

COMMUNITY-COORDINATED RESEARCH AS HIV/AIDS PREVENTION STRATEGY IN NORTHERN CANADIAN COMMUNITIES

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ABSTRACT

The Tłı̨chǫ Community Services Agency's (TCSA) Healing Wind Strategy identifies a number of activities and interventions to address the prevention of STI/HIV/AIDS in the Tłı̨chǫ region of the Northwest Territories of Canada. As a part of this strategy, the TCSA and CIET facilitated research to develop a foundation for interventions targeting sexually transmitted infections. The project recruited and trained community-based researchers who conducted a research survey on sexual health attitudes and behaviours in the four Tłı̨chǫ communities, covering 65% of the population above 9 years of age. The research process, outcomes, and the strategic plan that arose from the research findings produced a clear framework for interventions that are grounded in the community, but could also influence national and territorial policy. The approach may be relevant in other settings.

Keywords: HIV/AIDS, capacity building, community-based research, CBPR, survey, STI, youth

INTRODUCTION

In 2006, the Tłı̨chǫ Community Services Agency (TCSA)¹ invited CIET to serve as technical advisor for the community-driven initiative to conduct a survey, with support from the Public Health Agency of Canada and the Canadian Aboriginal Aids Network. The survey provided baseline information on the levels of knowledge and sources of information currently available about HIV and other sexually transmitted infections (STIs), and the present status of prevention activities for the Tłı̨chǫ communities of the Northwest Territories. A related goal was capacity-building among the community members. This study is an example of community-led health research, guided by a CBPR framework (Minkler and Wallerstein, 2003; Israel, Eng, Schulz, and Parker, 2005).

The Public Health Agency of Canada (2006) reports that HIV is seven times more prevalent in Aboriginal populations than in the general population. Although HIV/AIDS is not yet a serious health problem in the Tłı̨chǫ communities there is a high rate of sexually transmitted infections and the leadership has chosen to make prevention of STIs and HIV a priority health issue. A recent systematic review of condom use in Aboriginal populations in Canada and the United States confirms that “a concerted effort in primary research is needed to inform effective condom promotion interventions” (Devries, Free, and Jategaonkar, 2007, p. 53).

Research is not new to the Tłı̨chǫ, whose considerable experience in this area has shaped current TCSA policies and programs (Tłı̨chǫ Community Services Agency, 2006; Zoe-Martin, 1999). CIET’s role was to provide training for the survey process, technical support for data analysis and interpretation, and a draft report. CIET’s international research on HIV/AIDS relies on a process whereby community-based researchers (CBRs) are trained to collect survey data from target populations within their own communities.

THEORETICAL FRAMEWORK

This study combined the Tłı̨chǫ integrative perspective (inclusive of education and social services under the health umbrella) with an ecological framework. Ecological theory provides an inclusive approach whereby the

1. The community is named in this article because they are pleased to share their knowledge and experience with others.

research issue is examined within the context of various levels of environment (Bronfenbrenner, 1995).

RESILIENCE APPROACH TO PLANNING

The exact concept of resilience is the source of much debate and there are evolving definitions, many of which suggest good developmental outcomes despite high risk status (Werner, 1995; Luthar et al., 2000). In this project, we see resilience as more than just protection against adverse conditions (Health Canada, 2004; Dion-Stout and Kipling, 2003; Anthony, 1987). We understand resilience to combine spirituality, family strength, Elders, ceremonial rituals, oral traditions, identity, and support networks to build futures (HeavyRunner and Marshall, 2003; Rook, 1985) beyond the negative tone implicit in “the capability of individuals and systems to cope and flourish successfully in the face of significant adversity or risk” (Reid et al., 1996/97, p. 83). The primary prevention logic of this line of research is simple and compelling: build on original strengths to avoid negative outcomes in future generations (Dion-Stout and Downey, 2006).

ETHICS

This project received ethics approval from the Ottawa ACADRE board, which has membership from each of the five national organizations (Assembly of First Nations, Congress of Aboriginal Peoples, Métis National Council, Inuit Tapiriit Kanatami and the Native Women’s Association of Canada), and is licensed by the Government of the Northwest Territories through the Aurora Research Institute. Community-led discussions around target populations, forms of consent and recruitment ensured appropriate protocols and techniques for data collection. Guidance from the Community Advisory Committee and the TCSA ensured that the research met the standards of the Tłı̨chǫ leadership.

