University of Alberta

A First Nation Community's Perspectives of Tuberculosis

by

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“If we are together nothing is impossible. If we are divided all will fail.”
-Winston Churchill

Abstract

Aims: This study aims to 1) provide a platform to discuss and document one First Nations community's experiences and impacts of tuberculosis (TB); and 2) to understand the social context occurring within the community which may promote continual disease transmission.

Methods: This Community-Based Participatory Research study was guided by postcolonial theory. Semi-structured interviews (n=15) were conducted in a northern Alberta First Nations reserve community with a high incidence of tuberculosis. Purposive and snowball sampling was used to obtain our sample. Study inclusion was open to any community member over 14 years of age, who had personally or through an immediate family member, experienced the effects of the disease. Data collection and analysis was iterative, using qualitative content analysis. A Community Advisory Board, which was comprised of community members, Elders, and two community co-investigators, guided the project.

Findings: Participants describe the exclusion resulting within, and because of sanitoriums. Exclusion was categorized into 1) the racial segregation of Canadian sanitoriums, where Aboriginal TB patients were excluded from mainstream institutions; 2) the exclusion of Aboriginal culture and practices of healing within the treatment of TB; and 3) the exclusion internal to community members, where members of the community internally labeled the healed individual post-sanitorium as an 'other'.

Participants describe the effect of inadequate housing and overcrowding on the high incidence rates noted in their community. Reasons for inadequate housing are defined broadly to include the impact of cultural norms, endemic crowding, addictive behaviors, and the effects of transitioning to the city.

Dissemination: The findings of this study were used to create a community-owned educational video. This video documents 1) the personal and unique stories of community members dealing with TB, and 2) the educational/biomedical aspects of TB.

Conclusion: By asking to hear participant's experiences and understanding about TB, this study sheds light on the conditions (both historical and current) which influence TB transmission today. The findings of this study demonstrate the complexity of health on-reserve, as well as the many ways colonial experiences influence disease progression today.

Acknowledgement

Over the course of my PhD I have had the privilege to work with many inspirational and wise people. It is a great pleasure to acknowledge those who have supported and guided me through my time working on this dissertation.

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Chapter 1: Project Overview

Introduction

Tuberculosis (TB), a communicable disease which is co-located between the interplay of social inequities and biomedical constructs (King et al, 2009), affects the most disadvantaged within Canada- predominantly Aboriginal and immigrant populations (Canadian Tuberculosis Standards, 2007; Health Canada, 2009). Within this dissertation, Aboriginal refers to those who identify as First Nations, Métis, and Inuit. As noted physician Sir William Olser stated, "tuberculosis is a social disease with a medical aspect," (Grzybowski & Allen, 1993), and in general TB follows a strong gradient, where the poorest peoples have the highest risk of infection (Lönnroth, 2009). The reasons for such disparities are complex and irregular across communities (Canadian Tuberculosis Standards, 2007); however understanding the disparities which surround the disease is a critical component to controlling disease transmission.

TB remains much more common amongst First Nations peoples in Canada, both on and off reserve, than in Canadian-born non-First Nations peoples. In 2007, 20% of reported TB cases occurred within Aboriginal people (Ellis et al, 2008), despite the fact that they comprise only 3.8% of the total Canadian population. (Statistics Canada, 2006c) This means that Aboriginal cases are reported approximately five times more than the Canadian rate, constituting the highest reported rate of TB within Canada (Ellis et al, 2008). For example, the 2008 incidence rate of TB disease among Canadian Aboriginal populations was 28.2 cases per 100,000, compared to a rate of 0.8 per 100,000 population within the Canadian-born, non-Aboriginal populations, and it has been suggested that up to 30% of Canadian Aboriginal peoples may have latent TB infection (Health Canada, 2010). Within Alberta, between 1999 and 2008 the incidence rate amongst status First Nations was 33.0 times higher than the Canadian-born non-Aboriginal population, with higher rates noted on-reserve than off-reserve (Jensen et al, 2012).

The First Nations peoples of hyper-endemic communities, the basis for this dissertation, are long suffering and the burden of disease within their communities represents a major obstacle to health and well-being among First Nations peoples. A total of 1,010 active cases of TB were reported on reserves across the Canadian provinces from 2000 to 2008, meaning First Nations people living on-reserve during this timeframe were 29.6 times more likely to have active TB compared to the Canadian-born, non-Aboriginal population (Health Canada, 2009). Active cases varied greatly across Canada, with higher rates (Health Canada, 2009) and more advanced disease at presentation (Tuberculosis Standards, 2007) noted within the Prairie Provinces.

The project discussed within this dissertation was born out of a large Canadian Institutes of Health Research (CIHR) and Health Canada funded collaborative (Alberta, Saskatchewan and Manitoba) research project titled *The Determinants of TB Transmission among the Canadian-born Population of the Prairie Provinces (DTT Project)*. This mixed method study spanned two years, and included interviews of hospitalized individuals with infectious pulmonary TB. Findings suggest that most TB transmission in First Nations people is taking place in a number of reserve communities in each province- in Alberta it is mainly three communities which continually experience TB disease; one of these communities was the community that participated in my project.

Building upon this existing study, and recognizing that very few studies in Canada provide a voice to the communities most affected by TB and actively seek their input to the problem, the overarching goal of this dissertation was to provide the platform for one of the First Nations identified in the DTT project that are continually experiencing a high incidence rate of TB, to better understand their perspectives, understandings, and thoughts of TB within their community. High incidence, as defined by the Canadian Tuberculosis Standards (2007), refers to a community which has a rate of sputum smear-positive pulmonary TB of 15 per 100,000 or greater, for an average of three years. After many meetings with the various people involved in the project discussed within this dissertation and consultations with the participating community, it was decided the two objectives of this project would be-

1) To document the historical TB experiences within the community
2) To understand the relationship between the social environment, housing, and the ongoing transmission of TB noted within this community

Ethics

Ethics was approved from the University of Alberta's Research Ethics Board on May 13, 2011 (Appendix A contains the Notification of Approval - Delegated Review form). Ethics negotiations with the community occurred first with Chief and Council, and subsequently with the director of health of the on-reserve health center. Before I entered the community and began to discuss the idea of a TB project I arranged to have a detailed conversation with Chief and Council. Together we discussed many preliminary issues of the project, such as the benefits to the community, where the data would be housed, and how the findings would be used for my dissertation. Chief and Council agreed that the data would be housed at the University; however both Chief and Council and the director of health could have access to the data at any point throughout the project; this meant they could review and examine the data at any point throughout the project. The Chief and Council also required a written report at the close of the project, which would provide a summary of the project findings and the disseminations strategies. The director of health required regular updates of the project's progress, which occurred with me meeting in her office to debrief approximately once a month.

My initial negotiations with the director of health were similar to Chief and Council. With the director, we discussed the health benefits to the community, the benefits to the health center, who would participate as co-investigators and their role throughout the project (discussed below), and other administrative considerations (for example, what room at the health center would be used to hold interviews).

Lastly, ethics involving Elder participation was negotiated initially between myself and the director of health (and subsequently between myself and the co-investigators who were consistently helping to ensure the project remain conducive with community ethics and values surrounding Elder participation).

The director of health was concerned that the project must include Elders, and as such these individuals must be treated with the respect outlined by community norms; the director highlighted this should be an important role for the co-investigators, which I fully agreed. I personally ensured my actions aligned with the University of Alberta's (2011) *Elder's Protocol and Guidelines* document, which is a document summarizing issues such as honorariums and other customs which honor and respect the role of the Elder throughout a research project. Additionally, the two co-investigators provided consistent invaluable insight into how to respectfully include Elders throughout the project (for example, how to formally seek guidance and input from Elders and how to honor this input).

Overview of Those Involved in the Project

Community Advisory Board

The project was guided by a Community Advisory Board (CAB), comprised of Elders, healthcare staff, and community members from the participating community. The purpose of the CAB was to

1) provide guidance in the planning, development, and implementation of the project;

2) ensure community concerns were addressed;

3) ensure the cultural values of the community were respected; and

4) provide guidance on dissemination plans.

The CAB formally met three times throughout the project for a day-long meeting, and were provided an honorarium for their guidance. Members of the CAB were recruited through the community health center, with many of the members also sitting on the community’s Elder Senate, a group independent of this project. The CAB was central to all aspects of the project, guiding us on every step as we moved forward. For example, guidance was provided on the areas of TB we would examine with the resources brought to the community through this project (the CAB felt the history of TB within the community and the experiences of the sanitoriums should be examined), how we collected our data, our recruitment strategies, our disseminations strategies, etc.

In addition to the CAB, and with the help of the director of health, we recruited two community co-investigators into the project who were also members of the community as well as staff of the on-reserve health center. The co-investigators were an important component to the research, acting as a vital link between the academic research and the community. The co-investigators ensured the project was conducted with cultural sensitivity, and that Elder protocols and community norms were respected throughout the project. Together the co-investigators and I operated in partnership, with the three of us forming the research team, who were responsible for ensuring the project was continuously moving forward. Details of each individual’s responsibilities within the project were collaboratively constructed in a research agreement (an unsigned copy of the research agreement is presented in Appendix B).

The research team (myself and the two co-investigators) met almost weekly, either in person or through a teleconference, throughout the life of the project. To promote capacity-building, co-investigators received TB and research training in a two-day workshop at the University of Alberta.

Myself and my Time in the Community

I am a researcher who is passionate about social justice and the connection between health and the social context in which one resides. As someone who is not Aboriginal, I became aware, as a young child driving through some of the reserves in Ontario, that not all Canadians live in the same conditions which I was growing up in. When I entered my undergraduate studies at McMaster University, my passion for social justice was intensified through my volunteer work at the Hamilton AIDS Network, when I observed that most of our clients were Aboriginal women and men.

I began the project in 2009 and completed the video in 2012 (the video is discussed in Appendix C). I was in the field for a year and a half before we began collecting data, and in this time, I was busy trying to learn and understand the community’s cultural traditions, norms and values. I attended many cultural events, met with community members from all corners of the reserve, and drank numerous cups of coffee while discussing whatever community members held dear to their heart on that given day. I cannot stress how important these interactions were to the project, and to me as both a researcher and a person. I am incredibly humbled by my time in this project, and hope to continue along this journey through similar projects as I progress in my academic career.

I also recognized there are many ways of knowing and understanding health, and my time in the project helped me to consider disease outside my narrow, biomedical lens. My own worldview, which borrows heavily from standpoint theory (Campbell & Wasco, 2000), subscribes to a belief that one's viewpoint in life is greatly influenced by their social location, experiences, race, and gender, and therefore, there are many truths and ways of seeing and experiencing the world. I went into this project aware that how I saw and understood health likely may be different from community members. I learned that health was defined by members of the community beyond germs and bacteria, which is how I understood TB. Instead, health, wellness, and subsequently disease was much more complex; these concepts were defined broadly by community members and were intertwined with the fabric of the language they spoke, the cultural traditions they practiced, the manner in which they treat their youth and Elders, how they perceived themselves as individuals and as a Nation, etc.

My definition of time, and the connection between time and experiences, also became much more fluid after working on this project. For example, I learned how the past experiences can very much influence current behaviors; the past experiences with TB control can greatly influence current health behaviors. This understanding of time was an immense learning moment for me, as it can have profound implications to TB control, which is discussed more in chapter 3.

Brief Overview of the Community

This study was conducted with a high TB incidence reserve in Northern Alberta, and utilized a community-based participatory research (CBPR) approach. The community has a well-established infrastructure, such as an on-reserve school, several churches, and an on-reserve health center, the site for much of this project. The community also has several Elder senates, comprised of many Elders throughout the community who provide advice on various issues of importance to the community. There has been a momentous movement radiating within the community to reclaim their traditional ways of life, with a strong effort to re-establish their traditional language and cultural practices. Children and Elders are awarded much respect within this community, with Elders viewed as the custodians of community ways of knowing, and children viewed as the key to future health and harmony. Within the community, there is an established hierarchy among a handful of families, where sectors of the community (for example, education and health) are run and operated predominantly by specific families. There was some conflict among many of these families which created a barrier in collectively mobilizing the community and including sectors other than health in the project. This division likely speaks to the level of lateral violence which exists in this community. Lateral violence has also been referred to as a form of internal colonization (Derrick, 2006), and results when a marginalized person or group acts harmfully towards their peer. Essentially, the abused can become the abuser. This community experienced high levels of lateral violence, where community members would exclude other members of their community, reinforcing the community hierarchy and perpetuating an imbalance of power.

I should point out that although the community experienced a strong level of lateral violence, this was a community filled with strength. The foundation of the community has been built by many members who are diligently dedicated to the well-being of their community. These individuals are working hard to mend the fences created by community hierarchies, and as such, are working to overcome the lateral violence experienced throughout the community. Overall, this is a strong community who cares deeply about one another and is quick to look out for each other. I was continually amazed and inspired by my time in this community and learned many important lessons about perseverance, kindness, and resilience.

Involvement of Elders

The involvement of Elders throughout the project occurred primarily through the CAB. We were very lucky to have key community Elders participating with this committee, as this ensured their invaluable guidance remained at the core of the project. Elders contributed in every aspect of the project, from advising the co-investigators and I on how to initially involve the wider community (e.g., they recommended we host a community barbeque at the start of the project) to recommending how to effectively disseminate the project's findings in a manner sensitive to community norms and values (e.g., they recommended a video with strong participation of the children in the community).

I cannot stress how important the involvement of Elders was to the success of the project. Not only did the guidance provided by the Elders and the CAB immensely strengthen the project outcomes, the Elders involved were incredible champions for us. Through their support as leaders in the community, we were able to open doors likely not possible without their involvement. For example, it was through the support of the Elders who sat on the CAB that we were able to recruit as many participants as we did, especially considering how stigmatized TB was in the community. Through Elder involvement the project was seen as being 'safe' by many participants, likely alleviating some of their anxiety in speaking to us. I truly believe that without the Elders on our CAB we would not have achieved the level of success that was obtained through this project. I would greatly recommend other researchers interested in engaging with an Aboriginal community to seek the guidance of community Elders as early in the project as possible.

Methods

Participants were recruited into the project through purposive and snowball sampling, ranged in age from 19 to 63 years old, and included 11 women and 4 men. Purposive and snowball sampling allowed the research team to target participants with TB experience. Inclusion criteria were open to any community member over 14 years of age, who had personally, or through a family member experienced TB disease. Inclusion was kept as broad as possible to ensure a complete picture of the social context in which TB exists was documented. Of our 15 participants, 7 had spent time in a sanitorium, 3 had a family member institutionalized in a sanitorium, 1 had been treated for TB in an outpatient setting, and 4 had spent time in a sanitorium *and* had a family member institutionalized in a sanitorium

A total of 15 semi-structured in-depth interviews and 3 semi-structured in-depth follow-up interviews were conducted with members of the community, describing their personal and community's perception of TB. The 15 initial interviews were conducted by myself and the co-investigators. After discussion with the co-investigators, we decided three of our original interviews were superficial and more information could be gathered through follow-up interviews with these individuals. Together, we decided I would conduct the follow-up interviews on my own, with a conjecture that as an outsider these individuals may feel more comfortable talking to me alone (this hypothesis proved incorrect, as the follow-up interviews did not uncover any new information) At the end of each of the 15 initial interviews, with the exception of our final interview, we asked participants if they could suggest any one who may be interested/relevant for us to additionally talk to.

With written consent by participants, the interviews were audio recorded and transcribed verbatim by a transcriptionist not involved with the study. Data collection and analysis was iterative, with qualitative content analysis utilized. Transcripts were analyzed line by line, with codes important to the project objectives identified, and revisions to the interview guide made. Together we decided that I would conduct the analysis, with a weekly meeting between the co-investigators and I to reflect on and assess the codes being identified. Additionally, a meeting with the CAB was held midway throughout the data collection phase to present what we had been hearing through the interviews, to review the codes and developing categories identified to date, and to reflect upon the changes made to the interview guide. This midway meeting allowed us to ensure we were remaining aligned with the project objectives. The coding process occurred until saturation was reached; that is, until our coding became redundant and nothing new was being contributed to our categories.

A number of frameworks guided me and this project. As discussed above, the principles of CBPR shaped every aspect as we moved throughout the project. Additionally, how I approached the project, the choices I made, and the actions I took, was guided by post-colonial theory. Post-colonial theory, with an epistemological foundation rooted in sociology, anthropology, and political science, is interested in understanding the relationship between the ‘colonized’ and the ‘colonizer’, and the effects of this relationship to society (Manlove, 2001). Using post-colonial theory as a lens to approach the project was a logical choice, as life on a reserve and subsequently health and health inequities, are influenced by colonialism (Browne et al, 2005). For example the Indian Act (discussed more in chapter 4), the basis for legislative colonization of First Nations and Inuit people in Canada, dictates much of reserve life, from housing, employment opportunities, band membership, and Treaty rights, all of which impact health and well-being of a community. I was interested in understanding the impact of such legislation on tuberculosis transmission on-reserve. By adopting this approach to the project I was able to understand, for example, the connection between housing ownership among individuals, the band, and the federal government, and how this can greatly impact disease transmission. The codes I chose to include in analysis and the conclusions I drew throughout the project, were therefore reflective of my viewpoint and understanding of post-colonial theory.

