

**Surviving the system:  
Regaining resilience.**

**The experience of Tobique First Nation with Tuberculosis**

**Final Report**

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### **Abstract**

**Context:** The population of aboriginal people in Canada was decimated by Tuberculosis, beginning with the colonization by the first Europeans. In the First nation of Tobique, there is a long history of TB. Recently, there have been cases of extrapulmonary TB. Many of the Elders at Tobique were dramatically affected by their personal experiences with TB, both in their own lives as well as that of their families and communities. The lessons from these past experiences need to be taken into account when planning health promotion programs to prevent the recurrence of TB.

**Objectives:** To identify the factors that are related to the attitudes toward TB and the beliefs about how it should be handled among the members of the Tobique community. The stories of the Elders of Tobique were collected and the data was analyzed by the research team as a group. Implications for future health promotion and screening programs were identified based on the data.

**Methodology:** A research team consisting of members from the Tobique Wellness Center and researchers from the University of New Brunswick worked together to plan, carry out and report on this study. A participatory action research study, using a grounded theory methodology was conducted with the Elders of Tobique First Nation, as well as other groups within the community, including adolescents and traditionalists.

**Findings:** The basic social process through which the Maliseet people of Tobique worked to maintain balance and to survive the epidemic of TB was identified as Regaining Resilience. This occurred in the context of poverty, that arose out of the oppression by the state. Oppression by the church extended the acculturation set in motion by the oppressive policies of the state that were intended to assimilate aboriginal people with the larger society. TB threatened the balance and health of aboriginal people through physical, social, emotional and mental effects. It affected not only individuals but also the families and whole community. To regain resilience the people of Tobique used strategies of maintaining culture and keeping the family together.

**Conclusions:** The community of Tobique overcame the threat of TB by regaining their resilience. Their cultural and family structures and beliefs enabled them to survive the oppression, poverty and illness of the TB epidemic. Understanding their strengths is an important tool in supporting their efforts to eliminate TB from their community.

## **Acknowledgments**

There are many members of the community of Tobique First Nations who have contributed to the success of this project. The Health Advisory Board, including has given wise and thoughtful advise to this research team throughout the project. The Staff at the Tobique Wellness center have taken their time to provide support and have contributed to making the many hours of research planning, and data analysis more comfortable. They have shared their cultural understandings and been willing to contribute many hours to the interpretation of and coding of the data, so that the process of surviving the system and TB and regaining resilience could become apparent.

In particular, we wish to thank the Elders of Tobique for their willingness to share their memories about their experiences with such a painful subject as TB. They have been generous in their openness to being interviewed in their own homes and to respond to our questions. They have also taken their time and energy to come to the Center to participate in focus group discussions of the findings and their experiences with TB. We also thank the adolescents and traditional leaders who shared their understandings of the experience of aboriginal people with illness and healing.

We also wish to thank the sisters who willingly shared their time and memories with us.

## **Tobique: Experiences of Tuberculosis**

The Maliseet Nation at Tobique (Negkootgook), located at the confluence of two river systems, the "St. John" and the "Tobique" in New Brunswick has an on-reserve population of approximately 1495 people in 2002. This community is served by a community health center with many health promotion and health maintenance and treatment programs. It is staffed by two nurses, and a part-time physician, nutritionist and dentist. There are also several Community Health Representatives and Home Care workers who provide health care and support to families within their homes on Tobique.

In the 1940s, tuberculosis was common among members of Tobique. For example, in one family of 12 children, all except one of the children died of TB ( D.L. personal account, 2000). Unfortunately, a fire destroyed the medical records of many of the Elders of Tobique, so that there is no record of who in this generation had been diagnosed and treated for TB.

During the early half of the twentieth century, sanatoria were built to care for people with TB. The sanatoria were largely built in the countryside, outside the main towns and cities, ostensibly to ensure that there was plenty of sunlight and clean air to help these patients recover from TB. Grzybowski and Allen (1999) note that in Canada, "because of the misguided parsimony of the government with respect to the suffering of aboriginal people, aboriginal patients were rarely offered sanatorium treatment in the 1930's. However, after protests and investigation, care for aboriginal people improved and by the end of 1953, 2627 aboriginal people and 348 Inuit were in sanatoria" (p.1026). This presentation of sanatoria as positive forces in the treatment of TB among aboriginals demonstrates the paternalistic "white man's approach" to caring for indigenous people. This care was enforced by law. The Notifiable Disease Act includes provision for detention of people with active TB until they are no longer infectious (NB Notifiable Disease Act; Campion, 1999). From the perspective of many aboriginal people who became ill with TB, even though they were cared for and provided with good food, adequate rest and medications in the sanatoria, this treatment was not their choice and, indeed, the perception of many was that they were incarcerated in a sanatorium for several years at a time.

Aboriginal peoples' susceptibility to TB has been used to stigmatize them by those who first exposed them to the disease. Many families at Tobique have experienced their family

members being taken away to a hospital, sometimes never to return. Others have had a history of TB themselves and have memories of being sent to the sanatorium themselves. The collective memory of these events has coloured the attitudes of people at Tobique about TB, leaving them with fear of those with TB and the desire to isolate persons found to have TB or even a positive Mantoux test. Among the Elders in Tobique are a number of people who remember this time, some of whom have a positive Mantoux response but were never treated prophylactically for TB. The fear, that continues to be imbued by the thought of TB, was evident when an elderly resident of Tobique had a positive Mantoux test and was isolated by other members of the reserve. Since there is at least a 5% chance that some of these elderly people who are PPD+ will develop active TB, there is a need for more careful health screening, supervision and health education about TB, so that TB can be detected and treated early.

In 1999, there were at least three cases of extra-pulmonary TB on Tobique demonstrating that TB continues to pose a health threat for the residents of Tobique. The purpose of this study is to understand the psychosocial process that affected the experiences of the people of Tobique in regard to TB and to use this information to guide the development of a health promotion program aimed to help the population of Tobique acquire the knowledge, attitudes and health behaviors that will enable them to prevent the transmission of TB and the development of tuberculosis.

## **Current Knowledge about TB and TB Prevention Efforts, and the Health of Canadian Aboriginal Peoples**

### ***TB: The Global Challenge***

Tuberculosis, an ancient and 99% treatable bacterial disease continues to be the leading infectious cause of death for adults on a global basis (Fanning, 1999; Grzybowski & Allen, 1999). However, the majority of those who acquire TB live in the developing world where over 95% of the worldwide TB mortality occurs (Enarson, 2000; WHO Infectious Diseases Report, 1999). The focus under the World Health Organization's program on TB after the 1950's when treatment became available was on case identification. The cost of this case finding in poorer countries often meant that money was not available for adequate treatment. As a result, the treatment was

sub-optimal among the poorer countries of the world. Consequently, fewer people with TB died, but many more of them remained infectious, escalating the epidemic. In 1978, some countries had decided to focus on decreasing smear-positive TB for those that were symptomatic. This strategy was evaluated by the World Bank as successful, and the World Health Organization declared TB to be a “global emergency” in 1993 (Enarson, 2000) and reinvested in the WHO Tuberculosis Program. This program’s main intervention was the DOTS (Direct Observed Therapy Short course) program, which focussed on increasing the patients’ compliance with anti-tuberculosis treatment as well as maintaining a good data base of cases (Enarson, 2000). DOT is now the standard of care for aboriginals with TB in programs under the Medical Services Branch of Health Canada (FitzGerald, Wang, & Elwood, 2000).

The use of the DOT program has meant that fewer people with TB need to be hospitalized and when they do need to be hospitalized due to their level of infectiousness or their severity of illness, it is for shorter periods of time (Levy & Alperstein, 1999). The issue of compliance with prescribed medication regimes, however, continues to be a challenge that can be enforced by law. In fact, during the escalating epidemic of TB in the USA in the late 80's and early 90's, the regulatory powers of New York City were increased to provide for the detention of anyone with TB who was at risk of not completing the prescribed regime. While this meant that they were kept on a secure hospital ward, it still deprived those people of their liberty (Campion, 1999). In light of the history of aboriginal people being detained in sanatoria for long periods of time, this move to broaden the laws curtailing the civil liberties of people with TB has the potential to increase the fear of aboriginal people about going for diagnosis when ill, so that they may prolong the time between symptom development and diagnosis.

One of the challenges that is being confronted in the developed world is to maintain a public health infrastructure that can respond to outbreaks efficiently. To detect the development of active TB from the many latent cases as quickly as possible is essential, in order to prevent the transmission of TB to new people (Enarson, 2000; Fanning, 1999; Levy & Alperstein, 1999).

### ***TB in Canadian Aboriginals***

While there is evidence of tuberculosis in ancient remains as long ago as 800 years prior to the arrival of Columbus (Anderson, 2000), the epidemic of tuberculosis among aboriginals in

Canada coincides with the coming of European settlers and today varies among aboriginal peoples according to the time period in which they first encountered Europeans. As a result, aboriginal people in Atlantic Canada, the first to be infected with TB through their contact with Europeans more than 300 years ago, now have the lowest incidence rates of TB of any aboriginal peoples in Canada (Grzybowski, & Allen, 1999). Nevertheless, TB continues to develop in small numbers in New Brunswick; 10 were identified between January and the end of October, 1999 (NB Epidemiological Report, 2000). In a study on the St. Mary's reserve in New Brunswick, a Maliseet community, 45% of people who had had a contact with a person with TB were PPD+ (Dutcher, 1996).

Between 1965 and 1995, the incidence of TB in Canada decreased from 29.0 to 6.5 /100,000 people / year (Long, Njoo, & Herschfield, 1999). Indeed, among Canadian born, non-aboriginal citizens of Canada, the rate of 1.5/100,000 is close to the rate at which TB is said to be virtually eliminated (Fanning, 1999). However, the decreasing rate for all residents of Canada has levelled off, largely due to three main factors:(a) the increased immigration from countries with high prevalence of TB, (b) the continuing prevalence of TB among aboriginal people and (c) the increasing number of HIV+ people among the poor and marginalised populations in Canada (Long, Njoo, & Hershfield, 1999). In fact, in 1996, the rate of TB among Status Indians, in Canada, was 43/100,000, compared to a rate of 1.5/100,000 among Canadian born, non-aboriginal people (A Second Diagnostic of the Health of First Nations and Inuit People in Canada, 1999; Grzybowski, & Allen, 1999). The fact that this rate varies across particular First Nations is an important understanding. For example in Saskatchewan in 1997, there was a new case rate of 11/100,000 for the provincial population, but among Status Indians the rate was 91/100,000 of whom 67% were under 20 years of age. Of the new cases of positive cultures of mycobacterium tuberculosis, 20% were extra-pulmonary. Contact tracing of 2853 contacts of infectious and/or primary cases of TB found that 23% were PPD+ and 6% of these had active TB (Saskatchewan Public Health services, 1999). This illustrates the risk of clustering, or having two or more cases that have similar genetic fingerprints among aboriginal people, indicating the line of transmission and strengthens the need for early detection of active TB (FitzGerald, Black, & Kunimoto, 1996; FitzGerald, Wang and Elwood, 2000; Kulaga, Behr, & Schwartzman, 1999; Saskatchewan Public Health, 1999).

The continuing epidemic of TB is fueled by several factors, including poverty, stigmatization, poor quality crowded housing, homelessness, and injection drug use (Campion, 1999; Fineberg & Wilson, 1996; Grzybowski, & Allen, 1999). These conditions are prevalent among the First Nations people living on reserves, such as Tobique. The dual infection of HIV and TB has escalated the number of people, who were already PPD+, who develop active TB or other evidence of tuberculous illness (Fineberg & Wilson, 1996). In fact, a person who is HIV+ and has a latent TB infection, has an 8% risk per year of developing active tuberculosis, to a cumulative risk of 30% over their lifetime (Fineberg & Wilson, 1996). Since the total lifetime risk of developing TB for a person with latent TB who is not HIV+ is 10% , HIV infection is responsible for many more current cases of active TB. The rate of active TB among aboriginals who are HIV+ is thus exponentially increased.

Since TB is now seldom found among the general population in Canada, it is not as consistently included in the case history and may not be considered by a physician who may never have actually seen a case of TB in his/her practice (Rao, Mookerjee, Obasanjo, & Chaisson, 2000). Moreover, detection of active TB may be more difficult because not all cases of active pulmonary TB are smear positive (Cantanzaro, et al., 2000). As a result, it is important that the presence of clinical symptoms and evidence of disease on chest x-rays be treated as active TB and the patient treated, even if the smear is negative and mycobacterium tuberculosis has not been cultured (FitzGerald, Wang & Elwood, 2000). Since the early symptoms of TB are so general, with a slight fever, fatigue, brassy cough, it is understandable that diagnosis may be delayed. In fact, Long, et al (1999) noted that “the typical patient has been symptomatic for several weeks or months, usually with systemic symptoms and chronic cough” (p. 1186). Unfortunately, the longer the diagnosis is delayed the more likely that TB will be transmitted to others. In western Canada, one study found that 42 % of cases were recently infected from people who were unknown to have TB (FitzGerald, Wang & Elwood, 2000).

Tuberculosis is given a head start when diagnosis is delayed or treatment is inappropriate because TB is not considered early for symptomatic persons (Cantanzaro, et al., 2000; FitzGerald, Wang, & Elwood, 2000; Long, Njoo, & Hershfield, 1999; Rao, et.al., 2000). When an aboriginal patient with respiratory symptoms has completed a course of antibiotics but

continues to have symptoms, it is important that a chest x-ray and sputum sample be taken for a smear and culture for acid-fast bacilli. Among aboriginal patients with TB, a clinician can expect to find some differences in the evidence of TB, including less lymphadenopathy or pleural disease. Usually these patients will have had prior contact with TB. Twice as often, patients who have pulmonary disease will have cavitory disease (FitzGerald, Wang, & Elwood, 2000).

Inadequate or inappropriate treatment of TB, results in continuing transmission of TB and in development of drug resistant strains of *Mycobacterium tuberculosis* ( Long, et al., 1997). While development of drug resistant TB is more likely to occur among immigrants, especially those that come from Asia, it is also more likely to occur in reactivated TB, rather than in newly acquired TB, although this can occur. Long, et al (1997) found a rate of 6.9 % who were resistant to at least one anti-tuberculosis drug in those with TB in western Canada. However, 14 % of those who had immigrated from Asia were drug resistant. By 1999, Hersi, and associates found that in western Canada, 10.3% were drug resistant and 6.6 % were multi-drug resistant (MDR). Of those with MDR TB, 33% had been newly infected with a MDR strain of *Mycobacterium tuberculosis* and the remaining 67 % had acquired the MDR TB through ineffective treatment. Of those with MDR TB, only 33% were “cured” by drug therapy but this took over two years to occur, rather than the 6 months that many patients with TB need. Moreover, the mortality rate among people with MDR TB in this study was five percent.

