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The Path of Creating Co-Researchers in the File Hills Qu'Appelle Tribal Council

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Abstract
Currently, there is a need for implementing ethical, culturally safe practices when engaging in research with Indigenous communities. As a result, best practices in culturally-safe Indigenous health research have been created to mitigate the existing barriers in health and health research stemming from Canada's colonial history. This article includes a brief examination of those best practices, including community-based participatory research, OCAP® principles, knowledge translation, and positioning communities as co-researchers. Furthermore, it provides an overview of a community-based research project that examines community members' knowledge of and experiences with dementia. The central themes that emerged during this project are also discussed, reaffirming the need for a culturally safe dementia research model in Indigenous communities.

Keywords
Indigenous community-based research, dementia, Indigenous community-based research methods, ethically engaged research

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Indigenous communities in Canada, despite an aggressive colonial history, including policies and practices that have impacted their health and well-being, remain resilient. When engaging Indigenous communities to examine the existing health disparities, it becomes critical to use a community-based participatory research model that situates communities as co-researchers and implements Ownership, Control, Access, and Possession (OCAP®), knowledge transmission, and reciprocal learning principles. This is important because it enhances the relevance and value of the research by including community members. It grounds the research in the real-life experiences of those being researched and creates the potential for ongoing research relationships between researchers and communities. This prevents harmful top-down approaches that recognize academics as experts and objectify participants. It focuses on locally-identified priorities, rather than issues put forth by academics (Westfall, VanVorst, Main, & Herbert, 2006). Priorities include using combined education and experience to breakdown stereotypes, acknowledging and resisting colonial practices and beliefs, implementing cultural safety, and learning from past research mistakes. Once communities are engaged as "researchers," they are better positioned for self-determination and can begin to take steps to implement necessary health interventions based on community-identified needs. This article explores the best practices for creating a culturally safe ethical engagement model that can be used when exploring dementia and other related health conditions in First Nations communities. Specifically, we examine the ways in which several First Nations communities in the File Hills Qu'Appelle Tribal Council (FHQTC) region can access dementia information and support services by engaging community members as a vital part of the research process in order to determine how programming and supports should be delivered. Furthermore, we provide a detailed account of the ways in which these communities were ethically engaged through the implementation of a community-based culturally safe research model, which can be used in the future to explore other health topics both in this region and beyond.

Using Non-Indigenous Health Research Methodologies

When establishing best practices in ethically engaging Indigenous communities, it is beneficial to examine previous community-based projects, particularly those that failed to engage communities respectfully. Several studies, both from the past and very recently, highlight our colonial history and the opportunistic and exploitative ways in which researchers have interacted with Indigenous Peoples. This includes the exploitation of Indigenous Peoples in Canada, often at the hands of health or science researchers for the purposes of performing experiments that would be deemed unsafe and unethical to perform on members of the non-Indigenous population. Evidence was recently discovered which verified that nutritional studies were performed during the 1940s on Indigenous children who attended Indian Residential Schools, which were church-run industrial schools funded by the federal government. These nutritional studies examined the links between an inadequate food supply and the negative health outcomes of long-term starvation on the body, such as anemia, significant bone and muscle loss, and brain development (Mosby, 2013). The sub-standard living conditions and subsequent malnourishment of these children was considered acceptable—it was seen as an unexpected opportunity to conduct otherwise grossly unethical medical experiments on children (Mosby, 2013). This research demonstrates the Canadian government's direct role in this exploitation and exposes the neglect that Indigenous children suffered daily (Mosby, 2013).

More recently in the Canadian Arctic, environmental organizations and researchers have been attempting to engage Inuit communities in discussions and actions in order to address the impacts of climate change. However, these organizations have not used community-based practices and, as a result, problematic initiatives have been implemented. For example, when Ford et al. (2015) began their research, they chose to only consult with local Inuit leaders, instead of the longer and more involved process of building a research project with the community. The researchers outlined the research questions and how they intended to do their work without consultation with or input from the community. Furthermore, the project lacked long-term funding in order to continue the work of reducing the impacts of climate change once the study was discontinued (Ford et al., 2015). Eventually, when the project dissolved, the community members who had been employed by the project felt frustration and a loss of power, which increased the vulnerability of this already marginalized population (Ford et al., 2015). Furthermore, many community members reported that the research methods used, including in-depth interviews, felt intrusive. They were often viewed as a distraction because of the frequency and number of interviews, and because other personal issues within the participants' lives had to take precedence. Others were uncomfortable with the questions asked, as researchers often forced participants to speak about the future world, a concept that does not align with Inuit spiritual beliefs (Ford et al., 2015). In this case, and in many other examples of researchers working in Canada's Indigenous communities, the research was not complementary to or primarily concerned with the community's overall well-being.