Trustworthiness

To ensure the project was trustworthy, a number of steps were taken throughout the project in alignment with Mayan's (2009) in *The Essentials of Qualitative Inquiry*. To ensure credibility, prolonged time (over one year) was spent in the community prior to data collection. Additionally, the data were checked with members of the project on an on-going basis. Once a week data were presented to the co-investigators to assess if the analysis was representative of the interviews and stories heard through these interviews. Data were also presented to the CAB at two points throughout the project- once during the approximate half-way stage of data collection, and once when the co-investigators and I believed saturation had been reached. To ensure dependability, substantial time was dedicated to creating a strong audit trail. For example, while driving home from the community I would audio record myself reflecting on the day, talking aloud about what I had observed or the experiences that had been shared with me through the interviews. I would also memo in a journal to document my reactions and emotions, which additionally strengthened the audit trail as well as achieved confirmability. Lastly, final data were presented to the Community Advisory Board to verify key themes expressed in the data.

Lastly, to ensure transferability, when possible a thick description of the research setting was provided. I should note that the ability to provide a thick description of the community had to be balanced with the apprehensiveness community members felt about being identified as a high-incidence community. This likely speaks to the intense stigma which still surrounds TB throughout the reserve. At many instances throughout the project, community members expressed their concern that the project would identify the community, and as such I had to continually reassure them that they would not be identified. Recognizing this may limit transferability, I believe (as would any ethics board) that is was imperative to honor this wish, and as such have excluded any details which could identify the community.

Regardless, there is a degree of transferability which can be taken from this dissertation, as much of the broader stories shared by participants will likely be seen in other First Nation communities. For example, the connection between infectious diseases and overcrowded or insufficient housing (discussed in chapter 4) is likely a lesson consistent within many reserves in Canada. To ensure some degree of transferability could be seen in this dissertation, whenever possible I made sure to provide a thorough overview of the context of the project.

Structure of the Dissertation

This dissertation contains 6 chapters, which collectively seek to provide an understanding of the community context of continual TB transmission. Chapter 2 provides an overview of the relevant literature that guided my thinking throughout the project. The literature review has been structured into an overview of CBPR, some of the core documents valuable to research with Aboriginal people, and a historical overview of First Nations, TB, and housing.

Chapter 3 documents community member's experiences and reflections with the sanitorium system, and describes how these experiences influence current health seeking behaviors. Participants describe the exclusion resulting within, and because of sanitoriums. Exclusion was categorized into 1) the racial segregation of Canadian sanitoriums, where Aboriginal TB patients were excluded from mainstream institutions; 2) the exclusion of Aboriginal culture and practices of healing within the treatment of TB; and 3) the exclusion internal to community members, where members of the community internally labeled the healed individual post-sanitorium as an 'other'. To our knowledge this is the first study to document the experiences of a First Nations community with the sanitorium system, examining both the effects such TB control practices had on community well-being and the residual effects such experiences may have on current health behaviors.

Chapter 4 focuses on TB and housing and highlights the lack of control participants experience in their daily lives. The findings presented in this chapter suggest housing must be considered beyond infrastructure to include the political and cultural environment in which the individual resides. Participants described the effect of housing on TB transmission, which was explained beyond simply a lack of available or adequate housing. Participants discussed the cultural norms in their community which were promoting TB transmission, including a belief of 'looking out for their own', addictive behaviors present within the community, and being forced to move to the city to find adequate housing. This study is unique from current literature, which has adopted predominately an epidemiological perspective to investigate on-reserve housing and TB transmission, as it considered the holistic picture of housing- examining both the infrastructure and social environment created through current on-reserve practices.

Chapter 5 presents my reflections as a doctoral student engaging with a First Nations community through a CBPR approach, and describes some of the additional tools I identified which would have greatly assisted work on a CBPR project. CBPR can be complex, challenging and immensely rewarding. Unlike many other university-based programs as it requires the student to be in the field, often working with marginalized and oppressed individuals. Before working on the project, I required additional tools to prepare me for the unique experiences that occurred during my time in the community. Additional skills such as project planning, project and conflict management, relationship building, and skills to negotiate the social context that occurs in many marginalized communities would have been valuable. Lastly, I needed to accept the constraints placed upon me by the very nature of CBPR work, for example time constraints which slow the publication of findings. Universities are seeing an increase in demand from students interested in partnering with communities for their dissertation work, yet little is written from a perspective of the graduate student.

The last piece of this dissertation, which is briefly discussed throughout the chapters, was the construction of a community-owned educational video which was based upon the findings of this study. This 20 minute video is internal to the community and documents 1) the personal and unique stories of community members dealing with TB, and 2) the educational/biomedical aspects of TB. Video production, which was contracted to a community-based production company and utilized community actors throughout the video, ran from May 2012 to November 2012. An overview of the video is provided in Appendix C.

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Chapter 2: Literature Review

Overview of Community-Based Participatory Research

I began this project with the understanding that it is no longer acceptable to conduct research in Aboriginal communities without considering the needs of the community and tailoring the project accordingly (Gracey & King, 2009; Canadian Institute Canadian Institute of Health Research, 2010). With the sentiment that many Aboriginal communities have been researched to death (Jacklin & Kinoshameg, 2008), and the recognition that Aboriginal people remain a heavily marginalized population (King, 2009) I decided that this dissertation would utilize a Community-Based Participatory Research (CBPR) approach. Minkler & Wallerstein (2003) define CBPR as a-

> collaborative approach to research [which] equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate disparities (p.4)

CBPR is not a prescriptive approach to conduct research; rather, this is an orientation to research that is dedicated to partnerships and producing outcomes which are beneficial and relevant to the community (Wallerstein & Duran, 2006).

The research process cannot be another tool for oppression or exclusion (Mohammed et al, 2012), an idea which CBPR actively attempts to overcome through equitable inclusion. It is therefore not surprising that CBPR is utilized in many projects that include marginalized populations, such as Canada’s Aboriginal peoples, a group which has often been excluded from making meaningful contributions to the research process (Jacklin & Kinoshameg, 2008). Through the marginalization of the voice of Aboriginal communities, in past research projects, we have defined and skewed what is considered scientific evidence and created a hierarchy among what is held as valuable knowledge (Flatt, 2012). The inclusion of community members as partners within all aspects of the research process, from conception to completion, aims to overcome the errors of past research creating more indepth and insightful findings (Jacklin & Kinoshameg, 2008).

Recognizing that health is deeply rooted in the contextual factors and experiences in which a person resides (Assai et al, 2006; Gracey & King, 2009; King et al, 2009; Arim et al, 2012), CBPR focuses on the influence of the social, systemic, political, and/or environmental inequities (Israel et al, 2001) to the health and wellbeing of individuals. CBPR projects are often referred to as ‘community-based’, rather than ‘community-placed’, meaning the work is conducted alongside community members, with equitable roles, responsibilities, and power sharing among academic and community partners (Minkler, 2005). Community ways of knowing and understanding, and the context of the community, remain at the core of CBPR projects (Hadley & Maher, 2000).

Born through the earlier works of Paulo Freire’s participatory research (Burgess, 2006) and Kurt Lewin’s action research (Holter & Schwartz-Barcott, 1993), CBPR is rooted in the commitment to share power, respect divergent epistemologies, and enact social change. Unlike traditional research approaches which aim to better understand a problem or occurrence, CBPR is two-pronged-aiming to not only understand the occurrence, but also to empower, educate, and shed attention to community disparities and social inequities (Blumenthal, 2011).

Working within a CBPR project requires the researcher to wear many hats, moving from their traditional role as an academic researcher to a role which is rooted within the context and needs of the community. As Israel et al (1998) explains, a CBPR researcher must-

> be willing to provide technical assistance that may not be directly related to the specific research effort… to carry out this role, a community-based researcher needs skills and competencies in addition to those required in research design and methods, for example: listening, communication (e.g. use of language that is understandable and respectful), group process, team development, negotiation, conflict resolution, understanding and competency to operate in multicultural contexts, ability to be self-reflective and admit mistakes, capacity to operate within different power structures, and humility. (p. 187).

Utilizing a CBPR approach within a research project can be at times difficult and challenging, which is a topic often discussed within the literature. For example, Blumenthal (2011) has defined some of the key challenges to CBPR, which include the difficulties in defining the community as a collective unit (for example, who is included and excluded in a community), the potential barriers in recruiting and engaging marginalized populations, problems identifying community members who truly represent the community, difficulties generating continuous/long-term commitment to the project, obstacles obtaining and meeting the requirements of university-based research ethics boards, and lastly the difficulties which may arise from atypical timelines. In addition, researchers have noted the difficulty academic researchers can experience being an outsider to the community, something often cited within Aboriginal-engaged research (Minkler, 2004; D’Alonzo, 2010; Maar et al, 2011). Several researchers have highlighted the difficulty in obtaining funding for CBPR projects (Kennedy et al, 2009; D'Alonzo, 2010; Ross et al, 2010); however, this is often cited as a vital component to the success of any CBPR project (Israel et al, 2001). Lastly, researchers note possible tensions which can exist between university and community partnerships, stemming from previous experiences of exploitative research conducted on communities without providing many benefits to the community (Kennedy et al, 2009; Ross et al, 2010; Mohammed et al, 2012).

To overcome some of the potential challenges to CBPR projects, several researchers have written their own principles or standards for conducting credible and dependable CBPR projects. Israel et al (1998) provide one of the most commonly cited set of principles within the CBPR literature which include: 1) recognition of the community as a unit of identity; 2) the ability to build upon the strengths and skills of the community; 3) a collaborative partnership that includes the community in all aspects of the project; 4) knowledge generated within the project must be beneficial to the community; 5) co-learning; 6) a cyclical and iterative process; 7) an ecological and holistic model of health; and 8) an understanding that knowledge or findings will be shared with all partners..

Aimed at creating guidelines for ethical and successful community engaged research, Silka et al (2008) have defined their own set of core principles, based upon their numerous experiences with CBPR. The core principles identified by this group include 1) the research must be helpful to the community's development; 2) working with the community will generate results with more depth and will make for better science, and 3) relationships must be built upon fairness and positive exchanges.

The University of Washington's School of Public Health has also developed a set of community-based research principles (note, they do not include the 'participatory' in CBPR) to guide researchers interested or already engaged in CBPR. These principles include 1) community members should be involved at the earliest stages of the project, helping to define research objectives and having input into how the project will be organized, 2) community members should have the ability to influence project goals, mission, and methods, and ensure these are adhered to, 3) the research processes and outcomes should benefit the community, 4) community members should be hired and trained whenever possible and appropriate, and the research should help build and enhance community assets, 5) if appropriate, community members should be part of the analysis and interpretation of data and should have input into how the results are distributed, 6) productive partnerships between researchers and community members should be encouraged to last beyond the life of the project, and; 7) community members should be empowered to initiate their own research projects which address needs they identify themselves.

The Community-University Partnership for the Study of Children, Youth, and Families, an organization based within the University of Alberta and affiliated with this dissertation, defines their community-engaged principles as 1) the research remains mutually beneficial to both university and community partners, 2) the research is a cyclical process, 3) the research builds on strengths and increases capacity on and off campus, 4) all partners are encouraged to engage in the research according to their interests and expertise, and 5) knowledge mobilization activities are included throughout the project.

Overview of Aboriginal Health Research

Beyond the core principles identified above, Aboriginal-specific approaches to CBPR projects are also identified within the literature and tend to be more focused than the broader principles general to all CBPR projects. For example, Bartlett et al (2007) created an approach for Aboriginal community-engaged research and identified six points specific to Aboriginal CBPR projects as- 1) the need to understand the history and impact of colonization and how this influences identity and health, 2) the need to enable on-going equitable partnerships, 3) a commitment to ongoing and healthy negotiation of research relationships, 4) research which utilizes indigenized methods and approaches to research and privileges Aboriginal ways of learning/knowing, 5) the need to promote reciprocal capacity building, and; 6) research which credits Aboriginal knowledge.

Maar et al (2011) conducted focus groups with Aboriginal health managers to determine suggestions for future community-engaged research projects, with results suggesting that in addition to CBPR principles, academic researchers should also 1) consider and respect the roles of culturally-based research ethics outside of the university-based research ethics boards, 2) decide early in the project how to best maintain transparency throughout the project's timespan, 3) utilize culturally congruent methodologies and consider what is culturally taboo to share or discuss, 4) decide how to respectfully recruit participants, which may mean thinking outside traditional academic approaches, 5) consider the important role of adhering to a proper process of gaining community authorization (for example, how to consult with Elders), and; 6) consider the importance of getting to know, and being known within the community.

Lastly, and although not specific to CBPR, academic researchers working with an Aboriginal community must consider the role of self-determination and the right of self-governance within a project. The OCAP principles (Ownership, Control, Access, Possession), and the Canadian Institute of Health Research's Ethics of Health Research Involving First Nations, Inuit and Métis People (2010) were created to ensure projects are conducted in an ethical manner (First Nations Centre, 2007), and as such are heavily cited within the Aboriginal-specific CBPR literature (Vukic et al, 2009; Jacklin & Kinoshameg, 2008; Boffa et al, 2011; Maar et al, 2011).

History of TB within Canadian Aboriginal Populations

A substantive piece of this dissertation was the examination of the sanitorium experiences among the participating community. Before we can understand the santorium system fully, we need to understand the history of tuberculosis among Aboriginal Canadians and the historical manner in which TB among Aboriginal Canadians has been treated. Endemic TB was likely present long before European traders made contact with North America; however the social conditions which resulted from European contact and colonization resulted in a switch from small, consistent rates of infection to a larger epidemic of TB transmission (Hoeppner & Marciniuk, 2000). Early after the initiation of the numbered treaties on the Canadian Prairies and the subsequent establishment of the reserve system, TB rates within First Nations populations became a devastating threat to their health and well-being (Daschuk et al, 2006). Similar to patterns noted today, the effects of the disease were not uniform across reserve communities; rather some regions were ravaged by TB while others remained relatively unaffected (Daschuk et al, 2006). In the early 1900’s Aboriginal Canadians living on the prairies were 20 times more likely to die from TB than non-Aboriginal Canadians (Sproule-Jones, 1996).

Light was first shed on TB rates among Aboriginal Canadians in the early 20th century, when public health officials began to notice the number of First Nation and Inuit deaths occurring across Canada (Sproule-Jones, 1996; Kelm, 2005). Unlike today, where race is considered a social construct rather than a biological reality (Ford & Harawa, 2010), many race-based explanations dominated TB research during this time, offering possibilities for why Aboriginal peoples experienced a disproportionate burden of disease. Such theories included the notion that Aboriginal Canadians possessed genetic defects leading to inherent racial susceptibilities, the virgin soil theory (which subscribed to a belief that ‘primitive’ peoples lack of exposure to TB explained their high rates of infection), or the quantum blood theory which suggested individuals with higher quantities of ‘Aboriginal blood’ were more susceptible to the disease (McMillen, 2008).

Although the minority, there were some early public health officials who suggested TB among Aboriginal Canadians was connected to social conditions. For example, Dr. Peter Bryce, the Chief Medical Officer for the Department of the Interior and Indian Affairs, was a tireless promoter of the need to improve conditions on-reserve (Sproule-Jones, 1996). Within the Canadian Association for the Prevention of Tuberculosis Report in 1903, Dr. Bryce reported that the disproportionate burden of disease within First Nations peoples was related to the adverse living conditions on-reserve. Dr. Bryce was also one of the first public health officials to formally criticize the systemic unsanitary conditions on reserves and among residential schools. In 1922 he published *The Story of a National Crime,* critiquing the management of Aboriginal health issues in Canada, suggesting that the Department of Indian Affairs deliberately withheld knowledge of the appalling health conditions among Aboriginal Canadians from the general public (Bryce, 1922).

The 1940-50’s marked the beginning of a change of thinking, signaling a small shift from the idea that TB was connected to race, to a new idea that TB was connected to the social context in which the individual resides. For example, in 1955 the director of the World Health Organization, Johannes Holm, stated that TB was connected to the conditions promoted through poverty, not race (McMillen, 2008). This statement paired with the earlier pioneers such as Dr. Bryce, pushed forward the idea that the Aboriginal TB epidemic was likely a result of the conditions stemming from colonial practices, poverty, and systemic racism dominating Canadian society at this time.

Along with this new idea of TB causation, this period marked the beginning of the new era of TB treatment, the age of the sanitorium. Prior to the discovery of anti-tuberculosis drugs, those suffering from TB were institutionalized into TB sanitoriums for ‘rest-cure’, which was the dominant means of TB treatment at the time. Treatment included rest, relaxation, emphasis on proper nutrition, and exposure to fresh air and sunshine, creating an ideal environment to promote healing and prevent transmission (Long, 2007). From 1945 into the 1950’s rest therapy was gradually replaced with anti-tuberculosis medication and chemotherapy, such as streptomycin, isoniazid, and para-aminosalicylic acid (Drees, 2010), and universal and selective prevention campaigns that focused on the use of the bacille Calmette-Guerin (BCG) vaccine (Long, 2007).

