

A Problem of the Government?
Colonization and the Socio-Cultural Experience of Tuberculosis in Nunavut

Masters Thesis

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April 21st, 2005

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1. Introduction

1.1 Genesis of the study

From October 1997 to June 1999 I worked in 3 different communities in Nunavut as a nurse, primarily with tuberculosis (TB). Several Nunavut communities were experiencing TB epidemics at the time, and, although the incidence of TB in Nunavut¹ has been fairly constant over the past 20 years (Health Canada [HC] & Canadian Lung Association [CLA], 2000), its incidence in the Eastern Arctic historically exceeded the rest of Canada many-fold, with 25 times more active cases per capita in 2001 (HC, 2003).

In the past, TB seriously affected many communities, families and individuals (Grygier, 1994; Tester & Kulchyski, 1994; Tester, McNicoll & Irniq, 2001). Working and living in Nunavut, I had the impression that this was still the case. I came to believe that people's lives were affected emotionally and socially because of the disease in and of itself, the particulars of the protocols and regimens that are used when dealing with TB surveillance, treatment, and follow-ups, and because of practices, beliefs and attitudes within the healthcare system generally. For instance, it has been suggested that not only language difficulties and the need for interpreter services, but also the attitude of the *Qallunaat*² healthcare professional toward the Inuit patient creates a barrier in communication and understanding which affects the encounter (O'Neill, 1989). It has also been suggested that information provided in the field from one Qallunaat healthcare worker to another "often carries a message that community members are dependent on and have little in common with the providers" (Eng, Salmon & Mullan, 1992:10).

While working as a nurse I experienced the understanding among my colleagues and among other Qallunaat professionals³ that *they* (the Inuit) were different from *us* (the Qallunaat), and as much as I tried to be perceptive, open, and to hear and understand the people I saw in clinic, I probably incorporated this division to some extent. As a nurse, and later working with the TB program for Nunavut's Department of Health and Social Services, I learned that some Inuit stopped medication before their course of treatment was finished,

¹ Nunavut became Canada's newest territory on April 1st, 1999. Prior to that day it was the mid and eastern part of the Northwest Territories. Most of Nunavut's landmass, which covers an area bigger than Europe, is situated above the Arctic Circle and has Greenland as its closest neighbour, to the east. Nunavut has just fewer than 30,000 residents, of which 85% are Inuit (Vincent 1999).

² Qallunaat is the Inuktitut word (east Baffin dialect) describing any non-Inuit person regardless of ethnic background and nationality (Brody, 2000:319). Qallunaaq is the singular of Qallunaat.

³ Professionals include elementary and high school teachers and principals, law enforcement officers, and social workers.

and that healthcare professionals sometimes found it difficult to carry out the surveillance thought necessary, because some community members did not respond to requests to come to the health centre for examination. Both were believed to contribute to the high incidence of TB in Nunavut.

My experience from living and working in Nunavut and from historical and current literature about TB made me wonder how Inuit experience and make meaning of TB, how this is influenced by the protocols employed in relation to TB, and the particular practices, beliefs and attitudes in the healthcare system, and what this means in relation to the continuing high incidence of TB in Nunavut. This led me to pose the following questions, which guided my approach.

1.2 Research questions

1. How do Inuit experience and make meaning of TB?
2. What are the consequences of the TB protocols and regimens on the daily practical, social and emotional lives of individuals, families, and communities? How do these consequences influence the way that Inuit experience and make meaning of TB?
3. How are particular practices and beliefs in the healthcare system manifested in relation to the disease TB, its protocols and its regimens, and how do these practices influence the way that Inuit experience and make meaning of TB?

During fieldwork my research questions did not change; however, as my fieldwork progressed an additional question arose. When discussing which issues might influence the prevalence of TB in Nunavut, one informant suggested:

Another thing that might be, is the government problem, not the government itself, but 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? Why should I be responsible? Let the government take care of it; it's the government's job.

Other informants talked about how being forcibly settled and forcibly schooled by the Qallunaat, and how the imposition of different institutions by Qallunaat, adversely

influenced Inuit society. I realised that it is not possible to *only* examine how Inuit experience and make meaning of TB, and attempt to understand it in the context of specific practices, beliefs and attitudes in the healthcare system, or the use of specific protocols and regimens in relation to TB. Rather, I found it necessary to view these practices, beliefs and attitudes as reflections of general practices, beliefs and attitudes shared by many Qallunaat in Nunavut, and to situate them in the current and historical socio-political context. Testimony such as this compelled me to do so:

I feel like a minority in my own territory.... 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.

Consideration of the effects of the region's history of colonization and current socio-political state on how individuals experience, make meaning of, and respond to the disease, and how this might affect the magnitude of the problem of TB, seemed essential. In other words, Inuit culture and the culture of the healthcare system are only two of several variables among complex networks of factors that account for people's actual behaviour (Pelto & Pelto, 1997) and their feelings about, and experience of a disease. Therefore, I also posed the following research question:

4. How do Nunavut's colonial history and current socio-political state affect the way individuals experience and make meaning of TB, and what effect do they have on the incidence of TB in Nunavut?

1.3 Colonization and the meaning making of TB

In this thesis I argue that colonization bears much responsibility for the way that Inuit experience and make meaning of TB, and for the continuing high incidence of TB in Nunavut. It is responsible on several levels. First, colonization in the Canadian Arctic has historically had, and currently has, a de-culturing effect on the Inuit, which has led to a loss of cultural identity and concomitant social issues such as domestic violence and abuse, alcohol and drug abuse, and levels of education lower than those in the rest of Canada (Hicks &

White, 2000; Lane, Bopp & Bopp, 2003; Statistics Canada, 2004). Second, the history of the healthcare system in the Arctic is colonial. It included “medicalization” of the Inuit, where an increase in “the control of medical professionals and ideology” (Whyte, van der Geest & Hardon, 2002:16) took place through the Arctic healthcare system being designed and healthcare delivered by Qallunaat (Grygier, 1994; McNicoll, Tester, & Kulchyski, 1999; Tester & Kulchyski, 1994). Thus, Inuit “lost control over their own health care,” not only in connection with TB, but also globally (Tester, McNicoll, & Irniq, 2001:136). During the early TB epidemics and after, Inuit learned that medical care is something which is given to them as “passive recipients of Qallunaa[t] largess, and that they have no role to play in its delivery” (ibid.). Third, there is continuing colonization in Nunavut. This is evidenced in the healthcare system, the educational system (Berger, Epp, Moeller, in press; Rasmussen, 2001), and the socio-economic discrepancy between Inuit and other Canadians (Hicks & White, 2000; Statistics Canada, 2004). It is also seen in the present Inuit experience of discrimination (Brody, 2000).

To make the argument, I use experiences and empirical material recorded in Nunavut during five months of fieldwork from October 2003 through February 2004. I also utilise experiences resulting from presenting findings from this fieldwork in several Nunavut settings while teaching there in October and November of 2004. To support the argument I draw on literature from anthropology and other social sciences, as well as medicine, philosophy, and history.

Although I acknowledge that cultural differences exists between the way that Inuit and Qallunaat view the body, health, and disease, I argue that these differences, although essential to acknowledge and respect in the meeting between Inuit and Qallunaat, may have less significance than the effects of historical and continuing colonization on the way that Inuit experience and make meaning of TB, and their approach to health and disease generally.

1.4 A brief history of Arctic colonization

To contextualize this work it is important to know something of the colonial history of the area, which started with Europeans appearing in the 1500s. Beginning in the early 1800s, significant influence was exerted on the Inuit by whalers, explorers, trading companies and missionaries. At that time, and as the pelt and whaling industries waxed and waned, the relationship between the trading companies and some Inuit started to resemble a

feudal one. This resulted in hunger, disease and despair for many Inuit, particularly in the late 1800s and early 1900s (Grygier, 1994; Tester & Kulchyski, 1994).

More focused colonization of the land and its inhabitants by the Canadian government began in the first part of the last century, and peaked in the time of 'relocations,' between the 1930s and 1960s, when Inuit were moved by the Canadian government in order to secure sovereignty (Brody, 1991; Tester & Kulchyski, 1994). During this time the government attempted to assimilate Inuit to mainstream Canadian norms, forcing them into settlements, sedentary living (Aodla-Freeman, 1980; Brody; Tester & Kulchyski), schooling (Aodla-Freeman; Berger, 2001; Napartuk, 2002; Nungak, 2002; Okakok, 1989), and Christianity (Brody; Tester & Kulchyski). As a consequence many became dependant on Southern goods and services (Tester & Kulchyski), and lived in deplorable conditions in houses provided by the government. These were not insulated, had no central heating, running water, or toilet facilities, and most often were comprised of just one room where all activities took place (ibid.). In contrast, houses provided for the Qallunaat administrators, the police, priests, and teachers, generally had modern conveniences (Brody; Grygier, 1994; Tester & Kulchyski). The standard of living in Canada's newest territory is still lagging behind the rest of Canada, as is general health, levels of education, and access to many services. These are indicators of a colonial relationship (Smith, 1999), one that will be discussed further in Chapter 4, and linked to the ways Inuit experience TB.

1.5 The field

Fieldwork took place in two communities in Nunavut where TB was, or had recently been, epidemic. One community was Iqaluit, Nunavut's capital, where approximately 6000 people reside. The other community was among Nunavut's other 27, most of which vary in size from 300 to 1600 people. It was situated in the same region as Iqaluit, the Qikiqtani Region (formerly the Baffin Region). Because Iqaluit is the educational and employment centre of Nunavut, many individuals and families move there temporarily in order to upgrade their education, and others temporarily or permanently to find work. As a result, interviewees represent 6 different communities that vary in size, the degree to which inhabitants speak Inuktitut rather than English, and the degree to which they rely on hunting and fishing activities for food and for the making of skin clothing.

I spent October and November 2003 in Iqaluit, December 2003 in the smaller community, and January and February 2004 in Iqaluit, where I also taught part time at

Nunavut Arctic College. Upon arriving in Iqaluit, I was asked to teach a course on English medical terminology to Inuit medical interpreters⁴, and jumped at the opportunity, as it meant spending my mornings with Inuit who worked in health centres in several of Nunavut's different settlements, and collaborating with an Inuk colleague, who taught the Inuktitut medical terminology in the afternoons.

In Iqaluit I lived at the Arctic College residence with approximately 80 other residents, about 95% Inuit, the majority of whom were mature students. Observing, socialising, conversing, and discussing with my co-residents allowed me to gain knowledge, insight, and experience, which differed from that gained through the formal interviews. In the smaller settlement I rented an apartment. Having previously lived and worked in the community allowed me entrance to conversations and socialising, which would likely not have been possible otherwise.

After teaching the medical terminology course in January and February of 2004, I was invited to return to teach the course again in October and November. I used the opportunity to communicate and discuss the findings from the fieldwork, and formally presented the findings to community members and to the health professionals at the nursing station in the smaller community. In Iqaluit, I formally presented the findings to health professionals (nurses, doctors, and administrators) and to nursing students and their teachers at Arctic College. I also discussed the findings with the interpreter students and people living at the residence, and people from the community.

This feedback supported the conclusions I had drawn from the five months of fieldwork, and my choice of adding a research question on colonization. It also offered me further insights. Throughout the fieldwork, I enjoyed the friendship of two Inuit women who allowed me the privilege of taking part in their lives and families, and with whom I shared many hours of company and talk. I also had the privilege of sharing the confidence and company of many people I formally interviewed, and others who spoke with me casually. In order to respect the people who have volunteered to be interviewed or otherwise share their thoughts and feelings with me, I use pseudonyms for all informants, and have changed personal information that could reveal their identity. When presenting the voices of people from this study, and when referencing my field-notes, the quotes are presented in italics.

⁴ Medical interpreters function as interpreters between health care professionals who are non-Inuktitut speaking and Inuit health-care seekers who are not fluent English speakers. Over an 8-week period human anatomy and physiology and basic pathology as well as the role of the interpreter and other health care team members is reviewed and discussed in both languages.

1.6 Structure of the thesis

In chapter 2 I discuss the methods used to obtain the empirical material, starting with positioning myself, and exploring my influence on the material as researcher and anthropologist. I then discuss how and why formal interviews and informal conversations, observations, and participant observation, were used. I focus particularly on interviewing individuals about their TB illness stories and narratives surrounding TB, and individuals' experiences of a family member's illness with TB, and describe some of the challenges and insights that my methodological choices brought me.

Chapter 3 begins with a review of the aetiology of TB from a biomedical perspective, in order to provide a context for an Inuit view of health and disease as it is described in the sparse current literature on the topic. I then discuss this Inuit view. Both of these sections contextualize the discussion of how contemporary Inuit experience and make meaning of TB, health, and disease generally, and which cultural factors such as social norms and conventions influence these experiences and meaning making processes, as interpreted from the empirical material.

Chapter 4 opens with a discussion of the history of colonialism in the Canadian Arctic and the history of TB and healthcare in the area, which itself is a history of colonization. It continues with a description of TB as it exists and is dealt with in Nunavut today, which, I argue, can be seen largely as a continuation of colonialism. Chapter 3 and the first part of chapter 4 lay the foundation for describing the effects of this history on an Inuit approach to TB, health and disease, and how this history in and of itself affects Inuit health, as exemplified in the empirical material.

Chapter 5 describes the continuing state of colonization in Nunavut as it is described in the literature, and experienced by contemporary Inuit. This leads to a discussion on how this affects the health of contemporary Inuit, and their approach to and ways of making meaning of TB, health, and disease generally.

Chapter 6 provides a summary and discussion of key points from the preceding chapters, and explores the possible implications for public health and public health programming in Nunavut. It includes recommendations based on these implications, and Chapter 7 concludes the thesis with thoughts on colonization and decolonization.

2. Methodology

2.1 Whose story is it anyway? Positioning the researcher

As an anthropologist and researcher, I am positioned and part of my material (Hastrup, 1986; Okely, 1992). I “interpret people’s own interpretations of themselves” (Bruner, cited in Mogensen, 1995:24), and at the same time I serve as my “own informant” because my “response to the informants is...part of the material” (Hastrup, 1986:11). This necessitates that I, not just as an anthropologist as suggested by Bourdieu (2000), but also as a human being, have learned and continue to learn about my self and my practice.

I concur with Briggs when she writes that we are affected by and interpret culture, cultural elements, and intrapersonal transference⁵ differently at different times (Briggs, cited in Chodorov, 1999:204). Briggs’ sentiment was made particularly clear to me during fieldwork. Based on my previous work in Nunavut as a nurse, I had made assumptions about the magnitude of the influence that TB has on people’s lives today, as well as how and why TB influenced them. Spending more time in the community as an anthropologist doing fieldwork rather than as a nurse, and spending more time with Inuit community members while occupying a very different role, I felt some of my assumptions begin to crumble. Furthermore, I often more easily identified with Inuit than with Qallunaat sentiments. This does not imply that I ceased to be affected by my background, or that I can see and understand that which individual Inuit see and understand, but that with my new position my perspective shifted. I am aware then, of the different ways that the same actions, words and sentiments may be interpreted at different times by the same person. Writing this thesis, I have tried to embrace the reflexive ‘I’ and write it into the ethnography (Oakley 1992) in order to situate myself for the reader, “at a determinate point in social space-time” (Bourdieu, 2000:119).

As informants offered their experiences, knowledge and feelings, I also offered the knowledge I have gained through work with, and literature about TB. I did this when asked, and otherwise when my conscience told me to; I found it morally and ethically indefensible not to do so. I also volunteered personal information when asked or when it otherwise seemed appropriate, believing that this provides for an ethically more sound interview situation, and that “finding out about people through interviewing is best achieved when the relationship of

⁵ Chodorov (1999) defines intrapersonal transference as the process in which one person affects the other, and her perception of reality through projection and introjection.

interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her personal identity in the relationship” (Oakley, 1981: 41)⁶.

Involving myself as a person in the interview situation might be interpreted to be leading or suggestive. My presence and interest may, as Bourdieu (2001) argues, engender thoughts about the individual’s or others’ practice that had not previously existed in the informant, and which would then be reflected in the communication. I believe that individuals relaying their experiences, telling their stories to anyone, is part of an ongoing reflection, which contributes to changes in the way that the individual relates to that which was experienced. Through involvement, the interview can become a dialog where both sides contribute, are taken seriously (Mogensen, 1995) and learn. In sum, I concur with Reimer (1996), who believes that the benefits of a personal engaging approach outweigh the possible drawbacks⁷.

Still, I am conscious of being a representative of the colonizing power (Archibald & Crnkowich, 1994), a Qallunaat, and also that I could be viewed as a representative of the healthcare system. This might mean that interviewees would not divulge negative experiences with the healthcare system specifically, or with Qallunaat generally. Thisted (2002), in her book about the contemporary art of storytelling in Greenland, wrote that none of the interviewed Greenlanders spoke negatively about the colonizing regime or the colonizing people, although it would have been obvious to do so. I too experienced this to some degree.

Unlike the people I had casual conversations with, most people I formally interviewed, although they shared very personal and intimate parts of their lives, did not critique Qallunaat or the healthcare system, or they did it very indirectly. Similarly, few interviewees overtly presented local understandings of disease that were different from biomedical understandings, whereas Inuit I had casual conversations with, readily did. This may have been a result of interviewees seeing me as a representative of the biomedical system, and not knowing whether they could trust me to respect their views. Some interviewees, in later casual contact, did share local understandings of disease.

⁶ Oakley (1981), in research on pregnancy and motherhood which she did with pregnant women who became mothers as the research progressed, answered personal questions and questions about pregnancy and labour to the best of her ability.

⁷ Reimer (1996), in her article on Inuit female consciousness, states: “in retrospect I would now suggest that the pretence of neutrality on my part as an interviewer may have been counterproductive... I suspect I would understand more about Inuit women’s lives...if I had taken a more reciprocal approach to interviewing” (ibid.:97).

The differences in that which interviewees and casual conversation partners felt comfortable addressing, speaks to the importance of being immersed in the field, because the “anthropologist and informant are not...equal; both are caught up in a global web of unequal relations” (Farmer, 1999). Interacting as a person rather than an anthropologist makes it easier to untangle or partially shed this web. In an interview situation, where I define the topic of research and ask specific questions, or otherwise lead the conversation, the “asymmetry of power” (Kvale, 1994) is much more tangible. Spending time in people’s homes, visiting, chatting, eating, being silent and just hanging out, taking part in community events, or going for a coffee or to the bar, allowed for more equal togetherness without the role-based power. In these situations I was still Qallunaat, but people did not seem to censor themselves as they might have if I had been perceived as a representative of the healthcare system or colonizing power. In this respect, being Danish rather than Canadian may also have been an advantage, and allowed me to be less associated with the colonizing power.

On the other hand, in social settings two Inuit women got angry with me. I wonder whether it was my representing the colonizing power, my lack of being “streetwise,” or whether it had nothing to do with me. I was not able to understand why, or exactly what had taken place between us in the situations. Retrospectively, I wonder if in one instance my inquisitiveness spurred the anger, realising that this may not be acceptable behaviour⁸. In the other, the fact that I am vegetarian was brought up. Although I neither abide by nor mention this when I visit people and am offered food in Nunavut, somehow the woman knew. In each case these women may have felt that I did not respect Inuit ways, or that I thought Qallunaat ways were superior. They may also have known that I was in Nunavut to do fieldwork as an anthropologist (and Qallunaat) and resent that, given the less than flattering history of research among Canada’s northern population (Menzies, 2001; Rasmussen, 2001; Weber-Pillwax, 1999).

2.2 Interviews and illness stories

2.2.1 Illness narratives, which leave the meaning making to the audience

I used interviews to learn of the informants’ experiences of TB - their illness stories - and frequently learned about participants’ lives, life situations, and thoughts and feelings about other topics at the same time. Retrospectively, I believe that including

⁸ Searles (2000) writes about the unacceptability of asking questions and being asked directly when he did once “why do you ask so many questions” (ibid.: 248)

questions on these topics, or taking more of a ‘life history approach,’ as was done for the book *Saqiyak* about three generations of Inuit women (Wachowich, 2001) would have enriched the material and given me further insight. Although interviewing individuals about their illness stories informed me at many levels about the wider society, socio-culturally and historically, those interviewees who told me general stories about their life, and did not focus on illness stories specifically, allowed me a deeper and wider appreciation of their ways of making meaning of TB and other aspects of their lives which influenced this meaning making. Doing this kind of project through life histories, however, would be very time consuming and would allow for fewer participants.

The choice of interviewing people about their illness stories is based on the work of Kleinman (1988). With his book *The Illness Narratives*, he introduced the usage of narratives with a focus “especially on the patient’s subjective experience and understanding of the illness [and] the crucial importance of *social* and *cultural* factors for the interpretation of symptoms” (Steffen, 1997:99, emphasis added). I believe that illness stories have the ability of revealing “the context in which individuals make decisions regarding their health and showing what elements enter into decisions... since they make visible the logic that links specific events over time” (Yoder, 1997:141).

I have found inspiration for the use of illness stories in the works of Farmer (1992, 1997, 1999, 2005), Good (1994), and Mogensen (1995, 1997)⁹. What these authors have in common, I believe, is that they go beyond a traditional applied medical anthropological model where local knowledge about health, disease, and health practices are identified, often in order to help create and provide “more ‘culturally appropriate messages’ and interventions” (Yoder, 1997:132). These authors show how illness stories also inform about the effects that socio-economics, politics, and history have on health, knowledge and behaviour. They supplement Kleinman’s (1988) earlier work and are supplemented by his later work (1995).

