

Leaving our stories everywhere: Tales of tuberculosis and colonization

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Abstract

Historically tuberculosis [TB] had a great impact on people's lives in Nunavut socially and culturally and levels of TB in Nunavut continue to exceed the rest of Canada many-fold. My experience as a nurse working with TB taught me that some people are reluctant to be examined and treated for TB. This study examines how Inuit experience and make meaning of the disease today. For many Inuit participants in this study, ways of knowing and ideas about what counts as knowledge differ from those of EuroCanadians, and the preferred way to receive health information is orally, personally and in context rather than textually and abstractly as is common in public health education today. In order to decrease TB in Nunavut decolonizing measures in the form of culturally appropriate health education that acknowledges Inuit ways and knowledge is necessary.

Keywords: Nunavut, tuberculosis, health education, colonization

Introduction

The history of tuberculosis [TB] in the Canadian Arctic is significant. The disease has had a great impact on people's lives both socially and culturally (GRYGIER 1994; TESTER & KULCHYSKI 1994) and levels of TB in Nunavut have exceeded the rest of Canada many-fold (*ibid.*). Today, although the incidence has significantly decreased and examination and treatment for TB has significantly improved, Nunavut continues to be much more affected by the disease than the rest of Canada. In 2005 Nunavut had 25 times more active cases per capita than the rest of Canada (PUBLIC HEALTH AGENCY OF CANADA 2006).

When I lived and worked as a nurse in a community in Nunavut from 1997 to 1999, I realized that healthcare professionals there were generally EuroCanadians who spoke English as their mother tongue and community members generally Inuit who spoke Inuktitut as their mother tongue. Educational levels and the economic resources of Qallunaat healthcare professionals appeared to be much higher than those of almost all Inuit community members, an observation corroborated by Statistics Canada (2001a, 2001b). I also experienced that most healthcare professionals led lives that were quite different and separated from those of Inuit community members. Little 'community' existed between the two.

A TB epidemic erupted 3 months after I started work as a Community Health Nurse at the Health Center and I began to work solely with the TB program, later traveling to offer short-term support to the TB programs in two other Nunavut communities. Because of community-wide screening in my home community I had the opportunity to meet all community members and to have contact with many who received treatment twice weekly over 6 to 9 months. It allowed me to meet people in their schools and work environments and with their families at home as well as at the Health Center. I got to know some people in the community better and also got to work closely with some community members as colleagues

Through my work as a TB nurse and later as a TB consultant I realized that some Inuit feel reluctant to be examined and treated for TB and to name people they have been in contact with when they have TB. This is thought to be partly responsible for the continuing high levels of TB in Nunavut (CASE & WHITE 1999). The study was designed to investigate how Inuit experience and make meaning of TB, in part in order to investigate the connection between this reluctance and the high prevalence of TB in Nunavut.

Methodology

I had some ideas about people's reluctance to be examined and treated, including the history of the disease in the area and the social, cultural and language differences between healthcare givers and healthcare recipients. The questions that guided my research therefore were: How do Inuit experience and make meaning of TB today? How are these experiences influenced by the protocols used and the practices, beliefs and attitudes in the healthcare system that exist in relation to TB? And, how may this influence the continuing high incidence of TB in Nunavut? Soon after I had begun fieldwork, statements from interviewees made me aware that I also needed to incorporate a research question about how Nunavut's colonial history and current socio-political state affect the way people experience and make meaning of TB. My awareness grew from statements such as the following two. When I asked an Inuit man of about 40 why he thought some people felt reluctant to be examined and treated for TB, he said:

Another thing that might be, is the government problem; not the government itself, but by the people who resent the settlement, being put in a settlement from their camps. They might say well, they kill our dogs and they settle us here why don't they just cure us? Let the government take care of it. It's the government's job. There might be people who might think like that.

Another man stated: *"I feel like a minority in my own territory,"* and when asked to elaborate, said:

People from outside tell people here what to do, how to do it. People from the outside tell us what is right and what is wrong. Maybe if people from the outside knew more about our values and way of thinking they would not be so condescending.

The research was conducted through 7 months of fieldwork in 2 Nunavut communities. It included observation and participation in community life, 42 interviews with 29 Inuit who had experience with TB and 7 non-Inuit healthcare professionals who had worked with TB, numerous casual conversations with community members, and document review. Inuit interviewees came from 6 different home communities. Interviews were used to learn of participants' experiences of TB – their illness stories or narratives, and how they contextualize these in their lives. Observation and participation in community life such as volunteering in a women's center, teaching medical interpreters at Nunavut Arctic College, partaking in social activities, and sitting in on debates in the legislative assembly offered insight into how experiences related in individual stories resonated with the experiences of the community and of the territory. These activities often led me to further insights and richer data.

