first emotion that I felt the strongest. It was the only emotion that I was able to stand being alone with if that is possible. Maybe the most interesting aspect of this time was that I could be in total denial and still function.

Do your family and friends know?

Of course they do. They've known almost all along. They may not have been able to deal with it, but they were right there with me learning as fast as they could. My Mom is a part of the Circle of Life HIV/AIDS Support Group, a new group that had just been started on my reserve at the time of my diagnosis. They have a policy regarding people living with HIV on our reserve. It is positive and states that no one shall be discriminated against if they are HIV positive.

How did you get infected?

Drunk, stoned and stupid. I was stupid enough to believe that I couldn't get infected. I was stupid enough to believe I knew enough when I left high school about the world and that I would live long and prosper.

When did you start living with the Human Immunodeficiency Virus?

Living? I remember when I was first diagnosed, back in 1990, that the only thing I could think about was *dying*. I felt the only reason that I was living was to die, which, of course, is true for all people, that and paying taxes. I planned my memorial, who would be there, what songs they would play. We would have it at the gym on my reserve. I was raised Catholic. Hail Mary full of grace. It is not that I don't appreciate other people's beliefs, its just that there is no allowance for Two-Spirit people in the Catholic Church. The Church believes I am immoral and don't belong in the Kingdom of Heaven. That is why I want my memorial to be in the gym. I hated myself most of my life for being a Two-Spirit person, for being different, and I even attempted suicide. I guess I don't want to mislead the Church; they may think that I changed, that I accept their doctrine of discrimination and hatred.

At this memorial, I want people to see how many people knew me, to see how many people liked me and how far they would travel to pay their last respects. I haven't checked with my brothers yet to see if it's okay that they won't be pallbearers. I want some of my friends to have the responsibility. My brothers will have to support my Mom and Dad as well as their families. I have asked a former Chief from the Mohawk territory in the region known as Quebec, my best friend from Dallas, Texas, another friend from high school who is now in Edmonton, and my crazy best friend from when I was a brat on the reserve. We used to do crazy things, like our secret little gang, *The Borrowers*. In regards to *The Borrowers*, I refuse to answer any further questions on the grounds that it may incriminate me (and my friends swore me to secrecy).

I was also thinking about asking my friend's son. I met him when he was about twelve or so. His Mom invited me to stay with them when I took a temporary job at the Kamloop's Art Gallery. His Mom and my partner are my Powers of Attorney. I made all these plans for my death. Some of them are definitely valid; everybody should have legal documents drawn up. Otherwise, you and your belongings could become government property. We've all seen what they've done with the national debt–they've been able to manage that pretty well! We have a responsibility to take care of ourselves even in death.

Are you angry about being HIV positive?

I used to be. I used to blame the person who infected me. I blamed it on my drinking and on the drugs that I used to do. I blamed it on whomever I could. I hated the fact that my life was over, at least from what I could see. When I was diagnosed, there were little or no services for Aboriginal people living with HIV and AIDS. There were organizations that did educational workshops on prevention, but when it came to dealing with the virus, the medications, my family and friends, there was nothing. Nobody tells you about all the psychological challenges that you have to deal with. Yes, I was angry about becoming HIV positive. For awhile I asked myself, "Why me? What did I do to deserve this?" I was angry about the lack of services available, as well as the lack of response from Aboriginal leadership in regards to the Aboriginal HIV/AIDS epidemic.

So, what did you do?

At first I made statements at conferences and other public meetings about HIV and AIDS. I asked why nobody was doing anything about Aboriginal people who lived with HIV and AIDS. I learned as much as I could and applied for a job with Healing Our Spirit: BC First Nations AIDS Society. I started out as a Peer Support Worker, trying to help other Aboriginal people learn how to live with HIV and AIDS. I tried to help everybody I could. It was a great experience. I saw a lot of very angry people who just wanted somebody to do something. I learned more about myself from these other people living with HIV and AIDS than I ever had before. I definitely learned what true patience is and what a real virtue it is. I understand the diversity of the Aboriginal community and our issues. I recognize coping mechanisms and understand why people use them. I have learned more about acceptance of myself as well as everybody else.

How did you deal with your diagnosis in the beginning?

I didn't deal with it. It was easier at that time to hide everything. It seemed harder after I started telling people, like family and friends; they took it pretty hard, as you can well expect. One of the things that I wasn't expecting was the self-imposed exile and the feeling of constant judgment. I can honestly say that everything that I was doing or had recently done was being judged. Maybe I have been the hardest judge of myself, even more than the people who I was blaming for the judgment. Whether it was my Mom, sisters or brothers, I felt that they were always watching me. If I sneezed, coughed, stayed up to late, got a cold or anything, they would be hovering over me, ready to hand me a tissue, give me a cough drop or send me to bed. I got sick of that pretty fast. I stopped telling them anything, not that I told them anything much in the first place. I had some of the answers for myself but was afraid that what I would have to tell them would get blown out of proportion.

It reminds me of a story I once told at a conference about being a spider. The Spider sits on his freshly woven web, tentacles running off to his friends, family members, doctor and such. Spider wasn't even sure where some of the tentacles went or why. One day Spider sneezes, and in an instant, everybody surrounds him. His Mom and Dad, his sisters and brothers, and somebody he didn't even recognize. Everybody else around him looks at him and expects him to start cracking up, to break or to drop dead or something. Wow, that was weird! Spider learns after catching a cold that it is too much like work making everybody think everything is okay. It was too much like work to answer all their questions. Spider learned that it would be easier to just sit still and act like everything was just right. Everything is just perfect. Denial was easier to live with than to accept the disease and the dis-ease that everybody was in, including Spider. So Spider kept very still, trying very hard to make sure that his web didn't shake, not a shimmy, no quakes and no surprises, which is just what the disease wants: to be denied and left to its own devices. For about five years, this denial was just so: no real questions, no real answers, no real living going on, except for the virus which flourished.

How do you deal with your diagnosis now?

I am more realistic. I have medications to take in the morning and at night. It's hard sometimes not to miss doses, but every now and then, I do. This missing is bad according to the doctors. One thing which was the hardest thing about starting this medication, was accepting the idea that once I started these treatments, I would never be able to stop, unless of course, they stop working. This ineffectiveness could happen if the virus becomes immune to the medication. We don't want that to happen, so I try to take them as regularly as possible.

The medications, like everything in life, have their effects on my physical, spiritual, emotional and mental well-being. In order for the drugs to be as effective as possible, I have to accept them mentally. In my mind, I tell myself that the treatments are good and beneficial. I also use my mind to remind myself to take the drugs. I mentally try to block out the negative connotations of the therapy.

My spirituality allows me to take the medications. Although they are not traditional medications and are, in fact, foreign substances of a chemical nature, they are a part of my spirituality. I pray that they are working and that I will not develop a resistance to them. I pray that they will keep me alive until there is a cure. I know that if I don't take the medications, I will be overrun by HIV.

When I do become overrun with the virus, my immune system slowly starts to break down, and I become depressed very easily. I lose some of the fight, which is mental. My response to almost everything around me becomes very emotional. I sense the anger rising in me because I feel helpless. Inside I'm screaming and outside, I become a Spider again.

When I take the medications, everything seems to even out. I can deal with my emotional self, and my response is, in fact, more level. My physical being becomes closer to the person who I want to be. I don't look sick or tired. I don't look as skinny. I hate it when people walk up to me and say how slim I look–maybe I have tapeworms, and it is none of your business. It gets hard because at that point I am usually feeling run down and emotional and tend to get mad.

I have my good days, and I definitely have my bad days. I almost don't smoke. Every now and then, I feel like lighting up. I usually have a pack with me. I like to smoke when I'm in the car on a long drive to kill a little time, and a little bit of myself, I guess. I know that is a bad thing to say. My doctor says that everything is fine in moderation. Smoking for me is a coping mechanism for dealing with some of the stress of work and of this disease. One thing nobody tells you is that learning to live with HIV is a lot of work. It's more than a full time job.

Do you have supports?

You mean like panty hose?

No, sorry, I mean do you have a support system of some kind?

I know what you mean. It was just getting so serious here. I definitely talk more to my family and friends now than I ever did. I still don't tell them everything, which is more for their benefit than mine. I have a couple of really close friends and my partner who know pretty much everything. I just don't let them talk to each other.

Are you afraid?

I've never not been afraid. Sometimes I look at death as a part of life. Most of the time I still ask "Why?" One of my biggest fears is that I have to cram the rest of my life into a small amount of time. That scares me and makes me mad. I have a lot of nieces and nephews whom I adore, and I am afraid for them. I am afraid for the three Godchildren that I have. I am always afraid that this Christmas is the last Christmas, the last New Year's Eve, my last birthday. I was afraid that I'd never see my thirtieth birthday, but I did. I was afraid I'd never see the end of this century, but now I have. I'm not afraid of death itself; I'm afraid I'll miss something, like the day they find a cure for AIDS.

Do you have any friends?

I have a lot of friends, most of whom I take for granted. It is hard for me to show my appreciation to everybody because I usually over do it. My worst habit is that if somebody likes something that I have, I usually give it to them. That is a really bad habit. I have to grow out of it. I have lost some of my friends along the way, when they found out that I am HIV positive. They weren't true friends though; just along for the ride.

Do you have any family close by?

They are never more than a phone call away.

How is your partner taking this?

He is taking it a hell of a lot better than most people would. He lost his best friend when we first met. He had no idea about me. One night I told him he could ask me any one question he wanted to ask. After a while, he just said that he already had an idea that I was HIV positive.

How has your HIV status affected your intimate life?

My partner is negative, and I am positive. We are what they call sero-discordant. Ultimately, I will never do anything that puts him at risk of contracting this virus. I'm more touchy-feely than he is, so I guess for him it's not too big of a deal. For me, it's hard to say. Some things just aren't as important as they used to be. Now, that's a sign of old age isn't it! Yeah, sex just isn't what it used to be so I gave it up...!

Do you have a plan for if you become ill?

Yeah, I'm going to milk it for all its worth.

Day to day, how do you feel physically?

Pretty good. I have a hard time getting up out of bed and starting my day. I should probably go to bed earlier. I don't suffer from fatigue at work, but I usually take a nap at home in the evening. Physically, I have no complaints. I have the occasional headache, a side effect from the drugs but nothing that I can't handle so far.

What medications are you taking?

I take Ritonavir gel capsules and Crixivan. Ritonavir is also available in liquid form that you pour into little gel capsules yourself. The major problem for me was the flavor and the smell of the liquid medication. It got so bad last summer that I couldn't swallow them at all. That was really gross. So, my doctor requested that I have special access to a gel capsule form which is easier to take. You can't really taste it, and my doctor says that it works very well with the Crixivan, also known as Indinivir, both of which are called protease inhibitors. I take them in combination with Lamivudine, also known as 3TC. In the United States, it's known as Epivir. The other drug in my combination is Stavudine. Like all the other drugs used in the fight against the virus, I think it has issues - complex identity issues. Anyway, Stavudine is also known as D4T or Zerit. I don't know why they give these drugs so many names. 3TC and D4T are classified as reverse transcriptase inhibitors.

Just in case you are still following me, I take two capsules of the Crixivan, and one of each of the other three drugs twice a day. I also take a prophylaxis drug called Septra. Not to be left out, it is also known as Bactrim. Chemically it is called Trimethoprim-sulfamethoxazole. It is an antibiotic used to fight off pneumonia called pneumocystis pneumonia.

There are other prophylaxis therapies which help prevent other opportunistic infections.

How much do the medications cost?

The Ritonavir is covered under the Special Access Program, which I believe is supported by the drug company which makes it. I don't know how much it costs. The other drugs cost about seventeen hundred dollars a month. The Medical Services Plan covers the Sulfatrim.

Who pays for the medications?

The BC Centre covers the HIV drugs for Excellence in HIV/AIDS at St. Paul's Hospital. They dispense the medications from a pharmacy right at the hospital. In the US, the medications can be mailed right to your home. The St. Paul's Hospital assists patients in handling some of the side effects. They keep files on all the patients. My doctor picks up my medications for me. The reason he does is that on one occasion my prescription was changed without consulting my doctor or me. So, now, he picks them up, and I pick them up from him whenever it is convenient for me.

Is access to treatment a problem?

The only problem that I've had is having a busy schedule. I work full time and volunteer a lot. I spend a lot of time on the road, in the air and in hotels. My current schedule has me booked almost all the way up to July, even though this year has just started. Accessing the therapies or drugs is hard if you are constantly on the go, and you have to book a month in advance for an appointment at the pharmacy. Basically, the drugs are there if you want to take them. The drug therapies aren't for everybody. Some people can't handle the side effects. Some people can't handle the strict regimen. Some people choose not to be on the drugs. For me, the major problem with accessing the drugs is taking them for granted. Nobody has ever told me that I can't have them, so if they weren't there, or if I couldn't get them anymore, that would be a problem.

Do you face discrimination because you are a Two-Spirit person?

Not really. There are some very great Two-Spirit people who have walked this path before me. People like Art Zoccole, Dr. Terry Tafoya, Naz Therriault. Their courage in sharing their stories and teachings about Two-Spirit people has helped me understand who I am. Being a Two-Spirit man is so much more spiritual than sexual. The gift of being a Two-Spirit man means that I have a purpose. A part of my purpose involves my day to day living, some of it is in the work that I do, both paid and as a volunteer. As people, we never stop growing mentally and spiritually because we always have something to learn or we always have something that we can teach to someone else. I believe that I can only be discriminated against if I allow myself to be.

What about discrimination because you are HIV positive?

That would be illegal. The United States discriminates against people living with HIV/AIDS by not allowing them into the country. Here, I am just as free as everybody else to do what I want, when I want and how I want to do it. The only difference between now and that age when you think "If I only knew then, what I know now" is that I can afford to do all the things I want to. I've become the person I used to envy. I can take long vacations wherever I want to, whenever I want to. Then, I get to be discriminating. After all, I'm a Two-Spirit person, born with good taste and an amazing sense of myself and my own personal style.

As I said before, some people don't talk to me anymore. They were never really my friends, and I consider it their loss. If they ever need me, I'll be here for them.

Are you on a special diet or an exercise program?

No, I haven't changed anything since I've become positive. I try harder to eat better foods. I have a high metabolism, so it is hard to gain weight. I have set a goal to gain about twenty-five pounds this year. I have a list of things to do in 2000; one of them is to exercise more regularly. I try to drink only bottled water. Caffeine isn't good for me, so I try to limit my intake. I try to have vegetables and fruits in the house and juices and cereals. It's hard work to eat breakfast, anything more than coffee. Breakfast is always a challenge for me. On weekends, my partner and I have breakfast together. There's nothing special about my diet. I guess I am afraid that I would make diet too big of deal, and I could never afford it longterm, especially if I got sick.

Exercise? I have roller blades and want to buy a bike. I should walk more than I do. Maybe I'll take up jogging or running cross-country. I've always wanted to do a triathlon, but that would get really expensive really fast: bike, shoes, running shoes, swim suit, goggles, running shorts, bottles of water. See, too expensive already, and I haven't even started.

What keeps you going?

There was this one time when I was having a hard time. I was drinking too much and not taking care of myself; my job was really stressful, and I just wanted to give up. My doctor and I were discussing what it was that made my life what it is. One of the things he asked me was, "What do you want to live for?" I didn't answer him just then. He referred me to a therapist who wanted me to join an AA group, to go to just one meeting. I couldn't do it. I couldn't go to a meeting because of my on-going difference with the Church. I appreciate the sentiment of the Serenity Prayer, I just can't pray to God. So, I stopped going there, to the therapist. I never did go to an AA meeting.

All I could think about was what my doctor had asked me. "What do you want to live for?" After about three weeks, I went back to him with what I thought was a great answer. I reminded him of the question and told him that I didn't know what I wanted to live for, but I knew that I didn't want to live like this. That was about a year ago. I swore I would give up the stressful job, which is on my 'List of Things to Do in 2000'.

I want to finish a children's book I've been working on. I want to finish a couple soapstone pieces that I started a long time ago. I promised myself that I would learn to play guitar, take voice lessons and sing in front of anybody who is willing to listen. I also want to start an acting/modeling portfolio. One of these days I will have my own studio and/or gallery. That's what I want to live for.

What do you see as missing in Aboriginal HIV/AIDS work today?

There were no long-term survivors when I was newly diagnosed. We need more Aboriginal people who have survived with this virus to tell their stories. We need them to advise newly diagnosed people about the challenges of learning to live with the virus. There is a big difference between a 'newly diagnosed' person and a 'newly dealing with' person. It took me six years to realize that I had never really dealt with my diagnosis of HIV. I didn't start living with this virus until the last two or three years, so I guess, I am 'newly dealing with' my HIV.

We need to teach about the gifts of life including Two-Spirit people and how they have worked to become leaders in the fight against the spread of this virus.

We need to learn more about how to celebrate the diversity of our Aboriginal communities.

We need to teach about two different gifts - the first being HIV and the second being AIDS. This disease is so complex; we need to break it down a little so that it's not so much to absorb.

We need to teach responsibility. It is easy for us to say the leadership isn't doing anything. That takes some of the focus away from the work we could be doing on our families, our organizations, our communities and ourselves.

We need to teach more about the fact that HIV is preventable and that HIV disease is treatable. The cure for AIDS is stopping the spread of HIV.

Do you have any final comments?

Living with HIV is the hardest thing that I have ever done. It has been the most rewarding in regards to the friends I have found because I'm living with HIV. I have learned respect for myself, which makes it so much easier for other people to respect me. I have no limits on my life anymore, and so I should have no regrets. Living is easy; living without regrets is a challenge. I have learned to lead; I know when to follow, and I know when to get out of the way. I have learned that the only thing constant in this life is change and that's that.

Kukstemc, le 7 enc tu!

Teacher, Helper: My Relationship With HIV

Richard Jenkins

Tansi! My name is Richard Jenkins. I am a Cree/Metis from Moose Mountain, Alberta. I am currently living in Edmunton, where I have worked off and on over the years for the Nechi Training Research and Health Promotion Institute. I have been HIV positive for nearly ten years, and this article is about my journey with the virus.

I want to share my journey because it has been, by and large, a positive experience (no pun intended!). Of course, I do not like having HIV, and there have been many difficult and painful experiences along the way. But, the disease has also taught me many things, and the level of support I have received from family, from friends, and from work has been just amazing. I believe this disease has come to me as a helper and a teacher, a shape shifter that has given me access to many new insights and experiences.

My relationship with the disease started in the late 1980s. At that time, I had a partner who was HIV positive although I was not aware of his health status at first. For the three and a half years that we were together, we did not practice safe sex. I was a consenting adult in these relations, and, for my part, I just did not think I was going to get the virus. I figured, "*I'm young; it won't get me*". I went for HIV testing several times during those years, and every time I was tested, I tested negative. These results allowed me to perpetuate the idea that I was not going to get the virus. I stopped testing for HIV in 1987, and when the relationship ended in 1989, my approach was, "*Well, I guess if I don't have it by now, I probably won't get it. I will just practice safe sex, and I won't get it.*"

In 1991, I had moved to Ontario and was working for the Ontario Federation of Indian Friendship Centres (OFIFC). That fall, I decided it was probably time to go for another HIV test, just to check things out. I went for a test and after waiting the two-week period, I discovered that the lab had lost my results. It took me another few months after that to work up the courage to go and get re-tested. By the time I went back, they had found my original test results. I was informed that I had tested positive but that they needed to do another test to be sure because of the original lab mix-up. I was not really worried about it. I figured, *There has always been a possibility that I might contract HIV*; I am, *after all,* in a high risk group.. It was like when I was young, and I used to walk across the field in the middle of the night, in the dead dark. I was terrified about coyotes, bears or wolves getting me, but I used to think, "*Well, if they are going to get me, they are* *going to get me. If it is my time to go, it is my time to go, and there is not a whole lot I can do about it anyway.*" That was my philosophy of life, and that was how I reconciled it to myself while I was waiting for my second test results.

When they called me in again and told me that, yes, I had tested positive, I realized that I was not as prepared as I thought I had been. I reeled for months: got depressed, got short and angry with people, went through the usual "Why me?" phase. I had a lot of guilt about having contracted the virus because I did not drink and I did not do drugs; I was not an intravenous drug user, so I really beat up on myself with thoughts of *I should have known better.* I did not blame anybody, but I did go through a period of self-blame. I knew that it was my own lack of prevention, and so, in a positive way, I took responsibility for it. But, I still felt guilty and ashamed, thinking, *Oh my God, I am a Queer. It is God's wrath on me*, knowing full well that it was not true. I also felt guilt and remorse about my sexual promiscuity. After several months of this guilt, I finally came to the realization, "*Well, you know, I could have cancer; I could have leukemia; I could have diabetes; I could have any kind of chronic illness. It is irrelevant how I got it.*" I began to lose the shame and the guilt and think about how to work with the disease.

At first, I only told a few people about it: my boss and a close friend who was also HIV positive. I also felt it was important to tell people with whom I chose to have sexual relations, and I respected their choice not to have sexual relations with me. I did not talk to my family right away even though they had begun to ask me about it. The fact that they were even asking me was, I suppose, good. I had come out of the closet about being gay at the age of nineteen, so they were aware that it was a possibility that I might get this disease. But, it took me some time to approach them and to find a way of talking to them about my condition. I was living in Ontario, and the majority of my family was living in Alberta, so our contact was mostly by phone. Telling your loved ones that you have HIV is not something you do over the phone, at least not for me[1]. I wanted to be with my family when they found out, so I arranged a trip home. I had a friend call and organize a meeting with my mother and my four sisters that were living in Alberta; I instructed her to simply tell them that someone was travelling to meet them and share some news with them.

The reaction from my family members was diverse. Some broke down and cried, processing bits of their grief immediately. Others did not display much emotion, downplayed the news, or seemed annoyed that this

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[1] I had to tell one sister over the phone because I was unable to visit her.

news was something that they would then have to explain to their children. But, *no one blamed me*, which is what I had feared. After their initial reactions, they all simply asked a lot of questions, such as, How long have you known? and Are you sick yet? They had been paying attention to the reports and watching the news, a lot of which had to do with the horror stories about AIDS-related deaths. So, I told them, "well, you know, I could live forever. Or, I might walk out of here and get hit by a truck! I don't know." There is just so much that the medical profession does not know. So let us not bury me yet! So we managed to have some laughs about that.

The word eventually got around to my extended family, and to my relief, nobody disowned me. To them, I was still their grandson, their nephew, their cousin. Their approach was, "So you are HIV positive. Big deal. You are still part of this family, this community."

In short, my coming out about being HIV positive with my family was almost anti-climactic. Their reaction was simply, "When are you going to come home?" Their response speaks to the love and acceptance that I have as a brother to my sisters, and a son to my mother. My family has never approached me as "my brother the queer," or as "the one with HIV." To them, I am simply a good brother, a good person, someone who does good work for the people. So it is that my family's support acts as the foundation, the feather pillow on which I can rely when things become difficult.

My relationship with the community has grown from there. I am fortunate to have been employed by progressive organizations which have valued and honoured my role as a worker and as a community member. This was particularly helpful during a period where I had to live through the AIDS-related death of my former partner, Brockton. I had met Brockton in 1992 and had a wonderful relationship with him until he died in August of 1995. In the six-month period preceding his death, I was under tremendous stress which made it difficult for me to work. I was losing concentration, getting short with people, becoming easily angered and frustrated. I got to the point of handing in my resignation. My employer responded in a way that honoured me both as a human being who was struggling, as well as as a valuable employee. The executive committee of the organization for which I was working unanimously supported providing me with a paid leave of absence to enable me to assist Brockton through his dying process and to deal with my own related grief.

I returned to work a few months after Brockton died but was unable to manage the stress along with my grief. After six months, I went on short-term disability, only returning to the organization to finish some business before resigning. Again, my employer honoured me by recognizing me at their Annual General Meeting by presenting me with a gift, and by thanking me for all the good work I had done. I could have continued working. My employer has always made me feel that my HIV status in no way impedes what I have to give as an employee. But, in spite of that supportive environment, I felt a need to go home to Alberta at that time. Toronto was not a good place for me emotionally, mentally, physically or spiritually. There were too many memories. I felt alone and felt a need to reunite with my family. I needed to be in a place where the pace was slower, where I could find that sense of community that I needed in order to regenerate.

The land called me home as much as my family did. While I was still in Toronto, the land would speak to me in my dreams. It was a draw. Sometimes, it was so strong I could feel as if I was home, sitting in the bush, or sitting at my house in Alberta, being around the land. Although I could call on the spirits to help me in the city, I wanted to be where my ancestors are most firmly rooted. I can more easily connect to "all my relations" in the land of Northwestern Alberta, in the trees, animals, rocks and plants of my home territory. And, being around home, being able to walk down the road, to see old places where I used to play and to feel the energy of the land was tremendously healing. Even simple things like having wild meat were positive and rejuvenating in terms of my health. I soaked in that environment, just as I soaked in the love and acceptance of my family.

It is three years later now, and I am healthy and working again in Alberta. My intention is to build my skill capacity so that I can return home at a later date, and for now, I am enjoying all of the lessons that continue to come my way. I am able to reflect on all of the teachings of my journey thus far, and I appreciate everything I have been given.

I now understand this disease to be a shape shifter. It is like those people in our communities who were traditionally known to change their form. They could shift themselves into a different physical space, taking on the appearance of a wolf, or a coyote for example. This new way of being helped them to survive, to go to different places, to access different things. Similarly, HIV shifts the shape of our cells inside, which thereby enables us to explore new ways of being, to see things differently, to play a different role. On a basic physical level, we are much more vulnerable to things which are going on around us because of the changes to our immune system. There are dangers involved, and HIV teaches us to pay more attention to our bodies and the environment in which we find ourselves. But, if we pay attention, we can see and be aware of all kinds of good things too. Our sensitivity can open us up to all sorts of new possibilities on emotional, mental and spiritual levels.

I am learning to work with this helper, this spirit which has come to teach me something about life, about faith and belief and about what community means. The strength I have taken from this teacher has manifested itself on several levels in my life: from individual, to family, to community.

Self-Acceptance.

It was a struggle to accept that I had HIV, as it is a struggle for anyone with a chronic illness to accept their disease. People who find themselves in these circumstances need to work at accepting that they are not somehow weaker or less human than before they had the disease. This struggle ties into overall issues of self-acceptance. Unfortunately, some people react in a negative way, and they become harder not only on themselves but also on other people whom they perceive as being weak as well. I have simply come to accept the disease as a new way of being in the world, and this acceptance has been a liberating experience.

For those of us who are HIV positive as well as homosexual, acceptance of the disease is linked to our self-acceptance around sexual orientation. If we have contracted the virus through sexual activity, it can evoke old feelings of anxiety or shame about what other people will think of us, and maybe about how we think of ourselves. These feelings can be even worse if a person's family or community are unaware that he or she is gay. I was lucky because I did not have to worry about my family. I have seen some people suffer shame and guilt they think, *Oh my god, I am HIV positive, and I will probably get AIDS, and then I will die and my family will find out that I was gay, and they never knew.* Even so, my first few months with the disease were not without the anxiety and blame which often accompany the first stages of a relationship with HIV. It was like a relapse to a time when I would worry about how other people would see me because of my sexual orientation. For a brief period, I saw myself again through the negative lens of other people's eyes.

Telling my family was helpful in terms of self-acceptance because their support gave me the strength to see myself just for who I am. This self-acceptance was critical in terms of dealing with negative and anxious feelings when they tried to creep in again, such as the first time I spoke publicly about my journey with HIV. I had decided to give a talk at a health conference, and, in spite of my confidence that I was doing the right thing, it did cross my mind that people might no longer perceive me simply as Richard Jenkins; that I would become "that faggot with HIV." In the end, it was liberating to speak publicly about my HIV status because it confirmed my understanding that *I* am the one who creates my image. If other people wish to see me in a negative way, those images belong to them.

To me, the most empowering tool we can have as individuals is self-acceptance. If we can see ourselves in a positive way, what others see becomes less important. As a gay Aboriginal man who is HIV positive, I have had plenty of opportunities to put this into practice. My experiences have taught me that I do not have to wear other people's negative images, be they about Natives, homosexuals, or people with HIV, because those images come out of *their* negativity. And, I find that the more I have this positive attitude about myself, the less I see negative attitudes in other people. I do not engage in negativity and shame about HIV, so I do not invite it. I surround myself with positive, accepting people, and that is my reality. When negative people come in contact with me, I see something different, and they, in turn, respond. Thus, the more I create my own image, the broader it becomes in my mind. The bigger it gets as a picture, the more it comes out of me. I find, too, that people want to be around that type of positive energy; they want to discontinue their own negative thinking.

It is important to accept that having HIV does not mean that we are any less worthy of love and acceptance from ourselves, from the Creator, or anybody else. I know that I am worthy of love. I am worthy of my own love, and I know that the Creator is totally accepting and full of unconditional love for me.

Building Support

Once I had developed self-acceptance, it became easier to build support networks around me. I believe that the acceptance moved from me, to my family to my community.

I am lucky because my family has always been supportive. They are my foundation. For this reason, even though I am in Edmunton now, I maintain regular contact with them. I phone a family member almost nightly because this is my way of maintaining those relationships that are so important.

My family accepts me and loves me for who I am. This acceptance is sadly not the case for every person who is HIV positive, but there are ways of developing that inner circle, that "family" in the absence of a supportive biological family. (And, if we can not find that type of "family" acceptance, it is perhaps worthwhile to revisit our own self-acceptance). With that inner circle of support, we are more able to go out and pro-actively engage in the community. For example, it was my family's support and acceptance that gave me the strength to be public about my HIV status. Most people whom I know and with whom I work are aware that I am HIV positive, and this knowledge is not a hindrance to my participation in community life. I have been fortunate over the years to have been employed by progressive organizations who value my role as a worker and as a community member. They have enlisted progressive policies to support me in my times of need, and they have honoured me. Because I have that support, I do not have to worry about someone not hiring me because I have

HIV. I know that I have a community that supports me and recognizes me above and beyond the disease.

Relating to purpose: Seeing value in my role as a community member

Being HIV positive has allowed me to reflect more about community, about the support I receive from community and about my role within community. My family's response to the disease has been to appreciate the many skills and teachings I have to offer them and to my community back home. The fact that there is a perception that I could die in the near future has reminded them to call on me to come and to share what I have learned.

The role I play as an uncle is a reminder about the value of extended family and community – that it takes more than just two heterosexual parents to raise children and to make the community work. Some of my sisters say, "I want my children to benefit from what you have to offer." As an uncle, I know I have parental responsibilities in the true sense that it takes a whole community to raise a child." Because I want my nieces and nephews to benefit from some of the opportunities that I have had, my focus has always been to bring home what I have learned from the many years I have spent working and learning in Ontario.

I believe my purpose has always been to be a servant of the people. I am now even more secure in the knowledge that I am a vibrant part of the community. I know I have something to give and that I am honoured and respected for what I have to give.

Having Faith

I have always had the simple faith that death is merely a passage to a different place, a different reality, a different place of being. Being HIV positive has brought me that much closer to a realization of death. It has led me to contemplate my own mortality--something that most people do not go through until later in life. In turn, I have been the primary caregiver for a partner who died of AIDS and that experience has taught me many beautiful things.

The biggest lesson I took from my former partner Brockton's passing is that death does not have to be an exclusively somber and sad experience. I see it as a journey back to the spirit world, back to the Creator, and so, in that sense, it is incredibly joyous. As the primary care giver for Brockton, I had the privilege of traveling with him on that journey as far as I was able. There is a real joy to be experienced in being that close to the doorway; watching Brockton communicate with the spirits as he got closer to death was a powerful awakening. In this awful physical time, spiritually, he was going through a real chrysalis process. It was as if he was coming out of a cocoon--he was a butterfly spiritually, and I was witness to that process. So, to some extent, as a primary caregiver, you also go through a transition process, a dying process. I was able to open up to my faith that the spirit helpers were there; I was reminded of those things that I already knew.

I carry the joy from that experience today. I have seen others so heavy and joyless in their partner's passing and wish that more people could be open to the joy of being that close to the doorway--that joy one feels in witnessing a spirit that has gone home. I remember at one point talking to an Elder who has helped a number of people pass away. She said to me, "I don't know if I can help any more people. The next person I might want to go with!" And, now that I have had that experience, I am not as afraid or as saddened by death. I see it as an honour to integrate all of those teachings into the rest of my physical life.

Lightening up!

Finally, when things get so serious and somber, it is a good reminder to us all to lighten up! I believe that if I think in a certain way and act in a certain way, I will prolong my life. My health will become better if I have a positive attitude and especially if I have a few laughs along the way. I may not like having HIV, but I have accepted this disease as part of my life now and have integrated it into my journey.

Maybe some day I will make amends with this spirit, this helper-teacher called HIV. Maybe some day I will make the deliberate choice and say, "Okay, I have learned what I need to know from you. I can release you now," and maybe then it will move on. In the meantime, I will remain open to the lessons that it has to offer about life, about community, about love. I do not see myself as a victim. I do not see myself as a survivor. I see myself as a celebrant of life.

Hiy Hiy!

Confronting HIV and AIDS: A Personal Account

Rene Boucher & Joyce Timpson B.Sc M.S.W. M.P.A. Ph.D.

Background

Rene Boucher is a 33-year-old First Nations man from Sioux Lookout Ontario who is living with AIDS. Since 1995, he has been an advocate and a speaker for HIV and AIDS awareness and education. This is his story of confrontation with his illness and the spiritual growth that ensued.

Sioux Lookout is a town of 5,000 people, 400 kilometres Northwest of Thunder Bay in the midst of a vast hinterland of boreal forests. To the North, 15,000 Oji-Cree persons live in 30 scattered First Nations. The area is part of the broad political group called Nishnawbe-aski Nation (NAN) (see Map).

Traditionally, the Nishnawbe-aski people were hunters and trappers who had limited contact with mainstream Canadians until the 1970s. The first language of most of the people is Ojibway or Cree, and many of the traditional ways of the people still exist and are practised. The Oji-Cree, as they are called, endured in the early days of contact with European society the devastation of famine, and infectious diseases such as small pox, measles and tuberculosis. Now, they suffer from life style diseases associated with moving off the land to settlements and changing to a European diet. The prevalence of diabetes and cardiovascular diseases, depression and suicide are disproportionate.(Young 1988) Likewise, tragedy, death and epidemics are no strangers to the people.