Although Kleinman’s main focus in 1988 was individuals suffering from chronic illnesses, he later expands this focus and defines suffering to be an “interpersonal or intersubjective experience: social suffering” which includes “every different kind of human

⁹ Byron Good (1994), doing fieldwork among Turks suffering from epilepsy, and Hanne Mogensen (1995) in her work among Tongans in the context of AIDS, both build on Kleinman’s idea, and both function as anthropological mediators between the individual’s personal experience and its representation. Through a narrative approach, Good and Mogensen reveal personal and cultural contexts and causalities not taken into account by health care planners and providers, but which affect the individual’s experience of and approach to health, illness and healing. Farmer also builds on Kleinman’s ideas in some of his works, in others he does not make explicit that he uses a narrative approach, although he uses individual illness stories to depict socio-economic, political and historical conditions in the world, and to advocate for political change.

problem that creates pain, distress, and other trials for people to undergo and endure,” and which does not “separate illness from political violence or from other forms of misery” (Kleinman, 1995:15). This definition of suffering is particularly meaningful, and I use it to interpret the illness stories provided by the Inuit participants in this research. These stories and the way they are structured are representations of experiences of the disease TB; they are also, however, representations of experiences of the world, much the same way that the narrative structure of Mogensen’s participants “was not just a reading of AIDS and kahungo, but also a reading of the world in general” (Mogensen, 1995:25). As such, the various illness stories become several common meaning making narratives about TB.

Having read Farmer (1999) and Mogensen (1995) prior to entering the field, I believed that a narrative approach would be useful for understanding how Inuit make meaning of TB. As Thisted (2002)¹⁰ and Wachowich (2001)¹¹ do, I focus on the temporal aspect of narrative and understand it as travel along a trajectory. I understand life to be a journey and behaviour the results of the narrative plot in life, which has one eye to the past and one to the future. Life, as narrative then, is processually organised and “driven forward by causality” (Kirmayer, 2000:172).

In this interpretation I bear Ricoeur’s (1991) argument in mind, that before narrative comes an understanding of the story told which involves “creative imagination” (ibid.:28). This implies that the story told is equivalent to life lived, examined, and interpreted, in order to be more than a mere “biological phenomena” (ibid.:28). Ricoeur, as does Desjarlais¹², also argues for a plot or a “poetics of coherence, continuity and climax - as narrative is usually defined” (Ricoeur, cited in Desjarlais, 1996:86). Ricoeur and Desjarlais see narratives as linearly oriented with a beginning, climax and ending. I believe, however, that “how we hear and tell stories is as much part of our cultural response to the human experience as why we tell the stories in the first place” (Erasmus, 1989:272); the structure of narratives are culturally specific. Narratives are “not necessarily linear...do not necessarily state a problem, develop a plot or provide a resolution” (Rosaldo, cited in Bruner, 1986:18).

¹⁰ Kirsten Thisted (2002) edited a selection of the Greenlandic stories which Karen Littauer taped as interviews to the film *I remember*. Thisted writes that the individual narrator’s chosen stories, when listened to again and analysed, form a temporal narrative. She sees one story as forming the background for the next although the narrator does not claim this connection.

¹¹ Wachowich (2001) edited the life stories of three Inuit women representing three generations.

¹² Desjarlais (1996) did fieldwork in a shelter for homeless and mentally ill people in Boston and found that people there generally did not experience in the way experience is normally understood, as “an inwardly reflexive process that proceeds, coheres and transforms through temporally integrative forms,” and that without ‘experience’ narrative is also lacking (ibid.:72).

Sometimes the narrator may not directly inform the listener of the “point” to his or her story or parts of the story, or the listener may simply fail to understand the implicit point (Erasmus, 1986). To illustrate this, when an informant, Lukta, was talking about her father being examined for TB and I asked her what her mother’s reaction was to the news that her father might have TB, she stated: “*she’s very proud of him.*” Lukta did not feel able to elaborate on her statement (or perhaps did not wish to), apart from adding, “*she does not think he is sick.*” I was left to make sense of the fragments.

Thus, although some Inuit present their stories or part of their stories as occurrences which *were* or *are* (Møller, 2003), and may not explicitly recount or interpret them according to a narrative linearity where plot, “coherence, continuity and climax” are key words (Ricouer, cited in Desjarlais, 1996:86), and in some cases the stories may not even seem relevant to the topic under discussion, I believe that the people I interviewed told their stories in the context that they did because the stories were meaningful in that context. I believe that Inuit, as do Persons of First Nations Ancestry, “recall the significant importance of the story of events, and leave the meaning-making lesson-finding to the audience” (Deloria, cited in Calliou, 1998:44)¹³. This seems to be what happened when a male participant, while talking about his experience with TB as a child, said that they were all very scared. When I asked him what it was they were scared about, he answered:

The whites, because usually the principal was the mean character in the settlement that goes from house to house. They were the people who controlled the town practically in those days. They check up on their students, even 10 at night, to make sure they're sleeping. It was that terrible.

The informant avoided talking about the healthcare staff and system. He did convey, however, that the white colonizers were in control, invoked fear, and that it was terrible. In other words, “we need to find ways to tune in to what people are telling us and why they do” (Wikan 1993:196), and “we need to listen in such a way that we heed the *effect* people are trying to make and the *relevance* of their worlds in terms of how they are positioned and where they want to go rather than the message that their words might seem to

¹³ Deloria also states that non-Persons of First Nations Ancestry, church and state are dependent on “print recorded history,” and in their history writing are “chronologically fixated, striving for objective and linear documentation” (Deloria, as cited in Calliou, 1998: 44).

create” (ibid.:197, emphasis in original). During the fieldwork I sometimes failed to understand the relevance of what the informants were telling me, which I discuss next.

2.2.2 Interviews as a tool for making meaning rather than reaching goals

Interviews did not follow any set pattern, and I used the list of questions in my interview-guide (Kvale, 1994) (Appendix B) only when people seemed to have little to say. I let the conversation unfold, allowing for the following of tangents which seemed important for the interviewee. This, at times, meant that the interviewee talked about very intimate and sometimes very difficult experiences and life situations, and sometimes discussed topics that I, erroneously, at first failed to see the relevance of.

After conducting and listening to several interviews I became aware that despite my desire to let the conversations unfold naturally, I was influenced by a preconceived idea about what the *goal* of the interview was and how it might be reached, and this idea seemed to be different from some of the people I interviewed. Many times I searched for purpose in the conversation. I searched for answers sometimes even to questions still unasked, rather than paying attention to what people told me, the *meaning* they were conveying.

I noticed this difference acutely when interviewing a man who, when asked to talk about his experience with TB, told me many other stories and occurrences which I found difficult to relate to the question. These included having been shot by mistake, having had hepatitis, not wanting to hunt from a community other than his own, and about how the white principal controlled his community when he was a child, as mentioned above. Later, when transcribing and rereading our conversation, I was able to see connections. I believe that this way of relaying information, knowledge, and experiences resembles that which Annahatak (cited in Moquin, 2004) describes. When a colleague asked her why she did not completely elaborate her idea in an article, Annahatak answered that Inuit “don’t put in everything; we give good hints and let people think” (Annahatak, cited in Moquin, 2004:15). Differing ideas about the meaning of an interview, and differing cultural communication patterns have an impact on the outcome of the interview. Trying to reach a certain goal may have distracted me from paying attention, and detracted from my ability to make meaning of what was being said.

Although I believe that variations in knowledge, belief and behaviour is as great within populations as between, I acknowledge Napartuk’s (2002) and Nungak’s (2002) observation that Inuit and Qallunaat, their cultural and traditional values, and their views and

decisions, are different. So are the stories we tell, and the way we choose to tell them, because the way we choose to represent ourselves, our practices, and our beliefs, hinge on our own experiences as well as the cultural, historical, and political context in which we find ourselves.

The outcome of an interview is also dependent on the skill and perceptiveness of the interviewer (Langness & Frank, 1981:43) and the location of the interview, as this can affect participant comfort (Hammersley & Atkinson, 2001). Most interviews with healthcare professionals took place at their place of work, whereas most interviews with Inuit informants took place in their homes, both according to their choice. Inuit who chose to be interviewed away from their home did so mostly because, as one woman said, “*there is no privacy in my house.*” Although valuable for contextualizing the interview, and for observation, some home interviews were not very conducive to the interviewing itself because of multiple distractions. The following example from my field notes (09.02.04) is very descriptive of one such interview situation:

When I came to interview Selima and Jopa, several people were present - Jopa's older son and Selima's boyfriend as well as another adult daughter. A teenaged son and a teenaged daughter and three other adults as well as Jopa's husband came and left, and some came back again. Four young children were present demanding attention. Two of them, a 3 and a 4 year old, were fighting for a toy, screaming at the top of their lungs. The television was running and one adult was talking on the phone while another was sitting on the floor folding laundry. When Selima quietly interfered and the children stopped fighting, one of them suddenly hung with her whole upper body out the window (we were on the second floor) and I yelped. This made Selima and Jopa laugh, say “she always does that,” and let her hang. The two smaller children sat in the couch, each with their baby-bottle filled with blue cool-aid, and different people entered and left the kitchen part of the room, some sitting down to eat and others grabbing something and leaving again.

These distractions generally seemed to exert a greater influence on me than the interviewees, and although subsequent transcribing of the interview was difficult due to extraneous noise, it at the same time gave a very vivid auditory flashback of the interview situation. This exposure to some Inuit living arrangements helped to contextualize the empirical material as I reconsidered and analysed it. The interview became very meaningful through participant observation, although I had initially felt that attempting to interview was meaningless because the ‘goal’ of the interview, finding out how individuals make meaning of TB, was difficult due to distractions and the language barrier.

2.2.3 When both interviewer and interviewee speak English as a second language: “*In Inuktitut I know it*” (Selima)

I did not speak the mother tongue of the majority of the informants, and English is neither my, nor the interviewed Inuit’s first language. In some instances this became a barrier. In two interviews where the interviewees said that an interpreter was not needed, I believe one would have been helpful. The following excerpt, also from the interview with Selima and Jopa, depicts one such interchange:

Selima: What is it TB means like?

Helle: TB, TB, do you know what TB is? (Selima shakes her head). Do you know why are you taking medicine?

Selima: Because (laughs and points to her TST reaction on her forearm).

Helle: That you have this reaction, do you know what that means?

Selima: That we have TB or something?

Helle: Yes; do you know what TB is?

Selima: In Inuktitut I know it.

Helle: Puvalluk?

Selima: Puvalluk.

Helle: Can you tell me what puvalluk means to you? [Brother interjects: puvalluk?] Mmm, puvalluk.

Selima: Puvalluk? [Laughs].

Helle: [It seems to me that Selima and Jopa both think the conversation is somewhat ridiculous. They laugh but do not say

anything. In order to acknowledge my awkwardness I laugh too, and continue.] I know...can you tell me where in your body you get sick with puvalluk?

Selima: I never been sick.

Helle: Okay, but if someone is sick with TB, where in their body are they sick; how are they sick?

Selima: Coughing a lot, fever, spitting.

With the presence of an interpreter I would have been able to pursue Selima's experience of TB as *puvalluk*. Instead, that part of the conversation revolved around TB facts, which I, and I suspect they too, found somewhat ridiculous and frustrating.

The linguists Dorais and Sammons (2002) found that "English encounters problems when it tries to penetrate the Inuit way of thinking; anything connected with the expression of one's innermost self is usually uttered in Inuktitut" (p.108). I too found that some informants had less accessible English vocabulary when it came to expressing feelings. When talking about why she thought that her daughter should stay with her very abusive boyfriend, one woman said: "*Too difficult to explain. Like if I had a lot of thoughts in my head that could come out I would let everyone know my feelings, but I, it just can't go out.*" That I did not speak Inuktitut and interviewees found it difficult to express feelings in English may mean that valuable information is not part of the empirical material.

Three informants spoke only Inuktitut, and an interpreter was utilized for these interviews. Using an interpreter may detract from the intimacy of the interview and from the level of detail obtained in accounts or answers to questions (Larsen, 1995). Because the interpreter may interpret not just words and phrases, but also "emotional realities," there is also a danger of over interpretation (Buur, 1999:63).

I knew the woman who interpreted in the smaller community through previous work, and knew that she was well liked and respected and had a lifetime history in the community. I generally saw her life history in the community, her 'knowing,' as a resource, and I did not detect a difference in the level of sharing of intimate information with, as opposed to without, her participation. Sometimes the interpreter offered her own view on questions, and other times she asked the interviewees to elaborate on their answers. When this happened the interview became even more an intersubjective rendering of the illness narrative, as the interpreter elicited, critiqued and drew "inferences from facets of the

unfolding account” (Ochs & Capps, 2001:2,3). An independent interpreter later heard one of the tapes and judged the interpretation to be excellent.

2.2.5 Other stories

As Garro and Mattingly (2000) do, I believe that “stories can provide a powerful medium for learning and gaining understanding about others by affording a context for insights into what one has not personally experienced” (ibid.:1). Although stories can be seen as “the closest to social logic that we get” (Michael Jackson, lecture, 07.05.03), I do not believe that individual stories or narratives can be used alone because, “where narratives are most coherent, they may also be formulaic and distant from sufferers’ experience” (Kirmayer 2000: 153). The coherent story has already been tied together “in a seamless explanatory framework...avoiding facets of a situation that don’t make sense in the prevailing storyline” (Ochs & Capps, 2001:4), because the story teller, in her attempt to make illness meaningful, consciously or unconsciously tells or omits anything she wishes (Wikan, 2000). What we get is original experience as interpreted, selected and retold by the narrator, where the narrator may have shaped “the moral of the story” (Mattingly, 2000:185).

Because of this, “data-source triangulation” by “respondent validation” (Hammersley & Atkinson, 2000:230) was used where, on several occasions, I interviewed two or more individuals from the same family. Respondent validation should not be seen as an attempt to find one truth. Rather, it allows for the finding of many truths and for a broader understanding. It helps to avoid that ‘a truth’ about culture or behaviour might be devised on the basis of particular and possibly unusual ideas or cases (Pelto & Pelto, 1997).

For example, a father described his adopted son, who had suffered from TB, to be a happy and healthy child. The boy’s birth mother, on the other hand, described him as having been depressed and suicidal because his birth father was imprisoned. The birth mother and the adopted father both saw an accident as contributing to the boy’s illness, although he was not physically hurt by the incident. The adopted father saw the accident to be a result of someone else’s carelessness. The mother saw it to be a result of the boy’s suicidal tendencies, and thought he had brought the accident upon himself purposefully. Thus, the interviewing of two people from the same family allowed for contradictions and confirmations, and enriched the story.

I also drew on accounts from informants “differently located in the setting” (Hammersley & Atkinson, 1999:230) through casual conversations and the interviewing of

healthcare personnel and people from the community. For example, one interviewee said that to her knowledge there had been no TB in her community since “*the old days.*” Another young woman from the same community informed me that 1½ years ago 3 of her family members had active, and several others latent TB, and more than 50 family members were examined for the disease. Relating this information to the initial interviewee prompted the response: “*It is not normal to ask if anything is happening to someone’s family, so people generally won’t know if something is going on with other families in the settlement.*” These occurrences deepened my understanding of people’s experience with TB, and Inuit views of illness and social norms. They also confirmed the limitation of relying on single source data, and my limitations as an outsider in Inuit culture, unable to easily access cultural knowledge to help in understanding people’s actions and beliefs.

2.3 Participation in community life

Observing and participating in community life offers insight into whether the reality of individual stories resonated with the reality of the community, they “anchor and offer *resistance* to a person’s telling-it-as-it- was” (Wikan, 2000:221, emphasis in original). These activities often led me to further insights and richer data. For example, I followed a health worker on her rounds to deliver medication in people’s homes, workplaces and the schools. Participating allowed me to observe interactions and reactions played out in connection with delivering medication, which I knew from delivering medication myself as a nurse, but not from an Inuk healthcare worker’s position. In one case I observed an interaction between the Inuk healthcare worker and a Qallunaat principal.

When we entered the school the principal stopped us and asked us who we were. The health worker explained herself. She had been delivering medication to the students since the school year started more than two months previously, but had never run into the principal. The principal explained that a new procedure had commenced last year, while someone else delivered medication, which demanded that all students who received medication were to do so in the general office. They were to be watched by the secretary, and their names recorded with the secretary’s and healthcare worker’s names and signatures in a binder created for that purpose. Throughout the encounter the principal questioned the integrity of the healthcare worker and also patronized her repeatedly, saying, “*I’m sure you understand that this is a safety procedure.*” The principal disregarded the health worker’s explanation that the students felt safer if she led them individually to a quiet place where they could take their medication,

away from the traffic of the general office. Nor did he recognize that in a small community where everyone knows everyone, some “safety procedures” might create barriers rather than benefits. After her initial explanation, the healthcare worker did not argue.

Living in the communities and spending time with friends, acquaintances, fellow residents, colleagues, students, health professionals, and other community members, participating and observing allowed me to situate the empirical material in a temporal, social, and political context, as did documents such as statistics, protocols, manuals and local newspapers. As demonstrated by the interaction between the principal and health-worker, this was especially useful in confirming participants’ accounts of continuing colonial attitudes and structures in Nunavut.

2.4 Participants

I recruited interviewees on a voluntary basis and included all those who were interested. I reached interviewees through posters, presenting the study to different groups in the community, over the local radio, and with the help of the staff at the community health clinics.

Of 29 Inuit interviewed, 22 were women. Many reasons may account for this, one being that I am a woman, and both men and women are likely more comfortable speaking in the company of their own sex. Another reason may be that speakers with limited power and access to public discourse will use other spaces for expression” (DeVault, 1999:57), because “forms of speaking presuppose the ‘right’ to speak and thus a position within a system of power relations” (Foucault, cited in Good, 1994:186). That many women in Nunavut continue to experience limited power seemed to be a recurring theme among the women that I interviewed, and has been described by others (Archibald & Crnkowich, 1995; Horsman, 1999; Zellerer, 1996). This may have predisposed women to volunteer to be interviewed.

No Inuit with a higher level of formal education elected to be interviewed, which may rest on the fact that the number of Inuit with a higher education and in a high-income group is comparatively small¹⁴ (Hicks & White, 2000; Statistics Canada, 2004). Furthermore, these individuals would have easier access to public discourse because they “tend to have better jobs and higher social standing and the advantages that go with them” (Marmot,

¹⁴ In 1996 5% of Canadian Inuit women aged 25-29 reported that their highest level of education was university, compared to 21% in the general female Canadian population, and the percentage of women above age 15 reporting less than grade nine was 41%, compared to 14% in the general female Canadian population (Jenkins et al., 2003).

1994:210). Thus, they may have less need to voice their concerns or may even experience fewer concerns. Knowing that TB is sociologically patterned (Farmer, 1999) as are diseases generally (Marmot; 1994), and that education is a “powerful predictor of health status” (ibid.:p.210), this group is likely under-represented among people who are or have been infected with TB¹⁵.

It is also possible that people with a higher education would not volunteer to partake in research conducted by a Qallunaat, given the less than flattering history of research among aboriginal peoples generally (Smith, 2002) and Canada’s northern population specifically (Menzies, 2001; Rasmussen, 2001; Weber-Pillwax, 1999). As one well educated Inuk woman in a powerful and well-paid position said to me (adding that I should not take her comment personally), “*I resent the fact that Qallunaat researchers come to Nunavut and tell Inuit what they already know.*”¹⁶

This research, then, describes and analyses the experiences, knowledge, feelings, and thoughts of 29 Inuit interviewed about their experiences of TB. Interview data are contextualised by 5 months (the initial fieldwork) and 2 months (teaching and discussing the initial findings) of living in Nunavut, which included numerous casual conversations with people (mainly Inuit but also Qallunaat), observations of and participation in community life generally, and interviews with 7 Qallunaat health professionals.

3. The *why* and *how* of TB, health and disease

I will first discuss the aetiology of TB as understood in biomedical terms, and how TB is treated today by western medicine. Then I will discuss approaches to knowledge and how Inuit ways of educating differ from those of Qallunaat, before describing an Inuit perception of, and approach to, health, disease and TB as it is presented in current literature. All are important in order to provide context for the presentation of how contemporary Inuit experience, make meaning of and approach health, disease and TB as evidenced in the empirical material. Their importance hinges on the fact that the healthcare system in Nunavut has been, and continues to be, governed and staffed by Euro-Canadians who generally have a biomedical approach to health and disease. Healthcare recipients, on the other hand, are Inuit, who have not traditionally utilised a biomedical approach (see, for example, Balikci, 1970;

¹⁵ I have not been able to access any statistics combining level of education and income with rates of TB infection in Nunavut; however, high levels of TB are associated with poverty and low levels of education in other parts of Canada (HC & CLA, 2000) and the world (Farmer, 1999).

¹⁶ It may, in this connection, be of interest that in some Inuktitut dialects the word for researcher and the word for spy is the same, namely, “*nautsiuriaqti*” (Schneider, 1985:199).

Boas, 1964, 1998; Freuchen, 1961; Rasmussen., 1930, 1931), and in many cases still don't, or at least supplement it with other understandings. I refrain from presenting how the literature describes Inuit traditional approaches to health and disease, because of space constraints and because it is more relevant to discuss a contemporary approach, including those traditional aspects that may have been retained.

