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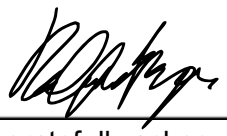
Summary (250 words max single spaced):

Historically, Indigenous communities in Canada have had to rely on a primary healthcare system developed and controlled by the Canadian government. Community action and research has shown the importance and benefit of community designed primary healthcare. These models of primary healthcare do not fit into conventional definitions. Within the context of a the larger Innovation Supporting Transformation in Community Based Primary Healthcare in First Nation and Rural and Remote Communities in Manitoba (iPHIT) study, two Manitoban case studies in an Anishanabee and Dakota community examined the Indigenous development of primary healthcare. Specifically, the case studies sought to describe current primary healthcare issues in each community and determine how communities innovate towards self determined community health goals. Data was gathered through a combination of focus groups, interviews, and phone conversations with the communities. Data was analyzed through grounded theory. Each community described a context of a health resource deplete environment and continuing effects of colonialism. However, both communities demonstrated a strong community identity which was critical to both defining and taking action on their primary healthcare goals within this context. The respectful research relationship that iPHIT has fostered was key for allowing Indigenous self determination in this project.

Student Signature 

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Envisioning Health: Anishanabee and Dakota Case Studies

Introduction

History of Indigenous Self Determination in Health

In the history of Canada, colonial control in health has come in many forms. For the last 200 years, this control has always been framed as benevolent. As Kelm states, "medical men put Native bodies under close study, hypothesized that racial contact was dangerous, and argued that massive medical, cultural, and social intervention was necessary to save the so-called dying race".[1] De Leeuw et. al (2010) trace the history of addiction policy in the Department of Indian Affairs policy in the 19th and 20th century.[2] Indigenous peoples were perceived as deviant by the government when they used substances. This allowed the U.S. and Canadian governments to exercise power and control, such as through prohibiting alcohol on reserve, under the guise of "good intention" or saving these "deviant" populations. These same "benevolent" and destructive practices have continued through the present day. The last residential school closed in 1996 only to be replaced by child protection as a way to remove indigenous children from their communities and culture.[3,4]

The work of Kelm in her book "Colonizing Bodies" adeptly describes this colonial relationship. Kelm illustrates how the Indigenous body was transformed through colonization in an attempt to make it compatible with the white settler.[1] She suggests that the colonial state defined a healthy body as a white settler, and the indigenous body as unhealthy. This echoes Focault's govermentality, that the government creates the citizen.[5] The western neo-liberal governments have defined a citizen as autonomous, directed at self improvement, self regulated, and seeking happiness and healthiness.[6] In the realm of health, any other identity is considered unhealthy.

However, Indigenous communities in Canada have always resisted colonial control of their health and sought self determination. One of many examples of Indigenous resistance to the colonial state in health comes from the Northern Saskatchewan Cree who signed treaty 6. The federal government did not follow a written and oral agreement that would provide healthcare to the treaty populations. In 1935 Cheif George Dreaver of the Mitawasis band successfully sued the federal government as band money had been used to pay for medications since 1919, not federal money as the treaties required. Later, four communities petitioned the Indian Health Service (IHS) to protest the closure of the local hospital. Similar protests occurred elsewhere in Saskatchewan and Alberta.[7] Another example is the use of traditional medicines in some of the IHS hospitals. Although the purpose was to promote western medicine, local nurses would support Indigenous people to practice traditional medicine, even in the hospital. [8] These stories are a few of many that demonstrate Indigenous peoples were always fighting for self determination of their own health against a relentless colonial government.

Research and Self Determination

In the past 20 years, academic literature and institutions have stubbornly started to reflect this resistance, as research is increasingly being led by Indigenous academics and community members. There is currently a wide range of community control in Indigenous health research. The most grounded approach is the Indigenous approach, where community members develop an approach without any outside involvement and may or may not seek collaboration to develop the approach.[9] An example of this is Finke et. al (2004) in which a Zuni community approached other partners and funding on their own to create a palliative care program for there community. With collaboration, they interviewed families in the community to develop a culturally safe

hospice.[10] The world leader in Indigenous developed health programs is the Nuka System of Care in Alaska. REF It is an entire healthcare system based on self determination. It is "customer owned" in that each user has multiple ways to provide feedback and even give ideas for program design. The CEO and most of the employees are indigenous. The board of directors are all indigenous. They have seen many positive health outcomes: over 95% have a family doctor, no behavioral health wait list in a year, same day access, etc.[11] British Colombia is seeing a similar level of self determination with the recent creation of the First Nations Health Authority, the largest scale of indigenous self determinative healthcare in Canada.[12]