Widespread community-based screening for TB antibodies has been discouraged, believing that these programs are not cost-effective in that they do not identify enough people who are PPD+, let alone have active TB to be worth their cost. Indeed the number of false positive results can be expected to be costly both in terms of the anxiety that the individuals who test positive and their families feel but also in terms of the follow-up diagnostic assessments that will be required (American Academy of Pediatrics, 1994; Starke, 1996). What has been encouraged instead, through the Canadian Tuberculosis Standards (2000), has been the screening of individuals who have been known to be in contact with a person with active TB. If the person who is screened is PPD+, and is believed to have recently seroconverted, he/she is offered prophylactic treatment with Isoniazid if under the age of 35 as long as the person’s health status, such as the condition of their liver, is good.

In 1997 in Saskatchewan, contact tracing of both active TB and primary infection cases found 23% of those contacted had converted to become PPD+. Of these 513 persons, 346 were offered prophylactic treatment. Only 69% chose to begin this treatment and 90% complied with this therapy as ordered, most of whom were receiving Direct Observed Therapy. Only one administered his/her own medication and this person was only 50% compliant with the regime prescribed (Saskatchewan Public Health, 1999).

In summary, TB continues to be a public health challenge in Canada, particularly among aboriginal peoples. Both identification of cases as early as possible and adequate treatment are important components of the program to eliminate TB from the lives of the First Nations' Peoples.

### **Health Factors that Increase the Risk for TB among First Nations' Peoples in Canada**

There are several risk factors for TB that are increased among First Nations' people these include; poverty, crowded poor quality housing, stigmatization, diabetes, HIV, an increased rate of respiratory illnesses, and poor access to health services. Indeed, the vulnerability of Canadian aboriginals' health status is most clearly demonstrated by the fact that their mortality rate is 1.5 times that of the Canadian population as a whole (Anderson, 2000; A Second Diagnostic on the Health of First Nation and Inuit People in Canada, 1999). The life expectancy at birth of an aboriginal male is 69.1 years, six less than for males in general in Canada. In 1996, thirty-five percent of the aboriginal population were less than 15 years of age, in contrast to the 21% in the general population. On the other hand, while the Canadian population has 11% of people 65 years of age or older, there are only 4% of aboriginals in this age category. Some of this early mortality is related to the increased rates of chronic illness, suicide, violence, drug abuse and infectious diseases among aboriginal people (MacMillan, MacMillan, Offord, & Dingle, 1996; National Forum on Health, 1997; Postl, 1997).

Approximately three times as many aboriginal people develop cardiovascular problems as do the general population. Non-insulin dependent diabetes is more than five times as common among aboriginal women as Canadian females in general, and is more likely to develop at a younger age and to lead to complications earlier (A Second Diagnostic, 1999; National Forum on

Health, 1997). In fact, diabetes leads to the death of two to four times as many aboriginal diabetics as it does Canadians in general (Anderson, 2000). People with Diabetes have been found to be at increased risk of developing active TB.

Poverty is the norm on many reserves, with the average earnings of 44% of aboriginal people being below the poverty line, compared to the Canadian population's level of 20% who are under this line. This poverty is evident in the crowded conditions under which many aboriginal people live (A Second Diagnostic, 1999).

### **Research Questions and Objectives**

*The research question* that will be investigated is as follows:

What are the factors that are related to the attitudes toward TB and beliefs about how it should be handled among the members of the Tobique Band?

#### ***Research Objectives:***

1. To collect the stories of members of Tobique First Nation about TB as well as their guidance about how to educate their children and grandchildren about TB.
2. To use the themes identified from these participants' interviews and their recommendations to develop a health promotion program about TB for Tobique.
3. To increase awareness among the people of Tobique First Nation of the importance of screening for TB.

### **Methodology**

#### ***Participatory Action Design***

The study had a participatory action design, in which the research team was composed of the Executive Director, nurses, health promotion coordinator and physician from the Wellness Center at Tobique, as well as nursing researchers from the University of New Brunswick, Faculty of Nursing. This research team worked together, from the inception of the project until the dissemination and utilization of the findings. The involvement of the community of Tobique was ensured through a sharing of responsibilities for the project as well as the following provisions:

1. The identification of the problem to be studied came from the community of Tobique.
2. The members of Tobique who are health care providers at Tobique were a part of the

research team, beginning with the identification of the issue to be studied and progressing throughout the study to the dissemination of the study findings and decision making about how to address the implications of the study.

3. Members of the Health Board of Tobique, which includes representatives from different constituencies at Tobique, such as the Band Council, and the Elders have served as an advisory committee for this study. These members of the Health Board have been consulted at the following periods: (a) the beginning of the study, (b) as the data analysis was progressing for their feedback on the categories that are emerging from the data, (c) after the theory had been identified and (d) after the report was written and before the reporting of the findings to the community of Tobique.

4. A member of Tobique was trained to conduct individual interviews as well as to assist with focus groups.

5. Members of Tobique have transcribed the interviews.

6. All members of the research team participated in the coding and analysis of the qualitative data as part of an analytical group process.

7. The information that was gathered through the interviews and focus groups will be used by the research team to develop a health promotion program on TB for the members of Tobique as well as to review a questionnaire to evaluate the effect of the health promotion program on the knowledge about TB, attitudes toward TB and people with TB and their willingness to be screened for TB if this is appropriate in their case.

8. Members of the research team will write articles on TB that will be congruent with the information in the health promotion program to be delivered through a health fair at the Tobique Band hall.

9. Members of the research team have reported the findings of this study to the population of Tobique through a community meeting.

10. A grounded theory approach to this research was used because it does not impose the framework of the researchers' understanding of the issues, but rather is inductively developed from the participants' own frame of reference (Getty & Stern, 1994).

The strength of community-based research is its ability to identify the health challenges, resources, and status of a particular community, including those that are marginalized (Getty,

Allen, Arnold, Ploem & Stevenson, 1999; Giesbrecht, & Ferris, 1993; Hatch, Moss, Saran, Presley-Cantrell, & Mallory, 1993; Israel, Schulz, Parker, & Becker, 1998; Lillie-Blanton, & Hoffman, 1995; Mittelmark, Hunt, Heath, & Schmid, 1993; Omenn, 1999; Sclove, 1997). Indeed, community based research approaches have been used successfully in studies with First Nations Bands, including the Haida Gwaii (Herbert, 1996) and Mohawk Nation of Akwesasne (Santiago, Asara, Morse, Skawennio, Hunt & Licker, 1998).

### ***Sample Selection***

The sample for this study was a purposive sample, acquired through a snowballing technique, a common method of selection of a sample for grounded theory studies (Haworth-Hoepfner, 2000; Ingram & Hutchinson, 2000; Jackson, Brown & Patterson-Stewart, 2000). The study was introduced at the weekly Elders' luncheon and they were invited to participate in this study, either through interviews or through focus groups. Individual and small group (2-3 participants) interviews were done with 20 seniors. Sampling continued until there was "no new information" being gathered.

### ***Theoretical Sampling***

As the interview data were analyzed, it became evident that we needed to interview some of the care-givers from the Sanatorium at St. Basile, where most of the participants had gone for treatment. Accordingly, we interviewed 3 nuns, two of whom were nurses and one was nurse administrator who had worked in the Sanatorium at St. Basile. The purpose for these interviews was to learn about their perceptions of the rules that were maintained for the patients in the sanatorium as well as their memories about the particular situation of their aboriginal patients.

Following these interviews, the findings were reviewed with the Health Board of Tobique and their advice regarding follow-up programs was elicited. Another group of seniors from the Tobique Band participated in a focus group to clarify some of the categories that emerged from the individual interviews and to verify the social psychological process that had been articulated. The study findings were presented to a group of adolescents to learn about their perspectives about how TB should be approached at Tobique in the future. Finally a focus group with a group of Elders who were traditional healers was held, to learn about their perspectives on the

treatment of TB and how this disease should be addressed at Tobique in the future.

### ***Data Collection***

***Semi-structured interviews.*** Interviews were carried out, in which participants were encouraged to discuss their memories about TB and their feelings about their experiences with TB among their families, friends and even themselves. They were also asked to make recommendations about how education in regards to TB in the community would be most effective and what other follow-up should be provided. In particular, they were asked to discuss the questions on the interview guide (Appendix A). The purpose of this approach was to learn about their own experiences, from their own point of view, rather than to limit their responses by the researchers' points of view (Fitzgerald, 1994; Stern, 1986; Swanson, 1986). The interviews were taped and transcribed by members of Tobique.

Several studies have found that participants are more likely to discuss intimate subjects, such as an illness experience when their privacy is protected (Getty, & Stern, 1994; Getty, Allen, Arnold, Ploem & Stevenson, 1999). On a reserve, such as Tobique, there are many political factions. It has been very important for the participants to be assured that their confidentiality would be maintained. The interviews were held in the participants' homes.

At the end of the interview, the participant was asked if he/she /they wished to review the study findings and add any other thoughts by talking with the interviewer again at a later time.

***Group or focus group interviews.*** Focus groups have been used to study the attitudes and beliefs of individuals about diverse topics, ranging from the causes of AIDS (Nyamathi, & Schuler, 1990), to business issues (Asbury, 1995; MacQuarrie & McIntyre, 1987). They are particularly useful when examining complex, sensitive topics (Carey, 1994). Three focus groups, one with Elders, one with adolescents and one with the traditional healers were conducted; each one being moderated by the interviewer together with the principle investigator. Each focus group was invited to discuss the themes that had been identified from the individual interviews and to add their personal experiences with and understandings about TB. They were also invited to address the recommendations that had been consistently identified by participants, such as to

offer TB screening widely.

Focus groups provided useful data because the interaction that occurred among group members produced insights that might not have been evident in individual interviews and clarified issues in which there may have been different points of view (Asbury, 1995; Barnsley & Ellis, 1992; Fontana & Frey, 1994; Krueger, 1988; Morgan, 1990). This sharing of views and memories was facilitated by their common culture and experiences related to TB (Asbury, 1995). It was important to have the Maliseet interviewer partner in facilitating these focus groups because she has an understanding of the culture and the context in which these participants live. Her way of responding and of interpreting what is said has enhanced the depth of the data gathered from the participants (Asbury, 1995; Krueger, 1995; McDonald, 1993). It was important that the groups be conducted in a manner that was respectful of the culture and traditions of the Maliseet people (Krueger, 1995, p. 528). Focus groups were congruent with the Maliseet culture where the oral tradition is very important and healing circles have been used to deal with painful and often shameful topics and to resolve differences between band members (Noble, 1995; Pranis, 1997).

### *Data Analysis*

Data analysis began after the first interview was transcribed and continued throughout the data collection period. The data from the interviews and focus group interactions were examined line by line to identify the processes that were evident, a procedure called substantive coding (Fitzgerald, 1994; Glaser, 1978; Stern, 1980; Strauss & Corbin, 1990). Examples of substantive codes that were named were keeping the family together, sharing for survival, going to visit family. These codes were compared to one another to find patterns or clusters that fit together (Haworth-Hoepfner, 2000). For example, protecting the family, keeping the family together, family supporting their own, going to visit family, disruption of the family and having an extended family were combined into the category— keeping the family together. These categories were compared to new data, so that their properties were identified. This process of constant comparative analysis allowed the categories to remain grounded to the data (Glaser, 1978; Madill, Jordan, & Shirley, 2000; Shepard, & Hack, 1999; Stern, 1985; Stern, Moxley, & Allen, 1982; Strauss & Corbin, 1990; 1994; Wechselblatt, Gurnick, & Simon, 2000). This also served

as a method of verification of the emerging hypotheses, or a test of the "fit" of the data (Kendall, 1999; Strauss & Corbin, 1994; Wuest, 2000).

The data was coded, based on the method of constant comparative analysis, in a process in which several members of the research team discussed the data and came to a consensus about the codes to be assigned to each line of the data (Getty, Allen, Arnold, Ploem & Stevenson, 1999; Jackson, Brown & Patterson-Stewart, 2000). This process was useful in view of the need to have knowledge of the Maliseet culture in order to understand the meaning of the data from these aboriginal seniors (Madill, Jordan & Shirley, 2000; Petersen, 2000).

After the initial codes were assigned to the data, they were entered into the NUD\*IST computer program for sorting of data by codes, so that they could be compared to one another and categories identified. As the categories were compared to one another, similarities became apparent. Groups of categories were collapsed into a larger category or overriding structure (Kendall, 1999). Gradually, the basic social psychological process, or core variable which influences all other categories or themes and their relationships was identified to be Surviving the System ( Glaser, 1978; Ingram, & Hutchinson, 2000; Stern, 1985).

The properties of the core variable were examined and the relationship between categories explored through selective sampling of participants who differ in characteristics related to the categories (Getty, & Stern, 1994). The density of the developing theory was ensured through this process of theoretical sampling, i.e. gathering data from other participants who differ in particular characteristics or properties, such as the nuns and the non-aboriginal person who had TB and went to the Sanatorium to be treated (Denzin & Lincoln, 1994; Strauss & Corbin, 1994 ). Throughout the process of coding and categorizing, memos or notes about hunches, insights or ideas about the processes were made. These are being organized into the written reports of the research.

A conceptual framework was developed through a process called theoretical coding ( Glaser, 1978; Hutchison, 1986). The credibility of this substantive theory has been checked by reviewing it with the participants in focus groups as well as the Health Advisory Board of the Tobique community, who represent a group of community members, some of whom are Elders; persons who are respected for their wisdom (Morse & Fields, 1995; Petersen, 2000).

## **Rigor**

### ***Credibility of the Substantive Theory***

Much of the data that was gathered in the interviews focussed on the memories of participants. Croyle & Loftus (1993) categorise memory into "semantic memory" or general knowledge and "episodic memory" or memory about particular life experiences (p. 165). They note that episodic memory is susceptible to be changed, or forgotten more easily. Forward telescoping occurs when the individual remembers an event as having happened sooner than it actually did and backward telescoping where the event is remembered as happening longer ago than it really did occur. New information can be assimilated into the memory of a particular occurrence (Tulving, 1983).

Both under-reporting and over-reporting of particular health behaviours and problems and the use of health care resources are common (Jabine, 1987; Means & Loftus, 1991; Ross, 1989). In fact, Lin, Ensel and Lai (1997) contend that participants are more likely to under-report life events than to over-report them and that errors in memory are less likely to occur when the issue being remembered has to do with family experiences or personal events. Since memory of recurrent events tends to be more generalized and less particular, the data is more likely to be more accurate if additional cues are taken into account, e.g. the emotional significance of events (Croyle, & Loftus, 1993). The continuing dialogue that has been an inherent part of this study allowed participants to clarify their memories and explore the issues underlying these memories. This process lead to increased disclosure of information as the relationship between the participants and the researchers developed (Cotterill, 1992; Reinhartz, 1992). The common themes and experiences that were recalled by several members of the same family, such as sisters, or brothers confirmed the credibility of their data.

The oral traditions of the people of Tobique is clear as the elders of Tobique shared information about past events, including when they occurred. These accounts were echoed very closely by the written accounts of historians and the documentation gathered by the Royal Commission on Aboriginal Peoples (1996).