Before HIV was identified in North America, contact with Euro-Canadians was limited to visitors to the communities, such as nurses, teachers, technicians or Hudson Bay store managers. The chance of exposure to HIV was remote. With recent political movements and growth in economic, educational and health programs, travel to cities has escalated the risk of exposure. The concern about the effect of this disease on the North has been only quietly expressed.

With increased movement and more disposable income, it is feared that HIV could pose a serious problem in the North. To date, there have been less that five cases of AIDS, two known deaths, but the number of HIV identifications in the Northern communities is yet unknown (Medical Services Branch Health Canada). Although the incidence is much below that of Ontario[1], intravenous drug use is thought to be the most likely venue by which HIV will be spread among the Aboriginal population. (Canadian AIDS Society 1999)

Despite the creeping prevalence of the disease, much silence still shrouds this entirely preventable disease. Given the history of devastation by diseases in the past as well as new chronic illnesses and depression, the difficulty in facing another potential killer is understandable.

To prevent the needless spread of this devastating disease, the silence must be broken. As Rene's personal experience in contacting HIV illustrates, the lack of knowledge by not only the public but also by professionals is the greatest danger. Rene's passion to educate himself and others has transformed him from the status of victim to that of a survivor and spokesperson for hope.

Rene's story of confronting HIV and AIDS through knowledge and culture-specific survival skills is a story of promise and spiritual awakening. His illness opened spiritual paths about life's purpose that he never thought possible. His story not only brings awareness of the possibility of love and acceptance in a climate of fear and hostility, it breaks the silence. Silence and ignorance are the greatest danger. Openness and education are the greatest hope.

My Story

I come from a family of 15 children; 13 of us are still alive. I came into this world in October 1966, three days after my parents were in a car accident. I wasn't due until November, but after the accident, my Mom was rushed to the hospital. She told me I was a miracle baby because during her ordeal she prayed to God and asked Him to spare me. This fortune and grace have followed me through my battle with HIV and AIDS.

My Journey Begins

My mother was born in 1927 in Frenchman's Head of the Lac Seul First Nation near Sioux Lookout Ontario. Her parents were famous trappers, but they passed on before I was born. My father was also born in 1927 in Lac St. Jean, Quebec of French parents. In 1975, we returned to live in this area. I began to learn more about my native heritage and the many traditions

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[1] Data on HIV in the area is difficult to ascertain and this is likely an underestimation. HIV is reportable only in the area the testing occurred and since most Aboriginal people at risk for AIDS are likely to be living and/or diagnosed in cities, the incidence of HIV specific to this area is not known.

still practised. My mom began to talk about how it was growing up on the reserve. These traditions would come to be strong forces in my life.

When I was 12 years old, my parents, who were full-fledged Christians, did a lot of travelling from town to town hearing speakers preaching about God and His plan. After a meeting at one particular revival, a young woman came up to my parents telling her that she had a vision about their son, who was me. She said that she saw me standing in front of a large group of people carrying a strong message. What the message was she did not know, but she knew it was an important message from God that people needed to hear. My parents talked to me about it and told me they believed I would be a preacher one day.

My home in Sioux Lookout was where my son was born, but unfortunately, my relationship with his mother did not work out. In 1992, I moved to Vancouver to pursue a career in Accounting at a Native college. I was in my second year and doing well. During Christmas break, I went out partying with some of my peers. Sometime during that period, I became infected with HIV. At the time, I really never paid attention to the warnings because I felt HIV was not something I needed to worry about. All it took was one night of unprotected sex with a stranger to turn my life upside down. I remember waking up the next day and couldn't remember a name or anything.

In February of 1993, I came down with what I thought was the flu. I went to see my regular doctor to have a check up. While I was waiting, I picked up a pamphlet on the signs and symptoms of HIV. As I read it, I became concerned and asked for a test. I didn't think much about the test or what the results were going to be. Two days prior to getting my results, I began to worry. I questioned myself on how I would react if they came back positive but convinced myself I had nothing to worry about. My appointment finally came. When the doctor came into the room, he seemed nervous. He stumbled, dropping my medical file on the floor, and as he gathered it up, I noticed a coloured dot on my file that made me uncomfortable.

I remember it as if it was yesterday. "*I'm sorry Mr. Boucher but your test results came back positive for the AIDS virus.*" I was shocked and stunned. I wanted to scream out "*No!*" but nothing came. I asked him what that meant. It was obvious that he had never told anyone they had HIV before. He seemed uncomfortable talking about it and said he would try and get information on HIV/AIDS. With that, he left the room, and the nurse returned. She took me to the waiting area and asked the receptionist for some forms. We went into another room, and she began to explain what the forms were for. I signed them, and she arranged for me to see an expert in infectious diseases at St. Paul's Hospital in Vancouver. I asked her what did this all mean. All I could think was, "*What is happening? What does this* *mean? How long do I have to live?*" They were obviously not trained to handle an HIV patient. She just said, "*They'll answer any questions you have at the hospital*". They were not very knowledgeable about the illness, and with that, they sent me on my way.

I began to cry as I walked down the street. Reality began to set in, and I was overwhelmed. What do I do now? Who can I trust to tell? What does this all mean? I hopped on the sky train and headed for the bar. It seemed the only thing that made sense at the time. The emotional pain I felt was great, and alcohol seemed to numb it.

I continued to use alcohol and did not think much about my feelings or what had happened. I guess this was my denial period. I come from an alcoholic background, and I thought drinking was the only way to keep anyone from finding out. I kept my secret for three months. I finally shared it with a close friend. He was surprised and began to cry. He eventually convinced me to tell my brother. Together we called the rest of my family in Vancouver and told them too. We all cried and comforted each other. We decided to have a family meeting once a month. They wanted to help me come to terms with this as well as learn about it themselves.

I continued drinking, hoping this HIV was going to go away. I decided to find out more about the illness. I went to AIDS Vancouver and the Person's With Aids (PWA) Society. Before going there, I remember being paranoid about someone seeing me. After all, I was quite ashamed and afraid of HIV. I didn't tell any of my close friends. When I arrived there, I looked around and ducked into the building.

My life was spinning out of control. I was still drinking, feeling sorry for myself and hoping everyone else felt the same way. About six months later, I checked myself into a treatment centre. I was still afraid to tell anyone I had HIV. I eventually asked my counsellor if she could arrange an educational workshop on HIV/AIDS. Then, I would tell my peers. She agreed, and after the presentation, I stood and announced that I had HIV. I felt good to have it off my shoulders, and many came, shook my hand and hugged me. Another man stood up and told us he was HIV positive. It felt great to unload my burden. Eventually, I became strong after realizing I needed to accept that I was *living* with HIV and *not* dying from it. I left the treatment centre after two months. It wasn't the alcohol that was my problem but my diagnosis. I had already told my family, my Mom and Dad being the hardest people to tell. How do you tell a parent that there is a possibility that you might die before them? It was a very hard time for them, and at that time, I was very emotional. To this day, they are still trying to deal with it.

I began to learn about HIV/AIDS in small little morsels. I met others from PWA; it felt good to know I wasn't the only person with this disease. I wasn't aware how the disease was transmitted. My four-year-old son would greet me at the door with a big sloppy kiss. When I learned I had HIV, I began to turn him away and just pull him close and hug him. He and his mother were confused, and she questioned me. I realized I needed more education to relieve my extended family's confusion. I learned that it was okay for him to continue greeting me with a kiss. That part of my life returned to normal.

They sent me to a supposed AIDS specialist whom I refer to as "Doctor Death". He scared me into trying AZT (zidovudine which was the only licensed drug for HIV at that time in Canada). He had me sign forms for a clinical trial where basically you sign papers so the doctor is not responsible if something should happen. At that time, they prescribed me almost 2400 milligrams, and for the next 2-3 weeks, I took it. The AZT was making me very ill, and I would lash out at my family. I felt detached from myself. My family decided it was time they mentioned something because I was not acting like Rene.

I went to a support group where we talked about medications. I asked about changing doctors and if anyone knew of someone who was more compassionate and didn't push the drugs. So I left "Doctor Death" and began seeing another doctor. I later learned I was lucky I had quit the AZT because it became known that it was poisoning people, and the dose should have been half of what I was receiving. I attended many support groups, seminars, and an AIDS Mastery group. I became stronger and stronger the more I talked about it.

My spirituality began to kick in, and I thanked God for sparing me again during this difficult time. I yearned to be back in my home town where my parents and best friends lived. I had also heard that the Sioux Lookout AIDS Committee needed someone with HIV to speak out about prevention of the disease. The North's first person with AIDS, Norm, had been an avid spokesperson but had recently died. So, I moved back to Sioux Lookout in 1995. It was difficult because I was the first person with HIV actually living in the town. At this point, I had extensive knowledge of HIV and was very self confident. I decided not to hide my diagnosis because I accepted it. I moved home to my Mom's to be closer to my roots, family and friends. At the beginning, it was very difficult. Many of my friends turned their backs on me. Rejection is something an HIV positive person must go through. We must accept ourselves as we are. It hurt but I knew God would never give me more than I could handle. I was still asymptomatic and felt really good about myself.

Receiving Messages

After I moved back to Sioux Lookout, the Dryden High School asked me to speak to the students about HIV and AIDS. I asked my parents to come along. I was the last on a panel of three to speak. I told them about the vision of the woman at the church when I was 12 years old who told my parents that I would be delivering an important message from God to a large group of people. I introduced my parents, asked them to stand up, and told them that the vision had come true because here I was standing in front of a group of people telling them about HIV and AIDS and that I felt it was God's message. When we were driving back to Sioux Lookout, I asked my mother what she thought the vision meant, but Mom still wasn't sure.

Later, I was invited to a workshop in Thunder Bay called "Opening More Doors". There I met other PWA's and beautiful people who were the front line workers who were trying to learn more about this disease. I met an old acquaintance who asked if I would be willing to share my story with communities in Northwestern and Northeastern Ontario. Having some public speaking training, I decided to share a piece of myself to help others not only see the human face of HIV but accept it and prevent it. In 1995, at a workshop with Mary, the HIV educator for NAN, I had a dream but did not think anything of it. As we were driving back, Mary told me her story: One night five years earlier, Mary's partner woke her to tell a dream he had just experienced. In the dream, a dog-like creature was running around the reserve killing people, but nobody could see him. He kept trying to warn people about this dog, but no one was listening to him. Eventually the dog caught and killed him. He awoke and immediately wanted to tell Mary. He was talking as if something was going to happen to him. He said he needed to tell her this and that someday she would meet someone who she would know is the person she was to tell the dream to. A week later, he died in a house fire. She always remembered what he told her. Just the night before, I had an almost identical dream. I was being chased by a dog and was trying to warn people, but people were turning a blind eye. It was as if I was the only person who could see what was going on. I ran into a Church, found a basin of holy water, scooped it up, ran back outside and threw it on the dog. The dog vanished. After Mary told me her story, I knew what it meant, and that I was the one her boyfriend wanted her to tell. We were astounded as to what this dream was about. I now believe that the dog represented AIDS, and the people who were dying were not listening to the message about prevention, so they continued to get the disease. The experience was another spiritual awakening for me.

From there, I travelled, met and shared with many people. I spoke at conferences and on panels with other people infected and affected by HIV/AIDS. My family actually told met they were jealous of my travel and the recognition I had. They were receiving flack from other people who were ignorant about HIV. I helped them learn how to deal with this and realize these people were talking from ignorance.

I was not coping and felt isolated and alone. I found a counsellor who still remains my confidant today. To him I could talk about my isolation, my loneliness and my frustration.

Hope Emerges

In the spring of 1996, God would send me an angel because I still felt there was something missing in my life. I met someone, Joanie, who would later play a big role in my life. Unlike others, she would really listen. Although more than 20 years older than I, she became my best friend. She was going through her own difficulties. Six months earlier, my friend had lost her husband in a boating accident, and it took her a long time to accept this loss; to this day, she is still working on it. The way they parted was terrible. They had a misunderstanding and weren't talking the day he drowned. She lives every day with that fact, never seeing his body, never making amends. She knew someday God would send her someone. That someone was me.

Our friendship became a solid rock on which both of us could rely, a gift from God. We would talk into the wee hours of the morning about life and its many wonderful and sometimes difficult lessons. We would laugh and cry on each other's shoulders. Life didn't seem so precarious anymore. We didn't feel so alone. Joanie knows she will see her husband again and meet him back home. I may go home before Joanie, but we have learned valuable lessons, the two of us. We have learned that we can't take life for granted.

Townspeople began to talk about us, namely because of gender, age, race and my having HIV. Often people who knew Joanie would ask ignorant questions such as, "*Why do you wanna hang out with someone who has AIDS? If you're not careful, you're gonna get AIDS*", and "*Why do you want to get close with someone who's going to die? You will just be hurt all over again.*"

As I pursued my speaking, I became despondent and concerned that it was to no avail, and then an incident of hope occurred in an isolated community north of Sioux Lookout. An experience for me in Sandy Lake showed me just how people can change and was a remarkable awakening for me in my work. The Sioux Lookout area's first person with AIDS, Norman, was from Sandy Lake, and he had suffered immensely from violence and persecution in this community. He was unable to spend his last days at home because his safety and that of his family could not be guaranteed. Norman died in 1993, but his death resulted in a miraculous transformation of his community to one of the most ardent advocates of prevention and awareness. After doing two workshops there, I was down and discouraged one evening. Why, I do not know. I prayed to God and I asked Him, *"God If I am doing what I am supposed to be doing would you please show me a sign of some sort. I feel so down, and I need you now more than ever; I do not know with the work I am doing, if I am getting anywhere, if anyone is listening."*

The next morning my workshop partner went to the airport without me because there was no room for me on the plane. At the last minute, a seat came up; I made a dash to the airport, grabbing my bags and running to the road where a driver picked me up. The driver turned to me and said, *"I have a message for you. I want to tell you that it is a wonderful thing you are doing. You know it is in God's plan for you to talk about HIV or AIDS to not just young people but to everyone whether in our First Nations communities or in towns. If ever you are feeling discouraged, remember what I have told you here."* I thanked him and told him about my prayer and my feeling the night before. He said: *"You are doing what you are supposed to be doing. It is wonderful and just continue doing it for as long as you can."*

I was ecstatic. That was my sign, my message from God! I only told my friend Joanie what the driver said to me because I thought people would think I was crazy. They already thought we were crazy because of our relationship.

Confronting AIDS and Mortality

As time progressed, I would soon face the loss of friends from AIDS, and I would confront my own mortality. I had developed a friendship with a young woman named Tammy. She visited me because she had heard that I had HIV and wanted information about HIV for a friend who was HIV positive. We met often and became very close. In February 1997, I received a call from the hospital that Tammy was ill and wanted to see me. At the hospital, a teary-eyed nurse took me aside and asked me not to talk to Tammy about death because she might not make it through the night and had not come to terms with her death. When I saw Tammy, she told me that she had been in a Winnipeg hospital for six months with what she told everyone was terminal cancer. In fact, it was AIDS, she said. Nothing further could be done, and she wanted me to help her to tell her family. I now knew that the “friend” she talked to me about was herself.

We set up a meeting with her family, and we told them. I gave them information on AIDS. When I returned to Tammy’s room, she was getting weaker, and the family was arguing about whether the children should see her because they were worried they might catch AIDS from her. I tried to tell them that this was not possible.

When I left that night, Tammy said that she was going home soon and would see me there. That was the last time I would see her conscious. She passed away three days later. I knew then what she meant about "going home." I was asked to do the eulogy for the funeral. I asked my counsellor to review it. He said it was good but that the Rene he knew spoke from the heart. When I delivered the eulogy, I talked about Tammy on a personal level but still had not grieved her death.

The next day, I was giving a workshop for 50 nurses. When I was telling my story, I began to cry, but I felt a warm feeling come over me. There were many teary eyes in the audience. Afterwards, a woman approached me and told me that she and five others had seen a woman standing behind me who placed her hand on my shoulder. I knew it was Tammy's spirit. The loss of persons close to me from AIDS, and the grief I feel for their loss now allows me to understand what my family is going through.

Next came my diagnosis of AIDS. The HIV/AIDS spectrum involves two different things. When I had HIV, I was very involved in education because I was strong physically with no symptoms. I saw the doctor only every six months. Now, with a diagnosis of AIDS, I see a doctor once, even twice, a month. I am in the hospital frequently.

My life with AIDS began in February 1997 when a bad case of shingles[2] took over my body. I thought I had chicken pox, but one morning, I awoke in pain and the sores had become blisters. Usually shingles is in the small of the back. I had it head to toe and checked into the hospital. Sure enough, that is what it was. The probable cause for the shingles was my high stress level. I was ignoring my personal problems. I remained in hospital for 20 days.

When almost ready for discharge, I developed a secondary illness because I had such a low T-cell count[3]. My doctor needed to talk about it, but instead of telling me himself, he insisted on calling my family into the hospital. We had the meeting, which included my family, a doctor, a pharmacist, the head nurse, my counsellor and my friend Joanie. He announced he would now have to give me a diagnosis of AIDS. This statement hit me like a ton of bricks. The same feeling when I first learned I had HIV crept back. This news devastated me. There was silence. Everyone had questions except for me; I was feeling lost and devastated.

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[2] Shingles is a disease that is associated with weak immune system (Health Canada 1999).

[3] T-cells are white blood cells (lymphocytes) of the immune system divided in to groups, T4, T8 etc. They are much lower in people with HIV (Health Canada 1999)

With time and the help of my counsellor, I came to accept it. "Mortality" crossed my mind frequently. With the help of my friend, Joanie, I learned to live in today and to worry about tomorrow when tomorrow comes. For six months, I was in and out of the hospital with different illnesses. I could not travel or do workshops. Counselling made me realize I needed to put my health first.

In the fall of 1997, I was again hospitalized while on vacation. I had a huge stomach. I had joked about being pregnant, how the baby was kicking and trying to get out. On my discharge, they still were not sure what was wrong. They told me that basically I was *"full of 'shit', no pun intended."* I had developed Mycobacteriumavium intracellulare (MAI), an AIDS related bacterial infection which can affect the digestive system. Later, I was having very bad abdominal pain, and that night I passed about a litre of blood. I was immediately hospitalized.

My doctor thought I might have lymphoma cancer and put me in a room with three much older terminally ill patients. One evening, another patient was in much pain and wanted to get out of his bed. Sometime during the night, he passed away. My fear of death was overwhelming. Earlier in the week, we had discussed exploratory surgery for which the chances of surviving were 50/50. I was in such extreme pain that even Demerol did not work so they switched me to a morphine pump. I began at 15 mg every 12 hours. Nevertheless, as the days went on, it was increased. The surgeon pressured me to have surgery for a biopsy, but this surgery would not take away the pain I was having; in fact, the pain would worsen if it were cancer.

It was the morning of Princess Diana's funeral. I awoke, turned on the T.V. and saw her coffin in the procession. I cried uncontrollably and was filled with the fear of my own death. I began bargaining with God, reading my Bible and asking God to please give me more time, more time please! My mother, sister and Joanie arrived and began crying with me. All I would say is, "*I don't want to die. I'm not ready yet.*" We talked about it and discussed the exploratory surgery. By this time, my morphine pump was at 400 mg every 24 hours. I decided not to have the surgery. If it were God's will, then so be it.

By now, living alone had become impossible. I moved in with Joanie who agreed to be my caregiver. Mom and my sister Vera took care of me during the day when Joanie went to work and then she would take over when she returned. Every day they would warm up five or six hot water bottles and place them around my body because I was always very cold. They would keep me warm.

Not long afterwards, Vera and Joanie began to organize a surprise birthday party for me because they thought it would be my last. They called some of my family from Vancouver to come. I will always remember how emotional it was for everyone who thought it would be the last time they would see me alive. The day they left, as we cried and hugged each other, I thought to myself that the next time they would come would be for my funeral.

Reprieve and reclaiming spirituality

Around Christmas of 1997, I started a new combination of drugs that looked promising. I began to feel better. My bedroom was no longer a prison. I started to go out. This surprised many people in town because the rumour around town was that I was not going to live to see 1998. I was winning my battle to overcome the illnesses caused by HIV despite the side effects of taking 35 pills a day. I returned to doing workshops. We did a television workshop on the Sioux Lookout community channel. We had many people volunteering to help in producing it. We taped a T.V. talk show. There were two panels - AIDS educators, a drug and alcohol counsellor and a home care nurse; and myself, a woman also infected with HIV, my care giver and my sister. The show was a success; many people phoned in with questions and comments. The audience had 25 people or so, and there were many questions and comments. Sioux Lookout was not in a state of denial as I had thought.

In the spring of 1998, I become ill again with nausea and abdominal pain, and I lost much weight. They again changed my medications. By summer, I had gone through about six different HIV medications but was resistant to them all. I was hypersensitive to new ones. I began to question my life and wondered what was more important, quantity or quality of my life. I decided quantity of life was more important. I continued trying different combinations that caused me so much distress that I quit all drugs. My appetite improved. I gained my weight back. Still, the results of a battery of tests did not look very good. I would need to decide about taking medications again. I declined further tests for cancer. They increased my pain medication for MAI to 75 mg of Morphine, and I started another medication regime.

Later that spring, after this crisis, Ted, a fellow Lac Seul Band member, invited me to a sweat lodge. I was afraid, not just because of the unknown, but because my Mom was a strong Christian and does not believe in these things. I was torn. When I told her, she seemed against the idea of my going. I realized it was up to me to decide. I also had to bring a pouch of tobacco. I was quite nervous and still had ideas in the back of my mind of what my Mom told me. But, I was determined to get something out of it. Ted sat with me and explained the procedure. We decided that we would go four rounds taking five hours. When it was over, I felt wonderful. It was chilly outside, but I did not feel the cold. An elder who participated told Ted that a spirit spoke to her and told her my Indian name. She wanted me to come to a naming ceremony the next day. When I entered the sweat lodge, I had a 50-mg morphine patch[4] on my arm. I was also taking about 60 ml of Morphine in pill form. Later that night while telling Joanie about this wonderful experience, she noticed that my morphine patch had almost fallen off, and I had not noticed. She suggested I try to be without it for the night.

As the elder had requested, the next morning, Joanie, her grandson, my son and my sister went to the naming ceremony. Our group, Ted and the woman who had received my name, formed a circle with a blanket in the middle. During the ceremony, two eagles flew over. About half way through the ceremony, a butterfly landed in the middle for about 30 seconds. After the ceremony, Ted said that the butterfly carried a message to Joanie from her father. Just before her father had died, he saw a beautiful field of butterflies and said to her "Gee these drugs are making me hallucinate!" Since then, she has associated butterflies with him. Ted felt this was a message from him that he was OK and is still with her. At the end, I received my name, Geesh-sha-ba-Geeshik, which translates to "the whole sky horizon to horizon."

A few months later, in the fall of 1998, my health deteriorated more. They increased my morphine because my pain became unbearable; eventually, I returned to the dose I had been taking before participating in the sweat lodge. I became less able to do workshops as often as I had before. When I did, I was repeatedly confronted with the realities of death from this disease. At a workshop in Thunder Bay for on-reserve front line health workers, I sat on a panel with other people infected or affected by HIV/AIDS. An elderly gentleman first spoke and talked about living with AIDS and the number of pills he was taking. I had met him previously when he was well. He had lost a lot of weight. At another retreat a year later, I learned that this good person had died a month after the workshop and that they had diagnosed two friends who had also died. I was very upset and sad. Joanie and I sat up all-night and talked about it and other things. I felt better the next day and was able to lead a workshop for people infected with HIV/AIDS. I talked about losing a friend to this disease. It happened often that I would attend a workshop, meet others and at later workshops learn that they had died.

In March of 1999, I spoke at a workshop called 'Walking My Red Path'. Feeling over whelmed, I decided then to write my story. My memory was not as sharp as it had been, and often I would forget what I was talking about. When it was my turn to speak, I asked my son and Joanie to sit with

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[4] The "Fentanyl patch" allows for the gradual injection of morphine into the system over a 72 hour period.

me. It was a powerful and very emotional talk. Many people were choked up. It was then that I realized how important the support of caregivers is. People asked questions about care givers of someone with AIDS and who takes care of them? Joanie replied, her family, friends and a counsellor were her support.

During the spring and summer of 1999, I was very ill. My viral load[5] was almost half a million, which meant I must have been fighting off some other major illness. My T-cell count was at 19 while in a healthy person it is 500-1,200 (Health Canada, page 27). I was indoors most of the summer and continued monthly medical appointment in Winnipeg. As the millennium approaches, my health seems to be improving. My viral load has come down to 10,000 and my T cell count has increased to 99, a miracle in itself.

I am still not sure if my mother has accepted my diagnosis. Just recently we were talking, and she suddenly blurted out that not only children but parents have to hear about HIV and AIDS. She feels there is a missing link when we focus on the young people only.

I was spared when she carried me, and I have been spared many times in the eight years since my diagnosis when others were not. I will continue to spread the message of AIDS prevention as long as the Creator has it in His plan.

Summing up

I am reminded of a story that would probably encompass my life, and the many lessons it has taught me. Even when we are born, our journey through life is just the beginning. We are all facing death, but if we have faith and hope, the transition from life as we know it to death is only a small fragment in the eyes of our Creator. The cycle of life is never ending, and if we learn to accept death as a part of the cycle of life, crossing over to the other side can be a wonderful experience. Death only means that the shell we are given at birth is on loan. Once we die, we leave the shell behind and go on to better things. The butterfly while in its cocoon needs to struggle to survive. I, like the butterfly, continue to struggle to survive in order to move forward.

I still have unfinished business with people, places and things. Life has sent me a wake-up call that I sometimes wish could be different, but God works in mysterious ways and has been an ongoing force throughout my life. I know the road ahead may look bleak, but no one knows what

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[5] This test determines how much HIV is in the bloodstream.

tomorrow may bring. The only guarantee is that making the most of each moment is where the question and answer to life as we know it lies.

My illness has been a difficult challenge but I have been able to turn living with AIDS into a positive experience. Now, my faith in God has come full circle. God's presence in our lives is like the wind - you feel it, you sometimes hear it, but you cannot see it, but you know it is there. I know not what the next moment holds for me, but I know He will be by my side.

My life with HIV and AIDS has many milestones and lessons. Friends, family and support groups lightened my burden. I hope that my story provides inspiration and hope for those with HIV/AIDS. Life does not end because one has HIV. We are all given a gift. It is searching for and finding out what that gift is that makes us unique. Learning to love and accept ourselves for who we are is just the beginning of a long and exciting journey.

Afterward

Rene's story is a story of hope and transformation. Through the telling of this story, Rene has been a major force in breaking the silence surrounding HIV/AIDS in the Sioux Lookout area. His story has brought a human face to this illness and offers hope that life does not end with the diagnosis of HIV. In many ways, Rene's life only began in 1992 with his visit that day to the doctor's office where he learned he had HIV. HIV and AIDS forced Rene to confront his mortality, his family, himself and his Creator. It brought out his gifts as a communicator and an activist but most of all his gift of passion. With tireless energy, Rene has worked to bring the message of AIDS prevention to the people of the North. His passion to educate others about AIDS prevention, his love for family, friends and fellow human beings, however, are his greatest gifts.

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Section 2

Aboriginal Women's Experience

HIV, Sexual Violence and Aboriginal Women[1]

Carole Neron, M.S.W. & Rhonda Roffey, B.A. J.N.R.M.

A variety of factors contribute to HIV risk in Aboriginal women. One of these factors is the sexual violence they experience in their lives. Sexual violence is prevalent among all women, including Aboriginal women. While HIV is not nearly as prevalent, rates are increasing rapidly among Aboriginal women. Chances are great that all health care workers, even those not aware of it, are working with Aboriginal women who have experienced sexual violence and are at risk for HIV or currently living with HIV/AIDS. It is important that health care workers who work with Aboriginal women become aware of the connections between HIV and sexual violence. This includes health care workers who work at Aboriginal-specific services such as Native Women's resource centres, First Nations health centres and Aboriginal friendship centres, and at other services such as sexual assault centres, women's shelters, AIDS service organizations, hospitals, drug treatment programs and correctional centres.

This article will address the connections between HIV and sexual violence among Aboriginal women and offer some suggestions as to how health care workers and organizations can connect these issues in their work with Aboriginal women. It is beyond the scope of this article to address the full range of issues related to HIV and sexual violence. For a more thorough exploration of these issues, the reader is encouraged to seek out the suggested readings at the end of this article. Attempts have been made to cite existing research and literature on Aboriginal women. Lack of information in this area has made it necessary to cite some research and literature which is not necessarily specific to Aboriginal women.

Beliefs related to the social conditions affecting Aboriginal women have informed the writing of this article. The first belief is that sexual violence and HIV are major social and health problems which can potentially affect the lives of all Aboriginal women. The second belief is that multiple societal barriers such as sexism[2], racism[3], and colonialism[4]

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[1] The authors acknowledge the following document as the primary resource for this article: Neron, C. (1998). *HIV and Sexual Violence Against Women. A guide for counsellors working with women who are survivors of sexual violence.* Ottawa: Health Canada.

[2] Sexism refers to discrimination against women based on their sex.

[3] Racism refers to discrimination against people based on their race or skin colour.

affect the conditions of Aboriginal women's lives and may increase their risk of sexual violence and HIV[5] by:

- decreasing access to education and employment and increasing poverty among Aboriginal women;
- increasing Aboriginal women's social and economic dependency on men;
- reducing Aboriginal women's power and choice in their relationships and in other aspects of their lives;
- contributing to low self-esteem and poor health among Aboriginal women;
- reducing the availability of and access to gender- and culturally-specific information and services for Aboriginal women, including information and services developed and delivered by Aboriginal communities.

Definition of Sexual Violence

Sexual violence refers to any unwanted or non-consensual sexual touching, act or exploitation achieved through physical force, threat, intimidation and/or coercion. The continuum of sexual violence includes acts from sexual harassment through to childhood sexual abuse, sexual assault and murder.[6]

For the purposes of this article, the term "sexual violence" will be limited to acts that increase women's risk of HIV, specifically:

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[4] Colonialism refers to the policy and practice of establishing and maintaining colonies and settlements. The process of colonization by Europeans resulted in the physical, social, spiritual and cultural oppression of Aboriginal peoples in Canada.

[5] For further discussion on how racism, sexism and colonialism have affected the lives of Aboriginal women and increased their risk of violence and HIV, see: LaRocque, E.D. (1994). *Violence in Aboriginal Communities*. Ottawa: Health Canada; Ship, S.J. & Norton, L. (1998). *Triple Jeopardy: The Dynamics of Gender, Race and Class Discrimination, Aboriginal Women and HIV/AIDS* (unpublished paper). Kahnawake, Quebec: The National Indian and Inuit Community Health Representatives Organization.

[6] The definition of sexual violence was partially adapted from the following sources: Phelps, C. (1992). *Sexually Transmitted Diseases and HIV/AIDS in Adult Victim/Survivors of Sexual Assault in Colorado*. Denver: Colorado Coalition Against Sexual Assault; Rondina, M. (1994). *Vocabulary of Family Violence*. Ottawa: Minister of Supply and Services Canada.

- sexual assault;
- historical sexual assault (childhood sexual abuse and repeated sexual assault);
- woman abuse (sexual assault, sexual coercion and other acts of sexual violence against women in their relationships).

Sexual Violence and Aboriginal Women

There is debate in the literature as to whether or not violence against women existed in Aboriginal cultures prior to colonial intrusion by the Europeans. However, many authors do agree that the role of women in Aboriginal cultures shifted with colonialism (Chester, Robin, Koss, Lopez and Goldman, 1994; LaRocque, 1994; Maracle, 1993; RCAP, 1996; Van Kirk, 1985). As LaRocque (1994) states, "We can trace the diminishing status of Aboriginal women with the progression of colonialism. Many, if not the majority, of Aboriginal cultures were originally matriarchal or semi-matriarchal" (p.73). It also appears that all forms of violence against Aboriginal women increased with colonialism (Chester et al., 1994; LaRocque, 1994; Maracle, 1993). LaRocque continues, "There is little question that European invasion exacerbated whatever the extent, nature or potential violence there was in original cultures. Neither is there much question that Aboriginal men have internalized white male devaluation of women" (p.75). Today, colonialism works in tandem with sexism and racism to perpetuate sexual violence and other forms of violence against Aboriginal women, within and outside of Aboriginal cultures and communities.

There has been little research on the rates of sexual violence among Aboriginal women in Canada. A large-scale Canadian survey on violence against women was conducted in 1993 (Statistics Canada, 1993). However, it is not possible to determine how many Aboriginal women were included in the survey, as information related to race and cultural background was not included. It is likely that Aboriginal women were underrepresented because it was a telephone survey and therefore did not access women who live on the streets, in institutions and in households and remote areas without access to telephones. Many of these women may be Aboriginal women. Nonetheless, it is useful to highlight the major findings of this survey because there is no reason to assume that Aboriginal women would not experience sexual violence at least to the same extent as other Canadian women. Considering the multiple challenges and disadvantages many Aboriginal women experience as a result of sexism, racism and the effects of colonialism, it could be hypothesized that Aboriginal women may be at increased risk of sexual violence compared to white women.The results of a few small-scale studies of American Aboriginal women indicate that this may be the case (Norton & Manson, 1995; Walters & Simoni, 1993).

According to the 1993 Canadian survey, four of every ten women in Canada have experienced at least one incident of sexual violence since the age of sixteen, and more than half of these women have experienced repeated sexual violence (Statistics Canada, 1993). While all women are at risk of experiencing sexual violence, regardless of race, culture, sexual orientation, socio-economic status, age or ability, the risk is increased for young women and women with disabilities.

Street-involved women and women involved in the sex trade may also be at increased risk of sexual violence. While Canadian data related to the rates of sexual violence these women is limited, in one study involving 85 sex trade workers from the Downtown Eastside area of Vancouver, 62% had been sexually assaulted while they were working in the six months prior to the time they were interviewed (Currie, Laliberté, Bird, Rosa, Noelle &Sprung, 1995).

Women are more likely to be sexually assaulted by someone known to them, such as an acquaintance, a date, a boyfriend or their husband. In the 1993 Canadian survey, one in three women currently or previously in a marital or common-law relationship had experienced at least one incident of physical or sexual violence (Statistics Canada, 1993).

As a result of sexual violence, women can experience a range of physical, psychological and emotional symptoms although the presence, magnitude and duration of these symptoms vary. Headaches, general muscle tension and soreness, nausea and/or gynecological complications may occur after an incident of sexual assault. Many women experience fear and anxiety related to pregnancy and the transmission of sexually transmitted diseases (STDs) including HIV, any of which can occur as a result of sexual assault (Baker, Brickman, Davis, et al., 1990; Gostin, Lazzarini, Alexander, Brandt, Mayer & Silverman, 1994; Resnick, Kilpatrick & Seals, 1996). Emotions such as confusion, fear, shame, self-blame, guilt, humiliation and anger may surface.