Lauricella et. al (2016) describe the lower levels of community control, culturally grounded prevention programs and culturally adapted prevention programs.[13] Studies exist on a continuum between these. Culturally grounded prevention programs use “collaborative approaches” and develop from the “ground up”. Community based participatory research (CBPR), a collaborative research process, is a method of culturally grounded prevention. Participatory action research (PAR), a similar method with a greater focus on social change, is as well. Culturally adapted prevention programs are a lower level of community control. CBPR and PAR can also fall under this category. This is modifying an existing, non-indigenous or non-community based, intervention for the community in the research. It is a top-down approach where the intervention is often chosen on academic merit and brought to the community.[14]

There are a few studies that try to achieve true culturally grounded CBPR but fall short. In a recent literature review, Davison et. al (2015) suggest that global health inequities can be addressed by knowledge to action frameworks that scored highly on a “Health Equity Support” score.[15] One of the highest rated frameworks is from a quantitative and qualitative study with Dene communities of N’Dilo and Dettah in the Northwest Territories and the Inuit communities of Nain and Hopedale in the Labrador on identifying health risks in the environment. The communities and researchers then took part in a knowledge exchange process. The framework is presented in the narrative that the knowledge of health risks in the community was under the ownership of the researchers until it was exchanged back to the community.[16] A more extreme example is the randomized controlled trial of a diabetes prevention program.[17] This used a non-Indigenous designed prevention program and measured outcomes using the BMI scale. Regardless of the fact that the BMI is a crude and inaccurate health indicator, the study is clearly framing the research to be palatable to a biomedical audience by its methods of randomized controlled trial.[18] A true community based prevention would use ideas from the community to create a prevention program that is accessible to and serves all community members.

This narrative of institutional ownership of knowledge is particularly problematic for Indigenous health research. It suggests that communities aren’t creating knowledge and action on their own and that the research is responsible for change, not the community. That research needs to be “evidence based” in order to be “good research”. In fact, Indigenous communities have always understood what they need to be healthy.[19] The researcher is simply there to facilitate acquiring the resources and offering skills needed for action. The case studies that follow demonstrate that communities have an evolving body of knowledge and action that exists apart from but is aided by researchers.

Indigenous Primary Healthcare

Self determination in primary healthcare for Indigenous communities requires the definition of primary healthcare to be fluid. Health Canada defines primary healthcare as “an approach to health and a spectrum of services beyond the traditional health care system [including] all

services that play a part in health, such as income, housing, education, and environment." [20] The World Health Organization states that the ultimate goal of primary health care is better health for all. They identify five key elements to achieving that goal: reducing exclusion and social disparities in health, organizing health services around people's needs and expectations, integrating health into all sectors, pursuing collaborative models of policy dialogue, and increasing stakeholder participation.[21] Haggerty et. al 2007 consulted with Canadian primary healthcare experts to determine operational definitions. Their definitions were relatively broad including community orientation, cultural sensitivity, and advocacy. [22] The First Nations and Inuit Health Brach, the federal funding body for First Nations and Inuit Health in Canada, has developed clinical practice guidelines for nurses in primary care. These guidelines briefly discuss culture in the context of being culturally competent in practice. [23] The components of these definitions are certainly important for Indigenous communities, but not sufficient. It does not suggest the primary care provider should be a part of or involved in the community. It also still defines primary care within a biomedical and individualist framework. As Smith-Morris and Epstein explain, a non-indigenous healthcare provider must have a critical understanding of the biomedical framework and the "cultural capital" it carries in order to improve relationships with Indigenous patients.[24] The researcher must do the same to allow for a self determinative design of primary healthcare in Indigenous communities.

The objectives of this study are to describe current primary healthcare issues in each community and determine how communities innovate towards self determined community health goals.