Findings

While in the field and when I analysed interviews and field-notes 3 broad themes that in various ways coloured people's experience of TB, health and disease generally, became apparent. These dealt with: a) Concepts of sickness and health, b) Socio-political realities and the role of historical and current colonialism, and c) Knowledge and ways of knowing and learning.

I learned that Inuit participants often viewed health, disease and the body differently from EuroCanadians. It has been written that for Inuit, health demands a state of balance in the individual's mind, body and spirit, and in his or her relations with family, community, environment, and other sensate beings (BORRE 1994; OOTOOVA *et al.* 2001; THERRIEN & QUMAQ 1992). For the Inuit participants in this study, performing correct interactions according to social norms and conventions played an important role in the maintaining of this balance. Many noted that this included not talking about disease, bad experiences, and misfortune, as they thought they had brought it upon themselves through transgressions. I also learned that the history and effects of colonization, and

according to many participants' experiences, continuing colonialism, plays a significant role in people's approach to and experience of TB. This included living with poverty, violence and drug and alcohol abuse as well as with discrimination and racism from non-Inuit. I also learned that the way many Inuit participants and EuroCanadians perceive knowledge is different, and the way Inuit participants prefer to receive information about health and disease differs from the ways generally used in a Western healthcare system (MØLLER 2005). In this paper I focus on the latter theme concerning perceptions of knowledge and preferred ways to receive information.

Experience based knowledge

The anthropologist Frederic Barth (2000) writes that the ways in which people come to know and what counts as knowledge varies greatly across cultures, that this is influenced by how we perceive the world and our place in it, and that these, in turn, influence how we teach and learn. When I asked Inuit participants to tell me what they knew about TB many replied that they knew nothing. When I subsequently asked them to tell me their personal or family experiences with TB, or stories they had heard about the disease, it turned out that many people actually knew a lot.

A man of about 60 who was being tested for TB was asked if he would agree to be interviewed about TB. He said no, because, as he said, he had no experience with the disease and did not think he was sick. Therefore what he would have to say would just be "*a bunch of lies.*" My interpretation of his answer is that, because he had no personal experience with TB, he felt that he had nothing to share with me. Another man, a 34-year-old college student, had not had TB himself, but his sister had recently been treated for latent and his father and brother for active TB. I asked him to tell me what he knew about TB, to which he replied:

I don't [know anything] at all, I don't. Back home when they had the epidemic a few years ago, I knew it was serious. Otherwise they wouldn't have announced it on the radio. They were calling people that were active; they were always going over for pills.... That's it... TB, it's in the lungs isn't it?

I asked whether he had any experience with TB in his family or had heard people talking about TB. He said that his sister once had TB but that he did not think she was active (implying that he made a distinction between active and latent TB); he also said that both his parents had TB as children and had undergone operations. He had seen the scars over their lungs (an indication that he had an idea of where the disease was located) and he knew they had been isolated in order not to give the disease to other people (implying that he had an idea of the infectiousness of the disease). Rather than telling me something that may not have been totally accurate and perhaps be guilty of lying, having not had personal experience with TB himself, I believe that this man chose to let me validate his knowledge

by asking me what I knew.

This interpretation may be better understood seen in the light of Taamusi Qumaq's statement that when the individual Inuk speaks, he/she shares what is *in* (not on) his/her mind. "This sharing is highly moral, since 'the speaker says that he tells the truth'" (cited in DORAIS 1996: 93). It may also be understood with the work of Briggs (2001), Okakok (1989) and Stairs (1991) in mind. These authors discuss differences in ways of knowing and displaying knowledge between Inuit and EuroCanadians. Some of the differences they highlight are that many Inuit recount only that which they are certain of – and come from a background where silence is valued. Many EuroCanadians on the other hand tend to say something rather than nothing whether they have precise knowledge or not, because many come from a background where being vocal is rewarded. Further, they note that many Inuit test knowledge against their own experience whereas non-Inuit often take teacher and book knowledge as facts, a suggestion echoed by the Inuit elder Pauloosie Angmarlik who said: "I never say what I have heard, I only tell what I have experienced, because I do not want to lie" (ANGMARLIK 1999: 272). Particularly older Inuit have expressed that experience must ground knowledge for it to be of value and for it to be worthy of sharing (OOSTEN & LAUGRAND 2002). The statements of many participants suggest that today many Inuit still place high value on experience-based knowledge. This, I believe, has an impact on whether public health program information dissemination meets with success.

Information dissemination and learning preferences

Many Inuit informants said that the information about TB that is available in their home community is noticed and paid attention to by few, and that few feel that it is relevant if they do not have active TB themselves. Thirteen out of 29 Inuit interviewees had *no* recollection of seeing or hearing *any* information about TB in their home community, despite reports from the Department of Health and Social Services that many initiatives had been carried out to increase awareness about TB. Initiatives included training homecare workers about the disease, making and distributing posters and pamphlets in Inuktitut, and providing information in Inuktitut through radio-spots, at schools and in local groups.