These studies are not isolated examples; they point to a larger, systemic concern within Indigenous health research. There is often a narrow focus within mainstream health research in Indigenous communities that leads to a disproportionate number of studies relating to topics such as diabetes and little to no health information on other issues such as dementia (Jacklin, Walker, & Shawande, 2013). Examining past research studies also reveals the historical underpinnings of exploitive health research and ensures similar mistakes are not perpetuated (Walters et al., 2009). Stereotypes associated with poverty and social problems, which often serve as the foundation for misguided and potentially unethical research projects, must be broken down (Fine, Weis, Weseen, & Wong, 2003). These stereotypes may be broken down through Indigenous culturally based education programming focusing on health promotion and knowledge specific to Indigenous people for all health researchers and health care workers (Macaulay, 2009; Smylie et al., 2009). These education models must extend to all fields and sectors within health care and should include information about the negative impacts of colonization and the Indian Residential School system, as well as the role of the social determinants of health. Furthermore, there should be a sharp focus on improving education and employment opportunities for Indigenous Peoples, particularly in the health and health research sectors (Macaulay, 2009). We need to advocate for many culturally relevant changes in Indigenous health research, such as the inclusion of Indigenous-run organizations, the implementation of Indigenous knowledge and methodologies, the movement towards positive patient care, and the formation of reciprocal relationships between Indigenous communities and the health care system (Macaulay, 2009).

Community-based participatory research (CBPR) principles are integral to fostering these research relationships (Walters et al., 2009). As one Knowledge Keeper stated, "If we have been researched to death . . . maybe it's time we started researching ourselves back to life" (Castellano, 2004, p. 98). This statement acknowledges the complexities that have resulted from non-community-based research within Indigenous communities and populations. On the one hand, many Indigenous Peoples believe that they have been over-researched because they have experienced few benefits from the research and have rarely been agents of control or change in research. On the other hand, despite these perceptions, there are still areas of health research that go unexamined in Indigenous communities. The ethics-based fundamentals of CBPR are autonomy, justice, and beneficence (meaning that research should have beneficial results for the community). CBPR is a widely used research methodology, as it ensures that people will be invested in the project from the beginning and more likely to use the findings to create positive change in their communities (Smith & Blumenthal, 2012).

Dementia in Indigenous Communities in Canada: A Brief Overview

There is limited data available regarding the prevalence and incidence of dementia in First Nations[1] communities in Canada. However, it is viewed as an emerging health issue for all Indigenous Peoples as the rates for dementia are set to double among the general Canadian population in the next 30 years and, therefore, will also rise within the Indigenous population (Jacklin et al., 2013). In fact, many First Nations communities are already reporting similar trends in their communities. This has been attributed to several factors including population aging, higher reporting due to increased awareness of dementia, disproportionately higher rates of associated risk factors (including diabetes, high blood pressure, obesity, and smoking); impacts of the social determinants of health such as socioeconomic status, employment, and access to health care services; and co-morbid illnesses (including diabetes and depression; Jacklin et al., 2013).

Dementia has gone underreported, misdiagnosed, and unmanaged for decades in many Indigenous communities as a result of a lack of access to health care facilities and services, education, screening, and medications. Furthermore, some Indigenous Peoples view it is a natural part of the aging process, as opposed to a medical problem. This view is shared by many Canadian seniors, which can lead to a failure to access necessary and appropriate health care services (Cammer, 2006). For example, when talking to aging Indigenous women, Lanting, Crossley, Morgan, and Cammer (2011) discovered that many seniors viewed dementia as part of the circle of life, where aging and its effects on the brain and body are seen as a transition before passing to the spirit world. This viewpoint may run counter to the information provided by doctors and health care professionals who view dementia as a disease, which can lead to misunderstandings or patient distrust. Furthermore, many First Nations living on reserve report obstacles to accessing dementia information and health care interventions as a result of language barriers, transportation issues, culturally unsafe care, and a general fear and distrust of the health care system, particularly when the care is provided in larger urban centers (Cammer, 2006; Forbes, Blake, Thiessen, & Finkelstein, 2013).

Researching Dementia in the File Hills Qu'Appelle Tribal Council Region

The File Hills Qu'Appelle Tribal Council (FHQTC) is an organization that represents 11 distinct Indigenous nations from five linguistic and cultural groups —Cree, Saulteaux, Nakoda, Lakota, and Dakota—and covers a vast section of land in the Treaty Four Territory in southern Saskatchewan. The FHQTC is a service delivery organization with a governing body comprised of First Nations' leadership from the member First Nations of FHQTC. Included in this service delivery model is the commitment

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[1] In Canada, there are three main groups of Indigenous Peoples: First Nations, Métis, and Inuit.

to providing information and access to services and supports for a wide range of health issues. The organization provides services for health issues that are familiar and unfamiliar, including ever-present and emerging concerns. Dementia represents a cluster of unfamiliar diseases and conditions. The prevalence rates are also on the rise in the FHQTC area. This project had two goals: (a) to provide community members with access to dementia information and supports through existing community-based health initiatives, and (b) to gather input and information about community members' experiences through focus group discussions.

