Old Keyam – A Framework for Examining Disproportionate Experience of Tuberculosis Among Aboriginal Peoples of the Canadian Prairies

Kathleen McMullin, MEd, Department of Community Health & Epidemiology, University of Saskatchewan, Prince Albert, Saskatchewan

Sylvia Abonyi, PhD, Community Health and Epidemiology, University of Saskatchewan, Canada Research Chairs Program, University of Saskatchewan

Maria Mayan, PhD, Women and Children’s Health Research Institute, University of Alberta, Edmonton, Alberta

Pamela Orr, MD, Department of Medical Microbiology and Infectious Diseases, University of Manitoba, Winnipeg, Manitoba

Carmen Lopez-Hille, BScN, Department of Medical Microbiology and Infectious Diseases, University of Manitoba, Winnipeg, Manitoba

Malcolm King, PhD, Institute of Aboriginal Peoples’ Health, Canadian Institutes of Health Research, Edmonton, Alberta, Department of Medicine, University of Alberta, Edmonton, Alberta

Jody Boffa, MSc, Department of Family Medicine, University of Calgary, Calgary, Alberta

Richard Long, MD, Department of Medicine, University of Alberta, Edmonton, Alberta, Tuberculosis Program Evaluation and Research Unit, Edmonton, Alberta

ABSTRACT

On the Canadian Prairies, First Nations and Métis peoples are disproportionately affected by tuberculosis (TB) compared to other Canadians. Statistics show enduring transmission and high rates of active TB disease. Despite awareness of the social determinants of TB transmission—such as substance abuse, comorbidities, and basic needs being unmet—transmission and outbreaks continue to occur among Aboriginal people. The Determinants of Tuberculosis Transmission project is a mixed methods, interdisciplinary study that used quantitative questionnaires and qualitative interviews to look more closely at patients’ experiences of TB. Provincial Network Committees (PNCs) comprised of Elders, traditionalists, community-based TB workers, and health researchers in three participating provinces guided the project from inception through to data analysis, interpretation, and dissemination. The collaborative efforts of the patients, the research team, and the PNCs uncovered a continuing influence of colonization in TB transmission. Overwhelming feelings of apathy and despair for the hold that TB continues to have in the lives of patients, families, and communities is captured by the Cree word “keyam,” which may be translated as “to give up” or to ask, “What is the use?” This paper explores the concept of keyam in relation to TB transmission.
KEYWORDS
Cree, tuberculosis, colonialism, Aboriginal Peoples, healthcare

ACRONYMS
Canadian Institutes of Health Research (CIHR)
Determinants of Tuberculosis Transmission (DTT)
Federation of Saskatchewan Indian Nations (FSIN)
Human Immunodeficiency Virus (HIV)
Network Environments for Aboriginal Health Research (NEAHR)
Northern Inter-Tribal Health Authority (NITHA)
Provincial Network Committee (PNC)
Tuberculosis (TB)

KEY TERMS
The terms Aboriginal and Indigenous are used interchangeably to refer to the First Peoples of Canada, which includes First Nations, Inuit, and Métis. Any other direct reference to these individual groups or others (such as Native American) is intentional as the literature quoted may be specific to the named group (McIvor, Napoleon, & Dickie, 2009).

Keyam is a Cree word defining a sense of despair or of giving up, and reflects the attitude of defeat in the comment “What’s the use?”

Bad medicine may be used in a similar way to good medicine but with the purpose of inflicting injury rather than healing.

Couch surfing refers to temporarily staying with family, friends, or acquaintances.

Binning is the act of searching through trash containers for items or food.

Meds is a term for prescription medication.

Bootleggers are those who make, transport, or distribute alcohol for illegal sale. Bootlegging is sometimes a problem in communities that implement alcohol bans in an effort to curb alcohol abuse.
INTRODUCTION

On the Canadian Prairies, Aboriginal people are disproportionately affected by tuberculosis (TB). Statistics highlight ongoing transmission events and high rates of active TB disease. This paper draws on qualitative data produced by the Determinants of Tuberculosis Transmission (DTT) project, a federally funded, interdisciplinary, mixed methods study covering the period April 1, 2006–March 31, 2013. The objective of the DTT project is to understand the social determinants of TB transmission among Aboriginal people of the Prairie provinces (i.e., Alberta, Saskatchewan, and Manitoba). The ultimate goal is to prevent transmission, especially to the most vulnerable: children and people with immunocompromising conditions such as HIV. This paper gives an overview of a deeper expression of the experience of TB, where patients articulated an overall hopelessness and despair that 1) may contribute to ongoing transmission; and 2) has its roots in an experience of colonization that may be captured in the Cree story of “Old Keyam.”

