

TAKING CARE OF OUR OWN; THE MULTIFACETED RELATIONSHIP BETWEEN ON-RESERVE HOUSING AND TUBERCULOSIS OCCURRENCE

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ABSTRACT

Although a link between housing and tuberculosis (TB) is discussed in the medical literature, it is rarely considered from a community perspective. This paper looks at the link between social environment, housing, and TB transmission from the perspective of a First Nations reserve community. Using a community-based participatory research framework we conducted semi-structured interviews (n=15) in a First Nations reserve community with persistent TB. Data collection and analysis were iterative, using qualitative content analysis. A community advisory board, comprising Elders, community members, and two community co-investigators, was instrumental to ensuring cultural sensitivity. Participants discussed their experiences with a lack of control, and described the effect of inadequate housing and overcrowding on TB transmission. Participants linked overcrowding and addictions to high TB incidence rates, and also discussed the effects moving to the city had on culture and well-being. The findings of this study demonstrate that on-reserve housing 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.

Key words: First Nation housing, tuberculosis, social environment, overcrowding, public health

INTRODUCTION

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; Larcombe et al., 2011). Pulmonary TB, a disease spread by airborne droplet infection, means that living in smaller, overcrowded, or poorly ventilated homes increases the probability of TB exposure, and therefore transmission. Living in close household contact with someone with pulmonary TB (sputum smear 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 overcrowded 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 et al. (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 peoples because of the prevalence of inadequate and overcrowded homes on reserve. In a groundbreaking article Edwards et al. (1982) described the complex links between housing, health, and well-being, and suggested housing structures can promote detrimental health behaviours. TB, a disease where the social en-

vironment plays a large role in disease promotion (Grzybowski and 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 such as one's sense of belonging, one's sense of control over one's 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. We aimed to understand the relationship between housing conditions on-reserve and continual TB transmission.

METHODS

GUIDING THEORY AND FRAMEWORK

This study was a satellite project 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., 1998), 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 for 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 world views were at the core of this project, a community based participatory research (CBPR) approach was used. The foundation of CBPR emphasizes the participation of commun-

ity-based researchers, as opposed to participation of only academic researchers, who are actively engaged in all aspects of the research process (Israel et al., 1998; Jacklin and Kinoshameg, 2008; Getty, 2010). 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 used in research partnerships with many Aboriginal communities across North America (Petrucka et al., 2007; Worthington et al., 2010).

RESEARCH PARTNERS

This study was approved by the Research Ethics Board at the University of Alberta. In addition, a community advisory board (CAB) was formed early in the project. The CAB comprised nine community members (Elders, health care staff, and lay community members), the community co-investigators, 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 forward in a culturally sensitive manner; and 4) to provide insight on the dissemination plan. Meetings occurred at the community's health centre

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 players 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 unique and valuable insight, and creating a strong foundation on which the project was built.

Purposive and snowball sampling was used, and participants ranged in age from 19–63 years old. The sample included 11 women and 4 men from the same participating First Nation reserve. Purposive and snowball sampling allowed the research team to target participants with 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

All interviews were conducted at the community health centre by the research team, were audio recorded, and each lasted approximately one hour. Before starting the interviews, an interview guide was developed by the research team, which was approved 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 about the participant's personal experiences with the disease.

With consent, the interviews were audio recorded and transcribed verbatim by a non-Aboriginal transcriptionist independent of the study. Data was checked against the original audio recordings for accuracy by Jessica Moffatt. Data collection and analysis was iterative, and qualitative content analysis was used. Qualitative content analysis is the process of coding and categorizing patterns throughout the data (Mayan, 2009), and can provide a rich understanding of the text being communicated (Graneheim and Lundman, 2004). Transcripts were analyzed line by line, and codes important or consistent with postcolonial theory were highlighted. 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 Jessica Moffatt; however to align with the core values of CBPR (Jacklin and Kinoshameg, 2008), findings were regularly presented to the co-investigators and CAB to ensure cultural relevance and accuracy.

After many formal and informal consultations with the CAB, it was decided the primary product of the project would be an educational video. It was decided the video would remain internal to the community and would document the unique community experiences with TB. To produce the video

a community-based production company that was recommended by chief and council was used. The video documented the community's historical experiences with TB control and described some of the current conditions and biomedical aspects of the disease. The video was an ideal format to educate community members and could be used as a sustainable tool long after the academic researchers left the community.