3.1 The aetiology of TB from a biomedical point of view

TB is a communicable disease, which means that it is highly infectious and easily disseminated. It is a disease that can reside many places in the body, but in Nunavut is most commonly found in the lungs. The cause for lung TB is the bacteria mycobacterium TB (MBTB).

TB is spread when bacteria leave the infectious person's lungs through sneezing, coughing, singing, breathing heavily, playing, or just talking (HC & CLA, 2000). In order to find out whether an individual has been infected with TB, a Tuberculin Skin Test (TST)¹⁷ may be performed. If this is positive, or if the person had a positive test before, he or she is asked to deliver three sputum samples and have a chest x-ray taken.

The sputum samples show whether MBTB are present, and the x-ray shows whether cavities, inflammation or other changes particular to TB are present in the lungs. If these kinds of changes are present, or if the patient's sputum contains MBTB, the patient has active TB (HC & CLA, 2000). The infected individual produces either a smear positive or a smear negative sputum result¹⁸, and only smear positive individuals are considered infectious. A person with a positive TST, but no bacteria in the sputum, has what is called latent TB. Latent TB is not contagious and the person who is infected is not sick. If the individual does not receive prophylactic treatment, the infection stays dormant in the body, but may at any time in the host's life be activated if the immune system becomes compromised due to factors such as disease, stress, malnutrition, alcohol or drug abuse, or repeated exposure to active contagious TB.

Healing of the initial infection with TB (also called primary TB), which most often occurs in childhood, may take place without any treatment. After spontaneous healing, the

¹⁷ This involves an intradermal injection of a preparation of purified tuberculin into the forearm. The test identifies whether a person has a reaction to tuberculin antigens, which is an indication that he/she has been infected with TB, although he/she is not necessarily active (HC & CLA, 2000).

¹⁸ Smear positive indicates that bacteria are visible with direct microscopy of the sputum sample, whereas smear negative indicates that bacteria are present only after growing on a culture at some point within eight weeks).

person will have latent TB, which may later reactivate as secondary TB. Alternatively, when the individual does not heal or receive treatment, secondary TB may develop directly following the primary disease.

People who have active and contagious TB do not always feel sick. Some feel nothing at all, yet they may still be able to infect other people. People who do feel sick may experience coughing, tiredness, intermittent fever, weight loss, and loss of appetite, as well as a general feeling of malaise and swollen glands around the neck and upper chest (HC & CLA, 2000).

As with other diseases, in western biomedical circles several factors are believed to predispose people to TB. These are; a compromised immune system, which can be caused by stress (Katzenberg, 1987), concomitant diseases (particularly other lung diseases), malnutrition, latent TB, stimulant abuse including tobacco (HC & CLA, 2000), and possibly a genetic factor (Qureshi, Skamene & Malo, 1999); factors such as degree of re-circulation of air where the susceptible person is exposed (CLA 1986; Singh & Singh, 1984), indoor pollutants like burning of biomass fuel or tobacco smoke (Bruce, Perez-Padilla & Albalak, 2000), over-crowded or poor houses and homelessness, low levels of education (Baron, 1998; CLA, 1996); the amount of time spent close to an infected individual (CLA); and lack of sunlight¹⁹ (Gerrad, 1981; HC & CLA, 2000).

3.2 Containment, surveillance and treatment of TB today

The comprehensive Arctic anti-TB program that peaked in the 1960s, and which I describe in section 4.1, led to a steeper decline in TB rates among Inuit than among nations enjoying better infrastructure and medical facilities (Grzybowski et al., 1984). Partially on account of this success, funding for TB programs was reduced in the early 1980s, as “TB seemed to have been eradicated; not wiped out, but really put into a position where it was checked” (personal conversation, former Nunavut Minister of Health, Ed Picco, January, 2004). These cutbacks may play a role in the statistics, which reveal that the steep decline in TB has substantially flattened, with the annual numbers of active cases increasing from the 1980s (Case & White, 1999) and particularly through the latter part of the 1990s (Nunavut Department of Health and Social Services [NDHSS], 2002; Fitzgerald, Wang & Elwood, 2000). TB has continued to hit different communities in the Qikiqtani Region with epidemics over the last 20 years (Case & White, 1999), and has prompted a focus on TB programming,

¹⁹ Ultraviolet light kills MBTB (HC & CLA, 2000).

including the hiring of territorial and regional TB coordinators (Murphy, 2003) and intensified school surveillance (personal conversation, Ed Picco, January, 2004).

When someone is found to have active TB, contact tracing is done to find the source and to find out whether any of the person's family, friends, or colleagues have been affected. This happens immediately, and for some again after three months (NDHSS, 2004). Other surveillance measures include annual TSTs for students in kindergarten, grade 6 and grade 9, which are performed in order to gauge the rate of infectiousness in the communities (ibid.). As a protective measure, all children are given a Bacillus Calmette-Guarin (BCG) immunization at birth (ibid.).

TB can be treated and cured with drugs²⁰. In Nunavut, uncomplicated active TB is generally treated for about six months, initially with a four-drug regimen tapering to two during the last 3 months. In the contagious or acute phase medication is given daily. Those who are minimally contagious (individuals who have few bacteria in their sputum) may stay in the communities for daily treatment with 4 drugs until their sputum samples are no longer positive. This usually takes about 2 weeks. As a precaution in order not to infect anyone else, during this time they are asked to be minimally socially active unless outdoors, preferably only with the people with whom they reside.

Highly contagious individuals go through approximately the same treatment regimen as those who are minimally contagious. Only the first phase, until they are no longer contagious, is spent in isolation at a hospital, most often in Montreal or Yellowknife. The length of stay in hospital depends on the seriousness of the individual's disease. Generally, it lasts between two and four weeks.

Prophylactic treatment, which is given for latent TB to prevent the individual from eventually becoming active, is comprised of one drug for nine months. This treatment is voluntary, but encouraged, although individuals above the age of 35 are no longer customarily offered prophylactic treatment as side effects are much more prevalent in this age group (HC & CLA, 2000).

Both active (once the acute phase is over) and prophylactic treatment are given as direct observed therapy (DOT)²¹, twice a week, either at a health station or at the individual's home/school/ workplace. If a person skips several doses in succession, or skips repeatedly, disease and or contagiousness may develop or redevelop, as might drug resistant TB.

²⁰ There have been few cases of multi-drug resistant TB, which is not easily treated, in Nunavut.

²¹ DOT is recommended by WHO as the best way to ensure that treatment is received (HC & CLA, 2000).

Legislation permits individuals who are active and not adhering to the treatment to be apprehended by the police (Northwest Territories Ministry of Health, 1988).

Contemporary Inuit do not exclude biomedical explanations, but include other explanations and make different correlations as well when they make meaning of TB, and health and disease generally. I will return to this after discussing knowledge and ways of knowing, where I argue that ways of educating are informed by culture, values and ideas. I further argue that it has significance that the culture, values and ideas of the Inuit who are supposed to benefit from health information campaigns, are different from those of the Qallunaat who produce the campaigns, and that one outcome may be that the information conveyed is not received. I also argue that health education that is based on Qallunaat rather than Inuit norms contributes to Inuit continuing to experience colonization.

3.3 Ways of knowing, knowledge production, and knowledge display

Seen from a western public health perspective, the empirical material suggests that many people have limited factual knowledge about TB, its symptoms, aetiology, and treatment. From the same perspective, it seems that although many are able to report that TB has something to do with sickness in the lungs, coughing, and that it can spread from one person to another, many disregard that knowledge.

Hastrup (1999) writes that truth is not a defined entity; it is neither objective nor static. Nor is knowledge. Rather, “knowledge is constituted by the ways in which people categorize, code, process, and impute meaning to their experience” (Arce & Long, 1992:211). In other words, knowing is an active interpretive process where we use data or information and experiences to construct “concepts, models and schemes to make sense of experience, and we continually test and modify these constructions in the light of new experience” (Schwandt, 2000:197). Furthermore, concepts are created within an historical and socio-cultural context, “against a backdrop of shared understandings, practices, language, and so forth” (ibid.). This is also the case with “science and technological practices” (Lock & Kaufert, 1998:6). Ways of exhibiting and sharing our knowledge need to be understood within the same context and against the same backdrop. This means “the grounds for belief and the procedure for validation of knowledge claims will vary” (Arce & Long, 1992:211). Knowledge, ways of transferring it, and ways of exhibiting it, are part of our cultural heritage, our values and ideas. We should expect that people from different cultures have different approaches to its creation and dissemination.

3.3.1 Displaying knowledge

“I never say what I have heard, I only tell what I have experienced, because I do not want to lie” (Angmarlik, 1999: 272).

When asked directly about their knowledge of TB, many interviewees replied that they knew nothing. Connected to this, two entries in my notes are significant. One is written in the field and the other after leaving the field, while transcribing and coding interviews:

I am very conscious of a way of being together that I do not totally understand or master. A way of communicating which is far from clear, which does not explicate anything but suggests a lot, which does not make statements about facts but which inquires about and guesses at things. I guess it is the same sense I get when talking to people about their knowledge about TB. Most people say they do not have much knowledge, and will ask "how do you get TB anyway." This question seems almost obligatory by now.... I've started to question whether people actually do not know or whether they just do not like to come across as all knowing, brash or something. (09.11.03)

Listening to the interviews in light of what Dorais (1996)²² writes about how Inuit use language, it dawns on me that asking factual questions like “tell me what you know about” is likely not appropriate; that if people think they might say something that is not totally accurate, it is as if they are lying. I realize that often when I ask people to tell me something factual, they say, “what I have been hearing is,” or they buffer their answers with “maybe,” “I don’t know” or “could be.” (08.03.04)

Following my fieldwork I read the quote from an interview with Pauloosie Angmarlik (1999), referred to above, which brought home the truth of my reservations.

²² Linguist Louis Jacques Dorais has done extensive research among Inuktituk speaking people. Quoting Taamusi Qumaq, Dorais writes 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/she tells the truth’, that is, through his/her very speech act he or she tells what he/she is actually thinking” (Dorais, 1996:93).

Others, particularly older Inuit, have also expressed that “knowledge is only of value if it is based on experience” (Oosten & Laugrand, 2002: 4). They therefore only share that which they have gained knowledge of through experience (ibid). In my initial approach, likely because of my background in nursing, I was paying attention to cognitive elements as predictors of behaviour (Yoder, 1997). I focussed on the knowledge that people had, as seen from a biomedical perspective, although my interest in the research topic was initially sparked by the perception that differences exist in approaches to, and knowledge about, health and disease, and the belief that this had an effect on the success of health programmes.

Subsequently, I reread the interviews and my field notes with this in mind. Rather than focussing on what people said they did or did not know, and interpreting questions as signalling a lack of knowledge, I focussed on the stories and experiences that people shared with me, and have interpreted their questions to be a form of knowledge confirmation or validation. Doing this made it clear that all Inuit informants have knowledge about and conceptions of TB, and that these, as well as how they relate this knowledge and these conceptions, are informed by various experiences outside and within the healthcare system, and Inuit culture and values.

I now describe some of the differences in Inuit and Qallunaat ways of creating and passing on knowledge, and how they influence an Inuit approach to health education. At home, an Inupiaq²³ child is “taught not to say anything until he or she has observed and observed and *observed*, and feels certain that his or her answer is correct” (Okakok, 1989: 412, emphasis in original; see also Stairs, 1991:282). Qallunaat ways of educating, on the other hand, include giving rewards for correctly memorizing the right answer, “not for careful observation and reasoning,” which is valued in Inuit society (Briggs, 2001:239). Qallunaat educators often reward the students who are vocal, whether they know something or not, in order for the teacher to be able to evaluate their participation and level of understanding (Okakok), and in the Qallunaat education system teacher and book knowledge are taken as facts (Briggs). Conversely, Inuit test knowledge against their own experience (ibid.). Using Bourdieu’s (2001) term, the *habitus*²⁴ of a Qallunaat is to trust the knowledge of the book, to be vocal about her knowledge, to let herself be heard, and if necessary corrected. The *habitus* of an Inuk is *to recount only that which he/she is certain of* (Stairs, 1991), and, has tested

²³ Inupiat (plural of Inupiaq) are a distinct Inuit group residing in Alaska

²⁴ Bourdieu (2001) describes *habitus* as the generative encompassing concept that expresses an agent’s lifestyle; i.e., a total set of personal choices, benefits and practices. The agents’ *habitus*, then, are the “principles behind practices” (p.24) which govern how agents view and classify the world, as well as what they perceive as good or bad, tasteful or tasteless, right or wrong, fine or vulgar.

against his or her own experience, or according to Angmarlik (1999), *has experienced him or herself*.

Forty-year-old Sutiapik's parents had TB and were sent away for 1 ½ years when he was a small child. Now he is being screened for TB in conjunction with his father-in-law being tested. Sutiapik's father-in-law feels well, says he is well, and according to Sutiapik, looks well. Therefore, neither Sutiapik nor his father-in-law believes that he is sick and, according to Sutiapik's wife, neither does she or her mother. When, on my behalf, the clerk interpreter working with TB asked Sutiapik's father-in-law for permission to interview him about his experience, he replied that he did not want to be interviewed because he was not sick, and therefore would just be telling a bunch of lies. This could have been a polite way of saying no, but I believe that because Sutiapik's father-in-law had no personal experience with TB, he felt that he had nothing to share with me.

Thirty-four year old Pingwartok, a college student, has not had TB himself, but recently his sister was treated for latent and his father and little brother for active TB. I asked Pingwartok whether he had any experience with 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 is located). I then 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...it's in the lungs isn't it? What symptoms do people have if they do have it?

Rather than telling me something that may not have been totally accurate and perhaps be accused of lying, having not had personal experience with TB, I believe that Pingwartok, as did many others, chose to let me validate his knowledge by asking me what I knew. Many people who themselves had experiences of TB also asked what TB was. I believe this is connected to Inuit identity. Markers of Inuit identity include not boasting, but

being modest and belittling one's abilities, knowledge and accomplishments (Bennett & Rowley, 2004). I will discuss notions of Inuit identity further in section 3.3.3.

According to the literature then, what many Inuit recognize as knowledge differs from what many Qallunaat recognize, and Inuit and Qallunaat *habitus* regarding knowledge display is different. I believe that many Inuit informants limited expressions of knowledge to that which they have gained through their own experiences, and that some do not embrace knowledge obtained through others' experiences or educational campaigns. Furthermore, knowledge that people do have may not be displayed because markers of Inuit identity include being modest about knowledge and abilities. The knowledge that people have and display is not only dependent on how knowledge and knowledge display is valued, but also on what kind of information is accessible and in what ways.

3.3.2 Creating Knowledge

“People just leave their stories everywhere, and nobody's bothering to read them”
(Sutiapik).

Most Inuit informants expressed that the information about TB which is disseminated or available in their home community²⁵, is not noticed and paid attention to by many, and that few feel that it is relevant if they do not have active TB themselves. As Pingwartok 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.”* Sutiapik said something similar. I asked him if he knew anything about TB prior to reading a pamphlet, which he read *“out of boredom”* waiting to have his x-ray taken at the hospital. He replied: *“No, I didn't bother with it. So, judging by what other people are doing they won't bother reading those pamphlets unless it's too late I guess.”* Later in the interview, when discussing what could be done differently in order to reach people with educational campaigns, Sutiapik said:

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. People are just leaving their stories everywhere and nobody's bothering to read them. If you write it on

²⁵ 13 out of 29 Inuit interviewees had no recollection of seeing or hearing any information about TB in their community.

paper or put it on the wall, nobody will touch it; nobody really reads medical things.

Nawdlak, who is 40 years old and has active TB, echoed Sutiapik when I asked her if she had noticed or heard any information about TB in her community. She said: *“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.”*

Before the introduction of Euro-Canadian 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, and Berger (2001), who researched adaptations southern teachers make in order to teach Inuit students successfully, found that including elders and storytelling in the curriculum and the inclusion of more participatory activities were valuable.

Therrien (2001) makes another pertinent point: “In Inuit societies, medical knowledge never existed as an autonomous and formal body of knowledge as in modern Western societies” (ibid.: 1); therefore, much of the information available on TB may be seen by Inuit to be out of context. Dei et al. (2000), writing about North American indigenous knowledge, state that it includes “cultural knowledges of local people concerning everyday realities of living” which “are part of cultural heritage and histories of peoples” (ibid.:49,50). 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). I believe this is also the case for Inuit in Nunavut. One reason why information about TB is not accessible to Inuit may be found in the mould in which the information has been cast, one that is Euro-Canadian. Euro-Canadian ways of educating often work poorly when educating people who are not Euro-Canadian (Berger, 2001; Okakok, 1989, Stairs, 1991; Ryan, 1989), and worse, utilising Euro-Canadian or Euro-American ways of educating outside of these societies may teach students “to reject their own culture” (Okakok, 1989: 407).

Foucault’s (1990) notion that “where there is power there is resistance” (ibid.:95) may be embodied here. Presenting western biomedical health information using Euro-

Canadian methods in an Inuit society dismisses Inuit ways of understanding and learning. It reinforces that Qallunaat knowledge is superior to Inuit knowledge and sends the message implicitly that it is to Inuit's benefit to learn from and listen to the advice given by Qallunaat. It is in this connection that knowledge becomes power (Foucault), because the hegemonic Qallunaat knowledge implicitly, as well as explicitly directs Inuit actions and interactions. Being the possessors of the 'right' knowledge allows the Qallunaat the power to assume responsibility for life processes, including health and disease, and to control them (Foucault, 1991:264).

One way of offering resistance to the colonizing power may be to not pay attention to the messages communicated by that power, particularly when content and form differ from those Inuit would chose. In chapter 4 I elaborate further on Foucault's ideas of knowledge, power and resistance, and their ability to explain Inuit and Qallunaat behaviour.

Another reason why not much information about TB is received may be because not much is actually available or disseminated. Nelly, who had been in Nunavut the past four years and had worked with TB the last two years, thought that health professionals "*concentrate...so much on the clinical and acute and the treatment aspect that nobody really thinks about education and prevention,*" and Rita, who worked in the north for more than 15 years, didn't "*think there is a good public education of TB at all.*" She said that some, particularly transient, nurses do not believe that doing public health education in the schools and communities or having relations about health issues with the mayor is a nursing role. She also does not believe that "*there is a knowledge base [about TB] in nursing.*"

Thirty four year old Shelly has two children who receive treatment for latent TB. Shelly had the same opinion as Rita. She said that she never received any information about TB upon discovering that her children had a positive TST test, and added: "*It is never the same person who gives the children medication. I always have to explain what they have to do and why to a new person.*" Quaraq, who has worked as a healthcare worker with the TB program for a number of years, noted that nurses were not always available to be responsible for the TB program, and that she always needed to "*explain everything*" to the new nurses.

Inuit reported that not much information is available in their communities and not much health education on TB takes place. Little information has been disseminated from the health care system, as expressed by some health professionals, and where there is information, the way it is disseminated is inappropriate for Inuit ways of learning. Finally, health education is presented out of context, and the form and content are representations of

Euro-Canadian or colonising ideologies, rather than Inuit ideologies. This may inspire resistance to receiving the communicated messages.

Another factor which may make the material presented seem out of context is the fact, as suggested by Therrien & Qamaq (1992), that “Inuit and Qallunaat ideas and practices concerning the body are different,” and although “the body is biologically the same for all human beings, all human beings do not share [the] same understanding about body, health and sickness” (ibid:1). I discuss this further below.

3.4 The experience and meaning making of health, illness, disease and cure among Inuit

Because Inuit are “genetically distinct” and live under very special conditions, they have been seen as offering particularly “interesting opportunities for the study of natural history of disease” (Bjerregaard, Mulvad & Olsen, 2003:7). As a result, much has been written about Inuit health, illness, disease, treatment, and cure generally, and about TB specifically, seen from a biomedical perspective²⁶. Early anthropological works on Inuit life and culture include descriptions of their approaches to disease, medicines and cure (for example, Balikci, 1970; Boas, 1964, 1998; Freuchen, 1961; Rasmussen, 1930, 1931). Those works were, however, part of a much larger cultural inquiry, and the descriptions of health and disease often focused on exotic beliefs, curing practices, magic, and fetishism. In the beginning of the 1970s, when medical anthropology grew as a specialized field, indigenous medical practices and medicines were placed “in relation to the cosmology, ritual and knowledge of a local (often ethnic) group,” and seemingly exotic healing practices were shown to make sense (Whyte, van der Geest & Hardon, 2002: 10). At the same time, “a homogenous, static view of local culture and society” was often presented (ibid).

In the 1980s a change took place in philosophical and anthropological thought. This change included a shift in understanding of culture from one that was structuralistic and modernistic to one that was post-structural and post-modern (Hastrup, 1999), a shift from relying on meta-narratives to recognizing that cultures cannot be finitely described (ibid.). This change also had an impact on recent work done among Inuit dealing with health and

²⁶ *The International Journal of Circumpolar Health* (formerly *Arctic Medical Research*), which has existed since 1984 and is currently issued 4 times a year, deals with the health and diseases of Arctic peoples, among those the Inuit. Several books and chapters in books, and articles have also been written addressing the topic; more recent works include: Shephard & Rode’s (1996) *Health consequences of modernization: Evidence from circumpolar people Inuit*; Bjerregaard & Young’s (1998) *The circumpolar Inuit: Health of a population in transition*; Harvald & Hart-Hansen’s (2000) *Chapter 11: Arctic medical science* in Nuttall & Callaghan (eds.) *The Arctic*. Literature dealing specifically with TB from a bio-medical perspective includes, to name a few: Bjerregaard, 1995; Grzybowski, Stylbo & Dorken, 1976; Schaeffer, 1959; Wherret, 1969).

disease. Sparse literature is available on the subject, and this work is characterised by not being highly theorized. As a consequence of this paradigm shift, the voices that we hear in this recent, small body of literature are mainly those of Inuit rather than those of the anthropologists or other scholars who have edited or compiled the works. I draw on these voices in the following discussion on Inuit experience and meaning making of illness, disease, healing and cure, both generally and specifically regarding TB.