During data collection, interviewers asked permission from every potential respondent before commencing, informing them each of their right to refuse to participate, or to refuse to answer any question, and confirmed that no names, addresses, or any other identifying feature would be recorded during the interview.

The interviewer explained what the research was about, how the data collection would be performed, distributed the materials (pencils and forms), and collected them after the completion of the exercise. All com-

pleted surveys were put into an envelope, sealed, labeled, and placed in a locked box in front of the group or individual to confirm the privacy promised to them in relation to the content of the information gathered. Before leaving each group, CBRs asked the participants not to comment to their family, friends, or other community members who might not yet have completed the process.

RESEARCH PERSONNEL

COMMUNITY ADVISORY COMMITTEE

A committee of Elders, health service personnel, and TCSA staff members and a preliminary intervention program were in place prior to the initiation of the research. The TCSA, in conjunction with the community advisory committee, created a research component within the overall STI prevention program which is called *The Tłı̄chq Healing Wind Strategy* and invited CIETcanada to provide technical resources and training as part of the research process.

The goal of the broader Tłı̄chq Healing Wind Strategy is to reduce the incidence of sexually transmitted infections (STIs) in the region through promotion of healthy sexual practices in the context of respectful relationships. The overall objectives include:

- Develop a research base that will indicate how and why STIs are being contracted and spread throughout the region at such a high rate of infection;
- Develop a communication plan that will inform all Tłı̄chq citizens of the dangers of STIs and the importance of healthy sexual practices;
- Develop a knowledgeable effective network of community-based workers who can emphasize the importance of the STI messages in each community consistently;
- Develop an information system that will enable the project team to monitor and track cases of STIs and measure the results achieved through this strategy; and
- Review the school health program in relation to STIs and sexual health, and look for ways to improve the effectiveness of the teaching and learning.

As part of this strategy the TCSA initiated the research project, and continued to oversee the process, attending training sessions and workshops,

advising on CBR selection and role, sample selection, analysis, and planning interventions.

THE COMMUNITY-BASED RESEARCHERS (CBRs)

The Advisory Committee selected community-based researchers, most of whom were employed as Community Health Assistants. The training and survey exercise became part of their employment assignment. CIET researchers trained these 16 women from the four Ṭìcḥò communities (Behchokò, Gamèti, Whati, and Wekweètì) to conduct the surveys. Two men left the team early on.

PARTICIPANTS: THE SAMPLE

SAMPLE SELECTION STRATEGY

Although the target population for STI prevention is youth, the CBRs and Advisory Committee chose to include the entire Ṭìcḥò population above 9 years of age. The motivation was two-fold: to get as broad a base as possible about the current level of knowledge in all age groups, and to use the survey process as a community awareness tool. The goal was to survey 100% of the population over 9 years.

The effectiveness of this broad approach will be measured in the impact assessment, as the survey process itself will have become a source of awareness and information about STIs. The CBRs answered questions for the participants about HIV/STIs, but only following survey completion.

THE RESEARCH PROCESS: THE TRAINING AND FIELDWORK

Training began in Yellowknife during November 2006, with the goals to understand the objectives of the survey; to understand the instruments for data collection; to learn facilitation and interview techniques; to understand the importance of consent and confidentiality; and to learn about research methodology and how to translate it in practice. In the first 3 day workshop the CBRs learned how to use and implement the data collection instruments in both self-administered and interview-administered modes and discussed the importance of consent and confidentiality.

Most questionnaires were self-administered by the participants. Exceptions were made for participants who could not read or required help.

In this 29% (394/1354), the CBRs conducted the instrument interview-style and this was noted on the questionnaire. The survey was also translated into Tłı̄ch̄q for those who were not fluent in English.

The second 3 day training exercise provided an introduction to concepts of data management and entry. During the training, CBRs learned data entry using *Epilnfo* (Enter) software and learned the importance of double data entry and validation to account for keystroke errors. The second round of data entry was completed by the technical support team, as was preliminary analysis of the data.

A final 3 day training workshop in June 2007 completed the first survey cycle. The community team examined the findings in the draft report and developed an intervention plan. The effectiveness of the interventions will be measured within a year in the next survey cycle.

