

Effects of knowledge about tuberculosis on its prevalence in Inuit communities in Nunavut, Northern Canada: A mixed Methods study

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SUMMARY

Tuberculosis (TB) is an infectious disease that affects marginalized communities disproportionately. While TB incidences are rooted in factors that are characteristic of developing countries, some communities in developed countries, such as Canada, face a high prevalence of TB. Indigenous people, being a community alienated within healthcare, are the target population for this research proposal. Due to the historical Indigenous cultural ignorance that persists today, this research aims to employ a participatory approach to promote inclusivity and conduct research in a culturally sensitive manner. Findings from this research will provide insight into Inuit people's lived experiences and concerns, aiding in understanding the correlation between access to resources such as disease knowledge and its impact on TB prevalence. On a broader scale, this research will promote advocacy for communities excluded in healthcare and raise awareness regarding the poor living conditions often ignored in developed countries.

ABSTRACT

Rising tuberculosis cases are a global health issue that the United Nations Member States have committed to eradicating by 2030. In developed countries such as Canada, TB affects Indigenous populations disproportionately. Inuit people have 300 times greater risk of TB infections compared to non-Indigenous people. Due to Canada's colonial history, Indigenous people remain underrepresented in healthcare. Therefore, this research proposal aims to understand the link between the lack of access to resources, such as knowledge about tuberculosis and the rising TB cases, among Inuit people in Northern Canada. It is hypothesized that due to marginalization and cultural ignorance, preventative measures are not accessible to Inuit people and can influence the high transmission of the disease. Based on the results of the inclusive design of this research, future studies can aim to help voice the concerns of Indigenous people and advocate for their right to access equitable healthcare.

Keywords: Tuberculosis, TB, Infection, Indigenous health, Inuit People

INTRODUCTION

In 2018, all United Nations Member States declared a commitment to eradicate tuberculosis (TB) by 2030.¹ Yet, World Health Organization reports that TB still accounts for the highest mortality rates of all infectious diseases globally.¹ Research has shown that the prevalence of TB is mainly rooted in factors such as poverty, overcrowding, and the conditions of developing countries.² Research by Abdollahi et al.³ highlighted the disproportionate impacts of TB on the Inuit

population. As Inuit people experience 300 times greater rates of active TB infections, there is a need to understand factors which exacerbate infections in a developed country such as Canada.³ Abdollahi et al.³ also showcased the importance of the time-to-identification of TB in controlling its prevalence which is significantly longer for Inuit people. Current research does not focus on gaps in knowledge about the disease among the Indigenous.

An article by Hick⁴ sheds light on Canada's colonial history, which has neglected the Indigenous peoples in

all aspects, including healthcare. The cultural ignorance of Indigenous people is deeply rooted in the lack of appreciation of their existence, resulting in the lack of support available for them.⁴ The horrifying historical events represent a series of attempts to eradicate the Indigenous culture, which is why to this day, they remain excluded, marginalized, and alienated.⁴ The following research proposal, therefore, hopes to investigate the impact of a possible lack of access to knowledge about TB on the Inuit Indigenous community.

This proposal's rationale is further influenced by the key findings presented in research by Patterson and colleagues.⁵ The Inuit communities in Canada lack infrastructure, with few roads that limit access to healthcare and impede the ability of staff to visit.⁵ Moreover, communication is attenuated as the staff, upon arrival, cannot understand the cultural and other barriers, such as the language of the Inuit people.⁵ This tyranny of distance, combined with the barriers mentioned earlier, yields ineffective communication with the Inuit people. Research by Hick⁴ shows that the dichotomy created between Indigenous and non-Indigenous communities ignores aspects of the Indigenous culture that do not fit in the boundaries of "what is acceptable." In fact, most hospitals and hospital staff do not offer services in native Indigenous languages, which further impedes the transfer of knowledge to them regarding infectious diseases such as TB.⁴ Knowledge about diseases shapes patients' illness experiences and affects their outcomes.⁶ There remains an abundance of scientific research regarding cures for TB since the 20th century.⁴ Therefore, it deems essential to understand factors such as access to knowledge about TB among Inuit people and its correlation with the rising infections.