Over time, other symptoms may develop as a result of post-traumatic stress, such as sleep disruptions and insomnia, nightmares and night terrors, sexual dysfunctions, chronic anxiety, panic attacks, amnesia and memory flashbacks. Disassociative conditions may also develop, including altered and detached states of consciousness, detachment from body feelings and fragmenting of personality. This fragmenting, also called "splitting," is more likely to occur in cases of early, prolonged childhood abuse (Herman, 1992).

Several long-term consequences of sexual violence have been reported by women. These can include poor self-esteem, chronic depression, self-mutilation (e.g., slashing), eating disorders, suicidal thoughts and attempts, chronic bowel disorders and substance abuse. In two American studies involving Aboriginal women, substance abuse was associated with physical and sexual violence (Norton & Manson, 1995; Walters & Simoni, 1993).

Incarceration may be a consequence of sexual violence. While data on the proportion of women in prisons who have experienced sexual violence vary, one study found that more than half of women serving federal sentences in 1989 had experienced sexual abuse. These figures were higher for Aboriginal women, who are over-represented in the prison population: 61% reported sexual abuse, and the abuse was often prolonged and extensive (Shaw, 1994).

Living on the streets and becoming involved in sex trade work may also be consequences of sexual violence for some women. In the earlier cited study of Vancouver sex trade workers, the majority of women had experienced multiple forms of violence throughout their lives, and 73% had experienced childhood sexual abuse (Currie, et al., 1995). Seventy percent of the women in this study were Aboriginal.

Women who have experienced childhood sexual abuse often experience sexual violence as adults. Symptoms of abuse, such as poor self-esteem and feelings of powerlessness, can increase women's vulnerability to repeated violence (Allers, Benjack, White & Rousey, 1993; Herman, 1992; Johnsen & Harlow, 1996).

HIV/AIDS and Aboriginal Women

The human immunodeficiency virus (HIV), the virus that causes the acquired immune deficiency syndrome (AIDS), is spread through the exchange of body fluids, specifically blood, semen, vaginal secretions, pre-ejaculatory fluid and breast milk. The main routes of transmission are: (i) through specific sexual activities, such as unprotected anal and vaginal intercourse; (ii) through injection drug use by sharing used and uncleaned needles or syringes; (iii) from mother to child, in the uterus, during childbirth, or through breastfeeding.

HIV can also be spread through the sharing of equipment that is used when injecting drugs, such as water and spoons, and through unprotected oral sex, if blood, semen or vaginal secretions are exchanged (Edwards & Crane, 1998), such as when there are cuts, sores or burns in the mouth.[7] Although it has been possible to become infected with HIV through

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[7] Although the risk of oral transmission of HIV appears to be low, burns on the lips and inside the mouth caused by crack smoking may increase the risk of oral transmission of HIV. See: Faruque, S., Edlin, B., McCoy, C., et al. (1996). Crack cocaine smoking and oral sores in three inner-city neighbourhoods. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*, 13, 87-92.

contaminated blood, organ transplants or donated sperm, these risks have been greatly reduced as a result of screening procedures introduced in Canada in 1985.

HIV and AIDS have disproportionately affected groups marginalized by society. Initially, the epidemic in Canada was concentrated among men who have sex with men. Over the last ten years, other groups have become increasingly infected with HIV, including injection drug users, people who are incarcerated, women and Aboriginal people.

Information related to the HIV/AIDS epidemic among Aboriginal people in Canada has been limited. Historically, information on race or ethnicity within HIV and AIDS epidemiological data has not been recorded consistently across the provinces and territories. Other factors may contribute to the underreporting of HIV/AIDS data related to Aboriginal women, such as late diagnosis or misdiagnosis of women living with HIV/AIDS, and poor access to health care services and HIV-testing facilities for Aboriginal people, particularly those who live in remote areas.

From the available information, it is clear that Aboriginal women in Canada are at increased risk of HIV infection. AIDS cases and new HIV infections among Aboriginal women have risen steadily over the last decade, and this increase is more rapid than that for Aboriginal men and non-Aboriginal women (Health Canada, 1999b; Nguyen, Laframboise, Archibald, Patrick, Houston, Romanowski, Mill & Sutherland, 1997). Aboriginal women living with HIV/AIDS tend to be young. Recent data indicates that 34-37% of Aboriginal women with reported HIV or AIDS are under 30 years of age (Health Canada, 1999a).

One of the primary routes of HIV transmission for Aboriginal women is injection drug use. Transmission can occur through the use of contaminated needles, or through unprotected heterosexual sex with a partner who injects drugs. Among reported AIDS cases, Aboriginal women are more likely than non-Aboriginal women to have injection drug use as their exposure category (56.4% vs 17.7%) (Health Canada, 1999b).

The other main route of HIV transmission for Aboriginal women is heterosexual sex. Biological factors related to women contribute to increased risk of HIV from heterosexual sex. Women have a greater risk of becoming infected during vaginal intercourse than men, because of higher concentration of HIV in semen than in vaginal fluid, the larger surface area

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There are also a few anecdotal reports that indicate that inflammation caused by common throat infections, allergies or sexually transmitted diseases, such as gonorrhea, may increase the risk of oral transmission. See: Chen, W. & Samarosinghe, P. (1992). Allergy, oral sex and HIV. *Lancet*, 339, 627-628; Murray, A., Greenhouse, P., Nelson, W., et al. (1991). Coincident acquisition of Neisseria gonorrhoeae and HIV from fellatio. *Lancet*, 338, 830.

of the vagina and cervix, and the fragility of membranes in this area (Padian, Shiboski & Jewell, 1991).

Social conditions brought on by sexism, racism and colonialism – such as poverty, poor health, high rates of STDs and sexual violence – have contributed to Aboriginal women being disproportionately affected by HIV and AIDS. Poverty and poor health, which can increase vulnerability to HIV infection, are important risk factors for Aboriginal women. They are one of the most poorly educated and economically disadvantaged groups in Canada (Stout & Kipling, 1998). In addition, Aboriginal women have higher rates of suicide and violent death and are more likely to suffer from chronic diseases than non-Aboriginal women (Stout & Kipling, 1998).

High rates of STDs are another risk factor for Aboriginal women. The presence of an STD and/or a history of STDs can greatly increase the risk of HIV transmission. In some regions of Canada populated predominately by Aboriginal people, the rates of some STDs are 2-11 times the national average (Health Canada, 1996c). Lastly, sexual violence, within and outside the context of relationships, is another important factor which increases the risk of HIV infection for Aboriginal women.

Despite the steady increase of HIV and AIDS among Aboriginal women, gender- and culturally-specific information, resources and services for Aboriginal women have been lacking. Many existing HIV prevention and risk reduction strategies, support services and programs have failed to target Aboriginal women or to consider the social conditions they experience. To become meaningful for Aboriginal women, HIV prevention, education and support must acknowledge these conditions, including the violence they experience in their lives.

Connections Between HIV and Sexual Violence Among Aboriginal Women

Sexual violence can be both a cause and a consequence of HIV. When considering the connections between these two issues, it is important to note a few points. First, the connections are complex and reflect the range of experiences with sexual violence and HIV risk that many Aboriginal women face. Second, while these connections can be categorized, women's experiences do not necessarily fit neatly into these categories. Women are often repeatedly subjected to sexual violence, and as a result, they can experience more than one of these connections simultaneously or at different points in their lives.

Sexual Assault

Aboriginal women who have been sexually assaulted, whether by a stranger or by their partner, may have been placed at risk of contracting HIV through direct transmission of the virus from the assaulter. While the rate of transmission of HIV due to sexual assault is unknown, it is known that some factors may be present during sexual assault which can increase the risk of HIV transmission. They include the following:

- If the assaulter is known to be HIV-positive. The stage of HIV infection can increase infectiousness, i.e. times when viral loads[8] are high, such as recent infection or later stages of illness (Royce, Seña, Cates & Cohen, 1997). If HIV status is unknown, it should be assumed that the risk of infection exists.
- Direct contact (without a condom or with a broken condom) of body fluids (blood, semen) with the anus, vagina or mouth (if there are cuts, sores or burns in the mouth) (Gostin et al., 1994).
- The presence of anal and/or genital injuries (cuts, abrasions) which can create a more efficient route for HIV transmission. In various studies, 40% to 87% of women who were sexually assaulted showed signs of genital injury (Lacey, 1990; Lauber & Souma, 1982; Slaughter & Brown, 1992).
- Multiple assaults. The risk of transmission increases with the frequency of assaults and the number of assaulters (Gostin et al., 1994).
- A pre-existing STD. If a women or her assaulter has an STD, she has a three to five times greater risk of acquiring HIV if exposed to the virus (Wasserheit, 1992; Wasserheit, 1996).

Historical Sexual Assault

Increased risk of HIV can exist for some women who have a history of sexual assault, specifically women who have experienced childhood sexual abuse and/or repeated sexual assault. Women can develop a variety of mechanisms to cope with sexual assault and the associated post-traumatic effects, including risk activities associated with HIV, such as exchanging sex for drugs, money or shelter; having multiple sex partners; having a sexual relationship with someone who is at high risk for HIV; injecting drugs and sharing needles; and using drugs during sexual activity. In numerous studies, including one study with Aboriginal women (Walters & Simoni, 1999), childhood sexual abuse and repeated sexual assault have

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[8] Viral load is the amount of HIV in body fluids (e.g. blood) and tissues.

been found to be associated with risk activities which can increase women's vulnerability of exposure to HIV (Allers, et al., 1993; Johnsen & Harlow, 1996; Miller, 1999; Zierler, Witbeck & Mayer, 1996; Whitmire, Harlow, Quina & Marokoff, 1999). While the nature of the association between HIV risk and historical sexual assault is not entirely clear, it appears likely that the relationship is fairly complex, with historical sexual assault leading to short- and long-term post-traumatic effects (such as low self-esteem, depression and substance abuse) which can contribute to risk activities (Miller, 1999; Whitmire, et al., 1999).

Woman Abuse

Women who are in abusive relationships, including Aboriginal women, can experience physical, verbal, emotional, psychological and/or sexual violence, and often live in fear of their male partner. Their partner may control many aspects of their lives, including their finances, contact with others, and their sexual and reproductive choices. These conditions increase women's risk of HIV. Specifically, women who are in abusive relationships may be at increased risk of exposure to HIV due to the following factors:

- The fear and threat of further violence, rejection, abandonment and/or loss of economic support if they attempt to negotiate safer sex or refuse sex. In one Canadian study, 34% of Aboriginal women surveyed indicated that they were afraid of being abused if they refused to have sex with a partner (ANAC, 1996).
- Violent/rough sex or sexual assault by an abusive partner. In an American study of Aboriginal women who had been abused, 50% of the women in the study experienced marital sexual assault or an attempted sexual assault by their partner (Norton & Manson, 1995).
- Being forced to have sex with other persons or to participate in degrading sexual acts (McLeod, 1996).
- Being forced into prostitution by an abusive partner.
- Having unprotected sex with a partner who is having sex outside the relationship (Weissman, 1991; Worth, 1989).

Sexual Violence Against Women Living with HIV

All women living with HIV, including Aboriginal women, face some unique challenges connected to sexual violence. Disclosure of a woman's HIV status to her partner can increase her susceptibility to sexual and physical violence and may give her abuser further control in the relationship (North & Rothenberg, 1993; Rothenberg, Paskey, Reuland, Zimmerman & North, 1995).

Aboriginal women living with HIV may face the fear and threat of rejection and emotional, physical and/or sexual violence from acquaintances, friends, family members and their community. Aboriginal women living in remote and isolated communities may confront increased risk of stigmatization and even violence as a result of disclosure of their HIV status.

Another issue with which HIV-positive women must contend is the fear of reinfection, and its impact on future health. As a result of sexual violence, women living with HIV could be at risk of reinfection with a different strain of the virus which may be resistant to available treatments. The risk of acquiring another STD is also a concern for HIV-positive women because there is evidence to suggest that HIV may affect the progression and severity of symptoms of some STDs (Wasserheit, 1992).

If sexually assaulted, HIV-positive women must contend with the post-traumatic effects in addition to the numerous physical and emotional challenges they face as a result of their HIV status.

Making Connections Between HIV and Sexual Violence

It is important for health care workers to acknowledge the connections between HIV and sexual violence when working with Aboriginal women who have experienced sexual violence. However, the responsibility for addressing these connections extends beyond individual health care workers. Organizations providing services to Aboriginal women also have a role to play in this area. Identified below are some suggestions as to how health care workers and organizations can begin to make these connections.

What Can Health Care Workers Do?

- Acknowledge how sexism, racism and colonialism can lead to sexual violence and HIV risk among Aboriginal women.
- Develop an understanding of the connections between HIV and sexual violence and consider how these connections are relevant to their work with Aboriginal women.
- Become familiar with the key issues related to HIV and sexual violence – including HIV risk and transmission issues, risk reduction and HIV testing – and when and how to sensitively and appropriately address

these issues when working with Aboriginal women who have experienced sexual violence.[9]

- Become familiar with existing local and regional Aboriginal-specific referral sources for Aboriginal women who have experienced sexual violence, and may be at risk of HIV or living with HIV/AIDS including Aboriginal women's shelters, Native women's resource centres, First Nations health centres, Aboriginal friendship centres and respected elders and traditional healers. Other referral sources could include sexual assault centres, women's shelters, hospitals, drug treatment programs, AIDS service organizations, HIV testing sites, needle exchange programs, outreach programs for street-involved women and women who work in the sex trade, counselling centres and crisis lines.
- Help Aboriginal women link up with appropriate individuals and services in their community that include a holistic approach to healing, and that are familiar with and sensitive to issues related to sexual violence, HIV/AIDS and social and cultural issues affecting Aboriginal women.
- Develop a clear understanding of legal and ethical obligations related to confidentiality of information concerning sexual violence, HIV testing and HIV status. Consider how confidentiality can be maintained, particularly in small communities.
- Identify personal attitudes and values related to sexual violence, HIV/AIDS, gender, sexuality, race and culture, and how these attitudes and values may impact on their work with Aboriginal women. Identify strategies to overcome biases.
- Identify how personal experiences with sexual violence and/or HIV/AIDS may impact on their work with Aboriginal women. Seek support from co-workers, a peer support group or a healing circle, and/or consider counselling to deal with personal issues and feelings.

What Can Organizations Do?

- Develop a written policy on HIV and sexual violence which includes related issues such as HIV risk and transmission, risk reduction and HIV testing.

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[9] See the following document for an exploration of the issues related to HIV and sexual violence: Neron, C. (1998). *HIV and Sexual Violence Against Women. A guide for counsellors working with women who are survivors of sexual violence.* Ottawa: Health Canada.

- Develop a written policy on confidentiality of information concerning sexual violence, HIV testing and HIV status, which includes direction on the disclosure and documentation of information.
- Integrate questions and information related to HIV and sexual violence into existing assessment tools, questionnaires and educational materials.
- Integrate HIV and sexual violence issues into staff and volunteer training. Include skills building and values clarification.
- Ensure resources and pamphlets related to HIV and sexual violence are accessible to staff and the women with whom they work.
- Support and encourage information sharing related to HIV and sexual violence with other local and regional organizations.
- Support, encourage and advocate for Aboriginal designed and implemented programs for Aboriginal women who have experienced sexual violence and are at risk for HIV or living with HIV/AIDS.

Summary

As previously stated, there are a variety of factors contributing to HIV risk among Aboriginal women, specifically biological factors and social conditions which include sexual violence. The connections between HIV and sexual violence reflect the range of experiences with HIV risk and sexual violence that Aboriginal women face. Individual health care workers and organizations which provide services to Aboriginal women have a responsibility to understand the connections between HIV and sexual violence, to determine how these connections are relevant to their work with Aboriginal women, and to help Aboriginal women get the support they need to heal from their experiences with sexual violence and HIV/AIDS.

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"It's Hard To Be A Woman!"
First Nations Women Living with HIV/AIDS

Susan Judith Ship, M.A. Ph.D. (ABD) & Laura Norton, C.M.T.

> "I want to go home. I want to be accepted. I want a life back there. I have things I want to teach my kids. I just need to go home. I have that hope that somehow the CHR is like a key. I really hope that they open the door for me."

This paper focuses on the experiences and perspectives of First Nations women living with HIV/AIDS and explores how HIV/AIDS affects their lives differently from men's lives. It is based on original research carried out as part of a larger project on Aboriginal Women and HIV/AIDS for the National Indian and Inuit Community Health Representatives Organization in which we also explored the experiences and perspectives of female caregivers of people living with HIV/AIDS and women in "hard-to-reach" communities.

Our interviews with a small number of First Nations women living with HIV and AIDS reveal the clear links between HIV, cultural disruption, residential schooling and the legacy of multigenerational abuse in their lives. In addition to the multiple forms of stigma that seropositive men experience, First Nations women living with HIV/AIDS experience gender discrimination as women. Moreover, women's social roles as primary caregivers and nurturers in the family constitute a fundamental difference when compared to men and their experiences of HIV/AIDS because First Nations women are more likely to be single parents responsible for the health and well-being of their children, in addition to their own, with fewer resources and supports.

We begin with a brief discussion of the appropriate conceptual approach to this project that we suggest entails taking gender and women's subordination into account while situating them within the unique historical trajectory of First Nations in Canada. We then turn to an overview of the current literature on HIV/AIDS to show how gender bias and a problematic conception of "woman" as a social category renders First Nations women invisible in research, policy and services, followed by a discussion of some of the challenges we encountered in conducting our research. Finally, we explore the multiple ways HIV/AIDS affects First Nations women from their experiences and through their eyes.

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Gender Analysis and the Subordination of First Nations Women: The Legacy of European Contact

A focus on First Nations women and HIV/AIDS necessarily raises the issue of gender and women's subordination in addition to the unique socio-economic and historical factors which shape First Nations women's lives. Gender refers to the social construction of men's and women's social roles which are historically shaped, culturally contextualized and class specific (Ship1994:138). Understanding how HIV/AIDS affects women entails analysis of the socially constructed differences between men and women and their impact in shaping distinct female and male experiences. As Crowley and Feldman (1997:123) point out, this analysis involves looking at how women's social roles and social situations differ from men's, how women are treated publicly and privately, how HIV affects women's lives in different ways from men and how HIV affects the relationships between men and women.

Alternately, gender is usually taken to be synonymous with women in part because women continue to be subordinate in all spheres of economic, social, political and family life globally, in Canada and within First Nations communities. Women's subordination or gender inequality among First Nations people is largely a consequence of European contact and colonialism which altered the way First Nations men and women relate (Bourgeault 1989). The imposition of European notions of women's social position which occurred with the ensuing process of cultural disruption and residential schooling resulted in the dispossession of First Nations women's rights and the devaluation of women's social roles (Shawanda 1995). In addition to the legacies of multiple disadvantages and multigenerational abuse, which affect First Nations communities, families and individuals, cultural disruption and residential schooling served to deepen women's subordination to men.

Women's subordination to men places them as a social group at greater risk for HIV/AIDS (ICAD 1995). However, while women as a social group are disadvantaged relative to men, some groups of women experience multiple forms of discrimination and disadvantage in addition to gender based on poverty and racism such as is the case of many First Nations women and women of African descent in Canada (Stasiulis 1991). Women who experience multiple forms of inequality are at greatest risk of HIV. It is of no surprise that in Canada, HIV/AIDS does not affect women equally. It is disproportionately concentrated among historically marginalized groups, albeit with very different trajectories – First Nations and peoples of African descent. In 1990, the male-female ratio among white Europeans in Canada was 22 to 1, among people of African descent 2 to 1 and among Aboriginal peoples 3 to 1 (Berer 1993:46). The recent and

HIV/AIDS among First Nations women (Nguyen et al. 1997) demands that we place them on research and policy agendas.

The Invisibility of First Nations Women in HIV/AIDS Research

If women generally are marginal in HIV/AIDS research, policy and services, First Nations women remain particularly invisible (Ship and Norton 1999; 1998). From the beginning, gender bias and a problematic conception of "woman" as a social category of analysis have shaped research agendas in addition to homophobia. Women's invisibility in research, policy and services is in part the consequence of persistent and widespread public perception, both within Aboriginal and non-Aboriginal communities alike, that "HIV/AIDS is a gay male disease", reinforcing the widely held attitude that women are not at risk for HIV, despite growing evidence to the contrary.

In addition to homophobia, a pervasive gender bias which assumes that women and men experiences, perspectives and social positioning are identical serves to render gender differences in HIV/AIDS research, policy and services invisible. As a result, insufficient attention is paid to how social and economic inequalities along with women's distinct biology differentially affect women's health, HIV risk and capacity/resources to cope with HIV/AIDS. Women remain a disadvantaged group with regard to clinical research, diagnosis, treatment and health care (Health and Welfare Canada 1990). Services are generally geared to the needs of "gay men." The late inclusion of the clinical manifestations of HIV unique to women has meant that many health professionals may miss the HIV/AIDS diagnosis in women. Late or missed diagnosis impedes the provision of appropriate counseling, information, support and care to HIV positive women as well as contributing to higher mortality and lower survival rated for women living with AIDS (Health and Welfare Canada 1990).

Moreover, the lack of attention paid to how HIV/AIDS affects women is also related to a problematic conception of "woman" as a social category of analysis, which has dominated HIV/AIDS research agendas. What little research there was during the first decade of the AIDS pandemic in Canada, as elsewhere, focused on women solely as 'vectors of transmission" of HIV (through pregnancy or prostitution), with women's own health and well-being of secondary concern (McGovern 1997; Sherr et al. 1996; Patton 1994; Labelle and Decosas 1990). This view is embedded in current Health Canada epidemiological research: "the HIV epidemic among women is of particular concern because of the potential for transmission to their infants" (Health Canada 1999). Apart from reproducing dominant gender stereotyping of woman as "mothers" or as "whores", this narrow concern with women as "transmitters of the disease" has meant that inadequate attention continues to be paid to how HIV/AIDS affects women.

Even with the growth of social research on women and HIV/AIDS since 1990, there are only a handful of studies focussing on women living with and caring for people with HIV/AIDS in Canada. First Nations women barely figure in these studies (with few exceptions such as Kali-Shiva 1998; Salter Goldie and DeMatteo 1997; Allen 1994). Moreover, in spite of the growing need for this research, there have been no comprehensive studies of the experiences, perspectives and needs of First Nations women living with and caring for people with HIV/AIDS. Although Aboriginal women's HIV/AIDS knowledge base, attitudes to the diseases, risky behaviours and information needs have dominated research agendas (see Ship and Norton 1998 for an extensive review of the literature), little is known about First Nations women in "hard-to-reach" communities, particularly where the risk of HIV is greater than in the general population, among street youth, in the sex trade and in the prison population.

The invisibility of First Nations women in HIV/AIDS research, policy and services is further related to the general tendency to conceptualize "woman" as a homogenous social category with identical experiences, views and needs (Hammonds 1997; Patton 1994; Allen 1994; Manthorne 1990), notwithstanding the increasing recognition of the culturally specific but diverse life situations and material circumstances of First Nations women. As a consequence, there is little, if any, systematic research as to how poverty, racism, sexual orientation and age, in addition to gender discrimination, affect women's health, HIV risk potential, capacity to cope with HIV or AIDS and access to services. Moreover, little, if any, research has looked at the links between multigenerational abuse and HIV/AIDS among First Nations women.

Research Methodology: A Woman-Centered Focus: HIV/AIDS through First Nations Women's Eyes and from Their Experiences

As a consequence of the lacunae in the existing research and literature, little is known about First Nations women living with HIV/AIDS. Employing a culturally sensitive gender perspective in order to capture the unique aspects of their experiences, our research explored how residential schooling and the legacy of multigenerational abuse affects HIV risk among First Nations women and how HIV affects their lives differently from men. We wanted to identify positive women's physical, mental-emotional, social and spiritual needs and the challenges they face in meeting their own needs and the needs of their families.

Because this research was exploratory in nature, qualitative research methods based on semi-structured individual and group interviewing were utilized. Moreover, as we wished to put Aboriginal women's faces on HIV/AIDS statistics, qualitative research methods allow women's voices to be heard; voices normally silent within dominant discourses and representations of HIV/AIDS. Finally, as the primary purpose of this research was to develop training materials for Community Health Representatives (CHRs) to enhance their skills in HIV/AIDS education, prevention and care, qualitative research methods were utilized in order to provide a more personal and in-depth view of a range of HIV/AIDS related issues, particularly the under-examined social and emotional dimensions, as they affect and are experienced by women.

Our research with First Nations women living with HIV/AIDS consisted of a focus group lasting approximately two hours and selected interviews, each of which were an hour in duration, which served as the basis for a video and a resource manual, both entitled "Keepers of the Earth." The focus group and majority of the interviews were filmed. The focus group helped to delineate broad and general themes relating to multigenerational abuse, HIV risk behaviour and living with HIV/AIDS while individual semi-structured interviews with self-identified positive women willing to participate in the research allowed us to probe these general issues in more depth.

The Positive Women's Network, the Canadian Aboriginal AIDS Network and Healing Our Spirit were involved in finding participants for this research, arranging interviews and setting up the focus group, as well as reviewing the interview questions to ensure relevance, validity and screen out various kinds of potential bias. We interviewed eleven First Nations women living with HIV or AIDS, who are between the ages of twenty-six and thirty-nine years of age and who are from across the country. Two of the women were diagnosed with HIV over ten years ago while eight of the women had been diagnosed as seropositive within the last five years. One woman was in an advanced stage of AIDS. Sharing needles followed by unprotected sex appeared to be the main modes of HIV transmission. All but one live in Vancouver where dramatic increases in HIV/AIDS rates in general, among Aboriginal people, and in particular among Aboriginal women have been documented (Nguyen et al. 1997).

Limitations of This Research

Finding women willing to be interviewed on film proved challenging for a number of reasons. Given the highly sensitive nature of this research and the stigmas attached to HIV/AIDS, IV drug use and sex work, some HIV positive women and women on the street, refused to be interviewed on film or audio tape because they did not wish to be identified. The use of a male film crew posed an additional set of difficulties in organizing interviews. Two women's organizations whose facilities we utilized provide a "safe space " for women and consequently do not allow men on their premises. Furthermore, some positive women expressed discomfort with a male film crew.

As it has become standard practice to pay research participants in the HIV/AIDS world, we were obligated to pay honorariums to the positive women and women in "hard-to-reach" communities in order to obtain their participation in the focus group and individual interviews. Financial constraints set limits on the number of women we could afford to interview and locations to which we could travel. While we can assume that remuneration for the interviews affected the research, it is unclear what the impact was or how this may have biased participant responses.

One of the difficulties encountered in the research was participants' reluctance to disclose the extent of their involvement in risky behaviours related to unprotected sex, sex work and sharing needles, an observation also made by some health professionals we interviewed who work directly with Aboriginal women in "hard-to-reach' communities. As such, it was difficult to obtain an accurate reading of the extent to which these women engage in risky behaviours.

Given the limited sample of respondents who were also self-identified and willing to be interviewed, this research can only be considered as exploratory rather than representative. Moreover, because this research was part of a larger project which included both the development of educational materials and training sessions, time constraints did not allow for the construction of a larger sample nor the development of standardized interview questions with adequate pre-testing. Although the results from our research cannot be considered hard data, the interviews with positive women generated important insights for further research regarding gender differences in living with HIV/AIDS.

First Nations Women Living with HIV/AIDS: "On the Hem of Life"

> "We are fighting for a place in society, in our communities, to feel normal, just to feel accepted, and loved, and respected, let alone having to deal with...barriers such as sexual identity or childbearing."

Cultural Disruption, Residential Schooling: HIV and the Legacy of Abuse

The links between cultural disruption, residential schooling, the cycle of multigenerational abuse and grief, cultural and family breakdown and HIV are painfully clear in the lives of First Nations women living with

HIV/AIDS. Almost all of the positive women we interviewed told us that they came from families where one or both parents had attended residential schools, and where alcoholism was a major problem in the family. Eight HIV positive women admitted that they had been victims of sexual abuse as children. As one positive woman who was involved in an abusive relationship explained,

> "My mother and father drank. They were products of residential schools. I was the youngest. I was placed in a foster home...It's tough being an Aboriginal woman. I was part of an abusive relationship. What I saw in him is what I got from my family. I was sexually abused."

Many First Nations women who have been sexually and/or physically abused leave their communities and end up on the streets, as was the case of most of the women we interviewed. More often than not, abused women become victims of a spiraling cycle of abuse which includes alcoholism, drug addiction, prostitution and violence, a cycle which places them at greater risk for HIV; for some, this spiraling cycle of abuse culminates in HIV as these positive women confirmed,

> "I never told them. I was afraid I would get beat or they would send me away. One day I finally stood up. My uncle was sent away after that my mom died...My family is Christian. They are too proud to find out that their youngest girl has turned to the street and IV drugs. That's how I dealt with abuse."

> "It was a violent sort of encounter; having someone on top of you, pulling off the condom and then finding out a month later that you are HIV positive from this person...then being abandoned."

Nine of the eleven HIV positive women we interviewed have used alcohol and IV drugs extensively and some since their early teens. Five women admitted that they were still using IV drugs, mostly cocaine and to a lesser extent heroin, despite the fact that this is harmful to their health; as one woman said, *"It's scary knowing that cocaine is the worst thing for your HIV."* Some women still engage in risky behaviour such as sharing needles; an ex-addict pointed out, *"When you are 'jonesing' or 'whacked out', all you are thinking about is the next hit."* Almost all the women still drink and smoke pot. Drinking and using drugs are coping mechanisms to deal with abuse and HIV: they dull the intense pain they carry deep inside.

One woman said, *"I used drugs to forget. It made me feel good... sex and men... a big party but the poverty and my children. It's a coping mechanism; the stress. The pain is overwhelming."* Another woman relapsed back into heroin after she found out she was HIV positive: *"When I found out in 1994, I went into denial. I used drugs to kill the pain."*

Some positive women do find the courage to begin the healing process and stop the cycle of abuse so that their lives and their children's lives will be different. As one woman explained, *"I don't want my kids to have their spirit broken. I was sexually abused over and over again till I was eight."* Another positive woman conveyed a similar experience:

> "There is a need to reclaim family identity and community...residential schools polluted – It's a disease of the spirit. Our people need to move beyond this. They need to love one another. My family is making a conscious effort to change that cycle. It is a healing process reclaiming family identity. My daughter won't have to deal with this as I did, as my mother did and as my grandmother did."

HIV/AIDS Affects Women Differently from Men

Single Mothers with Children Living Below the Poverty Line

Unlike gay men, many First Nations women with HIV or AIDS are parents, and most are single mothers, living on low incomes. Almost all the women we interviewed live *"in the East Hastings area of Vancouver, the poorest postal code in Canada."* With one exception, all the positive women we interviewed were receiving social assistance.

Women's social roles as primary caregivers and nurturers in the family means that they are responsible for caring for themselves, their children, partners and families, more often than not with fewer resources and supports. For First Nations women living with HIV/AIDS, their health and well being is last on the list of priorities. As positive women explained,

> "I think for a lot of women, it is scary because when you find out (you're positive), you're responsible for the whole world. You're responsible for your children. You're responsible for your man. You're responsible for your home, for everything."

> "What I find for a lot of women who I talk to is that they are so busy taking care of everybody else's needs is that their own needs are at the bottom of life. Their health, their well-being, physical, mental, emotional and spiritual, doesn't count."

Life is a daily struggle because many positive women experience difficulty providing for basic needs - food, shelter, clothing and transportation – for their children and for themselves. Many women cannot afford expensive treatments and difficult choices are often made between purchasing medication for themselves and basics for their families. Many financial supports are geared to the needs of single men or single people, and most women do not have adequate housing for themselves and their families. One single mother explained,

> "A lot of women who I know are single moms like me. Your child is your first priority. All the money that you get if you live on welfare or have a job goes to your child, to your child's well being. Sometimes you get a little bit for yourself, whether that be money, time out or a chance to sit and share with other women."

For many First Nations women living with HIV/AIDS, their children's health, well-being, security and future take on a greater importance than their own needs, health and well-being. A universal primary concern is who will care for their children if they get sick and after they die: *"The first thing that popped into my head when I found out was who is going to take care of my children."* Many women expressed anxiety and guilt about how their children were coping with knowing that their mother was HIV positive, particularly regarding discussing their illness and its impact on their children's well being. Some women worry that their *"children are too sensitive"*, *"carry an added burden"*, *"grow up too fast"*, *"have too much to worry about"* or *"may not be strong enough to cope."* This woman explained, *"My daughter worries about me, and she is only nine. That stops me from showing pain when I feel pain because I don't want to worry her."*

Deciding when and how to disclose their HIV status to their children and to which children is a difficult, complex and stressful process for HIV positive parents but particularly so for single mothers with little emotional and social support. Some women chose to tell their children at an early age. These women felt it was important that their children know the truth and have the opportunity to work through their feelings, including coming to grips with grief, loss and death.

> "I know that children at different ages deal with grief, loss and death differently. One of the things I have tried to do; it becomes emotional to talk about it, she's my baby and I would like to protect her. But one of the things we've started doing is seeing a grief counselor. My daughter goes to an art therapist and this is a way for her to understand these changes in our lives and accept that these losses happen. We have to deal with them and we have to accept them."

But children are also a source of joy, hope, support and a primary motivation for First Nations women to find strength and courage to live with HIV. One woman declared, *"I have to live with it, and I have to stay strong for my children."* For women who feel that their own lives have been shattered, their hopes and their dreams are for their children.

Gender Discrimination as HIV Positive Women

Many positive First Nations women live in secrecy because of the multiple forms of stigma associated with HIV/AIDS; one woman living with AIDS explained,

> "It's the stigma that goes with it. It's not the death part. It's how you got it. You must be homosexual. You must have used IV drugs. You must have done something wrong. That's the fear for me, the rejection because of stigma."

In addition to the multiple stigmas associated with HIV, First Nations women living with HIV/AIDS suffer from gender discrimination because as women they carry the additional stigma of being branded *"promiscuous"*, *"bad mother"* and *"deserving of HIV/AIDS."* Secrecy is perhaps a bigger issue for positive women because of a need to protect not only themselves but also their children. *"Women are afraid of the shame and the guilt placed on them. People will not be so accepting of them and their families."* Many women fear disclosure of their seropositive status will bring discrimination and rejection, not only for themselves but also particularly for their children. One positive woman said,

> "It's hard being a woman with HIV in a society that rejects women who are HIV positive, that frowns upon mothers who are HIV positive and that rejects the children...
>
> It's still hard being a woman with HIV because of the discrimination. It seems more acceptable for a man who is HIV positive to be accepted than it is for a woman. I fear for my children."