Alberta was the second province in Canada (after Saskatchewan) to provide free sanitorium treatment to its residents, formally providing sanitorium treatment and diagnosis without cost under the Tuberculosis Act of 1936 (Baker, 1949). In 1943, 540 hospital beds were assigned specifically for the treatment of Aboriginal people in Canada, with approximately half of these beds occupied by TB patients (Shedden, 2011). In total 808 TB sanitorium beds were provided across Alberta, with two TB sanitoriums based in northern Alberta: Charles Camsell Indian Hospital and Aberhart Memorial Sanitorium (Baker, 1949). A federal institution, the Charles Camsell treated First Nations, Inuit, and war veterans TB cases from 1945-1985 (Lux, 2010).

Unfortunately many race-based ideologies were given credence and defined how Aboriginal cases of TB were addressed through the sanitorium systems. Aboriginal patients suffering from TB were often regarded as fundamentally weak and diseased, and blame was often attached to this population in regards to the high numbers of TB cases experienced (Kelm, 1998). First Nations reserves were often described as back-wards and filled with infections (Lux, 2010), with medical literature highlighting the threat of ‘Indian TB’ to non-Aboriginal populations (Kelm, 2005). The placement of blame on Aboriginal cases of TB was nothing new, but it is important to recognize how this may have shaped the sanitorium system. For example, Lux (2010) suggests that the discourse surrounding the ‘threat’ of Aboriginal TB cases to non-Aboriginal society justified the need for Aboriginal-only hospitals to address this issue. As she writes-

> The characterization of Aboriginal communities as unrepentantly backward and roundly infected reinforced the superiority of white colonizers, justifying further isolation and repression. But isolation of the ill in mission hospitals or in Indian wards of community hospitals could no longer contain what an increasingly shrill medical and bureaucratic discourse identified as the threat of rampant ‘Indian tuberculosis’.... Steady falling TB rates in non-Aboriginal Canada reassured the state and its ally, the Canadian Tuberculosis Association (CTA) that sanitorium treatment might conquer the ‘white plague’. And as the CTA argued, the state must include Aboriginal people in its calculations of national health, if only to keep them properly isolated. State run Indian hospitals also acknowledged community prejudices that demanded segregated health care.

To address the issue of Aboriginal TB, the Canadian government constructed and implemented the Canadian Indian Health Service (IHS) hospitals, of which the Charles Camsell was one hospital of 21 situated across

Canada between 1945 and 1950 (Drees, 2010). These hospitals were predominantly founded after the Second World War as a means of managing TB cases, and represented an organization of government run services offered specifically to Aboriginal patients in a time when publicly-funded healthcare was just emerging (Drees, 2010). The IHS hospitals were staffed mainly with non-Aboriginal staff including physicians, surgeons, nurses, and allied health professionals; however some of the ‘lower-ranking’ positions such as janitors, laundry personnel, or orderlies were filled by Aboriginal workers (Drees, 2010).

Very little academic literature is available describing what it was like for Aboriginal patients during their time in sanitoriums. Drees (2010) conducted in-depth interviews with Aboriginal ex-patients who were treated in the Nanaimo and Charles Camsell IHS hospitals between 1945 and 1965. The result of this study show that patients classified their time spent in IHS hospitals as both painful and humorous, with lasting effects on their wellbeing and personal resilience. Similarly, Olofsson et al (2008) conducted life-history interviews with former Inuit TB patients who were evacuated from their homes during the 1940’s by the Canadian government because they were suspected of being infected with TB. One of the hospitals Inuit patients were evacuated to was also Edmonton’s Charles Camsell IHS hospital. Many of these patients did not speak the language of the public health officials conducting the evacuation, many required long stays in Southern sanitoriums, and many never returned back to their communities, either dying in the sanitorium or choosing to remain outside the community once healed. The researchers involved in this study were interested in understanding how this experience may influence current health behaviors among former patients, and found that the experience of being taken from their home and adjusting to a new culture and form of healing was a traumatic event to participants but also one that helped individuals to develop a strong sense of resilience.

Macdonald et al (2010) conducted interviews with a current population of urban-based Aboriginal participants who had either themselves contracted TB or who knew of someone who had contracted the disease, to assess the level of understanding of the disease and to document the experiences of the disease. Although not specific to sanitoriums, the authors found that past traumatic experiences relating to the colonial history of TB treatment created a silence, where participants were reluctant to discuss the disease in present day. Barriers to TB testing identified within this study included a fear and mistrust of the current health system which may negatively influence access to care. These results are echoed in other studies not specific to sanitorium research, which conclude that historically perceived mistreatment at the hands of TB control has led to a deep mistrust in the current health system (Jenkins, 1977; Gibson et al, 2005).

Within the grey literature, Pat Sandiford Grygier (1994) wrote the book, *A Long Way from Home*, describing Inuit experiences of the TB epidemic during the 20th century. Utilizing patient interviews and records of the Northern Affairs Program, the authors provide an in-depth account of the misunderstanding and distrust that surrounded much of the efforts to minimize transmission within the Inuit populations, for example the confusion and chaos which surrounded the federal government's relocation initiatives and forced removal to Southern-based sanitoriums. The book centers on the idea that past treatment at the hands of TB control agents influenced current health behaviors and can affect one's sense of resilience.

While not specific to Aboriginal populations, Herring et al (2007) published a book, *Before the 'San': Tuberculosis in Hamilton at the Turn of the Twentieth Century,* describing TB within Hamilton Ontario. One of the central themes throughout the book is the understandings and experiences of patients and community members with the Hamilton Mountain Sanatorium during the early 1900s, with a focus on the stigma, politics, and successes surrounding the sanitorium movement in southern Ontario. The Hamilton economy at the time demanded long hours and dangerous working conditions for poor pay, which created an ideal environment for TB to flourish. The authors suggest one of the main drivers of the establishment of the sanitorium was the need to remove and isolate the threat of TB from the general population.

Also not specific to Aboriginal patients, McCuaig (1999) published a book, *The Weariness, the Fever, and the Fret,* documenting the historical campaign against tuberculosis in Canada during the early 1900s to mid-1950s. This book begins with the early social and political reforms, which eventually bred the push for sanitoriums, and concludes with the introduction of anti-tuberculosis medications. This book is very much rooted in the social determinants of health, applying a perspective of TB which considers the influence of the social determinants of health on the history of the disease in Canada.

As mentioned in chapter 3 of this dissertation, the sanitorium system was not based upon maliciousness; rather the sanitorium system, both IHS and general-admittance hospitals, were the state of the art at the time, in design meant to provide ideal conditions for recovery (Long, 2007). The fact that sanitoriums were provided free of charge to all Canadians, Aboriginal and non-Aboriginal, also speaks to the progressiveness of these institutions. Unfortunately, like many movements during this era, the grandness of the sanitorium system was at times overcrowded by ethnocentric ideologies, making the experience for many Aboriginal patients traumatic rather than healing.

Overview of First Nations TB & Housing

The second component to this dissertation addresses the current state of TB within Aboriginal populations with an emphasis on TB and housing, a connection that is well documented in the literature (Lowry, 1990; Jacobs et al, 2007; Larcombe et al, 2011; Public Health Agency of Canada, 2007; Durbin, 2009; Health Canada, 2009; Suglia et al, 2011), but has been primarily based upon cross-sectional or observational studies (Thomson & Petticrew, 2007), or purely epidemiological studies which fail to consider the relationship between housing and social determinants or the social environment (Bryantt, 2003). The connection between housing and health is not a new phenomenon; rather health researchers and professionals have been interested and aware of this connection for centuries (Jacobs et al, 2007). As Florence Nightingale pointed out "the connection between health and the dwellings of the population is one of the most important that exists" (Lowry, 1999, pg 839). This is a sentiment echoed in the Canadian Tuberculosis Standards (2007), which strongly recommends additional financial support be provided to ensure Aboriginal communities are able to acquire adequate, safe, and secure housing.

Approximately 40% of First Nations people currently live on reserves (Statistics Canada, 2006b), and of this cohort, individuals are more likely to live in overcrowded, inadequate homes compared to those living off-reserve. Reserves in Canada are often resource-poor, offering housing which does not adequately support band members and may create environments which are ideal for TB to flourish. Long (2012) summarized the housing conditions which may increase the probability of TB transmission as-

- Exposure of susceptible individuals to an infectious person in a relatively small, enclosed space;
- Inadequate ventilation that results in either insufficient dilution or removal of infectious droplet nuclei;
- Re-circulation of air containing infectious droplet nuclei;
- Duration of exposure
- Absence of sunlight
- The susceptibility of exposed persons

Approximately 26% of on-reserve First Nations people live in overcrowded conditions, with an average number of people per room being 20% higher than Canadians living off-reserve (Canadian Mortgage and Housing Corporation, 2011). As pulmonary TB remains the leading diagnosis for on-reserve active cases (Health Canada, 2009), living in an overcrowded environment with someone infected with TB drastically increases the risk of exposure (Hawker et al, 1999; Beggs et al, 2003; Canadian Public Health Association, 2007). Pulmonary TB infection is spread when an individual infected with active disease coughs or sneezes, releasing the mycobacterium germ via droplets into the air. A high droplet density increases the probability of infection, such that a smaller space with a large number of occupants would translate into a large number infected (Beggs et al, 2003). Clark, Riben & Nowgesic (2002) found that among First Nations reserve communities, an increase of 0.1 in the average number of persons per room was associated with a 40% increase of risk of two TB cases occurring in that community. Proper air ventilation can reduce the risk of exposure (Li et al, 2007; Nielson, 2009; Larcombe et al, 2011); however many First Nations houses do not have proper ventilation.

On-reserve housing is unique in that it is governed by the Canadian Indian Act, legislation passed in 1876 that established the federal government's obligations to the Aboriginal population of Canada and manages the many First Nation reserves. The Indian Act, more than any other Canadian policy, impacts and regulates much of reserve life. Within the context of housing, the Act states that government, not the community or the individuals living in the community, control land use and housing on-reserves. The Act states "No Indian is lawfully in possession of land in a reserve unless, with the approval of the Minister, possession of the land has been allotted to him by the council of the band"

(Department of Justice, 2011). Largely because of the Act, the ownership rate among those residing on-reserve is 28.5%, compared to 67% for non-Aboriginals living off-reserve, meaning the majority of on-reserve residents live in band housing (ie. housing which is built, managed, and owned by the band) (International Housing Coalition, 2006).

As such, most of the housing on-reserve is publicly assisted, with federal subsidies funding the majority of construction and purchasing of on-reserve infrastructure and reserve homes (International Housing Coalition, 2006). Houses are often federally designed and constructed, which has resulted in cookie-cutter homes which may not be appropriate for all Canadian climates (International Housing Coalition, 2006). On-reserve homes are often built to lower standards, have half the lifespan compared to off-reserve homes, are more susceptible to adverse environmental outcomes such as mold, and are often not equipped with adequate ventilation or enough space to accommodate large First Nation families (Barsh, 1994). According to the 2006 Canadian census, approximately one in four on-reserve First Nations people resides in a home which requires major repairs, which means these individuals are three times more likely to live in a dwelling in need of major repairs compared to non-Aboriginal individuals (Health Canada, 2008). Inadequate housing, such as insufficient ventilation systems or poor moisture management, is linked to injury, chronic and communicable disease, respiratory infections, and poisoning (Krieger & Higgins, 2002; Jacobs et al, 2007; Larcombe & Orr, 2007).

The impact of the Indian Act has profound implications to health broadly, and TB specifically, as ownership of one's home has been repeatedly shown to be an indicator of general health and well-being (Chakraborty, 2011; Howden-Chapman et al, 2011; Willows, 2009). We can surmise that TB, a disease strongly rooted in social and physical conditions, would also be impacted by the Act as well. For example, if a resident does not own their dwelling, they may be less likely to maintain or repair the structure, creating an environment conducive to TB transmission. If participants do not have incentive to personally keep their home in an adequate state, the end result can be the promotion of environmental biocontaminants (Thrasher & Crawley, 2009), such as increased prevalence of mold, dust, water intrusion and dampness, or poor ventilation.

Housing has long been understood to be an important indicator of the social determinants of health and social inequities (Dunn & Hayes, 2000; Evans & Kantrowitz, 2002; Bryant, 2003; Shaw, 2004), has been formally recognized as a basic requirement of health (World Health Organization, 1986), and has been shown to be a central nexus for the operation of many aspects of the social context which shape everyday life (Dunn et al, 2006). Within the context of First Nations housing, researchers have argued that housing must be considered beyond the physical structure to include the social dimensions of housing, one's sense of belonging, one's sense of control over their surroundings, housing security, the environment surrounding the house, and the domestic environment (National Collaborating Centre for Aboriginal Health, 2010). Suglia et al (2011) found that living in an overcrowding living condition has been linked to increased maternal depression, generalized anxiety disorders, and other forms of distress (Suglia et al, 2011). An extensive systematic review found a direct link between mental health and inadequate housing, suggesting that improvements to housing conditions could greatly generate mental health gains (Thomson et al, 2003). While mental health may not be directly linked to TB, it is understood that decreased mental health and increased stress levels can negatively impact immune function (Carpenter et al, 2012; Van Lieshout & Macqueen, 2012) , suggesting this may be an important consideration for communicable diseases such as TB. This may be especially important when considering on-reserve housing, as life on reserve is already associated with an increased risk of life stresses, mental health, and suicides (Mignone & O'Neil, 2005; Chandler & Lalonde, 2008; Eilas et al, 2012).

Conclusion

As indicated by the literature, TB among Aboriginal Canadians is complex and multifaceted. A long history of TB control, colonial practices such as the Indian Act and social inequities have perpetuated a disproportionate burden of disease within First Nations populations. The voices of Aboriginal people have historically been silenced within TB research, with minimal community input into the reasons for disease transmission, something that this dissertation attempted to overcome by providing a platform for community input into the discussion. This dissertation provides an opportunity for public health officials, TB physicians, health practitioners, and policy makers working within the field of Aboriginal health to understand and learn from the community's insight and knowledge of TB.

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Chapter 3: Sanitoriums and the Canadian colonial legacy: the untold experiences of tuberculosis treatment among a First Nations community in northern Alberta

An unfortunate experience Aboriginal people in Canada share is the effects of colonization. Aboriginal within the context of this study refers to First Nations, Inuit, and Métis people. Along with the fur trade came European colonizers, and subsequently policies which promoted European ideals through a system of forced assimilation. Colonization brought with it the banning of many traditional practices and the erosion of families and communities, spiritual practices, and traditional ways of life (Kubik et al., 2009). Further to this, the colonial system brought with it policies of racial exclusion (Blackburn, 2009). For example, under the Indian Act of 1876, First Nations and Inuit people were legally considered wards of the state- allowing government to dictate most aspects of their life (Fiske, 1995). With the end goal of assimilation, this law authorized the transfer of many First Nation and Inuit children to residential schools to become 'civilized', making it illegal for First Nations and Inuit peoples to own property, vote, or attend higher educational institutions.

Woolner (2009) argued that within the Canadian context, the lived experiences of Aboriginal Canadians have been excluded from the narrative of Canadian history. She referred to 'collective amnesia', where society jointly ignores significant aspects of history, including the context of health. Within this study we explored the stories of one First Nation community's experiences of the sanitorium system, which were hospitals designed for the treatment of TB. Although treatment was the same for Aboriginal and non-Aboriginal peoples, the eurocentric model that sanitoriums were built upon may have been difficult and confusing for many Aboriginal patients. The purpose of the study was 1) to describe the sanitorium experience from the perspective of a First Nations reserve community in northern Canada; and 2) to understand the impact of the sanitorium experience at a community level. To our knowledge, no academic literature exists documenting the experiences of First Nations peoples within sanitoriums.

Sanitoriums served a much-needed purpose in the decades preceding the availability of effective anti-tuberculosis drugs- they separated the infectious patients from healthy society and placed them into an environment that was designed to optimize their chance of cure. In the early 1900s Aboriginal Canadians living on the prairies were 20 times more likely to die from TB than non-Aboriginal Canadians (Sproule-Jones, 1996). Within the province of Alberta alone, 9000 people are reported to have died from TB between 1922 and 1962 (McGinnis, 1979), many of them Aboriginal peoples. Light was first shed on TB rates among Aboriginal Canadians in the early 20th century when public health officials began to notice the number of First Nation and Inuit deaths occurring across Canada (Sproule-Jones, 1996; Kelm, 2005).

Within the context of TB, public health officials were granted the authority to coercively institutionalize the affected, forcibly removing infected individuals and placing them into sanitoriums (Shedden, 2011). Prior to the discovery of anti-tuberculosis drugs, those suffering from TB were institutionalized into TB sanitoriums for rest-cure, which was the dominant means of TB treatment at the time. Once admitted to the sanitorium, patients were often required to stay for long periods of time- months or even years. Treatment included rest, relaxation, emphasis on proper nutrition, and exposure to fresh air and sunshine. Sanitoriums also performed an important infection control purpose in society in that they removed the infectious individual from healthy society (Long, 2007).

The History of TB Treatment of Aboriginal Peoples in Canada

In the early 1900's Aboriginal Canadians living on the prairies were 20 times more likely to die from TB than non-Aboriginal Canadians (Sproule-Jones, 1996). Within the province of Alberta alone, 9000 people are reported to have died from TB between 1922 and 1962 (McGinnis, 1979), many of them Aboriginal peoples. Light was first shed on TB rates among Aboriginal Canadians in the early 20th century when public health officials began to notice the number of First Nation and Inuit deaths occurring across Canada (Kelm, 2005; Sproule-Jones, 1996).