### ***Confirmability***

The ability to confirm the findings is facilitated by a second interaction with some of the participants who had been interviewed as well as with others in the focus group of Elders in which the theory was reviewed to determine whether it represents their experience. An audit trail was maintained in which each decision about coding and other processes were recorded in memos. In this way, another person could trace back through the documentation to confirm the findings of this research team (Leninger, 1994; Morse & Field, 1995; Rodgers & Cowles, 1993).

### **Ethical Guidelines**

Each participant who was interviewed individually or in a focus group was asked to sign an informed consent form (See Appendix B). Participants were assured that only the dialogue that occurred during an interview, to which they have formally consented, would be used in this study. As Punch (1994) states "if 'action research' actually seeks to empower participants, then one must be open and honest with them;" (p. 89). Open-ended interviews in which the participant was encouraged to tell his/her experiences and concerns about TB were conducted. The participants were assured that they were free to withdraw from the study at any time or to refuse to answer any part of the interview (Punch, 1994).

The interviews were tape-recorded for accuracy. Any identifying information was removed during the transcription of the interviews and the tapes were placed in a locked cabinet (Bulmer, 1982; Punch, 1994; Reiss, 1979).

### **Dissemination of Findings**

After the interviews were analyzed, the results were presented to a community meeting that was called to learn about TB and the results of this study. This workshop was recorded by the Tobique community radio station and was played on that station on April 2, 2001. The findings were reported to a workshop on TB, that was called by the First Nations and Inuit Branch of Health Canada (FNIHB), Atlantic Division. The final

report will be made available to the Band office as well as and the Medical Services Branch. Information about TB and the project findings and implications will be included in the health center's monthly newsletter that is available to all families on Tobique, as well as posted on the web-site for the Tobique Wellness Center.

The findings of this study will be reported to national conferences, such as the Canadian Public Health Association Annual conference, the Health Promotion Conference and the Qualitative Health Research Conference. It will also be submitted for publication to peer review journals, such as The Canadian Journal of Public Health, and the Journal of Advanced Nursing.



## FINDINGS

### **Regaining Resilience: The Experience of TB in the Tobique**

*Regaining Resilience* is the basic social process through which the Maliseet people of Tobique worked to *maintain balance* and to survive the epidemic of TB within their community. The active process of *regaining resilience* required individual, family, and community sharing, the development of strength, and the will to survive and flourish as they once had in the face of adversity imposed by the church and state. Ultimately, *regaining resilience* enabled the Maliseet people to move through and beyond the devastating effects of TB within their community, to support, restore and rebuild families, and to maintain their culture amidst overwhelming oppression, grief, loss and isolation. The balance of the physical, spiritual, emotional and social dimensions of the individual, family and community are portrayed in the Medicine Wheel, an image that depicts the perspective of aboriginal culture about health and well-being (Ellerby, McKenzie, McKay, Gariepy, & Kaufert, 2000; Garrett & Carroll, 2000).

*Regaining resilience* occurred within the context of systemic oppression by the church and state. Within such oppression the Maliseet people were acculturated and experienced a loss of their cultural beliefs, values and practices. Oppression led to extreme poverty which created a ripe environment for the epidemic of TB on the Tobique. Poverty produced conditions in which TB could thrive, and contributed to the inadequacy of care provided to those who contracted the disease. Thus poverty and oppression magnified the threat of TB within the aboriginal community.

To *regaining resilience* aboriginal people used the strategies of *maintaining culture* and *keeping the family together* to restore and preserve physical, mental, emotional and spiritual balance to ensure the health and integrity of the Tobique community. *Maintaining culture* and *keeping the family together* provided opposing forces to the negative pull created by the threat of TB amidst poverty and oppression. These strategies realigned, centred and preserved the physical, mental, emotional and spiritual harmony of individuals, families and the community.

TB threatened the entire community as members of families either contracted the disease, where required to care for those who became ill, or provided support for children who were separated from parents. *Disruption of families* and feelings of *isolation and loss* were pervasive

as members died or were involuntarily sent away to Sanitariums for years of treatment. The *threat of TB* presented multiple challenges to the balance and integrity of the individual, family and community.

The threat of TB created imbalance in the physical sphere of the aboriginal people as they faced *being screened for TB*, the fear of developing or *having the symptoms* of the disease, and *being forced to go for treatment*. The pervasive *lack of information* provided to, and the *stigmatization* of, the aboriginal people created imbalance in the mental sphere. Emotional integrity was continually threatened by the overwhelming *loss, grief, and isolation* imposed by the threat of TB and the oppressiveness of the environment. The impact of emotional turmoil continues to be evident in the long lasting and vivid memories communicated by participants years after actual events. Spiritual imbalance was created from the overwhelming forces of the church and loss of the right to openly participate and practice according to their aboriginal beliefs.

The disequilibrium created by the ongoing *threat of TB* led to the consequences of *uncertainty, acculturation* and *disruption of families* within the community. *Uncertainty* was generated by lack of knowledge regarding the disease, its cause, identification, treatment and management. *Uncertainty*, magnified by the withholding of information by health care professionals, the church and the state, caused aboriginal people to *follow the rules*. *Following the rules* occurred as the community abided by the standards for screening and treatment imposed upon them. There was generalized lack of external support provided to facilitate learning about TB, its detection, or management. The threat of TB led to further *acculturation* and *disruption of families* secondary to isolation, institutionalization, and death presenting persistent and powerful forces which challenged the equilibrium of an entire community.

### **Regaining Resilience: the Context**

The people of Tobique, a community of the Maliseet nation, were a healthy and nomadic population, traveling from place to place in order to hunt and gather food and materials to feed and cloth their families. They were a resilient people, adapting to changes in climate and availability of food and supplies necessary for their existence (Maliseet Nation at Tobique, 2001). As Anne, an elder from Tobique remembered about what she had learned when she was:

looking through the archives, and one of the things the white people... the Jesuits, remarked on, when people first came here is that the Indians in this part of the country lived to be like a hundred and forty, and they could not get over it. And that's right in the archives. So I think that the lifestyle that we had, the food that we ate... Everything was in our favour, but then when they came over and brought all the uh ....

Anne's perception that the aboriginal peoples of North America were a healthy population prior to their initial contact with European explorers and settlers has been attested to by several documents, including letters written by Jesuit priests of that period (Dickason, 1992; Special Working Group on Aboriginal Issues, 2001 ). This was affirmed by studies of skeletons from the precolumbian period where little evidence of diseases was found (Dickason, 1992; Royal Commission on Aboriginal Peoples, 1996 ).

Anne was also correct when she alluded to her conviction that the epidemics that raged through the First Nations' peoples of Canada arose out of the infectious diseases brought from Europe. These epidemics began among aboriginal people as early as the 1400's when Europeans first arrived in Canada. Anne's belief has been supported by archival materials, such as letters by Jesuit priests and the French colonists who learned from the Maliseet people how to survive in this hostile environment (Grzybowski, & Allen, 1999; Stead, 1997; Vogel, 1970). In return, as the Royal Commission on Aboriginal Peoples in Canada (1996) stated: " Hundreds of thousands sickened and died as a result of their encounters with Europeans."(p.6).

According to Kirmayer, Brass, and Tait (2000) "the history of the European colonization of North America is a harrowing tale of the indigenous population's decimation by infectious disease, warfare, and active suppression of culture and identity that was tantamount to genocide" (p. 607). There is evidence of intentional political planning of genocide in the early days of colonization of Eastern Canada. In fact, in 1744, a law was passed by the English in Nova Scotia, that awarded "a scalp bounty of 100 pounds of silver.... for every male Indian over twelve."(Maliseet First Nations in New Brunswick, 2001). Infectious diseases, genocidal policies and poverty eventually led to a decrease in the population of aboriginals in Canada from

about 500,000 to 102,000 by 1871 (Dickason, 1992; Dobyns, 1983; Wright, 1992).

Liz, a participant in this study, stated, “Maybe we were more susceptible to it [diseases in England], they brought them to us.” There is an underlying innuendo in several participants’ comments that the transmission of infections, such as TB, during the colonial period had an intentional element. One participant recalls: “Oh yeah, ...they brought us blankets and um, army stuff. Brought the disease on the reserve.” This contention is supported by several historians who have written that the aboriginal people of Canada would not have encountered TB or its effects without the influence of the Europeans who had immigrated to North America (Grzybowski, & Allen, 1999; Special Working Group on Aboriginals Issue, 2001). The similarity between what the Elders at Tobique described of this period in their history when they were exposed to new infections and such large numbers had sickened and died and the historical records in letters and other documents from this period is remarkable, demonstrating the strength of the oral tradition of the Maliseet people.

Poverty was the result of a type of environmental pollution which infected the aboriginal people requiring them to develop tolerance to its toxins:

...I’m surprised that so many of us are alive today given all the stuff we were exposed to that our systems hadn’t built up a resistance to, like alcohol for example. We never had alcohol in our societies and its, we’ve only been exposed to it for the past hundred some years, and so you don’t have the same kind of resistance as Europeans have.

Rather than recognizing that the source of the illnesses suffered by the aboriginal peoples arose in Europe, and was decimating a people who had no experience with these infections and substances such as alcohol, governments and health care workers began to look for the risk factors within aboriginals that predisposed them to these illnesses. This assessment on the basis of risk factors served to focus attention on the victims of the illness rather than on the social contexts in which these illnesses thrived. The concept of risk is frequently used to identify people whose culture, values, and language differ from that of the dominant culture so that assessment of risk becomes a tool for stigmatization of people who are different from the majority (Howard & Dryden, 1999). This focus on “risk” places the spot-light on and seeks to change the victim, rather than to understand the social factors that allow this illness to occur. It prevents people from

searching for ways to adjust the system that enabled this to happen in the first place (Chrisjohn & Young, 1994; Howard & Dryden, 1999; Ryan, 1985). The emphasis on risk also robs these people of the dignity of acknowledging the strength of their ways and their former healthy lifestyles.

Not only did the state blame aboriginals for their illnesses, it also used their misery to take advantage of them. Rather than acknowledging the land ownership of the aboriginals who were in Canada prior to their immigration, the Europeans squatted on land and declared it was the property of the European state from which they had come, rather than belonging to the people who had populated it for thousands of years. They offered tracts of land to the first nations' peoples, selected because of their lack of value to the European colonizers and their business interests (Kirmayer, Brass & Tait, 2000; Royal Commission on Aboriginal Peoples, 1996). Over time the amount of land on the reserve of Tobique was decreased through a deliberate plan between the church and the government in the 1800's (The Maliseet nation at Tobique 1700-2001). The one benefit of these reserves being isolated from Europeans was the decreased exposure of aboriginals to the infectious diseases transmitted by the colonizers (Dickason, 1992).

Europeans' political and government policies not only forced this group of Maliseets to stay on the reservation of Tobique but also removed their access to the hunting and fishing resources outside of the reserve (Maliseet Nation at Tobique, 1700-2001). Josey informed the researchers that " We weren't allowed to hunt or fish outside of the reserve - we were punished if they found us fishing down the river - you know beyond the line of the reserve." Rather than being free to earn a living in the ways traditionally known by these people, traveling to where the animals and fish could be found, the people of Tobique were required to limit their hunting and fishing to the area of land within the reserve. This resulted in increasing poverty and illness among these people (Dickason, 1992 ).

The British North American Act (now the Constitution Act, 1867) , set out the responsibility for the " Indians and lands reserved for the Indians" to the federal government of Canada. This established the paternalistic right of the government to make decisions for aboriginal people, as though they were incapable of making their own decisions or governing themselves (Maliseet Nation at Tobique, 1700-2001; Special Working Group on Aboriginal Issues, 2001). As a result of this legislative regulation, the policies of having an "Indian Agent"

hand out welfare money and make decisions about their lives, and of requiring their children to go to residential schools where they were punished for speaking their own language created an environment of oppression. This imposition of a hierarchical authority directly undermined aboriginal people's ethical value of autonomy and family-based decision making practices, contributing to their sense of shame and loss of control (Ellerby, et al., 2000).

The church and the health care system were entwined in their functions, with the nuns providing both nursing care and teaching the children in Tobique. While intending to minister to the people of Tobique, these professionals, in fact, also added to the oppression of this native population. For example, the priests sold vegetables and milk to this impoverished population and the nuns taught and disciplined the children when they spoke their own language or practiced their own customs. Together, the church and the state made decisions for the population at Tobique in relation to their ability to obtain the necessities of life, to educate their children, and to obtain care for their sick.

Even into the 1930's to 50's, TB flourished among the Maliseet people of Tobique, nourished by the context of oppression, from the government, the health care system and the church. Several members of many families succumbed to TB, leading to disruption of families when those with TB were sent to sanatoria for years at a time. Several participants in this study endured the loss of their mothers, fathers and siblings for long periods when they were hospitalized or indeed in death resulting from TB.

### **Surviving the System**

Out of this context of oppression and poverty, Maliseet people at Tobique persevered, so that the basic psychosocial process that emerged from the data of this study is *Surviving the System*. Survival is defined as the endurance of life, notwithstanding formidable circumstances. It includes persevering through difficult times, and has been described as weathering the storm, keeping the wolf from the door, pulling through and keeping afloat. All of these phrases apply to the experience of members of Tobique community who either had TB themselves or experienced its effects on members of their family. These Maliseet people endured oppression or being kept “down by harsh and unjust use of force or authority” (Funk and Wagnall, 1977, p.457).

The core variable that has emerged from this data is that of *regaining resilience*, which is a characteristic of individuals, families and communities in which they are able to adjust and adapt to pervasive negative and threatening factors, including poverty, abuse, and injury (Buckley, 1997; Hawley, 2000; Rutter, 1994). Resilience has been defined as “A set of qualities or protective mechanisms that give rise to successful adaptation despite the presence of high risk factors during the course of development” (Benard, 1991, p. 3) as well as “adjusting well in response to extreme amounts of stress” (Hawley, 2000, p. 101). One factor that is most important in the resilience of a child is a warm and caring relationship with at least one adult (Stein, et al., 2000; Wyman, et al., 1999; Werner & Smith, 1988). The strong extended family network of the Maliseet people gave children many choices for such a relationship. The role of the grandparents and other seniors in teaching the children allowed them to develop caring, continuing relationships with these children.

Through the oppression and illness, poverty and stigmatization, the people of Tobique First Nation persevered and were resilient, bending under the oppressive policies of the government and society surrounding them, enduring the poverty and illness that they were immersed in, not only as individuals, but also as families and a community. They were able to adapt to multiple stressors, maintaining their values and families throughout (Benard, 1991; Buckley, et al., 1997; Hawley, 2000). Walsh (1996) describes *resilience* in the family as the family’s ability to repair itself, even in the midst of multiple assaults on its integrity. All of the participants in this study described having several family members acquire TB, most of whom had spent long periods of time in the sanatorium, away from their family. Jim described how shortly after his father’s death, his mother and two siblings went to the Sanatorium, leaving him and another sibling home with their grandmother. When his mother returned home to care for her family, she would often have to go to other neighbors and family members to ask for food to feed her family. The value system of the people at Tobique, including the collective nature of their society, were strengths that allowed these families to adapt to the stressors of poverty, illness and stigmatization. Hawley (2000) contended that:

families with healthy schemas [strategies for coping] tend to emphasize a collective “we” more than “I”, generally adopt a relativistic view of life, often show a willingness to accept less than perfect solutions to life’s demands and are usually confident about their ability to overcome difficult circumstances as a family... (p.106).