While this paper reports on painful experiences of TB, it is important to note that the sharing of these experiences came from a place of strength. The 55 people who participated chose to do so out of a sincere desire to contribute to a disease-free future for their children and future generations. This paper is therefore dedicated to them and to that goal.

Project Structure and Process of Ethical Approval

The DTT project is a patient-based study that seeks to understand experiences of TB among patients on the Canadian Prairies. In this region of the country, the pool of participants is largely Aboriginal. This study followed an extensive engagement and ethical approval process with multiple jurisdictional as well as Aboriginal and non-aboriginal stakeholders. It was guided by the Canadian Institutes of Health Research (CIHR) Guidelines for Health Research Involving Aboriginal Peoples (CIHR, 2007), and by consultation throughout with Provincial Network Committees (PNCs) established to conduct the study. The PNCs are comprised of Elders, traditionalists, community-based tuberculosis workers, and health researchers. There was engagement with key First Nations and Métis stakeholders, including the Federation of Saskatchewan Indian Nations (FSIN); the Northern Inter-Tribal Health Authority (NITHA) in Saskatchewan; the Assembly of Manitoba Chiefs (AMC); and the Regional Health Co-Management Subcommittee at First Nations and Inuit Health Branch (FNIHB), Alberta Region. At the national level, the Assembly of First Nations (AFN) and the Public Health Agency of Canada (PHAC) were informed of the study and its developments. Additionally, each participating province’s Aboriginal health research centre (the CIHR-funded Network Environments for Aboriginal Health Research [NEAHR]) was included in the consultation and/or approval process. This process is described in more detail elsewhere (Boffa, King, McMullin, & Long, 2011).

METHODS

Data Collection and Participants

The DTT project incorporates a mixed methods strategy that includes the collection of quantitative and qualitative data. This paper focuses on the qualitative data. Researchers used a semi-structured interview tool to capture participants’ current experience and perceptions of TB, as well as a sense of their life history and experiences. The six questions invited participants to share general comments about themselves by way of introduction, and moved on to explore their regular daily routines both before and after becoming sick with TB. Participants were also asked to share their views on the characteristics and conditions of good health and poor health in general, and more specifically the illnesses that they or others in their community may be worried about. The interview tool went through an iterative review process with members of the PNCs, who also guided the conduct of each interviewer during their orientation to the tool. The team of interviewers represented a balance of science, sensitivity, and experience that included a TB nurse (Lopez Hille), a social scientist (Boffa), and an Aboriginal educator and health researcher (McMullin).

Participants eligible for the study (age >14 years) were Canadian-born patients diagnosed with culture-positive pulmonary TB on the Prairies between 2007 and 2008. Clinical staff gave the initial invitation to participate. Patients who expressed interest were introduced to the interviewer who then reviewed an information sheet outlining the project in greater detail. Patients who consented to the quantitative questionnaire and who were highly infectious (i.e., sputum smear–positive) were also...
invited to participate in a qualitative interview. Participants signed a consent form in English, with interpreters available upon request. A total of 55 self-identified Aboriginal persons took part in a qualitative interview (Table 1). Because this was a patient-based and not a community based study, participants were from a number of communities across the Prairie provinces (from remote reserves to major urban centres) and identified with different culture groups (e.g. Cree, Dene, Métis, etc.).

When participants gave permission, the interviews were audio recorded. The semi structured format, similar to the storytelling approach common in Aboriginal societies, allowed participants to include whatever they considered important. Interestingly, a number of participants noted that the interviews doubled as an opportunity to explore their own TB experience and its impact on their lives. Interviews were transcribed and participants reviewed their responses prior to analysis.