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Alberta was the second province in Canada (after Saskatchewan) to provide free sanitorium treatment to its residents, formally providing sanitorium treatment and diagnosis without cost under the Tuberculosis Act of 1936 (Baker, 1949). In 1943, 540 hospital beds were specificically assigned for the treatment of Aboriginal people in Canada, with approximately half of these beds occupied by TB patients (Shedden, 2011). In total 808 TB sanitorium beds were provided across Alberta, with two TB sanitoriums based in northern Alberta: Charles Camsell Indian Hospital and Aberhart Memorial Sanitorium (Baker, 1949). A federal institution, the Charles Camsell treated First Nations, Inuit, and war veterans TB cases from 1945-1985 (Lux, 2010).

Aims

This study explores the stories of one First Nation community's experiences of the sanitorium system. Although treatment was the same for Aboriginal and non-Aboriginal peoples, the eurocentric model that sanitoriums were built upon may have been difficult and confusing for many Aboriginal patients. The purpose of the study is:

- To describe the sanitorium experience from the perspective of a First Nations reserve community in middle northern Canada; and
- To understand the impact of the sanitorium experience at a community level.

Methods

Theoretical Framework

In this study postcolonial theory was utilized. Getty (2010, p. 7) stated that postcolonial theory

> provides a lens through which to examine underlying issues of power and the structural and historical institutions that benefited from this domination . . . it provides a systematic way to examine how the historically situated social relations that have created oppression continue to structure the social location of oppressed people and to decide on the tangible conditions of their lives.

In alignment with the objectives defined by Macleod and Bhatia (2008), postcolonial theory helped us to 1) examine the Canadian history of colonialism; 2) produce culturally relevant research; and 3) produce knowledge that empowers the colonized peoples. By using a postcolonial theoretical framework we were able to understand how knowledge generated within the participating community was shaped through the power relations of colonialism. Specific to TB, postcolonial theory allowed us to understand how colonialism played a role in participants' experiences of sanitoriums.

Ironically, one of the critiques of postcolonial theory is that it does not reflect Aboriginal ways of knowing (Getty, 2010). To ensure Aboriginal worldviews were the core of this project, a community based participatory research (CBPR) approach guided the study. Recognizing the inequalities tied to health, such as poverty, racism, and powerlessness, it was clear that researchers must consider a contextual ecological perspective, one which considers the social inequalities which shape our health (Israel et al., 1998). Central to CBPR is the emphasis on the participation of community-based researchers, as opposed to participation of only academic researchers, who are actively engaged in all aspect of the research process (Israel et al., 1998; Jacklin & Kinoshameg, 2008). Through this partnership we were able to understand the issue on a much deeper level. As such, a CBPR approach helped us to align with the Canadian Institute of Health Research's "Guideline for Research with Aboriginal People" (2007), which states that Aboriginal people should be given the option of a participatory approach to research. Unsurprisingly, a CBPR approach is increasingly utilized with research partnerships among many Aboriginal communities across North America (Furgal & Seguin, 2006; Petrucka et al., 2007; Worthington et al., 2010).

The People Involved

In alignment with the Canadian Institutes for of Health Research's Guidelines for Health Research Involving Aboriginal Peoples (2007), the project was initially presented to the community Chief and Council for approval. Through this meeting, concerns over community intellectual property, participant anonymity, and the overall benefits to the community were addressed. In addition to this meeting, the research team met regularly with the Director of Health at the community's health center to provide project updates.

Further, a Community Advisory Board (CAB) was constructed to ensure the project upheld the guidelines outlined by Chief and Council. The CAB constituted nine community members (Elders, health care staff, and lay community members), and met at various points throughout the project. One of the main purposes of the CAB was to ensure that the cultural values of the community were respected and that the project moved forward in a culturally sensitive manner. In addition to the CAB, two co-investigators were recruited from the community to work as partners with the academic researcher. The co-investigators were both champions for health in their community, and were interested in gaining research skills and knowledge. The people involved in the project- the CAB members, the co-investigators, and the academic researcher- formed an equitable partnership; with each member bringing unique and valuable insights to the project.

The project was introduced to the larger community at the annual Community Health Day. The research team presented an overview of the project which was followed by a community barbeque. At this gathering, community members were told where they could obtain more information if they were interested in participating in the project. Purposive and snowball sampling was used to obtain our study sample. Using this sampling technique allowed the research team to target participants with some experience of TB. Inclusion criteria included any community member over 14 years of age, who had personally or through a family member experienced TB disease.

Data Collection & Analysis

The project was introduced to the larger community at the annual Community Health Day. The research team presented an overview of the project which was followed by a community barbeque. At this gathering, community members were told where they could obtain more information if they were interested in participating in the project. Purposive and snowball sampling was used to obtain the study sample. Using this sampling technique allowed us to target participants with some experience of TB. Inclusion criteria included any community member over 14 years of age, who had personally or through a family member experienced TB disease.

Data were collected through 15 semi-structured interviews, with three follow-up interviews. The 15 initial interviews were conducted by myself and the co-investigators, while the 3 follow-up interviews were conducted by myself. The sample included 11 women and 4 men, all members of the same participating First Nation reserve. Of this sample, 7 participants had spent time in a sanitorium, 3 had a family member institutionalized in a sanitorium, 1 participant had been treated for TB in an outpatient setting, and 4 participants had spent time in a sanitorium *and* had a family member institutionalized in a sanitorium. Participants ranged in age from 19 to 63 years old.

Interviews were conducted by either one of the co-investigators or myself, occurring either at the community health center or at the participant’s home. Each interview lasted approximately one hour. Participants were initially asked questions about their general knowledge of TB, later moving to questions about personal experiences with TB. Community protocols, such as presenting tobacco when meeting with an Elder, were followed during all interviews to respect cultural values and to maintain rapport with participants.

With consent, interviews were audio recorded and transcribed verbatim by a non-Aboriginal transcriptionist not involved with the study. Data were checked against the original audio tapes to ensure accuracy. Data collection and analysis were iteratively conducted by myself, using qualitative content analysis until saturation was reached, that is until the coding process became redundant and nothing new was being contributed to the categories. Transcripts were analyzed line by line, and codes important to the project objectives were identified. This coding process occurred concurrently throughout the project. As each new interview was conducted, the transcript was immediately included in the coding process and the interview guideline was altered to reflect any new codes resulting from the previous interviews. Shkedi (2005) highlights the importance of ensuring the categorization process is empirically grounded and internally sound. Therefore, codes were initially identified by myself, verified through weekly meetings with the co-investigators, and presented to the CAB and community health staff outside the core research team to ensure cultural relevancy.

The major findings of the project were converted into a video, which is internal to the community and documents the community’s experiences with TB. A community-based videographer was contracted and community actors were utilized for several of the scenes (see Appendix C).

Findings

The findings reflect the impact of the sanitorium experience on participant’s sense of self, their families, the larger community, and present-day health behaviours. Results are grouped into: *Experiences within Sanitoriums;*

Experiences Returning from Sanitoriums; and, *Effects of Sanitoriums on Present-day Health Behaviours.*

Experiences in Sanitoriums

The act of being removed from the community, once diagnosed with TB, was described as a traumatic event. Many participants did not understand the disease, and therefore did not understand why they were being confined to a sanitorium. As such, the act of being removed from the community was surrounded by confusion, and had lasting effects on the individual. Participants described their entrance into a sanitorium as being ‘forced’ or ‘confined’.

> Being lifted from home and taken away without explanation really made an imprint on my mind and it was never, never talked about. It was never clarified.

Once admitted to the sanitorium, participants spoke of the isolation they experienced and the individualistic nature of their treatment. Traditional healing activities such as smudging, healing circles or other group healing practices were not permitted within the sanitorium. Participants also spoke of the predominantly white medical staff working at the sanitoriums. Medical staff were described as “unfriendly” and thought of as “people who didn’t have any knowledge of our culture”; however other in-patients were described in a more positive light. In fact, many life-long friendships were forged within the walls of the sanitorium. As one participant described

> I met a lot of friends there. I even met a girl there. I used to chum around with her, and she was my best friend. She had TB too.

Experiences Returning from Sanitoriums

The time an individual spent in the sanitorium had lasting impacts when they returned to their community. Once returning home, the TB health workers were still a constant presence within their lives. As one participant explained

> They were called health workers. They came from some Government office. They said you people are dirty, that's why you have TB. I still remember the health workers name, because my Mom would say the TB health worker is coming and I want you guys to go wash your face and make sure you are clean. Mid-day she would call us in and tell us to wash up and be ready for the TB health worker.

Since the sanitorium system required sick individuals to be removed from the community for long periods of time, months and sometimes years, disconnect was created between the community and that individual. When healed individuals returned from the sanitoriums, many aspects of their culture were forgotten. One participant described her first day returning to her family.

> When I got back from the sanitorium, everyone was happy to see me so we had a feast. My mom put the table cloth out and it was like a picnic every day for us because we didn't have tables. We just had the tablecloth

> on the floor and everybody sat around it. Everybody was sitting down to eat. Everybody was passing around the food and, just like a celebration, they are sitting down. Everybody was laughing, and here I am just quietly walking around, looking at everybody. My mom stopped and says, what's the matter babe, aren't you going to sit down and eat with us? I just looked at everybody, and I said do I have to sit down like an Indian? Everybody laughed at the time, but they didn't realize that I came back from the sanitorium with different ideas.

Similar to a loss of culture, participants highlighted the loss of language which resulted through sanitorium experiences. English was the dominant language spoken within the walls of the sanitorium. As most of the healthcare staff was non-Aboriginal, long periods of time were spent communicating in English. Participants described entering the sanitoriums fluent in their language, yet returning to the community unable to speak their mother tongue.

> When I was there, I had a good grasp of the English language and I spoke English fluently. When I came back into my community, I spoke not one word of my own language and I couldn't remember how to speak it. I haven't spoken it for many years and it's only now just coming back to me.

> When I was in the sanitorium, I lost my language. I came back to the community and I was fluent in English. My parents always told me this story of the first day I came back. They thought it was so funny. They didn't understand that it affected me deeply that I lost my language.

The loss of language meant some participants were unable to communicate with family members and other loved ones once returning home.

> When my brother returned from the sanitorium, he only spoke English and we spoke our traditional language. We had a communication barrier. But my grandfathers and my grandmothers they put us together and told us that we were separated, but not in blood.

Participants also described the disruption that occurred by the removal of a family member into the sanitorium. Having a loved one absent for long periods of time eroded the sense of family. Sanitoriums were seen as an institution which was extremely disruptive to families, something that "just kept us totally apart".

> My brother went to the sanitorium and stayed there for seven years because he was allergic to the medication. It took seven years for the tuberculosis to go dormant. I never knew my brother. My older sister has no memory of him. My siblings never met their brother until he was 13.

> He was a total stranger. That’s the emotional part- that we had a brother we never knew.

When a parent was institutionalized, this caused massive disruption to the family. One participant described her story as a little girl having her mother institutionalized in a sanitorium.

> One day my Auntie told me that my Mom had collapsed at work and they had to take her to the hospital. We didn’t see her for about three months I think. It was just before Christmas when we finally saw her again. There were eleven of us siblings. I’m the fourth oldest and we were home by ourselves. My older sisters tried to take care of us, but they were teenagers. One day Social Services came and split us all up. There was so many of us, they couldn’t keep us in one house so we were separated into different homes. My sisters, we all ended up in a home in the city. Another two of my siblings were just next door and were being fostered there. I didn’t know what had happened to my younger brothers and sisters. Three of them had ended up with one of my Aunties. We never saw each other all the whole time my Mom was in the sanitorium. I remember riding on the bus and seeing them playing on the road in the mud. I couldn’t even get off to go see them. During that time my Dad wasn’t around, because he was staying near the hospital so he could visit her. We never got a chance…nobody ever came to pick us up, bring her to visit or anything like that. Both my Mom and my Dad were gone.

When the healed individual returned to their communities, some had not met other members of their families. As one participant described it, “life on the reserve must go on”. While sick individuals were in the sanitorium, families had babies, deaths occurred, and life continued. Participants described the time and effort it took to re-bond as a family.

> So anyways, we ended up becoming the brothers and sisters we were supposed to be but it didn’t happen overnight. It was heartbreaking for our parents to see their kids were miles apart. I didn’t know my older sister. My younger siblings had no memory of my older sister because they weren’t even born yet.

A common thought expressed by participants was the idea that those returning from sanitoriums returned ‘White’.

> It was a very tough situation for the family because, we as siblings rejected him because he looked like a White kid. He looked like a White kid because he was in a hospital with no sunshine. He was really White…. Socially he became out casted and ridiculed. The other kids called him ‘snowman’ because he was so White. He was so White. I can’t explain how White he was.

Further to the idea of returning with paler skin, participants also spoke of the weight gain associated with sanitoriums. Being over-weight was extremely rare in the participants' community. Participants returning from sanitoriums with added body weight often faced further ridicule.

> When my brother got back from the sanitorium we called him 'Bunny'. He reminded us of a little, chubby, furry rabbit. That's what he reminded us of I guess, a White bunny. He was so chubby, and looked so White. We'd never seen chubby people when we were kids.

Children were quick to bully other children returning from the sanitorium.

> When my brother returned from the sanitorium it was socially isolating for him. People poked fun of him because you didn't see people like that. When we started school, everybody called him fat and they'd run after him and they'd push him and he would fall. At the end result, he got hurt in the knee. He had a hairline fracture that bothered him for years.

The impact of such body changes was something that affected participants throughout their lifetime. For example, one participant describes returning to the community as a young girl after gaining weight in the sanitorium.

> It took me a long time to get past the sanitorium experience because I was kind of withdrawn. I was a withdrawn child and I was not an outgoing person. I think I was withdrawn because of the experiences I had in the sanatorium. I was the heaviest in our family.

Effects of Sanitoriums on Present-Day Health Behavior

Participants described their fear of the disease returning, something that caused them to “walk on egg-shells” once returning from the sanitorium. They were “scared to get sick, to sneeze or even get a scratch”. This fear was felt by both the patient and their families.

> When I got back to the community, my family was scared that something would happen to me, that the TB would come back. I was kind of just held back and told, No don’t do that you might get sick again.

> There was a time if I ever got a cold, or anything like that, I was worried the TB was back. I was petrified I’d have to go back. Back to the sanitorium. What if I still have it, or catch it again? I don’t want to go back.

Due to the fear that the ‘TB was back’, many participants described their reluctance to seek medical care. To avoid becoming sick and having to seek medical care, preventative health behaviours were adopted.

> You know, ever since the trauma of being away for so long, I have learned to look after myself. I’ve learned to eat right to make sure I don’t go back to the sanitorium… When you go through a whole year like that

> institution, kind of unfriendly, you don’t want to go back there again. Now I take care of my health personally.

The historical experiences of sanitoriums were still very much alive to participants, and affected treatment behaviors and illness beliefs. Participants spoke of their belief that present day healthcare would be similar to the treatments they received within the sanitoriums. An example of this was seen when participants discussed medication, as they felt doctors were only interested in prescribing medications.

> Every time I see a doctor, just like the TB pill, all they want to do is give you pills. I don’t like taking pills. I’d rather use herb medicine. I had to take the TB pills because I wanted to get better, but they used to make me sick all the time.

Due to the belief that treatment options today are similar to those available during the time of sanitoriums, participants expressed that “the only time I go see a doctor is when I am really sick.” Healthcare was something to be feared, rather than something that could heal.

Discussion

Prior to the availability of TB medication patients were treated in sanitoriums. Lux (2010) argued that hospital systems must be considered as a residual byproduct of colonialism, something which has bred racial exclusion and segregation. The foundations of the sanitorium system were constructed under the premise of healing; however the eurocentric manner in which healing occurred would have been especially distressing for Aboriginal patients. Through a post-colonial lens we were able to identify the underlying power imbalance apparent within the sanitoium system, which was predominantly based on the exclusion of Aboriginal epistemologies. The exclusion experiences among participants of this study included 1) the exclusion of Aboriginal culture and practices of healing within the treatment of TB; 2) the internal exclusion, where members of the community labeled the healed individual post-sanitorium as the other; and 3) the exclusion internal to community members, where members of the community internally labeled the healed individual post-sanitorium as an ‘other’.

Exclusion was promoted through the lack of Aboriginal ways of knowing within TB treatment, which was likely a reflection of the lack of cultural competency apparent during this time period. It has long been argued that the medical system, including public health, are arms of the colonial system (Kelm, 2004; Shroff, 2011), one which exerts power and authority of those needing healing (Twohig, 1996). The very act of healing, something that was traditionally based on communality and connection to the community among many First Nations cultures (Winnipeg Regional Health Authority, 2009), was replaced by a eurocentric approach based on individualistic and biomedical healing. Participants spoke of the isolation and depression that resulted, and described treatment as something to ‘get through’ rather than a healing process. Traditional indigenous healing, although extremely diverse among populations, almost exclusively focuses on returning the sick individual into a state of balance- balance within themselves, their families and their community (Shroff, 2011).