These characteristics are evident in the families at Tobique as they shared what little they had, extending their homes and material possessions to other families at Tobique. Even though these families themselves were poor and had few other resources, they continued to care for children whose parents had been taken to the sanatorium or seniors who had no family left to care for them.

One factor that has been identified to be important to *resilience* in a family is the belief that the family is an important entity with extended family members being actively involved in sharing their family history through stories and family rituals. The role of these extended family members, often seen as Elders, was to be role models. They were perceived to be wise persons who helped families problem solve and who provided informational, emotional and instrumental supports. They helped the family access resources, as well as physical care and help (Johnson, 1995). This extended family structure, with Elders having responsibility for the education and care of children was an important factor in the *resilience* of families at Tobique. Children were instructed in the expected behaviors, or codes of conduct, learning what was truly important through the role modeling provided by the Elders. This respect for the Elders and their roles in the family are evident in the handbook written by the students of the native infant education and care program at Malaspina College:

Respect the Elders, Auntie, Uncle, Grandparents.....If you listen and obey to the Elders then you become well respected by them as well as other people.....If you listen to an Elder then you learn not only how to do it but respect as well. When someone tells you to do something it is because they care for you....It's true, if they didn't love you and care for you they wouldn't waste their time or breath talking to you (The Teaching of the Elders, 1986).

This respect for Elders and the teaching of their people was expected of children from the time of infancy. As a result, there was a rich and clear understanding of their culture and value systems evident among aboriginal people before the days of residential schools and sanatoria.

The value system of the Maliseet people, like many aboriginal people enabled them to persevere, remaining *resilient* in the midst of many stressors. Their belief in the balance of life, their respect for "Mother Earth" and their understanding of the connectedness of man and nature

have contributed to their *resilience* ( Martin, 2001). Bill told a story about a man who had TB who went into the woods, in order to protect his family from acquiring TB from him. This man went into the forest and lived on the land, expecting to die alone in the forest. Instead, he was healed over time, so that he was able to return to his family and community and live a healthy lifestyle. Bill expressed the belief that this man's healing process was related to the oxygen given off by the trees and the sense of being at one with nature. This anecdote relates the resilience of the aboriginal people in their view that they are part of nature not separate from it, and that healing may come through the use of herbs and other plants; a kind of wisdom that is conveyed by the elders to the younger generations who are willing to listen.

Their perception that the spiritual, emotional, mental and physical dimensions of life must be in balance has enabled them to retain their culture in the midst of organized and powerful forces that endeavored to assimilate them (Ellerby, et al., 2000; Martin, 2001; Safran & Safran, 1994). As Marianne, an Elder said "We never lost our 'Indianism' - it just went underground!"

Another underlying factor of the *resilience* of these families was their provision of a place where members felt safe and loved, an important resource in the midst of the stigma assigned to them by the rest of the society. One of the strategies used by families to maintain their *resilience* was *keeping the family together* in the midst of illness and despair.

The community of Tobique has also demonstrated over the years its *resilience* or its ability to persevere in spite of poverty, illness, oppression and acculturation. One strategy used by the community of Tobique was *sharing for survival*, in which neighbors shared what little they had. Many participants in this study described the sharing of meat or soup bones that were used in one family to make soup and then passed onto another to make soup at their home. One participant, June, described having an elderly woman come to live with her family when she was a child. This woman had TB but had no family in Tobique to care for her. This social support network in which families and neighbors helped one another was an important asset that enabled the people of Tobique to overcome the stressors and exigencies [urgent situations] of their lives.

### **Being Oppressed**

TB existed and was nourished within the context of severe oppression by the society in which

they were immersed, its government, as well as by the entwined church and health care system of this colonial society. This new society was founded on the European beliefs, structures and ways of doing things. None of the aboriginal values or system of caring for themselves and their communities were allowed in these early colonial times. The oppression that began when the English seized control over the lands of New Brunswick continued over several centuries, indeed many would contend that it continues to this day. It was evident and continued to be a factor when the seniors who participated in this study were children, 50-70 years ago. The remainder of this report will focus on the experiences of the seniors from Tobique in the 1930's to 1960's.

### *Oppression of the State*

The movement of aboriginal people onto reserves and other assimilation policies including the development of residential schools, further imposed European culture which contributed to the growing senses of shame in their own identity. One government official stated:

I want to get rid of the Indian problem. I do not think as a matter of fact, that this country ought to continuously protect a class of people who are able to stand alone. That is my whole point. Our objective is to continue until there is not a single Indian in Canada that has not been absorbed into the body politic, and there is no Indian question, and no Indian department and that is the whole object of this Bill (Chrisjohn & Young, 1994).

As one participant thoughtfully stated: “Maybe we didn’t have the right or you know, to eat...” Clearly the participants in this study believed that the oppression and poverty were imposed by the state. Bill commented, “Well, I don’t think that uh, given the way that we lived previous to this uh, white system being imposed on us. I think we lived very healthy:” In fact, the traditional ways of aboriginal people were derided and forbidden by the new powers of the state. The magnitude of this oppression increased over time and eventually overwhelmed the aboriginal people. Their choices were decreased, their way of life forbidden and their health destroyed.

Aboriginal people were stripped of their access to hunting and fishing rights off reserve and became dependant on the Indian Agent who maintained control of “welfare” money and made decisions about their lives. The provisions for food, clothing and shelter, provided by the state and distributed by the Indian Agent were minimal, forcing the aboriginal families to live in

squalor. Adam remembered: “..that’s how we got all of our clothing, from the Indian Agent. Brought all the stuff back in. I remember wearing the stuff all the time.” and Jim remembered, “We get our welfare cheque, \$7.00, it was already spent then. When the Indian Agent used to bring up cheques, we just take them over to Molly’s [a store]. That was it.” Other participants described the living conditions imposed by the state;

We didn’t have any mattresses. And the only blankets we had was those Army blankets. The thick heavy ones, all wool. We didn’t get any beds. We didn’t have any sheets, any pillowcases, any pillows. We had to sleep on the floor. The only time we get clothing order is twice a year. We only get two pairs of underwear and two pairs of socks, probably a jacket. We would wear gum rubbers and they were not insulated. And you got to wear them with cotton socks.

...the house was in pretty bad shape; there was no running water and no bathroom. There were community wells which were shared with community livestock. They ate food that wasn’t nutritional. They had to rely on the Indian Agent...

Another participant describes the conditions that such state control created, forcing families to risk further punishment by the church, which also wielded tremendous power. Bob remembered with a smile and a wince, “They had to rely on the Indian agent for wood and when they didn’t get any from him they had to steal wood from the Convent and risk getting caught.” This new law, imposed by the Europeans was the antithesis of the native custom in which goods were not seen as the property of one person but a shared resource, so that if another needed what one person had, it was expected that this resource would be shared. The idea that some property belonged to the person who had it and that if you needed it, you either had to buy it or ask to be given it, or that if the person was unwilling to give it to you, you had to go without was completely foreign to the Maliseets at Tobique. This incident demonstrates that even on the reserve, which had been ceded to the native people, European laws and ways of being were imposed. Even on the reserve, native customs were viewed by the State to be illegal.

The state also made decisions about education, sending some children to residential schools, in which aboriginal culture was prohibited. Participants reflect on their experience of this decision making process:

“It was the Agent. The Agent was the one that was going to send us away. We were living in a one-room house”, and “My grandmother and my aunt. They are the ones that sort of took care of us before we all went to Shubi (residential school)...my brothers and sister went to Shubi”

Shubi is one of the residential schools in which survivors are currently seeking compensation for their years of physical, cultural and sexual abuse. Children in this school were punished for speaking their own language or practising their own cultural rites. Even within the residential schools run by the churches for the state, aboriginal children continued to live with limited resources. Bob remembered: “At the residential school you only got one serving and that was it. And it wasn’t enough. So one orange wasn’t enough or an apple wasn’t enough... a slice of bread...” One participant commented that he had been taken from the residential school to the sanatorium where he found that the food was much more plentiful - he was allowed to eat until he was full, whereas in the residential school he described being hungry much of the time.

Education of the children of Tobique was a casualty of the oppression of the state as well as of the threat of TB because either children were sent away to residential school or were not encouraged to go to school. In the book, *Enough is Enough: Aboriginal women speak out*, Lilly remembered:

I went to school till about fourth grade, but couldn’t go to school in winter time - no shoes....One day my girlfriends father left the mother and the children. The mother got some help from the Indian agent, so that my little friend got a pair of rubber boots . She told me to go down and ask the Indian agent; she said, ‘He gave me a pair so I can go to school. You go down and ask him.’

I went down early in the morning and sat there. Somebody asked me what I wanted and I said I wanted to see the Indian agent. I sat there all day while he was seeing everybody else. I was only about eight years old and already nervous when I went in.

I was really nervous now; I had to get back before dark. So I was the last one sitting there and he said, ‘Do you want to see me?’ I was mad inside but nervous too. I asked him, ‘I can’t go to school. I need a pair of rubbers,’ and he said, “You’ve got a father. Let him buy

you shoes.” But my father was always in the woods all winter....So after all that the Indian agent wouldn’t give me shoes. He could have told me when I first went in, “You’re not going to get anything”(p.8 ).

This Indian agent’s cruelty and disregard for the needs of this child and her desire to learn was evidence of the disdain with which he viewed aboriginal people whose well-being he was charged to support. Finally, the education of those children who acquired TB was often ended when they were admitted to the sanatorium, where they spent several months to years. There was no provision within the sanatoria to continue the education of children.

When asked whether any of the children continued with their schooling when in the sanatorium, this nun looked puzzled and replied that the children were ill. It was evident that the idea of maintaining some schooling once the children were out of danger and were beginning to recover from TB had not occurred to these health care workers.

Over time, the influence of the state became so pervasive that some of the oppressive behaviour was adopted by the aboriginal people within their own governing bodies. As one woman recounts about the decision to send her to residential school: “My father and the chief and them must have talked about it, convinced my father to send us.” Another emphatically states: “I was around 7 years old. Well we had to go to school. If we didn’t, they would have send us away.” Subsequently these children were *acculturated* within the school system as the Maliseet culture and language was disallowed. Children who were not sent to residential schools experienced discrimination and were restricted from attending upper grades in the school in the neighbouring community.

Oppression by the state in Canada was systemic. As one participant stated, when asked why she believed that life was better for aboriginal people just across the border in the United States (U. S.) in a neighbouring community: “Because there was no discrimination (in the U. S.). The only ones that discriminated against us was our neighbours [in Canada].” Another participant described the discrimination she had experienced: “Yeah, it was everywhere. Yeah, everywhere. Discrimination was really, really terrible.” Participants recount vivid memories of aboriginal people not being able to go into the barber shops in Fredericton until the late fifties and that: “They didn’t sell liquor to Natives here either. My father used to have a white buddy that would

go in the liquor store and get him a bottle.” This pervasive experience of racism has been found to be directly related to health status of many ethnic groups (Saffron & Nazroo, 2002).

Although the stigmatization was evident in all aspects of aboriginal people’s lives, those who joined the Canadian Armed Forces (CAF) experienced brief moments of acceptance, as if their uniform masked the stigma. As one participant recalls: “When we joined the army we were getting like white men. You go right in there and get your liquor.” However, such acceptance was short lived, “When you take that uniform off, you better not go in there at all.”

Oppression of the state was further evident in the treatment that aboriginal people received when discharged from the army. Even after serving their country in the same manner as other Canadians in World War II, they received only \$2300 to build a home after discharge and were not offered the standard access to educational opportunities (Tom). It was as if the state did not recognize or believe that the aboriginal people were worthy, or capable of, personal success post discharge. As one participant states when asked about remuneration for their years of service, “I didn’t get anything” and yet another emphasizes, “I didn’t get a damn thing.”

### ***Oppression by the Church***

One of the first European institutions to interact with the Maliseet people was the Roman Catholic Church, whose priests and nuns were sent to proselytize the aboriginal people whose spirituality was seen as “heathen” by the church. The priests and nuns who were sent to Tobique in the 1920’s to 50’s were francophone and spoke neither English nor Maliseet. In most instances, these clerics made no attempts to learn the language of the Maliseet people with whom they had been sent to work. In the same time period, missionaries who went to foreign lands were required to learn the language of the people with whom they hoped to work. However, here in Canada, neither nuns or priests were required to learn the Maliseet language but instead expected the aboriginal people to learn and submit to their languages and customs. The nuns and priests who were assigned to Tobique came from French backgrounds, so that they could not even speak English with the residents of Tobique: “They couldn’t talk English. Plain English. But we went to the Priest he couldn’t talk English. Him a college graduate. Well that was what used to happen.” Participants recall trying to communicate with the nuns and priests. Anna recalled, “We managed

to communicate with the sisters with sign language, and eventually with words that they used. We were frustrated to learn after some time that one of them could speak some Maliseet.”

These religious leaders believed that they were ministering to these “Indians”, whom they perceived to be needing to be cared for or “looked after.” Sister Agnes described how she spent her life setting up health care on “Indian Reserves.” She described how difficult this was for her as she left her convent to serve at the Sanatorium where many of the members of Tobique First Nation who developed TB were sent. This was not an easy place to serve, since there was a danger of acquiring TB when caring for these patients. At least three nuns developed TB from working in the sanatorium. Sister Agnes, who had worked within a sanatorium, chuckled, remembering that some of the older boys were getting restless and difficult to control.

The older boys, you know - when they started to feel better and were able to get up more were into mischief all the time....I decided that they didn’t get to see animals very much, so we got some cows and other farm animals. I told the boys that if they behaved, these animals would be their responsibility and did that ever make them behave....They would be up and out of the place early every morning to look after the cows.....and again at night!

Participants’ descriptions of food and the efforts of people to acquire meat almost all include descriptions of the cows and pigs that were owned by the priest and by some of the more wealthy aboriginal people. These accounts attest to children’s knowledge about cows and other domestic animals. However, this nun’s assessment of the children’s experiences and knowledge may have been hampered by limitations in her ability to communicate with these children. While it is clear that this nun never considered that these children could benefit from schooling, she clearly was attempting to give them life skills that she believed would be helpful to them in the future.

The nuns who worked with the people of Tobique both in the schools and the hospitals did not share information about the reasons for their care or actions, treating the aboriginal people like children. While this was a common form of hierarchical power used by nuns and other professionals in this era, it was foreign to the egalitarian philosophy of these aboriginal people. Mabel remembered going to visit her mother who was in the sanatorium. She described her fears because her mother could not get up out of bed and she was not allowed to get onto the bed to touch her mother. She recalled a row of beds and people who had to be still and couldn’t move

around. She did not know why her mother could not get up but felt that it indicated that her mother was seriously ill. She went home very upset. However, Sister Madeline remembered that the patients in the Sanatorium often had to stay quiet in bed “or else they would haemorrhage.” She recalled that “even if they got excited, they could haemorrhage! It was awful until we learned that if you used red blankets then the blood didn’t stain the bedding!”