Analysis

A five-member team undertook a multi-stage, iterative coding process. The team included the three interviewers and two researchers trained in qualitative methods (authors Abonyi and Mayan). The team met to generate a code list drawn from relevant literature on the experiences of TB, social determinants of population health, Aboriginal health frameworks and determinants (Assembly of First Nations, 2005; National Aboriginal Health Organization, 2007), and a general review of the interviewing experience. Coordinators coded the transcripts for the interviews they conducted in their home province, and Abonyi and Mayan coded a selection of transcripts across all sites. Emergent themes were shared with the whole team for integration into the code lists. Frequent in-person meetings included opportunities for peer review and discussion of findings. The coding process was managed using the software ATLAS.ti 5.2. As the interview transcripts were coded, it became apparent many participants spoke a language of frustration, disappointment, and fear about their TB, whose roots extended well beyond their singular illness experience. These preliminary observations of the qualitative team were reported to the PNCs, who further guided the analysis and emerging themes. PNC members were interested in learning how the storytellers found meaning in the disease and how these experiences could be translated into preventive measures. The results and discussion of this study were reviewed and approved by the PNCs prior to submission for publication.

Limitations

A difference in interview location may have influenced the length, quality, and responses of the participants. In two of the provinces, participants were hospitalized at the time of the interview. In the third province, interviews occurred in various locations that included hospitals, patient homes, a hotel, a research lab space, a correctional facility, and a rural health clinic. A mobile TB clinic allowed patients in one province to access health care in their home communities; in the other two provinces patients did not necessarily have the same family and community supports during treatment. These discrepancies were taken into consideration in the data analysis, noting that participants expressed varying degrees of frustration about the treatment experience. Despite this difference in data collection strategy and the demographic, geographic, and cultural diversity of the participant group, the general tone was remarkably consistent across all the interviews.

RESULTS & DISCUSSION

One of the primary motivations for initiating the study was the need to understand what Marmot (2005) calls the “causes of the causes” that might account for high transmission rates among Aboriginal people. Marmot is referring here to the structure of social hierarchy and the resultant social conditions—for example education, income, and housing—under which people are born, grow, live, and age. More is known about the impacts of these social conditions on TB transmission than about how the structure of social hierarchy influences both these conditions and people’s overall response to sickness. The TB stories reveal a great deal about where in the social hierarchy our Aboriginal participants locate themselves, with an unyielding structure imposed as part of colonization. Our analysis of the stories about getting sick with TB, accessing medical treatment, and perceptions of TB uncovered a sense of indifference in participants’ attitudes, beliefs, and behaviours surrounding the disease. For some, this apathy was borne from a lack of support within the health care system or the idea that TB is a foretold disease destined to reappear as a continuing part of life. To some it is treated with the same normalcy as the common cold. One woman spoke of a seven month period between the time she began reporting excruciating chest pain to her doctor and when she was finally diagnosed with TB:
First time I knew something was wrong was July of 2007. . . . I felt this sharp pain. . . and I just tried to take a deep breath and I couldn't and I thought I pulled a muscle. . . . I'd buy muscle relaxers because my doctor wouldn't give me nothing. . . because he doesn't want his patients to get addicted so he really wouldn't give me nothing other than Tylenol 500s and that pain kept coming. . . . Towards Christmas, it started getting worse. . . but I started losing weight.

Other participants expressed feelings of depression, giving up, and perplexity about the disease, which was further reflected in the way they talked about their daily activities, relationships, home, and basic needs. An unemployed miner shared the impact TB had on his role as provider in his family: “Can't even get a job 'cause you have to fill out the résumé and. . . there's supposed to be no medical problems. . . . It's hard to get [used to] living on welfare.” The unifying thread in several of these stories is the idea of giving up or losing hope. As the team discussed the concept of despair, McMullin was reminded of a Cree word, “keyam,” that she felt aptly captured the tone of despair woven throughout the stories shared by the participants. This concept as told in the story of “Old Keyam” frames the interpretation of these findings in the next section.

**Framing the Findings: “Old Keyam”**

The idea of keyam was embodied by a fictional figure known as Old Keyam, imagined by Edward Ahenekew, a Cree Anglican Minister. Ahenekew used the voice of Old Keyam to convey the mood of his people, whose memories of healthier communities were altered with the imposition of the *Indian Act* and Euro Canadian policies:

Those of us who remembered Edward Ahenekew also remember that this gentle man, as ‘Old Keyam,’ personified not only himself, but the Indian People of his generation, people who were part of the struggle to harmonize competing cultures and survive with the spirit intact (Ahenekew, 1995, p. vii).