One of the central ways in which exclusion of Aboriginal ways of knowing was promoted through sanitoriums is through the use of language. Within the walls of the sanitoriums, English was the dominant language spoken; children were taught an English curriculum in the sanitorium schools, and patients interacted with the majority of other patients in English. Again this could speak to the lack of cultural competency during this time period, but likely was also connected to the insufficient number of Aboriginal health care workers employed in this era. As a result, a major theme in participant's stories was the loss of language resulting through their time spent in sanitoriums. Without the ability to speak their mother tongue, participants, especially those spending numerous years healing in sanitoriums, lost the understanding of their language.

The use of language, specifically through English-only institutions, was an important tool in the colonial process, one which enforced power and social hierarchy (Knowlton, 2008). The link between language, power, and health is well documented within the literature (McAlpine et al., 1996; Mohanty, 2000; Maffi, 2001). In a 2008 paper written for the United Nations Permanent Forum on Indigenous Issues, the enforcement of Aboriginal individuals into English-only speaking institutions was linked to "serious mental harm, social dislocation, psychological, cognitive, linguistic and educational harm, and, particularly through this, also economics, social and political marginalization" (Baer et al., 2008, p. 1). Further, Norton (1997) argued that language is a key component to both cultural and social identity. Cultural identity was defined as the relationships between the individual and other members of their group who share common histories, languages, and ideologies. Social identity was defined as the relationships between the individual and the larger society (Norton, 1997). Participants explained the loss of cultural identity once returning home from the sanitoriums. They could no longer communicate with their family members and their community, and described feelings of being an outsider.

Additionally, participants described returning from the sanitorium looking White, including returning to the community looking paler and having gained weight, and explained the rejection that resulted. Once returning home, their appearance was noticeably different than their fellow community members. They were once again branded as an outsider, and expressed feelings of disconnect from their culture. This is especially concerning, as disconnect from ones culture has been linked to higher rates of suicide, violence, depression, and addictive behaviors (Kirmayer et al., 2000). The pathway between internal cultural exclusion and TB has not been addressed, suggesting the need for further research into this topic.

The effect of the historical sanitorium experience was very much alive in present-day behaviors, influencing how and when participants chose to interact with the current health system (MacDonald et al., 2010). Similar to other arms of colonization, for example the residential school system in Canada, sanitoriums bred an atmosphere of distrust and exclusion. This distrust has been passed down through the generations, influencing present-day behavior of both those patients who had first-hand experiences with sanitoriums and the generations born after the sanitoriums closed their doors to TB patients. When asked about their feelings of today’s health care system, participants spoke of a fear of having to return to the sanitorium and a fear of forced confinement. Such fears have led to a general mistrust of the health system, which can have obvious and profound implications to TB control. Through a fear of TB control, we could expect to see very negative consequences, such as delayed diagnosis, poor rates of compliancy, and poor treatment outcomes.

Mistrust is a compounding, complex phenomenon, which has been built layer by layer as First Nations historically and continually experience instances of exclusion and discrimination. The sanitorium system is not solely responsible for the mistrust apparent within this study; however TB control was, and still is, based on a power imbalance where public health officials have the authority and mandate to protect others from infectious diseases such as TB. We do not suggest this authority is unnecessary; however the importance of cultural sensitivity in future TB control efforts is indicated within this study. Current TB control efforts should acknowledge the historical traumas many First Nations peoples experienced through the sanitorium system, and how these experiences may influence present day behaviors.

Public health officials working in TB control must adopt a culturally congruent approach to care, and acknowledge the traumatic experiences First Nations peoples have encountered at the hands of public health. McDonald et al. (2010) suggested health professionals must act with professional kindness when dealing with TB control among Aboriginal patients, which included acknowledging the structural violence that Aboriginal Canadians have experienced and the role TB control has played in perpetuating this violence. This is further echoed by the works of Waisbord (2007), who suggested TB control officials must look beyond the epidemiology, compliancy rates, and treatment outcomes, to include the social conditions and past experiences of the disease which may be influencing patient health care decisions.

Conclusion

This chapter is in no-way a critique into the validity and importance of sanitoriums. Sanitoriums served a much-needed purpose in the age prior to anti-tuberculosis drugs- they removed the infected patient from wider society and created an environment that promoted recovery. Rather, this chapter documents one First Nation community's historical experience with the sanitorium system, and highlights the prominent role public health officials working in TB control must adopt, to not only provide culturally congruent care, but to also acknowledge the traumatic experiences First Nations peoples have experienced at the hands of public health. Through our research, we are able to shed light on a significant, yet silent, part of Canadian colonial history- the sanitorium system.

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Chapter 4: “Taking care of our own": the multifaceted relationship between on-reserve housing and tuberculosis occurrence.

Tuberculosis and Housing

The inseparable link between housing and tuberculosis (TB) is discussed in both the international and Canadian literature (Clark et al., 2002; Public Health Agency of Canada, 2007; Lacombe et al., 2011). Pulmonary TB, a disease spread via droplet infection, means that living in smaller, overcrowded, or poorly ventilated homes increases probability of TB exposure, and therefore transmission. Living in close household contact with someone with pulmonary TB (sputum spear positive) drastically increases the risk of infection (Canadian Public Health Association, 2007). First Nations people are approximately five times more likely than non-Aboriginal people to live in over-crowded homes (Statistics Canada, 2006), with an average number of people per room being 20% higher compared to Canadians living off-reserve (Canadian Mortgage and Housing Corporation, 2011). Clark, Riben & Nowgesic (2002) found that among First Nations reserve communities, an increase of 0.1 in the average number of persons per room was associated with a 40% increase of risk of two TB cases occurring in that community.

Greater emphasis on the link between the social environment and TB transmission is needed. The social environment, a phenomenon which is shaped by the condition of housing, could be particularly important for First Nations populations because of the prevalence of inadequate and overcrowded homes on-reserve. In a groundbreaking article Edwards, Booth & Edwards (1982) described the complex links between housing, health, and well-being, and suggested housing structures can promote detrimental health behaviors. TB, a disease where the social environment plays a large role in disease promotion (Grzybowski & Allen, 1999), would therefore be affected by the condition of on-reserve housing in Canada. Researchers have argued that housing must be considered beyond the physical structure to include the social dimensions of housing as well, such as one's sense of belonging, one's sense of control over their surroundings, housing security, the environment surrounding the house, and the domestic environment (National Collaborating Centre for Aboriginal Health, 2010)

This study was conducted in a reserve community in the province of Alberta, Canada, with high incidence of TB. High incidence, as defined by the Canadian Tuberculosis Standards, refers to a community which has a rate of sputum smear-positive pulmonary TB of 15 per 100,000 or greater, for an average of three years. The idea of examining the relationship between the social environment and the ongoing transmission of TB noted within this community was generated by the community. In our initial interviews we concluded by asking participants why they thought TB transmission was continuous in their community, to which the majority quickly pointed to housing. Participants strongly felt housing was instrumental not only to TB transmission, but also a major hindrance to the overall health of their community. Considering the strong reaction participants expressed regarding on-reserve housing, we realized this should be one of the areas we examined within this project. Our aim of this chapter therefore is to examine the link between TB transmission and on-reserve housing.

Methods

Guiding Theory & Framework

This study was born out of a large mixed-method cohort study (for more details see Boffa et al, 2011), and was guided by postcolonial theory. Postcolonial theory allowed us to examine the underlying power dynamics of colonization (Getty, 2010). Recognizing the inequalities of health, such as poverty, racism, and powerlessness (Israel et al, 2998), it has become clear that research must consider a contextual ecological perspective which incorporates the link between colonization and social inequalities which shape our health. It is argued that on-reserve housing is indeed a product of colonial oppression and control, with profound implications to health. By utilizing postcolonial theory we were able to gain an in-depth understanding of the link between housing and TB.

Ironically, one of the critiques of colonial theory is that it does not reflect Aboriginal ways of knowing (Getty, 2010). To overcome this barrier, and ensure Aboriginal worldviews were the core of this project, a Community Based Participatory Research (CBPR) approach was utilized. The foundation of CBPR emphasizes the participation of community-based researchers, as opposed to participation of only academic researchers, who are actively engaged in all aspect of the research process (Israel et al, 1998; Jacklin & Kinoshameg, 2008; Getty, 2010). As such, CBPR aligns with the Canadian Institute for Health Research's *Guideline for Research with Aboriginal People* (2008), which states that Aboriginal people should be given the option of a participatory research approach. Unsurprisingly, CBPR is increasingly utilized in research partnerships with many

Aboriginal communities across North America (Worthington et al, 2010; Petrucka et al, 2007; Furgal, C. & Seguin).

The People Involved

A Community Advisory Board (CAB) was formed early in the project. The CAB was comprised of nine community members (Elders, health care staff, and lay community members) and one academic researcher. The purpose of the board was to 1) provide guidance in the planning, development, and implementation of the project; 2) to ensure community concerns were addressed; 3) to ensure the cultural values of the community were respected, and that the project moved forwrad in a culturally sensitive manner; and 4) to provide insight on the dissemination plan. Meetings occurred at the community's health center.

In addition to the CAB, two co-investigators were recruited from the community to act as partners with the academic researcher. The co-investigators were both champions for health in their community, and were interested in gaining research skills and knowledge. The people involved in the project- the CAB members, the co-investigators, and the academic researcher- formed an equitable partnership (herein referred to as the research team), with each member bringing a unique and valuable insight, and as such, creating a strong foundation upon which the project was built.

Purposive and snowball sampling was used, and participants ranged in age from 19 to 63 years old. Purposive and snowball sampling allowed the research team to target participants with a personal experience of TB. Inclusion criteria included any community member over 14 years of age, who had personally, or through a family member experienced TB disease. Inclusion was kept as broad as possible to ensure that a complete picture of the social context in which TB exists was documented.

The Process

In total, 15 semi-structured interviews were conducted, with three follow up interviews. All interviews were conducted at the community health center by the research team, were audio recorded, and each lasted approximately one hour. Prior to the initiation of interviews, an interview guide was developed by the research team, which received approval by the CAB. The interview guide began with questions related to the participant's general perception of TB (for example, what causes TB and how might it be addressed), and moved to questions relating to participant's personal experiences with the disease.

With consent, the interviews were audio recorded and transcribed verbatim by a transcriptionist independent of the study. Data waere checked against the original audio tapes for accuracy. Data collection and analysis was iterative, and content analysis was used. Transcripts were analyzed line by line, and codes important to the project objectives were identified. This process occurred after each interview was conducted, and revisions to the original interview guide were made to reflect any new codes. Analysis occurred until saturation was reached. Analysis was conducted by the academic researcher, with preliminary findings presented to the co-investigators to ensure cultural relevancy.

One product of the project was a video, which was internal to the community, and documented the unique community experiences with TB (video is discussed in Appendix C).

Results

The links between the social environment and housing are categorized below as 1) *Overcrowding & Inadequate Housing,* 2) *Lack of Housing & the City,* and *3) Cultural Norm & Addictions*. These results are not linear or independent; rather the social environment is complexly created through the intertwinement of the categories presented below.

Overcrowded & Inadequate Housing

Participants commonly linked endemic overcrowding on their reserve to the high TB occurrence of their community. As one participant stated, "if you have a bunch of people living in a house and one of them is sick, you all breathe the same air if you're all overcrowded it can pass along the germ".

> Overcrowded homes are an issue. That is how my cousins got TB, because after he got sick, this other person was sick as well. That person was always with them. If there are three or four families living in a house, it is very unhealthy.

Overcrowding was considered an issue beyond lack of housing structures, as some of the houses on-reserve were thought to be poorly constructed or inadequate and therefore uninhabitable.

> On reserves, TB and being overcrowded is a problem because of the lack of housing and the houses aren't done properly. They get worn out quickly because of the quality of the house, which falls apart easy.

Many of the reserve homes were inadequate and in such disrepair that some individuals and families needed to live with other community members. Of the homes deemed suitable to live in, participants expressed fears that these overcrowded homes require, or will soon require repairs, which were costly.

> We have so many generations living in one home. The wear and tear on the housing is very bad. There are too many people being forced to live in one house. The houses were not built for so many people to be living in it. The houses on our reserve have been built for two or three members of a family. There is so much wear and tear, and it requires a lot of renovations more so than if it is just a single family living there. There is never enough money to fix the houses.

Lack of Housing & the City

Due to the lack of housing on reserve, participants suggested community members were forced to leave their homes and move to the city. This was of great concern to participants, as they suggested moving to the city was leading to a loss of their language and culture. As one participant explains-

> A lot of our people have to move off the reserve and struggle in the city because in our community we don't have enough houses for them to live

> here. People can’t come home- once you leave the reserve it is hard to return. Our kids, our grandkids, they aren’t learning the language. They are away from their culture.

Moving to the city was perceived as a means to introduce the TB germ into the community. Participants felt TB was a problem originating outside the reserve, brought to the community by members who were exposed to the germ in the city. When these members returned to the reserve, it was believed they brought the diseases with them. Participants suggested that if members were not forced into the cities, continual TB transmission would not be a threat on the reserve.

> Our young families who have been forced to live in the city, they always have to go back and forth to visit the community. TB is an issue here because people are in transition all the time. There is always that back and forth. In the city there are always places where you can contract the disease.

Cultural Norm & Addictions

Furthermore, participants continually linked overcrowding to community norms, suggesting overcrowding was connected to the value the community places on communality, where people are quick to “look out for their own”.

> Native people really get the value of community. If somebody needs help, you help them. It’s just something we do. We are a little more apt to take people in even though there isn’t the room because we don’t want to see

> them hungry or we don't want to see them homeless or see children without a roof over their heads. This is a cultural aspect because that's how we are taught, how we are taught to be. It is part of our values and belief systems. We have a strong sense of community to help one another.

The idea of communality was considered a "tribal expectation in the reserve… if there is a homeless person in the community you take them in". This idea of sharing was generally perceived to be a positive attribute of the community, yet an attribute that was complicated when addictions were involved. Participants discussed how addictions further compounded overcrowding on-reserve, as many addicted community members would lose their own homes due to their addictions and end up living in another community member's house.

> Before, overcrowding was because there weren't enough houses. Still today, there are not enough houses, but people would rather live under the roof of the person who is striving then that way they don't have to spend their own money on their own home. They could spend it on addictions right?

> When you ask about drugs and alcohol, when there's addictions involved, the person can't maintain their own place so of course there's going to be overcrowding because they can't pay their bills at the place that they have, so they go to a member of their family. Everybody lives under that roof because that one is feeding everybody.

Participants continually suggested the connections between overcrowded homes and addictions was contributing to TB occurrence within their community, and were quick to discern the detrimental effect addictions can have on overcrowding. It was suggested that living with an addict was likely to result in the whole household engaging in addictive behaviors, and once their homes were opened to the homeless addicted community members, participants expressed little control in their ability to not participate in harmful addictive behaviors.

> These are a group of single people who have no home, and they now share everything. This one guy had a home and they shared with all of them, and they all drank together. Whatever alcohol they had, they shared. Whatever food they had, they shared. Whatever cigarettes they had, they shared.

> Everybody in our community, our family, they watch out for each other. They live together. They get one house, everybody moves in. If someone is abusing prescription drugs, they either make a dollar out of it or they join in. If someone gets sick, they all get sick.

Discussion

Housing conditions can be an important tool in understanding the link between the social environment and TB transmission (Shaw, 2004), as housing plays a crucial role in health and wellbeing (World Health Organization, 1986). Through a post-colonial lens we were able to identify the underlying power imbalances apparent in the housing conditions on-reserve. Participants spoke of the connection between overcrowded houses, inadequate infrastructure, being forced to move to the city, cultural norms, and co-morbid health concerns (addictions), which they linked to the high incidence TB rates plaguing their community.

Housing & Control

The underlying premise of this study was the lack of control participants have into the housing conditions on-reserve. The literature suggests people with limited control over their physical environment experience higher levels of psychological stress (Lepore et al., 2004; Bullers, 2005), yet this has not been linked to First Nations people living on-reserve. Social theory tells us that stress can be decreased by the ability to control one’s life (Mirowsky & Ross, 1986; Szreter & Woolcock, 2004); yet First Nations people living in an overcrowded environment have very little control over their physical surroundings. For example, participants of this study often spoke of housing being ‘outside of their control’. Living with high levels of psychological stress, and limited ability to remove or reduce this stress can weaken the immune system, compromising the body’s ability to protect itself from infectious disease (Yang & Glaser, 2002). This is an important consideration when discussing TB transmission, as stress has been linked to reactivation of latent infection (Moran, 1985).

The impact of the lack of control participants felt, and their inability to maintain their culture and social identity was apparent within the findings.

Participants stated housing was so inadequate within their community that community members were forced to seek housing off-reserve. Being forced to live away from the community can lead to erosion of community culture as those members faced the risk of becoming disconnected from their culture. This is disturbing, as research among Aboriginal peoples has found cultural discontinuity has been linked with higher rates of depression, substance abuse, suicide, and violence (Kirmayer et al., 2000). Further, a strong cultural identity has been shown to increase self-esteem and overall well-being (Usborne & Taylor, 2010).