3.4.1 Good health allows Inuit to do whatever they want

“[When I am healthy] I can do whatever I want. I have no misfortune”

(Qumaq, cited in Therrien & Qumaq, 1992:10-11).

Health is a “complex reality” consisting of “*breath (anirmiq), soul (tarniq), [and] name (atiq),*” and harmony and peace need to exist between and within these essential components of the human body for an individual to remain healthy (Therrien and Qumaq, 1992:11, emphasis in original). Borré (1994) researched the connection between seal and health in Clyde River on North Baffin Island. He explains that *tiimiut* is the physical body and its functions, and *tarn[i]g*, the mind, the emotional state, and the expression of consciousness. The integration of the two is that which creates a person. Health is present when “*tiimiut* and *tarneg* are adequately nourished and at peace with other sensate beings and the environment” (ibid.:5). Qumaq further explains health as “the absence of misfortune” (Therrien & Qumaq: 10), and that when an Inuk is *qanuinngituq*²⁷ he is comfortable, is deprived of nothing, has no disorder, has no need of care and is independent. Health is a state of balance or harmony, *isuaqtuq* (ibid.). Health, furthermore, “allows one to fulfil personal needs, the family’s needs, and social needs and results in a feeling of control and contentment which in turn generates high self-esteem” (Borré:5).

Both younger and older Inuit state that for people to be healthy they need to be physically, socially, and mentally able and active (Atagutsiak, 2001, Ootoova, 2001; Shea, 1989)²⁸, otherwise they will become “lazy, think too much and get sad” (Uyarasuk, 1999:264)²⁹. Many Inuit state that a healthy person is a happy person with happy family

²⁷ ‘Qanuipit’ is the Inuktitut translation of ‘how are you?’ It means literally “what is wrong with you?” In order to answer in the positive, that I am fine or well, I say ‘qanuinni.’ This is the negative form, that I do not have any misfortune; there is nothing wrong with me (Therrien & Qumaq, 1992: 10). Qanuinnigitug then, is equivalent to saying “he or she is well.”

²⁸ Ootoova and Atagutsiak were both interviewed for the series *Interviewing Inuit Elders* in the (2001) volume titled *Perspectives on Traditional Health* by Ootoova et al., which was edited by Michele Therrien & Frederic Laugrand. Shea’s (1989) study focused on concepts of health among young Inuit adolescents.

²⁹ Uyarasuk was interviewed for the (1999) book, *In the words of elders*.

relations (Ootoova, 2001; Shea), and in order to stay healthy it is necessary to have a cheerful demeanour, not to worry about things, and not to carry anger inside (Ootoova, 2001). As an older woman told Borré (1994), “you have to be happy to be healthy and you can’t be happy without country food” (ibid.: 9).

The eating of country foods or food from the land (or sea)³⁰ is thus also part of maintaining optimal health and preventing sickness (Borré, 1991, 1994; Freeman, 1992; Al Joamie, 2001; Pitseolak, 2001; Shea 1989), as is going out on the land (or sea), and the hunting, procuring, and sharing of land-foods (Borré; Freeman; Shea).

Although differing interpretations exist, current literature on Inuit concepts of health and disease agree that health is a combination of a strong mind in a healthy body. Being healthy means that the individual can do whatever he or she wants, is independent, and autonomous, though health is not an altogether individual matter. Rather, health is a holistic concept where harmony and balance need to exist between mind, body, and spirit, in interpersonal relations, and relations to game and the environment.

The maintenance of balance is important for health. I now explore what causes imbalance to occur, and mental or physical disease to develop. I also explore what can be done to restore this balance, and thus return to health.

3.4.2 Being sick and getting well

That so little current literature exists about how Inuit experience and make meaning of sickness and disease may be because, as McGrath (1991) writes, Inuit traditionally knew how to die, but did not, through tradition, learn how to deal with being seriously sick or disabled. As Donald Suluk states, “it has been said that one of the hardest things to do is cure a sick person” (cited in Bennett and Rowley, 2004:209). Interviews with and works written by Inuit and non-Inuit express the view that prior to settlement living or prolonged contact with Europeans, Inuit were seldom sick, and very rarely seriously sick, if they were not dying (Awa, 1999; McElroy & Townsend, 1985). For common ailments like earaches, stomach aches, infections, boils, injuries such as cuts, and broken and dislocated bones, remedies and cures existed and still do exist (Angugaatiaq, 1980; Awa, 1999; Bennett

³⁰ Food from the land, or country food, includes any food harvested by the Inuit themselves in proximity to their own settlement or which has been sent from family and friends from other settlements, around which it has been harvested. Seal, caribou, and beluga meat as well as char are common, but country food also includes walrus, narwhal, clams, geese and ducks, ptarmigan and other fowl and game, and local plants and berries, which vary from settlement to settlement.

& Rowley, 2004), and according to Inuit memory, people tended to heal quickly (Ootoova 2001; Awa).

When Inuit started to experience serious physical sickness through epidemics of diseases brought by the Qallunaat, among others TB, they were at a loss in terms of how to deal with them. Through the early TB epidemics Inuit learned that others, the Qallunaat, knew how to deal with these diseases, and that they were expected to comply with Qallunaat ways (McGrath, 1991; Minor, 1994, Tester & Kulchyski, 1994). When whalers, explorers and missionaries entered the Arctic, they brought diseases and sometimes also different kinds of treatment. During the TB epidemics of the mid-1900s, Inuit were sent to southern hospitals and were treated solely by Qallunaat. The people who did not receive Qallunaat treatment often died. Later, Qallunaat initiatives included the sending of Inuit women to southern hospitals to give birth (Bjerregaard & Young, 1998).

Inuit maintain notions about disease and cure that are different from notions maintained in western bio-medicine. For many Inuit sickness requires a holistic approach, and “mind, spirit, and physical body of the [sick] individual all [require] tending” (Bennett & Rowley, 2004: 219). Because “our mind is part of our body” (Atagutsiaq, 2001:96), mental pain has to be dealt with in order for a person to heal physically.

“Sickness is said to come from outside the body and have the ability to travel through the body,” and “therapeutic treatment implies the coming out of the offensive element” (Therrien & Laugrand, 2001:2). This might be in the form of a rash on the skin, passing blood from one of the orifices, or through speech (ibid.). For healing to occur at least two conditions need to be fulfilled, “the extraction of the offensive element from the body” (in the case of depression, talking it out), and “rehabilitation of the sick person in the community and eventually among the ancestors” (ibid.).

Although historically Inuit were not supposed to talk about bad, sad or difficult experiences, and many have been brought up this way, many Inuit today stress the benefit of talking about that which weighs them down mentally in order to get through it (Atagutsiaq, 2001; Kral et al., 2000; Ootoova 2001; Uyarasuk, 1999). Some state that if they do not talk, but keep worrying and being tense, they might not recover from mental or physical illness or they might become physically sick (Awa, 1999).

The participants in Rasing’s study of social order and non-conformity among Inuit in Igloodik mentioned open disclosure to be “a major strategy for dealing with unhappiness, depression, worry, anxiety, guilt, etc.” (Raising, cited in Korhonen, 2002:49). People need to

disclose their hurts, and the person who might have hurt them needs to apologize. After an apology has been given and the person has had the possibility to talk through the hurt, it is possible to forgive and start recovering (Korhonen). Words have healing power (Therrien & Laugrand, 2001).

Words, however, are not only seen to be healing, they can also hurt. Therefore, not everything shall be talked about. Transgressing social norms and conventions and for example talking, or even thinking badly or negatively about people (Katsak, 1999b; Ak Joamie, 2001; Al Joamie, 2001), or behaving disrespectfully towards people or animals may cause illness or other misfortune in the offender or his or her loved ones (Al Joamie; Ak Joamie). An elder; Imaruittuq relates a story about a man who shot and wounded a caribou and cut its nose off and ate it while the animal was still alive. Subsequently the man's nose decayed and fell off (Aupilaarjuk et al., 1999). And Lucassie, another elder stated that "we are disciplined for our actions through the weather" (ibid.:5).

Silence was and is still seen to have healing properties. Minor (1992) stresses the importance of the concept of *ajurnarmat*³¹, the silent acceptance of that which cannot be changed. She states that "the ability of Inuit to accept things as they are alleviated a tremendous amount of interpersonal struggle and clarified interactions and expectations" and continues that *if* someone asked for help he or she did so thinking that "there was a chance that the situation could be changed to benefit his own emotional health" (ibid.:54). Minor also mentions that silence can be healing in times of grief and stress when the one suffering shares the silent company of others who will "offer a warm and human, yet silent, companionship" (ibid.:55). This group support will strengthen the one grieving and enable him or her to move forward, while not burdening others. The key, though, is that the struggle and the healing is a group effort. This is also the case with physical illness.

As Bennett and Rowley (2004) write, "when individuals fell sick, the family members tried everything to assist them" (ibid.:219). All attempts are made to provide a sick individual with the food that she desires (ibid.; Al Joamie, 2001; Pitseolak, 2001). Particularly food from the land is helpful in the attempt to cure sickness, and certain animals or parts of animals are good for restoring health in case of certain illnesses (Angugaatiaq, 1980; Awa, 1999; Borré, 1994; Therrien & Laugrand, 2001). Attempts are also made to ensure that particular individuals the sick wish to see are present (Bennett & Rowley, 219).

³¹ Minor (1992) conceptualises *ajurnarmat* as the idea that "things are the way they are, and it makes no practical sense to despair over something that has already occurred and cannot be changed" (ibid.:53).

Sickness then, is something that comes from outside the body and has the ability to travel through the body. Often the reason that an illness invades a person's physical boundary is due to unbalance within the individual because of held-in anger, hurt, or other emotional stress, or because of the transgression of social conventions. Subsequently health can be regained by restoring balance. The healing process will often involve the passing of the offensive element from the body, either physically or verbally, and acceptance, communal silence, and the eating of special foods and company of special people can be helpful in both maintaining and restoring health.

3.4.3 Identity and health

Freeman (1992) writes that self-image or identity is central to the discussion on an Inuit conceptualisation of health and disease. This connection seems particularly pertinent, as many authors indicate that one effect of colonization on some colonized people includes a decrease in feelings of cultural identity (Dei et al. 1999; Smith, 2002). Furthermore, it has been said that individuals with "a solid foundation in their traditional culture are better adapted to subsequent stresses of life" (Freeman:2,3), and it has been suggested that acculturative stress is connected to increased susceptibility to physical and mental illness (Lane, Bopp & Bopp, 2003; Freeman.1992). I now discuss the notion of identity, highlight aspects of Inuit identity as described in the literature, and end with a description of the ways in which Inuit conceptions of health and notions of identity may be connected.

Dorais & Searles (2001) review classic as well as more recent work on identity and argues that collective or cultural identities and individual identities are social constructs used as a means to relate to other people and groups, "rendered malleable by exigencies of history and social experience" (ibid:17). As such, they become "manifest through dynamic processes" (ibid.), through the interactions and relations between people from different groups and social categories and through claims made for "political power, economic equality and social justice" (ibid.). Identity presupposes a "degree of conformity" and a sense of affiliation to one's fellows. It also presupposes that one is different from people not belonging to one's group (Jenkins, cited in Dorais:18), and that one possesses the power to act in a way that reflects one's values and ideas about oneself (Hensel, 2001). "Having an identity means that you can act on your surroundings. Individuals and groups, by acting on social situations, impose meaning on them and by so doing exert a degree of symbolic control" (Dybbroe, 1996:42).

Much has been written on that which is specific to Inuit identity. Stairs, for example, writes that *Inummarik*, which means “a most genuine person,” is “the basis for Inuit identity” (Stairs, 1992:117), and becoming *Inummarik* requires the development and maintenance of *correct interactions* with people, animals, and community. Other markers include being independent, autonomous (Bennett & Rowley, 2001; Briggs, 1970, 1982, 2001; Brody, 1991), able to respect others’ independence and autonomy (Briggs; Searles, 2000), social, generous, kind, and nurturing (Bennett & Rowley, 1994; Briggs, 2001; Stairs, 1992), not being inquisitive or interfering (Stairs; Brody; Searles), but humble, modest and discrete, disciplined (Bennett & Rowley), and not moody or aggressive (Briggs, 1970; 2001; Brody, 1991). Inuit identity is also closely tied to partaking in the procuring and eating of land-foods (Borre, 1994; Freeman 1992; Hensel, 2001; Rasing, 1999; Therrien, 2001) and to feelings of self-determination (Dybbroe, 1996; Searles, 2001).

Although few authors implicitly include ideas about identity in discussions of health, one exception is Freeman (1992). Writing on environment, society, health, and quality of life issues in the North, and after stating that a person’s quality of life depends on his self-image or sense of identity, Freeman continues that “a positive self image results more often than not in the perception that life is good, and that the effort required to improve one’s well-being is both worth-while and likely to be successful” (ibid.:3). Qamaq likewise combines health with several of the above mentioned notions of identity, stating that the healthy Inuk is independent and able to do whatever he wants, is able to “work, hunt, bring home food” and visit his family (Therrien & Qamag, 1992:1). Borré, although not making explicit the connection between health and identity, writes that: “health allows one to fulfil personal needs, the family’s needs, and social needs and results in a feeling of control and contentment which in turn generates high self-esteem” (1994:5).

I have discussed ideas about identity, and highlighted aspects of Inuit identity which include both emotive and social qualities such as being able to develop and maintain correct interactions, independence and autonomy, humility, non-aggressiveness and non-inquisitiveness, generosity, and nurturing. It also includes practical abilities such as being able to procure and eat land-foods, and it is tied to a sense of self-determination. Many of these qualities are the same ones that Inuit are said to need in order to be healthy. I have also pointed out that an effect of colonization is a decrease in cultural identity of the colonized, which authors have connected to development of disease. In the following, I focus on that which informants connect with the development of disease.

3.5 Correct interactions...with people, animals, community and environment

The basis for Inuit identity, *Inummarik*, includes the development and maintenance of “*correct interactions* through both attitude and skill with people, and animals, community and environment” (Stairs, 1992:117, emphasis in original). An *Inummarik* or “most genuine” Inuk (ibid.) is healthy when body and soul “are adequately nourished and at peace with other sensate beings and the environment” (Borré, 1994:5). If, as discussed in section 3.2.2, a person is not at peace and does not interact correctly with other humans, animals, or the environment, disease or other misfortune might befall him or her. This belief is the focus of the coming discussion, where I argue that Inuit knowledge about health and disease includes that individuals fall ill because of breaching social norms and conventions.

3.5.1 How people get sick and why exactly *they* do

Twenty eight year old Makituk, who had latent TB in 1993 and whose parents both had it, stated that her young son Ezeevadluq, who had active TB less than 6 months ago, had brought the disease (along with other misfortune) upon himself for wanting to commit suicide due to his father’s imprisonment for murder. The father committed murder shortly after Ezeevadluq was conceived. Makituk blamed her son for his own disease. Similarly, 48 year old Jukipa, who had TB several times in her childhood and youth and was sent out of her community several times, told me that her mother did the same; she blamed Jukipa for falling ill.

Many interviewees (about 40 %) expressed fear of being judged, blamed, avoided, and gossiped about if it became known that they had TB. As Iqajuktaq stated, “*having TB is like having the plague;*” when people get TB “*they just wanna be isolated ‘cause nobody’s gonna know that she’s got TB, cause otherwise she’s gonna be avoided.*” Quarak, who as a clerk interpreter works with TB, agreed:

I’ve seen people who were shy coming here to take their medication ‘cause they don’t want other people to know they have the disease, ‘cause the people might start to think, aah this person has the disease so I should stay away from her. Some [people] aren’t very pleasant. I mean like they start to blame them [the infected] for having gotten it like it is their own fault.

Nineteen-year-old Tye, who was infected with active TB two years ago and who comes from a community where TB had not been present for many years, but where there was recently an outbreak, expressed a similar sentiment. She said that the general perception in her community was that people get TB because “*of how people are, how they live.*” In her experience many community members, regardless of age, gossip about and avoid the people who have TB.

It appears that disease becomes a stigma in and of itself. I believe this is connected to the idea that disease or other misfortune befalls those who transgress social norms, as discussed previously. Although the literature stresses the benefit of talking about that which weighs you down mentally in order to recover from mental or physical illness or not fall ill, more than two thirds of Inuit interviewees and many others mentioned that discussing bad health or bad experiences is not done in their families. Some regret this, while others prefer that it stay that way.

The stigma of disease may partially explain why this is so. It may also explain why one of the two young women, discussed earlier, did not know that 50 of the other young woman’s family members had recently been tested for TB, and that several of them had been infected with the disease. Markers of Inuit identity such as non-interference and non-inquisitiveness (see 3.2.3) may also play a role. As the young woman said when I told her about the recent outbreak, “*it is not normal to ask if anything is happening to someone’s family, so people generally won’t know if something is going on with other families in the settlement.*”

Returning to the field for two months in the fall of 2004, I asked several Inuit whether it is generally accepted that social imbalance, talking badly about other people, and behaving socially inappropriately, can cause the offender or his/her relatives to become sick, and many concurred. Mainly, however, they concurred by saying how people other than themselves hold this conviction, without saying directly what they themselves believed it.

Twenty-five year old Tomasi, for example, said that his father was the sole survivor of a big family after a TB epidemic struck his childhood community in the 1950s. He said that other community members blame the family’s misfortune on “*something that someone had done wrong in the family.*” He said that his father’s family is still affected by those actions, and blamed when misfortune happens.

Aloo, a woman in her mid-forties, said that the recent suicides of several of her family members are blamed on socially inappropriate actions committed by her deceased

father. She said that she is blamed in her home community for having brought the sexual and physical abuse, which she suffered as a younger woman and recently, upon herself, by the mere fact that she is her father's daughter. Arnaituq, who is a 40 year-old woman, said that her father blames the hand tremor of a man from their community who suffers from Parkinson's disease on his long history of stealing. Oosten and Laugrand (2002) write that in the past, when cosmic or social norms were transgressed, it "would not only affect the offenders but also their relatives and their descendants" (ibid.:6). This seems also to apply today.

Many Inuit informants, after telling me about the *how* of TB, that it is an airborne, bacterial disease transmitted from one person to another, asked me, "*How do we get TB? What causes it?*" or "*Why do we get it?*". Nawdlak, for example, on the initial as well as the follow-up interview, asked *why* she got TB, and kept coming back to it. She also asked me "*how come these people don't have TB and I do?*" And she said that her family asked her the same question when she told them that she had active TB. Tye's response to becoming infected with TB was, "*why does it have to be me? Why do [I get] all these worse things?*" Twenty six-year old Mialia, after describing where she got TB from and how, said, "*how come I got it, how come my brothers didn't catch it.*"

Evans-Pritchard, who lived among the Sub-Saharan Azande people, wrote that they had explanations similar to those used by many Europeans about *how* people got sick or had accidents or other misfortune. At the same time, they had explanations for *why* particularly those people got sick, or were the victims of accidents or misfortunes. The Azande's answers were witchcraft, transgression of social norms, or violation of customary law (Evans-Pritchard, 1937). Other scholars have written about peoples who have explained illnesses, death or misfortune by combining the *why* of witchcraft, social transgressions or other violations with the *how* of biomedicine (for example: Farmer, 1993, 1994, 1997, 1999; Mogensen, 1994, 1997; Vecchiato, 1997). While no informants mentioned witchcraft or shamanism, I believe that like the Azande, some Inuit explain the occurrence, the *how* of disease or misfortune in particular individuals, with the transgression of social norms and conventions, the *why*.

For some Inuit, spirits of deceased ancestors, as well as animals, the land, and the environment in general, have the ability to bless humans with good fortune, useful weather, plentiful wildlife, health, and happiness, when humans fulfil their obligations and uphold taboos and social conventions (Aupilaarjuk et al., 1999; Bennett & Rowley, 2003). At the

same time misfortune like bad weather, lack of wildlife, hunger, starvation, disease, and accidents would occur if these obligations were not fulfilled or taboos and social conventions were not upheld (ibid.).

No informants spoke of witchcraft or taboos; many, however, declared themselves to be Christians and said that our thoughts, feelings, and actions are witnessed by God, who will deal with our sins while we live, or at the Day of Judgement when we die. The power to cause fortune or misfortune, health or disease, which traditionally was possessed by shamans and spirits, may today be viewed as divine providence. In a conversation with one Inuit man and four Inuit women, each one said that Judgement Day occurs after death, and that all actions, thoughts and feelings of the individual are weighed. It is decided whether he or she is to be sent to Heaven or Hell. Aningmiuq, a 22-year old woman who had TB as a child, and whose 5-year-old son presently receives prophylactic treatment, also believes in Judgement Day, and states that those who commit suicide will go to Hell. Elders interviewed for the series *Interviewing Inuit Elders* hold similar opinions. Aupilaarjuk, for example, states that in the past, the Angakkuit³² were able to discern if someone had done something wrong, and people would have to disclose their wrong doings. Today he says, “we keep things hidden. Only God knows. These things will all come out on Judgment Day” (Aupilaarjuq et al., 1999:23).