Study Context

The Innovation Supporting Transformation in Community Based Primary Healthcare in First Nation and Rural and Remote Communities in Manitoba (iPHIT) is a five-year research collaboration between the University of Manitoba, eight First Nation communities in Manitoba and the First Nations Health and Social Secretariat of Manitoba (FNHSSM), established in 2013 by the Assembly of Manitoba Chiefs (AMC), the political organization representing 63 First Nations in Manitoba. The jointly agreed upon objective of the research project is to understand and improve community based primary health care services by: working with First Nation communities that have developed different primary health care delivery models, describe these models of care, identify key ingredients for success from the perspective of First Nations, further develop healthcare models to improve the scope and delivery of community-based primary health care services, and through the course of the five years support the implementation of these models. The communities have control in each stage of the research. They have collaborated with researchers in data collection and analysis in each stage including the case studies. Papers with more detailed description of the data that communities collected and used to inform their innovation are currently in draft, including a paper on the development of the Mental Wellness Framework which will be heavily referenced. The case studies examine the process of the communities using this data in development of primary care related programs.

Methods

The data for the project was collected over two summers by the research student. An Indigenous health researcher accompanied the student on each visit to the communities. The researcher or student took detailed notes of all discussion at these meetings. The student had a previous relationship with each community prior to this project, having done community based work with iPHIT in the past.

With Pinaymootang, the student gathered data through: phone conversations, two interviews with the Health Director, and one focus group with the Health Director, an Elder and mental health worker, and a mental health worker. With Birdtail Dakota, the student gathered data through: phone conversations, one interview, a focus group with 15 community members, and a focus group with 10 community members.

The purpose of the three visits in each community was similar. There were two visits in the first summer and a third in the second summer for each community. The first visit was an initial meeting to share qualitative and quantitative results from data collected in each community about primary health care and mental wellness. With this data in mind, a discussion took place about what project the Health Director would like to pursue with $10,000 the iPHIT project was offering. This initial meeting was also to re-establish a relationship with the Health Director and explain the student's current role. In the first visit, Birdtail Dakota identified the iPHIT Mental Wellness Framework as useful for their process. So for the second visit, a focus group of 15 community members took place to determine how well the Mental Wellness Framework resonated with the community and if it could be used to evaluate their health services. In Pinaymootang, the second visit was further discussion with the Health Director on the specifics of the envisioning project she wanted to pursue. For both communities, the third visit consisted of a focus group to discuss how the envisioning projected was progressing and evolving.

The work of Kelm (1998) and Focault, previously described, formed much of the theoretical basis for analysis.[1,5] Beyond this, the literature on decolonization and self determination informed the analysis. This literature is expansive and a review is given in Appendix A. Particularly influential literature includes Bartlett's (2007) framework for decolonizing research which stresses listening to Indigenous voices without imposing any "non-culturally cognisant terms, concepts, and paradigms".[19] The First Nations Mental Wellness Continuum Framework is a strength based and indigenous designed health framework that offers a comprehensive model for designing health services.[25] The student is a white settler. Therefore, Carlson's (2016) eight principles of an anti-colonial research methodology were important to all phases of the research. [26] These are listed in Table 1.

Table 1.

Carlson's Eight Principles[26]	The research…
Resistance to and subversion of settler colonialism	recognizes the "illegitimacy of the settler presence on the land" and "works towards a new society on Indigenous people's terms".
Relational and epistemic accountability to Indigenous peoples	acknowledges an Indigenous worldview.
Land/place engagement and accountability	works directly or indirectly to return land rights.
Egalitarian, Participatory, and Community Based Methods	follows the expressed need of the community in all parts of the research.
Reciprocity	does not focus on researcher's advancement but on what researcher can give.
Self Determination, Accountability, and Autonomy	seeks to safeguard self determination and autonomy.
Social Location and Reflexivity	explains the social location of the researcher with regards to colonialism.
Wholism	attends to the heart, spirit, body, and mind.

Analysis was ongoing, the student kept a journal throughout both summers to organize thoughts and experiences as congruent with grounded theory. Through phone conversations with the Health Directors, and in the interviews and meetings, the process of innovation was clarified. Finally, all written notes from meetings and interviews were coded in NVIVO software with the themes that had already emerged in discussions with each community. The analysis was then sent to the Health Directors of each community for approval.