The role of the church and the oppression that it created was profound. The church, with its priests and nuns, sent to aboriginal communities to “save and heal” perpetuated the abhorrent oppression and poverty that existed by maintaining a patriarchal control over every aspect of aboriginal people’s lives. The church and most often the nuns took on the roles and responsibilities for education and health care. When asked if he ever was examined by a physician, one participant stated: “Uh yup. Uh, mostly by the nuns” Another recalls: “They use to come around and check them... They were like the nurses, the nuns. They were nurses too. They came and checked around.”

The nuns used their position of power and influence to maintain control. Participants reflect upon the lack of information about TB communicated to their community: “No. Not even the nuns. They were teaching us. They never mentioned anything.” Another participant remembered: “The convent, they used as a hospital. Whatever they found out they didn’t tell us.” The influence of the church and health care system was so intertwined that participants rarely recall any other outside services other than that of the nuns on the reserve: “We just assumed the nuns knew.” “All I remember is the nuns. They did that with nursing, I think.” and “I remember that hospital. All I remember being there is the nuns.”

One would expect that the presence of the church, with its wealth and influence, would have lessened the poverty within aboriginal communities. Instead, the church contributed to the poverty experienced by the people of Tobique through requiring payment for foods and other goods, and for blessings. The participants in this study remembered that the priests sold vegetables and milk to them, giving away only that which was not considered to be of quality. Many participants recalled their experiences going to the Priest for food:

They always had something in a great big garden. Right in front of the old priest house.

They use to have a great big garden. They grew everything. And I use to go over there and

after they milked the cow and separated the milk and the cream. They gave away, skim milk they called it. They sold real milk if you wanted any. But I used to go there and get skim milk.

Another participant recalled:

My grandmother would be cooking a small pork roast. We'd share that. We used to get it from the priest's house. Cheaper. My grandmother bought milk from the priest. Brother Frank had eggs. Brother use to sell that stuff.

One participant recalls the nuns providing them with leggings for warmth: "The nuns, [gave us leftovers], they used to give us their leggings." Another states: "I remember wearing them and everybody used to make fun of us, but we were warm!" These memories of receiving hand-outs from the nuns and priests and of paying for food from the priests in the midst of hunger are searing for the Elders who participated in this study. Jenny, an Elder who was also a healer stated her belief that one of the most important causes of TB among the people at Tobique was the poor quality of food that they were able to acquire. She compared it to the food that had been the diet of aboriginals prior to the coming of white men, which was "natural" and "full of nutrition" because it was wild, a product of the earth. In this way, the Church and its leaders directly contributed to the poverty and illness that the people of Tobique endured.

After persuading the people of Tobique to dispense with their traditional beliefs and to adopt Christianity, the church took on hierarchical power, as the representatives of the church. They endowed the priesthood with mystical powers of being the conduit [channel] from God to the people. Accordingly, priests began to be seen as healers of the sick and were sought out to offer prayer and to administer communion. Even within illness, the church expected to be paid to offer prayers and blessings, including healing. Jack recalled when a member of his family had asked for prayers for a brother: "That's how they knew that he was better and that there wasn't any more spots in his lungs. Even made Novena [a special financial offering for a prayer] for him."

### **Effects of Poverty**

Oppression of the state led to extreme poverty and loss. One participant highlights the magnitude of losing everything after his father had died of TB and his mother and sibling had been sent to a sanatorium: “Back in those days, they even burned your houses for nothing. All our clothes, bedding, blankets and everything. It was harder back then.” The misunderstanding about how TB was transmitted had resulted in the Indian Agent believing that “TB was in the house” and making the decision to burn the house to prevent further transmission of TB. This experience of having their home and all their belongings burned was shared by at least two of the families whose members participated in this study.

Poverty provided the context for the epidemic of TB on the Tobique, creating conditions in which TB could thrive, including lack of food, shelter and the basic necessities of life (A Second Diagnostic, 1999). As the participants responded when asked why they believed that so many community members developed TB: “I think it was the poverty..That was the thing.....poverty that drove it (TB).” Bill remembered:

The house was in pretty bad shape: there was no running water and no bathroom. There were community wells which were shared with community livestock. They ate food that wasn't nutritional. And a lot of it was caused by, back in the old days they had dirt floors. They really didn't have floors and their diet was really poor. And that's where that bug or whatever it is came along and just got passed down.

The general understanding that TB was spread in crowded conditions and that people whose immune system was weak, due to inadequate nutrition, were more likely to acquire TB was evident among many participants in this study. Many believed that TB was transmitted due to dirty conditions and believe that cleanliness is necessary to prevent the spread of TB. Others recall the specific factors created by poverty, most predominately, lack of food. Gina remembered:

Growing up we never had the proper food. We didn't have milk and vegetables, eggs. Like we didn't have those luxuries for breakfast.”

Mary echoed Margaret's memories, stating:

But we never ate right. Not because, you know they deprived us, we just didn't have it, we couldn't afford it. And I think most of the time that was the cause for everybody getting sick, because you just didn't eat right. So that's a contributor, I believe.

Weakened immune systems caused by poverty and hunger have been found to be related to the acquisition of TB (Campion, 1999; Fineberg & Wilson, 1996; Grzybowski & Allen, 1999). The resilience of the people at Tobique is demonstrated in their sharing what they had and taking what they could and needed from the land. Hunger and insufficient food intake has been linked to emotional irritability in children, as well as poorer school performance and cognitive delays (Alaimo, Olson, & Frongillo, 2001; Doll & Lyon, 1998; Gorman, 1995; Murphy et. Al., 1998; Strupp & Levitsky, 1995; Wachs, 1995). The children of Tobique had not only been deprived of adequate amounts and quality of food, but also were subjected to punishment for speaking their own language in school, being taught by nuns who did not speak their language fluently, and being forced to go to residential school and to the sanatorium for treatment for TB. The multiplicity of these stressors would be expected to lead to family breakdown and instability. One of the main consequences of this chronic hunger and food deprivation was evident in the susceptibility of the children to develop TB. The nuns who provided care for these aboriginal children during their stay in the sanatorium did not recall any other children in the sanatorium.

Many participants in this study had several siblings who were sent to the sanatorium for treatment of TB. This is the best evidence that the situation for the people at Tobique was more dire in terms of poverty than that of the surrounding white communities.

Even the food that the aboriginal people did have access to was often second rate food which was given to them by outsiders who had no use for it. Mabel recalls: “Cheese, we used to get that cheese for free. The “not to be sold cheese.” As one woman recalls the effects of such an oppressive environment:

We hardly ate any eggs. We were too poor to buy eggs. We never drank milk. I don't think we ever drank milk until we went to school. We didn't have any milk. Well we were at the farm [went to the farm], but we didn't have any money to buy it. We drank lots of butter milk. It was free. We could get all the butter milk we wanted.

Another participant explains how her family could only afford to buy bargain boxes from merchants in the neighboring town:

Bargain Box. We had (ate) everything in it. We had that, what you call dog bones now. Soup bones, you know. They had a lot of hamburger meat, and scraps of, you know,

probably what they used, leftovers from cutting up their meats. And we would get that box every Saturday's and [that's] what we had on Sunday's.

On the other hand, the descriptions of the food that these Elders did have was of basic foods, like vegetables and wild meat and fish. Gina remembered:

We had to eat - our basic meal was oatmeal porridge in the morning. Of course we had fresh bread most of the time. Fresh bread, oatmeal. But we ate a lot of potatoes, we ate a lot of macaroni we ate a lot of beans. You know stuff like that. Lot of starches.....

Ya, summer time we had a garden.....Rabbit. Whenever they were in season. Fish, we didn't have to much fish as far as, like my father going out fishing or somebody bring us fish, we didn't have that even if when the salmon runs. We didn't really have that much. But we did have a lot of berries. Fiddleheads and stuff like that because we had to, the kids had to go out and gather all that stuff and she would put them up for the winter.

Their resourcefulness in gathering what nutritional elements were available from the land may have prevented the cognitive delays and emotional irritability that have been documented in other populations who were chronically deprived of food (Alaimo, Olson & Frongillo, 2001; Doll & Lyons, 1998). Hunger was not the only effect of the poverty experienced by the members of Tobique. For many, the lack of the basic necessities became their way of life. Participants described the average living environment of aboriginal people at the time:

We didn't have any mattresses. And the only blankets we had was those Army blankets. The thick heavy ones, all wool. We didn't have any sheets, any pillowcases, any pillows. We had to sleep on the floor. We didn't get any beds. Didn't have any sheets, any pillowcases. The only time we got clothing order is twice a year. We only got two pairs of underwear and two pairs of socks, probably a jacket. We'd wear gum-rubbers and they're not insulated. And you got to wear them with cotton socks.....We never had any running water in the house. We wasn't clean as we are now. We didn't have bathrooms. Couldn't flush toilets like we can now. We only had a pot in the room where you go to during the night... Dump that the next day. That wasn't very clean. We had to lug water. Everybody

dumped their pails in that water. Water pail and brought it home. All the germs must go in there. Everybody there. Even horse pails they dump. Cows would come around and go right over the barrel, drink right from the barrel. So it wasn't very clean. All that comes into your house. You have to be clean to stay healthy. All that dirt, germs, a lot of germs. Ultimately, the extent of the poverty experienced by aboriginal people on Tobique influenced every aspect of their lives increasing the magnitude of the hardship experienced by families in day to day survival. The overwhelming effects of poverty cloud many childhood memories of the people of the community who were affected by TB. One participant reflects:

Anything you had to do [was difficult], especially on a wash day. It would take you the whole day just to get enough water, go back and forth to the house. There was no options them days. We had a hell of a time. Some went from one day to another. Some days you don't eat, some days you do. You go to bed hungry. It's hard ...my mother, I could imagine what she went through. Just to keep us alive.

The resourcefulness of many women helped their families to survive the poverty. Many of the fathers of these participants were either in the sanatoria or were away working. Alie remembered: "We were a little better off because mom worked all the time. She walked down and would ride back on the train. And she worked for a lot of prominent people there in Perth." This mother had walked about 15 kilometers every morning to work as a house keeper in the home of a wealthy family in a near-by town, returning by train to care for her own family and home every evening. This strong work ethic was apparent in many of these families.

In the period when these elders had been children, the role of women in the larger society had focused on women as mothers and home-makers. These aboriginal women not only maintained these roles but also became the wage-earners in their families. Albelda (1999) points out that having women enter the work market often does not remove them from poverty, it simply increases the size of the population who are the working poor. While this work enhanced the self-esteem of these families and provided more options for them to have adequate food, it did not necessarily change their overall quality of life. If they were working they did not receive the money from the Indian agent, because it had by this time been construed as "welfare" money, not money due to aboriginal people for the land and resources taken from them by the white society.

The toll that these conditions made on women was evident in that many of the mothers of the participants in this study had acquired TB and been sent to the sanatorium, *disrupting the families* until, and if, the mother recovered and was able to return home. Sometimes the mothers returned to find that there was nothing left - their homes and belongings had been burned, in the belief that these inanimate objects held TB and could infect the people who lived and used them. Bill remembered:

We didn't have a house, so we stayed with my Uncle and Aunt. And that was a house. Two story house. We stayed there until they got us another house, but there was TB in there.

These mothers who had been in the sanatorium for several years, and returned home after spending periods of time on bed-rest and with very limited activity returned to care for their children and homes. They were often responsible to feed their families, sometimes because their husbands had died from TB or were also ill from TB. Bob remembered his mother's desperation in trying to feed her family on the meager amount that was handed out by the Indian Agent:

Very poor. My mother would go house-to-house to bum around, to feed us. She did this after she came back from the Sanatarium. She had a harder time then. She had to go house to house to bum for food. Then they were only getting \$7.00 a month on welfare. And she had to feed the whole family.

In spite of recovering from TB and learning how to care for her home and children again, Bill's mother demonstrates her *resilience* in persevering to find resources to feed her family. Others recall the tiring effects of living within poverty: "I had a hard life. Growing up together. They never used to let us go over \$7.00 a month, it was already spent then (before the next cheque came). I was sick of that in my life."

Every member of the family was expected to help in providing for the necessities. Children's roles included hauling water from community wells, gathering wood for heating and gathering whichever wild products could be found on the reserve, including such foods as berries, and fiddleheads. Joe remembered this stage of his life and remarked vehemently:

I was sick of that in my life. A lot of times I had to go up in the woods and cut wood. That

I remember. And lug water. There was heavy barrel where we used to get our water. And that was an open well all of the time.....Them days there was no running water. We had to go out and cut our own wood. Freeze half to death. Gardens, there were very few gardens that I recall them days on the reserve.

The experience of ongoing poverty created a feeling of shame amongst many aboriginal people about their aboriginal identity. One participant summed up these feelings when he said: "I hated to be an Indian in those days, because I didn't have no food." Just as many whites had looked for the risk factors for aboriginal peoples in their predisposition to becoming ill with TB, in fact blaming the victims (Chrisjohn & Young, 1994; Howard & Dryden, 1999; Ryan, 1985), many members of the Tobique community were led to believe that TB was a disease of aboriginal people. Norman stated: "They made us feel, like they always say "It's mostly the Indians that have TB. I always had that fear." In fact, aboriginal people often blamed their identity as "Indian" for their poverty, rather than seeing it as a result of the social situation in which they had been kept. Only in recent times, have many aboriginal people been able to voice the belief that their poverty was the result of the colonization of Canada, not their own nature. Indeed, the fact that they were able to retain their identity to the degree that they have, demonstrates their *resilience* and ability to retain their culture and values in the midst of a hostile and unjust environment.

Even within their own community there were clear differences in the level of poverty experienced by its members. One participants exclaims when asked if there were differences in the levels of poverty on the reserve: "Very!! Some Indians had a lot of bic-say [salt pork]." These differences often depended on the availability of work for family members in the community or surrounding area. As these participants recall:

My grandmother took care of us until we had to go to school. We moved around so that my father could go to work. He worked in the potato house until April and I really don't know about the others. But my father used to work in the railroads, CPR. We didn't get any welfare. Because my father was working. He was getting \$1.00 a day. See what can you buy, even with that?

The ability and willingness for families to work together demonstrated their *resilience* in

surviving a system that imposed poverty on this community. As these participants recalled: “We just ate natural things. My mother and father always had a big garden. Hunt for deer, moose or rabbit. Fish...” For a people who had been hunters and gatherers to grow a garden required adaptation and learning new skills, demonstrating their resilience. Another participant recalled how his mother managed to keep potatoes for the family:

Our cellar floor was nothing but dirt. So she laid everything. Potatoes - you could see the potatoes with the sprouts. We had potatoes growing on potatoes from when we picked potatoes from the farmers.

The potato harvest provided work for a few weeks, just prior to winter. People from Tobique accepted this work and also benefited from being able to pick up the discarded potatoes from the fields after the harvest was finished; an important form of gathering potatoes for the winter.