Research by Orr⁷ shows the benefits of tuberculosis control programs in connecting with individuals from diverse backgrounds. Projects such as "stop tuberculosis" involve intimate education protocols that help raise awareness, including door-to-door visits.⁷ These initiatives have shown success in engaging diverse communities at the street level, empowering those in need, and ensuring the delivery of culturally sensitive care.⁷ Looking at the example of the United States, TB control efforts by communicating with the public intimately have prevented more than 300,000 people from developing TB disease.⁸ These efforts have re-

duced the prevalence of TB to 2.4 cases per 100,000 persons.⁹ Conversely, the disparity in TB cases can be seen by the striking 170.1 cases per 100,000 people among Inuit people compared to 0.6 cases per 100,000 non-Indigenous Canadians.¹⁰ Based on the success of other countries, it would be advantageous to establish strong partnerships with the Inuit to understand their conditions and remove barriers to care.

1.1 PHILOSOPHICAL ORIENTATION

Adopting the pragmatism orientation will allow innovative and dynamic research to be conducted. This orientation perfectly aligns with the research question due to its belief that objective and subjective realities can co-exist.¹¹ The knowledge regarding TB that previous research has constructed needs to be further developed by analyzing the challenges faced by marginalized communities and their personal experiences. It is also vital to understand the cultural differences and barriers, including language, that bolster the lack of awareness. Therefore, a pragmatism philosophy deems appropriate as it accounts for the lived experiences of individuals to co-create knowledge.¹¹ The person-in-environment perspective is the main feature of pragmatism, which suggests that it is not possible to completely understand a person's situation without considering the impacts of their environment.¹¹ When working with the Inuit, it is vital to examine their environment with regard to knowledge transfer regarding TB following the historical disconnection with the Canadian government.

Relationships and Networks

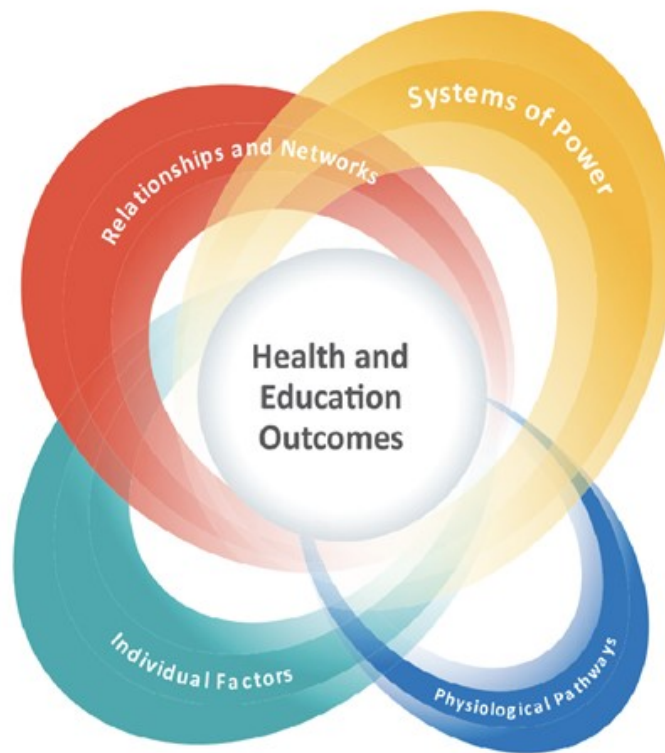
Connections with family, friends, partners, community, school and workplaces that:

- + Promote health equity through support systems that encourage health-promoting choices
- Intensify health inequities through social networks that enable health-harming behaviors

Individual Factors

A person's response to social, economic and environmental conditions that:

- + Promotes health equity through attitudes, skills and behaviors that enable their personal and community's health
- Intensify health inequities through attitudes, skills or behaviors that cause harm to their personal or community's health

**Systems of Power**

Policies, processes, practices that:

- + Promote health equity through fair access to resources and opportunities that enable healthy lives
- Intensify health inequities by allowing unfair social, economic or environmental advantages for some groups over others

Physiological Pathways

Factors that:

- + Promote health equity when a person's physical, cognitive and psychological abilities are maximized
- Intensify health inequities when a person's environment or experiences has impaired their physical, cognitive or psychological functions

Figure 1: ETR's Health Equity Framework

Note. Education, Training and Research (ETR) is a non-profit organization committed to improving health outcomes and advancing health equity. From Peterson A, Charles V, Yeung D, Coyle K. The Health Equity Framework: A science-and justice -based model for public health researchers and practitioners. *Health Promotion Practice.* 2021 Nov;22(6):741-6.