Evaluation of the training centred on written evaluations at the end of each training day to measure comprehension and satisfaction. This was complemented by verbal debriefing sessions with the CBR leaders.

During the survey period, telephone calls with the lead CBR monitored progress and provided trouble-shooting as challenges arose. By keeping notes through the phone calls, we were able to evaluate the longer range effectiveness of the training, identifying weaknesses and areas to emphasize in the next training session.

At the start of each of the three training sessions, an oral discussion of the process thus far served as an evaluation tool, as many of the team members were more comfortable speaking than writing. With the permission of participants, these sessions were taped and analyzed later for content relevant to evaluation.

EVIDENCE BASE

Community-based researchers (CBRs) collected data between November 2006 and January 2007 from the four communities, as well as from the Chief Jimmy Bruneau School, attended by students from all four communities. CBRs also identified Tłı̄ch̄q community members who had relocated to the nearby urban centre, Yellowknife. Participation rates were high, with more than two-thirds of the total target population taking part in the survey: 1354 respondents answered an “adult” questionnaire (for those aged 14 and older), and 241 answered a “youth” questionnaire (for those aged 9–13). Parental consent was obtained for those 9–15 years, either directly or through the school.

QUALITATIVE DATA

Many people (96) took up the option to add hand-written comments to the questionnaire. We collected, tested, and analyzed them by themes. Some comments were very brief, while others took up most of a full page. We reviewed the comments for key words; these were wide ranging. The following categories emerged: (1) personal reflections; (2) problem identification; (3) intervention recommendations; and (4) support for the survey process. We integrated these into the final report.

ANALYSIS

The data collection and analysis methods relied on modern epidemiology and participatory research techniques used by CIET in over 50 countries worldwide (Andersson, 1985; Andersson et al., 1989). Analysis in May 2007 involved three CBRs who had taken on supervisory roles during the data collection phase. They received intensive hands-on training around analysis and provided preliminary feedback on the results.

Analysis relied on open source analysis and geomatics software, *CIETmap*. Population weights ensured the sample was balanced in relation to the four communities. All reported findings are weighted results. We relied on the Mantel-Haenszel procedure (Mantel and Haenszel, 1959) to examine sub-groups, reporting only statistically significant results (95% confidence level). The narrative provides proportions among those who answered the question, and the denominator for each proportion is presented to convey the extent of missing data for each question. Missing data refers to those who did not respond. We describe associations using the Odds Ratio (OR) accompanied by a 95% confidence interval.

RESULTS

SUBSTANCE ABUSE

One third (440/1291) of adult respondents claimed they got drunk a few times a month. Some 2% (28/1306) claimed to have injected street drugs within the past six months, and the same proportion (32/1289) claimed they planned to in the future. Respondents who did not have sex while using alcohol or drugs were more likely to engage in safe sexual behaviours (such as using condoms) than respondents who did have sex while using alcohol or drugs. Among the youth, 17% (41/236) overall had tried drink-

ing alcohol; however, one-third (23/65) of those over the age of 12 had tried drinking alcohol. One-fifth (53/237) overall had tried smoking cigarettes and just over 6% (16/236) had tried taking illegal drugs.

SEXUAL BEHAVIOUR

The average age of first sex was 16 years; 12% (121/985) first had sex at age 13 or younger. High proportions of respondents do not use condoms for oral, vaginal, or anal sex, and only 42% (463/1104) claimed to have used a condom the last time they had sex. When asked if it was okay to expect sex without a condom, 12% (156/1316) felt it was okay, and 22% (284/1316) did not know. Nearly 10% (124/1307) claimed to have had sex with more than one person in the last month. Among the youth, 41% (101/237) had previously had a boyfriend or girlfriend, and 4% (11/237) had previously had sex.

FORCED SEX

Just over 16% (210/1302) of adult respondents claimed they had previously been forced to have sex, and 5% (71/1302) did not know. Some 4% (54/1307) admitted they had forced someone else to have sex, and 6% (77/1307) were not sure if they had. Respondents who had never been forced to have sex were less likely to admit they had forced someone else to have sex than respondents who had been forced to have sex. Among the youth, 56% (142/238) claimed they had been picked on or bullied in the last year. Additionally, 7% (18/231) claimed that an adult had touched their private parts, and an additional 7% (14/231) did not know.