To ensure methodological soundness for the study, Tracy's (2010) "Big Tent Criteria" for Qualitative research were used. These criteria are: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical, and meaningful coherence.[27]

Findings

Pinaymootang is an Anishanabee, or Ojibwe, community in the Interlake region of Manitoba on Treaty 2 land 240 km northwest of Winnipeg. The band has 3,276 members with 1,280 living on reserve, 1,996 living elswhere.[28]

Birdtail Dakota is a Dakota community 334km west of Winnipeg. There are 427 band members living on reserve and 475 living elsewhere.[29]

The follow themes and quotes described below are intellectual property of the two communities. As recommended by…

Working in System with Depleted and Poorly Allocated Resources

Many of the barriers faced by the Pinaymootang Health Centre come from the system. "We don't have enough resources to support this". The health centre worries about how to deal with case management. There is only one mental health therapist in the community that works one day a week, which is provided by First Nations and Inuit Health Branch . Physicians only stay 2-3 years as they are international graduates. The community currently does not have a physician at this time due to shortage of physicians within the Interlake Region. Recently, the local hospital emergency room 50km away in Ashern was only open 1-2 days a week. In February 2016, a child died on route because of on-going emergency closures. As well, the hospital has a poor history of communication with the health centre. The community wonders "How is the region going to handle the flood evacuees" that will return soon?

Birdtail Dakota are focusing on mental health but are lacking in resources. "We go through lots, we are in constant crisis. We are the crisis management team." "Nurses here need to be able to do what Northern nurses can." "We are becoming isolated." "We need to have expanded scope of practice". "We need our own treatment centres, so that people can learn to deal with things in their own community. "There are a lot of people using their drugs. They get them from doctors."

Resources could also be better allocated by the system, based on what each community defines as important for their health. In Birdtail Dakota, a discussion specifically about their own definition of health occurred. "It is not about clinics or hospitals." A nurse at the health centre talked about the environment of the health centre, "As soon as there is trust, it is more welcoming… The entrance should be welcoming... There should be more place for gathering than just the waiting room." In other discussions about health, "Horses are an important part of the Dakota people", we need "Language immersion from K to grade 5". The Chief of Birdtail

Dakota emphasized that the community is seeking self funding for the traditional practices that they want to undertake rather than relying on the government because "[the] government put in lots of money to destroy our culture than they do restoring it."

Pinaymootang also sees health as much more than just clinics or hospitals. As will become clear in the next sections, Pinaymootang also has a strong connection with their history that is important to their health. Relationships and research were emphasized. Pinaymootang had once been in mediation process with its local hospital to improve relationship building with the community, specifically the need to be recognized as part of the health care system. The Health Director partakes in the Interlake Eastern Regional Health Authority's cultural competency working group in hopes of providing awareness of cultural differences. "The hospital needs an [Indigenous] patient navigator." The community has also done research, advocacy, and created a report entitled "Honouring Jordan's Principle". In partnership with McGill University this report is based on obstacles and challenges families faced in accessing services and is available on Pinaymootang Health Website.[30] This work that is outside the funding from the First Nation and Inuit Health Board (FNIHB).

Historical and Community Identity

In Pinaymootang, much of the discussion was around the 2011 Lake Manitoba flood when the provincial government decided to divert water from Lake Manitoba to save cottages, agricultural area, and communities. Over 4,000 First Nations people were displaced from 8 communities in the region, one of which was Pinaymootang. [31,32,33] This is not just recent history, an elder said that when the church and the Canadian National Railroad first came to their community, they took the higher ground and forced the community to the low grounds. Pinaymootang has a strong history and relationship with 3 neighboring communities all of which were "decimated" by the flood: Lake St. Martin, Dauphin River, and Little Saskatchewan.

It was shared by an evacuee that, "Even 5 miles from my old home, 6 and a half years later it doesn't feel like home." The flood has caused trauma for all 4 communities. People are still displaced by the flood and the health centre tries its best to support people from the neighboring communities. The health director shared that there had been many deaths, and more recent a youth who was killed recently. Now, the communities are in the process to move back. There will be many issues to come, particularly in mental health and well-being. Many have faced, "broken homes, young people joining gangs, and family connections lost". "It's like looking at the horizon and seeing the storm clouds coming".