1.2 CONCEPTUAL FRAMEWORK

The conceptual framework represented above shapes the study purpose and research question, as well as explains factors anticipated to influence the disproportionate rates of TB infections among Inuit people. The "Systems of Power" of the ETR framework guide the research question as a disconnect exists between the Canadian government and the Inuit people.¹² Therefore, access to resources, the proposed variable of interest, is to be analyzed. In alignment with the pragmatism philosophical orientation, this proposal acknowledges the subjective experiences of Inuit people relevant to the reasons for high TB incidence among them. Thus, this proposal conceives access to knowledge about TB as an opportunity embedded in social relations through which its meaning would emerge. Here, the "Individual factors" outlined by the ETR framework guide the outcome of interest: how access to knowledge can reduce infection rate while explaining current barriers to knowledge based on their living conditions.¹²

2.1 STUDY SETTING

The number of reported cases per year in Nunavut has increased drastically, from 138 cases in the 2001-2004 period to 464 cases in 2017-2020.¹³ Inuit people constitute more than four-fifths of the total population of Nunavut.¹⁴ With regards to the age structure of the Inuit in Nunavut, more than one-third of the Inuit people are younger than age 15.¹⁴ The territory of Nunavut comprises 28 villages.¹⁵ Of these, this study focuses on Iqaluit, the most densely populated region in Nunavut, with the highest number of people identifying as Inuit.¹⁵ Not only this, but Iqaluit is the largest community in Nunavut, with a population of 7,250.¹⁶

Inuit people in Iqaluit are exposed to the impact of social determinants of health, such as contaminated water supply.¹⁷ Research also indicates that 5.7% of Inuit people here have no English or French knowledge as of 2016.¹⁸ There are, in total, six schools in Iqaluit, and only one post-secondary educational institution, the Nunavut Arctic College.¹⁶ In Iqaluit, there are only four healthcare facilities catering to the needs of the entire population.¹⁹ Furthermore, reports show the lack of broadband coverage in the area exacerbates the

disconnect between the government and the public.²⁰ Within the territory of Iqaluit, and by extension, Nunavut, there remains a shortage of healthcare staff.²¹ The healthcare system relies heavily on short-term healthcare providers, as most individuals trained within Iqaluit prefer to practice in areas outside of Nunavut.²¹ Statistics indicate that more than half of healthcare personnel are on a contract of fewer than 20 days.²¹

3.1 RESEARCH QUESTION

This paper aims to address the following research question: “Does the level of knowledge regarding the pathophysiology of tuberculosis (TB) affect the incidence of the disease among Inuit Indigenous communities in the Territory of Nunavut, Northern Canada?”

- **What:** Education regarding the pathophysiology of tuberculosis:

Understanding the pathophysiology of TB helps raise awareness regarding how the disease is transmitted, what it does to the body, and ways to improve health outcomes. Thus, disease education can be vital in early detection, prevention, and effective treatment measures.

- **Who:** Inuit Indigenous communities:

The Indigenous Peoples of Canada are divided into three groups: First Nations, Inuit, and Métis. These are distinct groups with diverse histories, languages, beliefs, and cultural values. The word “Inuit” translates to “the people” in their native language, Inuktitut.²²

- **Where:** Territory of Nunavut, Northern Canada:

This region covers 2 million square kilometres (km²), with 33,330 residents. Of these, 28,000 (84.0%) identify as Inuit.¹⁶ Given the high incidence of TB in this region, it is essential to investigate factors that siphon attention and energy from prevention measures.

3.2 HYPOTHESIS

The lack of access to knowledge about the etiology of TB and preventative measures are correlated with the disproportion rate of infections among Inuit People.

4.1 STUDY DESIGN AND METHODS

A mixed-method explanatory sequential design would help determine how many individuals are knowledgeable about TB and the number of individuals unaware of TB. The knowledge to be assessed involves what TB is, how it is transmitted, how it affects the body and preventative measures that can reduce its spread. Based on the individuals' level of knowledge, they will

be assigned to the “knowledgeable” and “non-knowledgeable” categories. Following this data collection, a histogram will be used to document the frequency of individuals belonging to the two knowledge categories mentioned above. As the variable of question (level of knowledge) is a categorical variable, a histogram allows for gathering numerical data while reducing errors by the identification of outliers.²³ Furthermore, the number of TB cases for the “level of knowledge” will be quantified. A line graph allows researchers to evaluate trends clearly, and by adding the line graph to the histogram chart, comparisons between the two variables “TB incidence” vs “Level of knowledge” can be made swiftly.²⁴ After using these methods and removing outliers, a regression analysis will be conducted to examine the relationship between our two variables of interest.²⁵ This analysis will allow us to understand if an association between the level of knowledge and the risk of TB infection exists.²⁵

After analysis, the next step is to collect qualitative data to understand why knowledge regarding TB helps reduce the prevalence and current barriers within the Inuit people, which minimize access to knowledge. The qualitative data collection process is driven by quantitative data analysis. By first assessing the number of TB infections relative to knowledge about the disease, we can explore the reasons for the relationship between both variables.