The following statements represents the reciprocity experienced by the aboriginal people within the poverty stricken community:

Very seldom, we don't have meat, we've had vegetables. Boiled dinners, mostly on Sundays. My grandmother would be cooking a small pork roast. We share that. We use to get it from the priest house. Cheaper. Brother Ernie sold eggs. And very seldom I eat an egg. Milk, we hardly used it. I wasn't allowed to drink it except to put on cereal.

Everything was limited. I recall my mother going house to house. The people that really helped my family in the days was Horace Samis and Chrystle. My mother use to go to her and ask her if they could help us. There was another family, that was a bad one. They were really poor because their side of the family..... And my mother always helped them.

She always find a way to help them to keep that family going. It was a family type unit here. But everybody knew everybody, and everybody knew the situation. They learned to help each other. That was a big, big family. I felt more sorry for them than I did for myself.

This *sharing for survival*, the sense of being responsible for those less well off than your own family was evident in these people as they shared what little they had so that all could survive.

### **Being Threatened by TB**

TB, a consequence of oppression and poverty, threatened the entire community of

Tobique as several members of many families contracted the disease. Tom remembered:

my brother had TB.....[I was]... six... seven. [He was] Quite a lot older. A lot of people had TB.... Dave's mother had it. Dave, James, and all them. She died of TB. Uh, let's see, Gina, she used to live in our house too, she had TB. [Dave's mother] - she died when I was seven years old.

A diagnosis of TB was feared within the community. As participants in this study suggest "My mother thought of it in the same way, the way we think about cancer now, that it's a death sentence when you get cancer, that's how my mother thought of TB", and another "As far as I know, there was just a lot of that sickness around when I was growing up. People were just scared. Everybody was scared. There was no treatment."

The diagnosis of TB carried with it the threat of death. Marie remembered: "there was a lady right next to where we lived. She had TB. She died of TB in her house." Marie remembered her mother's body being returned to Tobique after she died of TB while at the sanatorium:

I think my mother passed away during the year. It must have been around March or April when I remember. All I remember is when they brought the body home. And my father was standing right next to me. Hugging the casket and crying. I couldn't see anything because I was small... I knew it was my mother.

Marie went on to describe what happened when her brother developed TB:

He had a separate bed and [we would] give him separate things. Towels, cups, dishes and everything. Wash his clothes separately. I don't know how long that went on at home. They made arrangements for him to go to the Sanatorium. He must have been gone for a good 4 years maybe. And he came back. He really looked good. But, thinking back now, if I remember him, he was always a sickly person. Like when we were very young he couldn't walk. He didn't walk until he was about 12 years old.... He just crawled around.

Because nobody knew what was going on because there was so many people dying from it. "Oh, its just natural death." That's what people was saying. Nobody knew. There's a lot of people that must have died from that because they were dying so fast.

This fear of illness, separation from family by being sent to the sanatorium and even possible death as a consequence of acquiring TB was expressed by all the participants in this study. These feelings were echoed by an older man from Pakistan whose son, a physician informed that his daughter might have TB rather than lymphoma, thinking that his father would be less frightened at the thought of his daughter having TB than cancer. This elderly man

recalled how she [his sister] had been quarantined, away from her family. On the few occasions that I was taken to visit her she would, I am told, gently kiss my tiny feet on seeing me, hoping to avoid passing on her lethal disease. Cure? There was no cure for tuberculosis in Pakistan at that time (Sheikh, 1999, p.979).

The threat of TB was magnified by ongoing uncertainty among the community members, influencing those who had been and those who had not been diagnosed with TB. Thus the threat of TB presented multiple challenges to the balance and integrity of the individual, family and community. Others were required to care for those who became ill, or provided support for children who were separated from parents.

Ongoing threat, disruption and fear challenged the belief systems of the aboriginal people which “emphasize achieving balance and wellness within the [four] domains of human life (mental, physical, emotional and spiritual)”(Ellerby et al, 2000, p.1). Healing can be accomplished only through unification between the self and the universe which requires balance and intactness of spirituality and relationships with families and community (Ellerby et al., 2000, p. 6). Survival of the individual is dependant upon “the family and the community” (Garret & Herring, 2001). The symbol of the circle, evident in the medicine wheel, represents the interconnectedness of nature and relationship to all creation (Perley, 2001, retrieved from [http//www. -----](http://www.-----), September 22). TB within an already impoverished and oppressed community presented constant threat to both personal and cultural interconnectedness. The threat of TB altered aboriginal people’s ability to “maintain rhythm and lead a balanced life” (Perley, 2001). Balance and harmony are perceived to be necessary for health and survival (Garret & Herring, 2001). The threat of TB created imbalance in the physical, emotional, mental and spiritual spheres of the people within the community of Tobique, potentiating disruption of families and acculturation.

### ***Threats to Physical Balance***

TB created imbalance in the physical sphere of aboriginal people in Tobique. The physical sphere represents knowledge and understanding that one “must see a doctor” (Perley, 2001). Inherent within this acknowledgement is that healing benefits are derived from obtaining balance through the use of both contemporary medicine and traditional approaches (Garrett & Herring, 2001). Within the physical sphere TB created forces which led to disequilibrium as each individual within the community faced *being screened for TB*, the fear of developing or *having the symptoms* of the disease, and *being forced to go for treatment*. The health care system, strongly influenced by the church, did not acknowledge or facilitate the use of traditional approaches to addressing the experience of TB. This singular approach challenged the aboriginal belief that “cure (restored balance) requires interwoven healing (Garrett & Herring, 2001, p9 ).

### ***Being screened for TB.***

Screening for TB was carried out within the community either upon the emergence of the symptoms associated with TB in an individual, family member or acquaintance, or in response to screening programs carried out by the church or state. The experience of screening in the schools is explained by Anne: “And we use to have, in school they would come in and do a TB test as well. Whatever the results were I never knew”. Another participant describes her experience:

I don't know. They often gave us, you know the nurse would come to the Indian day school we had on the reserve here and they would scratch our shoulders and put a patch on it or on the arm. Depending on what appeared on the patch. They were able to tell us if we had TB or not.

A feeling of uncertainty, concern and confusion about the symptoms of TB and its contagiousness often served as the catalyst for seeking TB screening. The extent of those affected by TB is clear in this participant's account of the rationale for screening for TB: “ You couldn't help but know about it. And they used to give us test in school. And ha, oh we were very conscious of it. I mean

there was so many people who had it.” Another recalls:

Cause they were dying so fast. The children at the school had to take a TB test and they put us on a table and give us three scratches on each side of our back with a needle. Six scratches of these to test us with.

However, learning the results of the screening tests generally did not provide clarity to those who had undergone the screening process:

Well, they told me that uh, he explained to me that I tested positive for tuberculosis. And they said they were going to do a test on me. And they said that they weren't really sure if it was active. That's what their main concern was. You know to see if it was active. And that was pretty well it.

Another participant proclaims his relief that he did not test positive, after being mis-diagnosed by his physician: “My God. Do you realize what it means if you have TB? Two or three generations of your family all had to go down and get tested!”

Those who tested positive, were frequently sent away to the Sanatorium for treatment, leaving their families and friends with little understanding of where or for how long they would be gone:

You know like I mingled with everybody. And with the testing that I get, I guess I got worse and then finally they had to send me to the Sanitorium. To keep me away from everybody else I guess.

However, those who tested positive, but did not have the symptoms or those who were negative, continued to live with the fear that they would soon contract the disease. As this participant thoughtfully recalls:

I think they used to do that every six months. A long time ago. I know Boris, Boris came up positive that time, I did too. Or so, they told me, three times it came up positive, but they said no (that they did not have TB) because we had x-rays taken.

Little or no information was provided by health care professionals to those who were screened about the process or the significance of either a positive or negative result. The effects of this lack of health education continues to be evident in the participants present day

understanding of the screening process. Bernice said:

Yeah, but um, like when I have a TB test or whatever it's called mine is always positive...and it always came up positive, but they told me I was allergic to the thing itself because it swelled up so much. So I don't know if that was caused by being around it or if it was an allergy.

Clearly Bernice understood that the tuberculin test was a test that looked for an allergic response to the substance with which she was injected. However, her knowledge was limited because she did not understand that this reaction tested for antibodies to *Mycobacterium tuberculosis* and meant that she had been infected with TB, although not necessarily having an active TB infection. She also needed to know that once a person tests positive on a TB test, they are likely to remain positive for life. It was not appropriate for Bernice to continue to be tested for antibodies for TB after she had tested positive once and it exposed her to uncomfortable lesions where she was injected. This speaks to the lack of knowledge of the health care workers, usually the nuns, about the purpose and meaning of the screening.

Screening was frequently carried out by the nuns on the reserve. These women recall their vivid memories of the experience of being screened: "That nurse used to come around every month, Sister Murdoch. She use to give us a needle every month" and another painfully remembers: "But when I was a little girl, I had um, the nuns used to give us these great big scratches. I still to this day have scars". The experiences remain indelible in the memories of those who were tested. Other participants describe their childhood experiences:

When my back was scratched and mine was always positive and I always had to go back for more, and I used to scream and fight and punch them and everything, and my parents used to try to hold me down because you know it hurt. It hurt getting that. And it always came up positive.

The number of painful memories of being screened reflects the magnitude of the terror of the experience of TB within an already damaged community, "What was the test that they used to take from here? I remember that. That hurt.", "Yes, it was a scary feeling. They did so many of them, you know. One is bad enough" and "Some needles must have hurt. I remember Warren

running away. They couldn't catch him."

Those who tested negative continue to believe that they had been spared, and that somehow, they had escaped the dreaded disease but did not question why or how this might have occurred. The people of Tobique continued to follow the rules prescribed by an oppressive health care system amidst a cloud of uncertainty. No further information was provided by those who performed the screening. Such an approach, imposed by the state, challenges the belief of aboriginal people that helping relationships are those that are personal, sincere and based on trust (Ellerby et al., 2000; Garrett & Herring, 2001). Absence of questioning, or searching for a rationale for their negative screening results is evident in these participants almost fatalistic responses: "Good thing I came out healthy." and "Only test me here. They give us a scratch here, give us something if you had TB. If you don't, your all set. They give you a germ I guess. Later I don't know what they did".

### *Having the symptoms.*

Uncertainty was further manifested by the development of symptoms thought to be associated with TB. Knowledge of symptoms that were related to TB developed over time through hearsay within the community as well as the experience of living with the disease. The group of symptoms associated with TB included weight loss, fatigue, and loss of strength. Participants describe those who had the symptoms: "He was coughing his head off.", "She was coughing. Coughing up some phlegm." Others remember family members who were "Sick. She lost a lot of weight I guess." The symptoms of TB, coughing, fever, weight loss and malaise (FitzGerald, Wng & Elwood, 2000; Long, 1999) were accurately named by the participants in this study .

The overall sadness of the experience of having the symptoms is reflected in this participant's memory of his sister "the only thing that I remember is her being cold all the time, all snuggled up next to the wood stove being in so much pain all the time. Crying." The consequences of being sent away and/or dying once displaying these symptoms became clear to the aboriginal people, magnifying the fear and threat of TB within the community. Such memories of loved ones with TB remain vivid in participants minds years after the experience. One woman recalls

memories of her sister who had contracted TB, of her being:

Cold and sickly all the time. She was so frail. Her glands were swollen all the time. My mother took her to the old hospital here. It must have spread all through her. She was tall.

But I remember her being skinny and having a hard time to walk. Poor little thing, she didn't even want an open casket here. She didn't want people to see her how she looked.

Although people within the community demonstrated symptoms associated with TB, friends and family members were frequently unaware of precautions to take with these individuals.

You know, just like that ...(ate from her plate), or drank from her cup or anything you know? But she used to cough and cough all the time you know. Anyway, I went in and I went for a test. I told the doctor the reason why. I said, she and I were close. We went to church together, shopping together, ate together, everything you know. So I got tested and it came up negative

Frequently either the presence of symptoms, or contact with someone who was later diagnosed with TB were the reasons people considered being screened.

### ***Being treated.***

The vast majority of those who tested positive and showed the signs and symptoms associated with TB were forced to go to the Sanitarium for treatment. Being sent away for treatment was especially traumatic for the aboriginal community, many of whom believed that health care institutions were dehumanizing and traumatic (Ellerby et al., 2000). Those who were sent to the Sanatorium were isolated and separated from their families for undetermined amounts of time without choice. Institutionalization imposed prescribed isolation, loneliness and often years away from family and friends, or the ultimate consequence of untimely death . Such separation presented challenges to aboriginal people whose identity is rooted in community membership and being a part of a greater whole (Garrett & Herring, 2001).

Some of the children grew up in the Sanatorium. One woman describes her sister: "My sister, Angel, we went to go see her, went by train. She grew up there, right in bed. Never walked or anything." Another participant described her aunt's experience: "My auntie Laura is 94 now,

and she had TB but where they sent her was to the lakes. Five years. She wasn't allowed visitors for five years."

Some aboriginal people remembered their time in the sanatorium as being boring and the schedule as rigid. Gina stated " You just had to do whatever they told you to do." Dwayne remembered his 14 months in the sanatorium:

One of the things that really annoyed me was that you had to sleep and rest all the time. And I had a lot of energy. I just couldn't tolerate having to sleep every afternoon. But it was a requirement of the hospital and we were getting medication.....I didn't feel sick. I was wondering why I was always being sent there.....We had to sleep everyday at 1:00 PM and wake up at 3:00 PM.... we had to eat our meals three times a day....

This description was echoed by the nuns who had worked at the sanatorium at the time that these seniors were there. Sister Abegail described: "there were two rest periods every day - the little rest - that was in the morning and they could read or play cards or do something quiet and then there was the big rest, when they had to sleep." The importance of this rest was emphasized when Sister Mary was asked about the use of bed rest for patients in the sanatorium. She responded that:

when the person had holes in their lungs, if they got excited..even listening to a hockey game could make them haemorrhage.....It was a problem before we learned that if the blankets on the bed were red, then you couldn't see the stains afterward....

Several of the participants in this study remembered their fear when their mothers were unable to get out of bed or even play with them on their bed when they went to visit. Tom remembered that his mother:

was not allowed to do any of that stuff [playing with him], that's why she had to lie still.

When I got back, I thought more about it. It took me a long time to get over that trip. I kept thinking about her all the time. My brother was there too. The same time as my mother was. He wasn't as bad as my mother was. At least he got up.....It was a bad trip for me.

This prescription of bed rest separated families even though other family members were also patients in the same sanatorium. The nuns described that the men were on the main floor and the women in the middle with the children on the top floor. If a parent was on total bed rest, even visits

with his/her child who was on the third floor were not allowed, so that the family was disrupted even when several were in the same institution.

One of the benefits of being sent to the sanatorium was that food was plentiful and they could eat as much as they wanted. For people who had often been hungry in their lives this was an important advantage of being institutionalized. Some of the participants described that they were even better fed in the sanatorium than they had been in the residential school where their number and size of helpings were limited. Dwayne stated that to eat well “was a requirement of the hospital and we were getting medication. And the food was good. I liked the food and everything.”