VIEWS ABOUT HIV AND SEXUALLY TRANSMITTED DISEASES

Overall knowledge around several key issues was low. For example, 44% (588/1333) did not know if you could tell someone had HIV just by looking at them. Additionally, more than one-quarter (340/1321) disagreed that condoms could prevent HIV, and 29% (384/1321) did not know. Some 40% (539/1331) felt that people living with HIV/AIDS should be forced to leave their community, and 31% (412/1331) did not know if they should.

TESTING

One-third (461/1297) of respondents had previously had an HIV test; however the majority of these had only one test in the last two years. Some 10% (43/461) of those who reported getting tested did not know the result of their test. Seven respondents reported a positive result on their most recent

test for HIV. Nearly one-third (413/1292) of all respondents claimed they were worried about the accuracy of HIV tests.

FEELINGS OF SUPPORT

The majority of adult respondents (88%, 1184/1339) felt their family showed them support, and nearly 80% (1023/1297) felt they had friends they could count on, even when they disagreed. Nearly half (588/1291) of respondents felt their community gave them all the opportunities they needed to become what they wanted to be, and 88% (1122/1274) felt there was someone in their life they respected. Among the youth, two-thirds (159/236) claimed there was someone other than their parents that they looked up to. More than one-third (92/239) agreed that their parents or guardians did not understand the problems they face, and an additional one-third (85/239) did not know. Nearly two-thirds (155/235) said their parents or guardians set clear rules for them to follow, but only half (127/237) said they get into trouble when they do not follow the rules. As stated by one male participant: "We need a great deal of healing in our communities. We need to stop blaming, being victims, and start helping ourselves and others to heal. We need to teach our Elders to help us teach our youth."

CULTURE AND SPIRITUALITY

In terms of culture, 92% (1178/1283) of respondents said they were proud of their culture and 96% (1285/1344) said they respected their Elder's teachings. More than 90% (1202/1321) had taken part in traditional Aboriginal practices (i.e., drum dance) in the last year, 64% (852/1354) had taken part in cultural activities (fishing, trapping) in the last year and 63% (833/1331) had been to a traditional Elder.

SOURCES OF INFORMATION

Popular sources of information included school, clinic, TV, and family/friends. Nearly all respondents had access to TVs and radios. Among the youth, just over two-thirds (163/236) had heard of HIV or AIDS, and 7% (19/236) did not know. When asked what their main source of information was, school was the most commonly mentioned source, followed by TV and Internet.

STRATEGIC PLAN

The strategic plan includes both short and longer term interventions based on the survey findings. An immediate activity (youth sessions) will continue

to develop existing CBR and youth capacity. A *Tłı̨ch̨o Healing Wind Advisory Network* will oversee implementation of the strategic plan in a meaningful and timely manner and to support community ownership of and leadership to address regional issues around healthy sexuality.

Data analysis outcomes generated a research base that informs methods of addressing the major objectives of the *Healing Wind Strategy*. In the final workshop, the team of community-based researchers and other associated health professionals from the Tłı̨ch̨o communities began discussions around the survey findings. They identified these priority issues:

- Lack of knowledge of healthy sexual practices despite the seeming availability of STI/HIV information messaging in the community;
- An association between higher levels of risky sexual behaviour and substance abusers compared to those who were not substance abusers;
- Lack of knowledge/awareness about the purpose of STIs and HIV testing and accuracy rates; and
- An association between sexual abuse survivors becoming the perpetrators.

UNEXPECTED RESULTS

LANGUAGE

The Tłı̨ch̨o have a history of colonization and missionaries had a strong influence on their language. During those years, new words were introduced to the Tłı̨ch̨o language to refer to sexuality and many of these had negative images and connotations in Tłı̨ch̨o. The CBRs found this handicapped the survey process in the Tłı̨ch̨o language, and thus developed alternative terms and phrases to make discussions around STIs less value-laden and judgmental. A research product will be an educational video using this new terminology to open discussions about STI prevention in a more positive and constructive environment.

TRAINING

Within the three CIET-facilitated training sessions, CBR leaders emerged to coordinate the survey process, monitor the populations being reached, and store the completed questionnaires in a secure place. The role of the leaders grew to include problem solving, motivation of CBRs, and eventually training of additional team members.