As one man pointed out: *"Well I saw what was posted, but I did not read them. [TB] didn't bother me.... I wasn't affected, so I didn't really care about it."* When I asked a woman who had active TB if she had heard or seen any information about TB in her community, she replied: *"Those words, just words. Coughing, fever and all that you mean? Just the poster. It's just hanging on the wall. Nobody talks about it."* And the man whose parents had TB when he was a child said: *"People are just leaving their stories everywhere and nobody's bothering to read them. If you write it on paper or put it on the wall, nobody will touch it."* When I asked him how people might learn about TB, he continued: *"A person talking about it helps a lot. A person talking about it is saying something to*

everybody, but paper is just staying there without anybody knowing about it."

Maybe these remarks should come as no surprise. Before the introduction of EuroCanadian schools to the Canadian Arctic, individuals gained their knowledge and abilities through oral traditions, listening to stories, one-on-one contact with knowledgeable adults and elders, and through observation and participation (ANGMARLIK 1999; EKHO & OTTOKIE 2000). Okakok (1989) believes that for Inupiaq students this approach to learning continues to be most appropriate. I think this may also be the case for Inuit in Nunavut; the use of oral traditions in health education should be seriously considered. It may, as suggested by 8 participants, be more appropriate to use oral rather than textual information and to include personal stories and experiences with TB as a means to educate about the disease.

Okakok also points out that for Inupiaq, education, which is a lifelong process, "is the sum of learning acquired through interaction with one's environment, family, community members, schools and other institutions and agencies" which includes learning "about responsibilities to the extended family and elders" (OKAKOK 1989: 412). Stairs (1992) reports that this is similar for Inuit. In conjunction with Therrien's (2001) observation that medical knowledge did not exist "as an autonomous and formal body of knowledge" in Inuit societies the way it did and does in Western societies (*ibid.*: 1), this may explain why many participants in this study included, when they made meaning of TB, that falling ill had highly moral connotations; disease would befall those who had transgressed social norms. Several examples were given of family or community members who had fallen ill or who had misfortune due to transgressions such as stealing, wanting to commit suicide or sexually or physically abusing someone.

This may mean that much of the public health information on TB is seen by Inuit to be out of context. If learning is usually done through interaction and good health is connected to moral living, then health education based on posters and pamphlets discussing TB as an isolated entity, out of context, may not be very useful. In other words, one reason why many Inuit do not notice public health information about TB may be found in the mould in which the information has been cast, one that is EuroCanadian. EuroCanadian ways of educating often work poorly when educating people who are not EuroCanadian (BERGER, EPP & MØLLER 2006; OKAKOK 1989; RYAN 1989; STAIRS 1991). Similarly to Irene Daes' (1994) contention that the diverse indigenous ways of life and ways of knowing "can only be fully learned or understood by means of the pedagogy traditionally employed by these people themselves" and that in this, indigenous peoples' own languages are pivotal (para 8), so too is it necessary to employ indigenous pedagogy and incorporate indigenous ways and knowledge when educating about health. As suggested by Pedersen (2004) with Greenlandic newspapers, although translation is important it is not enough. The ways of formulating and presenting the message need also to be changed.

Implications for public health education

For many Inuit participants in this study, ways of knowing and ideas about what counts as knowledge differ from those of EuroCanadians, and the preferred ways to receive health information is orally, personally and in context rather than textually and abstractly. It may not be difficult to imagine why many people do not pay attention or notice public health education. Public health pamphlets and posters are translated into Inuktitut and in some communities Community Health Representatives give some health education in community groups; however, the programs are still developed within the realm of a southern system that reflects southern ways of thinking and educating.

Not only is health education not in context, it is often provided by nurses who are not part of the community, have no shared experiences with community members, and may only be present in the community for 3 months (and sometimes even less). This makes it difficult to build any kind of relationship, let alone a balanced relationship, between healthcare providers and recipients. It may be more appropriate to have very localized health education where community elders and others with specific experiences about a health issue are invited to come to smaller groups and talk about their experiences or share their stories of “strength and survival” rather than having healthcare personnel tell people how they should conduct themselves in order not to get TB, or how they should conduct themselves once they have contracted the disease.