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**TABLE 1. DEMOGRAPHIC FEATURES AND PROVINCE OF RESIDENCE OF PULMONARY TB PATIENTS PARTICIPATING IN A QUALITATIVE INTERVIEW**

<table>
<thead>
<tr>
<th>Demographic Feature</th>
<th>Alberta No. (%)</th>
<th>Saskatchewan No. (%)</th>
<th>Manitoba No. (%)</th>
<th>Total No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>No. Assessed</strong></td>
<td>14 (100.0)</td>
<td>23 (100.0)</td>
<td>18 (100.0)</td>
<td>55 (100.0)</td>
</tr>
<tr>
<td><strong>Age (Years)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15–34 (range 16–34)</td>
<td>4 (28.6)</td>
<td>13 (56.5)</td>
<td>5 (27.8)</td>
<td>22 (40.0)</td>
</tr>
<tr>
<td>35–64 (range 36–62)</td>
<td>10 (71.4)</td>
<td>10 (43.5)</td>
<td>13 (72.2)</td>
<td>33 (60.0)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8 (57.1)</td>
<td>10 (43.5)</td>
<td>8 (44.4)</td>
<td>26 (47.3)</td>
</tr>
<tr>
<td>Female</td>
<td>6 (42.9)</td>
<td>13 (56.5)</td>
<td>10 (55.6)</td>
<td>29 (52.7)</td>
</tr>
<tr>
<td><strong>Population Group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First Nations</td>
<td>9 (64.3)</td>
<td>14 (60.9)</td>
<td>14 (77.8)</td>
<td>37 (67.3)</td>
</tr>
<tr>
<td>Métis</td>
<td>4 (28.5)</td>
<td>9 (39.1)</td>
<td>4 (22.2)</td>
<td>17 (30.9)</td>
</tr>
<tr>
<td>Inuit</td>
<td>1 (7.1)</td>
<td>---</td>
<td>---</td>
<td>1 (1.8)</td>
</tr>
</tbody>
</table>
The voice of Old Keyam poses questions and statements such as “What does it matter?” and “I do not care!” (Ahenekew, 1995, p. 52). For Ahenakew, Old Keyam symbolized the struggle to accomplish goals in the face of the individual and collective adversity experienced by Saskatchewan First Nations Peoples subjected to late 19th- and early-20th century health care policies and practices.

The quality of health care enjoyed by First Nations when they could access medicines and medicine people outside the confines of reservations steadily eroded. The self-determination and individual self-efficacy for many Aboriginal people was challenged and some grew dependent on non-Aboriginal government systems (Møller, 2010). Viewed from the perspective of Marmot’s work on the social determinants of health (2005), the structure of contemporary social hierarchy is set here, locating Aboriginal people at the bottom and in distress. A Northwest Mounted Police historian described the despair of reserve inhabitants in this way:

At every post there was an intangible feeling of impending upheaval... a cry, as it were, from a people so distressed that conciliation by constitutional means, administrative tolerance, unfailing foresight and charity would be the only means of adjustment (Goodwill & Sluman, 1992, p. 37).

This collective despair is represented by Old Keyam, whose being gave a face to the Aboriginal Peoples who endured reserve confinement, cultural assimilation, and broken treaty promises.

Many of the participants in this study are descendants of the signatories of Treaty 6 signed in 1876. This treaty, which involves part of present-day Saskatchewan and Alberta, is of special significance in health care due to its clause stipulating the provision of medical care and relief from famine and pestilence. Oral tradition, however, shows that First Nations people expected the promise of a medicine chest for each reserve to mean “state-of-the-art medical care that would evolve over the years” (Waldram, Herring & Young, 2006, p. 181). Instead, the spirit and intent of this treaty obligation was ignored and, at the discretion of some government agents, was reduced to a single “first aid kit” per reserve (Cuthand, 2002). It is little wonder that Ahenakew and the people of his time grew to mistrust the government and struggled in the face of such deceit. Old Keyam is a metaphor for the disparity and associated responses to the paternalistic confines of the Indian Acts of 1869 and 1876. The experiences and stories described by participants in this study similarly underscore the longstanding and ongoing impact this legislation has had on the erosion of wellness and continued transmission of diseases like TB among Aboriginal people across Canada. The interviews highlight reasons for the overrepresentation of TB among Aboriginal people. These certainly include the social determinants of TB transmission commonly discussed in the literature (such as housing, income, and employment), but they are embedded in much more complex circumstances that, when taken together, fit the framework of Old Keyam. Here we sketch out this dynamic using a storytelling approach consistent with Ahenakew’s Old Keyam, oral tradition, and Aboriginal discourse in general. The four composite stories below capture the array of feelings, thoughts, and behaviors of participants who had difficulty conceptualizing good health and whose feelings of conflict were expressed throughout their responses to the interview questions. Like the character of Old Keyam, the characters in these summaries are based on common experiences, in this case drawn from the stories shared by the 55 participants in this study.