RESULTS

Using a postcolonial lens helped us to uncover some of the power differentials which shaped housing on reserve. The links between the social environment and housing are categorized below as 1) Overcrowding and Inadequate Housing, 2) Lack of Housing and the City, and 3) Cultural Norm and Addictions. These results are not linear or independent; rather the social environment is complexly created through the intertwinement of the categories presented below.

OVERCROWDED AND INADEQUATE HOUSING

Participants commonly linked endemic overcrowding on their reserve to the high TB occurrence of their community. As one participant explained,

If you have a bunch of people living in a house and one of them is sick, you all breathe the same air and if you are overcrowded it can pass along the germ.

Participants felt strongly that the state of housing in their community was at the core of continual TB transmission. As one participant stated,

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 are 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 AND 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 al-

ways that back and forth. In the city there are always places where you can contract the disease.

CULTURAL NORMS AND ADDICTIONS

Participants suggested 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, but 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 than 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 in 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 behaviours, 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 behaviours.

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 postcolonial 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 of TB rates plaguing their community.

HOUSING AND CONTROL

The underlying premise of this study was the lack of control participants have over 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. Stress can be decreased by the ability to control one's life (Mirowsky and Ross, 1986; Szreter and Woolcock, 2004); yet First Nations people living in an overcrowded environment have very little control over their physical surroundings. For example, partici-

pants 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 and 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 in the findings. Participants stated housing was so inadequate in 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 linked cultural discontinuity 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 and Taylor, 2010).

Much of the control has been taken from First Nations people by systemic policies, an example of which can be seen in the Canadian *Indian Act*. The *Indian Act*, a race-based piece of 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) 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 in the context of health. Not only was lack

of ownership identified as a barrier to healthy housing on-reserve by the 2005 Canadian Aboriginal Roundtable, 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 connected to TB, a disease strongly rooted in social and physical conditions. For example, if residents do not own their dwelling, they may be less likely to maintain or repair the structure, creating an environment conducive to TB transmission. If participants have no incentive to personally keep their home in an adequate state, the end result can be the promotion of environmental biocontaminants (Thrasher and 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 or indirectly to TB, or have been shown 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. This was 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 provided approximately \$1.4 billion from 2004–2009 which allowed 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 outweighs 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 improve or mediate the lack of control and autonomy on reserves or address some of the systemic barriers apparent on reserves which hinder healthy housing (for example, endemic addictions). As this study highlights, housing conditions on reserve are complex, and will therefore likely require a complex, multifactorial approach.

OVERCROWDING AND TB

In 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 might 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 and Carpiano, 2010; Carpiano and 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 nonresidents 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 exacerbate a weakened immune response, such as smoking (Wetter and Young, 1994) and diabetes (Resnick et al., 2003); both of which are prevalent among First Nations peoples and both of which are significant when considering TB control.

OVERCROWDING AND 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 behaviour, 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 coinhabitants, regardless of whether their behaviour 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 for individual health, but for the collective health of this population. 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 in 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 addictions support on reserve and off reserve and prevention programs, or addictions support that 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 behaviours are connected to TB (Millet et al., 2012), suggesting this is an important consideration for TB control. For example, in the literature alcohol abuse is continually linked to an increased risk of tuberculosis (Brudney and Dobkin, 1991; Fleming et al., 2006) and TB fatality (Millet et al., 2011). Alcohol abuse has also been shown to decrease compliance with treatment (Burman et al., 1997; Friedland, 2010) and increase instances of delayed diagnosis (Nguyen et al., 2011), suggesting that 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 comorbidities tied to addictive behaviours; 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 shown to adversely affect TB through an increased risk of reactivation of latent TB infection (Friedland, 2010), TB incidence, and TB mortality (Millet, 2012). Diabetes, another comorbidity associated to addictive behaviours such as chronic alcohol consumption and drug abuse (Mattoo, 2011) has been associated with an increased prevalence of active TB (Dooley and Chaisson, 2009; Sullivan and Amor, 2012) and poorer treatment outcomes (Baker et al., 2011).

CONCLUSION

The findings of this study demonstrate the complex relationship between 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 cul-

tural environment heavily influence housing conditions, which in turn influence disease prevalence. Housing in a TB context cannot be considered as simply four walls and a roof; rather the underlying conditions, such as inadequate housing, overcrowding, addictions, and legislation such as the *Indian Act*, create an environment with many pathways to the promotion of infectious disease.

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