As a consequence, many First Nations women living with HIV/AIDS under-utilize both First Nations and non-Aboriginal services. *"If I go there, I might see one of my relatives and they are going to go around and say they saw so-and-so here. There are a lot of questions about whether you should come out and disclose your HIV status in the community."*

Multiple Barriers to Services

First Nations women encounter multiple barriers based on gender, racism and class in accessing a broad range of services. Gender barriers persist in women's access to treatment and clinical drug trials; one woman noted, *"I think in the AIDS world we've been at the bottom of the ladder in terms of treatment and clinical trials because of our reproductive capacities."* Moreover, there is a lack of services and supports for positive women and their children because *"most AIDS services are geared to gay men, not to women and their families."* One positive woman explained,

> "I think that women as caretakers in society don't have a lot of places they can go and don't have a lot of support systems. There is only one organization in Vancouver that is specifically an AIDS service organization for women. All the rest are 90% for men. They don't discriminate against women, but there is really no place for them."

In addition to gender barriers and stigmas around HIV, some positive women acknowledged encountering subtle forms of racism in their interaction with non-Aboriginal, mostly white, health professionals. As well, women noted the lack of culturally appropriate services and counseling for First Nations women living with HIV/AIDS. Many health professionals and service providers need to improve their understanding of First Nations cultures and traditions. Almost half the women we interviewed expressed the need *"for more Aboriginal counselors, particularly who know street life."* Some women felt it was important to combine traditional healing and western medicine. One positive woman explained, *"HIV/AIDS takes your spirit away. We need to find a way to use the sweat lodge and the white man's medicine."*

Pregnancy, Reproductive Choice and Sexuality

A number of women we interviewed discovered they were HIV positive when they were pregnant, either as a result of a routine check-up or because they were experiencing difficult pregnancies. While some women felt they received adequate counseling, information and support, other women reported less than satisfactory treatment. One woman reported,

> "When I first found out I was HIV positive, I was five months along going into six. I was having a lot of problems...Back at home, my doctor was quite ignorant of HIV. The way I found out was very bad because he was so overwhelmed by the results that he didn't know how to tell me. He left his door wide open and he was practically shouting at me and waiving the piece of paper...he stood across the other side of the room and talked to me. The whole time he had his rubber gloves on."

Women who are HIV positive or who have partners living with HIV have often been discouraged from becoming pregnant. Many women have been counselled to avoid pregnancy, delay or abort. In addition to worrying about their own and their baby's health, positive women desiring to have children have to come to grips with the stigma associated with pregnancy and HIV. One positive woman explained,

> "I was just trying to be a normal pregnant woman without having to worry about whether I was going to be responsible for infecting my child. The judgement was that if I was an HIV positive woman making a choice to have a child, I was treated differently than if I was just an innocent victim happening to find out that I was HIV positive."

If reproductive issues are fraught with difficulty, sexuality and intimate relationships for positive women are as well. Violence can occur when women ask men to use condoms: *"It's just hard to be a woman and to be having to ask to use a condom. It can get abusive to ask your partner to use a condom... abusive physically, emotionally and verbally."* Disclosure of HIV status to a potential partner or mate is stressful, but positive women run the risk of encountering violence consequent upon informing a sexual partner of her seropositive status.

> "There were some women who experienced violence in their relationships because the men didn't know they had the virus and found out later...I was too scared to say that I was living with the virus because I was afraid of the violence that comes with the men knowing when you tell them that you are HIV positive."

Emotional and Social Isolation

As a consequence of multiple stigmas and barriers to services, First Nations women living with HIV/AIDS have little, if any, emotional and social support. Many women live in extreme isolation. The positive women we interviewed live in urban or metropolitan centers, far from their home communities because the city provides anonymity and because they feel there is greater acceptance of HIV positive women in the city: *"Vancouver has a good sense of community for women with HIV"* ... and, *"better access to services: "It's better for me to stay here. In my community, there aren't enough services and it is more open in Vancouver."*

All of the women we interviewed go regularly to the Positive Women's Network (PWN), which has a mandate *"to provide a safe environment for Aboriginal women."* PWN provides baby-sitting and transportation money to women who come in to access the food bank or to have lunch. In addition, individual counseling is available for women if they so desire. One woman expressed, *"It is there that I feel safe. I'm not alone. I get to be with other women. We are there for each other."* For other women, it is a place to *"make friends with other positive women who have children"* or *"for support for children living with people who have HIV."* But, many First Nations women are *"afraid to come to PWN"* for fear of being identified.

Many positive women desire and need to return home. One woman stated, *"I know a lot of people who live with HIV that have no sense of family or community and they die really quick."* However, many women fear isolation, rejection and discrimination should they return home, not only for themselves but also for their children and their families. Community responses vary. Some communities are very accepting of their members living with HIV/AIDS. One woman reported, *"Last spring I had a really good experience. I got to go home and I had 200 of my community, family, friends and extended family come and have a celebration with me."* Other communities are less accepting. One woman said, *"My family was* *isolated because I was home. People are afraid. They think you can catch it - through the air."* Some women were forced to leave their communities: *"When people found out, they reacted very badly. It wasn't safe for me to stay. It's a small community. Everyone knows everyone. I am the first person in the community to test positive."*

For First Nations women with HIV/AIDS who are living far from home, family, culture and community, their hope is that their children will one day be able to go home, as this woman so poignantly expressed,

> "I have been told by my doctor that I am dying and I have to go on anti-virals. It's a hard choice but I'm doing it because I want to live. I have two daughters. I want them to grow up, to be good people and to be good women. I want them to know their culture and to be able to go home some day because I do have land and a house back home."

Conclusion and Recommendations

Our interviews with First Nations women living with HIV/AIDS reveal how gender plays an important role in shaping their socially distinct experiences as women and as mothers. Women's social roles as caregivers and nurturers mean that they are responsible for caring for themselves, their children and their families. Providing for their basic needs and the needs of their children is a daily struggle for low-income single mothers living with HIV/AIDS who have few resources and little, if any, emotional and social support. Services and supports need to be geared to the needs of positive women and their children. Access to affordable, comfortable housing and income supplements for medication, alternative therapies and treatments, food, transportation, home support, daycare and babysitting services would go a long way to improve the quality of positive women and their children's daily lives.

Gender discrimination, racism and socioeconomic disadvantage impede the access of First Nations women living with HIV/AIDS to a range of medical and social services and supports which could enhance their own and their families' health and well-being. A greater range of culturally appropriate, gender-specific services, supports and counseling; particularly around accepting and living with HIV, sexuality, reproductive choice, sexual and physical abuse must be made available to First Nations women living with HIV/AIDS. Enhanced networking would help positive women who wish to connect with other women living with HIV and AIDS, reduce their sense of isolation, gain mutual support and share information.

Some positive First Nations women indicated to us that there is a need for more comprehensive family services in particular, family counselling, to help them and their family members work through and validate complex and contradictory feelings as well as learn new coping mechanisms. They also felt that family counselling to teach how to disclose HIV status, particularly in small communities, would be very helpful to all family members. Other women also wanted enhanced services for their children, such as grief counselling, on-going support and support (which could be extended to the entire family) in the event of the death of the parent living with HIV/AIDS. Some positive women felt their children may also need retreats to get away, to have fun and to be children.

Placing First Nations women living with HIV/AIDS on research and policy agendas as well as improving access to a range of health and social services and supports are essential if we are to more effectively meet the physical, mental-emotional, social and spiritual needs of First Nations women living with HIV/AIDS and their children so that they may live positively.

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Section 3

Community Development

“Point of Death’ HIV/AIDS & IV Drug Use Youth Awareness Video Project

Gary Adkins, Education and Training Consultant

Introduction:

Alcohol and other abuses have had a negative affect on Aboriginal Canadians as a whole. Across Canada, information, personnel, and the availability of services are at fairly close range for most of those wishing to utilize them. However, communities of the N.W.T are widely spread and sometimes do not have the tools necessary to cope with all issues facing them. Isolation, struggle for cultural identity, boredom, and a need to be heard, are some of the issues facing our Northern youth today. HIV/AIDS & IV Drug use, though highly prevalent in the rest of Canada, are just beginning to take a serious hold in the NWT. With the expansion of the diamond industry and the influx of people from the South, drugs are brought in, making access easier for northerners. With the increase of IV Drug use in the north, it is essential that communities be fully informed about the hazards of sharing needles. In some cases it is still difficult to get the message out that HIV/AIDS can be contracted through sexual contact.

Realizing the need for this information to reach our northern people, the Fort Smith Metis Council sought ways to work with the community youth to develop a format by which they could share this information with their peers throughout the north. As this project was aimed at youth at risk, it was felt that our community youth should be approached for interested participants. The goals of the project were as follows; work with aboriginal youth at risk in producing a peer awareness video, on IV Drug use and its relationship to HIV/AIDS & Hepatitis C and distribute copies of the video to all communities in the NWT, free of charge.

Project History:

During the fall of 1998 the Fort Smith Metis Council submitted a proposal to Health Canada, requesting funding to produce a 30-minute youth awareness video on HIV/AIDS & IV Drug use. Rationale for this project was based on the idea that youth understand and listen to youth better than they do adults. This project would provide participating youth with a project over which they could have artistic and information control. The original proposal requested $50,000.00 to produce this video. Health Canada responded by funding the council $75,000.00 to ensure we had adequate funding to complete the project.

The councils' Education & Training manager's role, was to produce the video. He had produced two previous videos: one dealing with teenage sexual assault and another on teen suicide. As well, he has worked with youth for several years in various capacities; for example as an alcohol counselor, youth program counselor and facilitator of suicide intervention workshops as far north as Grise Fiord on Elesmere Island.

The project began in October, with a call for community youth interested in forming a research team. Four youth were chosen to research the aspects of IV Drug use and its relation to HIV/AIDS. A local drama instructor was employed to work with the youth and the producer on development of the video. A local high school student was employed as co-producer to work closely with the youth and production crew. While the team gathered information, auditions for actors were held at the PW Kaeser high school. Fourteen youth showed up to audition for the main characters and supporting roles. The youth were given a script to read, and interviewed on their knowledge of HIV/AIDS. They were marked on posture, clarity and voice projection. A letter describing the project was sent to all parents along with a permission slip for them to sign allowing their child to act in the video.

The research team and actors were given information workshops on various aspects of the topic. A member of the Fort Smith RCMP detachment spoke on his experiences of working with IV drug users. Other members of the community spoke to the group as well. One speaker, a former IV user, spoke to the youth on the negative affects of using drugs in general but emphasized the added dangers of sharing needles with others. He also revealed that high risk behavior reduces the chances of a person making clear and rational decisions, which can sometimes lead people to have a careless attitude toward protecting themselves. By the end of the month, enough information was gathered to hand over to the actors so that they could begin working on the story line and script.

The first decision the group had to make was what presentation format would be the most powerful in getting the message across to their peers? It was decided to go with a documentary/ drama. This would allow various professional and community leaders to share their input while still giving the youth an opportunity to present their perspective through drama.

A professional scriptwriter traveled from Yellowknife to give the youth a two-day workshop on scripting and story development. The youth learned about the protagonist, the antagonist and how to maintain the audience's attention. He also provided them with information in a way that would make an impact on their outlook in using and sharing needles.

With enthusiasm and determination, the youth started building characters and a story line prior to scripting. How could this be written in a believable manner, so that people would realize that this topic is a serious one that affects all of us? What facilities or community support would we require? Would the cast be using needles? If so, how do we insure safety during use? These and many more issues were discussed as the project was developed.

While the writing crew worked on their scripting, the research team developed a brochure for distribution with the video. Additionally, they made suggestions about people to be interviewed and questions to be asked. Early in 1999, two youth traveled to Yellowknife and held interviews with the already identified key informants.

During the months of January and February, the youth worked on the script diligently and enthusiastically in anticipation of the March 5th to the 9th shooting dates. Shooting began on schedule with the cast and crew ready to combine all their hard work into a project of which they would be proud. The patience and determination of the youth to get each scene right while maintaining their composure was inspiring to watch.

The Video Script

Max, a small time dealer and pimp, has HIV but does not inform anyone. He uses a needle to inject his drug of choice and shares the same needle with others.

Cynthia, a troubled teen living with her mother and brother, gets kicked out when her mother finds a bag of pot in her jeans. She finds herself on the streets, living wherever she can find a place to stay for a night or two. Meeting up with Max, he offers her a place to stay and the possibility of earning some extra cash. From there, her life goes down hill; Max turns her out to hook for him by keeping her hooked on coke.

At the parties, everyone shares the same needle with the assumption that everyone is clean. At one of the parties, a new girl tells the others about contracting HIV/AIDS through sharing of needles, both during drug use or tattooing. Cynthia has her doubts and decides to use the clean needle.

When one of the girls contracts HIV, she attempts suicide by overdosing and ends up in the hospital where Cynthia finds her. Cynthia offers her support and tells her friend, "Just because you have HIV doesn't mean you have to give up. I'm here for you."

Cynthia confronts Max about knowing he had HIV when he was sharing needles and decides to get help. After receiving counseling and attending a rehabilitation program, Cynthia moves back with her mother and brother in hopes of straightening out her life.

The police apprehend Max when he is found with coke in his van.

The Video Premiere

On April 9th, a community feast was arranged for a premier viewing of the video. Three youth from the Aurora College Pre-employment Cooking program were hired to cater the event. As this was their first catering opportunity, the youth were very excited about the chance of putting into practice what they had learned over the past year. An estimated one hundred and thirty people attended the feast and twenty nine-minute production. Presentations were made to the actors and community members who had assisted with the project prior to the viewing. Televisions were set around the hall so everyone would be in a good viewing position. The nodding heads, shed tears, comments like "I didn't think these kids had it in them" and a standing ovation were positive indicators that the youth had produced a video with an impact that would help others with knowledge of high-risk behavior and of steps to protect themselves.

The video was shown on the community channel the same evening, which allowed community members who were unable to attend the premier to view it at home.

Outcome

In April of 1999, the youth were invited to make a presentation at the "Alberta Aboriginal AIDS Conference" being held in Calgary. The youth presented the video, discussed how the project was completed, and spoke about the need for this information to reach aboriginal youth whether they are at high-risk or not. The group had the opportunity to meet with other youth to discuss what was being addressed in their communities and exchange ideas on projects they felt were needed to bring this information to their peers. Copies of the video were handed out and names of those interested in having a copy mailed to them were taken. As the video would be free to anyone wishing a copy, we received a lot of requests. Many viewers were impressed with the production and the hard work done by the group.

Over the next few months, copies of the video were distributed across Canada, while a few more were sent to England, Australia and the US.

The Yellowknife Correctional Institute and AIDS Yellowknife have worked with the inmates in forming a peer group which utilized the video as part of their presentation to other inmates in their institution. As well, the video is distributed to correctional institutions in other communities. Upon speaking with the warden, I was informed that since the presentation of the video, they have not found any tattooing paraphernalia on the premises. Likewise, a nurse from one of the communities mentioned she had an influx of inmates wanting to have blood tests. When asked why the sudden interest in blood test, she was told about the video presentation by the peer group.

During the production phase, several of the youth mentioned that it would be a good idea to make a CD from the video sound track. Once again, Health Canada granted funding to have a CD produced. It was decided to take one of the tracks and use it to send awareness messages in all the languages used in the North: Cree, Chipawan, North & South Slavey, Dogrib, Gwichn, Inukitut, Inuinaqtun, English and French.

Dynamics of the 1999 AIDS Walk in the 31 First Nations Communities: The community within the community approach.

Gabe Saulnier, B.S.W. & Renee Masching, B.A., B.S.W.

Visioning Through Community Partnerships

The overall Atlantic First Nations community consists of 31 distinct Maliseet and Mi'kmaq Nations with populations ranging from 60 to almost 3,000. HIV/AIDS has found its way into several Atlantic First Nation communities. It can probably be assumed that all of these communities, at one time or another, will have members who are affected by this disease.

The response to HIV/AIDS in Atlantic Canada began in 1991 when the Nova Scotia Mi'kmaq AIDS Task Force, founded by T'uma Young and Elizabeth Paul, became concerned about HIV/AIDS and the effect it could have on our communities. The two founders asked others throughout the region to share in teaching our people about the virus. In 1993, the Atlantic First Nations AIDS Task Force (AFNATF) was formed, and First Nations communities across Nova Scotia, New Brunswick, Prince Edward Island and Newfoundland joined in the effort to inform our Native communities about HIV and AIDS.

The Atlantic First Nations AIDS Task Force operates using a community-based model. As a coalition of the 31 First Nations communities in the Atlantic region, the AFNATF is sustained through the support of each community. Support is renewed on an annual basis by the Chiefs and by the Atlantic Policy Congress, which meets as a regional body on a quarterly basis. Based in Halifax, Nova Scotia, the AFNATF is governed by a board of directors from across the region.

Directors represent each community from tribal councils. Drug and alcohol treatment directors are also represented, and there are directors who are themselves living with HIV. This coalition is unique in Canada because of its reserve-based mandate, which also extends to the off-reserve population, under the direction of chiefs and councils. The AFNATF educates and supports Native persons who are HIV positive or who have AIDS, whether they live on or off reserve.

One of the major goals of the Atlantic First Nations Task Force was to encourage our communities to participate in the 1999 AIDS Walk. This paper reflects the experiences and processes undertaken to organize AIDS Walk Canada in communities across the Atlantic region.

[redacted] to organize AIDS Walk Canada in communities across the Atlantic region.

AIDS Walk Canada is a nationally co-ordinated event, which takes place during the last weekend of September each year. The AIDS Walk has taken place in Canada for 5 consecutive years. In 1999, it was estimated that over 55,000 walkers took part and raised over two million dollars across Canada.

The Walk has two purposes. First, it is an event which increases awareness of HIV/AIDS by drawing public attention to the issue. Second, it is designed to raise funds for HIV/AIDS work, to provide financial assistance to AIDS service organizations, and to help persons living with HIV/AIDS to achieve a better quality of life. In the AFNATF, the money raised is directed towards maintaining the office, staff development and a support fund which helps First Nations individuals with HIV/AIDS.

The AFNATF has been involved in AIDS Walk Canada for several years to varying degrees. Despite insufficient funding and limited staff resources, the AFNATF undertook the 1998 Walk with enthusiasm and hopes for new funding. Participation in the walk involved the immediate staff (four to six people) and several communities in the Atlantic region. That year, our office had faxed out the call for walkers, and two First Nation communities answered our request. We were ecstatic! The combined efforts of our office and the two communities raised over $1800.00. This was a triumph. Never before had we raised so much money.

It was then decided that we should attempt to involve all 31 Atlantic First Nation communities in the 1999 AIDS Canada Walk. Although we were concerned as a staff about the logistics of co-ordinating 31 Walks at 31 different sites, we decided to "go for it."

We had a vision. As our vision for a Walk in each community grew, we began to identify the resources necessary to make this event happen. We understood that in order to make money we would have to take a risk and invest money in the people, travel and supplies necessary to make the Walk a success.

Motivating communities would involve more than just a fax or a phone call. This goal proved to be a challenge because of the stigma associated with HIV/AIDS within many First Nation communities. The challenge for us was to convince community members that they could advocate for AIDS education by participating in the walk, without being stigmatized by an association with HIV or AIDS.

The AFNATF has worked extensively with the Atlantic First Nation communities over the years to address the stigma associated with HIV/AIDS. From the beginning, it has been an uphill battle; people were reluctant even to attend workshops on the topic. The mistaken belief that "HIV/AIDS will not affect us" has been the obstacle.

This hurdle was overcome by "reaching around the problem" and using the concept of a "community within a community" as our guide.

The Community within A Community... A New Understanding

The “community within a community” concept was developed during the Sustaining First Nations AIDS Programming Project. In our preparations for training sessions with community-based agencies within First Nation communities, we had assumed that all First Nation communities have similar structures and values; but we were wrong. For example, some communities and agencies smudge before undertaking a specific task and some do not. There is no consistency from community to community, or agency to agency. Thus, not only do communities differ from each other, but individual agencies within communities may also have unique values and practices. As such, these agencies form “a community within a community”.

All First Nation communities contain several of these “micro communities”. **Diagram I** illustrates how this concept can be applied.

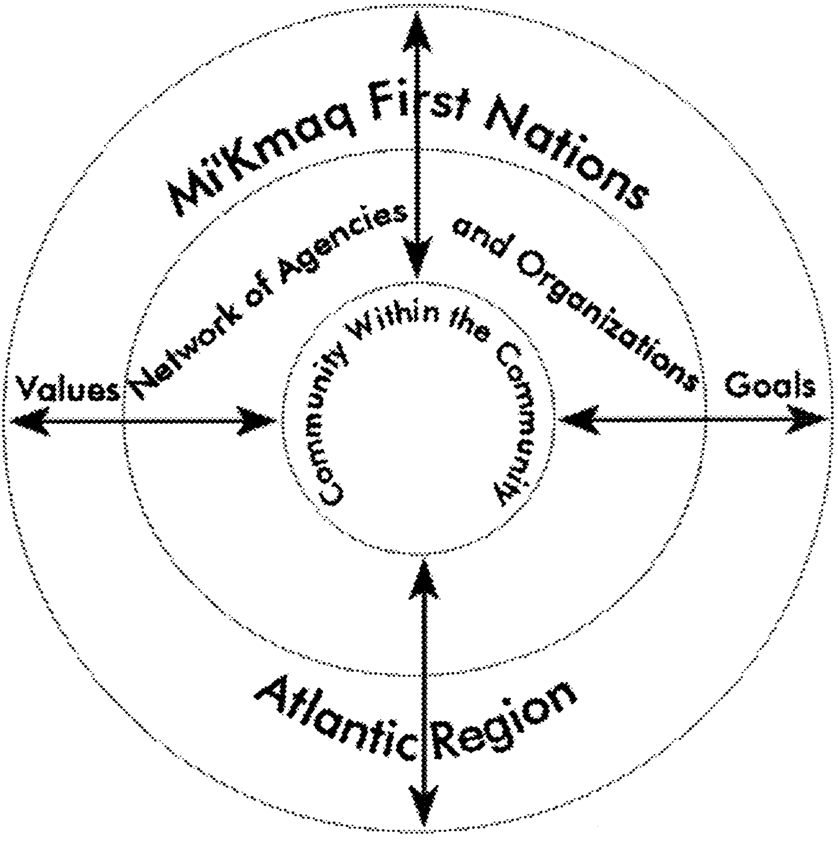
We decided to apply the "community within a community” perspective in trying to organize the AIDS Walk. Within most First Nation communities there are several persons that will support a cause and become fully involved. It was our goal to find these individuals and begin to network with them. Through networking with these community leaders, we would begin to break through the abovementioned barriers to organizing around the HIV/AIDS issue in First Nation communities.

In order to acquire the human resources necessary to do this networking, funding was obtained the human resources development offices of both the province of Nova Scotia and the federal government to hire two summer students to coordinate the walk.

Time was also a factor. Since the funding was a bit late, some of the deadlines for AIDS Walk Canada had passed. Communities had to be notified, and it was decided that initial contact with communities was to be done by telephone.

The most obvious community contacts regarding HIV/AIDS issues would be the community health representative (CHR) or the community health nurse (CHN). Although it seems obvious that a CHR or CHN would be at the forefront of issues such as HIV/AIDS, it does not hold true in every community. In most communities, CHRs and CHNs are dealing with multiple issues and do not have the time or energy to dedicate to yet another task. Understanding this reality, we nonetheless actively sought the help of the CHRs and CHNs to identify other community leaders.

Diagram 1: Community Within the Community Relationships AIDS Walk 1999



The Healing Our Nations organization provides services to Mi'kmaq and Maliseet First Nations. The Diagram represents the Community within the Community relationships specific to Mi'kmaq First Nations.

Throughout the months of May and June 1999, we developed our community contacts -- people who were willing to undertake the co-ordination of the Walk in their community. Once we had identified the leaders, we were challenged to empower their communities to participate in the 1999 AIDS Walk.

To begin with, community leaders had to develop trust in the co-ordinators. This task could have been a problem because First Nations people are weary of being told what to do and when to do it by people from outside their communities, a result of years of oppression by various governing bodies. Thus, the co-ordinators had to analyze each community to decide whom to approach.

Another obstacle the co-ordinators identified as a potential problem was that one of the co-ordinators was not of Native descent. Traditionally, the First Nation communities in Atlantic Canada have "adopted" non-Native persons in their communities. More recently, however, communities have opposed non-Native people working in our communities. The AFNATF office has a policy to hire Native people first; however, over the years, we have also "adopted" several non-Native people into our professional family.

The non-Native co-ordinator was accepted as an equal in the AFNATF office. Before leaving on the tour, she was briefed on the history of our communities and the potential problems. Through her studies, experiences and work on the AFNATF, she had developed a very respectful understanding of the issues she might face and knew that she had the full support of the staff in the office.

Fortunately, the non-Native co-ordinator also won the support of the communities through her concerned and caring attitude. The non-Native issue was quickly set aside, and the co-ordinators discovered that each community accepted them with open arms. With trust and credibility established, the co-ordinators found themselves better able to communicate their message. As Bill Lee (1997:61) states, "The organizer is becoming more visible, not as a leader, but as someone who cares about people and the issues and who appears confident that the citizens can work together and produce something of good quality."

Finding the "right person for the job" to co-ordinate the walk in each community proved to be difficult. Many times the designated person would be reluctant to take on the organization once they realized the scope of the task. This pattern proved to be another challenge because each time someone refused, another potential organizer had to be identified, and the entire process of explaining the dynamics of the Walk had to be repeated. For this aspect of the job, personal contact with potential organizers was essential.

Logistical Co-ordination

The AFNATF co-ordinators began an AIDS Walk tour which involved visits to the 31 First Nations communities in Atlantic Canada. The tour was developed based on the notion that personal contact, putting a face to the voice, and the "community within a community" approach would develop trust between the AFNATF co-ordinators and the communities. The tour covered all of Atlantic Canada (excluding Newfoundland, since contacts there had been made previously).

Time once again proved to be a challenge. The summer student grants began in late May. By the time the co-ordinators were hired and trained, it was middle of June. Traditionally, July and August are both months that band offices close for vacations. Nonetheless, after many phone calls and faxes, the tour was set for the last two weeks of July. The tour was modified to visit 25 of the 31 communities. Teleconferences with the remaining communities were set up.

The tour began in the province of New Brunswick. The co-ordinators planned a loop of the province to visit each community on the schedule. Time frames proved to be challenging because of the distance between each community. The driving time from one community to the next was approximately one to two hours with an average of 100 to 200 kilometers between. Some days the co-ordinators found themselves arriving with literally minutes to spare before a scheduled meeting.

Credibility for the AFNATF and the co-ordinators had to be established within each community. The AFNATF had done groundwork over the years. This groundwork included workshops such as AIDS 101, Family Based Support Model and Best Practices on Child Sexual Abuse. In previous years, the AFNATF had also contacted the communities regarding the AIDS Walk for that particular year.

Another facet of this under-taking was the issue of "quality vs. quantity." Involving the 31 First Nations communities was in itself a monumental task, but were the coordinators able to provide quality in the form of committed workers in each community and a realistic plan for achieving the goals?

The answer to this question was yes. This quality was accomplished by taking the time to explain each facet of the Walk in person and giving the contact individuals ample time to question any aspect they found perplexing. A detailed but flexible work plan was provided for the months leading up to the AIDS Walk for each community. The contact persons also had access to the co-ordinators on the AFNATF toll-free line any time.

The co-ordinators had set a goal for 300 registered walkers and $7000.00 to be raised from all of the communities in Atlantic Canada. This estimate averaged out to approximately $225.00 from each community, a seemingly realistic goal. To track the progress of the Walk, two thermometer scales were posted in the lobby of our office, and on a daily basis, new communities and more walkers were registered.

Reflections and Implications

After the Walk was concluded, the co-ordinators found that their efforts had been rewarded by an overwhelmingly positive response to the project. Although not all communities participated, the goal of $7,000.00 had been surpassed. The Walk raised over $18,000.00.

As we reflected on the event, we found that the "community within a community" approach had indeed been a useful model to apply to the Walk. This experience showed us that targeting the various "communities within communities" was the key to success when introducing a new concept -- in this case, the AIDS Walk.

The 1999 AIDS Walk was by far the largest community driven event that the Atlantic First Nations AIDS Task Force had ever undertaken. The 1999 AIDS Walk was a financial success, raising over $18,000.00 in the Atlantic First Nations communities. One community alone raised over $3,000.00 alone. As well, a prize consisting of a trip for two to anywhere in North America was won by one of the participants.

The AFNATF will continue to work on breaking down the barriers to the understanding of HIV/AIDS, and educating Native communities. Someone once said that "assumption was the mother of all mix-ups", but the AFNATF was blessed in making correct assumptions about the potential of the "community within a community" strategy. Organizing the AIDS Walk 1999 has provided the AFNATF with a model and experience which has proven more useful than countless hours of classroom learning.

Celebrating Community Knowledge Encouraging Involvement, Achieving Ownership and Building Confidence Through Comprehensive Community Consultation.

Todd Armstrong, B.A.

Introduction:

Pauktuutit Inuit Women's Association of Canada has demonstrated a historical commitment to addressing health care issues among Inuit communities, and HIV/AIDS is no exception. Since the story of Leetia Geetah, the first Inuk woman diagnosed with HIV, hit the news in 1988, Pauktuutit has been increasingly involved in HIV/AIDS issues. Leetia Geetah's experience as an Inuk living with HIV/AIDS has had a profound, lasting impact on Inuit communities and Inuit who have since been diagnosed with HIV. Her diagnosis coincided with the birth of her youngest child in the late 1980s. To say that a lack of confidentiality and HIV/AIDS awareness resulted in a community ill-prepared to understand, much less respond to Leetia and her young son's needs, is a gross understatement. The true result was a community terrified by the prospect that HIV/AIDS was among them, a community determined to get rid of the cause by whatever means necessary. Threats of violence fuelled by fear and misinformation followed the breach in confidentiality. Media coverage spread the alarm across the north.

For their own protection, Leetia and her son were confined to a hospital while health officials attempted to identify a safe alternative resource. In February, 1989, Leetia and her son boarded a plane and left their community and their family. Caring, yet culturally ignorant strangers from the south would now provide the support they needed most.

The Inuit experience with HIV/AIDS and Inuit culture differs significantly from those of First Nations and Métis. For example, despite the fact that Inuktitut is a living language, the first language of most Inuit, little HIV/AIDS information has been produced in Inuktitut until recently. The lack of accessible educational materials has resulted in a poorly informed population, unmotivated to deal with the threat of HIV/AIDS and years behind their southern counterparts with respect to HIV/AIDS awareness.

The distinct nature of Inuit culture, traditions and beliefs has rarely been reflected in HIV/AIDS educational materials developed for Aboriginal peoples. The medicine wheel and sweet grass are examples of two corner stones of First Nations culture which are irrelevant to Inuit. The lack of cultural representation and context in educational materials has provided an opportunity for Inuit to ignore and sometimes to deny the likelihood that they are at risk of contracting HIV.

While intravenous drug use is a major risk factor in the spread of HIV/AIDS among southern Aboriginal populations, it is a far less significant risk among Inuit. Games like "torture and chicken" are a more substantial risk to Inuit children and youth. Likewise, while "two-spirited people" are a focus of substantial HIV/AIDS education for some Aboriginal populations, for Inuit, the focus is unprotected heterosexual intercourse. Focusing on risk groups and risk behaviors less prevalent among Inuit has resulted in a very limited recognition at the community level of the need for HIV/AIDS community action.

Inuit communities are geographically isolated, spanning the Arctic from the Northwest Territories to Newfoundland / Labrador (including Nunavik, Arctic Quebec), in size, an area more than one-third the total of Canada. Subsequently, there are broad variations from region to region and community to community. All fifty-three Inuit communities of the Arctic are coastal, and only one is accessible by land. There is a dramatic range of population among communities from approximately one hundred and fifty to four thousand. Inuit have often used geographical isolation to deny the threat of HIV/AIDS; however, many communities have large transient populations, which increase the potential for the introduction of HIV into even the smallest community.

The delivery of health services to Inuit communities is the responsibility of five governments: the federal government, the governments of the Northwest Territories, Nunavut, Quebec and Newfoundland/Labrador. The complexities of this health care delivery system create situations unique to Inuit and to Inuit communities with respect to continuity of service and care, as well as consistency with information and access to treatment. Additionally, the health care needs of urban Inuit are the responsibility of the province in which they live. Often, for Inuit living with HIV/AIDS and their families, this structure can create a difficult or impossible situation with respect to family reunification, consistency in treatment and the accessibility of optimal care and support.

Although community health workers and others have developed educational materials in some communities, the bulk of information available to Inuit is southern, white and male-oriented. By and large, it does not reflect the reality of life among Inuit communities in the north. It provides accurate information but lacks the necessary context to make it effective.

Pauktuutit began the process of developing HIV/AIDS prevention material for Inuit communities in 1998. Through funding (received in August 1998) provided by Medical Services Branch of Health Canada, that we have been able to provide Inuit communities with six booklets about HIV/AIDS available in English and in one dialect of Inuktitut. (Translation of the books in a second Inuktitut dialect is in process)

The value of comprehensive community consultation in the development of educational materials cannot be overstated. Community consultation sends a message of respect. It is recognition of the value of community expertise. One of the most important things to recognize is that your audience are invaluable experts.

In response to a resolution passed at the 1993-94 Annual General Meeting of Pauktuutit, we hosted a three-day HIV/AIDS/STD training workshop in Iqaluit. The goal of the workshop was multi-faceted, primarily focusing on increasing knowledge about HIV/AIDS issues for community health workers. It was also intended to gather information about attitudes and community needs as they relate to HIV/AIDS. The need for culturally appropriate, linguistically sensitive material about HIV and AIDS was identified as a priority.

This sentiment has been echoed by community representatives involved in other HIV related workshops including the Iqaluit Youth HIV/AIDS workshop (1998), the CHR Knowledge conference on HIV/AIDS and STDs (1995), and the Sharing the Message HIV/AIDS training seminars (2000). All participants seem to agree that the lack of relevant HIV/AIDS information hampers their efforts to provide their communities with accessible, appropriate education about HIV/AIDS.