Much of the control which has been taken from First Nations people has been done so by systemic policies, an example of which can be seen in the Canadian Indian Act. The Indian Act, a race-based legislation (Blackstock, 2011), controls many aspects of reserve life, such as 1) who is entitled to be registered as status First Nations; 2) what individuals are considered a part of a band (or part of their community); 3) and lastly, and important to housing, the legislation controls how band members may use land on reserve (Department of Justice, 2011). The Act states the government, not the community or the individuals living in the community, control land use and housing on-reserves. This is clearly declared in section 20(1) which states “No Indian is lawfully in possession of land in a reserve unless, with the approval of the Minister, possession of the land has been allotted to him by the council of the band” (Department of Justice, 2011).

The impact of the Indian Act must be considered within the context of health. Not only was lack of ownership identified as a barrier to healthy housing on-reserve by the Canadian Aboriginal Roundtable, occurring in 2005 in Ottawa (Assembly of First Nations, 2005), but ownership of one's home has been repeatedly shown to be an indicator of general health and well-being (Willows, 2009; Chakraborty, 2011; Howden-Chapman et al., 2011). The Act is likely impactful to TB, a disease strongly rooted in social and physical conditions. For example, if a resident does not own their dwelling, they may be less likely to maintain or repair the structure, creating an environment conducive to TB transmission. If participants do not have incentive to personally keep their home in an adequate state, the end result can be the promotion of environmental biocontaminants (Thrasher & Crawley, 2009), such as increased prevalence of mold, dust, water intrusion and dampness, or poor ventilation. These are all conditions which have been linked directly to TB, or have been show to decrease the body's immune response to TB (Larcombe et al., 2011).

The Government of Canada has taken some steps to provide safe and affordable housing on-reserve. In 1960 a housing program was introduced by Indian and Northern Affairs Canada (now referred to as Aboriginal Affairs and Northern Development Canada) to support the construction and renovation of on-reserve homes, which was later revised in 1996 to ensure more flexibility and autonomy to First Nations people (Indian and Northern Affairs Canada, 2008). The bulk of federal support occurs through financial contributions and grants, or through promoting capacity of First Nations people to seek market-based housing themselves. Under the First Nations Market Housing Fund, an initiative which aims to increase private home ownership for people living on-reserve, 13 First

Nations have been approved for credit backing across five provinces (First Nations Market Housing Fund, 2010). In partnership with the Canadian Mortgage and Housing Corporation, Aboriginal Affairs and Northern Development Canada have provided approximately $1.4 billion from 2004 to 2009 which has allowed for the construction of 9,362 new units and major repairs to 13,018 units (Office of the Auditor General Canada, 2011). It should be noted, these investments have not kept pace with demand for housing and the number of units requiring repair far out-weighs the current financial supports provided to address the issue (Office of the Auditor General Canada, 2011). For example, the Assembly of First Nations suggests 87,000 new units are required to adequately address the housing shortage on-reserve (First Nations Market Housing Fund, 2010). Further, while financial support for housing is an excellent start to addressing the issue, it does not address or mediate the lack of control and autonomy on reserves or address some of the systemic barriers apparent on-reserves which will hinder healthy housing (for example endemic addictions). As this study highlights, housing conditions on reserve are complex, and will therefore likely require a complex, multifactoral approach.

Overcrowding & TB

Within this study overcrowding was linked to the community cultural norms and values which govern reserve life. Participants were quick to provide shelter to fellow members without a home, regardless of how overcrowded their home may already be. This is a very positive characteristic of the community, and demonstrates the presence of a strong social support network, one which has been linked to improved health and well-being (Hystad & Carpiano, 2010; Carpiano & Hystad, 2011). However this also demonstrates another way in which participants were not in control of their environment as they were required, through the cultural norms governing the reserve, to provide shelter to community members regardless of their own overcrowded state. An unintended consequence of the social networks common on many reserves is the potential for an increased number of persons exposed to airborne pathogens. In a recent study Larcombe et al (2011) demonstrated how on-reserve overcrowding was exacerbated by the frequency of overnight visitations from non-residents of the household, which they suggest is common in many First Nations communities.

Living in an overcrowded home can result in several biomedical responses which create an ideal environment for weakened immune response, and therefore an increased probability of disease transmission and reactivation. For example, living in an overcrowded environment has been linked to disrupted sleep patterns and sleep deprivation (Reynolds, 2005), and empirical data supports the important role sleep plays in proper immune function (Frey et al., 2007; Ruiz et al., 2010; Okun, 2011). Sleep deprivation has also been linked to several other comorbidities which can further exasperate a weakened immune response, such as smoking (Wetter & Young, 1994) and diabetes (Resnick et al., 2003); both of which are prevalent among First Nations population and both of which are impactful when considering TB control.

Overcrowding & Addictions

Participants further tied their cultural norms and overcrowded conditions to addictions. Participants suggested living with an addict may result in other occupants partaking in unhealthy behavior, yet cultural norms prevent them from turning someone in need away. This again speaks to the lack of control over one's life, as participants could not control their co-inhabitants, regardless of whether his or her behavior was perceived as detrimental to the health of the household.

Addictions among Aboriginal people are a complex issue, tied to colonialism, residential schools, and the many forms of abuse which resulted from these traumatic experiences. Present-day social segregation, discrimination, and institutional racism further perpetuate chronic substance abuse, with implications not only to individual health, but to the collective health of this population. As such, many First Nations communities describe substance abuse as a serious concern to well-being. A 2003 survey found 74% of on-reserve participants identified alcohol and drug abuse within their community as their biggest health concern (Indian and Northern Affairs Canada, 2004). This adds another layer for consideration when addressing TB occurrence, as past studies clearly document the detrimental relationship between substance abuse and TB (Oeltmann et al., 2009; Buff et al., 2010; Mitruka et al., 2011). This may suggest the need for stronger on- and off-reserve addictions support and prevention programs, or addictions support which removes caregiver burden from others in the home. This is imperative not only to TB control, but also to mental health and addiction care on-reserves.

It is well established that addictive behaviors are connected to TB (Millet et al., 2012), suggesting this is an important consideration for TB control. For example, within the literature alcohol abuse is continually linked to an increased risk of tuberculosis (Brudney & Dobkin, 1991; Fleming et a.l, 2006) and TB fatality (Millet et al., 2011). Alcohol abuse has also been shown to decrease compliancy to treatment (Burman et al., 1997; Friedland, 2010) and increase instances of delayed diagnosis (Nguyen et al., 2011), suggesting those who chronically consume alcohol have a higher risk of developing more infectious cases of TB. Problem drug abuse has also been connected to TB, including poor adherence (Friedland, 2010) and reduced follow-up care (Story, 2007). Similarly, in a large systematic review examining the relationship between smoking tobacco and tuberculosis, Slama et al. (2007) found an association between smoking and an increased risk of TB in 25 of the reviewed publications.

When discussing addictions and TB control, we must also consider the co-morbidities tied to addictive behaviors; for example HIV and diabetes, both of which are prevalent among many First Nations populations. HIV, an opportunistic comorbidity well established in its connection to addictions (Friedland, 2010), has been show to adversely impact TB through an increased chance of latent reactivation (Friedland, 2010), TB incidence, and TB mortality (Millet, 2012). Diabetes, another comorbidity associated to addictive behaviors such as chronic alcohol consumption and drug abuse (Mattoo, 2011) has been associated with an increased prevalence of active TB (Dooley & Chaisson, 2009; Sullivan & Amor, 2012) and poorer treatment outcomes (Baker et al., 2011).

Conclusion

The findings of this study demonstrate the complexity of health and housing on-reserve, which is an important consideration for TB control. The original intent of this study was to examine the relationship between housing conditions on-reserve and continual TB transmission. What we learned, however, indicates that housing must be considered beyond infrastructure, rather the political and cultural environment heavily influence housing conditions, which in turn influence disease prevalence. Housing within a TB context cannot be considered as simply four walls and a roof; rather the underlying conditions, such as inadequate housing, overcrowding, addictions, and policies such as the Indian Act, create an environment which contains many pathways to the promotion of infectious disease.

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Chapter 5: The toolbox: reflections of a doctoral student on community-based participatory research.

Community-based participatory research (CBPR) is increasingly utilized as an approach to research, especially for research projects aiming to better understand the connections between social inequities and health. Rooted in both the earlier participatory research movement of Paulo Freire, which emphasized the process of knowledge generation as an effective way to overcome inequity (Burgess, 2006), and the action research movement born through Kurt Lewin (Holter & Schwartz-Barcott, 1993), CBPR aims to empower and educate those affected by the issues being studied, and to highlight social inequities persistent within society. Although many definitions of CBPR are found within the literature, that of Minkler & Wallerstein (2003) is considered one of the best:

> a collaborative approach to research [which] equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate disparities (p.4)

At the core of CBPR stands the need for effective and equitable partnerships- partnerships which are ‘community-based’, rather than ‘community-placed’ (Minkler, 2005), meaning partnerships which are beneficial to the community and produce relevant findings.

Through the engagement of the community in all aspects of the research we are able to understand the issues on a much deeper level (Fletcher et al, 2011). Issues or contexts which the researcher may not consider can be better understood by including the people who are directly affected, as this allows their thoughts and experiences to take center stage in the research process. The social determinants and inequities within our society can be identified and subsequently addressed by engaging those traditionally excluded from the research process. By adopting a CBPR approach we are able to produce findings which are of relevance to those most in need, creating opportunities for change (Jacklin & Kinoshameg, 2008). This is not a prescriptive set of research methods; rather CBPR is a research approach to provide opportunities for empowerment and social change.

As CBPR allows the voices traditionally excluded from the research process a central location within the discussion, it is not surprising that CBPR is a preferred approach for working with Aboriginal peoples, an often marginalized population within Canada. Within the context of this chapter Aboriginal refers to First Nations, Inuit, and Métis peoples. Aboriginal Canadians experience disproportionate burdens of illness, poverty, co-morbidities, inadequate living conditions, lower educational attainment, and violence (both at the systemic and individual levels). Gracey & King (2009) connect social injustices among Aboriginal populations to the multifaceted effects of colonization, such as oppressive policies which threatened cultural traditions and languages, and demolished family and community support systems. The authors' conclusions match the core principles of CBPR, as they state Aboriginal people should be trained and included as active members in the process of overcoming these inequities. It is no longer acceptable to conduct research *on* Aboriginal people; rather research must be conducted *with* Aboriginal participants. Culturally relevant research must be based upon equitable partnerships, empowerment, community control, mutually beneficial findings, an end result of action, and a project centered on communication and respect (Jacklin & Kinoshameg, 2008), all of which align with the core principles of CBPR.

Recognizing this, I began the process of a CBPR project on a First Nations reserve in Alberta. The aim of this paper, written from the perspective of a PhD student engaged in health research, is to document the experiences and personal reflections of our time working with a CBPR approach. CBPR is increasingly encouraged for health-based graduate work, yet little is written from the first perspective of the graduate student. Khobzi & Flicker (2010), both doctoral students engaged in CBPR health research, provide some of their key lessons learned from their time in a CBPR project; however the perspective of this chapter focuses on the potential barriers to the dissertation rather than the potential barriers to the community partnership. The key lessons identified include the need to 1) comprehend the difference between a traditional doctoral dissertation and a CBPR approach to a doctoral project, 2) be aware of, and be able to articulate the advantages of CBPR, 3) acknowledge the plan to address possible barriers to a CBPR project, and 4) recognize how a CBPR project can contribute to the success of a dissertation.

While not specific to CBPR, Gibbon (2002) identifies some of the potential barriers to the utilization of a participatory action research approach to a doctoral project, and considers the obstacles to both the dissertation as well as the community partnership. The author considers her own personality, the fact she was an outsider to the community, methodological obstacles, institutional barriers, timing of the project, and the problems she encountered translating the findings into an academic format suitable for publishing.

Although not specific to the graduate student's perspective, Dehaven et al (2011) provides an overview of a training program offered to medical students interested in a CBPR approach to research; however the perspective of this paper focuses on the student's attitude about the program and knowledge gained through their time in the program (for example, the students felt they understood the health condition being examined on a deeper level due to their utilization of a CBPR approach). Similarly, Masuda et al (2011) describe a training program in British Columbia for graduate students; however this paper also focuses on the components of the training program rather than the student experiences with CBPR. Herr & Anderson (2005) have created a guide, The Action Research Dissertation: A Guide for Students and Faculty to aid students engaged in action research. The guide considers ethical issues, the researcher's positionality, research design, validity, and concludes by providing three concrete examples of participatory action research projects; however it does not provide the reflections of graduate students.

The reflections here are based upon my own experiences as a student, and will highlight the complexities, challenges, and benefits I experienced through choosing to participate in a CBPR project as a doctoral student, and may be instructive to future students looking to engage in a similar project.

Our Project and Process

The University of Alberta is the center of a large Canadian Institutes of Health Research (CIHR) and Health Canada funded collaborative (Alberta, Saskatchewan and Manitoba) research project examining tuberculosis (TB) titled *The Determinants of TB Transmission among the Canadian-born Population of the Prairie Provinces*. For detailed information please see Boffa et al, 2011. This project, along with the understanding that three communities within the province of Alberta, continually experience a high incidence rate of TB (high incidence, as defined by the Canadian Tuberculosis Standards, refers to a community which has a rate of sputum smear-positive pulmonary TB of 15 per 100,000 or greater, for an average of three years), led the university team to believe a grassroots project within one of these communities may be beneficial to understanding continuous transmission.

The idea of the project was presented at a Band Council meeting in 2009 to one of the three identified communities. The first community approached was chosen because of pre-existing relationships within the community and a relatively easy ability to travel to and from the community from Edmonton. The three principal investigators from the above mentioned project, as well as myself, a new PhD student, presented the idea of the project to the community Chief and Council. We went into the meeting hoping the project would spark the interest of the Council, but also understanding that the principles of CBPR stress that the community must be involved in all aspects of the project- from inception to completion. We were therefore willing to walk away from the project if the

Council was not receptive. One of the members of the Council was the Health Director for the community health center, who recognized the need to address TB within her community, and became a strong champion for the project. With this buy-in the Council voted to allow the project to proceed.

With the approval of Chief and Council I arranged an initial meeting with the staff at the health center. At this meeting we began to discuss the idea of the project in more depth. Many of the health care staff had not heard of CBPR, but were very receptive to this way of working. Our discussion provided insight into the community context and we began to identify community health needs. Staff members at the health center identified TB as a health problem and were willing to act as champions for the project.

My next major step included the hiring of two community co-investigators. The decision on who to hire for these positions was left up to the Health Director. Our only input into this decision was that 1) the individuals must be interested in the health of their community, and 2) they must have the time to participate in the project. The Director ended up hiring two women who also worked at the health center. The co-investigators were brought to the University of Alberta for a two-day training session that outlined the principles of CBPR, provided a brief overview of the epidemiology of TB, and reviewed the ethics of academic research (for example, the rights of confidentiality).

With the training of the co-investigators complete, the three of us then put together a Community Advisory Board (CAB), which was comprised of nine community members (Elders, health care staff, and lay community members). We advertised for this position through posters that were distributed throughout the community. The purpose of the board was to 1) provide assistance in the planning, development, and implementation of the project; 2) ensure community concerns were addressed; 3) ensure the cultural values of the community were respected; and 4) provide guidance on dissemination plans. We ended up meeting formally three times throughout the project- once in the early stages of the project, once to discuss our findings, and finally to discuss the dissemination of the findings.

Through the first CAB meeting it was decided the project should be used to document the community's experiences (both historical as well as present-day) of TB. As an academic researcher, I was interested in understanding how the community contextualizes TB- how they make sense of the disease, and what factors in the community were promoting disease transmission. Together we decided the project could accommodate both goals respectively, and the co-investigators and I constructed an interview guide that focused on these two goals.

In the summer of 2010 the co-investigators and I presented the idea of the project to the community at their annual Health Day. This event starts with a community-walkabout, where stations dedicated to specific health conditions (diabetes, cancer, heart disease, and TB) are placed at various checkpoints along the path, and ends with a community BBQ. The majority of the community attends this event. We were not only able to get TB on the agenda for the day, something not seen in previous years, but we were also able to give a short presentation to the community about our project. This acted as an information session and provided the first opportunity to recruit potential participants to be interviewed.

The co-investigators and I began the interview process in the late winter and early spring of 2011. An initial interview guide was created by the co-investigators and I and was presented to the CAB for their input. The interview guide was continually revised to reflect the stories heard in the previous interviews. In total 15 people were interviewed, with three follow-up interviews. All interviews were conducted in a private room at the health center, by either myself or jointly with the co-investigators. Findings were presented to the CAB, as well as the Director of Health, to ensure we were capturing an accurate picture of disease in the community, at both the approximate half-way point in the data collection phase and once saturation had been reached.

The last component to the project was the construction of an educational video documenting the community's experience on TB (more information is presented in Appendix C). CAB members decided this video would be used to educate fellow community members of the disease as well as document the community's experiences with TB treatment (for example, historical experiences with sanitoriums). The CAB, co-investigators, and I decided the video would be owned solely by the health center, rather than co-ownership between the community and the university, as this would give the community autonomy over future use. Funding for the video was provided by Health Canada. In keeping with the core values of CBPR we contracted a community-based production team to help us construct the video. Filming began in September 2011 and ended May

2012. The first draft of the video was shown to the CCI's, those who participated in the video, and the Health Director to ensure that the video was aligned with the original plans and hopes for the video, and to identify any revisions they would like to see. Those revisions were incorporated, and the CAB approved a final version of the video.