This observational cross-sectional study also aims to pursue a community-based research (CBR) approach as per the chosen community of Inuit people. Given the colonial history, a culturally sensitive approach such as CBR allows a participatory study driven by the Inuit peoples' priorities concerning TB prevalence.²⁶ Therefore, through CBR, the Inuit people of Iqaluit are to be involved in the entire research process: from the proposal to analyzing the results to taking appropriate actions using outcomes.²⁶ By prioritizing the needs and interests of Inuit people, CBR empowers Indigenous communities to pursue a co-learning process regarding our variables of interest.²⁶

Open-ended structured questionnaires and surveys will gather quantitative data on the number of TB cases and level of knowledge among the selected sample of Inuit people in Iqaluit. The questionnaires/surveys will start with an introduction explaining the study purpose, components, and outcomes to ensure transparency and provide them with context. The questionnaires/surveys will include the following questions:

- 1) What is your age?
- 2) What is your place of residence?
- 3) Do you identify as an Inuit person?
Yes
No

- 4) Are you knowledgeable about the causes, mode of transmission, impacts, and preventative measures of tuberculosis (TB)?
 - Yes
 - No
- 5) Are you currently infected with TB, or have you tested positive in the past?
 - Yes, I am currently infected
 - No, but I have been infected in the past
 - No, but I have been infected
 - Don't know
- 6) Do you consent to participate in this study?
 - Yes
 - No

To gather qualitative information, focus group discussions will be conducted with study participants. Here, trained researchers will put the Inuit participants at the center of the discussion and prioritize actively listening to their experiences, beliefs, and perceptions about whether knowledge helps reduce TB prevalence.²⁷ Interviews will also be prioritized to accommodate one-on-one qualitative data collection for individuals preferring this method. Door-to-door visits, as per the aforementioned CBR design, will allow for surveying individuals while building strong relationships and empowering Inuit people to ensure further transparency will occur.²⁷ Moreover, key informant interviews will be conducted both online and in person with partners such as healthcare providers, Iqaluit district officials, and residents that possess first-hand knowledge about the impact of knowledge about TB on its prevalence. These interviews and discussions also aim to identify bottlenecks and ways to improve the delivery of knowledge about TB to the Inuit population.²⁸

Questionnaires and surveys can be distributed to a large number of people at once, which can save time and hence reduce costs.²⁹ The yes/no answer format allows a simple collection of data, which can be easily analyzed. However, the disadvantages of these quantitative data collection methods include Inuit people refusing to participate as the matter is a sensitive topic and requires culturally appropriate methods.³⁰ Also, the responses are superficial and in-depth data cannot be collected, which can lead to different interpretations of questions from the participants and can impact the accuracy of responses.³⁰

For the qualitative methods chosen according to this study design, there are numerous positive and negative aspects. Focus group discussions with Inuit people allow researchers to look beyond facts and numbers and instead learn the meaning behind those facts shaped by participants' experiences.³¹ However, weaknesses of this method include the high costs required to conduct these sessions and the limitation of some Inuit people not being able to voice their concerns

freely.³¹ To counter these weaknesses, interviews with key informants and participants will allow sharing of beliefs one-on-one while fostering trust.³² The interviews provide more open-ended questions to explore the Inuit peoples' behaviours and experiences that shape access to knowledge and its impacts on TB infections.³² However, this method lacks cost-effectiveness and can place emotional stress on the interviewees, which needs to be considered.³²

In addition to the tools above, electronic tablets will be utilized to administer surveys/questionnaires to the sampled Inuit people. Online free-to-use translation software will be used to make the surveys accessible to Inuit people in English and their native language, Inuktitut. To ensure accurate translation, a translator fluent in Inuktitut will be assigned to review the surveys/questionnaires. The responses will be screened to see if the data fits the inclusion/exclusion criteria. To do this, survey/questionnaire responses will be entered into the Statistical Package for the Social Sciences (SPSS) software, which can screen quantitative data according to the research requirements outlined earlier.³³ This software can also conduct statistical analysis such as regression, histogram, and line graph formulation.³³