**Annie**

Annie lives in a remote northern community that is only accessible by road for part of the year and by airplane the rest of the time. Annie is sometimes overwhelmed by taking care of three generations under one roof. The cost of groceries flown from the south prevents the family from enjoying a balanced diet and consequently, the extended family suffers serial bouts of colds and flu. The wracking sound of coughs in the small dwelling is so common that it goes unnoticed, until one day Annie cannot lift herself from bed to attend to her crying grandson. Albert, her husband, had recently fallen ill and could not go for the winter hunt, and now Annie is worried that she too has encountered the “bad medicine.”

**Brian**

Brian had TB symptoms for one year before diagnosis, and worked until he noticed blood in his sputum and was simply too weak to leave his home. Jobs are hard to come by in his northern hamlet, and he ignored what he called “a normal cough.” One evening, when his neighbour Jim came over to play cards in the steamy kitchen, Brian confided that he had lost his job because he did not have the energy to skid logs anymore. His boss had accused him of being lazy and sent him home early that day.
A Framework for Examining the Disproportionate Experience of Tuberculosis

Carrie

Carrie is a Métis woman who has lived in the city for years. She is homeless and stays at a shelter when she has run out of luck couch surfing. She goes “binning” for scraps of food before the sanitary trucks arrive. While sharing her story, she puffs on a cigarette butt that she lifted off the ground in front of a hotel. She waves to the TB nurse in the distance who has searched her out to deliver her meds. She refers to the nurse as her close friend, hoping that no one finds out that she has TB.

Elsie

Elsie began losing weight and her teacher asked her how she did it. Although she was not sure, she explained it could be the meds she was taking for her TB. The teacher then turned on Elsie and publicly humiliated her in front of her classmates, saying that she was contagious and had no business being in school. Her classmates looked at her with confusion and fear as the teacher continued her rant.

Although these stories differ in detail, they illustrate some of the common experiences of TB found in the qualitative interviews. The details of these experiences are articulated thematically in the next section.

Basic Needs

The stories highlight the fact that marginalized communities often do not have the resources to support the basic needs of adequate housing, transportation, and childcare. Even when those supports are minimally available, problems arise as in the case of a recently widowed mother of three children who became ill during the night:

I was crying. I told the nurse that I was coughing out blood and what should I do. She told me to go up there (nursing station) and that pissed me off because I don’t wanna go up there when my kids are here and I was still coughing out blood.

This mother’s struggle to take care of herself and her children was compounded by the inefficient structure of the new band house in which she lived. She described a house fraught with plumbing and sewer problems to the point that she expressed hopelessness with her own band and asked the housing coordinator to “fix something and quit sending Indians over here. . . [and] send somebody that’s trained that knows what they’re doing.” The voice of Old Keyam here was directed to her local government and band council. She spoke at length of her depression and how she coped by sleeping and alienating herself from others: “I don’t feel like associating with other people and I just wanna sleep, and at times I feel like killing myself but it, it doesn’t work.” To the relief of the interviewer, she spoke of the strength her children gave her to keep going in the face of adversity.

Social Hierarchy

On-reserve hierarchies are another source of despair. One participant described the social structure on his reserve as a class system that produced different levels of confidentiality around a TB diagnosis. This individual spoke of a time when everyone in his community learned of his TB after a medical transportation worker made him wear a mask in front of all the other passengers on a ride home from the city clinic. However, when a member of a family in power contracted TB, there were significant efforts to hide the diagnosis, perpetuating the shame and stigma associated with the disease:

I just recently found out that this one certain family was riddled with TB and nobody has heard a word about that, whereas. . . just because of my last name I’m on a lower class scale and everybody had heard that [I had TB] and then there’s even poorer people than me. . . everybody hears all about them. . . If you’re gonna keep it quiet then keep it quiet for everybody.

He felt helpless to complain to families in power about how his right to privacy had been violated. Other participants mentioned similar incidents of differential treatment, supporting findings about family-based factionalism and resource poor reserves (Brizinski, 1993).