Many interviewees, while understanding the ‘*how*’ of TB from a western medical perspective, are searching for a ‘*why*’ for TB. I believe that the *why* of the disease may be understood as a result of a breach of social norms and conventions, perhaps even by a family member, resulting in the development of disease. The link between the transgression of social norms and disease, in turn, may cause sick individuals to be blamed, gossiped about, and avoided. I suggest that today, the punishment of individuals for these transgressions may be understood as divine intervention, rather than, as it was traditionally understood, as the result of the activities of shamans (Aupilaarjuk, 1999).

If transgression of social norms does not lead to disease, it still leads to gossip and avoidance. This may have other implications for a person infected with TB, which I discuss next.

³² Angakkuit is the plural form of angakkuit which means shaman (Aupilaarjuk et al. 1999)

3.5.2 The impact of proper social conduct

“I can't say don't come visit ...that's not right” (Nawdlak).

An example of proper social conduct for many Inuit is to leave their doors open and welcome visitors into their homes. Many participants stressed that it is not acceptable to deny friends or relatives the right to visit. This is also true for people who have active TB and are treated in the community during the initial contagious state. Nawdlak confirmed that even if you are sick, *“it is still not right.”* Jukipa said, *“I would find that very hard because everybody's related to everybody in a small community.... We're very closely knitted. It's impossible.”* Pingwartok, Quarak and Tasiutaq all said that they would find it hard to say no to visitors, even for a short period, that people would be gossiping about them, that they would probably manage, but that they would prefer to be sent away if diagnosed with active TB. Mialia, who was initially treated at home and had to tell people not to visit, ended up asking to be admitted to hospital because she found it too difficult. She said that her brother-in-laws frequently visited, and telling them not to would

make them feel uncomfortable, like “why is she acting like this,” like “how come I can't visit my own brother - she shouldn't be like that;” and then they [will] start calling me names. I know they are gonna start calling me the ‘B’ word, so I told [the doctor] that I wanna stay at the hospital for two weeks.

Iqajuktaq has very sensitive lungs. She easily catches other people's colds, flues and infections. She and her husband receive many visitors every day and Iqajuktaq often finds it difficult. She would prefer that they did not come, particularly if they are sick, smoke, or bring their sick babies, but she does not feel able to tell people this:

Whenever anybody comes into my door coughing and sneezing, I wanna get rid of them, but I don't know how to get rid of them...women coming with their sick children like coughing or barfing. That part I don't like and I can't get rid of them. They would say “mean old bitch.” It would be written all over my door, “mean old bitch” ... and the men they come every single day - every single day - to play games with my husband. I sometimes ask them, “could you please take him to your house so you could have him to

yourselves all day,” but they just don't wanna do it, they just wanna come to my place.”

I asked Iqajuktaq if she did not feel able to ask them to leave, to which she replied: “*No way...that wouldn't work. I would be black and blue all over saying that...living in fear in the home is very bad!*” Thus, for some Inuit it is not an option to tell people that they should not visit for a while, not even to protect the prospective visitors when someone in the household is sick. This social convention may be tied to Inuit identity that ideally includes being social, generous, kind, and nurturing (Bennett & Rowley, 1994; Briggs, 2001; Stairs 1992). I believe it is compounded by the fact that being sick is not something people feel comfortable talking about, in part due to the stigmatising effect of disease, tied as it is to transgressing social norms and conventions.

Visiting and receiving visitors is for many part of the fabric of Inuit communities. Lack of willingness to contribute to the maintenance of this fabric, to say no to visitors for whatever reason, is not taken lightly. This social convention, I suggest, may be tied to Inuit identity, and breaking causes gossip and avoidance, verbal abuse, and possibly physical abuse. The tie between the transgression of social norms and disease, I maintain, makes people uncomfortable in sharing that they are sick. Participants also expressed discomfort at the idea of interfering with another person’s choices and actions. I discuss this further below.

3.5.3 Respect, independence and identity

Trusting and respecting another person’s judgment, autonomy, independence, and sense of responsibility, is highly valued by Inuit today, as it was in the past (Brody, 2000; Minor, 1992; Stairs, 1991). These are some of the core values for many Inuit (Brody, 2000), important markers of Inuit identity as described above, and for many seem to define the *habitus* (Bourdieu, 2001)³³ of social interactions.

This respect for another person is revealed in several ways. Briggs (1998)³⁴ describes that the way questions are framed in Inuktitut serves to “avoid confrontation, demandingness and invasion of another’s mental space” (ibid.: 262). This is done by avoiding “open ended questions,” because closed questions “allow the person interrogated to answer

³³ See page 38 of this thesis for Bourdieu’s conceptualisation of the *habitus*.

³⁴ Jean Briggs lived in Inuit outpost camps during the 1960s and 1970s and has written extensively about the emotional aspects of Inuit social life (1978, 1990, 1997, 1998, 2000, 2001).

with a simple, unelaborated (and occasionally perhaps false) yes, no, or maybe, thus keeping most of the contents of his or her mind private” (ibid.).

Brody writes that “parents are inclined to trust children to know what they need. Individuals have to be left to make decisions for themselves, and children are individuals just as adults are” (Brody, 2000:31). Interfering may conflict with the “view of children as complete beings who are in charge of their own development and not to be directly formed by adult manipulation” (Stairs, 1991:283). The behaviour of Inuit children and adults in connection with TB treatment or follow-up needs to be understood with this in mind.

Laimiki, who was affected by not only her social circumstances, but also because the medicine made her stomach hurt, said that when she and her cousins had TB, “*we had to go and take those pills that make us sick.... I didn't think they were helping me, 'cause I know I felt good, you know. I felt healthy, but then again I had to take those pills.*” Tye also received treatment for active TB as a teenager, and she too experienced gastrointestinal side effects. She also did not want to take medication, along with many others in her community. Tye said:

A lot of people didn't feel like taking the pills. Even the nurses started to go to the school and those who had TB had to go to one room to take pills. Some of them wouldn't go and some of them would pretend to go to the classroom but they would go outside, so they wouldn't take the pills. There were so many people saying that they didn't want to take the pills so the counsellors started going to their place. The cops too, used to pick me up at my place sometimes.

Both young women tried to avoid treatment in various ways. Tye left her home community, while Laimiki left the hospital where she was admitted for treatment, and both stayed in hiding and did not show up for treatment. One was apprehended several times by the police, and the other was threatened with apprehension. Nawdlak, the 40 year-old woman with active TB, also avoided treatment, stayed in hiding and was close to being apprehended by the police. Common for the three women was that their family members did little or nothing to cajole, support, or force them to “turn themselves in” for treatment, although they knew where they were, that they had active TB, and that they were avoiding medical treatment.

According to Nawdlak's brother Yutai, her family members knew what was going on, where she was, and also asked her to go for treatment. They did not pursue the matter, however, when she declined. Neither did Pingwartok, whose sister rejected treatment, or Lukta whose father did too. Once they had rejected the advice to be treated, each trusted that their family member's decision was rational in his or her circumstances. This illustrates the respect Inuit maintain for others' autonomy, and their trust in others' ability to make correct decisions. It may also play a role that individuals cannot afford to estrange their family members by interfering, as Nichter (2002) found doing research among Philipinoes suffering from TB, as Inuit also continue to depend on each other for support in times of need.

Furthermore, as discussed previously, for Inuit being healthy and feeling physically and mentally strong and able, is linked to personal identity; therefore, complying with medical treatment may be seen as an assault on an individual's sense of self, as this would imply that he or she is not healthy. Knowing that being sick may indicate that one has not conducted oneself 'properly' in the social sphere, or may otherwise have behaved inappropriate, it comes as no surprise that some individuals prefer not to be associated with any kind of medical treatment.

All of the healthcare professionals who dealt with these women were reported to have made attempts at changing the behaviour of the 'dissidents' with education, explanations, appeals to their 'better reason', and as a last resort, threats of an actual police intervention. According to the women, none them were asked or interviewed about the motives for their lack of willingness to receive treatment, receive treatment in the way it was given, or be admitted to hospital. Laimiki was once asked by a nurse about her motive for leaving. She said that her young siblings were home alone, and reported that the nurse's response was: "*I'm sorry, but you have to stay here,*" and no further action was taken.

An additional reason for not complying with medical treatment may, again, be found in Foucault (1990): "Where there is power there is resistance" (ibid.:95). The healthcare system has implemented a form of treatment for TB which, certainly for some people, can be seen as coercive, which is enforced with the help of the police, an expression of ultimate power, and which does not respect the individual's autonomy at all. This medical system, governed by the people who historically colonized the Inuit, may give all the more reason to resist.

For many Inuit the *habitus* of social interaction includes trusting the individual's ability to make rational and independent decisions. This may prevent parents or family

members from interfering with a person's decision not to receive treatment for TB. Because being strong and healthy is a part of what constitutes Inuit identity, and because disease may be an indicator of inappropriate actions in other spheres of life, some Inuit may be reluctant to submit to medical treatment. Avoidance of treatment may also be a manifestation of resistance of the power exerted by the healthcare system, and thus the colonizing power.

More than correct interactions with humans, animals, and the environment influences a person's health or susceptibility to disease, and more than the way in which information is disseminated has an influence on an individual's ability to benefit from that information. Resources such as social support and a sense of control over one's own life and economy are other ingredients necessary in order to maintain good health (Farmer, 1997, 1999, 2005; Marmot, 1994; Pelto & Pelto, 2001; Yoder, 1997), and to be able to obtain, retain, and act on information that may help you to do so. Many interviewees talked about life conditions where available resources were used in the quest to merely live or survive, and they also spoke of struggling with experiences of discrimination and continuing colonial attitudes of Qallunaat, which is what I discuss next.

4. The colonization of the Canadian Arctic

“Colonialism and racism create and emphasize inequalities” (Brody, 2000:126).

Although Nunavut has been a territory with a territorial government run predominantly by Inuit since 1999, Canada's colonization of Inuit lands and people does not lie far back in history, and this colonizing history has had, and still has, an impact on the lives of present day Inuit, as evidenced in the empirical material. This impact is ubiquitous and often insidious, and is reflected not just in personal stories but also in governmental statistics and reports. In the following I highlight some of these statistics about Nunavut; then I describe the history of TB in the Canadian Arctic, which is also a history of colonization. Both provide an important context for the experiences described in the empirical material. I discuss Foucault's (1990) concept of *bio-power*, useful in understanding the effects of colonization on Inuit health and the way they experience and make meaning of TB, health and disease. The last part of chapter 4 will discuss these experiences as expressed by participants.

4.1 Social realities as presented in the statistics

It has been suggested that the effect of colonization in terms of lower standard of living, lower socio-economic status, and lower health status among the colonized people as compared to the colonisers, persists and will persist unless or until decolonising policies are implemented (Dei et al. 2000; Smith, 2002). I believe this is also the reality in Nunavut. The statistics below provide an idea of this reality, and serve to contextualise the experiences that Inuit informants have of discrimination and continuing colonization in Nunavut.

The median total income in Nunavut is 25% lower than in the rest of Canada, and educational levels are also much lower (Hicks & White, 2000; Statistics Canada, 2004). The unemployment rate, on the other hand, is significantly higher than in the rest of Canada, although it is important to note that the residents of Nunavut have “the *lowest* economic dependency ratio... of any provincial/territorial jurisdiction in Canada³⁵” (Hicks & White, 2000:41, emphasis in original). This may in part be because people without jobs live on very little cash, and rely heavily on “the sharing of food and money within extended families” (ibid.).

Nunavut’s population is young as a result of a high birth rate³⁶, and crowded housing is the norm for many (Picco, cited in Bell, 2002; Bjerregaard, 1995; Statistics Canada, 2004). In 1999 infant mortality in Nunavut was three times higher than in the rest of Canada (NDHSS, 2002; Statistics Canada, 2004) and life expectancy among Nunavut residents is 10 years shorter than elsewhere in Canada (Statistics Canada). Morbidity rates are also high. For example, deaths from lung-cancer are almost 4 times as frequent in Nunavut as compared to Canada as a whole, and the sexually transmitted disease chlamydia, which is generally linked to high numbers of cervical cancer, is 17 times more frequent in Nunavut compared to Canada as a whole (NDHSS, 2002). Smoking, marijuana, and alcohol abuse, are big problems in Nunavut (Picco, cited in Bell, 2002; Jenkins et al. 2003), as is suicide, particularly among the youth (Issacs et. al., 1999; Minor, 1994). These social conditions are reflected in the statistics from the criminal justice system, where the rates of reported violent crimes and sexual assaults in 1999 were 8 and 12 times higher than in the rest of Canada (Statistics Canada).

These statistics can be understood as a consequence of colonization, and many historical accounts serve to support this understanding. For example, early encounters

³⁵ Dependency ratio is described as “the standard measure of dependence on government” and “Statistics Canada defines ‘economic dependency’ as being total transfer payment to individuals divided by their total income” (Hicks & White, 2000:41).

³⁶ The median age in Nunavut is 22.1, whereas the median age in Canada is 37.9 (Statistics Canada, 2004).

between Inuit and Qallunaat within the healthcare system and elsewhere are described as fraught with ethnocentrism, racism, neglect, and misconceptions. Tester & Kulchyski (1994) write about the involuntary relocations of Inuit in the Eastern Arctic from 1939 to 1963, and the devastating consequences they had culturally, socially, and on Inuit health. One consequence was an enormous increase in TB. Another consequence was a “cultural breakdown” (Minor, 1994:87), which included a transformation of Inuit self-reliance in medical matters to a forced reliance on the Qallunaat healthcare system (Grygier, 1994; Tester, McNicoll & Irniq, 2001). This development is called “medicalization,” and is seen as leading to an increase in “the control of medical professionals and ideology” (Whyte, van der Geest & Hardon, 2002:16), a development which mirrored the increase in control by Qallunaat in other areas, and which was and is resented by some Inuit (Brody, 2000; Freeman, 1992). It is this historical development with its increasing problem of TB that is now examined.

4.2 A brief history of TB and healthcare in the Canadian Arctic

The high incidences of TB among Inuit have traditionally been explained with the idea of “virgin soil epidemics” (McGhee, 1994:572), nutritional deficiencies, deplorable living conditions, and climactic factors (Grygier, 1994; Wherret, 1969). It is thought that whalers and explorers exposed Inuit to TB between the 1600s and 1800s (Grygier, 1994; Mays et al. 2001; McGhee, 1994; Oswald, 1979), and accounts from travelling physicians and explorers indicating the presence of TB started surfacing in the first quarter of the 1800s. Parry, who in his quest for the Northwest Passage wintered two years in Igloolik, observed many cases of respiratory diseases in 1824 (Parry, cited in Keenlyside, 1990). Given the trading networks that existed among and between the Eastern Arctic Inuit and the Greenlandic Inuit (McGhee 1984, 1994), these respiratory diseases were likely caused by TB. The Greenlandic Inuit were recorded to have suffered from TB in the 1700s or even earlier (Oswald, 1979).

Sir Francis Hall, who journeyed to the Arctic with the aim of reconstructing the fate of the Franklin Expedition, wrote in 1861 that on Southern Baffin Island consumption (an earlier name for TB) had killed more Inuit than all other diseases combined (Grygier, 1994). Another arctic traveller, the ornithologist Lucien Turner, stated in 1889 that “half of the Inuit in Kuujjuaq died of ‘pulmonary troubles’” (cited in Grygier, 1994:56). In the 1920s Dr. Banting, a physician who as a private citizen had boarded an Arctic patrol vessel,

described TB cases, general malady, and deplorable living conditions among the Inuit at Arctic Bay and Port Leopold (Tester & Kulchyski, 1994). In 1934 another physician noted that extremely high levels of TB prevailed in Pangnirtung (Grygier). Accounts similar to these kept coming from doctors appointed to serve in the Arctic from the 1920s through the 1930s, asking officials for help in dealing with the all-consuming disease and the deplorable living conditions of the Inuit, and lobbying for the development of hospitals and nursing stations in the North (Grygier; Tester & Kulchyski, 1994).

From when Hall first wrote his account in 1861, until 1943 when an American base physician and other base workers situated along the DEW line³⁷ remonstrated about the appalling state of Inuit health and lack of medical care provided by the Canadian government, nothing much was done to change these conditions in the Eastern, Western, or Central Canadian Arctic (Grygier, 1994; Tester & Kulchyski, 1994; Vanast, 1991). On the contrary, money and effort spent by the Canadian government and others in the North was aimed mainly at assuring sovereignty (Brody, 1991; Tester & Kulchyski), pursuing commercial endeavours to enrich people from elsewhere (Tester & Kulchyski), or at ideologically transforming the Inuit to conform to Euro-Canadian religion, beliefs and values (Brody; Grygier; Tester & Kulchyski). Money was even spent documenting, for posterity, these “strange, happy and naive people” and their cultural curiosities, as it was thought that they would soon be extinct (Vanast, 1991:77). In the meantime, TB spread and proliferated (Wherret, 1969).

The pressure on the Canadian government to provide better healthcare grew to such an extent that in 1939 one Dr Wherrett was commissioned to survey “the health conditions and medical services in the North West Territories” (Grygier, 1994:62). When he finally presented his survey in 1945, he was very critical of the Canadian government and its efforts, and provided evidence that more money, facilities and staff were called for in the Arctic³⁸. Wherret’s recommendations included annual x-ray surveys, medical emergency airplane services, regular visits by physicians to settlements, and more nursing stations (Grygier).

Because responsibility for Inuit and Indian medical care was transferred from the

³⁷ DEW means Distant Early Warning. This was a military defence installation comprised of radar-stations scattered across the North, developed by the United States of America as protection against Russian missiles.

³⁸ Previously Dr. Wherrett, who in the late 1930s worked as a consultant for the Department of National Health and Welfare, had publicly stated that the increasing Inuit population indicated that TB was not epidemic or acute. He furthermore postulated that “medical treatment...[was] as satisfactory as can be expected, considering the terrain, the difficulty of travel, and the many isolated, small groups of Eskimos” (Grygier, 1994, p.60). By the time he presented the survey, he had changed his mind.

Department of Indian Affairs to the new Department of National Health and Welfare (Grzybowski et al., 1976), the Northwest Territories' administration sent a summary of "arrangements for medical care of Inuit" (Grygier, 1994:65), which chronicled widespread problems. It was documented that in 1939 the annual expenditure on each individual Inuk amounted to only \$4.77³⁹ (ibid.) so "the result on TB control at that time would have been nil" (Grzybowski et al., 1976:s8).

After the end of the Second World War the Indian Health Services launched x-ray surveys on ships for the whole Inuit population, evacuated individuals who had active TB to sanatoria and hospitals in the south, and immunized individuals who had no symptoms of TB (Grygier, 1994). The surveys, combined with the treatment of active cases in the south, immunization, and prophylactic treatment of people with latent TB, were perceived to be successful (Grzybowski et al., 1976; Wherret, 1977), at least by southern administrators. Many Inuit, however, experienced much more than a cure for TB during this 20-year campaign. Some experienced the agonising pain of spending years away from their families from when they were small children or even infants. Some came back from the South unable to speak their native language, and some did not come back at all; they had died, had been adopted by southern medical staff, or had disappeared because of poorly kept records (Grygier, 1994). On top of family separations, the Inuit also had to live under deplorable conditions on the ships which brought them south, and in totally unfamiliar and strange surroundings once there (ibid; Idlout d'Argencourt, 1977; Tester, McNicoll, & Irniq, 2001).

When the medical teams found someone whose x-ray was positive, he or she was not allowed to leave again to say goodbye to family and friends (Grygier, 1994), or arrange for others to take their places while they were away, and parents and infants were often separated (Grygier, 1994; Tester & Kulchyski, 1994). Once on board the ship, people were literally stowed in the hold. They spent several weeks there among strangers, with men, women and children in the same berth, very little space to move around, and with inadequate washing and toilet facilities. Once in hospital people were lonely, frightened, and worried about their loved ones at home (Grygier; Tester, McNicoll, & Irniq, 2001). At that time, the absence of a man or a woman "meant genuine material hardship" for the rest of the family, as the division of labour was strictly gendered⁴⁰ (ibid.:131). These needs, however, were not addressed by the newly created welfare division (ibid).

³⁹ This included doctors' and nurses' salaries, transportation of people from the Arctic to the south and back again (on the rare occasions that this took place), and medical treatment of any kind (Grzybowski et al., 1976).

⁴⁰ Excerpts from letters sent to Leo Manning attest to the difficulty people endured. He worked in the Arctic from 1934, with the Hudson Bay Company and in other capacities. He spoke Inuktitut and, as a social worker,

Grygier (1994) describes how new mothers had their babies taken away in order not to expose them to the mother's active TB. Some people disappeared because Inuit did not use surnames, and officials found it difficult to spell the names they did use, or because the identification plates which Inuit wore around the neck and which officials used to identify them sometimes got lost (Grygier, 1994). Some families had to wait for years before they were notified about someone's death, while some were not informed at all, and others were informed about the death but not the burial site. An Anglican minister who served in Povungnituk said to Grygier (1994) that many of these things happened because officials "did not think the Eskimo people were worthy of being informed....and the basic thing behind that, I think, is that they refused to believe that they were people" (ibid.:123).