An Aboriginal Australian nurse Chealse Bond (2005) writes that she and her non-Aboriginal colleagues had little success in their attempt to engage Aboriginal Australians in traditional health education programs. Most community members were much more enthused about “sharing personal stories of strength and survival,” (p.40) cultural revival and celebration. Bond writes that in her role as a nurse she found it difficult to reconcile health education and cultural revival and celebration. Her non-Indigenous colleagues agreed and thought the community members’ lack of interest confirmed the origin of their ill health. Bond herself, however, upon reflection, realised that:

Within the health-care system no value or worth was attached to being Aboriginal, as the success of the system was measured solely by it’s ability to bring the health of the Aboriginal people up to the same level as that experienced by non-Indigenous Australians. Underlying the quest to reduce health inequalities lay first the assignment of inferior status to Aboriginal people within the health programs. Is it actually any wonder, then, that we’d have to beg “Aunty” to come along to a presentation where she was depicted as nothing more than a subset of problems and unhealthy afflictions that could be remedied by simply telling her to eat better and exercise more? ... As time went by I began to feel that health promotion in the form of health education was not empowering but rather disempowering. (BOND 2005: 40)

She added that in the Australian healthcare system Aboriginal people “are seen as nothing more than a group of people who just don’t know what is good for us” (BOND

2005: 40). Unfortunately some of the healthcare professionals interviewed for this study expressed a similar sentiment about Inuit. Bond experienced a disregard by her non-Aboriginal colleagues for local ideas about how health education should be conducted. Findings from this study suggest that, while this disregard may be unintentional, it also exists in Nunavut and much can be learned from Inuit about effective ways to deliver health education.

Inuit healthcare professionals should be well-positioned to suggest culturally congruent and respectful strategies for public health education, but unfortunately Inuit nurses are being educated in an educational system that has been adopted from the south, where Inuktitut is not spoken and health not discussed in Inuit terms. One Inuit nursing student said to me: *“As an Inuk student I feel I have no freedom of speech.”* She continued that her views of the body, health and disease were labeled as unscientific and superstitious, and that some Inuit students felt discriminated against, leading some to drop out (MØLLER 2005). Problems encountered when educating indigenous professionals in Western paradigms also appear in the literature. In a review of Nunavut Arctic College in 2006 one nursing student was quoted as saying:

I learned Inuktitut terms for the body parts and such when I was young, but I am older now and I am losing it. I am in the nursing program and I would like to be able to use my own language, but there is no Inuktitut programming. I don't want to work with an interpreter later on, but if this continues I will have to. (cited in ALAGALAK & BARNABAS 2006:18)

Ryan (1992) stated that Native nursing students who were educated in a EuroCanadian educational system found the education culturally invasive in relation to teaching methods, language, and practices in the clinical encounter. Greenlandic nursing students were described as reporting similar experiences (JACOBSEN 2000; MADSEN 2000; Skifte, cited in KJÆRGAARD 1998; STEENFELT 1998). Continuing to educate Aboriginal people within the frames of a previous colonial power preserves and strengthens the effects of colonization (BATTISTE 1998; RYAN 1992; SMITH 2002). The effects of colonialism in Nunavut are evidenced in the health status, life expectancy and educational levels of Inuit, which are significantly lower than in the rest of Canada (STATISTICS CANADA 2001a, 2001b), and in high incidences of alcohol and drug abuse (NORTHWEST TERRITORIES BUREAU OF STATISTICS 1996), suicide (HICKS 2006), and violence (STATISTICS CANADA 2001b). This type of social dysfunction has been described by the World Health Organization (1999) to be an effect of previous and continuing colonialism.

With all of the above in mind, it is not surprising that Article 15 of the *Draft United Nations Declaration on the Rights of Indigenous Peoples*, which Canada voted against ratifying on July 29th, 2006, maintains that all Indigenous peoples should have the right to control their educational systems and institutions and to receive culturally acceptable education in their mother tongue (UNITED NATIONS 2006). Also understandable, Article 35

maintains that indigenous peoples have the right to develop and administer health programs in their own institutions (United Nations).

Conclusion

Continuing the offering of healthcare, health education, and the education of nurses in a EuroCanadian mode that excludes oral traditions and is conducted in English rather than Inuktitut, persistently sends the message that Inuit culture, values, and ways of thinking are inferior to those of Qallunaat. It also continues the acculturative process that historically has taken place in the Church, the schools, and the healthcare system, and which is known to have severe social and health implications (LANE, BOPP AND BOPP 2003).

It is time for non-Inuit health care professionals to heed the statement of an Inuit participant in a study about culture, education and work, who stated that:

I feel strongly that the cultural aspect of our lives should be present in everything we do in our workplaces. It shouldn't have to be something that we have to be ashamed of anymore, like it used to be. This way should be taught all the way from kindergarten up. We are working with people who are long-time northerners, and we hold nothing against them, but they do not understand what they are talking about sometimes (unnamed participant, in KENNY 2002:51).

Maybe as non-Inuit healthcare people it is time that we think about not leaving our stories everywhere and find ways that Inuit can share their stories in order to celebrate and improve health.

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