My Reflections

For doctoral students interested in the connections between social inequities and health, CBPR can be an invaluable approach, and as such, universities are seeing an increase in demand from students interested in partnering with communities for their doctoral work. Universities have generally been slow to offer formal training in community engaged research (Gibbon, 2004). The training I received through my doctoral program generally focused on the ethics behind community engagement, both from a university ideology (for example, the Research Ethics Board and other ethical training) and a community ideology (for example, training to ensure the community values are upheld and respected, such as the Canadian Institute of Health Research's Ethics of Health Research Involving Aboriginal People). I was instructed to read the works of CBPR scholars (for example the works of Meredith Minkler, Barbara Israel, Nina Wallerstein, and Amy Schulz), was expected to thoroughly understand the principles of CBPR, and was continuously challenged to consider divergent epistemologies other than the mainstream Western ways of addressing a problem.

While understanding the theoretical underpinnings of CBPR is absolutely vital to the success of both the project and the academic researcher, the very nature of CBPR work suggests additional training may be required. Working with a CBPR approach means the student will be required to be in the field, building relationships with community members, attending cultural events, and interacting with real-life problems. Community-engaged research, such as CBPR, is unlike any other approach to research as it not only requires strong methodological and theoretical understanding, it also requires that the researcher possess strong people skills and will likely require practical, 'hands-on' skills to effectively navigate their way through their project. One of the goals of a CBPR approach is to highlight social inequities and spark social change (Israel et al, 1998), and this will require a very different skillset than traditional research approaches. A CBPR researcher must be assertive and engaged, while still acting in a manner culturally congruent with the partnering community.

The ideas presented below are reflections of my own experiences with a CBPR project and provide some of the additional skills I have identified which would have benefited me throughout my time in a CBPR project.

Critiquing the Toolbox

A Dent in the Toolbox: CBPR & Time

Much has been written about the challenges of CBPR, including project timelines (Horowitz et al, 2009; Ross et al, 2010; Love, 2011). CBPR is time-consuming, and activities beyond what is considered within the conventional research process are required. Such activities include participating in local events, meeting with community members over a cup of coffee, participating in cultural ceremonies, or any other activity that helps to foster a collegial and open relationship between the student and the community. Students must be prepared to spend time in the community, learning the history, the community values, and the overall knowledge of the community. Once relationships and trust are established, students must be prepared to dedicate additional time to maintain these relationships.

The idea of additional time commitments within a CBPR project is not new (Gibbon, 2002); however the additional time needed to engage in CBPR is often neglected from a student's perspective. Students may feel pressure to produce academic publications. In CBPR projects, time will need to be balanced between community and academic obligations. As academics working in health, our position in the university is largely governed by publications and academic presentations, and as students this is especially important as we strive to establish a name for ourselves. Publications are essential for postgraduate students to show our defense committee we are able to publish and think critically. Once we move past our defense committee, our publication list is invaluable for consideration and securement of academic postings.

As a new researcher engaged in CBPR, I may walk into my defense with few if any publications on my project findings. In keeping with the principles of CBPR, the community should be involved in drafting and reviewing any academic manuscripts generated through the project. This adds an additional layer that delays publication and as a result, I needed to be prepared to publish at the end of the project rather than at intermittent points throughout the project. In the long-term, this will not be hugely impactful; however at the time of defense I may have limited publications stemming from my dissertation.

A Dent in the Toolbox: The Costs to the Student

Students should be prepared to handle additional unanticipated project expenses including travel to and from the community, additional tuition fees incurred as a result of extended project timelines, or simply the cost of a cup of coffee or a box of donuts brought to community meetings. Being a student is already associated with financial constraints, and these may be further compounded when factoring in the additional costs required in a CBPR project. Students must be financially and emotionally capable of handling both the anticipated and unanticipated costs associated with CBPR work, and the unexpected stresses required to manage these costs.

What Additional Tools Did I need?

Based upon my own experiences and observations I would like to reflect upon the way in which I was trained to become a CBPR researcher. I received a fantastic and comprehensive training into the rich conceptual underpinnings needed to engage communities in research; however, considering the complexity of the community I partnered with, there could have been additional skills or tools that would have helped me navigate my place within the CBPR process. While having such tools in my toolbox may not have hugely impacted the outcome of the project, they could have greatly impacted how I traversed my role and space within the project.

Additional Tool: Addressing Personality & CBPR

Establishing trust and relationships, the core of CBPR, is determined in part by the personalities of those involved. CBPR literature discusses the importance of building trusting relationships (Maiter et al, 2008; Dalal, 2009; Khobzi & Flicker, 2010), yet fails to prompt researchers on the importance of self-reflection and how their own experiences, beliefs and worldviews may influence the project. As a new CBPR researcher, it would have been extremely beneficial to engage in formal exercises to reflect upon my own personality and how this could impact a community-engaged project. While there are courses offered at the university that enable such reflection, these were outside my required classes and I was not exposed to or aware of their existence.

The importance of personality was highlighted because of my own personality traits that had the potential to impede the project's success. I am uncomfortable with confrontation and conflict, both confronting others and having others confront me, and additionally, I was acutely aware of the need to be culturally sensitive as a result of past traumas inflicted upon the community through previous eurocentric research. The intersection of these qualities led me to overlook problems that arose during the project. Rather than addressing these conflicts and problems in a constructive way, with the help of university resources available to me, I often ignored the problem and acted with "hyper-cultural sensitivity" for fear of portraying myself as another colonial researcher. For most of my time in the project I felt like I was 'walking on egg-shells', unsure how to deal with confrontation as it arose.

I would have benefited from practical tools to address confrontation as it arose, which could have included practical training on how to address co-investigators who failed to show up for meetings or showed up, but hours late. If one of the goals of CBPR is to enact social change (Israel et al, 1998), this cannot be done by ignoring confrontation; however the central role of partnership within CBPR can make confrontation terrifying, especially for an outsider and a new researcher. If confrontation is not handled in a sensitive manner we risk losing trust and compromising the partnership. In my experience I would have greatly benefited from practical training on how to better understand my personality and to gain some practical tools to ensure this did not act as a barrier within the project.

Additional Tool: Preparation for Community Conditions

As a new, relatively sheltered researcher, I was unaware of the adverse conditions occurring in marginalized communities. The conditions in the community I was working with were unexpected. Before beginning this project, I spent many hours reading the statistics pertaining to First Nations peoples in Canada. I had taken the required classes, and read the required textbooks and academic articles. Conceptually I understood that many First Nations people living on-reserve live in overcrowded, inadequate housing, face internal and external violence, and have higher rates of injury, substance abuse, unemployment, chronic and communicable disease; however until seeing firsthand one cannot truly grasp the conditions of those living on some Canadian reserves. Listening to community members as they discussed their experiences with violence, suicide, abuse, and trauma, made all of the statistics and textbooks I had previously read seem inadequate. I believe similar to my situation, many non-Aboriginal Canadians do not understand how devastating reserve-life can be.

Asking students to become familiar with the statistical knowledge of marginalized populations is the first step in understanding social context; however this was not be enough to prepare me for my work on a CBPR project within a marginalized community. Tools to help understand and process the conditions I was about to encounter working within a reserve would have been immensely helpful. Enacting social change is an important component of CBPR, however if the student becomes overwhelmed by the conditions occurring in the community there is a likelihood of missed opportunities.

Before partnering with a community, I would have benefited from the knowledge of more senior researchers working within similar communities. More experienced researchers and supervisors should make a definitive effort to prepare new CBPR students with a complete understanding of what should be expected once they enter the community. This could occur through a formal mentorship program, or through a requirement that students participate in CBPR internships or practicums before embarking on their own project, both of which would have been immensely helpful to me.

Additional Tool: Understanding and Mediating the Political Climate

Communities are not homogenous units, and often have entrenched hierarchical systems of social order. CBPR aims to engage the community and mobilize social change (Israel et al, 1998); however this premise assumes everyone in the community is experiencing the same level of marginalization. An example of this can be seen within the CBPR literature, where authors continually stress the importance of identifying and engaging respected leaders in the community (Israel, 1998; Ramsden, 2010; Zoellner 2012). This assumes leaders are in the same state of marginalization as the rest of their community, which may not be the case. It may be likely, even among marginalized or oppressed populations, that there is a hierarchy of social status, political power, and/or economic stratification (Israel et al, 2003). For example, within the context of Canadian reserves, many of these communities experience extreme internal disruption and lateral violence. Lateral violence, a form of internal colonization, occurs among populations experiencing continuous intergenerational traumas, racism, and discrimination, resulting in marginalized people harming their fellow community members in a similar manner in which they have been abused (Derrick 2006). The oppressed becomes the oppressor, creating community divides and disruptions, and perpetuating strong hierarchies among members.

Drawing from my own experience I was not prepared to address the lateral violence occurring in the community, and as a result the most marginalized within the community may have been excluded from participating with the project; this could have affected overall research impact. While it is very unlikely that I, as an outsider, would have any impact on addressing lateral violence, additional tools may have given me peace of mind that I tried to do *something*, enact some sort of social change for the betterment of the community and our project. Even if my efforts were not successful on a community level, there would have been an opportunity for success on a personal level, knowing I did everything in my power to mediate the situation.

Once again, it would have been beneficial to me to seek the advice from my supervisory committee to better understand their best practices to navigate political climates. This could have saved considerable frustration and delays within the project.

Additional Tool: Mediation and Negotiating Skills

CBPR is based on collaboration between a diverse group of individuals, where divergent personalities and perspectives gather around a table to address a problem from unique perspectives. Effective mediation and negotiating skills are of paramount importance to the CBPR process, and would have been a powerful skillset as a new researcher. While the role of an academic researcher is not to steer or direct the CBPR project, as a PhD student I had a definitive list of requirements I needed to achieve through the project to satisfy my doctoral requirements, and as such, there were times I needed to negotiate with the community to ensure these needs were being met.

A concept specific to Aboriginal populations but relevant to projects working with any marginalized community is the idea of ‘two-eyed seeing’. Two-eyed seeing is a model developed by Albert Marshall, a Mi'kmaq Elder, which stresses the importance of seeing with one ‘eye’ the strengths of Aboriginal peoples' ways of knowing and being, and seeing with the other ‘eye’ the strengths of non-Aboriginal ways of knowing and seeing. This model is in line with the principles of CBPR, and has been adopted by the Canadian Institute of Health Research’s Institute of Aboriginal Peoples' Health. At the core of this model is the idea of a shared respect for the many epistemologies involved in a research project, something that must be recognized before successful project management can occur.

Similarly, researchers often speak of the need for ‘ethical space’ (Wiener, 2001; Gobodo-Madikizela, 2008). Within an Aboriginal context, ethical space refers to the development and adherence to appropriate outlets for research which acknowledges divergent ways of knowing and understanding, and provides a venue to articulate some of the possible challenges of merging these different ways of coming to knowledge (Ermine et al., 2004). Again, this notion very much aligns with the principles of CBPR, and has also been adopted by the Canadian Institute of Health Research’s Institute of Aboriginal Peoples' Health.

Before two eyed-seeing can occur or an ethical space can be achieved, all parties must be equipped with the skills to understand the concept and negotiate their place within that framework. For more seasoned researchers this may be an easier job; however for new students such as myself, this seemed like a daunting challenge. As a student I was taught about the existence of power imbalances, the role outside researchers can play in perpetuating power imbalances- a concept CBPR strives to overcome (Israel et al, 2003), and the fact that we, as outsiders, may be initially viewed as being exploitative (Gibbon, 2002). With this firmly in my head, I felt very hesitant about asserting my position within the project, which resulted in my voice being lost at times.

I would have benefited from the proper tools to help honor the principle of two-eyed seeing or build my own ethical space while still asserting my own voice. Such tools could have included mediation and negotiating techniques, or other skills that would have allowed me to negotiate my position in the project, while still maintaining and ensuring a strong partnership.

Additional Tool: Project Management

Project management is a fundamental tool to the success of a project (Gresch, 2010), and it is surprising students are not formally required to participate in the basic training of this subject. I believe this should be a mandatory concept in any CBPR training, required before the student can fulfill their core set of classes. Project management within a research project includes activities such as the necessary administrative tasks needed on a daily basis, budget planning, addressing competing interests, ensuring team members complete their assigned tasks, etc. While this should not be left to the student alone, it is likely that community research team members will look to the student to address the bulk of the day-to-day operations needed to maintain project momentum.

There is a vast amount of literature available on project management (Erno-Kjolhede, 2000); however the available information on project management cannot be easily transferred to a CBPR context, as CBPR differs significantly from traditional research orientations (for example, in the sharing of power, which is an approach to research that is unique to CBPR). This signals a gap in our knowledge on how to provide new CBPR researchers with training on project management. Drawing from my own experience, a large component of our project was the construction of an educational video documenting the community's experiences with TB. This video was community-owned and driven, and in keeping with the principles of CBPR, we contracted a community-based production company to shoot and edit the video. A university contract was established between my department and the company, which clearly outlined the responsibilities of both parties; yet it was not long before we began to experience difficulties with this company (for example, failing to show-up to film interviews or failing to produce the final videos). The project team looked to me, as a university representative, to manage and mediate the situation. With limited tools in my toolbox, I was at a loss on how to address the situation in a manner that was culturally sensitive but still dealt with the issue at hand. I am very lucky to have seasoned thesis advisors who were able to provide insightful advice on how to best mediate the situation. If these tools were not available, my lack of training in basic project management could have been devastating to the final outcomes of the project.

Some Final Thoughts

The reflections provided here cannot be generalized to every doctoral student, as every student and project is unique and will require a unique set of skills. Rather than a prescriptive set of instructions, this chapter aims to document some of the missing practical skills I experienced working within one CBPR project, and highlights some of the considerations future students could address before undertaking this challenging work.

The process of CBPR provides opportunity for immense, deeply rich learning experiences, and I would recommend the experience to any doctoral student interested in the connection between social inequities, social change, and health. CBPR provides opportunities to develop skills not possible in traditional research projects. A CBPR project provides an understanding into social disparities and inequality, addresses the ethical implications of community engagement, and importantly creates a space for community empowerment and knowledge exchange (Blumenthal, 2011). As a doctoral student involved in a CBPR project at the University of Alberta, the lessons I learned are from the perspective of a student, balancing both the needs of the community with the needs to fulfill my academic requirements. Through my experiences with a CBPR project, I was presented with learning and teaching opportunities not available to my non-CBPR colleagues, and believe I will be a stronger researcher as I move forward in my career.

CBPR requires the student to be in the field, often working with marginalized and oppressed individuals. Unlike other dissertations, knowledge generated through a CBPR project will need to satisfy the needs of the community as well as doctoral standards, and as such the student will be required to juggle both demands equally (Herr & Anderson, 2005; Khobzi &Flicker, 2010).

Working within a CBPR project requires the researcher to wear many hats, and as Israel et al (1998) explains, researchers must-

> be willing to provide technical assistance that may not be directly related to the specific research effort… to carry out this role, a community-based researcher needs skills and competencies in addition to those required in research design and methods, for example: listening, communication (e.g. use of language that is understandable and respectful), group process, team development, negotiation, conflict resolution, understanding and competency to operate in multicultural contexts, ability to be self-reflective and admit mistakes, capacity to operate within different power structures, and humility. (p. 187).

Before I began working on a CBPR project there were some additional tools that could have better prepared me for the situations that occurred through my time working with the community. In my experience these tools were not provided in my core courses required to fulfill my dissertation, suggesting I should have sought the additional training from other sources. Whitmore et al (1999) suggests researchers interested in community-engaged research, such as CBPR, must consider whether they possess the capacity and toolset to effectively become involved in such a project. Additional skills such as project planning, project management and negotiating skills may not have hugely impacted how our project turned out, but they would have ensured that I felt I did the best job possible with my time in the project. For self-preservation, I should have sought out the skills to manage the social context occurring in many marginalized communities, and should have considered my own experiences, values and beliefs and whether there was a possibility these could impede the progress of the project. My supervisory team was an invaluable asset throughout this process, and I would recommend future students seek their own supervisory guidance whenever needed.

I needed to accept the constraints placed upon me by the very nature of CBPR work, for example the very likely possibility that the project and resulting publications could progress at a much slower pace than if I engaged in a non-CBPR project. As a new researcher, moving at the community's pace rather than at my own was frustrating at times. The concept of time within a CBPR project is governed by the need for strong relationship building and addressing the social and political landscapes occurring in many marginalized communities. CBPR teaches us patience, which is a lesson best understood at the beginning of a project.

Lastly, it is important to fully understand that although CBPR strives to include divergent ways of understanding into the core of the research process, it is still very much an academic, Western approach to conducting research. Most of the obstacles I experienced throughout my time in the project occurred when my academic needs, that is the needs to complete my dissertation, conflicted with the community's needs or understanding. For example, ensuring the project progressed at a pace which aligned with my academic deadlines (publications, my candidacy exam, etc.) was likely of little concern to the community. Community members cared about addressing the lack of adequate housing in their community or the need to reclaim their traditional language which has been threatened by years of colonization. We, as researchers, need to be prepared and willing to understand that the academic steps we see as being very important to the project may not be regarded with such high levels of importance by community members. CBPR acknowledges that there are multiple ways of knowing and understanding; however we must not forget that there are multiple ways of prioritizing an issue. Together, academic and community researchers must find a common ground on which the research project can be built; we need to come together and possibly readjust our academic lens through which we view the project. We must strive to find common priorities and understandings before a successful project can occur.