It is not strange that after a few years of visits by the examining ships, their coming was dreaded. People would flee inland to avoid being examined, and the risk of being sent south (Colbourne, 1998). Patients also fled from the sanatoria and hospitals, and some committed suicide while there. The foreign conditions that people had to live under were compounded by the belief that physical activity could spread TB in the person's body, which meant that some people were strapped to their beds, or had their legs put in casts to prevent them from walking (Grygier, 1994).

Drug treatment for TB began in 1946. During the 1950s more drugs became available and physicians were eager to try out the new drugs in order to find the best. People receiving treatment for active TB would get many pills and injections every day; some believed that they were taken to the south so that experiments could be carried out with them as guinea pigs, due the changing medical regimens. When tearing some sanatoria and hospitals down in southern Ontario, the workers found stashes of pills within the walls (Grygier 1994), a sign of resistance.

Although there were many kind and caring people who "worked hard to alleviate the pain and feelings of homesickness almost all Inuit experienced" (Tester, McNicoll, & Irniq, 2001), and although TB deaths decreased and then stopped, while the population grew and more money was spent to secure better health care, the TB campaign was not a singular success for the Inuit. The treatment of TB did improve during the latter part of the 1950s and early 1960s. More translators were hired, an effort was made to ensure that families knew where their relatives were going, activity programs were sponsored, and an effort was made

visited, translated for, and advocated for Inuit admitted to southern hospitals from the mid-1950s (Tester, McNicoll, & Irniq, 2001).

to provide the Inuit with more palatable food (Grygier, 1994). The sanatoria and hospitals to which people from the Qikiqtani Region were sent, however, were still situated thousands of kilometres away from people's homes, in places where everything was strange and foreign (Tester, McNicoll & Irniq, 2001).

From people spending years in the sanatoria in the early days, the average stay in hospital has significantly decreased with the availability of nursing stations and staff to provide DOT in the settlements. The numbers of active TB cases in the Northwest Territories peaked in 1955 (Grzybowski et. al, 1976), and then fell steadily until the 1980s, when they started climbing again (Case & White, 1999).

This historical background and introduction to the colonisation of the area is needed in analysing Inuit experiences of colonialism historically and currently, and relating them to the way in which Inuit make meaning of TB. I use Foucault's (1990) concept of *bio-power* to do this.

4.3 Governance, control and power

Foucault (1995) describes *bio-power* (I define the concept below) as emerging in Europe in the 17th century, and understands it to be an "indispensable element in the development of capitalism" (ibid.: 263). He sees it to be a replacement of the sovereign's right to "power of life and death," which in reality was "the right to take life or let live" (ibid.:259). What *bio-power* did, according to Foucault, was supplant the sovereign's power with a power focused on "investing in life through and through" (ibid.262). Within the norms stipulated by *bio-power* the individual now had a 'right' to life and health, which made resistance to this normalizing power almost a resistance to life and health themselves.

Foucault (1991) conceptualizes *bio-power* as containing two differing forms or poles of power. He calls the first pole an *anatomo-politics* of the human body. It centres on the body as a machine, and on the manipulation of individual bodies in order to get the optimal use of this body-machine. The manipulation of individual bodies is carried out through procedures of power and control exerted by the "*disciplines*" (Foucault, 1991: 262). He describes a discipline as a type of power, and at the same time that which makes exercising this power possible, its "instruments, techniques, procedures, levels of application, [and] targets" (Foucault, 1995: 215). As such, disciplines are the "techniques for assuring the ordering of human multiplicities" or populations (ibid.:218). The disciplinary institutions possessing the power to exercise these techniques include the army, the educational system,

the medical system and the juridical system. The ordering or managing of populations is made possible through the fixing, arresting and regulation of movement, which also serves to neutralize resistance. Apart from attempting to arouse as little resistance as possible, disciplines also attempt to exert their power at the lowest possible cost, and as discreetly or covertly as possible (Foucault).

The other pole, that which Foucault (1991) calls *a bio-politics* of the population, “focuses on the species body, the body imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births, mortality, the level of health, life expectancy and longevity” (ibid.: 262). These processes are supervised through interventions and control mechanisms executed through the collection of information such as mortality and morbidity, birth rates, longevity, housing, and migration, that is, demographics and other statistics about the public. Through this information norms are established and professed which then serve as a platform for regulating the public and private life and behaviours of individuals (Foucault, 1995; Lock and Kaufert, 2002).

Bio-power can be understood then, as a form of insidious power/control, which operates using subtle mechanisms rather than being overtly repressive, in order to regulate how people conduct themselves and relate to each other (Hogle, 2002). Because the ability to do this requires knowledge, the state is preoccupied with the collection of statistics. Through these statistics the so called experts, the disciplines, can label ways of behaviour as deviant, abnormal, or immoral, and bodily states as diseases, thereby legitimising systematic attempts at medicalization of both behaviour and body (ibid.). Bio-power, thus, “in creating a domain of expertise, constitutes its own objects of analysis to which it then responds” (Lock & Kaufert, 1998: 6). Because of the nature of bio-power, however, “subjects are made to feel autonomous; in fact there is a fetishism of empowerment that results in individuals being even more complicit with apparatuses of governmentality” (Rose, cited in Hogle, 2002: 236).

I believe that the development in Europe from a sovereign power over life and death to a normalizing and medicalizing power invested in life is mirrored by the development that took place during a much shorter time-span in the Canadian Arctic. Before the Canadian government had realised the possibilities of the Arctic, its inhabitants were allowed to die as a consequence of contact with explorers, traders and missionaries. Once the value of the Arctic was recognised, and in its attempt to gain sovereignty, the Canadian government also attempted to manage and normalise its Inuit inhabitants, in order to have healthy bodies living the north. The relocations and medicalization described above did this,

and I believe this normalization, in the form of continuing colonization and acculturation, is ongoing. I interpret the experiences of many informants to reveal this sentiment.

4.4 The colonizer and the colonized

Some interviewees shared experiences that they found difficult in the course of their own, or their loved ones' examination for TB, or treatment of TB. Other informants shared recent experiences (sometimes overtly and sometimes obliquely) where healthcare professionals or other Qallunaat exhibited lack of care and ethnocentrism, or acted discriminatorily towards Inuit. Informants also shared historical experiences of paternalism and discrimination, and the general feeling that Qallunaat are ethnocentric and discriminate. It is significant that statements about Qallunaat, and healthcare in general, came up during interviews about TB, and without my broaching the subjects. I believe, however, that the explanation is partially to be found in the idea that I spoke of in chapter 2, that Inuit "recall the significant importance of the story of events, and leave the meaning-making lesson-finding to the audience" (Deloria, cited in Calliou, 1998:44). These experiences must be important to the informants, and must impact their experiences of TB. I now discuss Inuit experiences of colonialism, historical and current, as presented in the empirical material. I then relate the experiences to statements made by Qallunaat health professionals, and to blame and accusation.

4.4.1 The government problem

As mentioned in section 1.2, when I asked Sutiapik what he thought might be responsible for the continuing high prevalence of TB in Nunavut, he replied that being forcibly settled and having their dogs shot have made some people resent the government. This, he believed, may make some people feel that it's the government's responsibility that people are sick. He said:

Why don't they just cure us? Why should I be responsible? Let the government take care of it; it's the government's job. There might be people who might think like that.... I think it's happening with suicides, you know. Lot of people blame the government because you settled us; we didn't want to settle down. Now that you promise us education it's

not happening, they're killing themselves. Those are the things that are happening. Might be the same with health, I don't know.

Several other interviewees brought up the forced movement to settlements and the shootings of Inuit dogs. Jukipa, when talking about her father sending her to school, stated:

But then he had no choice either, because by then we were sort of herded into one big community, and people say to my parents, "if your child doesn't go to school you don't get family allowance." And they took my father's dogs so that he just can't take his family and go live in an outpost camp.

Noah also mentions that Inuit were settled in communities against their will, and that their dogs were shot. Although the reason behind the shooting of the dogs remains contested (Moquin, 2004), the result was that many Inuit were left with no means of hunting and thus no means of providing for their families. Inuit and non-Inuit write of the forced settlement (Ipellie, 1993; Puric, 1992; Tester & Kulchyski, 1994), and of the involuntary relocations of Inuit (Aodla-Freeman 1992; Grygier 1994; Tester & Kulchyski, 1994), the killing of Inuit dogs (Pudlat, 1990, Tester & Kulchyski), and the forced schooling of the children in a very foreign educational system (Berger, 2001; Brody, 1999; McNicoll, et al, 1999; Napartuk, 2002; Nungak, 2002; Okakok, 1989).

According to some authors, the Qallunaat colonizers came to Arctic Canada, moved Inuit around, and told them where and how to live, in order to gain sovereignty of the vast area in which Inuit lived. In other words, the Canadian government exercised that which Foucault (1999) calls *anatomo-politics* over the Inuit. Although some were blunt in their comments about why the relocations should be carried out⁴¹, the colonizing politicians and 'experts' recruited from the south generally rationalised these sovereignty relocations as being in the best interest of the Inuit themselves. Justifications rested primarily on supposedly dwindling resources where the Inuit originally lived (Tester & Kulchyski, 1994).

⁴¹ See, for example, Tester & Kulchyski (1994). In 1953 Diamond Jenness makes, among other claims, the claim that Inuit, "whether from ignorance or not," are quite content to live without the "usual amenities of civilized life," including "medical, educational and other facilities" in a manner that the ordinary white man would never be. Therefore, he suggested, it would be no burden for the Inuit to be relocated to the uninhabited islands of the Arctic in the name of sovereignty (ibid.:111,112).

Before the relocations, however, adequate surveys of the subsistence possibilities were rarely carried out. Inuit, who supposedly were relocated to areas historically or anecdotally rich in game, arrived in places where no such game was to be found. Others were relocated to areas where game was plentiful, but the hunting of it was totally unfamiliar to the relocated people. Both situations ended disastrously (Tester & Kulchyski, 1994). Post facto, when the question of human rights was raised, the defence was given that “the government moved all the Inuit great distances to settlements, so they could be near health services” (Gerin, cited in Tester & Kulchyski:115).

The colonizers convinced themselves, and professed to the Inuit and to national and international observers, that they did what they did for the benefit, and with the consent of the Inuit population (Tester & Kulchyski 1994). Applying Foucault’s concept of *bio-power*, it appears rather that the government disguised their exertion of power, as ‘the disciplines’ are wont to do (Foucault, 1995). Citing Foucault, Hogle (2000) writes that in order to have control over a population’s health and well being while keeping expenditure to a minimum, certain interventions are required. This involves a number of experts telling individuals how to live (and where), how to work, and how to be healthy (ibid.). The Canadian government attempted to avoid responsibility for the welfare of the people inhabiting the lands over which it tried to maintain sovereignty. When this failed, they gathered the Inuit in settlements in order to minimize the expenditure that healthcare, schooling and policing would cost the state (Tester & Kulchyski, 1994). At the same time, gathering Inuit into settlement served to manage the population, as their movement was thus ‘arrested’ and ‘regulated’ (Foucault, 1995).

The Book of Wisdom for Eskimos, which was produced in 1947 in an attempt to “regulate bodies and practices of Inuit to suit the exigencies of the welfare state” (McNicoll, Tester & Kulchyski, 1999; 199), instructed the Inuit on how to live, work and be healthy. It is in part a “compendium of health and hygiene advice” often totally unsuitable for Arctic residents (ibid.:205). The Canadian government perpetuated the medical politics outlined in European countries in the 18th century of organizing “the family-children complex as the first and most important instance for the medicalization of individuals” (Foucault, 1995:281). Bottle-feeding was advised rather than breastfeeding (McNicoll, Tester & Kulchyski), and giving birth became, and still is, a concern of the government, as the healthcare system sees women sent to southern hospitals to give birth (Bjerregaard, 1998), often against their will (Paulette, 1990; Tokolik, 1990). The privileging of hygiene and medicine became an

“instance of social control” (Foucault, 1995:282). I believe *The Book* offers an accurate reflection of the general Qallunaat attitude towards Inuit, an attitude of paternalism, placing power and knowledge with the white colonizers and infantilising the Inuit, while placing the blame for poor Inuit health on the Inuit themselves. Their way of living was responsible, it suggested.

After Inuit settlement living commenced, extensive biomedical examination and research on the Inuit also commenced, thus providing the government with the statistics necessary to govern and regulate. R. Katsak (2001) speaks to this when she reminisces about Qallunaat researchers coming to Pond Inlet in 1971-72 to study the “Eskimoes” (ibid. 176). One of the many things the researchers did was take skin grafts from Inuit children’s arms, and attempt to transplant them to their sibling’s arms. The researchers did not explain what they were doing, and the Inuit did not say no, although they wanted to. They generally did whatever the Qallunaat told them to. “The Qallunaat have always been the people with the authority...They were the ones who ran the town...who said what was appropriate and proper and told us what needed to be done. If the Qallunaat say so, then it must be so (ibid. 176).

The history of TB in the Canadian Arctic also includes evidence of the medicalization, which took place in the middle of the last century, and the paternalistic and discriminatory way in which it was done in many instances. Several of the older informants spoke to this, and Noah’s experience (mentioned in section 2.2.1) of being fearful of the whites, and his feeling that they were the ones controlling the settlement of his childhood, supports this account of the history of colonization.

Several Inuit spoke of the history of colonization while relating experiences of TB, although only one directly connected the high levels of TB in Nunavut today with these experiences. I believe, however, that raising the issue of colonization in conjunction with TB is an indirect way of allowing me to think and make the connection, and find out the lesson of the story by myself. This leads me to believe that some Inuit hold the colonizing power partially responsible for TB, both historically and currently. Some Inuit feel that Qallunaat continue to disrespect and discriminate against Inuit, although others blame themselves for being treated badly. These points, which may be seen as either end of a continuum, are part of the several layers of blame and accusations involved in being sick with and treating people for TB, which I address below.

4.4.2 Blame and accusation

Farmer (1993) writes about several layers of blame and accusation in the context of AIDS in Haiti. The first layer involves accusations of sorcery at the village level, and the blaming of the afflicted for having evoked the sorcery. The second layer involves North American accusations of Haitians as the bearers of the disease, and Haiti as exporter and origin of the disease. The third layer involves Haitians counter-accusing America for having devised conspiracies against Haiti and Haitians, for political reasons.

In Nunavut several layers of blame and accusation exist around TB, which resemble and yet are different from the ones described by Farmer (1993). In the first layer, some Inuit blame the afflicted person for falling ill (as described in section 3.5.1) because of a transgression of social norms and conventions. In the second layer, some Inuit blame the colonizers for the presence and persistence of TB in Arctic Canada (as discussed in section 4.4.1), and accuse them of treating Inuit discriminatorily, ethnocentrically, and paternalistically within and beyond the healthcare system, thus making Inuit less likely to seek medical attention. The third layer involves some Qallunaat health professionals holding Inuit partially responsible for falling ill because of their way of living. This leads to the fourth layer, where some Inuit blame themselves, if not for falling ill, then at least for failing to meet expressed or unexpressed Qallunaat expectations. They internalise and accept Qallunaat blame. It is these accusations I now wish to address.

4.4.2.1 Discrimination against Inuit in the healthcare system and elsewhere

“I guess they don’t care about other people’s health”(Mialia).

Few interviewees who had received TB treatment, or whose children had, expressed dissatisfaction with the way that this treatment had been handled. If they offered any critique, they did so subtly or indirectly. I do not think, however, that this reflects a general satisfaction with the healthcare system, since many Inuit readily expressed dissatisfaction in casual conversations. The lack of criticism expressed in the formal interviews may (as suggested in section 2.1) have been the result of me being seen as a representative of the healthcare system and colonizing power, and to the inherent power imbalance in the interview situation.

Mialia, who initially received her treatment at home during the infectious phase, was concerned about some of the ways in which her treatment for TB was handled. She did not feel that it was possible for her to refuse visitors for the duration of her contagious state,

and requested to be hospitalised. Mialia said that the doctor responsible for her treatment did not want her to be admitted, which made her feel that the doctor did not care about her, or about people's health:

I don't like this. [The doctor] did not really like me staying at the hospital for two weeks. [The doctor] really wanted me to stay home. I did not want to stay home, 'cause I am afraid to pass it on to other people, plus, my husband's brothers, they come here to visit too. And it is difficult to tell them not to, 'cause its gonna make them feel uncomfortable... so I told [the nurse] that I wanna stay at the hospital for two weeks but, for what I know [the doctor] didn't really like me staying at the hospital.... I guess they don't care about other people's health.

Alasi, who is in her mid 60s and had TB as a young person, and who was investigated for TB when her granddaughter had active TB five years ago, expressed a similar concern. Alasi's chest x-ray revealed changes suspect of active TB. She was admitted to hospital for isolation and further examination. Later, after being treated for a while, and having had severe side effects from the medication, it was found that she did not have TB:

It made me feel bad, that they did not say that they were sorry or anything for having given me medication when they found out that I did not have TB, even though they knew that it had been so bad for my body. They did not tell me that I was negative or anything, they just discharged me. I got no information about the results or anything... even the nurses are scared of one when they think you might have TB. They come into your room and stay only for a few minutes, then they disappear again and stay away for a very long time.

Neither Alasi nor Mialia felt that their voices had been heard or that they had been respected. Lack of respect and distrust were two sentiments repeated by several others

when discussing the treatment of Inuit by health professionals. One afternoon when I discussed healthcare with 4 Inuit women, one said:

Healthcare people do not treat patients with respect. It is as if they don't care to explain anything, like the patients won't understand anyway and the healthcare people know better. People are generally not told about things. They are not informed so that they can have a choice. The doctors or nurses choose for them.

Another woman added, *"I don't go to the hospital unless I am dying. They don't care. They don't help people. You go there to get help and they send you away with nothing."* This prompted everyone to relay different examples they knew of where people ended up being very sick and even dying because their initial complaint was not taken seriously. One woman stated: *"It is particularly bad in the communities. The nurses will not send people out to specialists."* This prompted another woman to conclude that *"so many deaths could have been avoided if people and their complaints were taken seriously and people were listened to."* Pingwartok also mentioned two people in his community who allegedly died because the healthcare personnel did not take their complaints seriously. And Noah described a friend of his who was dismissed when he went to the health station complaining of a sore neck and throat, only to return after 6 hours, almost unable to breathe because of swelling.

Perhaps it is not difficult to imagine that some people may choose not to turn to the health centres for examination or comply with medical treatment when they are requested to do so, if previous experiences with health professionals includes having not felt respected or listened to. Sumartojo (1993) writes that research conducted on TB and treatment failure revealed that changing clinic hours and improving the *attitude of the professional staff* led to a decrease in missed appointments from 36% to 6 % after 5 years.

The idea that changing the attitude of the healthcare professionals improves program success again suggests a Foucauldian (1990) understanding of power and resistance, introduced in section 3.3.2. This resistance to power is particularly apparent when considering more aspects of Nawdlak's story; although she does not use the word discrimination, she expresses a feeling of being dominated. She said that upon returning home from hospital, and having received treatment for a while, she did not show up for her

medication and stayed in hiding to avoid it. This resulted in a threat of apprehension by the police:

One time they were close to calling the RCMP⁴², because I was hiding from them. Because, my goodness, they better stop calling. Because I got fed up with medication.... This was two months... what... somewhere in June. When they were close to calling the RCMP, I went down. I felt guilty, so I'm not hiding from them anymore."

When I asked Nawdlak if she could tell me what made her hide and not want to take the medication, she said: *"it's just the thought... that it's something I have to do. I can't decide; it is the TB coordinator's decision, or whoever that person is. I'm never explained anything, I just take what's coming to me."* As mentioned earlier, historically "efforts to directly influence another or to penetrate in any way another's space were simply not tolerated"(Ryan, 1992: 94). I believe this is true for many today. I interpret Nawdlak's resistance to her treatment regimen to be resistance to the healthcare system's efforts to control her, as much as resistance to treatment altogether, and her comment about never having things explained points to feelings of being treated unjustly.