The CBR team changed somewhat through the process, with several who were trained at the start withdrawing for personal or employment-related reasons. The leaders simply recruited and trained others to fill those spots, selecting new people with social or employment networks that enhanced their ability to reach the population groups that were missing from the survey process to date, e.g., a nearby urban centre, out-of-school youth.

LIMITATIONS

Surveying 100% of the population over 9 years of age in 4 remote northern communities involved a substantial work load for the CBRs. The age range will be limited in the impact assessment, most likely to 14–29 years, to target the most-at-risk groups of youth. However, the data collected from the older participants in this cycle indicated a strong commitment to prevention. Similarly, the Elders indicated a commitment, and also a need for more current knowledge. The inclusiveness served a useful purpose.

Finally, the CBRs had some difficulty reaching an adequate sample of the out-of-school youth population. This group will be targeted more strategically in the next round.

INTERVENTIONS/NEXT STEPS

Through round table discussions and small-group work, the research findings informed the development of a work plan of shorter and longer term initiatives that reflect and utilize regional and territorial resources. Of the main findings, the association between substance abuse and the lack of condom use was identified as an issue that could be readily addressed in a short-term intervention within existing resources.

IMMEDIATE INTERVENTION: HEALING WIND YOUTH OUTREACH

A series of Addiction and Condom Use Youth Training Sessions will be offered to high-risk youth (maximum of 20 per group) by four to five community based researchers at the Friendship Centre in Behchoko one evening a week from 9–11 PM for a five-week period.

Participant recruitment strategies will include posters in key community locations where these youth can be found (the store, youth centre) and via word of mouth. The sessions may be divided into two groups if participant response merits this, and will cover:

- Baseline information from youth to inform the development of additional interventions;

- Information to guide target-specific programming; and
- Youth who participate in the sessions become messengers as they share the lessons learned within their own peer groups.

A network of trained community workers and health care professionals will ensure that this type of preventive intervention is not merely a one time event.

INTERMEDIATE INTERVENTIONS

1. *Tłı̄chq Healing Wind Network*

A sustainable *Tłı̄chq Healing Wind Network* will allow the TCSA to respond to survey findings with meaningful and timely interventions (short and long term), and also to support community ownership of and leadership to address regional healthy sexuality issues.

This network will be inclusive of a *steering committee* to oversee the broad application of the strategic plan; a *preventive teaching team* that will lead the development and implementation of community interventions; and a *counselling team* inclusive of health care professionals and trained community liaisons that will aid with culturally appropriate messaging and follow up.

Research findings indicate that the majority of community members do not feel there is a lack of healthy sexuality information available, yet there is a disconnect between information availability and implementation of that information into practice. The *Healing Wind Network* will address this issue directly by assessing elements of the existing system such as overall human resource capacity methods of information dissemination, as well as teaching and counseling practices.

Anticipated outcomes

- Strong, trained core teams of community leaders;
- Strategic, sustainable, long-term leadership for programs, resources and research related to STI prevention; and
- Opportunities for community leadership development across the age span to ensure continuity of leadership and community relevance.

2. *Increasing Human Resource (HR) capacity*

There are a limited number of *Tłı̄chq* health professionals within the current system and their ability to fulfill the demands of their regular roles and

responsibilities as well as take on new initiatives is restricted primarily by lack of time. Likewise, the external health care professionals who are hired by the TCSA to work within the region are also limited in their ability to meet all the needs within the communities due to the broad nature of their job descriptions, increasing demands, and high turnover amongst their colleagues (community and non-community based). The Healing Wind strategic plan outlines the need to develop a knowledgeable, effective network of community-based workers who can emphasize the importance of the STI messages in each community consistently and this can only be accomplished through building regional and local capacity.

The first step in creating and bolstering the HR capacity of the Network is to engage current employees within TCSA whose job descriptions are naturally suited to contribute to the healthy sexuality strategic plan (i.e., Community Health Workers (CHRs), wellness workers, and social development programmers).