The lack of contextual information is the predominant reason Inuit communities and community members have failed to "buy in" to southern HIV/AIDS prevention messages. Encouraging ownership of an issue is almost impossible when information used to promote it inadvertently provides a message of exclusion.

Providing less relevant information allowed Inuit to view themselves as outside any particular risk group and diminished the need to evaluate their own behavior with respect to the risk of HIV. While AIDS organizations in the south are wrestling with issues like homophobia and the "Gay Plague", in northern communities, we wrestle with our own sort of misinformation: that HIV/AIDS is a southern white male disease unlikely to affect the north.

Underlying principles:

Interestingly enough, this on-going project is sponsored but not directed by Pauktuutit. It is community-driven. Past experience taught us that ownership is a function of participation. It taught us that the success of this project would largely depend on our ability to perform our role as a facilitator and leave the decision making in the hands of the broader community.

Project Goal: To broaden the scope of understandable, relevant, accessible HIV/AIDS prevention, treatment and care information for Inuit communities.

Although this project goal may appear straight forward, it was, in fact, substantially more complex. It became apparent at the first meeting of the steering committee that producing the materials would not be sufficient unless we developed a process that encouraged ownership. Ownership, we came to realize, was the key to ensuring the documents were going to be used.

Rather than imposing a design for community consultation or picking a standard model, we remained flexible and allowed the process to shape itself. The process we used to encourage ownership and involve the community evolved. We were guided by a set of principles with respect being the primary one, respect for cultural expertise and regional difference, respect for the right of communities to determine their own standards, and respect for the fact that communities and community members knew what information they were ready to deal with and where they needed to begin the process of HIV/AIDS education.

For many reasons, Inuit have viewed HIV and AIDS as less of a threat than many other populations. On the face of it, the answer may seem quite simple: isolation. In reality, one of the main reasons Inuit have been slow to respond to the AIDS crisis is that they have been given permission to ignore it. As previously stated, until recently, the majority of HIV /AIDS educational material available to Inuit has been southern, Caucasian-based and provided only in English.

The Inuit language, Inuktitut, has been maintained from generation to generation. It is written in three ways and spoken in more than eight dialects. It is one of only three aboriginal languages, in Canada, expected to survive. Producing HIV/AIDS materials respectful of each dialect is a goal, although, a questionably realistic one. Although international law supports the rights of individuals to be educated in their own language, accessing the resources necessary to provide dialectically appropriate materials has proven impossible to date. When material is irrelevant and inaccessible, populations are not only robbed of the opportunity to recognize their own risk but are given tools which allow them to avoid connecting their own risk behavior with the threat of HIV/AIDS.

Methodology

We sought the help of the six regional health boards and requested that they select a regional representative to sit on an HIV/AIDS steering committee. We recruited an additional three members, one representing youth, one representing urban Inuit and one Inuk living with HIV. Our health coordinator represented Pauktuutit. The ten-member steering committee met for the first time in September 1998 to define the focus and basic format of the education materials, to determine an initial consultation process and to select an author for the documents.

The seven-month duration of the project meant that everyone involved in the project would have to work together and within explicit deadlines to meet the project goal. Fortunately, our project coordinator is a remarkably organized, highly motivated woman. Her skills, background in education, and cultural awareness provided the foundation necessary for the project to succeed. The steering committee was also able to identify an author with extensive HIV/AIDS community program experience, some Inuit cultural awareness and a connection with the north.

At their initial meeting the steering committee established the necessary criteria to guide the development of the educational materials. They identified topics to be included in the document, the language level and basic layout guidelines. Working together, under the direction of the steering committee, the coordinator and the author managed to produce one-hundred and fifty page draft document within the six week deadline necessary for project completion.

Community Consultation

The process of developing these educational materials taught us that technical expertise and cultural/community awareness are equally important in the fight against HIV/AIDS. “Recognizing knowledge” is a statement about expertise - expertise beyond an individual’s technical knowledge or their ability to maneuver condoms in public. It is a combination of technical skill, experience, and cultural and regional awareness. It involves a deep knowledge of community standards and community needs. Developing information, which is both accessible and relevant, requires expertise only found that within the population the education program is designed to reach.

We learned that community consultation is a valuable tool because it is able to increase the effectiveness and the likelihood of ownership of the material and enhance distribution. The idea of community consultation is not a new one; however, it often only involves the “community” close to the end of the process, which provides a role more akin to evaluation - a sort of report card of program design. Our approach differed somewhat in that we included the broader community early in the project, provided them with a role which respected and recognized the value of their expertise, and gave them both an individual and collective voice. We also provided alternate options for participation that included using community members to distribute the final document. The formation of the steering committee was the beginning of a comprehensive community consultation process which was somewhat cumbersome, time consuming and more costly, but based on the number of requests for additional documents, it appears to have been effective.

In addition to reviewing every draft, each member of the steering committee agreed to "recruit" as many as ten document reviewers. The only qualification the reviewers were expected to have was a willingness to read and comment on the documents. As a result, they came from various backgrounds, HIV/AIDS awareness and expertise levels.

Although predominantly Inuit, some of the recruited reviewers were non-Aboriginal. Each reviewer was provided a copy of the draft document and was asked to review and comment on the language, content, layout, and cultural appropriateness of each section. Reviewers were encouraged to share the information with other community members and to include any comments they felt were interesting or pertinent. Through this process, more than sixty community members reviewed the document in draft form. There were also several additional medical, legal, and governmental reviewers involved in the process.

The reviewers were given clear instructions about how to reference their comments and an extremely tight deadline for return of their responses. Communication with community reviewers was a function of each of the steering committee members. The coordinator worked closely with the steering committee members, the author and the "professional" reviewers, encouraging follow-up and confirming their progress with respect to the short deadlines.

Once the reviewed draft copies were returned to Pauktuutit, the coordinator began the onerous task of compiling the reviewers' comments page by page. The compilation of comments was reviewed, debated and decided upon by the steering committee, page by page, then passed to the author for review and an initial edit.

A second steering committee meeting was held in December when it became clear that a balance had to be struck between culture and essential content. Culturally, some of the issues addressed in the document were difficult for community members to deal with. Inuit are not particularly different than other ethnic groups in their reluctance to discuss sex and sexuality. Traditionally, these issues are viewed as very private issues, which are generally not discussed in mixed company, a particularly difficult situation with respect to information about HIV/AIDS. That discomfort, however, had to be balanced with the rights of community members to know how to protect themselves. Decisions about finding a balance were made at this meeting

During the second steering committee meeting, discussions centered on the responsibility of health educators to provide information and on the need of the regional representatives to avoid offending the people they represent. One of the fears was if the information was too far beyond the community standard, the document would be rendered useless. Beyond sharing different points of view, the meeting provided an opportunity to listen to alternative ways of explaining or justifying to the community the need for the information. Collectively, the steering committee and the author were able to find a suitable balance and recognized how important on-going communication with the community would be to achieve the "buy in" necessary to make this document effective. In effect, we came to understand the broader scope of community consultation.

Armed with the direction provided at the second steering committee meeting, the author and the coordinator began the arduous task of editing the draft document for final review. Once the changes were made, the steering committee was provided with copies of the final draft document for approval.

The questions that remained seemed, at first, to be rudimentary. What font to use? What paper weight? What color/type of cover? In truth, we learned from previous experience that even these decisions would impact the effectiveness of the document and would require community input. The steering committee was provided with options and rationales and asked to decide on each component of the design. One of the best examples displaying the importance of design relates to the final layout of the publication. As it happens, an evaluation of another health related project was nearing completion as we faced decisions about the layout. One part of the evaluation focused on how well the document in question was being used by community health educators. It is a large, glossy, well-designed product complete with video and support information in one big binder. The evaluators' initial finding was that the size alone was intimidating to the people intended to use it. Even some of the people involved in the design process confessed they had never even opened it because it was overwhelming.

When that information was provided to the steering committee of the HIV/AIDS project, they recognized the need to rethink the original layout idea of one large book and find ways to make this document more user friendly. The steering committee guided the process down to how much information was on each page and what font they felt would be easiest to read.

The end result is a series of six smaller booklets, each addressing one HIV/AIDS issue written for Inuit communities. Each has a different colored, plain, heavy stock cover. Inuit artwork was used, and the series is dedicated to the memory of Leetia Geetah. Each of the six booklets cover a different HIV/AIDS issue in less than fifteen pages. Booklet one, *The Basics*, covers the facts and fiction about HIV and AIDS. Booklet two, *Your Immune System and Testing for HIV*, describes the immune system and the effect HIV has on it in simple language. Testing methods and the implication of being tested are also covered in booklet two. Booklet three, *HIV: The Risks*, is about risk behaviour at home and at work. Booklet four, *Protecting Yourself from HIV*, is a guide to safe sex, safer sex and universal precautions. Booklet five, *Women and HIV/AIDS*, is a booklet dealing with issues specifically for women from pregnancy and sexual assault to post exposure prophylaxis. Booklet six, *Sexually Transmitted Diseases and HIV*, describes other sexually transmitted diseases emphasizing the increased risk of HIV infection when a person has STD.

Community consultation did not stop there. Recognizing that the review process was overwhelming for some of the people who wanted to participate, we enlisted their talents as distributors of the booklets. Rather than shipping the completed booklets to a health centre, school or other community building, we shipped them to these "community distribution consultants". Each of them used their community knowledge to identify the people and agencies most likely to share the information with other community members. Several of the community distribution consultants have since expressed an interest in becoming more involved in other HIV/AIDS projects.

Recommendations for Best Practices

From our perspective, the notion of identifying the content of this article or the following conclusions as "best practices for Aboriginal communities" is presumptuous at best. Inuit know all too well what it is like to be lumped in with others, more often due to difference from the majority rather than similarity to the minority group in question. The cultural difference between Inuit and other cultures, including other Aboriginal nations, are distinct. Out of respect for other aboriginal groups the following can only be termed food for thought. Something you might think about as tools which may be useful as you explore what your experts share with you.

Broad community representation and meaningful community consultation is at the forefront of our recommendation. Often the assumption is made that one member of a group is sufficient representation.

One Inuk cannot adequately represent the needs of all Inuit any more than one person living with HIV or AIDS can represent the varying needs of all people living with HIV or AIDS. Beyond culture, representation is about gender, age, regional difference and life experience. It involves the balance between modern life and traditional life.

Inclusion

The basis of community consultation is inclusion. Too often, the standards set for membership in a consultative group exclude many community members who have much to share. Although individuals may need to be recruited in order to ensure broad and inclusive representation, when the primary qualification for membership in a consultative group is interest in the topic in question, everyone benefits. More people feel they have a voice, and a broader range of perspectives is represented.

An additional benefit from this type of inclusion is increased community interest in the end product. To some degree, the members of the consultative group become project advertisers by emphasizing their involvement, by sharing what they have learned, and subsequently, by stimulating a broader base of community interest. Ultimately, a larger part of the population has a vested interest in the project.

Increasing Culturally-Based Resources

There are opportunities for community consultation, which are often overlooked because the tasks seem to be strictly administrative. People are often reluctant to participate in a project because they feel their talents do not apply. Recognizing that community consultation is about sharing information and not only gleaning it can help open up possibilities for participation to a larger part of the population. Providing opportunities for involvement in a project at a comfortable level for an individual increases options for capacity building. Too often people who are seen to have capacity are called upon to participate in too many projects. Individual capacity can be developed through project participation at varying levels. Over time, it provides us with an increase in culturally based resources.

Appreciation of Participants

It is important to recognize that the members of the consultative group are volunteers. Likely this project is not their first priority. The task may sound manageable when they agree to participate but may, in reality, be more than they bargained for. Clearly define your expectations and include a realistic indication of the time participation would require.

Whenever possible, allow people to share participation either by sharing a position or splitting a task.

Support of Participants

Keep in mind that participation may involve activities or processes, which are new to members of the consultant group. Consistent communication and support are necessary to ensure tasks are completed. It is important to clearly explain deadlines, including who sets the deadlines and the effect of non-completion on the overall project. Emphasizing the value of someone's contribution is generally motivating. Too often people think that their contribution is less important than others.

Our project involved sending large amounts of information to the consultant group for review. Experience taught us that clear directions were paramount. Be specific about what you need them to do. Remember that your involvement in the project may make things obvious to you, but it may not be clear to someone only working on a portion of the project. State the obvious. An example, from our experience with this project, involves referencing comments to page numbers. Reviewers were provided with instructions, which included "make sure to tell us the number of the page you are commenting on". Although this may seem somewhat condescending, it was, in fact, a necessary direction for reviewers who had never participated in a process like this one before.

Language

Never underestimate the power of words. Remember that for many people, and almost all Inuit, English is a second language. Often people with limited written language comprehension skills dislike reading and avoid it whenever possible. Focus on information, which is essential. Avoid information that could be termed "nice to know". Make messages clear and simple. Use language that is commonly used and easily understood. Keep sentences short.

In publications like this one, community standards are often reflected in the language that the consultant group chooses to use. In the case of our booklets, some language is paired -medical with vernacular - as a balance between what might be common to many and what is believed to be most appropriate. Community consultants were provided with options such as sperm, semen and cum and asked to choose. In the end, their choice reflected what would be tolerated and understood by the majority.

Context

Context is an important component of all education. It is the component that makes information valid, useful, and real. Context is about language, making references to circumstances or to events to which people can relate. It is also about allowing people to see a reflection of themselves in the material intended for their own education. Lack of context is at the root of why people often discount the HIV/AIDS messages. Our community consultants were asked to provide contextual references and to identify parts of the documents they felt distanced them or could distance others from the message. An Inuit artist was commissioned to provide the artwork for each of the booklets. It reflects the circumstances of community life with symbols and faces that are clearly Inuit.

Conclusion

Comprehensive community consultation prevented us from producing a document which was too large and possibly too technical to be effective. Without it we may have produced a document which was remarkably thorough and completely accurate but which no one would use. In the final analysis, comprehensive community consultation made the difference between providing HIV/AIDS education materials and providing, in essence, nothing.

The proof, for us, is in the enthusiasm we are encountering now as we embark on our next projects. Recently, we were asked to adapt a pamphlet on *Women, Sexual Assault and HIV*. Unlike our previous project, where we had to encourage participation, community members have approached us, asking to be involved in the review process.

We are continuing to develop educational materials for Inuit communities, in fact, booklet seven, Living with HIV/AIDS, a guide for Inuit living with HIV/AIDS and their caregivers, was released in February of this year. Several other booklets are planned and will be developed, as funding becomes available: one for teens, one for elders and parents, and one specifically for Inuit men.

On a much larger scale, we are beginning the process of developing the Canadian Inuit HIV/AIDS Network. The fact that the community was so intimately involved in the development of the booklets has provided the "buy in" necessary to make this Inuit specific networks a reality.

A Community- based Approach to Reducing HIV/AIDS Infection in the Wikwemikong Unceded Indian Reserve

Scott Cooper, Marion Maar & Mary Ann J. Peltier

Introduction

Wikwemikong Unceded Indian Reserve has long been committed to self-determination in the development of local community services. In light of this commitment, we examine in this report the response of this rural Native community to the HIV/AIDS (human immunodeficiency virus/acquired immune deficiency syndrome) epidemic. Over the past years, the Nahndahweh Tchigegamig Health Centre in Wikwemikong has developed a community-based HIV/AIDS Education Program with a strong cultural element. We review programs and interventions which have been implemented through HIV/AIDS Education Program in Wikwemikong and recommend a further course of action which will hopefully lead to a significant reduction in the transmission of HIV/AIDS and sexually transmitted diseases (STDs) in the community.

Background

The Wikwemikong Unceded Indian Reserve No. 26 is located in the Georgian Bay, Lake Huron area and is situated on the eastern part of Manitoulin Island. It is the traditional home of the Odawa, Ojibway and Pottawatomi tribes.

The health centre is located in the main village of Wikwemikong where about half the population lives. The other half of the population lives in rural areas in seven small but distinct satellite communities, which consist of South Bay, Buzwah, Kaboni, Wikwemikongsing, Murray Hill and Rabbit Island and the Point Grondine Reserve on the mainland. As of March 31st, 2000, the total membership of Wikwemikong is 6,383. Approximately 2,743 members live on reserve while another 3,640 members live off reserve.

Self-determination and Health Services in Wikwemikong

The Wikwemikong Band Council passed a resolution in 1968 which expressed the desire to work towards the realization of local self-determination by taking control of all services delivered in the community.

The health transfer initiative proposed by Health and Welfare Canada was seen as a major step in realizing this goal in the health care sector. A band council resolution to pursue health transfer was passed in 1986. At that time, the band noted:

> The complete absence of health promotion and the escalating costs of treatment services note the current health care delivery system. This chance to institute change from treatment to promotion occurs at an opportune time and, is also a chance to influence the health care delivery in the non-Native community (Wikwemikong Unceded Indian Reserve 1989).

Health transfer was seen as an option to shift health program emphasis from a curative orientation to health promotion and illness prevention and to increase the involvement of the community in health programs through participation and consultation:

> Health care needs should be met through community-based programs and facilities, so that the community has ownership and responsibility for its health care. Any health care system that is not delivered by the community does not own the system, but is owned by the agency that develops the system. All community programs and systems must begin with community consultation with the residents of the community (Wikwemikong Unceded Indian Reserve 1989).

In 1986, Wikwemikong developed a proposal to transfer health services. Pre-health transfer activities included the development of a comprehensive community health plan to be overseen by a full-time co-ordinator and an assistant. An assessment of available health services and community needs was conducted. A local Health Steering Committee was formed to guide the process of health transfer. The newly constructed Nandah Weh Chi Gegamik Health Centre opened its doors to the community in the same year. Since then, many new services and structures have been added to the local health care system in a relatively short amount of time.

It is not surprising, that HIV/AIDS was not identified as a community priority during the health pre-transfer community consultation in 1988. It was difficult to estimate the risk of this disease to Native communities at that time. Incidence statistics were not known since the ethnicity of individuals undergoing an HIV test was not recorded prior to

1988 (Maar 1996). By 1990, Health and Welfare Canada identified Native Communities as being particularly at risk for HIV/AIDS infection due to poor health status, higher rates of STDs and reduced access to health care (Canada 1990).

The Wikwemikong health centre responded to the growing epidemic with a first HIV/AIDS awareness presentation to Band employees in July 1991. Soon after the HIV/AIDS awareness presentation, the Community Health Representatives (CHRs), Community Health Nurses and National Native Alcohol and Drug Addictions (NNADAP) workers initiated HIV/AIDS awareness presentations in local schools, at community events and on the community television channel. The health centre also began networking with the Access AIDS office in Sudbury.

In August of 1992, there were 33 Wikwemikong band members known to be HIV positive; five of these people had developed full-blown AIDS. These numbers represented 28 percent of the HIV positive cases in the Sudbury District at that time although Aboriginal people represent only three percent of the total population within this district. It was extremely difficult to determine how many of the infected Band members were living on reserve, but the statistics were alarming. It became evident that established reporting procedures failed to provide a clear picture of the prevalence of HIV/AIDS in Native communities.

Subsequently, HIV/AIDS awareness gained priority in Wikwemikong. The health staff worked towards increasing community awareness of HIV/AIDS through community workshops and other promotional activities. In 1993, the Wikwemikong Chief broadcasted live on the HIV/AIDS status in Wikwemikong on the community channel. A talk show hot-line question-and-answer period was also conducted by the health centre in collaboration with Sudbury Access AIDS.

By February 1994, the statistics remained alarming: the number of band members with full-blown AIDS had increased to 10 people. In August 1994, there were two major HIV/AIDS presentations conducted in the community. Knowing that Native people living with HIV/AIDS (PHAs) have a great impact as HIV/AIDS educators, the health staff invited Native guest speakers living with HIV/AIDS from Wikwemikong and other Native communities to speak. HIV/AIDS education videos were also shown on the local community channel and in the health centre lobby. Educational pamphlets and condoms were made available on an ongoing basis at the health centre and at major community events. HIV/AIDS education and prevention components were incorporated into many health programs including the Family Violence Prevention Program, the Nutrition Program, the School Health Program and the Nursing Program.

By 1995, the statistics had climbed again. There were now 45 Wikwemikong band members known to be HIV/AIDS positive. Then, in

1996, the health centre was no longer able to track the number of community members infected with HIV/AIDS due to anonymous testing legislation and related changes in the reporting procedures. At that time, it was anticipated that the First Nations Health Information System (HIS) designed by Medical Services Branch (MSB) could provide a mechanism to track the incidence of HIV/AIDS on reserve. Yet, the HIS did not prove to be useful in determining the prevalence of HIV/AIDS in the community for many reasons. A major factor is MSBs lack of resource allocation to cover data entry and site management expenses of the system at the community level.

In 1997, Wikwemikong health service providers still did not have a good idea of the prevalence of HIV/AIDS on reserve. Later on that year, a videotaped interview on HIV/AIDS was conducted with an HIV/AIDS Educator from the Union of Ontario Indians and a local Community Health Representative. The interview focused on the effect of HIV/AIDS on Native communities and possible strategies to combat the spread of this disease.

In January 1999, the HIV/AIDS Education Program officially became a distinct health program and an integral component of the health services system in Wikwemikong. The goals of the HIV/AIDS Education Program included the following program priorities:

- the provision of a community-based HIV/AIDS education program, including a healthy sexuality program with emphasis on children and youth, and education for adults at community events.

- the provision of support services for people affected with HIV/AIDS and

- the establishment of base-line data, which will allow the health centre to track the success of the program.

The services have a strong cultural component and clients are able to choose between Traditional and Western health services. A Community Health Representative with specialized training and experience in HIV/AIDS education staffed the position of HIV/AIDS Educator. Under the federal health transfer agreement, the current health care system in Wikwemikong provides enough flexibility for program development and adjustments according to community priorities. Although this flexibility is a positive aspect of the agreement, in terms of the Wikwemikong HIV/AIDS program, this kind of flexibility is only a short-term solution. There is no funding allocation in the health transfer agreement for HIV/AIDS programs.

Redesigning a CHR position to encompass the responsibilities of an HIV/AIDS Educator allows the community to address a current health priority, but it also creates a staff shortage in the CHR program.

Because HIV/AIDS is a relatively new health problem and was not identified during the pre-health transfer needs assessment, no resources were allocated to deal with this health problem at the time of health transfer and at this point in time, an HIV/AIDS education program can only be provided in Wikwemikong by reallocating the already scarce resources. To support the ongoing operation of the HIV/AIDS Education Program, the health centre will require an enhanced funding commitment from Medical Services Branch during the upcoming Wikwemikong health transfer re-negotiations (see also: BC Aboriginal HIV/AIDS Task Force 1999:41).

Local Barriers for the HIV/AIDS Education Program

One of the main priorities of the newly established HIV/AIDS Education Program has been to reduce barriers to effective HIV/AIDS prevention program delivery in the community. A major obstacle to effective program development with which most HIV/AIDS prevention workers are struggling is the deep-rooted denial which often pervades communities regarding HIV/AIDS (Ontario Aboriginal HIV/AIDS Strategy n.d.:23). Seeing as this denial was also an issue in Wikwemikong, the HIV/AIDS Educator felt that is was important to begin with a strategy to increase awareness of HIV/AIDS with the community's leadership and health care workers. An HIV/AIDS education session was held in conjunction with the annual health centre staff retreat in May 1999. This session raised the awareness of HIV/AIDS with local health care providers and increased the support for the program with the community's health board. To raise awareness in the community at large, the program invited a PHA from the community to speak at the local high school at a community event.

An HIV/AIDS protocol for Wikwemikong is currently at the draft stage. This protocol will reaffirm the rights of PHA's in the community, outline pre- and post-test counselling procedures for locally administered HIV tests, and provide guidelines for staff to use universal precautions in the health field.

Healthy sexuality school program

A healthy sexuality program, which incorporates a strong traditional component, has been implemented in the Wikwemikong elementary and secondary school system. The goal of this program is to educate children at an early age about healthy sexuality. The elementary school education component begins in grade five. The purpose of this program is to raise awareness of healthy sexual development. Traditional teaching are used to teach healthy male and female roles. The good touch/bad touch segment gives children an opportunity to learn and practice assertiveness skills. The HIV/AIDS Educator introduces new topics every six weeks. The high school program is designed to raise awareness about HIV/AIDS and STDs, and it includes sessions designed to increase students' capabilities to talk about and practice safer sex.

Support for People Affected With HIV/AIDS

When support services are provided for people with HIV/AIDS who have returned to their community, it is important to ensure that clients have access to all available services. When working with PHAs, it is particularly important to provide case co-ordination and advocacy not only within the health sector but also across the social services agencies. The housing shortage is a particular concern in Wikwemikong. Living in crowded conditions with family members increases chances for PHAs to contract secondary infections. Counseling services and support for families affected with HIV/AIDS, are provided by HIV/AIDS Educator. Traditional support is available through the traditional medicine program.

Base-line data

Base-line data on health indicators related to sexual health need to be collected in order to measure the impact of HIV/AIDS education in the community. We need to answer questions such as: What are common high risk behaviours in this community? Are high-risk behaviours decreasing in the community due to HIV/AIDS education programs? And, ultimately, is the incidence of HIV/AIDS decreasing in the community? When concrete goals for this program were first established, the HIV/AIDS Educator had a clear sense of what needed to be accomplished. Indicators of success included the reduction of teenage pregnancy rates, the decline of the incidence of STDs in the community and an increase of HIV testing in the community. Compiling base-line data and tracking indicators such as the incidence of STDs and teenage pregnancy rates requires a considerable amount of additional work for program staff, but they comprise the tools which will allow the centre to evaluate the effectiveness of HIV/AIDS Education Program.

Recommendations for On-Reserve HIV/AIDS Program

Close collaboration between community-based HIV/AIDS prevention programs and the existing community health network is required to maximize program impact. For example, inter-program collaboration can lead to pr-natal care, which includes HIV/AIDS screening as part of the routine pre-natal screening. The school health program is an ideal interface for HIV/AIDS prevention education for children and youth. In Wikwemikong, we are planning to add a teen-wellness clinic to the school health program. The clinic will be delivered at the local high school and will benefit from collaboration between the Nursing program and the HIV/AIDS program. Community events sponsored by the NNADAP Program are ideal venues for HIV/AIDS education. In order to reach young to middle-ages men, it is necessary to collaborate with programs outside of the health sector. Combining HIV/AIDS education with sports events is a more effective way of reaching this target group than through health centre sponsored community events.

We found that national and provincial tracking procedures fail to provide an accurate assessment of the prevalence of HIV/AIDS on reserves. Programs rely on prevalence estimates by health care workers, such as CHRs or Community Health Nurses, who are recognized as experts in community health. Many related indicators are easier to track and still provide useful data for HIV/AIDs program evaluations. They include community statistics on the number of teenage pregnancies, the rates of STDs, and the number of HIV tests.

Evaluation of the effectiveness of healthy sexuality education programs in changing attitudes, awareness and behaviours, particularly among youth, is also a very important component of a community-based HIV/AIDS prevention program. This kind of data is very valuable but labour intensive to collect and analyse and may require collaboration with staff with experience in program evaluation.

Funding sources are urgently needed to support the development of community-based HIV/AIDS education programs in First Nations since most federal and provincial funding sources currently target urban centres. Similar to many other reserves, the main source of community health funding in Wikwemikong is provided through a health transfer agreement with Medical Services Branch. As part of health transfer, health program dollars have been essentially capped. Drawing on the sparse health transfer budget can at this point, only support the delivery of the HIV/AIDS education program. However, community-based programs, such as the HIV/AIDS Education Program, require ongoing developmental dollars to provide effective services in First Nations. A training budget to educate and keep staff current on issues related to HIV/AIDS is needed. HIV/AIDS education program resources need to be tailored to suit local culture and social norms, which requires research and evaluation of resources at the local level. Access to these types of resources can prove beneficial for all community-based programs. An ongoing resource commitment is also required to support long-term community health program planning, development and implementation at the local level.

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“Honouring and Caring for Aboriginal People and Communities in the Fight Against HIV/AIDS” Healing Our Spirit BC First Nations AIDS Society –Providing Prevention, Care, Treatment and Support Services for Aboriginal Peoples in British Columbia

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Abstract

This paper provides an organizational overview of Healing Our Spirit BC First Nations AIDS Society (Healing Our Spirit) and introduces the holistic healing and Aboriginal specific service delivery model that Healing Our Spirit uses to address the HIV/AIDS epidemic. The HIV/AIDS epidemic compels many Aboriginal communities to deal with the complex issues associated with HIV/AIDS. While in the process of strengthening and regaining cultural and social systems, Aboriginal peoples also face inter-generational, interconnected, and socio–economic issues. Specifically, these issues include sexual abuse, homophobia, shame, lack of housing, lack of education, alcohol and drug use and addiction. In large part, these are a legacy of colonization and residential schools. Healing Our Spirit has developed culturally sensitive and relevant community development strategies to address the multiple and complex challenges in the field of HIV/AIDS.

Introduction: HIV and Aboriginal peoples in British Columbia and Canada

Among Canada’s Aboriginal peoples and communities, the HIV/AIDS epidemic has become yet another disease Aboriginal peoples contract at rates higher than the non-Aboriginal population. Though being Aboriginal itself is not a predictor of risk for HIV, there are many underlying social determinants that contribute to Aboriginal peoples being at increased risk of infection. Many of the behaviours, which place one at risk of HIV infection, are associated with poverty and disempowerment. The effects of colonization and the residential school system must be acknowledged as contributing to the current poor health conditions of Aboriginal people. Other socio-economic factors, such as systemic racism, poverty, marginalization, and lack of education, have also adversely impacted the health status of Aboriginal peoples (Report of The Royal Commission on Aboriginal Peoples, 1996).

As of the end of 1998, 11,525 Canadians have died from AIDS (Laboratory Centre for Disease Control, 1999b), and 40,100 Canadians are living with HIV (Laboratory Centre for Disease Control, 1999c). In the past few years, the number of reported AIDS cases has dropped significantly in Canada. Much of the drop in death rate has been attributed to the success of antiretroviral therapies. While the absolute number of reported Aboriginal AIDS cases has also dropped, the percentage of new AIDS diagnoses with Aboriginal ethnicity has steadily increased. From 1989 to 1998, recorded Aboriginal ethnicity has risen from 1.2% to 10.9% of reported cases. Since 1994, this figure has gone from 2.6% to 10.9% (Laboratory Centre for Disease Control, 1999a). This increase may be attributed in part to better recording of ethnic information. Regardless, the bottom line is clear: HIV/AIDS continues to affect Aboriginal peoples in a manner disproportionate to the rest of the Canadian population.

Figures commonly cited to explain higher HIV rates among Aboriginal peoples include: higher rates of teen pregnancy (BC Ministry of Health, 1996); higher rates of sexually transmitted diseases (Health Canada, 1996); higher rates of incarceration (where risk activities are high) (Rothon et al., 1994; Red Road, 1999); higher levels of addictions including injection drug use; and high rates of mobility between rural and urban locations (Report of The Royal Commission on Aboriginal Peoples, 1996; Red Road, 1999).

Among Aboriginal populations in BC, women are infected relative to men at a rate far higher than in non-Aboriginal populations. In fact, BC Aboriginal women are infected at a rate approaching that of Aboriginal men. Of the 69 Aboriginals who tested positive for HIV in BC in 1998, 43% (30/69) were female and 57% (39/69) were male (BC Aboriginal AIDS Awareness Program, 1998). These numbers compare with 16% (66/404) and 86% (338/404) respectively for non-Aboriginals who tested positive for HIV in BC in 1998 (BC Centre for Disease Control, 1998). 73% (22/30) of new HIV positive tests for Aboriginal women were associated with injection drug use (BC Aboriginal AIDS Awareness Program, 1998).

These statistics dispel any notion that HIV/AIDS affects only "gay white men" a perception still held in many Aboriginal communities (Report of The Royal Commission on Aboriginal Peoples, 1996). Both male and female Aboriginal peoples are at risk through unprotected sex, be it homosexual or heterosexual, and through the sharing of needles. As

Aboriginal women become infected, their unborn children also are put at higher risk of contracting HIV.

As we are in the early stage of the epidemic, we will see a much greater need for care in Aboriginal communities. HIV/AIDS is fatal but preventable, so public prevention and education activities will remain paramount in the fight. For prevention to be effective, it is necessary to continue and to enhance HIV/AIDS education programs in Aboriginal communities. It is imperative that Aboriginal individuals and communities begin planning and implementing care, treatment and support for Aboriginal people living with HIV/AIDS who want to go home. Healing Our Spirit is working to facilitate achieving these goals in prevention and care. The remainder of this paper will explain in greater detail the mandate and work of Healing Our Spirit.

History of Healing Our Spirit BC First Nations AIDS Society

Healing Our Spirit was incorporated in 1992. The co-founders, Frederick Haineault and Leonard Johnston were of the Cree Nation. Both Leonard and Frederick anticipated the need for a society that could help raise the consciousness of Aboriginal people toward the rapid spread of HIV/AIDS in their communities. Frederick and Leonard have passed on to the spirit world, but their memory, their important work initiated in BC, and their personal contributions to the field of HIV/AIDS remain with us. Today, Healing Our Spirit has developed into an HIV/AIDS service organization, which provides: education and prevention, care, treatment and support, and research and evaluation services to Aboriginal peoples in BC.

Mandate of Healing Our Spirit BC First Nations AIDS Society

The mandate of Healing Our Spirit is to prevent and to reduce the spread of HIV and AIDS and to provide care, treatment and support services to Aboriginal peoples infected and affected by HIV/AIDS. It is the society's belief that: "Everyone is a part of our traditional healing circle, including people with HIV and AIDS. Communities in balance keep the circle strong by working together in caring, supporting and healing." (Healing Our Spirit HIV/AIDS Educator Manual)

Specifically, the primary goals of Healing Our Spirit programs and services are to:

- Increase the awareness of HIV and AIDS in both urban and rural Aboriginal communities
- Provide educational workshops throughout BC on the prevention of HIV and AIDS

- Provide support to individuals living with HIV and AIDS, as well as to their families and caregivers
- Increase community accessibility to HIV and AIDS educational material and resources
- Increase acceptance of people living with HIV and AIDS in their communities

What is the Role of Aboriginal People Living with HIV/AIDS in Healing Our Spirit?

Healing Our Spirit is a community based non-profit Aboriginal HIV/AIDS service organization. Free memberships are available to Aboriginal people living with HIV/AIDS, as well as to Elders and to the youth. Aboriginal people living with HIV/AIDS are recognized as Lifetime Members. Currently there are over 120 Lifetime members of Healing Our Spirit. Over time the number of member's change. This change reflects the loss of members who have gone to the spirit world, and the addition of new members who have been newly diagnosed. The membership of Healing Our Spirit, in particular Lifetime Members, provides direction for the organization in its service delivery.