Inuit Informants also relayed experiences of Qallunaat colonial discrimination outside the healthcare setting. This was evidenced, for example, in the quote in section 1.2 where Pingwartok related that he feels like a minority in his own territory, because people from the outside tell people in Nunavut what to do and how, what is right and wrong, and are condescending, although they know nothing about Inuit values and ways of thinking. He continued that when working in a mine, many of his co-workers expressed prejudice about Inuit: *"They asked me if I lived in an igloo, if I had gone to school... if we had televisions and telephones. Like, we have everything here just as anywhere else, and these people were Canadians too."* Then he added that he is not like his father and grandfather; he is different. He is not into hunting and does not want to stay in his home community. He does not wish to live 'traditionally' and currently attends college. I believe Pingwartok represents the complexity that Inuit are faced with today where many retain 'traditional' Inuit values and ideas while also embracing that which they have been exposed to through contact with Euro-

⁴² RCMP Royal Canadian Mounted Police

Canadian culture. I do not think that one excludes the other, rather I think one can complement the other when the individual has some choice in what to embrace and what to exclude. Other writers describe Inuit who themselves feel that combining these worlds is both possible and desirable (Fogel-Chance, 1993; Thomsen, 1997)

Pootoogoo, an Inuk nursing student asked to talk to me in private after I had presented my preliminary findings for the nursing students and their teachers. When we met, she said: *“as an Inuk student I feel I have no freedom of speech. When I talk about how my people view health and disease, ‘they’ [Qallunaat teachers and students] tell me to prove that things are as we see them, and tell me I should be careful with what I say.”* Pootoogoo continued that Inuk students stop the education because they are told they are superstitious and unscientific. They also feel discriminated against because they are evaluated on their mastery of the English language and their western biomedical understanding of health and disease, whereas the English speaking, Qallunaat students are not evaluated on their Inuktitut speaking abilities or their knowledge of traditional Inuit understandings of health. No teachers are Inuit, no books are in Inuktitut, and the language of instruction is English. Furthermore, she said, the nursing school had decided not to use a book about traditional Inuit views on health based on interviews with Inuit elders, because it was not “peer reviewed.” This “champion of Western ideals at the expense of distinctive native practices” (Ryan, 1992; 92) results in deculturation of the Inuit students. Similarly to the nursing teachers depicted in Ryan’s (1992) article on the connection between nursing practice and the erosion of native communication styles, I doubt that the nursing teachers Pootoogoo refers to see themselves as being discriminatory, because a western approach in nursing is necessary in order to reach the objectives of western healthcare. Using a Foucaultian analysis (1991, 1995) the educational institution as a *discipline* has the power to determine which knowledge is the ‘right’ knowledge, and has the ability to normalize through the professing of this knowledge.

Apart from these examples related by informants, I witnessed many occurrences where Qallunaat acted paternalistically or discriminatorily, expressed colonial attitudes towards Inuit, or expressed discriminatory sentiments to me about Inuit. This included some Qallunaat individuals who themselves had Inuit spouses.

Not seeking medical attention because of feelings of not being helped or taken seriously can have a negative impact on health; however, the impact is much bigger and more insidious than that. That Inuit are continuously told, however subtly, that their feelings,

values, thoughts, and ways do not have value, or have less value than those of the people who colonized them, means that the colonial relationship and colonization continues. The effects of colonization are perpetuated. These effects include a “stripping away” of the standing of the colonized in their own eyes, and an undermining of their ability to determine their own destinies (Smith, 2002:173). Research suggests that the degree of agency human beings feel they have over their own lives is directly proportional to their level of health (Hertzman et al., 1994; Marmot, 1994).

4.4.2.2 *Ilira* and self-blame

“*I felt like I was the one to blame*” (Tye, 2004).

At the same time as Nawdlak, mentioned previously, reacted to the healthcare system and its protocols, she also blamed herself for not living up to the expectations of her by the same system and protocols. She felt guilty. While Nawdlak was isolated in the hospital for three weeks she cried every day, but did not feel she could talk to the hospital staff about her feelings. She said: “*I was hiding it from them. I was shy I guess.*” Hearing the word ‘shy’ used often by Inuit gave me the sense that it implies something different in Inuktitut than in English. I asked an Inuk colleague which Inuktitut word she would use for feeling shy. She said *takkusivuuq*, which means that the person feels embarrassment and fear in front of someone to whom she has done wrong (Schneider, 1985). When the English word shy is used, it appears to have connections to the Inuktitut word *ilira*, which I discuss further below. Nawdlak may also feel guilty for having TB altogether, as discussed in section 3.5.2, as some Inuit connect sickness to personal wrongdoings.

Thisted (2002) noted that rather than blaming the Danish colonizers for feelings of inferiority, participants blamed themselves. Other researchers have also stated that it is uncommon for Inuit to express dissatisfaction with Qallunaat decisions or actions, because of fear and awe of the Qallunaat (Brody, 1999; Minor, 1992), what Brody (2000) identifies as *ilira*. Brody (2000) relates how an Inuk elder explained that the feeling of *ilira* is a feeling of danger, a fear because someone has power and is unpredictable, can lose his temper for no apparent reason, and is able to prevent Inuit from obtaining things they need. Brody continues that “*ilira* goes to the heart of the colonial relationship...it helps explain the many times Inuit...say yes when they want to say no... *ilira* speaks to the subtle but pervasive results of inequality” (ibid.:43).

The Inuit experience of *ilira* may complement and compound the mechanism of control that Foucault (1990) called *bio-power*. Through instilling in subjects a “fetishism of empowerment” (Rose, cited in Hogle, 2002:236), *bio-power* produces individual compliance to norms and standards (Foucault 1977) and also produces self-correction rather than the necessity of coercion. Individuals become complicit with the governing power (Rose, cited in Hogle), if not in action, then in thoughts and feelings.

Tye and Laimiki both experienced healthcare professionals who threatened them into submitting to treatment. When Tye avoided treatment because it made her dizzy and gave her nausea, she said the nurse told her: “*we're just going to let you stop and if you get sick it's going to be your fault. If the TB comes back to you and gets worse we're not going to do anything about it.*” When I asked her how she felt about the nurse’s comment, Tye responded, “*I felt like I was the one to blame.*” Laimiki, who evaded treatment because it made her stomach hurt, still expressed that complying with treatment as a 13 year old was her own responsibility, and that she was a “*spoiled brat*” when she didn’t. She was also told by a doctor in Yellowknife that if she tried to leave the hospital, the healthcare system would cease to feel responsible and would not pay Laimiki’s and her mother’s plane ticket to go home again. Again, Laimiki was quick to say that it was her own fault.

At the same time then, as they resist the power that governs their lives while being treated for TB, individuals feel wrong for resisting, and it is possible that they also blame themselves for having fallen ill in the first place.

4.4.2.3 Blaming the victim

“People tend not always to take responsibility for their health” (Nelly, healthcare professional).

Some individuals afflicted with TB blame themselves for their affliction and for some of the less pleasant experiences they encounter in the healthcare system. Some healthcare professionals also blame the victims of TB, directly or indirectly, for having fallen ill. These accusations generally revolve around lack of ability to take care of their own health, control alcohol and drug consumption, and manage money. For example, when discussing responsibility for TB and TB treatment, Nelly said:

I do find that people tend not always to take responsibility for their health, and you know... in a perfect world people shouldn't have to be

sort of chased and almost harassed to come in and do things for their own benefit and the benefit of their families.

Prior to this statement Nelly mentioned that many factors play a role in the high incidence of TB in Nunavut, including crowded housing and poor nutrition. Other contributors, she said, were lack of knowledge and misconceptions about TB among both Inuit and healthcare professionals, and staffing issues such as high turnover and few possibilities for nurses to upgrade their knowledge. She does not, however, place socio-economic realities in a wider historical context, or seek to explain the reasons for poor nutrition and crowded housing, and the impression left is that these conditions are an Inuit responsibility.

When discussing the reason for the high levels of TB in Nunavut, Audrey, another healthcare professional, said:

You think of them [the Inuit] making all this money carving, etc, but they haven't learned how to wisely use it and they end up in these situations where they're drinking, using drugs, gambling, whatever... they all end up in these situations where it's a perfect place for it [TB] to take off.

In other words, by behaving badly individuals invite disease to take seat in their bodies. Anna May, another healthcare professional expressed a similar sentiment about poor Inuit conduct in Ottawa, stating that when Inuit are flown there for medical reasons or to escort a patient:

They do all the things that are probably inappropriate...they drink all night, they destroy hotel rooms, they destroy boarding homes...they get into the wrong crowd, they find the drugs.... It's like teenagers running away from home.

Anna May continued that she is made responsible for their actions, because she is the one who has allowed them to go. These sweeping generalizations are not limited to Inuit with TB, who are not 'able' to act according to Qallunaat norms. Anna May related how her Inuit staff are not willing to inform her about the stability of individuals who wish to escort a

family member, and said they do not want to make decisions about anything. Of one clerk interpreter, she said:

Maybe the reason she actually makes decisions is because her mother is European, which means that she has been given other than a sole Inuk upbringing; but then again, I don't find that her decisions are trustworthy.

Racist attitudes and blaming the victim for falling ill are not phenomena limited to health professionals in Nunavut, or only directed at people with TB. Blaming the victim is endemic to healthcare settings and systems in many places and at many levels. It is evidenced in the way that public health programming and health education is generally focussed on changing individual behaviour, rather than on political interventions, such as those aimed at decreasing socio-economic inequality (Yoder, 1997). In Nunavut systemic interventions are needed, an idea supported by strong evidence in the empirical material.

5. A matter of survival

My experience working with TB led me to believe that today, as in the past, many people's lives are affected by TB. I have come to believe that as much as people are affected by the disease itself, the effect is often compounded by a compilation of complex life-circumstances, which also affect individuals who do not have TB, but may compromise their health and make it more probable that they get it. What I interpreted as a struggle to live through a diagnosis of, and treatment for TB, may be a general struggle to live with or survive already difficult present and historical life circumstances. In other words, TB may not be the main issue. For the infected individual the disease does, however, often make an already difficult life-situation worse, through stigma about the sick (as discussed in section 3.5) and the imposition of a treatment regimen mirroring colonial overbearingness. This is not to imply that the majority of people who become infected with TB live in a difficult life situation, or do not benefit from the available treatment. Nor is it to imply that the people who volunteered to be interviewed, or with whom I had casual conversations with did not, or would not, complete treatment for latent or active TB. Several informants did, however, speak of life circumstances, present and past, which seemed to take precedence over concerns for their health. In the following, I highlight some of these. The individuals

themselves did not always connect these other life circumstances to their experience of TB. Analysing them through a narrative lens, however, I understand them to form and be part of a continuum of life experiences which have significance in relation to TB, health generally, and also to colonization.

5.1 Physical and sexual abuse

Mialia, who was introduced in section 3.4.1 and who recently finished treatment for active TB, said that as a consequence of TB she had stopped seeing her mother often. Later the 'real' reason for the estrangement emerged. This involved long duration childhood sexual abuse by her mother's common-law partner, now dead to suicide. One time during Mialia's TB treatment her mother revealed that she still loved and missed the perpetrator, causing their estrangement. When talking about this, Mialia said: *"I usually said in my mind, if you really miss him, if you really love him, go ahead and kill yourself, and go to him; I don't care."* Mialia said that the perpetrator's brother, who lives in the same community as Mialia, also abused her, though he denied the charges and was acquitted at trial. Mialia is hoping that he will change his mind; as she said, *"I'm still waiting...for that man to apologize to me, for sex."* Mialia's experiences have meant that she has no memory of her childhood or young teenage years, and she grieves her lost childhood. She says that the sexual abuse

stopped my life when I was growing up. I hardly know my childhood. I don't know about growing up, it's blacked out. I really want to know how I grew up as a child with my friends.... I can't really remember my childhood days, 'cause I used to black out every day.

As a consequence of the sexual abuse, Mialia received medical treatment for severe depression some years ago after a period of not eating, losing a lot of weight, and losing her hair. She said that she has recovered from that, and presently does not feel that any form of therapy would be helpful to her, that the only thing that would give her peace of mind is if the man would acknowledge what he has done and ask for her forgiveness. As mentioned in section 3.4, some Inuit believe that holding on to bad experiences and anger can cause sickness. Disclosure and apology from the offender can bring recovery. At the same time, however, showing anger is socially inappropriate, and the cause of a person's disease or

misfortune is often the result of the person's own deeds. This may leave the individual in a bind and prevent him or her from attempts to change things.

Although sexual and physical violence were not among the topics that I raised, more than 1/3 of the interviewed Inuit women spoke to me of personal experiences of sexual and/or physical violence, and many relayed similar experiences to me in casual settings. In Nunavut, the rates of reported violent crimes and sexual assaults in 1999 were 8 and 12 times higher than in the rest of Canada (Statistics Canada, 2004). Many of the women who had experienced abuse added that they had been mentally and/or physically bullied to keep quiet about it. This was also the case with Mialia, who was told she would be killed if she told anyone. Some of the women who were vocal about the abuse reported that family or other community members blamed them for the abuse, and did not offer support if the woman wanted to leave the relationship, but rather tried to make her stay, endure, and make the relationship work. Iqajuktaq, who herself had suffered abuse, said she would not support her daughter if she wanted to leave her abusive spouse because, as she said:

It is the woman and man on their own, so no one interferes. If they interfere the whole town is gonna know what happened in one little home, and that's not to be allowed. Like they are trying to hide it from the community...it doesn't have to be exposed to everybody. That's how it is.... If I let [my daughter] leave her [commonlaw], he's just gonna end up killing himself.... Then we will be blamed; we will all be blamed by his whole family. [My daughter] is special... and I don't want anybody to hit her...but I'm not to interfere, even if I wanted to.... It's just gonna get worse later on.

Horsman (1999), who researched violence against aboriginal women and its effect on their ability to learn and educate themselves, quotes Chandler: “being forced to stay in a place of terror breaks down health and prevents those who are oppressed from having the energy to make other decisions,” and “those who are oppressed are unable to pay attention to the functioning of their own body” (ibid. 193-194). Lane, Bopp & Bopp (2003) express something similar and state that children who have experienced physical or sexual abuse often will become abusive or seek abusive relations themselves.

When I returned to Nunavut in the fall of 2004, more women spoke to me about difficult life situations and one in particular exemplified the detrimental effects violence may have on a person's health, mentally and physically. Aloo, who was introduced in section 3.4.1, was severely beaten some years ago on her body, face and head. She never sought medical attention. Since then she has experienced increasing numbness in areas of her face, and decreasing control of her facial muscles, but she has not had the problem examined. Because of the other things that happen in her family, her health does not seem that important. In another instance, I witnessed the immediate result of a woman who had been severely beaten. Even several weeks after the attack, she had difficulty remembering and said that she sometimes had difficulty speaking clearly.

Tasiutaq, Lukta, and Mannik are among others who talked about experiences of physical violence, which for them were further compounded by difficult economic circumstances. Lukta attends college outside her home community. She described herself as an alcoholic, and said: *"My husband is violent. He tried to kill me several times."* She lives with him, but emphasised that she doesn't love him, and added *"but if I was not with him, if I wasn't, I would be wasted as a drunk. I can't leave him, we've got two adopted kids."* As long as Lukta is studying, she is entitled to housing in the community where she studies. She is not eligible for public housing in her home community because she owes the housing corporation a lot of money. She and her family lived with different relatives there, and they will need to take up this cohabitation again if they move back, a prospect she does not look forward to.

One night I met Mannik in the street. She told me that she was sad because she never sees her mother anymore, as her boyfriend does not want her to. When I asked her why, she started crying, and told me about her boyfriend who is *"controlling her,"* not wanting her to go anywhere, see anyone or do anything on her own unless, as is the case this night, she is selling art. Mannik kept looking over her shoulder and said, *"I should go, he is probably watching."* Her boyfriend beats her and bites her if she does not do as he says: *"I've got so many bite marks all over my body, and I have scars everywhere."*

Many of the Inuit women interviewed live or have lived in relationships with a high degree of physical and psychological abuse, which it may be difficult to break loose from. This would make caring for their own and their dependents' health difficult.

It is important to note that many abusers have experienced abuse themselves and have grown up in families characterised by alcohol abuse (Herman, cited in Lane, Bopp &

Bopp, 2003)⁴³. As previously noted, smoking, marijuana, and alcohol abuse are very prevalent in Nunavut (Picco, cited in Bell, 2002) and many interviewees talked about their own or family members' drug or alcohol abuse, or noted that drug and alcohol abuse was very prominent in their home communities. Some noted that they knew their abuser had been abused, or mentioned abusive people in their community whom they knew had been victims of abuse themselves. Tasiutaq, for example, related how it turned out that many of the "*angry and aggressive*" men in her community were victims of sexual abuse by a Qallunaat teacher, who taught in several different communities across Arctic Canada in the 1970s and 1980s. As she stated, "*Now I understand why [they are angry and aggressive]. They have so much hurt and grief they need to get rid of.*" Iqajuktaq's husband, for example, was sent to boarding school where priests sexually abused him.

Many writers draw "explicit links between socio-historical processes such as colonization, missionization...and the patterns of violence now prevalent in many aboriginal communities" (Lane, Bopp & Bopp, 2003; 22) since these processes entail "loss of traditional land base and sources of livelihood, the systematic destruction of languages and spiritual foundations and the purposeful assault on aboriginal family structure" (ibid.). In other words, "*fundamentally social forces and processes come to be embodied as biological events*" (Farmer, 1999: 14, emphasis in original) and "the scale of income differences in a society is one of the most powerful determinants of health standards" (Wilkinson, cited in Farmer:15).

5.2 Alcohol and drug abuse

Feelings generated by alcoholism or chemical dependency and feelings generated by oppression seem to be so "similar as to be indistinguishable from each other" (White Hat, 2004). Recognizing that human beings unconsciously seek to reproduce recognizable feelings and patterns in their lives (Berger, 2000), violence as well as alcoholism may be seen in part as products or effects of the oppression of colonization. These patterns, then, are reproduced or "recycled" (Herman, cited in Lane, Bopp & Bopp, 2003) from one generation to the next, as can be seen in Laimicki's experience.

⁴³ Under the auspices of the Aboriginal Healing Foundation, Lane, Bopp & Bopp (2003) did a comprehensive review of research and program literature specifically related to aboriginal (Inuit, Metis and First Nations) people residing in Canada, including a comprehensive review of aboriginal approaches to healing from the impact of trauma, as part of their study of aboriginal domestic violence in Canada, and their development of an "interactive set of dynamic models and processes for intervention" (ibid.:4).

Alcohol and drug use and abuse were not a topics I raised. Nine out of 28 Inuit interviewees nevertheless reported living with, or having lived with a spouse or parent who abused alcohol or drugs. Laimiki, who had difficulty taking her medication on an empty stomach, was not always able to eat before going to get her medication because her parents spent the money on alcohol rather than on food. Because Laimiki's parents were not able to support and enforce her treatment, and the healthcare workers were not always able to locate her, Laimiki ended up not getting her medication. She was forcibly admitted to the hospital for isolation and treatment. Even this regimen proved difficult. Laimiki said:

I used to sneak out and go home, find my sister and brother alone, my parents gone out drinking.... I was isolated for two weeks and I worried about my brother and sister. I had to sneak out. I didn't want my sister and brother to be alone while my parents were drinking.

Laimiki's circumstances have not improved much since then. Her father died recently and she now lives with her mother, her mother's boyfriend, and her two younger siblings. Her mother has just been fired from her job, the result of sabotage as her boyfriend did not want her to work. Laimiki's reaction to the present domestic situation was:

Now we're gonna be short of food 'cause she does not have a job and he is just trying to take drugs. So that's why I had to carve or something to make earrings and pins, to feed my little brother and sister.... He [the boyfriend] works but...use the money to buy drugs...some of them.

Laimiki feels particularly responsible for her siblings since her father died. Her mother, she said, has always slept a lot, cries a lot, and does not seem able to care for Laimiki and her siblings. Laimiki said that it looks like her mother

doesn't have any self-esteem or something, like she doesn't believe herself or something; she thinks she is worthless.... I know my mom she is hurt inside for some reason, maybe when she was just a kid. I don't know her childhood, so it could be that too.

Laimiki herself does not attend school. She does not feel able to get up in the morning, although she said that school “*is fun*” and that it is just she who is lazy. She does not think she will be able to finish high school, although she thinks education is valuable, and would like to be a teacher. Laimiki’s life circumstances are too overwhelming to allow for good health and in my interpretation too overwhelming to allow for attending school regularly. She blames herself, however, for not attending school and for the lack of ability to adhere to her treatment for TB. I see Laimiki as someone who has internalised the rules of the *disciplines*, (Foucault, 1991, 1995) in the form of the healthcare system and the educational system.

Ning told a story similar to Laimiki’s, although her present life circumstances seem to be less difficult. Ning is a 21 year-old woman without any personal or familial experience with TB. Her parents were separated when she was a teenager and she stayed with her father, who is Qallunaat. Her mother “*did her own thing.*” Often there was no food in the house and as a schoolgirl she worked in order for her and her younger siblings to eat. Her father used drugs, and some of the money that Ning earned was appropriated by her father in order to support his habit. In her late teens Ning refused to give her father any more money for drugs, so he told her to find another place to live, which she did. Now they do not see each other, although they live in the same settlement. Although Ning doesn’t drink or use drugs, she stated that her two brothers also have problems with drugs and alcohol. It is evident that drugs and alcohol often affect not just the abusers, but the children of the abusers too (Horsman, 1999).

Pingwartok smokes marijuana every day. He supports his habit by dealing a bit as well as bootlegging alcohol. He stated:

Yes, I drink. I do all the things I watched my parents do when I was a child and did not like. I drink, get stupid, get into fights, black out. They used to drink a lot when I was a child and do stupid things. My mom has said she was sorry, but not my dad. He never talks about the past, only the past before I was born. Sometimes I wish they would drink and do the same things as they did when I was little, today while I was around; then I could give them shit. But it does not help. They do what they want to do and I can’t change it.

I asked Pingwartok why he drinks and uses drugs, and his answer was: “*Because I want to. It feels good. I want to, so I do.*” Later Pingwartok expressed that he feels like a minority in his own territory because Qallunaat govern Inuit and tell them how to live. Brody (1999) met a similar sentiment when discussing the effects of NATO development on Innu land in Goose Bay, Labrador. Talking about the White people, the Innu man Sebastian said: “They harass us even when we have done nothing, we have to have some pleasures so we drink. It’s the one thing we’re allowed to do. Our way of life seems to be illegal. It’s hard for us to be ourselves” (Brody :235).