The location of data collection is Iqaluit, Nunavut. Houses will be randomly selected via the Iqaluit demographic surveillance site, which is free for public use.³⁴ Houses will receive visits from a team of trained researchers, along with a translator fluent in Inuktitut, to ensure accurate relaying of information. Furthermore, Iqaluit City Council representatives will also be involved in making visits as they possess knowledge about the conditions of Inuit people in Iqaluit and can help foster research success by suggesting changes to research protocols. Taima TB is an organization dedicated to reducing the disproportionately high prevalence of TB in Iqaluit.¹³ As our study design calls for a CBR approach, partnering with these organizations can help solidify the research purpose and collaborate with Inuit people effectively. As the Council hosts regular meetings with the residents of Iqaluit, the Inuit people might be more comfortable conversing with council members about the study purpose.¹⁶ Survey data will be stored in encrypted password-protected files to avoid any breach of privacy and maintenance of confidentiality.³⁵ The names of participants will not be included in the questionnaires/surveys to maintain participant anonymity. The expected duration of this study is six months; one month for quantitative data collection, one month for data analysis, two months for qualitative data collection, one month for data analysis, two months for qualitative data collection, and two months for data analysis.

4.2 STUDY POPULATION AND SAMPLING STRATEGY

Our population of interest is Inuit people living in the community of Iqaluit within the territory of Nunavut, Northern Canada. The age group that this research aims to target is 18-40 years. According to Health Canada³⁶, individuals aged 18 can provide consent in Northern Canada and participate in research studies. Furthermore, research has shown that the cognitive abilities of individuals start to decline around age 40.³⁷ Although the decline does not maximize until approximately age 60, this study focuses on the 18-40-year age bracket as relevant to retaining knowledge about infectious diseases and consenting to research participation to avoid potential confounding variables. Furthermore, the private dwellings, identified as 3093 in total, will be sampled from the Iqaluit demographic surveillance site.³⁸

For research sampling, both probability and non-probability methods will be utilized to select a sample from the population of interest. The quantitative data collection methods outlined earlier will use multi-stage sampling, whereas qualitative methods will require purposive maximum variation sampling. The first step for multi-stage sampling would involve dividing the Inuit people in Iqaluit into clusters. These clusters will be developed based on the 3093 private dwellings accessible by roads.³⁸ In stage two, systematic sampling of these dwellings would occur where at least one person between the age of 18-40 resides. Therefore, the final sample left would include Inuit people who consented to participate in this study, which is challenging to predict. For the purposive sampling, we intend to select information-rich cases that would provide insight into how knowledge about TB can influence its prevalence. Inuit people with diverse experiences would be sampled here to allow researchers to look at the interaction between our variables of interest through multiple angles to develop a robust understanding of the phenomenon.³⁹

As per probability sampling, the multi-stage sampling method reduces bias as individuals within our target population of interest are selected randomly.⁴⁰ The purposive sampling method outlined earlier provides benefits such as gathering large amounts of information while pursuing the CBR approach to working cohesively with the Inuit people. However, this method opens points of selection bias as Inuit people with experiences of maximum variation are more likely to be selected over others.

Since the estimated time for the study is a few months, it is critical to make adjustments to ensure participant retention. Firstly, this study aims to reduce the burden on Inuit people and facilitate participants through re-

imbursement. Inuit people will be provided with remote access options if they are unable to attend in-person interviews or focus group discussions.⁴¹ Also, transportation costs would be reimbursed to participants that commute to ensure continued participation.⁴¹ The study progress will be communicated through newsletters and update phone calls, facilitating participants' engagement.⁴¹ Lastly, the personal reflections of Inuit participants will be collected in a meaningful manner to empower them and remind them of the larger cause they are tied to.⁴¹

4.3 INCLUSION CRITERIA

Inclusion criteria for individuals participating in this study are: (i) identifying as an Inuit person living in Iqaluit, (ii) dwelling accessible via road, (iii) belonging to the 18-40 years age bracket, and (iv) providing informed consent. The eligible dwellings will be screened, asked for informed consent, and enrolled in the research study. Therefore, with the help of the Iqaluit City Council and Inuit representatives mentioned earlier, research assistants (RAs) will visit and screen dwellings. Here, the study will be introduced, and the participants' inclusion criteria will be verified. Once informed consent is received, the individual will be recruited to the study and presented with the questionnaire/survey.