Aboriginal people living with HIV/AIDS are the centre of HIV/AIDS program development and service delivery at Healing Our Spirit. The hiring and retaining of Aboriginal people living with HIV/AIDS is an ongoing priority for staff development, and is supported by current employment policies. These policies incorporate and support people living with life threatening illnesses and address the special needs of those living with HIV/AIDS. Despite the commitment to employ Aboriginal people living with HIV/AIDS, the reality is that job-related stress can adversely affect one's medical status and thus affect one's ability to maintain employment. The need for creativity and flexibility in employee policy development is important, especially in the area of retaining Aboriginal people living with HIV/AIDS as employees.

Healing Our Spirit also seeks Aboriginal people living with HIV/AIDS to sit on the Board of Directors. By providing capacity building for those whose experience with boards is limited, a diversity of board members are ensured, and the society gains the first-hand expertise of those who live with HIV/AIDS.

Aboriginal people living with HIV/AIDS are honoured for their vision and courage through traditional and contemporary ceremonies held at the Healing Our Spirit annual conference. The society recognizes that many times these contributions have been made at great cost to the individual, and their strength and courage to publicly address what are often painful issues is a gift to Aboriginal communities. In keeping with the tradition of honouring, the Fourth Annual Conference in 2000 is dedicated to "Honouring Our Children and Families " who are infected with and affected by HIV/AIDS.

What is the role of Aboriginal Culture and Values in Healing Our Spirit?

With approximately 24 distinct linguistic/cultural groups, BC's First Nations reflect great diversity. In addition, Aboriginal people from many other nations in Canada live in BC and utilize Healing Our Spirit's services. This diversity is reflected in the employees, board, and membership who, throughout the history of the society, have come from Aboriginal nations across Canada. Healing Our Spirit provides services for all Aboriginal peoples in BC: those living on reserve, off reserve, non-status Indians, Inuit and Metis. For Healing Our Spirit, respecting Aboriginal culture and values is an important component of decision making, community and team development.

While diversity of customs, values and beliefs exist, many core Aboriginal values are similar. The traditional values of caring, sharing, and taking care of one another are a part of every Aboriginal culture. Healing Our Spirit's programs and services are delivered in a culturally sensitive manner, which respects and honours the diversity of the cultural values of all Aboriginal members of the society.

How Can the Teaching of the Medicine Wheel Address Barriers that Exist in Communities for Aboriginal People Living With HIV/AIDS?

The health of the human spirit includes an unconditional love of self, which is shared with all other aspects of creation. Disconnection and loss of balance first occurs at a personal level and reverberates in the home, the workplace, and the community. Communities in balance keep the circle strong by working together to heal the spirit with support for the person who is HIV positive and for the family (Healing Our Spirit Fact Sheet)

Healing Our Spirit recognizes that prejudice among individuals and in communities can have a direct impact upon Aboriginal people living with HIV/AIDS and their ability to access appropriate services. Aboriginal people living with HIV/AIDS face a number of barriers to achieving their optimum health. Prejudice against drug users, transgendered persons, and those within or re-integrating from the prison system, issues of homophobia, fear and stigma may be barriers to providing services for those who are infected, or at risk of being infected with HIV/AIDS. Aboriginal leadership has a key role to play in assisting communities to address these barriers (Lambert, 1993).

Healing Our Spirit to address the exclusion of and prejudice against those who are infected and affected by HIV/AIDS uses the medicine wheel teaching. The medicine wheel encompasses the four directions and all peoples. Application of the medicine wheel in community settings encourages the re-integration of Aboriginal people living with HIV/AIDS and promotes healing. The medicine wheel represents many things, including the four areas of holistic health–physical, emotional, mental and spiritual.

The medicine wheel can be a useful tool in community healing and development processes (Lambert, 1993). Many issues associated with HIV/AIDS affect all four areas of holistic health. For example, in the spiritual aspects, Aboriginal people living with HIV/AIDS are now seeking traditional medicines, healers, spirituality and elders. Thus, communities need encouragement to extend healing practices to those living with HIV/AIDS.

Prevention and Education "Taking Care of Each Other for a Safer Path Through Life's Journey"

Prevention of the spread of HIV/AIDS formed the initial and founding work of the society. The founders, Leonard Johnston and Frederick Haineault, recognized that one of the most effective ways to educate others is by example. Hearing the stories of those who are experiencing HIV/AIDS first hand was the first and most important component of the prevention message. The speaker's bureau has developed from this approach and currently brings people living with HIV/AIDS to communities to share their experience with participants in workshops facilitated by educators. Many of the HIV positive education speakers are Healing Our Spirit Lifetime members.

Healing Our Spirit conducts workshops for approximately 1,500 participants annually and reaches approximately 4,000 people through the information booth program. The goal of the education program is to reach Aboriginal people across BC and to empower them to educate themselves on risk behaviours. The program encourages respect for oneself and others, self-awareness, seeking appropriate medical and health care, and educating one's community about the need for acceptance and support of those who are infected with HIV/AIDS.

Prevention workshops are designed for a cross-section of audiences: communities, schools, transition houses, prisons, women's groups, youth, elders, colleges and universities, powwows, and conferences. As has been the case across the country, Healing Our Spirit workshops are delivered to suit the audience and Healing Our Spirit works in collaboration with organizations and communities to tailor training to the specific needs of the group (Crown et al., 1993; Mill, 1996; Lambert, 1993). The variety of workshops range from understanding the basics of HIV/AIDS to advanced knowledge of the interrelated psychological and social issues that impact on HIV/AIDS transmission, biological transmission, and treatment processes.

The education program has evolved over the years to address the barriers Aboriginal people face in protecting themselves adequately. These include; homophobia, women's issues, addictions, the impact of sexual abuse, and access to care. The education program is currently working with the Residential School Healing Foundation project, "Reclaiming Our Pride, Families and Communities" to develop curriculum for residential school survivors.

The community development aspect of the education program focuses on skill development and information sharing to assist individuals and groups in responding effectively and appropriately to the complex issues related to HIV/AIDS. Community development activities are especially encouraged for health professionals, chiefs and councilors, and tribal councils.

Assessment and evaluation of workshop participant knowledge has become an important method for enhancing the education program. Initiated by the Healing Our Spirit education program, the Building Research Capacity Project produced its first study, "Attitudes Towards HIV and AIDS Among Aboriginal Peoples Living in BC", which was analyzed from information collected during workshops. An oral presentation of this research was given at the 1999 International AIDS Impact Conference in Ottawa.

The Outreach Program - Providing Care, Treatment and Support Services for Aboriginal Clients Living With HIV/AIDS

While the initial phase of Healing Our Spirit's development was prevention of the spread of HIV/AIDS, the second phase of organizational and community response is providing care, treatment and support services for Aboriginal clients who are living with HIV and AIDS. Many Aboriginal people living with HIV/AIDS now live in urban centres. There are a number of reasons why a person living with HIV/AIDS would move to an urban centre. For example, Victoria and Vancouver in particular, have broader care, treatment, support networks, and more medical professionals with expertise in HIV/AIDS and than most other urban and non-urban locations in the province. Also, research centres such as the Centre for Excellence in HIV/AIDS at St. Paul's hospital allow persons living with HIV better access to researchers conducting clinical drug trials.

Currently, these services and resources are not offered, or are difficult to access, in many rural and remote areas (Red Road, 1999). This issue is one that communities will need to address in the near future and to plan for financially. Healing Our Spirit has submitted a grant proposal to examine cost and access issues of providing services for Aboriginal people living with HIV/AIDS on reserve and in rural areas. Barriers to accessing services are not the only barriers that Aboriginal people living with HIV/AIDS face in returning to their communities. In many cases, Aboriginal people living with HIV/AIDS would like to return to their home communities but are discouraged by a fear of discrimination and by the threat of physical violence (Schneider et al., 1999; Red Road, 1999).

The Healing Our Spirit Outreach office was opened for clients in February 1997 and provides three main areas of service for Aboriginal people living with HIV/AIDS. They are: emergency assistance and facilitating access to ongoing social services, community support and network building, and outreach to those who cannot access services themselves. Annually, outreach staff assist approximately 1200 client drop-in visits. Through Healing Our Spirit, clients access support, peer counseling, residential school syndrome counseling, nutritional supplements, referrals, the HIV/AIDS information resource centre, and advocacy in housing discrimination and human rights issues.

Peer support and advocacy workers make hospital, hospice, correctional facility and home visits and co-ordinate street outreach in the urban core. The Outreach program promotes and enhances a sense of cultural community among Healing Our Spirit clients by organizing dinners, retreats, and travel to attend powwows.

Healing Our Spirit also provides outreach to families of those living with HIV/AIDS. Families coming to Vancouver are helped, sometimes financially, and clients are similarly supported when visiting their home communities. Healing Our Spirit works with communities and families in all regions to help coordinate funeral and memorial services for clients.

The harm reduction model is utilized in the provision of outreach and onsite service delivery. Clients face multiple barriers to accessing housing, social services, and achieving financial independence. Many deal with emotional traumas stemming from issues of abuse and social dysfunction among family and community, which are made more complex by addictions to legal and illegal drugs. Providing services to clients struggling with these issues is both rewarding and challenging. As a social service organization, the society faces the reality that street involved clients may present a threat of violence for staff and members. Healing Our Spirit has taken steps to address this issue by implementing safety policies for staff and clients.

The housing advocacy program provides ten mobile housing subsidies for HIV positive Aboriginal people in BC, which are provided through BC Housing. This number in no way meets the housing need for Aboriginal people living with HIV/AIDS, and as a result, there is currently a long waiting list for this program. It is a priority to address this need by lobbying for more housing subsidies for Aboriginal people living with HIV/AIDS. In addition, referrals for affordable housing for Aboriginal people living with HIV/AIDS are made to Vancouver Native Housing and L'uma Native Housing. These Native housing agencies are partners in providing suitable, subsidized housing for Aboriginal people living with HIV/AIDS.

Finally, there is the volunteer program, which is an indispensable component of Healing Our Spirit. Volunteers provide vital assistance in all areas of the organization. Operating community information booths, administration tasks, production of the Healing Our Spirit play, "How Health and Healing Came Together", and special events are some of the activities during which volunteers often provide assistance. Volunteers have offered their unique skills that range from providing haircuts to clients to holding spiritual and cultural ceremonies for Aboriginal people living with HIV/AIDS. The volunteer program provides opportunities for Aboriginal people living with HIV/AIDS and others to make valuable contributions in the fight against HIV and AIDS.

Currently, the volunteer program has established a Council of Aboriginal people living with HIV/AIDS, which provides direction to Healing Our Spirit in the areas of program and policy development. The council was formed to ensure ongoing input of Aboriginal people living with HIV/AIDS. This will assist in the long term development of the role of Aboriginal people living with HIV/AIDS in Healing Our Spirit, as those involved with the council will have enhanced opportunity to become involved in decision making on the Board of Directors.

Healing, Skills and Capacity Development Provided to Aboriginal Communities in BC at the Annual Aboriginal HIV/AIDS Conference

The first annual Healing Our Spirit conference was held in Vancouver in 1997 and was dedicated to the memory of co-founders Leonard Johnston and Frederick Haineault. Subsequent conferences were held in Prince George and Nanaimo. The Fourth Annual Conference is to be held in Cranbrook in the year 2000. Aboriginal communities are encouraged to co-host the conference as representatives of their region in BC. By bringing together leaders in the HIV/AIDS field, Aboriginal health and healing professions, Aboriginal people living with HIV/AIDS, community members, funding bodies, and political leaders, a forum is created where Aboriginal people can come together to learn skills, current information and culturally appropriate models. To facilitate full participation, full and partial scholarships are made available to Aboriginal people living with HIV/AIDS, community health professionals and workers, and community members.

Healing Our Spirit special events are designed to raise the visibility of HIV/AIDS issues, to fundraise, and to encourage open dialogue in Aboriginal communities about HIV/AIDS. Annually, Healing Our Spirit works in collaboration with other organizations and communities to host an Aboriginal Fashion Show & Silent Art Auction, a Golf Tournament, and an Aboriginal/International AIDS Awareness Day Event. These events promote community collaboration, awareness and personal growth.

In addition to addressing HIV/AIDS in the Aboriginal community, Healing Our Spirit participates in larger local events, such as the annual AIDS Walk, and the Gay Pride Parade. Participation in larger HIV/AIDS events raises awareness of the effect of the epidemic on the Aboriginal community.

Community Liaison – Creating Linkages and Advocating Accountability to Aboriginal People Living With HIV/AIDS

The community liaison is a newly formed initiative of Healing Our Spirit. The goals of the community liaison are to improve and to facilitate communications of the society with provincial and national HIV/AIDS funding and co-ordination bodies. The liaison provides current and relevant information to the society, which assists in organizational and program planning.

The current practice of the liaison is to provide strong advocacy from the perspective of Aboriginal people living with HIV/AIDS on matters impacting and pertaining to Aboriginal people living with HIV/AIDS. In this respect, the community liaison assists in the improvement of accountability of HIV/AIDS services and provides a networking capacity to Aboriginal people living with HIV/AIDS. The importance of accountability to Aboriginal people living with HIV/AIDS is advocated at all levels, from the national level to the provincial and community level as well as internally at Healing Our Spirit.

Addressing the Impact of Residential Schools with the "Reclaiming Our Pride, Families and Communities" Residential School Healing Project

After many years, the negative socio-economic impacts of the residential school system are beginning to be acknowledged and addressed through healing initiatives and the court system. The legislated Canadian residential school system contributed to a prevalence of physical and sexual abuse and the disruption of culture and community for Aboriginal peoples. Formation of the Healing Foundation initiated a national healing strategy to assist individuals and communities in their healing journeys. The Healing Our Spirit Residential School Healing Project operates from the belief that those who have been adversely affected by residential schools have the ability to be empowered to heal themselves and others. This self-empowerment is achieved by accessing traditional Aboriginal and Western therapies which are delivered by Aboriginal people.

The mission of the Residential School Healing Project is to:

> Reconnect, reclaim, and rebuild First Nation culture and spirituality by integrating and healing the mental, physical, emotional and spiritual aspects of individuals traumatized by residential schools.

Western and traditional healing options provided include one on one counseling; group sessions; traditional arts and crafts; traditional healing ceremonies; therapeutic tools and skills, and related up-to-date information. The First Nations program counselors bring professional backgrounds in anger management, sexual abuse, alcohol and drugs, and Substance Abuse Subtle Screening Inventory (SASSI) client assessment.

Support and advocacy is also provided for clients in court settings. Education and sensitivity training in confidentiality issues related to HIV/AIDS and residential school syndrome are provided to social services and the legal system, which thus creates more understanding and sensitivity to residential school and HIV/AIDS issues.

Transferring Skills and Control of Research to Aboriginal Communities – the Building Research Capacity Pilot Project

Research partnerships formed by the University of British Columbia (UBC) and a number of Aboriginal AIDS service organizations during the Community Health Resources Project (CHRP), and the First Nations Community Health Resources Project (FN-CHRP) provided the foundation of the Building Research Capacity Pilot Project. The mutual respect of differing strengths, exchange of technical and cultural skills, and working collaboratively to address the lack of research capacity in the Aboriginal community are primary characteristics of the Healing Our Spirit, UBC partnership.

Healing Our Spirit obtained funding from HIV/AIDS Prevention & Community Action Programs (PCAP), Health Promotions & Programs, Health Canada, to provide training and assistance in the development of Healing Our Spirit's capacity to do research. The mandate includes helping build research capacity of other Aboriginal AIDS Service organizations in Vancouver. The research project team consists of three Healing Our Spirit staff, two academic research consultants, and Healing Our Spirit management. Academic expertise is utilized on a project by project basis. The development of a research infrastructure and tools of high quality, and developing culturally appropriate dissemination methods are key aspects of Building Research Capacity Project.

Capacity building project activities have included: analysis of education knowledge, attitude and belief assessments, re-design of education assessment and evaluation tools, database development for housing advocacy, and joint application to conduct research on the economic cost, resource impacts and access to care for Aboriginal people living with HIV/AIDS on reserve and in rural areas.

Research results have been presented at the AIDS Impact 1999 International Conference and the Red Road HIV/AIDS Network quarterly meeting. Healing Our Spirit has met with Aboriginal AIDS organizations, the First Nations House of Learning at UBC, and the UBC Co-ordination Office of Research Services to discuss the development of an Aboriginal ethical review committee. The Aboriginal specific committee would be based with UBC Research Services, and would be accessible for Aboriginal community based research in BC.

Healing Our Spirit has utilized the partnership with the university to further the research agenda for Aboriginal HIV/AIDS in BC. Healing Our Spirit seeks to provide research capacity building for communities, and conduct research independently in the future. The process of building research capacity through academic partnership is an interim measure to address the current lack of research skills and expertise in Aboriginal communities.

Conclusion

Aboriginal people are currently over-represented in HIV/AIDS statistics. Like many other diseases, Aboriginal people are affected at disproportionate rates to the larger population. As new infected and affected groups emerge, new challenges and inter-related issues need to be addressed in the areas of prevention, care, treatment and support. For many Aboriginal communities, the challenges of HIV/AIDS lay ahead. Aboriginal people currently living with HIV/AIDS will require care, treatment and support services as will their families and children when their illness progresses. The costs of providing medical and holistic therapies for HIV/AIDS are currently very high. Aboriginal communities in the process of developing their own health services need to plan for these costs and to ensure that HIV/AIDS services are provided. The creation of community based, culturally appropriate HIV/AIDS strategies to provide prevention, care, treatment and support services must be a part of Aboriginal and regional health plans.

The costs of not providing Aboriginal HIV/AIDS services are high, not only the monetary costs, but the social and cultural costs. The involvement and education of Aboriginal communities is crucial to preventing the further spread of HIV/AIDS, which continues to have a devastating impact on Aboriginal people. The community development approach is a unique and successful one in Healing Our Spirit's service provision for Aboriginal people infected with, and affected by HIV/AIDS.

Through the development and delivery of culturally appropriate education, prevention, care, treatment, support, research and evaluation services for Aboriginal people in BC, Healing Our Spirit addresses HIV/AIDS in Aboriginal communities at the individual, community and political level. The vision and practice of Healing Our Spirit is to work collaboratively with Aboriginal communities and community based organizations to address the social and systemic barriers to prevention of HIV/AIDS and the full integration of Aboriginal people living with HIV/AIDS in their communities and society. Only the involvement of Aboriginal people living with HIV/AIDS and Aboriginal communities at all levels will ensure the success, accountability and legitimacy of this process.

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Section 4

Research

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 Nations and non-First Nations samples were compared using 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 n=10 (%)	non-First Nations persons n=52 (%)	p – value
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:			
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). The 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.

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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.

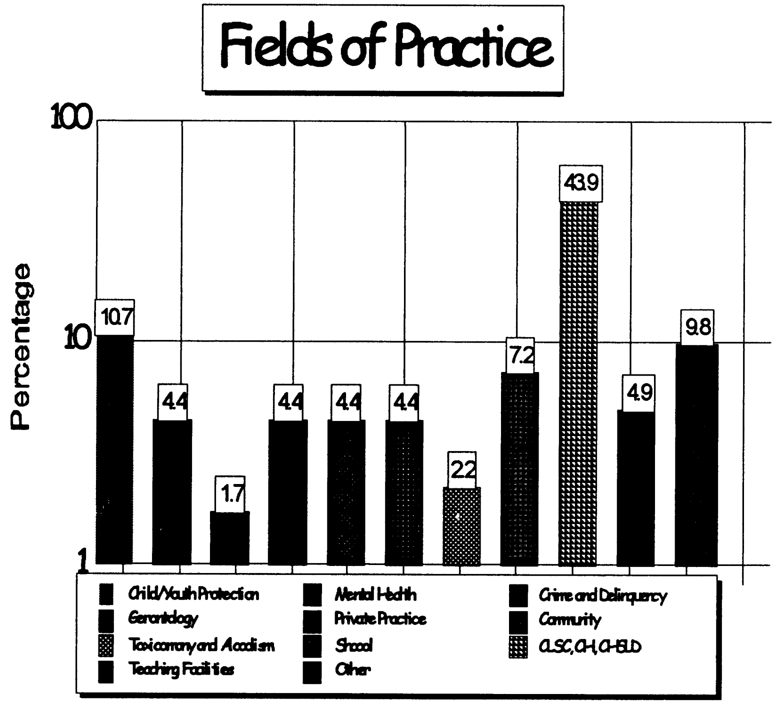
Analysis of the Data

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 specifics 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

	Right		wrong		dont know	
question	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

	Right		wrong		dont know	
question	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.

Table 2

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

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Table 3

	right		wrong		dont know	
Question	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

	right		wrong		dont know	
question	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

	right		wrong		dont know	
question	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

	right		wrong		dont know	
question	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

	right		wrong		dont know	
question	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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Attitudes and Beliefs Towards HIV and AIDS Among Aboriginal Peoples Living in British Columbia

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Abstract:

Healing Our Spirit, BC First Nations AIDS Society (HOS) provides outreach and education services for First Nations and Aboriginal people living with HIVAIDS (APHA). These services, including educational workshops, are provided to diverse clients and communities throughout British Columbia (BC), including remote villages and reserves. Over the past three years, workshop participants have completed questionnaires. Using this collected data multivariate logistic regression is used to examine attitudes and beliefs about those who are living with HIV. This analysis shows that men ($p<0.001$), persons living in rural ($p=0.022$) and remote ($p=0.017$) communities and persons between the ages of 10 and 15 ($p<0.001$) are less likely to score positive attitudes towards people living with HIV/AIDS. This result suggests a need for more educational programs in rural communities, and in particular, programs which focus on men and adolescents.

Introduction:

Healing Our Spirit, BC First Nations AIDS Society (HOS) provides outreach and education services for First Nations and Aboriginal people living with HIV/AIDS (APHA). Specific HIV/AIDS educational workshops are designed for three primary audiences: youth, health care workers and Aboriginal community members. With limited resources to support education programs, HOS wants to invest in areas with the highest return, the return being better care for those living with HIV and fewer new HIV infections. If a major objective of education is to develop awareness and positive attitudes towards HIV and AIDS, we must target and design education programs for those with poor attitudes and beliefs. Thus, we want to learn more about where attitudes and beliefs about HIV and AIDS may vary.

It is with this goal in mind that we asked the following question: *Is it possible to identify differences in attitudes and/or beliefs towards HIV* *and AIDS among Aboriginal peoples?* If we could identify differences, this information would help HOS better develop and target future education programs. The primary data collection tool for this following paper is generated from questionnaires, which have been completed at a number of HOS educational workshops throughout BC.

At the beginning of these HOS workshops, participants were asked to complete a questionnaire, which assessed participant knowledge and attitudes. Data was collected for several years but never analyzed due to a lack of funds for database design, data entry and analysis. Recently, HOS received funding from HIV/AIDS Prevention and Community Action Programs, Health Canada (PCAP) to develop research capacity. An initial project was to evaluate the workshop questionnaires. An Aboriginal researcher was hired by HOS, and consultants helped provide training for database development and basic data analysis. To do this project, an initial research question addressed differences in attitudes towards HIV and AIDS within Aboriginal populations. The data used in the following analysis comes from 1304 workshop questionnaires.

Objectives:

In this analysis, we look at characteristics associated with positive or negative attitudes and/or beliefs towards HIV/AIDS for Aboriginal persons living in British Columbia. In particular, we examine attitudes and beliefs about accepting or isolating people who are HIV positive or have AIDS. Our intent is to investigate whether systematic differences in attitudes of people exist based on categories such as age, gender, and location of community, be they urban, rural or remote.

This type of information is important for education planning and priority setting at HOS. The outcomes of this research also help us better design requests for funding from public and/or private granting agencies.

Background:

For individuals and communities, HIV/AIDS affects all four health components of the medicine wheel: emotional, physical, mental and spiritual. Exactly how the disease exists within a community will define the community's response to the disease. In some Aboriginal communities it is possible to live with the full support of friends and family. In other Aboriginal communities, this environment is not possible because fear, lack of information and misinformation about the disease persist (Lambert, 1993; Red Road, 1999). Importantly, this collection of attitudes and beliefs determines how people protect themselves from contracting the virus and how they treat those who have become infected.

The small amount of research which does exist, both qualitative and quantitative, points to the need for a better understanding of how HIV/AIDS exists within Aboriginal communities. This need is especially true for rural and remote communities (Northern Health Research Unit, 1998). One study, The Ontario First Nations AIDS and Healthy Lifestyle Survey (Myers et al., 1993), has looked at attitudes and beliefs about HIV/AIDS. This study examines beliefs and attitudes within several First Nations communities in Ontario. In this study, questions about beliefs and attitudes were grouped into six categories: AIDS anxiety; isolation of people living with AIDS; communication with sexual partners; traditional values & AIDS education; embarrassment obtaining condoms; and other. The questions used to measure attitudes towards isolation of people living with HIV in Myers et al. are similar to the questions used in our study presented below. Their analysis consists of bivariate comparisons using categories of gender, age and location. Myers et al. found that 57% of respondents scored the highest possible score for the set of questions examining the isolation of people living with HIV. Hence, the majority of respondents felt that HIV positive community members should be supported. There was no significant difference in isolationist attitudes between women and men. The mean response for older (40 years and older) respondents was lower (less inclusive) than for the younger age categories. Differences between regions were not reported for responses to the isolation questions.

In contrast, 32.3% felt that their community would ignore APHA, and 12.7% felt APHA would be told to leave the community. Also, 80% of respondents felt that homosexuality and men having sex with men was wrong.

Other studies have shown that negative attitudes exist. The reasons for this are complex but include issues around homophobia and a seeming conviction that HIV/AIDS affects only gay white men (Report of The Royal Commission on Aboriginal Peoples, 1996). Also, HIV/AIDS is associated with injection drug use, another reality that holds negative connotations within many Aboriginal and non-Aboriginal communities.

We believe that an important first step in HIV/AIDS education is to dispel fear of the disease by building knowledge through culturally appropriate teaching. For HIV/AIDS, this teaching includes addressing issues around homophobia and addictions. In the following study, we use a multivariate logistic analysis to identify differences in attitudes and beliefs towards HIV/AIDS.

Data and Methods:

Healing Our Spirit developed a short, two-page, questionnaire, which examines knowledge, attitudes and beliefs about HIV/AIDS. The questionnaire is used throughout BC in community HIV/AIDS educational workshops hosted by HOS. Workshop participants complete the questionnaire at the beginning of each workshop. In most cases, a workshop facilitator reads out the questions and possible responses while the questionnaire is being completed. This reading is done to accommodate differing levels of literacy. The facilitator gives personal attention to a workshop participant (hence compromising confidentiality of responses) only if the individual participant requests assistance. This assistance is an uncommon occurrence, and for the vast majority of completed questionnaires, the responses can be considered self-administered and confidential. In total, the questionnaire contained 27 questions and took approximately 10 minutes to complete. Data for the analysis presented here comes from 1304 questionnaires completed over a 3-year period spanning 1996 to 1998.

In order to examine attitudes and/or beliefs towards HIV and AIDS, responses to four specific statements were aggregated to construct a new variable. The specific statements used are:

- People with AIDS should be allowed to attend pow-wows and other social gatherings?
- People who get AIDS through sex or drug use deserve the disease?
- People with AIDS should be allowed to work with food in restaurants?
- People with AIDS should be allowed to go to public school?

In response to each statement the participant is given a choice of five responses on a Likert scale. The continuum of response range from strongly agrees to strongly disagree. For questions 1, 3 and 4, a response of strongly agree is considered to be the most positive and strongly disagree is the most negative with respect to attitudes and/or beliefs towards HIV/AIDS. For question 2, strongly disagree is considered to be the most positive and strongly agree the most negative. For analysis, a new variable is created using an aggregation of the four responses.

Each of the five possible responses to each of the four statements above are coded from 1 (most positive response) to 5 (most negative response) and added to give an aggregate score domain of 4 to 20. A score of 4 is considered the most positive and a score of 20 the most negative.

This new variable is labeled BELIEVE. We elected to choose the mean domain score of 12 (i.e. half way between 4 & 20) for BELIEVE to divide the responses into a binary category of either positive or negative attitudes and/or beliefs towards HIV/AIDS. A score of 12 or more is deemed to represent negative attitudes towards HIV/AIDS, and a score of less than 12 is deemed to represent positive attitudes.

The new binary dependant variable was then used in a logistic regression analysis using STATA software (Stata Corporation, 1999)

The independent variables used included dummy variables for age categories, gender, and location of the workshop be it urban, rural or remote. For the later categories, the definition of location was decided using a Delphi panel, which included education and outreach workers from several Aboriginal HIV/AIDS organizations. Each workshop location was unanimously placed in one of the three categories. In general, Urban included major urban centres including but not limited to Kamloops, Kelowna, Nanaimo, Prince George, Vancouver and Victoria. Remote regions were areas that were at least two hours traveling time by vehicle or boat from an urban centre and away from any major highways. Rural communities were considered to be those within two hours ground or water transportation travelling time of an urban centre or slightly longer travelling time but with easy access to a good highway kept open throughout the year. A quick consensus was reached in categorizing each location. Age categories used were 10-15, 16-25, 26-35, 36-45, 46-55 and 56 and older. Dummy variables omitted from the model are those aged 26-35, women and those living in urban areas.

Missing data for some questions reduced the total sample number for the logistic model to 764. There is no significant difference between those in the sample who coded missing for BELIEVE and corresponding age categories (Pearson chi-square=0.431) and location categories (Pearson chi-square=0.388). There is a significant difference between those who coded missing for BELIEVE and gender where men were more likely to code missing (Pearson chi-square=0.002).

Results:

27.3% (n=209) respondents live in remote areas, 26.6% (n=203) live in rural areas and 46.1% (n=352) live in urban areas. 62.6% (n=478) of participants are women and 37.4% (n=286) are men. The mean value for BELIEVE is 8.41 (s.d. 3.19). The distribution of ages is shown in Chart 1. Most workshop participants (594/764) are between 10 and 35 years of age. The multivariate logistic estimate shows that respondents living in rural to remote regions are less likely to score positive attitudes (p=0.017 for remote & p=0.022 for rural). Men are less likely to score positive attitudes

($p<0.001$), and those in the 10-15 age category also are less likely to score positive attitudes ($p<0.001$). The full results of the Logistic regression are shown in Table 1.

Using the Odds Ratio for interpretation, men are a little less than half as likely (odds ratio = 0.4660) to score positive attitudes/beliefs. Those in rural and remote communities are a little more than half as likely (odds ratios = 0.5635 & 0.5527 respectively) to score positive attitudes/beliefs. Finally, those in the 10-15 age category were about one quarter as likely (odds ratio = 0.2579) to display positive attitudes/beliefs. No other age categories had an odds ratio significantly different than one; hence, significant differences in attitudes/beliefs among these other age groups are rejected.

Limitations:

The sample used for this study represents people who have chosen to go to HIV/AIDS workshops conducted by Healing Our Spirit. The sample is by no means stratified or random. The stigma, which surrounds HIV/AIDS and the voluntary nature of workshop attendance, makes it reasonable to assume the sample population does not necessarily represent the general population. Further, it is reasonable to assume that a self-selection bias exists in this sample population where attitudes and beliefs, a priori, are more knowledgeable and accepting of HIV/AIDS. Hence, attitudes and beliefs of sample respondents towards HIV/AIDS should be more positive than attitudes and beliefs of the more general Aboriginal population.

In this study, the average values of the variable BELIEVE is 8.41. This falls in the range categorized as positive attitudes towards HIV and AIDS (4 to 11 equals positive attitudes and 12 to 20 represents negative attitudes). Given the above discussion of sample bias, we argue one should be careful not to generalize the 8.41 figure to the broader Aboriginal population. If anything, this value represents a lower bound on the general rate of positive attitudes (remember, the lower this figure, the better the average attitudes and beliefs).

This bias does not alter the conclusions drawn in this paper. The primary finding is that significant differences in attitudes exist among different demographic and regional groups. Even with the sample bias previously discussed, significant differences in attitudes and beliefs have been identified. If the workshops attract those who tend to have better attitudes and beliefs towards HIV/AIDS, it is reasonable to assume that differences identified in this study would be equivalent or greater in the general Aboriginal population.

The sample here represents Aboriginal peoples living in various regions of BC. The results here may not be generalized to other parts of the country.

The non-response bias of men for the variable BELIEVE should not affect the conclusions if the men who are not responding have attitudes equal to or worse, on average, than men who do respond.

Discussion:

This analysis shows that men, persons living in rural and remote communities and persons between the ages of 10 and 15 are less likely to score positive attitudes towards HIV/AIDS. This result suggests a need for more educational programs in rural communities, and in particular programs that focus on men and adolescents.

A major difference between the results of our study and Myers et al. (1993) is that the average responses to the attitude questions were higher (more positive) than what we found. Because the instruments are different, these values are not directly comparable. Still, both methods involve creating a summary statistic from four similar questions. Given the methods used in this analysis, we would be hesitant to conclude that attitudes towards APHA in Ontario are better or worse than attitudes in BC. There is also the consideration of time. We do not know if change of attitudes within a community is linear with time. As a community comes to terms with HIV/AIDS from a point of initially hearing about the disease, it is possible attitudes worsen before they get better. This phenomenon may be especially true if a period of poor or mis-information exists prior to receiving better information through various educational sources. To our knowledge there are no longitudinal studies, which address these issues among Aboriginal communities.

Another difference is that we find that the attitudes of women are better, on average, than men. We also find no difference between any of the age categories above 16 years of age. An interesting point is that before multivariate analysis, those above the age of 66 had significantly worse attitudes than younger groups; however, after controlling for gender, this relationship fell away. The poor attitudes of older men were creating an apparent age effect when there was only a gender effect. Other than a significant difference in attitudes by gender, the results of this study are not inconsistent with the related findings in Myers et al. (1993).

HIV/AIDS education programs in Aboriginal communities are important both for prevention and for care, treatment and support. If fear, misinformation and stigma shroud HIV and AIDS within the community, it prevents the community from dealing effectively and openly with the disease. As a consequence, the virus has a better chance to spread.

Individuals may be less likely to test for HIV, and those living with HIV may be less comfortable disclosing their status to others. Basic information which helps protect those at risk from infection, for instance using barriers during sex, using new needles or learning how to safely clean needles etc., may not be discussed or supported within the community. As a result, little good information and/or a lot of misinformation about HIV/AIDS can persist within the community. A lack of such information can also help harbor fear and misunderstanding about the disease.