I asked Pingwartok whether he would have taken prophylactic TB medication if he had been infected, although alcohol consumption is then discouraged. He said yes, although he first paused and said that “*maybe I wouldn’t have to take treatment.*” He also mentioned that his sister stopped taking prophylactic medication halfway through the treatment because she “*missed out on the fun*” of sharing joints with her friends; they did not want to smoke after her because they were afraid that she would pass the disease on to them.

Many of the Inuit interviewed live with experiences of spousal or familial alcohol or drug abuse, or are abusers themselves. The empirical material suggests that alcohol and drug consumption, whether by parents of the person with TB or the person him or herself, may interfere with treatment and with maintaining health in general.

As mentioned above, alcohol and drug abuse, like violence and disease, are connected to acculturation and to the feelings of oppression resulting from colonization. Informants’ stories about alcohol and drug abuse, about experiences of violence, and about experiences of discrimination and oppression, weave a narrative about TB and its continuing high prevalence in Nunavut that describe the effects of colonization. As expressed by Kleinman (1995), suffering, in this case from TB, includes “every different kind of human problem that creates pain, distress, and other trials for people to undergo and endure,” and which does not “separate illness from political violence or from other forms of misery” (ibid.:15).

6. Summary and Recommendations

Colonisation bears much responsibility for the way that Inuit experience and make meaning of TB, and for the continuing high levels of TB in Nunavut. The colonial history of the Canadian Arctic, the colonial history of the health-care system, and the continuing colonisation of Nunavut are important contributors. I now summarize key points

from the preceding chapters that support this argument, make recommendations, and conclude with final thoughts on colonization and decolonisation.

6.1 The *why* and *how* of TB, and inappropriate TB education

This study has found that Inuit participants make meaning of TB, health and disease through a combination of a biomedical *how* and a socio-cultural *why*. The socio-cultural *why* relates an understanding about body, health, and disease, which differ from western medicine (Therrien & Qumaq, 1992). In western tradition the health of the adult individual and the curing of potential illness is the concern of that individual and his/her medical practitioner, and the finding of a cure is based upon specialized scientific medical knowledge held by the medical professional (Foucault, 1995). The Inuit approach to health and disease, on the other hand, demands that there is 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 (Bennett & Rowley, 2004; Therrien & Qumaq). In order to maintain balanced relations the ability to perform correct interactions according to social norms and conventions is important (Stairs, 1991).

For Inuit participants in this study, acting correctly includes respecting other people's space, rights and decisions, including the decision of children who reject TB treatment. It also includes not talking about disease, bad, or sad experiences, which the literature suggests is avoided so as to not spread unhappiness (Uyarasuk, 1999). The informants, however, relayed that acknowledging that one had TB (for example by refusing visitors) or that one had been the victim of other misfortune or abuse would cause blame, judgement and avoidance from other community members. This is so, they said, because these things happen as a result of the transgression of social norms and conventions. The power to punish the individual for transgressions, which traditionally was possessed by shamans and spirits, seems to be viewed today as the divine intervention of a Christian God.

The study also found that what Inuit informants recognize as knowledge differs from that of many Qallunaat, that Inuit and Qallunaat *habitus* regarding knowledge display is different, and that Qallunaat and Inuit ways of educating are also different.

These differences are important. Apart from two recently graduated nurses, there are no Inuit healthcare professionals in Nunavut. Healthcare, like education, is therefore offered in a Qallunaat mould by Qallunaat. This results information being presented out of context, and disseminated in ways that are inappropriate for Inuit ways of learning. The form and content

are representations of Euro-Canadian or colonizing ideologies, rather than Inuit ideologies. Since “where there is power there is resistance” (Foucauld, 1990: 1995), this circumstance may in itself inspire resistance by Inuit to receiving the intended messages. Furthermore, both Inuit and Qallunaat participants in the study were of the opinion that not much education on TB or health generally takes place in Nunavut communities.

6.2 The role of health education on individual behaviour

In traditional applied medical anthropological projects, what would likely have been deduced from this study is that more, and more culturally appropriate education is needed. Health education based on this formula would supposedly supply individuals with the knowledge necessary to help them make health enhancing rather than illness inducing choices. It would serve as a tool for positive behavior change. I do not believe, however, that more, and more culturally sensitive health education is what is required, or that wishing for *Inuit behavior change* is justified.

Yes, the socio-cultural *why* stigmatises the individual who is a victim of the disease, but it has little impact on whether Inuit submit themselves to examination and treatment. Although the stigmatisation might make it socially very difficult for the individual to acknowledge having TB, or that investigation for TB is necessary, relating specific modes of understanding disease to behaviour, and thus levels of TB in Nunavut, is unwarranted: “Recent investigations have emphasized that verbal illness categories, explanatory models and other knowledge are not predictive of behaviour” (Rebel and Hass, cited in Yoder, 1997:137-138). Local knowledge of illness may be useful “for understanding the logic of actions, but cannot be expected to predict individual behaviour” (Yoder, 1997: 138). Furthermore, *no* research has shown that health education is a predictor for TB program success (Farmer, 1999), and “research on adherence to treatment for other diseases has shown that education alone is not a highly successful intervention” (Sumartojo, 1993).

6.3 The value of anthropological knowledge in understanding health and illness

I went into the field thinking that complex cultural differences between the healthcare system and Inuit accounted for the low impact public health programs have on levels of TB, and that I, through this study, could help illuminate these differences. Through the fieldwork I came to believe that my role and my work as an anthropologist needs to have a broader scope, and that if it does it may have a much bigger impact. Medical

anthropologists have previously discussed this role, and the impact it has on public health programs and policy.

Yoder (1997), in extensive work on evaluating health communication projects, worked in co-operation with mass communication specialists, epidemiologists and health educators. As a consequence, survey questionnaires predominantly asking about knowledge and behaviour were used. Their analysis, however, “rarely found a close correspondence between changes in knowledge and changes in behaviour.” This result convinced Yoder that anthropologists need to “propose models of behaviour change to the public health community that can replace the ones derived from social psychology” (ibid.:132). Our skills in doing ethnographic research should involve more than collecting information about local culture and knowledge in order to design more culturally appropriate public health interventions (Yoder). Yes. We need to acknowledge that models of behaviour change may need to be focused on the behaviour of the healthcare professionals and the wider society, rather than (or in addition to) a focus on the behaviour of the healthcare users. Sumartojo (1993) found that positive change in healthcare givers’ attitudes towards clients significantly increased TB program success. Furthermore, our work as medical anthropologists can, as Yoder (1997), Farmer (1999, 2005, 1993, 1998) and Pelto and Pelto (1997) point out, be used to describe, and make known, the historical, political and socio-economic realities of our informants, and help to advocate for them. These realities, as this study shows, often have a much larger impact on the way that individuals make meaning of health and disease than cultural particularities.

6.4 A Matter of survival

This study found that the lives and experiences of Inuit are framed by a colonial history and by the continuing colonisation of Nunavut. This colonial framework is evident in the healthcare system and the educational system, both of which were developed and are still governed predominantly by Qallunaat, following Qallunaat norms. This perpetuates the acculturative process commenced with the historical colonization of the Canadian Arctic. It is also evident in the everyday experiences expressed by Inuit informants. In relation to TB, this colonial framework is structurally supported by several layers of blame and accusation similar to, yet different from those described in the context of AIDS in Haiti by Farmer (1993).

In this study, the first level involves blaming the afflicted for falling ill because

of the transgression of social norms and conventions. The second layer involves some Inuit blaming the colonisers for the presence and persistence of TB in Arctic Canada, and accusing them of treating Inuit discriminatorily, ethnocentrically and paternalistically, within the healthcare system and in the broader society, thus preserving a colonial hold on Nunavut, and causing Inuit to feel that seeking medical attention is to no avail. The third layer involves some health professionals and others holding Inuit responsible for falling ill or otherwise experiencing misfortune; in other words, blaming the victims because of their way of living. This victim-blaming includes accusations of a lack of the ability to take care of their own health, to control alcohol and drug use, and to manage money. The fourth and final layer includes some Inuit blaming themselves for falling ill, for a lack of ability to adhere to medical treatment, and therefore for deserving to be treated badly by Qallunaat. Foucault (1977) would suggest that this may be seen as an internalising of the control-mechanisms devised by the powers that be. These layers of accusation and blame inform and are informed by the acculturative processes connected to colonization.

Acculturation processes are in turn connected to violence, crime, suicide, child neglect, alcohol abuse and disease (WHO, cited in Korhonen, 2002; Lane, Bopp & Bopp, 2003). Therefore it comes as no surprise that many informants reported that physical and sexual abuse, and alcohol and drug abuse, significantly influence their lives and health. In order to live under these conditions, some have to use available resources just to survive rather than to think about and act on healthcare measures, whether preventative or curative. Exacerbating this is the fact that “the scale of income differences in a society is one of the most powerful determinants of health standard” (Wilkinson, cited in Farmer, 1999:15). The differences in income, education, morbidity, and mortality between Inuit and other Canadians is significant, and poverty (including relative poverty) “and racism increase the likelihood that one will become infected with *Mycobacterium tuberculosis*” (Farmer 1999). Thus, social conditions eclipse and compound the effects of TB on individuals, families, and communities, and make the occurrence of TB more likely: “*Fundamentally social forces and processes come to be embodied as biological events*” (Farmer, 1999:14, emphasis in original). Thus, the colonial history of the Canadian Arctic and the continuing colonialism in Nunavut are responsible for high levels of TB, and for influencing the way that Inuit make meaning of the disease.

6.5 How, rather than why, culturally adapted health education is relevant

Does this mean then, that culturally appropriate health education is of no importance? No it does not, but it does mean that healthcare providers may need to revise their intent with health education, and the way it is offered.

That health education is conducted in a culturally inappropriate manner reinforces the historical message that Inuit ways of doing things are inferior to those of Qallunaat. It reinforces the ethnocentrism and discrimination that informants report they experience inside and outside the healthcare system, and which some health professionals displayed in this study. Some informants say that this attitude prevents people from seeking medical attention, and that Qallunaat should know more about Inuit knowledge and values and respect them. Maintaining a healthcare system and offering health education in a Qallunaat mode 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 & the healthcare system, and which, according to informants, continues to take place in Nunavut today.

Different understandings of body, health and sickness become more significant when these differences are dismissed, and Inuit knowledge discarded and labelled as unscientific and superstitious, as exemplified in the experiences of the Inuk nursing student. Such circumstances lead to perpetuating colonialism and skewed power relations, where knowledge is synonymous with power, and power synonymous with being Qallunaaq or having adopted Qallunaat ways. Embracing and promoting Indigenous knowledge - Inuit knowledge, on the other hand, “works towards agency and the empowerment of oppressed groups” (Dei et al., 2000) towards decolonizing.

Health education in Inuit communities can be valuable when knowledge is shared in smaller groups in the community, facilitated by a nurse or other health professional living in that community. This situates the sharing of knowledge in context, rather than delivering it out of context. It allows health professionals and community members to know each other and allows individuals the freedom to speak or ask questions if they so wish. Health education delivered in this manner signals respect and acceptance. It may not change behaviour, but it will build trust between the healthcare system and community members by showing that the health professional is willing to invest him or herself, and has an interest in the individual community member’s wellbeing. Thus, it contributes to a decolonisation of the

healthcare system, a necessary condition if the dissatisfaction expressed by many Inuit informants is to be reversed.

6.6 Recommendations: Decolonization

In order to address the high incidence of TB in Nunavut, and improve Inuit health, it is necessary to intervene socio-politically in the wider society and in the healthcare system. Although colonialism must be addressed at all levels, my main focus here is on the healthcare system.

Health education must be delivered in a culturally acceptable manner, with educational material developed and delivered by healthcare professionals and Inuit community members in co-operation. Intervention programs should be delivered by healthcare staff who, if not from the culture, have knowledge about the culture in which they are immersed. They must be accepting and respectful, and able to develop a personable relationship with their clients. This demands stability of personnel, which is why the education of Inuit within the health sciences must be politically promoted and supported. Inuit should decide on the form of this education, which might be based on an Inuit understanding of health and sickness *and* western biomedical knowledge. Until adequate numbers of Inuit health professionals are available, efforts should be made to educate healthcare professionals from outside Nunavut in the communities, and strategies developed to retain them. They should be educated about Inuit culture, and be required to work closely with community members about health issues through Community Health Representatives, local health boards and the mayor's office. For this to occur, adequate funding must be made available. These changes are necessary to create a system which respects Inuit culture, and to increase the effectiveness of the system. With today's high level of mobility, and the co-morbidity of AIDS with TB, this must be recognized as a national, not just a territorial priority.

Because individuals within, as well as between communities are different, health professionals must discuss the terms of treatment with individual families and find out what they are most comfortable with, including where medication should be delivered. DOT should be given by Inuktitut speaking health workers who are known and trusted in the community, and who ask whether the treatment causes side-effects every time medication is delivered. This would help to address other factors that may complicate treatment, such as the lack of food available to a patient. Creative solutions to problems may be found working

together from a basis of respect. For example, during a presentation of the preliminary findings, a nurse with experience in Northern Saskatchewan said that after consulting with a patient, she hung a health centre sign on his door prohibiting visitors while he was contagious. It helped his potential visitors to understand that refusing visitors was not his desire.

TB will simply not be a priority for those who live under extremely difficult social circumstances. Therefore, it is imperative that poverty be addressed, and that alternative programs be developed for community based healing and reconciliation for sexual and physical abuse victims and offenders, which support the needs of both. Interventions must also be developed which assist parents in dealing with the pain that causes them to be alcohol or drug abusers, in order to break the cycle.

7. Conclusion

Colonization bears responsibility for the way that Inuit experience and make meaning of TB, as well as the high levels of TB in Nunavut, in several ways. Historically, colonization of the Canadian Arctic assaulted Inuit culture, creating dependence, concomitant identity and role confusion, and social dysfunction. The healthcare system has been part of the colonization, and has taken responsibility away from Inuit in medical matters, ignoring Inuit knowledge about health and sickness. Continuing colonization in Nunavut perpetuates these patterns, helping to make TB a secondary consideration in the lives of Inuit, but one that is more likely to occur, and more difficult to deal with.

Interventions aimed at reducing the prevalence of TB amongst Inuit, or at improving Inuit health generally, will have to take colonization and its effects into account. Health education programs, for example, need to be culturally congruent, although not on the grounds usually claimed by public health policymakers and medical anthropologists. This type of intervention will probably enjoy limited direct success, but its power lies in symbolism. Signalling a shift towards decolonization, a move toward acknowledging and privileging Inuit ways and voices, would be a powerful message indeed.

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Appendix A Map of Nunavut

Appendix B: Interview guide

of people in household hold, ages, jobs, etc.

Please tell me about your experience with TB. It does not have to have been you who were sick, I am also interested in your experience of someone else's illness.

People in family with TB now? In the past? Active/ latent?

Tell me how you discovered that you- the person(s) you know had TB and what happened?

What was your reactions? What was other person's reaction?

Do you know someone else in family outside of this household have TB?
Or who had TB in the past? What were their stories?

What are other people's reactions when they know someone has TB?

What has tuberculosis meant for you/ your family/ other people you know?

What has tuberculosis meant for your community /territory?

Are there stories about tuberculosis from the past that you are familiar with, what do they mean to you?

Are you familiar with any stories about tuberculosis in the community?

How do you think it is possible to prevent TB?

What do you think is the best way to treat TB?

Is there anything that would prevent people from getting TB?

When someone is found to have active TB what happens?- what do you think should happen?

What are your/ the community's/ the healthcare- system's / the nurses/ the CHR's / the doctor's responsibilities in order to prevent TB?

What do you think/feel/believe is your responsibility if you or someone your care for in your community have TB?

What should the healthcare system/chrs /nurses /doctors do when TB is present in a community?

What should the community and individuals in the community at large do when TB is present.?

How is TB is investigated/ treated in your community? What do you feel/think about that?

Appendix C Summary of the Thesis

A Problem of the Government? Colonization and the Socio-Cultural Experience of Tuberculosis in Nunavut

Summary

Nunavut is part of Canada's Arctic, which has been ravished by tuberculosis (TB) epidemics since the first part of the 1800s (Grygier, 1994). The number of known TB cases in Nunavut peaked in the mid-1950s, then, with the advent of new medication and the sending out of all cases to be treated in southern hospitals, numbers fell (*ibid.*). Many accounts exist describing the deplorable conditions under which the Inuit were transported to and treated in southern sanatoria (*ibid.*). Others testify to the ethnocentric and inhumane treatment of the Inuit that occurred during Canada's quest for sovereignty, including involuntary relocations (Tester & Kulchyski, 1994), and movements into settlements, forced schooling, missionization and medicalization (McNicoll, Tester, & Kulchyski, 1999).

From the beginning of the 1980s, new TB cases in Nunavut started climbing, resulting in numbers of active cases of TB 17 times higher than in Canada as a whole in 2002 (NDHSS, 2002). Living, and working as a nurse with TB in a community in Nunavut hit by an epidemic in 1997-1999, I wondered which forces were at play to maintain these high levels of TB. I wondered how significant it was that healthcare was developed and offered by Qallunaat (non-Inuit), representing one culture, while being received by Inuit, representing another. I also wondered what the stringent mode of surveillance and treatment characterising the public health program dealing with TB, meant for the way that Inuit made meaning of the disease. These questions spurred the fieldwork, though I soon realised that I also had to take into account the history of colonization of the Eastern Arctic, and the continuing experience of colonization expressed by informants during the fieldwork.

Fieldwork took place over 5 months from September 2003 through February 2004, and was complemented with a two-month visit in the fall of 2004. Methods employed for the gathering of empirical material included 42 formal interviews of 36 individuals, 29 Inuit, and 7 Qallunaat health professionals. These were complemented by numerous casual conversations, observation, participant observation, and the review of relevant documents.

Interviews were used to learn of informants' experiences of TB - their illness stories or narratives. The use of illness stories builds on the work of Kleinman (1988), who focused "especially on the patient's subjective experience and understanding of the illness [and] the crucial importance of *social* and *cultural* factors for the interpretation of symptoms" (Steffen, 1997:99 emphasis added). The narrative approach is inspired by the work of Farmer (1993, 1997, 1999), Good (1994), and Mogensen (1995, 1997). These anthropologists go beyond the traditional applied medical anthropological model often used to help create and provide "more 'culturally appropriate messages' and interventions" (Yoder, 1997:132), to show the socio-economic and political connections in society.

In my fieldwork I found that Inuit and Qallunaat ideas about knowledge and how to educate are different. This is significant, as health education is produced and delivered by Qallunaat, but aimed mostly at Inuit. Historically, Inuit education relied on oral transmission and delivering education in authentic contexts (Stairs, 1991). Qallunaat, on the other hand, often educate through textual material. I also found that Inuit and Qallunaat understanding about body, health, and disease differ. A Qallunaat concept of health is often individualistic (Foucault, 1995). An Inuit concept of health is often holistic, where harmony and balance need to exist between mind, body, and spirit, in interpersonal relations, and relations to game and the environment. This balance can be disturbed by transgressions of social norms, causing illness. According to participants, this belief meant that people with TB could be gossiped about, avoided, and blamed for their disease.

Differences between Inuit and Qallunaat conceptions of health were, however, dwarfed by the several layers of blame and accusation (Farmer, 1993) revealed by Qallunaat and Inuit informants. These involved the blaming of the victim for falling ill by other community members, the blaming of Qallunaat by Inuit for the presence and persistence of TB in Nunavut through continuing colonial actions and attitudes, the blaming of the Inuit victims by Qallunaat for falling ill because of the way they lived, and the self-blame of the afflicted Inuit for falling ill and thus deserving Qallunaat wrath.

The differences between Inuit and Qallunaat were also dwarfed by (particularly) Inuit women's expressed reality, living under difficult social conditions characterised by violence and alcohol or drug abuse. These conditions, I argue, need to be seen in light of the colonial history and prevailing colonial conditions which exist in Nunavut today. These include lower socio-economic and educational levels among Inuit compared to other Canadians and levels of morbidity and mortality that are higher than other Canadians

(NDHSS, 2002). Furthermore research has repeatedly made connections between colonization and violence, abuse, and disease (WHO, cited in Korhonen, 2002) as well as lower socio-economic status and levels of education (Rasmussen, 2001).

Analysing the different parts of the empirical material and relating them to each other I conclude that although informants express a lack of knowledge about TB in Nunavut, and although Inuit and Qallunaat modes of relating knowledge and their understanding of body health and illness differ, what is called for is not, more, and more appropriate health education in order to be able to change individual behaviour from illness inducing to health enhancing. *No* research has shown that health education is a predictor for TB program success (Farmer, 1999). Changing the attitude of healthcare personnel, on the other hand, does enhance program success (Sumartojo, 1993).

Although culturally appropriate health education may not change behaviour, it would have value as a decolonizing measure. Health education conducted in a culturally inappropriate manner reinforces the ethnocentrism and discrimination that informants report they experience, and discarding and labelling Inuit knowledge as unscientific and superstitious, which one informant experienced, leads to perpetuating already skewed power relations, where knowledge is synonymous with power and power synonymous with being Qallunaaq. Embracing and promoting Inuit knowledge would work towards “agency and the empowerment of oppressed groups” (Dei, et al. 2000), a step towards decolonisation.