With Pinaymootang Health working with improving its internal mental health service, they will hopefully be a support to the returning communities. The community church is already carrying some of the after effects of the relocated communities. They have been hosting other communities on their burials. Although there is increased demand on already depleted resources, the community members of Pinaymootang expressed pride that it is a part of their culture and identity to provide assistance and supports as it considers the communities as family. They always have and will continue to provide support.

In discussing how to adapt the iPHIT Wellness Framework to their community, Birdtail Dakota demonstrated a sense of who they are that has been getting stronger Much of the discussion was around the strength and definition of their traditional culture. The group had a discussion about whether to use the word elder or knowledge keeper. "We are not knowledge keepers, we pass it on…share it". In the second summer, the conversation about whether to use the word elder continued. "Some of our young people know more than our elders now. Some old people

don't know the traditions. This was a prophecy that the young people would bring back the language, bring back our strength, the seventh generation. How can we distinguish this? Young elders?". In the first of the focus groups, the Chief strongly opposed the common misconception that "Indians are dying, their language and their culture is lost" because to him, looking at the Mental Wellness Framework, "we [Birdtail] have not lost anything, we just need to strengthen it." The Chief also stated that the model demonstrated to him how important it was to get language in the school. Finally, "The degree of balance and connection makes the medicine wheel work".

Christianity is also a strong part of their identity, 60% of the community identifies as Christian. Some of the community thought the inclusion of traditional medicines in the model may exclude some people. It was difficult to reconcile these complex and seemingly conflicting spiritual beliefs into the framework and discussions continued across the summers. "You developed this but you did not ask me". In the second summer, it was determined that traditional medicines don't have to mean a certain spirituality. "Spirituality can be anything, it is your own beliefs, the model should not be connected to any one spirituality." Birdtail Dakota is both a strong Christian community and a strong traditional community.

Innovation

Innovation in Mental Wellness

In the first summer, the Pinaymootang Health Director stated they want staff to retrain in mental health and wellness so "we are able to spring into action in the future". The community needs a "crisis intervention working group". The end goal would be "self sufficiency in mental health". "We want to understand the needs of the community and develop a mental health plan. We want to know how the flood has affected us. We need a strategy of crisis intervention" that includes "CFS, the band, and the RHA". We need a "long term plan" that "strategizes for continuity".

By the second summer, the community had taken many innovative steps based on their history and, partly inspired by the data they collected from iPHIT. "You gave us that push to begin the project." In the year between, they organized a 3 day First Nations Mental Health First Aid Workshop and invited communities to partake. 20-25 people were trained. They also hosted a community Mental Health conference in October. A directory of available mental health resources within the region was distributed. Now the community and its stakeholders are preparing for a flood repatriation planning meeting for the return of the communities that were flooded out and how to better prepare for this process. The Health Director has indicated her intentions to work and collaborate with communities to develop a crisis response team that will best meet their needs.

Overall, Pinaymootang stated "There is pride of accomplishment as it relates to the Jordan's Principle work mentioned earlier, many communities have scheduled time to visit the community in regards to their Jordan's Principle Program. It's for the people". In reference to the work preparing for the return of the communities, "We are giving like our ancestors, and the creator gives back to us."

Innovation in Access

The Birdtail Dakota Health Centre felt there are parts of the community that they don't reach. They want to understand why they are not accessing these populations. "How do we get them to our health centre?" They want to evaluate their health program based on this, with patient

empowerment in mind. “How can we empower all of Birdtail Dakota to participate in the health centre?”. It is difficult to balance different health goals for all members of the community. For example, as the community seeks ways of engaging young people, they said care must be taken not to impose traditional practices on them, or to “shame and embarrass” them but rather to share the knowledge with them. They decided to use the iPHIT Mental Wellness Framework to evaluate their health services with the hope of improving access as it resonated with them as a holistic model of health.

In the second summer, some ideas to improve access were shared. They expressed the need to bring the youth in more, “comfortable then, comfortable later”. The health centre needs to build relationships with people in the community. Some ideas had already been implemented. There is now language immersion in the school starting in September. There is improved connection and communication in the community. “We now have the circle of care and prevention team, in both of these all programs get together and most importantly leadership is at the table.” “When we are all together, we stop blaming people and find solutions.”