As patients in the sanatorium stabilized and were evaluated to be healing, they had more freedom to move about within the sanatorium and its grounds. Dwayne remembered:

Like you know they did their evaluations. And after that I was able to roam around in the wing, where I was...And then after so many months I was able to go out on the lawn ....but I know I spent a lot of time inside....

Other participants, especially those who were adolescents, enjoyed this time of being able to move around within the sanatorium and its grounds. For example, Sally developed a romance with a boy from another reserve while in the sanatorium. Since transportation was not easily available in that period, she stated that she might not have met him had they not both been patients in the sanatorium at the same time. She had many positive memories of this period in her life.

Even when returning home from the sanatorium, people often continued to need medication, usually delivered by the nuns in the community. One participant describes his experiences with these nuns:

Well the nuns used to tell me ‘you better come here and come and get your needle or if you don’t we’ll come after you’. And you come back, every time they told you to come back

Given the separation of those with TB from their family and community, an understanding of the treatment for TB was often derived from the care that was either directly observed by family members or communicated to them by those who had been institutionalized. One participant recalls her memories of visiting her parents in the Sanatorium as a child.

I remember that train. I remember staying there one day. Came back on the train again.

My parents, I have pictures where they are so skinny. They were not allowed to get up from their beds. I don't know why. They weren't allowed to get up or sit up or anything. As there was no formal education provided by caregivers, the information communicated through hearsay was often unclear or incorrect. A few received care at home, but without any health care supports or information.

### ***Threats to the Mental Balance***

The pervasive *lack of information* provided to the aboriginal people about the experience of TB and its management created imbalance in the mental sphere of the individual. *Uncertainty* became the overwhelming force within the Tobique community. The mental sphere represents the direction of thinking (Perley, 2001). The mental sphere is important to the balance of the intellectual aspect of the individual enabling him or her to “acquire, predict...[and] interpret hidden messages” (Perley, 2001). Thus, the lack of information and ongoing uncertainty challenged the people of Tobique's ability to anticipate the effects of TB and to interpret the meaning of the experience. Lack of information and uncertainty challenged traditional beliefs that wellness is related to being “in control” of one's emotional and mental harmony (Garret & Herring, 2001).

***Lack of information.*** Lack of knowledge was fostered by health care professionals who held multiple roles within the community and who did not provide information to individuals and family members regarding the etiology of TB, its prevention, detection or treatment. There was lack of clarity regarding the roles of health care providers who delivered care to those being screened for or diagnosed with TB. When asked who performed TB testing, this participant stated:

It might have been a nurse or it might have been a doctor. It's that medical person who came to the reserve and tested the kids at the school. And that's where it all started. It could have been. No, I think it was a nurse or a doctor. The nurse could have been a doctor too. I don't know.

The people of Tobique also believed that information was withheld secondary to the perception of the state that they were not worthy of quality health care, as evidenced by this woman's suggestion

that “The veterinarian, Dr. Jones, he was a dentist, he was a veterinarian Indian doctor. I guess uh, nothing was too good for the Indians. Had to get a vet to be an Indian doctor.” The withholding of information challenged a belief system that was rooted in oral history (Ellerby et al., 2000).

In addition the nuns performed multiple functions on the Tobique, enabling them to control the information provided to the aboriginal people:

So I was one of the guys that had the TB. So my initial treatment was getting needles at the convent by the nuns that ran the convent here on the reserve. So on a daily basis I went after needles there.

Another participant remember: “But they never told us (Nuns) that you could catch it or anything. They would just say ‘don’t be afraid of getting TB, its already fumigated.’” Others discuss their interactions with various health care professionals and the lack of information provided to them: “They might have scrapped the TB off or something. I don’t know what they did. They didn’t tell me all that stuff. All I know that she had TB of the bone”, and “At the conclusion of the two year hospitalization, the doctor discharged her with a pat on the back and the instruction to ‘have a good life.’”

Although TB was rampant throughout the community of Tobique, the aboriginal people were provided with little information about how the disease was acquired, its signs and symptoms, or its management. Lack of information about even the most basic information about a disease that was ravaging an entire community is evident in these participant’s recollections: “I didn’t know too much about TB at the time. All I know it was a sickness. How bad of a sickness, I wasn’t sure”. “ I didn’t know what it was at the time. I knew it was a sickness of some kind, but what kind of sickness?”and as Jose queries “I just couldn’t get over why so many of us on the reserve had it. Was it spring born? I never understood the disease. I know it had something to do with lungs and breathing.”

Even those who were tested for TB were uncertain about the significance of the results or the rationale for subsequent treatment. However, they continued to follow the prescribed rules even in the absence of explanations. Lack of basic information challenged the decision making abilities regarding care of those with TB which was normally dependent on process and

interpretation of values within the context of family and community (Ellerby et al., 2000). One participant recalls his experience:

When I was going to school in Presque Isle they did a test on me, and it tested positive. I don't know they said it was like a precaution. They weren't sure if I really had TB, whether it was active, or you know, like uh, non active. So just to be on the safe side, they put me on medication. And then um, I kept throwing, bringing up, mucus, and you know spitting into a jar to see. I never did find out if it was active or not. They just put me on medication for eight months.

Clearly, this participant did not understand what "active TB" meant or the fact that had he developed active TB his treatment would likely have been much longer and he would have been sent to the sanatorium rather than being allowed to live freely at home.

One of the problems faced by people who continued to live at home but were receiving treatment for TB was the isolation that some faced in their community. Dwayne remembered:

some of the kids would say, "Oh gee, we're not allowed to play with him." I think some parents were warning their children not to play with us because we were sick.....once they knew I was a possible person that had TB, people sort of, I don't know, stayed away.

As a consequence, some people at Tobique who were being treated for TB continued to feel isolated, even though they were living at home. Discrimination, based on fear of contagion of TB was endured while receiving treatment at home. In this way, they suffered from a double source of discrimination, their compliance with being treated for TB and their racial identity. Others however, continued to be cared for and integrated into their extended family and their community.

***Uncertainty.*** Understanding about TB was developed within the community through loosely connected information generated by individuals and families experiences with the disease and word of mouth. One participant relays his understanding of how his childhood friend contracted TB:

We were playing tag down by the river, skates eh, and there was an opening there and when he fell down he couldn't stop himself, he was going too fast, he went right in the water. ...right after that, that's when he started getting sick, he got Pneumonia, and uh, got

TB and he died from it and he never even got better. That's the way I remember it. Another recalls how many community members became ill: "I think we had a barber here that had TB and everybody went and got their hair cuts from him. He would be coughing his head off." Yet another participant emphasised how she realized she could spread TB from another member in the community: "I didn't even know I was supposed to separate myself. Somebody, who was that, Susan Smith, told me." John states, "I mean I wasn't informed by a medical. A woman from the reserve had to tell me that."

Uncertainty was magnified through lack of understanding of the symptoms and the significance of the results of screening and need for treatment. Uncertainty compounded fear and led to alienation within the community of those thought to have TB:

The kids would say, "Oh gee, we're not allowed to play with him." I think parents were warning their kids not to play with us. So you know, I think a bit of that when I was here on the reserve before I went to the sanatorium.

The effects of uncertainty were experienced by those who did not have TB, "They told me I couldn't go anywhere, was some lady down the road here had TB. They couldn't go there. Might as well say they were ostracized. You know." as well as those who had contracted the disease, "While you're going through it, that's a different deal. How people look at you and how people distance themselves from you. And stuff like that. It's just hard"

The historical influence on information gathering and related uncertainty about TB continues within the Tobique community today. Lack of understanding and clarity is noticeable when participants respond to questions about their present perceptions about TB:

Because like I said, I don't know anything about the disease. I just hear bits and pieces here. And as far as I'm concerned it's hereditary. I keep hearing that maybe we might have one or two cases. I don't know, for all I know it might be rumours. But I heard there was a couple of people on the reserve.

As this woman queries: "You know, that's what I always figured, you know he had to be a carrier or whatever. They had to be hospitalized, don't they?, do they? I don't even know"

### ***Threats to Emotional Balance***

Emotional integrity was continually threatened by the overwhelming loss, grief and isolation imposed by the threat of TB and the oppressiveness of the environment. Emotional balance reflects the direction of feeling that is experienced in a healthy and open manner (Perley, 2001). Imbalance is created when emotions are suppressed secondary to negative responses and reactions of others (Perley, 2001). The impact of emotional turmoil continues to be evident in the long lasting and vivid memories communicated by participants years after the actual events:

I remember she scared me because she lost so much weight. They took out all her teeth. Her teeth had all fallen out or something and she was like a skeleton. She reminded me of one of those things on the cross, Jesus Christ nailed to the cross. You know how boney they were.

The threat and fear of TB continues today. As participants who lived through the epidemic explain: "So, I always feel like I have it. The first thing that crosses my mind was, "maybe I have TB. And I'm always tired. But again, that's the symptoms of asthma" Another notes: "It's hard to shake it off, you know, when you were reminded of it when your smaller, you know, it's hard to shake it off." The lasting emotional impact of TB on aboriginal people in Tobique and the influence of the church is reflected in the following statement:

Sister stated that Indians were carriers also, not only that they have TB, but they are carriers. And I remember her saying that. And I always felt like I was a carrier after that. So that kind of scared me for the longest time.

### ***Threats to Spiritual Balance***

Spiritual imbalance was created from the overwhelming forces of the church and loss of the right to openly participate and practice according to their aboriginal beliefs. The spiritual aspect one of the most powerful and generally unseen concepts and is considered to be the mirror image of the physical aspect of the individual (Perley, 2001). Spiritual beliefs of the aboriginal people generally include the values of holism, pluralism, autonomy, and cultural and family beliefs, rather than those that rely on Scripture and text (Ellerby et al., 2000). The management of TB during this

epidemic was determined by the church with its overwhelming control over health care. Thus, aboriginal healing and related customs were disallowed within the community, creating imbalance between the spiritual and the physical realms of the person. Such external control was counter to the aboriginal belief that “no-one should have the power to interfere or to impose on others which path is the best to follow” (Garret & Herring, 2001, p. 8).

The church, with its priests and nuns, sent to aboriginal communities to “save and heal” perpetuated the oppression and poverty that existed by maintaining control over every aspect of aboriginal people’s lives. The church and most often the nuns took on the roles and responsibilities for education and health care. As one participant recalls: “They use to come around and check them. They were like the nurses, the nuns. They were nurses too. They came and checked around.” The nuns used their position of power and influence to maintain control. Participants reflect upon the exchange of information in their community: “No. Not even the nuns. They were teaching us. They never mentioned anything.”, and another states “The convent, they used as a hospital. Whatever they found out they didn’t tell us.”

As occurred within other oppressed aboriginal communities, the overwhelming presence of the church and its influence over health care within the community created a division between Christian values and aboriginal values about healing (Ellerby et al, 2000). Priests rather than traditional healers were generally perceived to be healers of the sick and were sought out to offer prayer and to administer communion. Tina remembered that when she was 15 years old, she was ill with TB and was in a hospital being cared for by the nuns. She recalled:

One of the sisters told my mother she (Tina) won’t last till morning.....Everyone was crying. I didn’t know what was going on. So when the nurse (nun) left, my mother asked me if I wanted to see the healing priest in St. \_\_\_\_\_ ..... Then my mother said we’ll take you up there. ....The healing priest was right in bed.....That priest said, “My goodness you’re too young to have that disease”. We told him that I have TB. So he was praying for me. I was all numb. I went numb. I felt funny. He gave me some pills in a small bottle, a few pills, about 5 or 6 .....Anyway, the priest must have cured me. ....He told me, every

morning walk. You get up and walk around and take deep breaths...And he said you have to give up something. I didn't know what to give up..... So I thought I wouldn't dance.

### **Disruption of the Families**

The ongoing threat of TB led to the *disruption of families* within the Tobique community, as a result of several factors, including (a) the isolation of those having or suspected of having TB, (b) prolonged and often involuntary institutionalization of those diagnosed with TB, and (c) the death of many family members. Such overwhelming loss challenged the equilibrium of an entire community, since the community and the family were so closely interwoven.

TB affected whole families; many became ill while others lived amongst and cared for those who had contracted the disease. Sandra remembered: "Oh, I never thought much of it because I've always had somebody, you know, cousins and relatives who had it." Dwayne stated: "But there was a lot of people on this reserve that had TB. A lot of them. A lot of other families had TB." The restrictions imposed by caring for people with TB were evident when Molly remembered the situation when her brother had TB and was cared for at home:

my mother had to keep him downstairs in a separate bed and give him separate things.

Towels, cups, dishes and everything. Wash his clothes separately....

well, gee, you know I can't go there. We can't go there at all. You're not allowed to go to that house when there is sickness like that in that house! That's all I was told.

The threat of TB and the losses associated with the disease scarred an already impoverished community as families became ill resulting in the death of parents and siblings and the institutionalization of others. Mike recalled that his mother and father and two sisters had died from TB. This multiple loss was echoed by Tom who remembered: "There were a number of people here that were dying all the time from TB. I'm no doctor or anything. But I remember there was a lot of it here." This perspective that many people from Tobique had acquired TB was

echoed by Dick who recalled: "I only saw her [his mother] once at the Sanatorium. I've seen that Sanatorium full of people. Scary place!"

Prolonged separation caused profound disruption in families:

I think they all died of TB. My father had it in his lungs. He was in the Sanatorium. My mother had it on her hip. Had TB in the bones. And they operated on her. She never could heal up, never did. But she healed enough to come home. She came home before my father had went back to the Sanatorium.

Such disruption within the family unit was exceptionally difficult for the people of Tobique who believed that survival was closely linked to cohesiveness of family, and whose elders were looked toward to provide care and guidance to the community (Garrett & Herring, 2001). Such abrupt and extended separation from families for extended periods of time denied them the opportunity to "transmit and maintain cultural identity" (Kirmayer, Lawrence, Brass & Tait, 2000).

The toll that was exacted on individuals and families when families were separated by members being sent to the sanatorium for treatment was enormous. It was exacerbated by the lack of information about TB among those who were left behind. Not only did they not understand how TB was transmitted but they also did not know what was being done to care for their family members in the sanatorium. Tom remembered going to visit his mother and brother in the sanatorium:

I didn't enjoy that trip at all. It bothered me afterward. I kept thinking about it. People laying in beds. My brother wasn't happy. He wasn't happy at all. He was glad to see me. My mother, she didn't get up. They didn't get her up; she looked awful laying there. It scared me.

The lack of information about why his mother was on bed-rest and needed to lie still, frightened Tom. Children who were left behind when their parents and/or siblings went to the sanatorium, needed to be informed about why their family had been disrupted and what was happening to their family member. This need for information has been consistently found amongst children who have illness in their family (Buckley, Thorngren, & Kleist, 1997; Johnson, 1995; Sloper, 2000). Usually, parents are the primary source of information about the illness of family members. However, the

heavy toll of TB on parents, especially mothers and the short periods between diagnosis and hospitalization prevented this from occurring. Anna remembered:

They never talked about it. My grandmother never talked about it. Never even talked about my mother. We never bothered asking her. So we didn't know too much about TB.