My hope is that the mistakes I made, the obstacles I overcame, and the lessons I learned will provide useful information for future health students interested in CBPR. One of my central messages is that the very act of making mistakes, learning to overcome barriers, and learning to work with divergent personalities was a great learning experiences and a chance for personal capacity building. CBPR is messy and complex, and it is likely to be difficult and at times very frustrating. However at the end of the day, when the dissertation has been written and the project has concluded, I have been provided with amazing opportunities to better understand health, understand how a community cohesively works both together and against each other, and through the mistakes and messiness I have been provided a chance to understand how I work, what I believe in, and how I function as a member of this world. I am not only a better researcher because of the lessons I learned in this project, but I believe these experiences have made me a better person.

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Chapter 6: General Reflection and Conclusions

Recognizing that very few studies actively engage and include the voices of the communities most affected by tuberculosis (TB) in Canada, the ultimate goal of this dissertation was to better understand a First Nation community's perspective of TB. Unlike most TB literature, where Aboriginal people have traditionally been silenced from the research dialogue and in which no attempt has been made to include First Nation people in the discussion on TB transmission, this study was dedicated to ensuring a First Nation perspective was at the core of the project. To secure the community at the core of this project, a Community-Based Participatory Research (CBPR) approach was utilized. Through consultations with the community, we decided the two objectives of this project would aim to:

1. provide a platform to discuss and document one First Nations community's experiences and impacts of TB; and
2. understand the social context occurring within the community which may promote continual disease transmission.

The dissertation is divided into six chapters, each examining a different component of the project. Chapter 3 examines the experiences of the community as they dealt with the sanitorium system, which participants describe as traumatic and which continues to influence health behaviors today. Participants describe the exclusion resulting within and because of sanitoriums, and overall this chapter highlights how a well-intentioned institution such as the sanitoriums must be considered within the Canadian colonial landscape. Although sanitoriums were implemented under the premise of healing, participants view these institutions as another means of exclusion by the hands of the Canadian government.

The purpose of chapter 4 was to examine the participant's perspectives of the current state of TB on-reserve, which resulted in many participants discussing the housing conditions within their community. Through the discussion and interviews with community members it is apparent participants experience a lack of control in their daily lives and the complexity of housing conditions on-reserve. The findings presented in this chapter suggest housing must be considered beyond infrastructure to include the political and cultural environment in which the individual resides. Unlike many other studies examining housing conditions and TB transmission, a holistic perspective of housing was adopted; we considered the social environment created through housing infrastructure, the influence of addictions on overcrowding, and the role of systemic policies which govern First Nation housing.

Finally, chapter 5 discusses my reflections as a doctoral student engaging with a First Nations community through a CBPR approach. I found my experience complex and immensely rewarding, but also very challenging. Overall this chapter presents some of the additional tools which would have made my time in the project more productive, and tries to move beyond the theoretical understandings required to conduct community engaged research to identify some of the practical skills which are also needed. Additional tools such as project planning and management, negotiating skills, and skills to manage the social context occurring in many marginalized communities would have been valuable.

Lastly, I highlight some of the constraints tied to the very nature of CBPR work, for example the constraints which slow the publication of findings.

Taken together these studies highlight some of the multifaceted reasons why TB transmission may be ongoing within the community, considering both historical and current instances which influence disease. Through the inclusion of Aboriginal ways of knowing and understanding, the findings of this project present a community-generated representation and understanding of TB transmission. The findings of this study suggest future TB control measures on-reserve must adopt a multi-strategic approach, considering the community's past experiences with TB control, the current state of health on reserve, and how the systemic policies which govern much of reserve life might influence the health of the community. Similar to previous research (Kelm, 2004; van Holst Pellekaan & Clague, 2005; Brown et al, 2012), the findings of this study highlight how the definition of health must be broadened past the eurocentric definition often central to TB control. In addition to being free of TB, participants spoke of health in terms of reclaiming their language, strengthening connections with the community and their families, and regaining control of their social environment.

Limitations

TB on-reserve is a complex problem, tied to the long history of colonial practices and social inequities experienced by First Nations people in Canada. Through the inclusion of a First Nation perspective we aimed to provide a platform for community input, and therefore aimed to examine the issue on a much deeper level; however, the complexity of continual TB transmission would suggest that we did not cover all factors which may promote hyper endemic disease. For example, this dissertation does not address some of the factors equally important to TB, such as poverty, lack of employment, or chronic health conditions such as HIV/AIDS or diabetes which other studies suggest are important considerations for TB control (King, 2009; Orr, 2011; Harres, 2012).

TB is traditionally highly stigmatized within the participating community, meaning it is very likely some community members would have chosen not to participate in this study. Regardless of the attempts made to ensure a bias was not introduced through our sampling strategies, it is appropriate to assume that the participating sample may have missed some valuable experiences, insight, and understanding of the disease.

In addition, similar to most CBPR projects (De las Nueces, 2012) the findings of this project were unique to the participating community. While the specifics of the project cannot be placed upon another community, there is a degree of transferability achieved through this project and many of the overarching experiences discussed by participants will likely be seen in other Alberta reserves. For example, the lessons learned such as the idea that housing must be considered broadly within TB control, the lack of control those living on reserves are likely experiencing, and the influences of historical TB efforts to current health behaviors can likely be transferred to other Alberta reserves. To ensure a degree of transferability, I made sure to provide a thorough overview of the context of the project so future researchers can decipher how much of our findings could be transferred to similar contexts. As discussed in earlier chapters, I was careful to balance the community's wish to remain anonymous with an ability to achieve transferability.

Lastly, it should be noted that this project only examined the issue from the perspective of the community. One of the continuous stories we heard throughout our time in the project was the racism and prejudice people of this reserve experience at the hands of non-Aboriginal society. While these stories highlight the persistent inequality in Canada, I do not believe non-Aboriginal Canadians intentionally set out to enforce such disparities; rather I think this speaks to the ignorance that is alive and well in our culture. Most of us do not understand the conditions some Canadians living on reserve experience on a daily basis. Boil advisories, homes that make us sick, and continuous threats of violence are unimaginable to most Canadians, myself included. It is therefore very easy to push from our minds inequalities that exist within Canada, simply because we do not understand it and it does not directly affect us. My personal belief is that the solutions to address the issues experienced by marginalized society must come from collective society, both Aboriginal and non-Aboriginal. Adverse conditions on-reserve is not an Aboriginal issue, this is a Canadian issue. While projects such as this one are the first step forward in creating a truly healthy society, I believe that the larger solution lies within Canada as a cohesive nation. Once all citizens are educated about the conditions some of our brothers and sisters are subjected to can we truly as a nation make informed decisions to address inequities; I believe TB, a disease which thrives in such inequities will remain a threat to Canadians until we all come together to fight the unjust conditions some Canadians are living with.

Conclusions

This dissertation provided a platform to ensure the Aboriginal voice was included in the TB discussion, allowing the issues promoting continuous TB transmission to be understood on a much deeper level. Through the use of a CBPR approach we were able to consider factors which may not have been examined without the engagement of the community. The findings of this project will be of interest to public health officials, TB physicians, health practitioners, and policy makers working within Aboriginal health, and suggests future TB control efforts must be inclusive and holistic in their approach.

I would like to conclude by highlighting some of the strengths I experienced through my time working with the community, as too often health researchers focus solely on the adverse conditions and weaknesses occurring on reserves. During my time working in this project, I was amazed by the pockets of individuals diligently dedicated to the health and well-being of their community. Much of the literature discusses the problems that Aboriginal people face (Bagley, 1991; Cutcliffe, 2005; Gliksman et al, 2007), which has presented a one-sided perspective of reserve life. While the participants of this project face many adverse conditions and challenges, this is a strong and tight-knit community who look out for one another and are quick to take care of their own. As many participants spoke of the painful events they have endured throughout their lives, these same individuals also highlighted the resilience needed to overcome trauma.

I was often inspired and amazed by the community members I had the privilege to work with. Rather than only considering the barriers to health on-reserve, it would be wise for future TB control professionals and health researchers to acknowledge and build upon the many strengths linked to life on a reserve.

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Appendix A: Ethics Notification of Approval - Delegated Review Form

UNIVERSITY OF ALBERTA
FACULTIES OF EDUCATION, EXTENSION, AUGUSTANA
CAMPUS SAINT-JEAN RESEARCH ETHICS BOARD

308 Campus Tower
8625 – 112 Street, Edmonton, AB T6G 1K8
Phone: 780.492.2614

Notification of Approval - Delegated Review

Study ID:	Pro00013132	
Study Title:	Community Perspectives of Tuberculosis	
Study Investigator:	Jessica Moffatt	
Study Supervisor:	Maria Mayan	
Date of Informed Consent:	Approval Date 5/13/2011	Approved Document Informed Consent
Funding/Sponsor:	AHFMR - Alberta Heritage Foundation for Medical Research	AHFMR

Thank you for submitting the above ethics application to the Education, Extension, Augustana and Campus Saint-Jean Research Ethics Board (EEASJ REB). I have reviewed your application and, on behalf of the EEASJ REB, approved it as of May 13, 2011. The approval will expire on May 11, 2012.

A renewal report must be submitted prior to the expiry of this approval if your study still requires ethics approval at that time. If you do not renew before the renewal expiry date, you will have to re-submit an ethics application.

If there are changes to the project that need to be reviewed, please file an amendment. If any adverse effects to human participants are encountered in your research, please contact the undersigned immediately.

Sincerely,

Dr. Stanley Varnhagen
Chair, Education, Extension, Augustana and Campus Saint-Jean Board (EEASJ REB)

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix B: Co-investigator Research Agreement

Co-investigator Research Agreement

XXX First Nation:

Project: Community Perspectives on Tuberculosis

Academic Researcher: Jessica Moffatt
Supervisors: Maria Mayan
2-281 Enterprise Square
Edmonton, AB
Canada T5J 4P6
(780) 492-9230
moffatt2@ualberta.ca

Community Co-investigator(s):
Xxxxxx
Xxxxxxx
xxxxxxx

You have agreed to participant as a co-investigator in a Community Based Research project examining Tuberculosis (TB). You are being asked to help because of your traditional knowledge and your role in the community. Below you will find the terms and conditions of the research relationship. If you find these terms reasonable and wish to accept the role of co-investigator, please sign both copies.

Community based research project in an Aboriginal Community (XXXXX). This money will cover travel and hosting costs for two individuals during the study; it will also cover wages for the co-investigators at $13/hr for up to 10 hours/week.

Co-investigator responsibilities include:

1. Ensure the project remains aligned with community values, morals, needs, and ethics
2. Ensure community protocols are respected
    a. If the project inadvertently acts in a manner not aligned with community protocols, the co-investigators should make Jessica aware immediately
3. Be part of ALL aspects of the research
4. Organize community meetings when needed
5. Organize Community Advisory Board meetings when needed
6. Participate with research in the following ways
    a. Arrange logistical aspects of interviews (for example, booking interview rooms, contacting participants, etc.)
    b. Lead or co-lead interviews
    c. Help to draft interview guides
    d. Help to recruit participants into the study
    e. Help to create a dissemination strategy which benefits the health of the community
7. Agree to dedicate 10 hours per week to the project
8. Agree to meet weekly to discuss the project

If you find these terms stated above reasonable please sign both copies. A copy of the following consent form will be left with you, and a copy will be taken by the academic researcher.

I, …………………………… ……..……………………………………………………….
have consented to participate as a co-investigator in the above research project.

Name:
……………………………………………………………………………………….

Signature ……………………………………………...… Date
…………..………………..

Academic Researcher's signature : ……………………………………………

Date …..…………………

Appendix C: Overview of Video

An important piece of this research was the production of a community-owned educational video for the purposes of disseminating the stories and experiences shared with us throughout this project. This video is the property of the community's health center, and the University researchers do not have access the final draft. As the video contains emotional and very personal stories of the community members, it was important to the health center staff and the Community Advisory Board (CAB) that this be a resource controlled solely by the community.

Waisbord (2007) argues that the communication of the tuberculosis (TB) message is an important component to understanding and addressing TB. The author suggests the message being communicated should be sensitive to the unique experiences of the audience, should include both socio-cultural and health components, and should recognize that marginalized groups are likely to experience TB much differently than non-marginalized populations. The decision to make a video was made between the CAB, the Community Co-Investigators (CCI), and me, who collectively recognized the exceptional opportunity to document the community's experience with TB. In alignment with Waisbord (2007), we decided the video would be based upon the findings of the study, would address both socio-cultural and biomedical components to the disease, and would be unique to the participating community. Funding for the video was provided by Health Canada.

The concept of the video was considered for two reasons. First, we recognized that one of the goals of a CBPR approach is to highlight social inequities and spark social change (Israel et al, 1998). However, after preliminary discussions with the CAB, it was apparent that the topic of TB was not something openly addressed within the community. TB in general was stigmatized within the community (for example, one participant described his fear that people would think that if he had TB, he would also have HIV/AIDS), and attached to many traumatic experiences that were not openly discussed. We understood that before social change can occur, the stories and experiences of community members must be formally recognized and shared (Burgess, 2006; Jacklin & Kinoshameg, 2008). The discussion of TB control must begin before any form of social change can occur, as people must understand and contextualize their history. Through a video, the community was formally presented with a platform to document their personal experiences with TB.

Second, CBPR researchers often discuss the importance of project sustainability, meaning the project benefits should exist long after the academic researchers are no longer working within the community (Minkler, 2005; Minkler et al, 2006). Project sustainability was an idea the CAB, co-investigators, and I strongly felt should be upheld within our project. The video created an ideal format to educate community members and could be used as a sustainable tool long after I left the community. The CAB decided the video would be owned solely by the health center, rather than co-ownership between the community and the university, meaning the community could choose to utilize the video in the future however they see fit.

In keeping with the core values of CBPR (Jacklin & Kinoshameg, 2008), we contracted a production company that was comprised 100% of members of the community, who came recommended to us by Chief and Council to help us produce the video. The video company had a history of working on similar health projects within the community. Filming began in September 2011 and ended May 2012. The first draft of the video was shown to the CCI's, those who participated in the video, and the Director of Health to provide an opportunity to identify any revisions. The video was edited jointly by myself, the co-investigators and the production company. After these revisions were incorporated, the draft was shown to the CAB and Health Canada representatives for their input. The final version of the video was previewed at the health center over a catered lunch, attended by study participants, CAB members, the co-investigators, as well as many other community members not directly involved with the project.

Two perspectives were presented within the 20 minute video. We wanted to document the personal and unique stories of community members dealing with TB which were based upon the interviews conducted throughout the project. The research team decided we wanted to document the complete picture of the community's history with TB treatment, and therefore we included interviews from sanitorium survivors as well as their families. The stories included were both happy, (e.g., the story of a young man who would sneak into the sanitorium kitchen at night to steal cookies) as well as traumatic (e.g., the story of a woman whose family was separated into different foster homes after her mother was sent to a sanitorium).

We also wanted to provide education on the biomedical aspects of TB, including the symptoms of TB, stages of TB, treatment options, and the importance of taking anti-TB medication. We interviewed the community health nurse to explain the biomedical components to the disease. Within her message there was a strong emphasis on the communal aspect of TB, the importance of medication compliance, and the social determinants of TB. With permission from Health Canada, we included cartoon figures created by First Nations and Inuit Health specifically for Health Canada employees to educate First Nations people about the symptoms of TB.

We also recognized the other social movements occurring in the community parallel to our CBPR project, and wanted to incorporate these into the video. For example, within the community there is a strong movement to reclaim the traditional language lost through years of colonial practices. Recognizing this, it was important to us that the traditional language with accompanying subtitles be utilized at times throughout the video. Additionally there is a strong recognition within the community of the important role children play in moving the community forward to a place of healing, and as such we felt it was important to include community children throughout the video. In addition to interviewing past sanitorium patients and their families, we also created two short skits based upon the stories heard within the interviews. These were acted out by the community children. One skit involved two children being treated in the sanitorium and highlighted some of the fun patients had during their time in the hospital (for example, sneaking off to race wheelchairs in the sanitorium basement). The second skit involved a young women returning to her community after much time spent in the sanitorium. This skit focused on the loss of language and loss of culture many participants spoke of after being removed from the community for long periods of time.

Lastly, we wanted to ensure insightful discussions were generated after watching the video, and as such we created a discussion guide to accompany the video. The guide was developed to promote discussion and to prompt the viewer to consider the many ways in which the community was and is affected by TB. The discussion guide is property of the health center and cannot be included within the pages of this dissertation; however questions included in this guide were-

1. What were the difficulties faced by family members and patients who spent time in a sanitorium?
2. Do the past experiences with sanitoriums affect how people seek health treatment today?
3. What could the doctors and nurses who worked in sanitoriums have done to make the experience easier on First Nations patients?
4. What are the benefits of taking your TB medication?
5. Why does TB remain a problem today?

The video has been well received, and has formally begun the discussion of TB within the community. At the last video screening, community members were very receptive to the video, which sparked thought-provoking and emotional reactions by many viewers. We hope the video will be utilized to provide continuous discussion for a long time to come.

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