Further, if stigmas or fears of violence toward those who are HIV positive are especially strong, the short-term personal consequences of revealing one's HIV status might outweigh the risk of potentially putting others at risk. Hence, people living with HIV might engage in risk activities and feel prevented from letting others know they are HIV positive. If HIV can be openly discussed in the community without repercussion, this scenario is largely mitigated.

Education has a tremendous impact on the quality of life for those who are living with HIV/AIDS. For those people familiar with HIV/AIDS, knowing you cannot get HIV through the air or water may not be news. Still, information at this basic level is not commonly known in some communities (Red Road, 1999). Simple things such as letting people know it is okay to hug or kiss people who have HIV or AIDS can make an important improvement in the lives of both the person who has HIV or AIDS and their friends, family and neighbours. Other issues, such as discrimination towards Two-spirit Aboriginals, are also important components of HIV/AIDS related education. A safe and well-informed environment is a crucial foundation necessary for those living with HIV to receive quality care, treatment and support.

Many Aboriginal people still feel that they could never return to their home community because of the stigma that HIV/AIDS continues to hold. Often, APHA want to return home but feel they cannot because of the shame they would bring to themselves and their families and/or because the feel they will not be accepted by the community. As a consequence, they spend their last living days far from the place they really want to be, their home community. This situation is part of the current tragedy of HIV and AIDS among Aboriginal peoples (Report of the Royal Commission on Aboriginal Peoples, 1996; Red Road, 1999).

Taken together, we see that the ability of a community to respond to HIV and AIDS in an informed, caring and compassionate way will help prevent new infections and allow for the provision of better care, treatment and support for those who are living with the disease. Increased, and appropriately targeted, education programs will help build capacity within Aboriginal communities so that they can better respond to the many challenges of HIV and AIDS. This study provides HOS with more information to better wage the battle against HIV and AIDS. From this research, HOS will be better able to target its current educational programs and to develop new programs. HOS can also approach potential funders with sound research which supports ongoing and increased funding for education targeted at men, the young and those living in rural and remote regions of BC.

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Appendix A: Table 1 & Chart 1

Table 1: Results of Logistic Regression

Independent Vars	Odds Ratio	P>|z|	[95% Conf. Interval]	
gender	0.4660	0.0000	0.3112	0.6976
remote	0.5527	0.0170	0.3393	0.9004
rural	0.5635	0.0220	0.3445	0.9216
age 10-15	0.2579	0.0000	0.1406	0.4732
age 16-25	0.6162	0.1110	0.3395	1.1181
age 36-45	0.9681	0.9370	0.4353	2.1533
age 46-55	0.8257	0.7050	0.3061	2.2274
age 56+	0.4807	0.2980	0.1211	1.9089

Section 5

Two-Spirited People

A Historical Overview of Two Spirited People: A Context for Social Work and HIV/AIDS Services in the Aboriginal Community

Céleste Le Duigou, M.S.W.

Introduction

This paper is divided into two sections. Part One, "The Historical Record," will describe several areas of interest regarding the legacy of two-spirited people of the First Nations and how this legacy interacts with modern circumstances, specifically, the HIV/AIDS crisis which began roughly in 1981. First, I will discuss the historical record of two-spirited people of the First Nations. Second, I will discuss their suppression and oppression by both religious authorities and state policies which were patriarchal, assimilationist, and genocidal in nature. Finally, I will discuss how these policies serve to magnify the intensity of the AIDS crisis for Aboriginal Communities today.

In Part Two, "What is Happening Today?", I will examine how homophobia and AIDS-related stigma impact upon two-spirited people, provide some statistics on the prevalence of HIV disease/AIDS in the Aboriginal community, as well as suggest the most appropriate role for the social worker as an ally.

Part One: The Historical Record

The definition of *winkte*[1] is a physical male who is non-masculine and does not fulfil the standard male role, sometimes referred to in anthropological and historical documents as *berdache*. He is better described as androgynous than effeminate and he holds a social position that is clearly defined and recognized. The role of *winkte* is in no way synonymous with the modern Western categories of homosexual or transsexual. Homosexuality is defined in opposition to heterosexuality, and

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[1] Berdache is a term which came originally from European colonizers in North America, from the Persian *bardaje*, then migrated to Italy as *bardasso*, and Spain as *badaxe*, or *badaje*, and then appeared in France in the 1600's as *bardache*. In two dictionaries it is defined as "a young man who is shamefully abused", or "a young man who serves another's succubus, permitting sodomy to be performed upon him." (Williams, 1992, p.9) As many two-spirited people find this term offensive and inaccurate, and there are as many terms for what anthropologists call *berdache* as there are tribes who have them, for the sake of clarity I will use the Lakota term *winkte* as a generic term.

transsexuals, unhappy with their gender, feel trapped in the wrong body, and change it through technology to identify completely as the other gender. *Winkte* is a third gender role, which incorporates aspects of both the female and male role, turning difference into an advantage for the community.

Winkte existed in the majority of aboriginal societies before contact with Europeans, from the Colombia highlands to Aleut, Alaska. Many anthropologists believe that the wide distribution of this social phenomenon indicates its antiquity. *Winkte* were prevalent in four areas; the Prairie and Great Western Lakes, the northern and central Great Plains, and the lower Mississippi Valley; second, in Florida and the Caribbean; third, in the Southwest, the Great Basin and California; and fourth, scattered across areas of the Northwest, Western Canada, and Alaska. There is no written historical record in the eastern North America, with the exception of Florida. (Williams, 1992) Sue-Ellen Jacobs, of the University of Washington, researched the prevalence of two-spirited people in Native American tribes, and of 99 tribes, there was mention of them in 88, and additional 19 references to two-spirited women. In 21 tribes, there is mention of specific offices: in 12 they were medicine people or shamans, in Illinois, Cheyenne and Crow societies, they fulfilled special ceremonial roles, in 3 they had a special funereal function, and for the Winnebago, they were oracles. (Deschamps, 1996) The early explorer Jacques Marquette noted that among the Illinois and neighbouring tribes, "berdaches were present at all of the solemn ceremonies of the sacred Calumet pipe: 'They are summoned to Councils, and nothing can be decided without their advice. Finally, through their profession of leading an extraordinary life, they pass for Manitous–That is to say, for Spirits-or persons of consequence.'" (Williams, 1992, p.17) They were renowned as excellent weavers, potters, beadworkers, and matchmakers.

The Navajo believed that *nadle* were shamans with exceptional chanting abilities, that they had the power to cure illness, insanity, and were of great help during childbirth. Among the Lakota, they were responsible for medicine, childbirth, and love advice/potions. The Cheyenne always took a *he man eh* along with war parties to care for the wounded because they were seen as both gifted in healing and stronger than either a man or woman. (Williams, 1992) They are often seen as more powerful than mere mortals, as this tale from 1801 of the Saulteaux Ojibwe in Manitoba demonstrates: 'Ozaw-wen-dib' (Yellowhead), as his people knew him, single-handedly held off a Lakota Sioux war party and saved all of his people. When his band was attacked, he told them to find safety and leave him to take care of the Sioux "as he feared no danger. He then faced the enemy and let fly his arrows." (Deschamps, 1996, p.17) The Saulteax often spoke of his bravery. In the Ojibwe language, he was called *ogokwe*, or "wise woman". (Deschamps, 1996) [2] In Hidatsa oral history, there is a story of the famous and respected warrior Four Bears, who, with his raiding party, made the mistake of attacking an Assiniboine Sioux *winkte*. He said to Four Bears, "You can't kill me because I am holy. I will strike coups on you with my digging stick" [a female implement]. (Williams, 1992, p.38) The *winkte* then chanted a magic song and began to chase the warriors, who were struck with fear and ran for their lives. Four Bears shot an arrow at him, but it bounced off, which lead him to believe in his supernatural powers. As Four Bears had been successful in his past raids, and as he did not wish to jinx this one, he cancelled the party. The hero learned his lesson, which was that *winktes* are powerful, and you had better respect that power or suffers the consequences. Similarly, Prince Alexander Maximillian, of Weid, Germany, told a story from the Northern Plains Indians, whereby a warrior once attempted to force a *winkte* to dress as a man, which he refused. The warrior tried to shoot him with an arrow, but the *winkte* cheated death by turning into a pile of stones. Likewise, among the Mandan, there is a myth that once their people tried to force the *mihdacke* to give up their special status and dress, and the spirits punished them with death. No Mandan ever interfered with a *mihdacke* from this point on. (Katz, 1976)

How did one become *winkte*? The most commonly offered explanation is that the role is a natural one for the boy's own individual character, which is more feminine than that of other boys. For the Navajo, who greatly value individual freedom, the child's own behaviour is the guide as to whether or not they become a *nadle*. The Zapotec Indians of Oaxaca, Mexico would never consider that a berdache has chosen to live as he does and defend their *ira'muxe* by the belief that "God made them that way." (Williams, 1992, p.49) It is this emphasis on the person's character or spirit that is one of the most important elements of *winkte*.

Some tribes believe that the characteristics are evident from birth, while others believe that they are not evident until the ages of 3-5. Fine features, a soft voice, and a preference for cooking and cleaning are all signs, and even if the child is exhorted to hunt or play war games, they resist. (Williams, 1992) The family changes to accommodate the child and not vice versa.

Ceremonies and tests existed to see if the child would grow up to accept the role. The Mojave lead the boy, aged 10-12, into the middle of a circle of his kin and neighbours, and a hidden singer would sing a song to

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[2] There are numerous parables, which serve to encourage respect for *winkte*. The following three are obviously cautionary tales; that no intelligent person should ever try to coerce a *winkte* or interfere with their spirit as only folly and calamity would ensue.

which only women dance to. If the child begins to dance, and he does so for four songs, he is accepted as *alyha* and given a skirt and a new name.

Other tribes interpreted the imagery young men saw on their vision quests. A white buffalo calf, or a double woman symbol seen in the sky, would confirm their status as *winkte.* (Williams, 1992)

How is it that societies differ so wildly on issues of gender variations and sexual mores? Sexuality is not only a biological imperative necessary for reproduction but also an ever-varying historical construct dependent upon both the modes of production and prevailing social and political realities. (Foucault, 1998) Why is it that Western societies persecuted and vilified those who transgressed boundaries of sexual orientation and gender role expectations, while, for the most part, Aboriginal societies were fairly relaxed about both? The organization of European societies necessitated patriarchal family relations and the clear demarcation of genders into hierarchical binary opposites, while the organization of Aboriginal societies did not. Some societies recognized up to five different genders. (Jacobs, 1968)

Generally, cultures deal with variation in two different ways. They attribute powers to that which they do not understand, either by assigning negative powers, like pollution, witchcraft, or sin, or by sanctifying that which they do not understand (Williams, 1992). While feudal Europeans regarded homosexuals or different genders as possessed by the devil, Native people regarded them as mediators between the spiritual and physical worlds.

Native sex and gender systems were totally different from those of Europeans. The morphological body always equals gender role; heterosexuality is viewed as compulsory, and behaviour leads to classification. (Whitehead, 1993) It is part of a worldview, which prefers dichotomies to ambiguities. In Aboriginal societies, a person could engage in same-sex behaviour and not be reclassified, and an Aboriginal man could have sex with a *winkte* without being considered gay, or even less than manly.

The Colonial Process and the End of Diversity

The colonizers of the New World came from patriarchal, religious monarchies where there was no separation of Church and State. Because of this background, they held racist, sexist, and heterosexist ideas. No one would contest this fact. Yet, it is a mistake to assume that they were informed only by these ideas as we look at their actions as they tried to reshape Native people's values in their own Christian image. Their ideologies were based upon economic, political, and religious systems from their homelands, and they sought to recreate the same kind of society in the

New World. Consider the following passage, an example of a common historical fallacy:

> Many years ago explorers came to this great country looking for something that they were not to find. There were no gold or jewels littering the countryside. This land was certainly not the short route to the "Orient". *Nothing could validate their expeditions except conquering people with cultures that were open, friendly, and focussed on living a good, communal, way of life.* (Sanderson, 1997, p.1)

The Spanish, French, and English did not come to North America to conquer Natives, steal their culture and force religion down their throats. Instead, they wanted to exploit the New World for any wealth it could provide. The inseparable Church and State were interested primarily in the primitive accumulation of capital for the metropole. The existence of Native people was an obstacle to this goal.

The violent suppression of *winkte,* and the ideas, which legitimated it, has its roots in the history of 16th century Spain. This suppression was also connected to the patriarchal suppression of the rights and status of Aboriginal women. It flowed from the feudal mode of production as well as social and political realities of Spain at the time. (Williams, 1992)

The Spaniards had been engaged in seven centuries of war against the Moors, who were superior in technological, intellectual, artistic, and cultural realms. The Moors also had very relaxed views about homosexuality, which the Castillian monarchy and religious authorities railed against. For propaganda purposes, the Spanish needed to differentiate their culture from that of the Moors, and "religious fanaticism sustained them in their struggle to drive" them out of Spain. (Williams, 1992, p.177)

In addition, they needed to repopulate their nation because they had lost 50% of their population to the bubonic plague, and the protracted war against the Moors had further depleted their numbers. This loss led to a pro-propagation, anti-non-reproductive sexual act (sodomy) stance. Sodomy was a crime more nefarious than murder and less serious only to heresy and insulting the King. (Williams, 1992) Considering these circumstances, in the Pre-Enlightenment era, the fanatical persecution of same-sex behaviour makes a certain amount of sense. In most European countries, there were mass executions of men suspected of sodomy, so-called witches, and heretics (non-conformists).

It follows then that "The condemnation of Indian homosexuality was a major factor in proving the virtue of the Spanish conquest, and the conquistadors acted resolutely to suppress it by any means necessary." (Williams, 1992, p.136) The fact that Indians were "sodomitic unlike no other generation of men"[3] was justification enough to kill them without hesitation. Spanish officials lavished praise upon Vasco Nuñez de Balbao, who saw in Panama "men dressed like women; Balbao learned they were sodomites and threw the king and forty others to be eaten by his dogs, a fine action of an honourable and Catholic Spaniard." (Williams, p.147)

There began a systemic process of the destruction of *winkte* by the church and civil authorities, who mandated compulsory heterosexuality, and promoted patriarchal family relations. (Cannon, 1998) Where women suffered a loss in social status so did *winkte,* because their esteemed position was inextricably linked to the high status of women. Many Aboriginal cultures regarded men as possessing only half of the characteristics necessary to attain full humanity, while women possessed all of them. Therefore, *winkte* were seen in their communities as incredibly powerful because they held all characteristics and then some; in contrast, Europeans felt *winkte* were crazy to give up their male privilege to debase themselves in such a cowardly fashion. (Williams, 1992)

The earliest missionaries went to the Americas at the behest of European states to "civilize" the Native population along Christian and patriarchal lines. Same-sex eroticism and gender flexibility was condemned. The earliest missionaries expressed horror and disgust at the sight of men in women's clothes. They described *winkte* as "men cowardly enough to live as women...they believe they are honoured by debasing themselves to all of women's occupations; they never marry." (Jesuit Joseph François Lafitau, 1711-1717) Another Jesuit, Jean Bernard Bossu, (1751-1762) described Aboriginal people as "morally perverted and addicted to sodomy" (Whitehead, 1993). The discovery of 'moral perversion' among indigenous people and of their 'savage and heathen sexuality' provided the perfect justification for killing, subduing, and ultimately regulating the population by confining them to reserves.

Christianization by missionaries was part of the cultural genocide; it destroyed Native religion and replaced it with one based upon hierarchy, which paved the way for the introduction of patriarchal gendered domestic relations.

In any case, both early colonialists and religious authorities knew that *winkte* would not survive the pressures brought to bear upon them, and that the agent of their destruction would be the church. Near Santa Barbara in the 1780's, priests were horrified at the "nefarious practices of the *Joyas*, and placed their "trust in God and expect that these accursed people will disappear with the growth of the missions. The abominable vice will be

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[3] Spanish chronicler Lopez de Gomara - the year 1519

eliminated to the extent that the Catholic faith and all other virtues are firmly implanted there, for the glory of God." (Williams, 1992, p.139) Indeed, by the 1820s, *Joyas* had been eliminated or driven underground to such an extent that a missionary at San Juan Capistrano was able to report to his superiors that even though *Joyas* were once numerous among them "at the present time this horrible custom is entirely unknown among them." (Williams, 1992, p.139) These men were so full of righteous morality, given the blessings of their mother countries, it never occurred to them to leave Native people in peace with their customs intact.

The Church and State went hand in hand, pushing forward onto new frontiers, settling new lands. In Canada in the 1930's, they established the reserve system with the intent of settling Indians into British agricultural and Christian patterns of behaviour. (Frideres, in Whitehead, 1993) The American Allotment Acts of 1887, and the Indian Act of 1876, gave land only to male heads of households, which guaranteed that *winktes* could not own land, and the ban on Native religions guaranteed that *winktes* lost their social status gained from their ceremonial roles.

The Indian Act enshrined marriage as the only means by which Indian status could be conveyed, which effectively legislated compulsory European heterosexuality for First Nations communities that wished to be recognized as legal entities. The sole recognition of patrilineal descent eroded matrilineal traditions, the position of women, as well as that of *winktes.* In 1852, the government further institutionalized patrilineal descent by giving Native people the power to police each other in sexual matters. People doubting the legitimacy of any band member were encouraged to contest their status as Indians by reporting their suspicions to the Indian agent. (Cannon, 1998)

Indian agents in both Canada and the United States cut the hair of *winktes* and forced them to wear men's clothes. One community in Montana has a living testament as to what Indian agents did to Osh-Tisch, the most venerated *badé,* and others like him. Bristow, the agent in the 1890's, incarcerated all of the *badé,* cut their hair, forced them to wear men's clothes, and perform manual labour; planting saplings. Surrounding the Department of Indian Affairs in Montana is a huge ring of oak trees, which grew from the saplings, and the community still remembers why they grow there.

Nadles discovered in missionary schools were forced to change, and the influence of religious teachings caused *winktes* everywhere to lose the respect of their communities. (Whitehead, 1993) Christianized Sioux ostracized *winktes,* and they were not allowed burial in the local cemetery, which had become Christianized. Missionaries taught the Sioux that instead of giving a family good luck and wealth, *a winkte* was an omen of misfortune and would hasten their downfall. Communities responded either by eliminating the tradition entirely, or by shielding them by removing their presence from the scrutiny of religious and civil authorities. (Whitehead, 1993) These processes were replicated all across the New World, anywhere Native people with this tradition came into contact with religious proselytizers backed by the power of civil authorities.

The State and Church were very successful at introducing homophobia into Aboriginal communities, which honoured and respected *winkte*. Those who were acculturated into the Christian religion turned on them, and many ran away or committed suicide. (Williams, 1992)

Part Two: What is Happening Today?

The tradition of *winkte* was almost entirely eliminated although some elders and traditionalists still carry with them first hand knowledge of their people's teachings on the subject. Some people believe that homosexuals are "evil, diseased, criminal, god-awful, and going straight to hell" (Ogilvie, 1999), and children who come out to their parents often face this attitude. If the child is lucky and their grandparents still retain the traditional knowledge, they will pull them aside and tell them how "people like them worked closely with medicine men." One young gay man said "what she [his grandmother] told me made all of the difference in my acceptance of myself. She said that many of the holy men were gay and it was totally acceptable. They were almost seen as belonging to the tribe as a whole, that is, kin to everyone." (Williams, 1992, p.225)

In many ways, the cultural renaissance and new pride in traditional teachings occurring among Native North Americans has been a great advantage to young gay men coming out to their families and communities. A woman describes the process for her cousin, who is half Lumbee and half Navajo, who came out in the late 1960's. The Lumbee side of the family was very Christian, while the Navajo side held traditional spiritual beliefs. The Lumbee side "condemned the cousin, but the Navajo side was supportive. The Navajo grandmother told the children not to be upset because their respected great-uncle, a *nadle*, was 'also like that.' The grandmother saw *nadle* and *gay*, in their essence, as the same." (Williams, 1992, p.225)

With the collapse of Native spirituality in many communities, Christian taboos took hold and isolated many gay Native people from their communities. The homophobia that exists is not organic; it has no basis in the traditional culture of Aboriginal people.

Marcel Dubois, an AIDS educator at the Native Friendship Centre in Montreal, states "[t]he evidence suggests that homosexuality was considered okay in many Native cultures traditionally ... but many Natives have adopted the Judeo-Christian framework, and therefore, have embraced homophobia." (Hays, 1997, p.18) Billy Merasty, a gay Cree actor from Brochet, Manitoba, laments the homophobia he sees in his community, saying, "we like to talk about how Native Communities are more tolerant than other nations. Of course no-one mentions the gay youth being chased out of town, or the man who died of AIDS who wasn't allowed to be buried in the community cemetery." (Morisseau, 1996, p.25) For Dubois, the biggest barrier to developing a support group for two-spirited people was the homophobia in Aboriginal communities. "I've heard of cases of some gay men actually chased off the reserve by people with rifles;" he notes that it often forces gays and lesbians to escape to urban centres like Montreal. "Others [who stay] have their tires slashed. The gays who are effeminate, the ones who can't hide it, are really screwed." (Hays, 1997, p.18)

For Aboriginal gay men, there is little support, and in addition, they may not be welcome in mainstream gay (mostly white) organizations or agencies because of racism. Danny Maxwell[4], an Aboriginal man who is HIV positive, has heard at such organizations, "Oh, look at the Indian. I wonder where his bottle is." (Maxwell, 1999) White gays and lesbians have more resources available to them, and Aboriginal people are both poorly represented and invisible in the gay community. (Ogilvie, 1999)

There is much interlocking oppression, which have an impact upon two-spirited Aboriginal men. Class racism and homophobia all work together to confer unequal access to resources for Aboriginal people. Unemployment and poverty impact negatively upon the physical, psychological, and spiritual health of Aboriginal people, along with the damaging psychosocial effects of racism (stress in particular).

For two-spirited Aboriginal men, racism combines with homophobia to create barriers to accessing health care. Forty-eight percent of two-spirited men surveyed by the Canadian Aboriginal AIDS Network (CAAN) felt that mainstream hospitals and health clinics were disrespectful of their culture and lifestyle. CAAN also found that because of the difficulty in accessing non-judgemental services geared towards Aboriginal people, they present much sicker than non-Natives when they finally do get treatment.

Moreover, homophobia increases the likelihood of contagion of HIV disease in the community through two rivulets of the same stream. First, the attachment of a stigma to AIDS as a gay disease causes people to think they are not at risk. Secondly, the lack of self-esteem (created by internalized oppression) among men who have sex with men (MSM) encourages risk-taking behaviour.

Risky or unprotected sexual behaviour is the main route of transmission of HIV in Canada. When you write about HIV disease and

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[4] A pseudonym

AIDS in the Aboriginal community, you have to talk about men who have sex with men, because "the fact is, 80% of native cases of AIDS involve gay or bisexual men." (Hays, 1997, p.18)

Internalized homophobia caused by both societal prejudice and rejection by one's family and community can express itself in many ways: feelings of isolation, depression, fear, loneliness, substance abuse, shame, guilt, or ultimately, suicide. (Vanderhoef, 1998) For two-spirited Aboriginal men, these are all psychosocial factors which can result in a kind of carelessness regarding protecting themselves from injury (RCAP, 1996) or HIV infection. Recklessness and potentially self-destructive behaviour may be caused or triggered by the powerful emotions of grief, anger, and hopelessness (RCAP, 1996): "If you don't feel good about who you are you don't feel you have the right to say, 'Excuse me, I'm going to protect my body' [with a condom]...and if you live on the streets, and somebody comes along and gives you some love and comfort and says, 'Sorry, I don't want to use one', you say O.K." (Ogilvie, 1999)

Prevalence of HIV and Aids in the Aboriginal Community in Canada

The status of the incidence of HIV/AIDS in the Aboriginal community is unclear due to the lack of accurate and comprehensive statistics available. At testing sites (doctor's offices, health clinics, hospitals, and nursing stations), data collection about ethnic origin is inadequate and there is a low rate of testing in the Aboriginal community. There is a lack of Aboriginal specific testing sites, a lack of awareness of those that exist, and two-spirited people tend to have a more transient lifestyle than heterosexual Aboriginal people.

What the available data shows is that 72.8% of Aboriginal people who test positive are men who have sex with men, (MSM) and younger than non-Aboriginal cases (29.8% vs. 18.6% diagnosed >30 years of age). Prevalence among Aboriginal people ranges in a variety of settings and populations. Among the Vancouver population of Native alcohol and drug treatment centres, inmates, and needles exchange users have a rate of infection between 1.4% to 2.5%. In an Alberta STD treatment clinic, the rate is 2.1%, and among those on six Ontario reserves *who have been tested for the virus,* the rate of infection is 7.9% (Health Canada, 1998): "First Nations people made up for just 5% of British Columbia's population but accounted for 16% of new HIV infections. About half of the new infections were found in the 30-39 age group, and Aboriginal women make up 40% of new HIV infections (compared to just 17% among non-Aboriginal women). The task force also found that Aboriginal people with AIDS die sooner than non-Aboriginals." (CAAN, 1999)

Aboriginal people appear to be more vulnerable to infection. "The overall health of Aboriginal people is poorer than that of non-Aboriginal people in Canada, suggesting that they have weaker immune systems in general." (RCAP, 1996) The high degree of mobility from rural to urban communities is also a significant consideration, as even the most remote reserves are vulnerable to the spread of HIV/AIDS. Rates of infection are falling off for all other groups, yet they are still rising in the Aboriginal community, which suggests a time lag in the dissemination and acquisition of knowledge of prevention methods and the shifting of attitudes between them and other groups.

AIDS-related Stigma, Symbolic AIDS-related stigma and Risk Groups

Homophobia is a factor which not only affects two-spirited people negatively but one which puts the entire community further at risk for HIV/AIDS. The extreme public response to the disease is called AIDS-related stigma: the stigmatization, prejudice, and fear of those who carry it. This stigmatization leads to polarization of men who have sex with men and heterosexuals from each other. The two aspects of AIDS-related stigma are fear (coupled with ignorance) of the disease, and the fear and hostility expressed towards those most affected by, and seen as responsible for spreading it. Related to this stigma is *symbolic AIDS-related stigma,* whereby there is transference of fear and anxiety about the disease to those who it hits hardest: gay men, IV drug users, sex trade workers, and Haitian immigrants. There now exists, in many people's minds, a permanent association between gay men and AIDS, which reinforces homophobic attitudes. People cling to these symbolic representations because it is easier to see HIV disease as belonging to 'hookers and fags' than as a disease which does not discriminate among groups of people. (Herek, 1990)

In the Ontario AIDS and Healthy Lifestyle Survey, 3000 Aboriginal people from six reserves across the province were queried about their safe sex practices and knowledge of HIV/AIDS. One question was "considering all of the different factors that contribute, what are your chances of becoming HIV positive?" Only 9.2% felt that they had 'some chance' of contracting the disease, while 71.9% felt that they had absolutely no 'chance' at all. Only 18.9% felt that their chance was 'small'. (Myers et al., 1996) The largest group, which feels they could never contract the disease, do not see themselves as belonging to a group that can be affected by AIDS. It is clear that they hold on to symbolic representations of the disease; 81.4% of the respondents in the aforementioned survey felt that AIDS is only a problem for men who have sex with men and those who share needles. (Myers et al., 1996)

Another practice which clouds the issue of who is at "risk" is the use of the epidemiological term, "risk group". This term, used in the press, gives the impression that members of that group have a greater risk simply by virtue of their membership in it. It does not focus on the behaviour, which leads to the transmission of HIV. The use of the term "risk group" leads people to believe that they are safe(r) for not belonging to that group and that they are less obliged to protect themselves and their partners. Furthermore, members of "risk groups" are marginalized and stigmatized, especially when contrasted to other groups, such as the 'general public', or, 'innocent victims'. (Herek, 1990)

Because HIV and AIDS are so closely associated with gay men, they are often seen not only as unnatural, immoral, and as abominations against God, but also as depraved carriers of disease as well. Disease = depravity and health = virtue is in the minds of many people. Tonie Ogilvie, former head of the AIDS prevention programme at Anishnawabe health, has often observed homophobia in Aboriginal organizations. When she suggested that a group of workers from an un-named organization do outreach at Church and Wellesley (the gay neighbourhood in Toronto), one of the volunteers spat out, "No way! I'm not going down there and touch those dirty faggots!" (Ogilvie, 1999).

Some reserves are in a state of denial with leaders who claim that "'It's a white man's disease', or that 'We don't have a gay problem on our reserve', or that 'It's something that only happens in big cities'". (Vanderhoef, 1998, p.26) It does not help that in most Native languages, there is no word for HIV or AIDS; the closest word to it in Saulteaux Ojibway is *akuusah*, or sick. (Maxwell, 1999)

Homophobia has increased both the promulgation and the application of AIDS related stigma to men who have sex with men to the detriment of everyone living in Aboriginal communities. Studies of adolescent youth show that increased levels of homophobia are associated with less perception of being at risk as well as less precautionary behaviour (for both genders). (Deschamps, 1996)

The Most Appropriate and Effective Role for a Social Worker and Ally

For a social worker dealing with the Native community or individuals, the most appropriate role is that of an ally. An ally does not claim to know what's best because they are an expert in the field or because they have taken a Native Issues course. An ally neither imposes solutions from above, nor assumes that people who are oppressed do not have the skills necessary to generate their own solutions. An ally will try to learn about the history and traditions of Native people but will not use that knowledge to try and impress them with her superiority. An ally will consult and not direct, will ask and listen to the response, and will assume that the people s/he is working with are experts in their own lives and communities.

AIDS has devastating effects on individuals, communities, and families, and there is an urgent need for prevention and education work by social workers and other health care professionals. Whether they are working with individuals or communities, they should act as both an advocate and an ally at the macro (policy) level. Decisions made at this level affect the health and viability of whole communities, and they need to be shaped by the communities themselves – with leaders, elders, women, youth, educators, two-spirited people, heterosexuals, and anyone who wishes to be at the table: "Community participation is of the utmost importance, particularly in First Nations communities, to ensure the successful implementation of culturally appropriate programmes. In the past, research was conducted without community input, resulting in feelings of loss of control over process and outcome, and lack of ownership." (Myers et al., 1996, p.3) A social worker should take the cue from Aboriginal health and AIDS prevention organizations as to what their goals, priorities, and needs are, as well as their vision of process and outcome.

There is a well-founded belief that culturally appropriate services are not only more accessible but also more effective. Eighty-six percent of 126 Aboriginal intravenous drug users agreed that culture is important when dealing with HIV/AIDS, and seventy-nine percent indicated that they would use an Aboriginal-specific service for HIV testing and HIV/AIDS information if one existed near them. Some of the reasons were: "It brings the community together"; "To have someone who shares the same social background and similar experiences and belief system means some unsaid communication can begin healing the spiritual hurt that is part of HIV."(CAAN, 2000)

A social worker should advocate for and help to plan the expansion of anonymous testing sites. The establishment of these sites is of the utmost importance, especially in rural and remote areas. (CAAN, 1999, p.5) One barrier to people being tested is that testing sites are often not as anonymous as they should be due to the internecine nature of the community. Usually, Aboriginal communities are small, which makes it difficult for people to assume the cloak of anonymity; especially if they access services targeted to Native people: "Here, [in Toronto] everybody knows everybody. Everyone is related somehow." (Ogilvie, 1999) A nurse processing coded HIV tests at Anishnawabe Health stumbled across a positive test for someone whom she knows. (Ogilvie, 1999) This breach of confidentiality should not happen, and when the stakes are as high as being shunned by your family/peers/reservation, this set-up is a powerful disincentive to finding out the truth about your HIV status. Testing must also be accompanied by effective pre- and post-test counselling. (Myers et al., 1996) On the reserve, the secretary or nurse at the health clinic who codes or files your results could be a neighbour.

Maintaining confidentiality was one of the most important establishing principles of the bi-weekly outreach HIV and STD testing clinics of Beardy's and Sandy Lake First Nations: "The clinics are not part of the Band or Tribal Council's operations. They are staffed by employees of the provincial Prince Albert Health District and funded by the Government of Saskatchewan." The clinic is housed in another building and testing results are kept off site, the key to gaining the trust of the community. Outreach workers and nurses provide condoms, counselling, and referrals. Over the past two years, the workers have built up credibility in the community, probably because the relationship between the Community Health Representative, reserve staff, and "nurses has been very good. As one brief report states, 'Crucial to the success of the program, is trust in the individuals providing the service along with strong community commitment, cooperation, and ownership.'" (CAAN, 2000)

Funding for education must increase; almost all concerned with the issue are in agreement concerning this need. Where the need is particularly apparent is on the reserves (Maxwell, 1999). Furthermore, it should not target only youth, who are assumed to be the most at risk as a result of youthful carelessness, because the cohort among which rates of HIV infection are rising the fastest is the 30-50 year old cohort. (CAAN, 1999) There are so many myths which need to be cast aside, and they can be held by anyone from teenagers to elders: for example, there is no gay problem on the reserve; you cannot catch it if you have a small penis; you can catch it from your sisters tampon box if she sleeps around a lot (Ogilvie, 1999), or only gays and junkies have to worry about it. (Myers et al., 1996) Because many two-spirited people divide their time between the reserves and urban centres, trusted and effective services need to be established in both places.

In addition, education should not be conceived or implemented as a one shot workshop, or even as a permanent education programme alone because "it is clear from the social nature and causes of disease among Aboriginal people that prevention cannot be limited to education and behaviour modification. Long-term strategies must address community norms for safe and careful activity, and, more important, the broad social conditions that promote recklessness and lack of self-care." (RCAP, 1996)

Education programmes should not be narrowly and individually targeted because there are so many co-factors, which lead to risky behaviour, such as "poor parenting skills, alcohol and drug abuse, emotional, physical, and sexual abuse, and historical abuse through the residential school system." (CAAN, 1999) The issue of self-esteem is so closely linked to the historical and contemporary oppression of Aboriginal people that it must be a component to effective prevention. As one elder said, "we need to deal with [it] to help our people want to protect themselves...This is not an individual programme, but one of community development." (Myers et al., 1996)

Education programmes need to be age/language/gender/and culturally appropriate. Because men aged 17-40 is a group difficult to reach in some communities and is a group more reluctant to seek out health information, in some communities, information is distributed at hockey games. Linguistically, certain risky sexual acts do not have clear descriptors in Native languages, so special attention must be given to clarity with the design of Aboriginal language material. In some communities, television may be the most effective medium of communication, for others, radio or perhaps a general community meeting. Flexibility is the key to effectiveness. (Ontario Ministry of Health – AIDS Bureau, 1994)

Social workers and activists need to work together to fight for consistent core funding (as opposed to one-shot project funding) which is needed to continue the work being done in the area of preventing the spread of HIV/AIDS in the Aboriginal community. Despite the fact that the HIV/AIDS prevention programme at Anishnawabe Health is serving an obvious (even glaring) need in Toronto, every year it must re-apply for funding from the Department of Public Health. This once a year distraction interferes with the day to day work of the organization. Unfortunately, the programme has been scaled down considerably for next year, and after that, who knows? At least the federal government has increased funding to fight and research AIDS over the years and has recently allotted 1.2 million dollars towards urban and off – reserve initiatives for Native people. Given the hot potato dance that the federal government performs every time the issue of responsibility for Aboriginal health comes up, this funding increase is a positive sign.