Anna's grandmother, like many other members of Tobique may not have discussed this because of her limited information. The demeanor of these elders, in the face of adversity, provided a sound role model and as they helped to interpret the events that had occurred (Mack, 2001; Royal Commission on Aboriginal Peoples, 1996). They provided the support that children need to survive the losses inflicted by TB. Children's ability to cope with the losses inflicted by illness within a family, or their resilience was increased when they had access to supportive relationships, such as were provided by these grandparents and aunts and uncles (Hobfoll, et.al., 2002; Sloper, 2000).

The care of children who were left behind when their parents went to the sanatorium shifted to extended family members and to the community. As one participant recalls of her uncle: "I never even thought of it. I just didn't even care, I mean, he just needed someone to take care of him and he raised me, so therefore, I just simply took care of him." Another participant stated: "Our grandmother brought us up during the two year period. Between our grandmother and that hospital. We were sharing accommodations there basically." As Marie described:

My mother died when I was 2 years old and my youngest brother was year and a half... he didn't stay very long in the hospital. Probably around six months I heard. And then my grandmother took care of us. They were going to send us away. There was four of us. My father wouldn't let them send us away to [the residential school]. We were too young. And he wouldn't let them. He said, "I'm not forcing my kids away." And he didn't, he stopped the agent. Agent was the one that was going to send us away. My grandmother kept us. We were strong and healthy. We were living in a one-room house.....

Despite their obvious economic poverty, her grandmother brought these children up, providing social support resources to her grandchildren. The *resilience* of these families was made possible by their strategy of *keeping the family together*. Their strong extended family networks and their

determination to remain a family enabled these families to maintain their balance and endure the losses and fears they experienced while their members had TB. They found ways to cope with the multiple stressors, including separation from family members, poverty, hunger, and fear for their ill member families through problem-solving, such as finding ways to feed and clothe the children, and teaching them about nature and their native culture and beliefs. This spiritual journey provided comfort, helped these families find meaning in their losses and enabled them to rebalance or *regain their resilience* in their lives (Johnson, 1995; Martin, 2001; Sloper, 2000).

The experiences of many of the participants in this study, who had parents either away in the sanatorium or who had died was echoed by the accounts of the women from Tobique, in the book, *Enough is Enough*. Lilly described her early childhood experiences:

When I was growing up, we always had hard times and hardly enough to eat. I was an orphan myself. My mother dies when I was two so I stayed with my grandmother and shifted around, sometimes with my older sisters. One would take me for awhile and then another one, because they hardly had anything to eat either (p.6 ).

The *disruption of the family* continued even when several members of a family were at the sanatorium at the same time. Sister Anne Margaret remembered that in the sanatorium, the men were on the first floor, the women on the second and the children were on the third floor. Even when a husband and wife were in the sanatorium at the same time, they were not admitted to the same room but instead to the different floors. This was also true if a mother and her children were admitted. If their TB was acute and the sisters feared that one or both would hemorrhage, they would be kept on bed rest on the separate floors. The importance of rest for the recovery from TB meant that children and mothers were only allowed intermittent visits with little or no understanding of the rationale for such rules.

When the children remained at home with their extended family, they could only visit their parent if they were able to get a ride to the sanatorium, since it was about 80 kilometers away from Tobique. Few people had transportation or the money to pay for a ride with someone else or a train. If a parent had cavitation tuberculosis and was at risk of hemorrhaging, (s)he was kept on bed-rest and even when children were able to visit they were not allowed on their bed, so that

remained somewhat separated from their parent. Some participants remembered that a member of their community would agree to take a car-load of people to the Sanatorium to visit every couple of weeks. This effort was important in *keeping the family together*.

The Royal Commission on Aboriginal Peoples (1996) noted that:

The family in Aboriginal societies stood between the individual and the larger society, playing an interpretive or mediating role. It helped individuals understand and respond to society's expectations and it helped Aboriginal society engage individuals in constructive ways and discipline them should they venture on a course that conflicted with prevailing social values and expectations of behavior (p.9).

The extended family provided a 'social safety net' for these children and other individuals when the epidemic of TB disrupted families and removed parents from their children and siblings from one another and their parents, in effect, *keeping the family together* until those who were ill could return.

Some families were forced to send children to residential schools after their parents were sent to the sanatorium. One participant explains the experience of visiting her brother who was being cared for by another family:

...they took good care of him, they were nice and clean with him when I always go to see him. But they never talked to us or anything like that. They were French. That's probably the reason why.

### **Acculturation and TB**

Acculturation of the aboriginal people of Tobique occurred through the laws imposed by the colonial governments, the regulations and policies of the federal government of Canada requiring aboriginal children to go to residential schools, as well as the influence of the Roman Catholic Church. Nuns also played a large role in disciplining children, often for behaviour that was characteristic of their cultural ways of being. They disciplined the children and taught them not only to read and write but also how they should behave. Even as adults, participants recount vivid memories of fearing the reaction of the nuns to their behaviour, and of doing favours and chores for them to avoid punishment.

Acculturation also occurred for many children who had been hospitalized after being diagnosed with TB. When they returned to Tobique, having been away for several years, they had forgotten their own language, and were only able to speak French, so that their families and friends at home could not communicate with them. Marie described her brother's behavior when he returned home from the sanatorium:

Yes, they fed him good. And he used to like milk. They must have treated him good because he was spoiled when he came home. He talked French, we didn't even understand him. And I had to dress him up every Sunday. He wanted to wear his little suit, he had a little suit. Red tie, white shirt, pants..... That's what we had to do. Dress him up..... he went to church. He had to [go to church] up there at the Sanitorium.

Marie's experience was similar to that of Bob who remembered his brother returning home from the sanatorium after being there for 2 ½ years:

He couldn't talk with us - he had forgotten how to speak Indian - and all he could say was in French! He insisted on dressing in these funny short pants and he wanted to go to mass on Sundays all dressed up!! We didn't believe in that stuff you know.... We used to tease him something terrible - we'd mimic him and joke around at him.....he never was able to be one of us again! I think that maybe that was what happened to him - he committed suicide when he was [a teenager]....

This account of assimilation of native children that occurred in the sanatoria speaks to their acculturation and despair upon returning home, having lost their abilities to be integrated with their family, friends and community. Their long awaited return to their homes was often a desperate disappointment to both them and their family because they found that they no longer fit into their environment. Despair and loss of their self-esteem were the consequences of this recovery from previous TB. In this way, the treatment in the sanatoria, like the experience of the residential schools resulted in cultural genocide, or loss of the cultural characteristics of their people and their identity. Indeed, the belief that "assimilation is genocide" has been asserted by

many aboriginal and other scholars (Chrisjohn & Young, 1994).

The disruption of families potentiated acculturation which was already prevalent in the Tobique community. Acculturation occurred more easily within a fractured community and an environment where there was ongoing fear, uncertainty and separation. Prolonged time in the Sanatorium away from family, led to acculturation of those who spent time in a foreign environment that did not support their culture, beliefs or values. Thus, many who were treated in the Sanatorium experienced extreme disconnection from family and community. Lack of control coupled with lack of information about TB and its treatment led to aboriginal people following the prescribed rules for treatment, questioning little about the rationale or effectiveness of the various interventions. Acculturation supported following of the rules which were developed by health care professionals, usually nuns, within an oppressed environment and contributed to further uncertainty and oppression within the community.

### **Summary**

TB has infected and affected many of the seniors at Tobique. They have born the brunt of an infectious disease that caused illness, disability and death to many of their family in the past. Many of them have been treated for TB and continue to carry the bacteria within their bodies. Throughout the epidemic of TB, in the context of poverty and oppression from both the state and church, these people remained *resilient*. They overcame the threat of TB for their own health and that of their family and community. They have shared many significant life experience with lessons that will teach us how to prevent such an epidemic of TB from ever again recurring.

### **Implications and Recommendations**

Those whose lives have been touched by TB were able to identify priorities for dealing with TB that were generated from their lived experiences and the participatory action research process. The implications are particularly important as they help to clarify the blurred lines that often exist in action research between “finding out more” and “doing something about” the issue

selected in the research project (Hart & Bond, 1998). Identifying meaningful implications and recommendations, generated by the participants is especially important for a culture of people who have been continuously researched, often with little input into the process or perceived benefit from such inquiry. The participants in the research study emphasized that given the profound effects of the epidemic of TB on the entire community of Tobique, they believe that it will take the efforts of the entire community to address and implement the emergent recommendations and implications of this research study. The recommendations revolve around increasing awareness and understanding of TB within the community and developing communication about TB and its treatment between the aboriginal people and the Western health care system.

#### ***Teaching and Learning Native Cultures and Values***

The participants in the study were unanimous in their belief that there must be ongoing teaching and learning about native cultures and values related to health and healing within the community. They stressed the importance of supports being made available to enable the Elders at Tobique to work with the children to teach them their native culture and values. Their wisdom gathered from their survival of TB, should be shared with the children and other community members. Their suggestions included ideas for arranged gatherings in the community, youth groups, and schools to facilitate dialogue between the Elders and the children.

#### ***Improved Communication within Health Care System***

The participants emphasized that there should be a formal process of referral developed between the western health care professionals and the aboriginal healers to facilitate understanding about, and treatment of, TB. Such a process would increase information exchange and an awareness of various approaches to identifying and treating TB. Thus, aboriginal people would have the opportunity to blend both traditional and western approaches to healing in the management of TB. Such communication could increase the health of the community and encourage continued communication around other health challenges. The participants also identified the need for ongoing communication between the Elders and western health care

professionals to ensure that the history of the management of TB with aboriginal people on Tobique is not perpetuated in the future, either with TB or any other health challenge. Essentially, we must learn from this experience and move forward to ensure quality health care that respects aboriginal culture and values.

It will be important for aboriginal elders to be included in the health care team, so that when aboriginal people are ill, they have access to the elders and to the healing ceremonies of their people, including the talking circles, sweats and cleansing ceremonies.

### ***Regular Screening***

Participants strongly supported regular screening for TB in the Tobique community. Many believed that screening should be offered to each family, through nurses' visiting each home to inform the family about the screening process, and the implications of both positive and negative test results. The screening should be offered in people's homes if they wish.

### ***Education***

Lack of information about TB and its treatment was pervasive during the TB epidemic and uncertainty about the cause, symptoms and treatment of TB continues to be prevalent within the Tobique community. Thus, there was overwhelming support for the need for education about TB and its treatment. Information about the symptoms of TB, how to get screened for TB, what happens if you test positive for TB, and what the treatment for TB currently is like should be made available to the general public at Tobique First Nation and to the children through their schools. Participants suggested that such education should take place within the community and in schools involving dialogue with Elders, health care professionals and through the use of multiple media including the community radio, newsletter, brochures, and presentations.

### ***Education of those at Risk***

The participants in the study recognized that the incidence of TB among the aboriginal population is increased due to a variety of socioeconomic factors. They suggested that people who are at increased risk of developing active TB, such as those with HIV, should be informed about what to look for regarding the symptoms of TB and should be regularly screened for antibodies to TB and if positive should be assessed for active TB.

### ***Elimination of Poverty***

Given the overwhelming effects of poverty, secondary to oppression of the church and state, and its impact of the TB epidemic, the study provided support for the need to address these social issues. Participants stressed that an assessment of the community should be made to identify children living in poverty, so that more services can be made available for those families. Food banks and kitchens should be available on the reserve. It was noted that people from the Tobique First Nations are not allowed to obtain food from the food bank in the surrounding towns.

### ***Availability of Home Care Services***

During the TB epidemic the majority of aboriginal people with TB were sent to Sanitoria. However, some were cared for in the community by family members. This care was provided in the absence of information or support from the health care system. Thus, the participants in the study stressed the importance of home care services being available for those families who are caring for a member with TB in the Tobique community.

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## **Appendix A**

### Interview Guide

1. Tell me about the earliest memory you have of TB.
2. Has TB affected anyone in your family or close friends?
3. What did you learn about TB as a child? From whom did you learn this?
4. How do you remember TB being handled by the doctors and nurses?
5. What things did you find helped people who had TB get better?
6. What was harmful in the way people with TB were treated?
7. What do you remember of the effects of TB on people who had it?
8. Do you ever think about TB now? Has anyone you know developed TB in the recent past?
9. How do you think TB should be handled today? What recommendations do you have for what we should teach children and other people about TB? and how it should be approached now?

**Appendix B**

Informed Consent Form

I understand that Grace Getty, and Penny Ericson, nursing professors from UNB as well as Roxanne Sappier and Dr. Mike Perley from the Tobique Health Center and Lisa Dutcher from the New Brunswick Aboriginal Home Care program and Sue Kelso from the New Brunswick Lung Association are studying the factors that are related to feelings about TB and beliefs about how TB should be handled among members of Tobique community.

I understand that an initial interview of about an hour will be taped. I am assured that after it is transcribed, the tape will be erased. I have been assured that my identity will be kept confidential and anything that might identify me on the tape will be changed to preserve my confidentiality. This consent form will be locked in a metal storage container to which only the research team have access. The forms will be kept for a period of two years from this time. At that point they will be destroyed by Grace Getty. Penny Ericson will be given a second key, so that should illness or accident prevent Grace Getty from destroying them in person, they will be destroyed by Penny without delay.

I understand that I am free to withdraw from this study at any time, or to refuse to answer any part of the interview

without penalty. I will not experience any repercussions related to my health care or other social services if I choose to withdraw.

I understand that the interview will consist of a discussion of my experiences with TB or with others who had experiences with TB.

I understand that I am invited to discuss this interview with the interviewer after it is transcribed, adding any other thought or experiences I have had in the meantime. This interview will also be tape-recorded and transcribed.

I understand that the findings of this study will be presented to the Health Board of Tobique, which is the advisory committee for this study. The findings will be presented in such a way that no one can be identified regarding his/her own story.

I understand that I will receive \$15.00 for my time in participating in these interviews. I understand that this is the only personal benefit I will receive from this study but that the findings will contribute to the development of a health promotion program on TB for the members of the Tobique community.

I understand that a copy of this study will be available at the Tobique Health Center as well as through the Medical Services Branch of Health Canada.

I realize that the results of this study will be compiled into a report that will be submitted to the Medical Services

Branch of Health Canada. They will also be written for publication in health care journals and the Tobique health Newsletter and will be presented at scientific conferences.

I \_\_\_\_\_ consent to participate in this study.

Date: \_\_\_\_\_

If you have further thoughts or concerns, please feel free to call Grace Getty at the Faculty of Nursing at UNB, 458-7644 or Roxanne Sappier at the Health Center at 273-5430.

### **Appendix C**

Health Promotion Program on TB

Developed by Lisa Dutcher for St. Mary's First Nation

Outline of topics:

1. What is tuberculosis?
2. How do you get TB?
3. Who is at risk for TB?
4. What are the symptoms of tuberculosis?

5. How do we treat TB?
6. What is HIV/AIDS?
7. What is the link between TB and HIV?
8. How is HIV transmitted?
9. Why reserves are at high risk for HIV and TB infections?
10. Testing for HIV.
11. Discussion period.