Discussion

Pinaymootang and Birdtail Dakota struggle for resources while trying to do the best for their communities. Both communities generally discussed a lack of mental healthcare and primary health care. They also discussed how resources are particularly lacking for projects that go beyond the scope of basic primary health. These are unique projects that connect with the community’s identities.

According to Warren and Warren’s (1977) community typology framework, as one of the four community characteristics a strong community identity is particularly enhanced by a shared history.[34] Both communities exhibited shared history and values, Pinaymootang as a support to the surrounding communities and Birdtail Dakota has a strengthening traditional culture. Both communities also have relationships with the land as part of shared history. Birdtail Dakota exhibited this through talking about the importance of horses and traditional culture. Pinaymootang exhibited this by the effect the flood has had on their community. With these strong identities, their primary healthcare goals were community driven and unique.

However, the identity of the communities continue to be negatively impacted by a colonial environment. Birdtail Dakota feels the government has never respected their traditional practices. Pinaymootang and their surrounding communities are dealing with the traumatic effects of relocation from flooding, a continuation of a history of relocation by the church and railroad. The relationship between identity and health is then hindered by colonial policies and politics. Currently, both communities rely on funding and follow the funding structure of FNIHB. Neither community feels this funding is sufficient or allocated correctly. So they must rely on surrounding communities and cities for healthcare. In Pinaymootang, the surrounding First Nations communities have had to rely on Pinaymootang for some health services. As well, Pinaymootang must rely on services from the nearby non-Indigenous community’s hospital, with which it has a strained relationship. Birdtail Dakota is an hour from the closest hospital. At this distance, Birdtail Dakota’s nurse need expanded scope of practice. Both of the communities have greater understandings of what their communities need to be healthy than the current funding structure allows.

Instead of relying on the insufficient colonial structure in place, the communities are creating their own primary health care models that do address their unique health issues. Analogous to this is Sunday et. al.’s (2001) study in an Anishanabee population living with diabetes. A few of

the study participants discussed how diabetes was “bringing the community closer” and caused a renewed interest in tradition and healing in communities. Like Pinaymootang and Birdtail Dakota, the strong community support and the traditional history of the communities have helped them cope and grow in the context of their community’s health issues.[35]

The strong sense of identity in these two communities creates health action through empowerment. Pinaymootang expressed empowerment and pride by supporting surrounding communities, “We are giving like our ancestors, and the creator gives back to us”. They are taking control of their own health and the power to do so comes from their history. Birdtail Dakota has already implemented language immersion in the school, an initiative partly inspired by a discussion with the community about their traditional identity. There is extensive literature on how effective community empowerment is for creating social change.[36] At the individual level as well, it has been shown how important Indigenous Identity is to health and healing.[37,38] As Lavallee (2010) states based on the seven generations Anishanabee teachings, “If you do not know where you have come from you will not know where you are going”.[37]

Finally, community identity worked alongside self determination to allow the communities to innovate. In this project, a colonial and non-self determinative approach would mean breaking any one of Carlson’s eight principles of anti-colonial research methodology for settlers.[26] These are described in Table 1 and have fully been realized by the student.

In research, self determination is contingent upon a fully engaged process of community based research and strong research relationships.[19,26] If a community takes part from development as they have in iPHIT, to data collection, to data analysis, and finally implementation, they are able to consistently build capacity and envision for their community. The trust that forms between researchers and community in a strong research relationship allows the community to be in control at each stage of the research. The innovation that both communities illustrated in their respective projects could only come from the community.

This study demonstrates how important culture, identity, and history of communities is for policy. If a non-community member is creating policy, they must engage in full partnership otherwise the policy is doomed to fail.[19,39] The Four Worlds Institute of Human and Community Development has developed a set of fourteen social determinants of health (SDOH) for First Nations populations that have a more “holistic and inclusive” approach to public health than the commonly used Public Health Agency of Canada’s SDOH. These include community solidarity and social support, spirituality and a sense of purpose, cultural integrity and identity, and healthy eco-system and a sustainable relationship between humans and the natural world.[40] This suggests that primary healthcare institutions must expand their scope of practice in Indigenous communities to accommodate their cultural, spiritual, traditional, and community contexts.