Self-Efficacy

According to Bruess & Richardson (1995), self-efficacy is the ability to strengthen the mind, body, and soul through personal efforts or with the additional force of spiritual sources of strength. People with low self-efficacy have difficulty in facing the challenges that disrupt their lives. Several of the respondents deliberately isolated themselves from family and community during their illness with TB, while others were forcibly alienated from every day life. The concomitant depression caused them to stop attending to their health and well-being. A number of participants explained that any motivation that they may have felt evaporated when they became ill with TB. Biomedically,
at least, this could be addressed by the inclusion of mental health workers in the TB treatment team.

**Community Obligations**

During the interviews, some participants tried to make sense of why and how they contracted the disease. Most declared that they had no idea, even when they were from communities where rates were comparatively high. One youth saw the disease as fate. He lived in a community that was supposed to be a dry reserve and cursed the “damn bootleggers” who brought discord to his people. He criticized leadership for not doing enough. It appeared that the community had given up on its attempt to create a healthy space; the young man saw TB as normal and with resignation stated, “That’s the way it’s probably written.” Given the link between healthy communities and healthy people as commonly reflected in population health frameworks, it is clear that when communities give up on the obligations that they set for themselves, the consequence is that their members give up on obligations to their own health.

**Loss**

Like the story of Old Keyam, the stories of TB patients contained elements of loss leading to despair. These narratives reflected a grieving process taking place over several decades. According to Auger (2000), “grief is usually experienced as deep or intense sorrow; it encompasses our total emotional response to loss” (p. 190). People who have suffered trauma lose interest in participating in daily activities and some people “become silent, refuse visitors and spend much of the time crying and grieving” (Santrock, 2007). This theme was apparent in interviews, where some participants described giving up on family and society, which normally supported them in times of need or loss. These experiences often occurred well before the diagnosis of TB. Participants described a loss of independence, a feeling of being exiled to the reserve, a loss of control over life, and a loss of freedom (e.g., incarceration). Participants also discussed the loss of the physical necessities and supports in life such as adequate nutrition, housing, and employment. Some talked about losing access to land and wild foods. Many described loss through death and the separation of emotional, psychological, and spiritual supports such as family and friends. Sadly, a large proportion of participants in this study had experienced a major personal loss of a loved one through death or the end of a relationship in the year prior to their TB diagnosis. Research has shown that this type of loss can negatively impact the immune response (Rook and Doherty, 2009). Participants described a loss of dignity and trust in systems that they expected to support them. They felt betrayed and humiliated in the face of racism and fear mongering around their TB diagnosis. One man explained:

> Before the doctors told me how sick I was, I started withdrawing, I started being insecure, less sure of myself. . . . I thought I was lazy but I was tired. . . . and because of the weight loss I was shying away, I didn't feel good about myself and I felt weak so therefore I started acting weak. . . . I became self-conscious and I started looking at my body as who I was, not the person I am inside and I’d have certain girlfriends, lady friends that knew who I was but yet I’d push them away because I started losing weight . . . . I couldn’t stand looking at my own body so. . . . I went into depression and that’s where I decided to [drink]. I knew what having a drink would do.

This story speaks also to the sadness that accompanies and accentuates loss. The TB diagnosis led to more loss and a cycle where pain is anesthetized with alcohol. However, like Old Keyam, there is a resiliency to the storytellers’ anecdotes in terms of internal and external strength. Keyam was not limited to the despondency of the time. In sharing his truth with his community, the participant above eventually found strength.

The participants in this study have survived many personal and historical hardships through experiencing positivity in themselves, their families, and their communities. On the road to healing, many patients spoke of their sources of strength. For example, many of the female participants befriended the TB nurses, and the women often chose healing for the sake of their children and grandchildren.

**Transforming Keyam to Hope and Action**

TB programs are addressing the biomedical treatment requirements of each patient, but these stories described more complex needs. Participants were primarily of lower socioeconomic status and had often given up hope for better housing conditions, better community and social supports, and better health care services. Many cannot afford to see a traditional healer because the cost of travel outside their community is too great, and to bring healers from a distance is also too expensive. They described incidents of emotional.
abuse through differential treatment at school, in health care centres, and in all levels of government. Participants spoke candidly about coping with their addictions to drugs, alcohol, or gambling. Others cope in isolation, trying to sleep away the physical, emotional, and psychological pains that are inexorable facets of TB. Then there are those who turn to spiritual and physical well being for strength to heal for their families, or other deeply personal reasons.