Healthy communities are inclusive communities, and one that is welcoming and non-judgmental towards two-spirited people who are living with HIV/AIDS can make all the difference in an individual's life: "My reserve has been really good. Everyone treats me as I was before. It's just another disease that we have to deal with. It's very comforting that I don't have to struggle with a lot of different things; the ignorance. All my other friends from the other communities treat me the same. I've been pretty lucky, I think. I feel lucky because of that." (Vanderhoef, 1998, p.336)

It is hard to imagine how wounded two-spirited people living with HIV/AIDS feel when they are rejected by their communities, and on top of this rejection, some of them are not even allowed to be at home to die with their families and people who love them at their side: "A lot of people, when they're gay, get ostracized or pushed away by the community. They know damn well what's going to happen when they come out of the closet, so they come to Toronto. When they are going to die, it is generally safer for them to stay in Toronto then get shipped home after they have passed on. That's really unfortunate for the community. This is the most shameful part of the whole process." (Vanderhoef, 1998, p. 357)

For example, a 22 year old woman who is HIV+ and in an abusive relationship, recently tried to return with her baby to the reserve where she grew up. She is sick and wanted to escape the abuse she was experiencing in the city and to reconnect with her family. She arrived on the reserve in the middle of the night only to be turned away at the door by her mother and then her aunt. They were afraid of contagion; consequently, she is living in Toronto again with the same man who beats her regularly and tells her that no-one will ever want her because she is HI V+. (Ogilvie, 1999)

The role of a social worker in these situations is a difficult one. Direct social work intervention, mediation, counselling, and education with the family is an option because it may help to bridge the gap between the woman and her family. However, depending on the family, indirect intervention may be a preferable option–perhaps a relative or elder could mediate between the woman and her family.

Social workers so often neglect spiritual matters because of their own discomfort with this issue. Sometimes this discomfort results from their atheist or agnostic beliefs and from their lack of understanding regarding the positive role that spirituality and faith can have in healing, both emotionally and physically. Or, because they do not share the same spiritual beliefs as their client does, they are not prepared for an inter-faith dialogue and avoid the issue altogether. Yet, tradition and spirituality can be powerful tools for clients and ignoring it can do them a disservice. Danny Maxwell, who is HIV positive, said "I finally found a place where I was being listened to, in a sweat with Vern Harper. There was a bunch of us with HIV *and it was fine, we were open.* We were in the sweat lodge for 6 hours. We opened it every hour to wet the grandfathers (stones)" (emphasis added)

Traditional beliefs and practices can be incorporated into many aspects of AIDS prevention. On one reserve, elders were asked for their input on the design of sex education at the high school: the "programme in the school was well received by the students. It dealt with self-respect and the Native tradition and sex education. Some was done with boys and girls together, and some was done with each group individually." (Myers et al., 1996, p. 144)

Using Aboriginal culture to design educational materials is not simply beneficial; it means that the material belongs to them; it is not written from the point of view of a white bureaucrat from Ottawa: "It must be clearly understood that, when dealing with First Nations people, whether it be in education or with health, it must be in the context of culture, whatever that culture may be, or it is just another form of assimilation." (RCAP, 1996)

For educators and learners, traditional beliefs and practices can provide support and strength, (Ogilvie, 1999) as well as direction. Ogilvie uses both the medicine wheel and the path of life as tools, which inform her practice. Her programme initiated a talking circle, which operates with the philosophy of harm reduction. People who use intravenous drugs and come high will not to be excluded if they have a desire to participate, provided that they are not disruptive to others in the circle. Many people, who use intravenous drugs do so every day, are high as much as they can afford to be, and are functional in this state. In more conservative Aboriginal service organizations, this behaviour would prevent them from ever participating in a talking circle and could prevent them from accessing information, which will save their lives.

The basic tenets and philosophy of harm reduction are in conflict with traditional models of drug and alcohol treatment, which insist upon absolute abstinence as a goal. These tenets of harm reduction are:

1) There are no moral, legal, or medical judgements made about drug and alcohol use.

2) People who use substances are treated with dignity and respect, and their use is not seen as immoral or irresponsible.

3) The potential for harm is the primary problem, and whatever can be done to prevent the transmission of HIV should be done. Options should be presented to the client free of coercion and judgmental attitudes.

4) Abstinence is not the focus although it can be a part of a programme for a client who wants to quit using drugs and/or alcohol. Reducing the harm associated with substance use is the focus.

5) The users have a role to play in harm reduction, and they should be empowered to make informed decisions for themselves. Their participation is crucial to Harm Reduction.

6) Interventions must be created with the involvement of the community. They must be holistic and treat all aspects of the individual and not only the symptoms.

(The American Harm Reduction Coalition, CAAN, 2000)

The holistic aspect of HIV/AIDS prevention and treatment is especially important because so often services are designed in a compartmentalized fashion, where a person can find treatment for addictions and sexual abuse but not in an integrated manner. Harm reduction can play a vital role in the integration of services.

The B.C. Aboriginal HIV/AIDS Task Force advocates harm reduction models. In its research document The Red Road: Pathways to Wholeness, it establishes the need to "increase community education about harm reduction to ensure currently controversial services can be understood in the context of the HIV epidemic." Albert McCleod, Chair of Canadian Aboriginal AIDS Network, has said, "the B.C. experience is on the cutting edge of what's happening within the HIV/AIDS field." (CAAN, 1999, p.5)

On an individual basis, when working with Native people, whether they are two spirited or not, HIV positive or not, it is important to be informed of their history, both positive aspects as well as the roots of their oppression. However, if you are working with people who have lost their history or their connection to their community, it is important not to take it upon yourself, as a social worker, to educate them about all of the things they do not know about themselves as Aboriginal people. (Brooks, 1999) This principle is *especially* true for non-Aboriginal social workers because it will only compound the clients' feelings of powerlessness. Of course, the dynamic is much different if both client and worker are Aboriginal. Many respondents in the Canadian Aboriginal AIDS Network survey of Aboriginal intravenous drug users (IDUs) perceived a greater level of comfort, understanding, and acceptance with social workers / HIV/AIDS educators who are Aboriginal. For social workers in this area, whether they are Aboriginal or not, "there's a responsibility there, and there has to be a lot of respect for the client...You've got to have a social worker who's educated in the field." (Maxwell, 1999)

Social workers should recognize that they do not have all the answers; on some issues, clients are more knowledgeable, and they should be asked for information or clarification. Gaining knowledge from clients, whether it is about a healing ceremony or which drug cocktails cause the least nausea, will arm the social worker to deal with clients more effectively in the future. (Ogilvie, 1999)

The issue of HIV/AIDS prevention in Aboriginal communities is very complex; yet, the path towards a reclamation of health for Aboriginal people, especially two-spirited people, can be found in their history. By looking inwardly for solutions, with the help of allies by their side, progress will be made. There is great hope for the future in the hands of the next generation.

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Section 6

Legal Issues

Working Together: The Canadian HIV/AIDS Legal Network - Canadian Aboriginal AIDS Network Project on Legal Issues, Aboriginal People and HIV/AIDS[1]

Stefan Matiation, B.A. Hon., L.L.B.

The Canadian HIV/AIDS Legal Network (the Legal Network) and the Canadian Aboriginal AIDS Network (CAAN) have recently completed part of a project on legal issues, Aboriginal people and HIV/AIDS (the Project). The Project has so far involved two phases, the first initiated by the Legal Network and the second undertaken as a partnership between the Legal Network and CAAN. The topics addressed include human rights and discrimination, jurisdiction and funding, and testing and confidentiality. Health Canada under the Canadian Strategy on HIV/AIDS provided funding for the Project.

This paper provides a description of the Project, including its history and goals, the issues addressed and conclusions reached, and identifies a number of recommendations for best practices in projects related to Aboriginal people and HIV/AIDS undertaken by non-Aboriginal organizations or for partnerships between non-Aboriginal and Aboriginal organizations. The recommendations may also be of interest to Aboriginal HIV/AIDS organizations undertaking such partnerships.

The results of the partnership undertaken by the Legal Network and CAAN suggest that HIV/AIDS issues for Aboriginal people can be addressed by non-Aboriginal organizations but only in partnership with Aboriginal organizations and where guided by Aboriginal expertise and governed by principles of mutual respect and, on the part of the non-Aboriginal organization, a willingness to learn about Aboriginal communities.

The Partners

CAAN is a national Aboriginal charitable organization with a membership which includes Aboriginal HIV/AIDS organizations, other non-governmental HIV/AIDS organizations with a significant Aboriginal component, Aboriginal people living with HIV or AIDS, and others involved in HIV/AIDS work with Aboriginal people. With its office in Ottawa, CAAN acts as a national voice on HIV/AIDS issues affecting Inuit, Métis, and status and non-status First Nations people regardless of place of residence. The network is devoted to strengthening the capacity of Aboriginal organizations and communities to respond to HIV/AIDS. CAAN carries out this goal by coordinating activities, lobbying the federal, provincial and Aboriginal governments and departments and drawing attention to the significance of HIV/AIDS issues for Aboriginal people.

The Legal Network is a national charitable organization with its head office in Montréal. It has made important contributions to HIV/AIDS education, legal and ethical analysis, and policy development in Canada. The Legal Network produces and facilitates access to accurate and up-to-date information and analysis on legal, ethical, and policy issues related to HIV/AIDS in Canada and internationally. In carrying out its work, the Legal Network consults its members and a wide range of participants, in particular, people living with or affected by HIV/AIDS. Further, it attempts to connect individuals and organizations working on or concerned by legal, ethical and policy issues.

History of the Project

The Project has its roots in a human rights internship involving Two-Spirited Peoples of the 1st Nations (TPFN) and the University of Toronto Faculty of Law during the summer of 1994. TPFN is an Aboriginal community organization in Toronto. Among other things, it conducts advocacy, provides HIV/AIDS services, and holds community events.

The materials gathered during this internship were incorporated into a research paper on legal issues, Aboriginal people and HIV/AIDS. The Legal Network later became aware of the research paper and expressed interest in conducting work in the area. The internship experience and the dedication of the people involved with TPFN have been a source of motivation throughout the Project.

The first phase of the Project involved discussions with key informants working in the field of Aboriginal people and HIV/AIDS, which included some front-line workers, executive directors of Aboriginal HIV/AIDS organizations, representatives of Health Canada, and others. These discussions were conducted in July, August and September of 1997. In October 1997, three draft discussion papers were prepared based on legal and policy research and on the discussions. The draft papers were distributed for comments, and comments received were incorporated in the first issue of the papers, published in March 1998. The discussion papers are titled: (1) *Discrimination, HIV/AIDS and Aboriginal People*; (2) *HIV/AIDS and Aboriginal People: Problems of Jurisdiction and Funding*; and (3) *HIV Testing and Confidentiality: Issues for the Aboriginal Community.*[2]

In addition, two articles were prepared: the first is an article based on the issues addressed in the discrimination paper, published in *First Perspective* , a national Aboriginal owned and operated newspaper3; the second is an article summarizing the discussion papers, published in the *Canadian HIV/AIDS Policy and Law Newsletter.*[4] The papers were also presented in poster format at the 12th World AIDS Conference held in Geneva in July 1998.

Although the papers were generally well-received by the people interviewed and by those from both the Aboriginal and non-Aboriginal community, concerns were raised about the fact that although an effort was made to gather and reflect comments from Aboriginal people working on HIV/AIDS issues, the Legal Network acted alone in publishing the papers.

In response to these concerns, the second phase of the project was conducted as a partnership between the Legal Network and CAAN. In December 1998, a series of nine information sheets was drafted and distributed for comments. In January and February 1999, follow-up discussions were conducted with key informants working in the field, which again included Aboriginal HIV/AIDS workers, Health Canada representatives and others. These follow-up discussions focussed on a number of topics, such as the content of the information sheets and discussion papers, and the role of the Legal Network in work on legal issues, Aboriginal people and HIV/AIDS.

In order to reflect the changes that have occurred since the first printing of the discussion papers and the comments received during the follow-up discussions, the papers have been revised. The form and content of the information sheets was also devised and completed. In addition, the author participated in two workshops: a skills building workshop organized by CAAN where the results of the Project were presented, and a workshop on testing and confidentiality issues organized by the Legal Network.

It is hoped that work related to the Project will continue and that the partnership between the Legal Network and CAAN will grow. To this end, in July 1999, the Board of Directors of the Legal Network adopted a number of recommendations regarding the conduct of further work by the Legal Network in the area of HIV/AIDS and Aboriginal people.

Goals of the Project

The goal of Phase 1 of the Project was primarily to bring attention to legal issues regarding Aboriginal people and HIV/AIDS, an area which has generally been poorly addressed in HIV/AIDS-related materials. A second goal of Phase 1 was to develop the capacity of the Legal Network to address legal, ethical and policy issues respecting Aboriginal people by increasing its resources in this area and its understanding of the issues, and by developing relationships with Aboriginal HIV/AIDS workers and experts.

The goals of Phase 2 of the Project were first to continue to bring attention to and develop the dialogue about legal issues, Aboriginal people and HIV/AIDS, second, to build on and strengthen the nascent relationships started during Phase 1, and third, to attempt to address weaknesses related to the process of the Project. It was determined that the latter two objectives could best be achieved by conducting Phase 2 of the Project as a partnership between the Legal Network and CAAN.

Issues Addressed in the Discussion Papers

Discrimination issues:

The discussion paper on discrimination issues indicates that Aboriginal people living with or affected by HIV/AIDS experience discrimination in many of the same ways that non-Aboriginal people do (Matiation, 2000a). Discrimination may come from a variety of sources: from band administrators and community members to health practitioners and the public at large. Discrimination is often associated with misunderstandings or lack of knowledge about HIV/AIDS and is often reinforced by discrimination based on other grounds.

What differentiates discrimination against Aboriginal people living with HIV/AIDS is the history of oppression, racism and social denigration experienced by Aboriginal communities. These factors often have the result of further marginalizing Aboriginal people affected by HIV/AIDS. It is with a regard to this context that the issue of discrimination, HIV/AIDS and Aboriginal people must be addressed.

To improve the human rights situation of Aboriginal people living with or affected by HIV/AIDS, the Project determined a number of approaches throughout the discussions undertaken for the Project. Significantly, very few of those interviewed, particularly from the Aboriginal community, expressed much faith in human rights legislation. Issues related to the human rights system include: (1) the application of federal and provincial human rights legislation to Aboriginal people and the application of the Canadian *Charter of Rights and Freedoms* to Aboriginal governments; (2) the impact of section 67 of the *Canadian Human Rights Act* on the human rights protections of Aboriginal people[5]; and (3) weaknesses in the human rights system, particularly for Aboriginal complainants.

Non-legal approaches to address discrimination against Aboriginal people living with or affected by HIV/AIDS were raised during the discussions for the Project. Many of those interviewed referred to the need for education efforts to continue in Aboriginal communities, both urban and non-urban, and to the importance of increasing the involvement of Aboriginal leaders in HIV/AIDS issues. Further, it was suggested that non-Aboriginal people working in the field of HIV/AIDS have to develop a better understanding of Aboriginal cultures and traditions. Most importantly, it was emphasized that Aboriginal people should be involved in all aspects of the control, design, and direction of HIV/AIDS initiatives for Aboriginal people.

Jurisdiction and funding issues:

The division of jurisdictions between the federal and provincial governments often adversely affects aboriginal people in Canada. Disputes about the scope of the powers and the responsibilities of the provincial and federal orders of government often result in a policy vacuum that hampers the implementation of an effective response to HIV/AIDS. The development of self-government initiatives adds another layer of complexity to the question of the scope of jurisdictional powers and responsibilities. The discussion paper on issues related to jurisdiction and funding suggests that the spread of HIV/AIDS within the Aboriginal community as a whole indicates a need to reduce the impact of jurisdictional boundaries on the development and delivery of coordinated and comprehensive HIV/AIDS programs and services (Matiation, 2000b).

The Project highlighted issues related to jurisdiction, HIV/AIDS and Aboriginal people, such as (1) funding problems, including the inadequacy of funds and limited sources of funding, (2) the impact of divisions between federal and provincial/territorial governments on the development and delivery of coordinated and comprehensive HIV/AIDS programs and services for Aboriginal people, (3) the impact of interdepartmental barriers, within the federal government in particular, on coordination and collaboration, and (4) the impact of divisions within Aboriginal communities (between status and non-status, and off-reserve and on-reserve people, for example).

Some initiatives are presently underway to improve collaboration and coordination between federal and provincial/territorial government agencies working in the field of HIV/AIDS, and between departments and branches within government bureaucracies dealing with Aboriginal issues. The value of these initiatives is greater where Aboriginal participation in discussion and decision-making is supported.

Aboriginal HIV/AIDS strategies are another source of increasing collaboration and coordination in the area of Aboriginal people and HIV/AIDS. The discussion paper suggests that, following the example of Ontario and British Columbia, the development of such strategies in other provinces and territories could be beneficial for Aboriginal people (Matiation, 2000b).

A focus on Aboriginal communities is now a program component in the Canadian Strategy on HIV/AIDS (CSHA). The discussion paper suggests that although this new focus indicates the recognition of a previously neglected problem - the impact of HIV/AIDS on Aboriginal people, the commitment of funding to Aboriginal communities under the CSHA is only a beginning in the development of a coordinated and comprehensive response to the increase in cases of HIV in the Aboriginal population.

Testing and confidentiality issues:

The low number of Aboriginal people seeking testing for HIV means that Aboriginal people with HIV/AIDS are often diagnosed and first receive treatment at later stages in their illness compared to other people with HIV/AIDS. The discussion paper on testing and confidentiality indicates that in order to address this problem and to be successful, strategies promoting HIV testing among Aboriginal people must reflect broader issues. These broader issues include racism in health services, the prevalence of low self-esteem among some Aboriginal people, particularly in some subgroups such as street-involved people, and problems of confidentiality in small communities (Matiation, 2000c).

There is now a consensus in Canada that people should be tested for HIV only with their informed, voluntary and specific consent, at least in theory and except in a few well-defined circumstances. Further, HIV testing should be accompanied by counselling and education before and following testing, and confidentiality of results or anonymity of testing should be guaranteed (Jürgens, 1998, p. 8). In practice, however, these conventions are not always followed. In particular, access to testing remains a problem for many people; testing for HIV without the specific informed consent of the person being tested is allegedly taking place more frequently; many people often do not receive adequate counselling; and, calls for mandatory or compulsory testing of certain groups of the population continue (Jürgens, 1998, p. 8).

These issues are as relevant to Aboriginal people as to the general population of Canada. However, as in the case of discrimination, an examination of testing and confidentiality issues must be conducted with an appreciation for the context of oppression and racism experienced by the Aboriginal community. These factors have contributed to the over representation of Aboriginal people in parts of Canada in some of the most marginalized groups, such as intravenous drug users, sex-trade workers, and the homeless. In addition, these factors have contributed to the problems of ill health, which make some Aboriginal people vulnerable to HIV.

The following issues were identified in discussions as being particularly relevant to Aboriginal people: (1) the control and ownership of research and data involving Aboriginal people, (2) accessible options for HIV testing which overcome problems of remoteness, cultural difference, and reluctance to use mainstream facilities, (3) culturally appropriate pre- and post-test counselling, and (4) confidentiality in small communities.

Aboriginal people living with or affected by HIV/AIDS continue to experience discrimination. While early detection of HIV infection is a pressing priority, it would be a mistake to dismiss the importance of respecting a person's rights to confidentiality in favour of early detection without confidentiality and the availability of counselling and support. Arguments supporting accessible testing based on specific informed consent, accompanied by quality pre- and post-test counselling, and under conditions of confidentiality, are as pertinent to Aboriginal people as to anyone else. To date, however, the HIV testing available to Aboriginal people falls short of the ideal for a variety of reasons, which include discrimination in health care against Aboriginal people, particularly those in marginalized groups. The inaccessibility of testing services and support for many Aboriginal people, and a lack of confidentiality in some Aboriginal communities. In order to reduce the impact of HIV on Aboriginal people and to provide timely care, treatment and support for those already living with HIV/AIDS and for those who are not aware of their status, barriers to HIV testing for Aboriginal people must be eliminated.

General themes:

During the discussions conducted for the Project, a number of general themes emerged. Although these themes arose in relation to discussions about discrimination, jurisdiction and funding, and testing and confidentiality, it is arguable that they are relevant to other issues related to Aboriginal people and HIV/AIDS. Accordingly, they may inform other work in the area.

(i) A context of racism and cultural denigration:

Aboriginal people continue to experience the devastating effects of colonization and a history of racism and cultural denigration. In too many ways, Aboriginal people and their communities have to deal with problems associated with this experience. A response to the HIV/AIDS epidemic in Aboriginal communities must begin with an understanding of the experience of Aboriginal people in Canada and must include consideration of and sensitivity to other social, cultural, economic and political issues.

(ii) Cultural reinvigoration and a time of transition:

Despite the legacy of racism and cultural denigration, resurgence is underway in Aboriginal communities. Advances in land claims negotiations, the implementation of self-government, and a reinvigoration of Aboriginal culture may have positive results for Aboriginal people. Although momentum is growing, there are many issues that continue to require attention and action. The advances made by Aboriginal people have required, and will continue to require, perseverance. In too many ways, Canada has been slow to recognize Aboriginal rights. Indeed, until fairly recently, problems affecting Aboriginal people were largely ignored. It is fair to say, however, that the changes underway for Aboriginal people are dramatic and have the potential to bring some benefits.

There is a risk that some people and some issues might be overlooked during this period of transition. HIV/AIDS-related discrimination makes this risk that much greater for people living with or affected by HIV/AIDS. It is important that attention be directed toward HIV/AIDS issues for Aboriginal people and the ways the variety of changes already underway may affect HIV/AIDS programs and services. The Laboratory Centre for Disease Control reports an increase in the proportion of total AIDS cases in Canada attributed to Aboriginal people from 2% before 1989 to more than 10% in 1998 (LCDC, 1999). Efforts must continue to halt this trend and to help those living with or affected by HIV to live in an environment characterized by understanding and acceptance rather than by discrimination.

(iii) Aboriginal control:

The driving force behind the resurgence in Aboriginal culture and identity comes from within Aboriginal communities themselves. The success of HIV/AIDS programs and services for Aboriginal people depends on the extent to which Aboriginal expertise guides, directs and implements the process. Aboriginal HIV/AIDS workers and Aboriginal people living with or affected by HIV/AIDS have a particularly significant contribution to make to the development of positive responses to HIV/AIDS issues for Aboriginal people.

Process Issues

In light of the reinvigoration of Aboriginal communities and culture, and the continuing desire among Aboriginal people for control over their own issues, data, resources and communities, it must be asked whether non-Aboriginal people and organizations have a role in addressing issues related to HIV/AIDS and Aboriginal people. Clearly, there is no place for paternalism in Aboriginal affairs. Aboriginal people neither want nor need non-Aboriginal people telling them what their problems are and how to address them. Nevertheless, based on the discussions conducted for the Project, there continues to be a role for non-Aboriginal people and organizations in work related to Aboriginal HIV issues.

There are a number of reasons behind this need which include: (1) the energies and resources of Aboriginal people and organizations working in this field are often over-burdened; (2) organizations like the Legal Network which have developed expertise in HIV/AIDS can be useful to other organizations and the communities they serve; (3) a comprehensive response to HIV requires collective action; and (4) the objectives of non-Aboriginal HIV/AIDS organizations are often relevant to and can be achieved through partnerships with Aboriginal organizations. These four points are addressed in more detail below.

Limited resources for Aboriginal HIV/AIDS-related work:

The allocation of resources to Aboriginal people made in the CSHA represents a milestone of sorts for Aboriginal HIV/AIDS issues, but this allocation follows a long period of neglect. For years, Aboriginal organizations sought funding on an unequal playing field and struggled for the broad recognition that there is an impact of HIV/AIDS on Aboriginal people.

The CSHA has not solved all the concerns for Aboriginal people regarding HIV/AIDS; resources continue to be over-burdened, capacity building within the Aboriginal community can be slow, and rates of infection continue to increase in the Aboriginal population. In light of the rising impact of HIV/AIDS on Aboriginal people, additional resources are necessary, which include shared resources from other organizations. Non-Aboriginal organizations can have a role in reducing the strain on existing resources in the Aboriginal community by assisting in the production of specialized materials that Aboriginal organizations may not have the time or resources to prepare. In addition, an organization like The Legal Network, for example, can contribute to the process of capacity building in Aboriginal communities through the wide distribution of their materials to front-line workers and to others and by promoting dialogue about issues related to Aboriginal people and HIV/AIDS.

Specialized expertise:

Some HIV/AIDS organizations have developed specialized expertise. The Legal Network has developed a reputation for timely high quality contributions to discussions about legal, ethical and related HIV/AIDS policy issues. CAAN has expertise in Aboriginal issues and service delivery and development for Aboriginal people. The sharing of such specialized expertise between organizations can be beneficial to both.

Although Aboriginal HIV/AIDS organizations and workers can benefit from the contribution of specialized expertise to their work on Aboriginal HIV/AIDS issues, non-Aboriginal organizations must recognize the limits of their expertise in relation to Aboriginal communities. These organizations can learn a great deal about Aboriginal perspectives by partnering with Aboriginal organizations.

The need for collective action:

All organizations benefit from information sharing, collective research and partnerships where appropriate. Resources for HIV/AIDS-related work are limited for all organizations, and there is a degree of similarity between the experiences of the various organizations addressing HIV/AIDS issues. In particular, few organizations, both Aboriginal and non-Aboriginal, have resources to address legal and ethical issues in the comprehensive fashion that the Legal Network can. Similarly, few non-Aboriginal organizations have access to information respecting Aboriginal communities that CAAN and other Aboriginal service organizations have.

With respect to non-Aboriginal HIV/AIDS organizations, it is important that communities that may be affected by their work are involved in the process. In the case of the Legal Network, the implementation of a partnership with CAAN represents a step in the right direction. A lesson from the Legal Network/CAAN partnership, however, is that partnerships between Aboriginal and non-Aboriginal organizations, as with any partnership, should be based on joint planning from the outset and a fairly clear agreement between the partners about the goals, objectives and plan of action for the work, and about the responsibilities of each party. Partly because the partnership started as a second phase of the Project, rather than at the beginning of the first phase, the Legal Network/CAAN partnership fell somewhat short of the ideal of joint planning.

Complementary objectives:

Many HIV/AIDS organizations, at a basic level at least, share complementary objectives. It follows from the mission statement of the Legal Network, with respect to the promotion of ethical responses to HIV/AIDS, that the organization carries a positive obligation to reach out to all groups affected by HIV/AIDS and to take steps to promote the human rights of all people. As the principle HIV/AIDS organizations focussing on work related to legal issues in Canada, the Legal Network has a responsibility to be vigilant about legal and ethical issues which impact marginalized groups, including Aboriginal people living with or affected by HIV/AIDS. Similarly, as the national HIV/AIDS organization for Aboriginal people in Canada, CAAN has a responsibility to ensure that Aboriginal HIV/AIDS issues, including legal issues, are appropriately addressed and that the perspective of Aboriginal people is reflected in research and policy work. By combining their work, the two organizations further their complementary objectives, which include their overriding goal: to assist people living with or affected by HIV/AIDS. Similarly, other HIV/AIDS service organizations share a concern for the interests of marginalized groups, a desire to help those living with or affected by HIV/AIDS in general, and a need to further their specific objectives effectively through the efficient use of all available resources.

Assessing the Partnership:

The goals of the Project can be summarized as follows: (1) to bring attention to legal issues concerning Aboriginal people and HIV/AIDS and to contribute to a dialogue about these issues, (2) to develop the capacity of the Legal Network to address legal, ethical and policy issues concerning Aboriginal people by increasing its resources in the area and its understanding of the issues, and by developing relationships with Aboriginal HIV/AIDS organizations and workers, and (3) to develop a partnership between the Legal Network and CAAN. Despite some problems related to process, particularly during the first phase, the Project has gone some distance toward achieving these goals.

The discussion papers and other materials produced, the activities undertaken in connection with the Project, and the discussions conducted have, to a modest extent at least, helped raise awareness about legal issues, Aboriginal people and HIV/AIDS. In addition, the partnership between the Legal Network and CAAN has been a positive initiative that may lead to more collaboration between the two organizations in the future. If the partnership is to continue both parties will have to be committed to maintain the relationships which have developed.

There are ways that projects involving Aboriginal and non-Aboriginal HIV/AIDS organizations can be improved: (1) partnerships and work plans should be formalized early on with each initiative which possess a clear understanding and agreement about the objectives and the plan of action, and with the involvement of the partners from the outset and throughout the process; (2) discussions contributing to the materials generated by such partnerships need to be as broad as possible and need to include face to face meetings with people from different regions, and discussions with more front-line workers and people living with or affected by HIV/AIDS; and (3) it is necessary that Aboriginal people with expertise in HIV/AIDS and related issues be approached to review and comment on materials, and in some cases, to assist in the development of work plans and establishment of objectives and subject matters for the work early in the initiative.

With these improvements in mind, non-Aboriginal organizations can play a role in addressing issues related to Aboriginal people and HIV/AIDS. Some aspects of this role include: (1) being sensitive to the impact of certain issues on Aboriginal people and the distinct concerns which arise with respect to some issues for Aboriginal communities; (2) maintaining relationships with Aboriginal HIV/AIDS organizations, sharing information about issues as they arise and evolve, and sharing expertise and assistance where appropriate; (3) working to develop partnerships with Aboriginal HIV/AIDS organizations and new initiatives with such organizations which address relevant issues; and (4) continuing to contribute to the dialogue about issues related to Aboriginal people and HIV/AIDS.

Finally, in all cases, it is important that non-Aboriginal organizations approach initiatives related to Aboriginal people and HIV/AIDS with respect, sensitivity and, most fundamentally, with an openness to learn.

Recommendations

Non-aboriginal organizations that wish to contribute to work related to Aboriginal people and HIV/AIDS may find the following recommendations to be of interest:

- Non-Aboriginal HIV/AIDS organizations should support Aboriginal HIV/AIDS organizations and those working in the field of Aboriginal people and HIV/AIDS by contributing their resources and expertise to Aboriginal HIV/AIDS organizations where appropriate. Aboriginal organizations will be able to indicate when such contributions would be appropriate.

- Non-Aboriginal HIV/AIDS organizations should make efforts to develop relationships and partnerships with Aboriginal HIV/AIDS organizations and Aboriginal HIV/AIDS workers. Formal partnerships should respect the authority of Aboriginal people to exercise control over work and over issues which affect them and should be based on: (1) joint planning from the outset; and (2) agreement between the partners about the goals and objectives of the work and about the respective responsibilities of the partners.

- Non-Aboriginal HIV/AIDS organizations should be vigilant about issues which have an impact on marginalized groups, including Aboriginal people living with or affected by HIV/AIDS, should consider Aboriginal issues related to HIV/AIDS, and should address these issues in their work.

- While recognizing that partnerships with Aboriginal organizations are preferable, non-Aboriginal HIV/AIDS organizations should act proactively in addressing Aboriginal issues in their work and in approaching Aboriginal HIV/AIDS organizations to offer support.

- Non-Aboriginal HIV/AIDS organizations should seek the participation of Aboriginal people in their activities and as members in their organizations and on their boards of directors.

- Work on HIV/AIDS issues should generally include consultation with Aboriginal people. Moreover, work on Aboriginal HIV/AIDS issues should be guided and controlled by Aboriginal people and organizations.

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Endnotes

[1] This article is based on information contained in the three discussion papers prepared for the Project: *Discrimination, HIV/AIDS and Aboriginal People*, *HIV/AIDS and Aboriginal People: Problems of Jurisdiction and Funding*, and *HIV Testing and Confidentiality: Issues for the Aboriginal Community*, an article by Stefan Matiation ((1999, Spring). "Where Are My Human Rights?": Aboriginal People and HIV/AIDS. *Canadian HIV/AIDS Policy & Law Newsletter, 4(2/3)*, 31-34), and a report prepared by Stefan Matiation for the Board of Directors of the Canadian HIV/AIDS Legal Network ((1999, June 30). *Report on Phase One and Two of the Project on Aboriginal People and HIV/AIDS: The Role of the Network.* Montréal: Canadian HIV/AIDS Legal Network).

[2] The revised discussion papers and the information sheets are available on the website of the Legal Network at www.aidslaw.ca and through the Canadian HIV/AIDS Clearinghouse (tel: (613) 725-3434; email: aids/sida@cpha.ca).

[3] See Matiation, Stefan. (1997, December) *First Perspective* , *6(10).*

[4] See Matiation, Stefan. (1999, Spring). Ibid at 1.

[5] Section 67 of the *Canadian Human Rights Act* R.S.C. 1985, c. H-6 (the CHRA) provides that: Nothing in this Act affects any provision of the *Indian Act* or any provision made under or pursuant to that Act. The effect of this provision is to immunize the legislative provisions of the *Indian Act* R.S.C. 1985, c. I-5 and that which is done by the federal government and band councils pursuant to that Act from scrutiny under the CHRA. This provision has been interpreted narrowly. To review how the judiciary and the Canadian Human Rights Commission have considered the

provision, see *Canadian Human Rights Commission v. Canada (Department of Indian Affairs and Northern Development)*, [1995] 3 CNLR 28 (FCTD) at 40, *Re Deslarlais and Piapot Band No. 75*, [1990] 1 CNLR 39 (FCA), and *Courtois v Canada (Department of Indian Affairs and Northern Development)*, [1991] 1 CNLR 40 (Cdn Human Rights Trib). For more details, see Stefan Matiation. (2000a).

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