This paper validates an extensive body of literature on the importance of relationships in Indigenous research (Appendix A). However, there are only a few studies that have the structure of relationships as in the iPHIT project. In iPHIT, an Indigenous organization with extensive communities ties, FNHSSM, acts as the research manager and liaison between the university researchers and community. Boffa et. al (2011) shares a lot with iPHIT in terms of the engagement and the structure. It is a multi-community, multi-organizational project. It has university and community involvement, but like iPHIT there is an indigenous based body that manages and controls the project.[41] Ellis et. al (2003) is a broad-based coalition, which included American Indian community members, policy makers, and public health professionals.[42] This study adds to a small body of research that demonstrates this structure as effective for forming respectful research relationships.

The limitations and strengths of this study were identified using Tracy's "Big Tent Criteria".[27] The first three criteria, worthy topic, rich rigor, and sincerity have been met. For rigor, enough data has been collected to support each claim made in the paper and the method is transparent. Credibility, the fourth criteria, could not be fully met because of time constraints. It is suggested that triangulation or crystallization be performed in the data analysis, in other words that multiple analytic methods be used to ensure validity of the data. This was not possible due to the time constraints on the student. However, multivocality, another component of credibility, was achieved as the health directors reviewed and validated the student's analysis. The final four criteria have been satisfied: resonance, significant contribution, ethical, and meaningful coherence. For resonance, the study is comprehensible to the target audience. As well, the findings are transferable to other community based studies in the process of implementing research or envisioning community goals.

In conclusion, this study has demonstrated how communities innovate their own primary healthcare around their identities in a context of self determination. The findings call upon primary healthcare institutions to expand the scope of funding in Indigenous communities. Finally, it demonstrates the effectiveness of the iPHIT structure of research in creating respectful research relationships.

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Appendix A

Collaboration with Indigenous Populations in Health Research

Collaboration with Indigenous populations in health research is receiving increasing attention among academic and research institutions internationally. Historically, these institutions employed methodologies that were intended to serve the purposes of the researcher. Models were utilized in which knowledge was extracted and used with or without any direct benefit to Indigenous populations. In some cases, the intent was specific benefit for the colonial state. This is now commonly referred to as "helicopter research".[1,2] Current government policies, such as parts of the Australian government's "Closing the Gap" initiative, continue to neglect Indigenous engagement.[3,4] On the other hand, collaboration with community has shown to result in better health outcomes as well as the building of respectful relationships.[5,6] In a review of community participation by Preston et.al, 14 of the 37 studies reviewed showed positive health outcomes associated with community participation.[7] In order for institutions to effectively collaborate and engage indigenous communities in health research, community participation can no longer be viewed through biomedical, positivist frameworks. Dominant paradigms must be challenged and decolonized in order to hear community voices.[8-10]

Recent work in Australia, Canada, and the United States has attempted to reconcile this practice of colonial health research.[11] This is based on an understanding that with community collaboration, immediate positive outcomes in physiological health indicators are not always the goal. An exchange of knowledge and practice can also be a valuable outcome of community based research.[12] An opinion piece on an intervention in the Northern Territory (Northern Territory Emergency Response) describes how a lack of community collaboration has negative effects, but an environment of collaboration allows for an acknowledgement of and learning from mistakes. The two successful components of the intervention, child health checks and primary care funding were a result of good community engagement. Other components of the intervention were acknowledged as racist and colonial but the researchers learned to further engage community to critique and change their methods.[13] Another CBPR study gave first aid training to community members in a remote Northern Ontario community. They conducted focus groups and a sharing circle as part of the training. The paper concluded that although mortality may not be affected, empowering the community with this knowledge and the community feeling they are part of a response to injury may help in dealing with the burden of trauma in critical health emergencies.[14]

Several examples abound of how collaborating and sharing knowledge can give voice to the diversity of community views. This is useful practice in health service implementation and health improvement. Gibson et. al illustrate this in a study with the Nishnawbe Aski Nation in Northwestern Ontario on the applicability of a telemental health service.[15] Other studies have examined community needs and views and service implementation in palliative care on reserve in Northwestern Ontario[16] and Saskatchewan[17], an ACCHS in an urban centre[18-20], design of an H1N109 prevention plan with Aboriginals in the remote Tamworth and Inverell of New South Wales,[21] training of young Aboriginals in Australia in research methods in a project to determine explore young people's perspectives on resilience in relation to blood borne viruses and sexually transmissible infections,[22] uptake of the impending HIV vaccine in urban Ontario Aboriginals,[23] and others.[24-34]