The second step in enhancing the capabilities of the network includes mentoring and training additional community workers. A training component will be added to the *Addiction and Condom Use Youth Training Sessions*. The first phase of the five-week youth sessions will be considered a “pilot” in which each team member will mentor a “facilitator-in-training.” Trainees will preferably be existing TCSA staff requiring facilitation experience and/or youth from the communities who show leadership potential. Participation in the pilot will provide trainees with hands-on facilitation experience and a reference point for future facilitation training. After the pilot sessions are complete, the existing Healing Wind *preventive teaching team* will provide directed facilitation training to prepare trainees to lead *Addiction and Condom Use Youth Training Sessions* in their own communities. Job descriptions of current TCSA workers may need to be reviewed to ensure compatibility of roles and responsibilities with the Healing Wind strategic plan.

Anticipated outcomes

- Trained personnel with relevant range of skills and resources to address STI prevention in communities as part of their professional relationship.

3. Assessing teaching and counselling practices

The survey revealed that nearly all respondents had access to information sources such as radio, television, and print, and many claimed to have heard

about HIV from these sources, yet there was little evidence to suggest any of them had any impact on sexual behaviours (such as condom use) or getting tested for HIV, Hepatitis, or Chlamydia. There were also no protective effects around behaviour found with regards to other programs such as those who learned about HIV/AIDS through the schools or clinics. Therefore, an assessment of the existing counseling and teaching practices will be undertaken to explore how the information is being shared and why the application to healthy sexual practices is not occurring. The school health program will also be evaluated in relation to STIs and sexual health teaching practices, for ways to improve effectiveness. These initiatives will be designed by the steering committee and applied by the *preventive teaching and counseling team*.

Anticipated outcomes

- Stronger partnership among teaching and health personnel;
- Shared programs specific to STI prevention;
- Development and implementation of targeted and culturally appropriate educational and health promotion resources; and
- Enhanced skill set for teaching and counseling personnel around STI prevention.

4. *Improving information sharing and follow-up activities*

Issues of information dissemination are multifaceted. An evaluation of the current educational materials used in the programming for cultural relevance and language use may be needed based on the outcomes of teaching and counseling assessments. Potential issues with current information sources may include lack of cultural relevance and language discrepancies or miscommunications.

A broader information sharing issue relates directly to the distribution of data and results from studies by the Government of the Northwest Territories (GNWT) Department of Health and Social Services to the TCSA health care staff. Access to patient statistics and outcomes on a real-time basis would enhance counseling and follow up, increase positive end results for patients, and may very well prove to be an essential component to reduction of STI within Tłı̄ch̄q communities. Improving communication between the appropriate TCSA network members and the GNWT will improve monitoring and tracking of cases of STIs and aid in measuring the results achieved through this strategy. This will require team building between the

GNWT and the Preventive Teaching and Counselling Team. Local personnel can play an important role in follow-up.

Anticipated outcomes

- Stronger partnership between TCSA and GNWT STI personnel/networks;
- More efficient system for communicating STI incidence rates;
- Increased capacity of local personnel specific to STI prevention; and
- Development of an efficient and culturally appropriate follow-up system.

COMMUNITY INPUT AND SUPPORT

Survey participants provided many suggestions and recommendations on how to help the situation in their communities. Most recommendations stressed the need for various workshops for all groups within the communities, general health workshops, specific workshops on the issues, related programs for youth, and more research.

Elders were also mentioned several times as a potential resource as long as they were made aware of the issues. One 28-year-old male suggested that Elders have to be made aware of the problems at hand:

Sometimes they are left in the dark, and not understanding why young kids are dying and doing bad things.

An Elder said,

We need to have all Elders involved and their input on this questionnaire. This way Elders will be able to help by sharing this idea and their knowledge to make this program work in the lives of people and youth, which will bring peace among all. We all need one another's strength and cannot leave the wise people out.

Youth programs were also mentioned. For example,

As a mother I would like to see the changes in our community and in our homes. I hope you will quickly put in many programs regarding health issues. I have a great love for my children and for my brothers and sisters and please, please do something good for us to see.

With regard to the research process and the implementation of the survey, one 21-year-old survey participant requested:

The whole community should take part in this problem and should explain how serious it is! There are many people including myself that doesn't know much about HIV/AIDS, STIs/STDs and other diseases. We need to learn how serious it is, how it can be avoided and prevented, but mainly how to tell if you have it or not. There are many things we have to learn. TEACH US!

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