5.1 OPERATIONAL AND ETHICAL CONSIDERATIONS

As this study aims to work with Indigenous communities, ensuring compliance with ethical standards is critical. This study will utilize the CCGHR principles as a guideline to adopt ethical and equitable forms of global health research.⁴² Therefore, as part of the "Inclusion" portion of the CCGHR framework, we will ask the important question: "How do our research practices proactively promote the involvement of historically marginalized people?"⁴² By virtue of their social, cultural, and economic identities, this study understands that all these factors intersect to produce health and well-being.⁴²

Furthermore, due to the history of traumatization of Indigenous communities, this study acknowledges supporting Inuit people and the potential re-traumatization of study participants. Instead of solely focusing on the symptoms of inequities related to TB infections, this study will shift its gaze toward structural and social determinants of health, as mentioned in "Responsiveness to causes of inequities" in the CCGHR framework.⁴² Participants and non-participants will be provided support resources such as the Kamatsiaqtut Nunavut Helpline, dedicated to supporting the mental health needs of people in Iqaluit.⁴³

Moving forward, it is vital to consider the expectations of Inuit people while conducting this study. The "Authentic partnering" aspect outlined in the CCGHR is beneficial in engaging Inuit people by employing a series of dialogue workshops aiming to understand their needs and wants.⁴² Inuit people in Iqaluit have lived experiences of the level of access to knowledge about TB and the reasons for the gaps in knowledge. Thus, by authentically partnering, we can foster a strong partnership to help develop a holistic outlook toward the problems and formulate innovative solutions.⁴²

The "Shared benefits" aspect of the CCGHR framework will also be adopted to ensure equitable distribution of benefits for Inuit participants.⁴² Compensation will be used to encourage research participation only and will not be promoted before enrollment into the study to avoid swaying/influencing the consent process. Previous research has shown that financial incentives and compensation methods might unduly influence people to enroll in a study if the payment is high enough that they fail to adequately consider the risks of the research.⁴⁴ All individuals will be compensated, regardless of their continuation in the study, following consultation with Inuit community leaders to determine acceptable compensation methods. While the questionnaires/surveys provide a background of the study before the questions section, a separate consent form will be provided to all Inuit people approached by the research team. Sufficient time will be provided to Inuit people to minimize the possibility of coercion or undue influence. A verbal explanation will also be provided to the approach Inuit people to mitigate areas of confusion while addressing their questions and concerns. To further enhance the informed consent process, graphics and visual aids will be utilized to promote understanding of key concepts among study participants.⁴⁵

Upon ensuring these essential elements, the study protocol will be submitted to the Research Ethics Board (REB), which Health Canada shares with the Public Health Agency of Canada.⁴⁶ This committee reviews all research involving human participants. Upon approval from the ethics board, permission will be obtained from the Regional Inuit Association (RIA) in Nunavut to access and use Inuit Owned Lands in Iqaluit for the purpose of this research.⁴⁷ Simultaneously, a review by the Nunavut Planning Commission (NPC) will be pursued to assess potential impacts and determine if this project conforms to the regional land use plan.⁴⁷ After obtaining approval, an application for a Scientific Research License will be sent to the Nunavut Research Institute, as per the policies regarding conducting research in Nunavut, Canada.⁴⁷

Additionally, it is vital to recognize the potential of power imbalances between marginalized Indigenous

communities and privileged researchers. The last principle of the CCGHR framework, "Humility," is key to ensuring positive power dynamics.⁴² By stepping away from positions of authority over others and pursuing a position of solidarity, curiosity, and openness, we aim to adopt an attitude of learning rather than knowing.⁴² By actively listening to the members of the Inuit community, we can ensure positive participant-researcher partnerships. It is also deemed essential to educate the team about the Inuit ways of living, cultural practices, and beliefs prior to visiting the area. Doing so will allow us to understand how to operate in their community in a culturally competent manner.

CONCLUSION

Given the disproportionate TB infection rates among Inuit people, it is vital to understand the reasons behind this high incidence. This research proposal helps guide one of the potential factors influencing TB rates among Inuit people: Knowledge about TB. By employing a community-based research design, we hope to work towards developing a deeper understanding of the Inuit communities in their contexts.

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