Old Keyam spoke the language of oppression and became a character who struggled to survive a system of adversity. A century later, not much has changed for Aboriginal Peoples. Statistical analyses reveal that Aboriginal people are far more likely to contract TB than other Canadians due to ongoing transmission (Kunimoto, Sutherland, Manfreda, Wooldrage, Fanning, Chui, & Long, 2004). Poverty remains an issue and according to the Royal Commission on Aboriginal Peoples (RCAP), “Aboriginal people’s living standards have improved in the past 50 years—but they do not come close to those of non-Aboriginal people” (1996). The conditions cited in RCAP are the same conditions under which Old Keyam was created. Social determinants of TB transmission such as substance abuse, poorly constructed and overcrowded houses, and high unemployment and incarceration rates are all associated with higher TB incidence and prevalence. It is no surprise to see people give up on personal obligations, relationships, and community supports with respect to their own health. Where they have not given up is in changing the future for their children and the generations that follow. Many candidly shared their experiences in the tradition of storytelling to collectively make sense of current events and their links to the past. Thus, the process itself became good medicine for the storytellers describing their experience of TB and life. One participant explained it in this way:

I really circled around the Spiritual Elders to get me through the depression when I didn’t know what was wrong with me, and that helped. Like I was still depressed, I was still anxious, my nerves were gone and my outlook on life, like I couldn’t work even if I wanted to but I couldn’t tell people and I think they were thinking I was lazy and then I went out drinking and they said, “Ah. There he’s going back to his old lifestyle” sort of thing and but just now lately the energy is coming back a bit. . . . I’m still not halfway but I’ll say even now this interview has really helped.

Taking Back Power and Health

From one of the youngest interviewees who saw his TB as an affliction that was “the way it was meant to be” to one of the oldest participants who resigned himself to dying—“either whatever I have will remit, go into remission or it’ll total me off you know, kill me”—the voice of indifference resonates long after the late 19th century to the start of the second millennium. Old Keyam, a character born of colonization, haunts the stories of these TB patients. The structure of social hierarchy and the conditions ripe for TB transmission a century ago, although somewhat improved, remain a reality in the 21st century. The stories link the concept of keyam to self-efficacy, community obligation, loss, self-government, federal agencies, and the spirit of caring. Participants were clear that in sharing their stories they were not looking for sympathy, but rather were interested that their candid contributions to this study would in some way affect change in the midst of a myriad of barriers to well-being. Many of the people spoke of a higher power as a source of strength, whether in the context of Christianity or Aboriginal spirituality. Although some people may have given up on personal obligations when depression, anxiety, and fear got the best of them during their ordeal with TB, none of them spoke of giving up on their sources of strength, which were most often stated as God or the Creator and their children. Sometimes people had given up on community leadership, local governments, and/or federal governments’ obligations to health care, but in most cases participants found that they could depend on family support in their times of need. People who turned to the traditional ceremonies were most often the ones who spoke in gratitude that balance could be recovered and that TB was just one of life’s many tests. A man who was disheartened with the way his band had treated him spoke lovingly of the individuals in his circle of friends who helped him recover in the emotional, physical, mental, and spiritual domains of self:
CONCLUSION

Old Keyam is a useful framework for understanding the dynamics of TB transmission and the overrepresentation of Aboriginal people from the Prairies among TB patients in Canada. The longstanding impacts of colonization must be considered as a reason for the intractability of TB in this region. An appreciation of these impacts, and how they influence patients’ responses to the disease and its biomedical treatment, should be part of the approach to prevention and treatment. As RCAP maintains:

Aboriginal people do not want pity or handouts. They want recognition that these problems are largely the result of loss of their lands and resources, destruction of their economies and social institutions, and denial of their nationhood. They seek a range of remedies for these injustices, but most of all, they seek control of their lives (1996, p.6).

In order to eliminate the overrepresentation of Aboriginal people infected with TB, patients need to become part of the remedy through having some control of their experience and shaping a more positive experience for those who follow. As a first step, the patients in this study were keen to be part of this process by having their stories heard and shared broadly. Future research could explore the ways in which the stories, and in particular the feelings shared here, may become part of prevention, treatment, and overall approach to TB infection among Aboriginal people. This research should address the “causes of the causes” (Marmot, 2005), laying Old Keyam, and the despair his character represents, to rest.

“At the centre of positive creative activity is the desire to bring health and enrichment into the lives of others” (Armstrong & Cardinal, 1992, p. 106).

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