Relationship building

Relationship building is essential for community collaboration, which often requires ample time and energy from researchers.[35-38] Christopher et. al made recommendations for relationship building from

their 11 year project with Crow Indians in Montana intended to increase cervical cancer screening. They make 5 recommendations for initial building of trust: acknowledge personal and institutional histories, understand the historical context of the research, be present in the community and listen to community members, acknowledge the expertise of all partners, and be upfront about expectations and intentions.[39]

Two-eyed seeing was a method of integrating Indigenous and Western ways of knowing for an integrative science program at Cape Breton University.[40] It has been suggested as a lens through which to build relationships in healthcare as well.[41] Further examples of relationship building in the literature include those between researchers and Saskatchewan Aboriginal Grandmothers,[42] researchers and disenfranchised Koorie men in mental health,[43,44] and between a university and community organizations in Saskatchewan.[45]

While some progress has been made, relationships between Indigenous and non-Indigenous peoples remains fragmented in some places. In Gapuwiyak, Northern Territory, a community development project was undertaken to reduce low birth weights in community in collaboration with a community women's group. However, the health professionals were unwilling to foster meaningful collaborations with the community with equal input in process and outcomes. This was evident through the selection of the issue to be addressed, the definition of the problem and solution, and the implementation of the community action strategy.[46] Often the community is relegated to the margins which results in poor community participation in the project or service offered.[47] The goal should always be to ensure that researchers are not engaging communities in the same patronizing and manipulating ways but that they are paving way for quality relationships leading to collaborative participation.[48]

Successful relationship building across the literature can be generalized to a commitment of time from both parties, involvement of indigenous peoples in planning, decision-making, and implementation,[49,50] values of mutual respect and accountability,[51] a willingness to learn from each other and from wrongdoings,[13] and an acknowledgement of individual agency along with social determinants of health.[52,53]

Involving Communities Meaningfully

Resistance by indigenous communities to engage in research collaboration with academia is based on well-founded fear. Past experiences in collaborative studies that have been criticized for the use of “poor methodology” marked by an unwillingness to invest required time and energy to build relationships, difficulty in developing a-priori hypotheses, difficulty maintaining funding as funding is usually capped at five years and here being a sense of abandonment when funding runs out, journal requirements for short articles not regarding indigenous methods for reporting, funders of large experimental design studies not wanting to fund studies with community collaboration due to the misunderstanding of indigenous ethical principles, community values and goals not aligning with traditionally sound methods, and budgetary restrictions in grants that may not include community engagement and capacity building activities.[54] The result is that there are few community based research publications with description of whole collaborations including relationship building, implementation, through to outcomes.[54] Samples are often small,[42,47] recruited through biased methods,[16, 21, 55] or have low external validity.[34] Follow-up without significant attrition is rare.[44] There are also varying levels of community participation, with some studies claiming a collaborative method but lacking in many respects.[33, 56-59] Kearns differentiates between two types of participation, democratic and consumerist.[59] Kearns suggests that democratic participation should most fundamentally involve

> "…engagement with not just the collective of users or consumers, but with the community which supports and encircles a service."

Publications often falter when they are focused only on the direct consumers as their collaborators rather than "citizens" or "community members".[59]

As the field of Indigenous community collaboration grows however, methods of evaluation and standardization of methodologies have evolved. The WHO has developed a toolbox that has 15 techniques and methods categorized under 5 stages of the action planning model: assessing needs and assets, agreeing on a vision, generating ideas and plan for action, enabling action, monitoring and evaluation.[60] This toolbox, recommends using models such as the ladder to depict community participation in a collaborative project. Recommendations such as this can be critiqued for being

institutionally focused, promoting hierarchy, appealing to the academic mind and lacking in effort to employ tools that would encourage understanding from a community perspective. Jolley and Lawless et al. (2008) suggest that a tool for evaluation of community partnership should not focus on outcomes solely but also the success of the partnership.[61]

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