Establishing & Implementing the Principles of Ethical Engagement in the File Hills Qu'Appelle Tribal Council Region

Ensuring cultural safety. Recent research into successful dementia interventions that yielded positive impacts within First Nations communities often focuses on a *sharing dementia care knowledge* model. This model centres on developing trusting relationships; accessing, adapting, and contextualizing the information provided to fit the perspectives of community members; and applying the information in a respectful manner (Forbes et al., 2013). Culture plays a significant role in implementing this sharing dementia care knowledge model. The success of dementia programming and services, particularly when looking at Indigenous perceptions of normal aging and dementia, relies heavily on the inclusion of the community's cultural needs (Cammer, 2006; Forbes et al., 2013). For medical interventions to be successful, they must ensure cultural safety. This includes incorporating the voices of community Knowledge Keepers (previously referred to in some communities as Elders). Communities are dynamic and fluid and their knowledge and perspectives on dementia have changed over the past century, which means that the causes attributed to dementia and the community's responses to those affected are not static.

Throughout the research project, cultural safety was the touchstone that grounded our research goals and initiatives. Cultural safety is a broad and complex concept developed originally in the 1980s by Indigenous Māori nurses in New Zealand. Cultural safety analyzes power imbalances in health care and the larger society. It addresses institutional discrimination, colonization, and relationships with colonizers as they apply to health care, and it requires an examination of how personal biases, authority, privilege, and territorial history can influence the relationships between health care providers and Indigenous Peoples. Cultural safety relies on both the self-reflection of researchers and the incorporation of critical reflection into the research project through the questions, data analysis, and reporting. A key element of culturally safe practice is establishing trust with the patients or research participants, and culturally safe care empowers people because it reinforces the idea that each person's knowledge and reality is valid and valuable (Brascoupe & Waters, 2009).

Cultural safety is a significant aspect of ethical engagement with Indigenous communities (Health Council of Canada, 2012). When people have negative experiences with the health care system, they are less likely to seek assistance in the future, which can have serious implications for the health of the individual and community (Health Council of Canada, 2012). Studies have found that when cultural safety is present and Indigenous patients feel safe and validated by health care practitioners, their engagement with the health care system increases and negative health outcomes decrease (Health Council of Canada, 2012). Cultural safety can be attained through creating a comfortable environment for patients. If Indigenous people feel respected and heard, and interactions are collective and mutual, Indigenous community members will begin to feel more comfortable. In addition, when Indigenous community members are also the health care providers and non-Indigenous providers take part in the learning process, great strides toward cultural safety can be achieved (Health Council of Canada, 2012).

Cultural safety is possible when health care providers acknowledge their own cultural background, perspectives, and personal biases and how these impact patient care, particularly, when the patient has a cultural background that differs from that of the practitioner. This model hinges on respect for cultural diversity, reciprocity, a redistribution of power, and constant reflection from all parties (Health Council of Canada, 2012). Cultural safety and competency are central to the Canadian health care system, since equity within health care services is lacking and, as a result, Indigenous people are facing a significant deficit that directly affects their health and well-being (Health Council of Canada, 2012). Researchers have a responsibility to the communities they work with to "be a champion for cultural safety and provide culturally safe care to First Nations, Inuit, and Métis People" (Health Council of Canada, 2012, p. 64). This includes ensuring that all Indigenous patients receive high levels of patient care with a focus on empathy, dignity, and respect (Health Council of Canada, 2012). When cultural safety and competency are practiced throughout the entirety of the research project, ethical engagement with Indigenous communities is more likely to be achieved.

In order to foster a culturally safe health care system, researchers also need to partake in culturally safe education, implementation, and reflection processes. While engaging in research that works with individuals or communities who are often ignored or silenced, it is important that researchers constantly reflect and question their work and their personal perspective in relation to the participants (Fine et al., 2003). When, in an attempt to remain neutral or dispassionate, we fail to reflect as researchers, we are also failing to act socially responsible and, instead, allowing harmful research practices to continue under the guise of researcher "objectivity" (Fine et al., 2003, p. 203). Cultural safety calls into question this type of objectivity and demands that researchers present their own biases, assumptions, privileges, and power in order to ensure greater integrity and validity of the research outcomes. Moreover, it is important to revisit past projects and learn from mistakes in order to establish best practices in ethically engaging with Indigenous communities.

The research team for this project was comprised of researchers from an Indigenous community-based research lab (Morning Star Lodge) operating in Regina, Saskatchewan, and community partners from the File Hills Qu'Appelle Tribal Council including community representatives, researchers, and local Knowledge Keepers. Throughout our research process, we implemented a culturally safe care model by focusing on researcher self-reflection, project reflection and discussions, and a redistribution of power during data collection and analysis. The researchers met prior to beginning the project to discuss any personal or professional biases they have, as well as to evaluate their own cultural background, knowledge, and understandings. This conversation also presented a wonderful opportunity for the researchers representing the FHQTC to lead powerful discussions on how to best engage the community and how to ensure the research was grounded in the local Treaty Four Indigenous protocols and processes. In addition, the research team focused on creating trusting and respectful relationships with their co-researchers, the FHQTC, and research participants. For example, during the focus groups, the researchers chose to audio record rather than take notes to ensure the participants felt they were engaging in an active conversation rather than being "observed" as test subjects. The participants were also able to exercise agency and autonomy over the direction of the conversation, instead of being interviewed or surveyed through a set number of stock questions, which had to be answered in a certain manner. They were able to tell their own stories, offer feedback and support to their fellow community members, and create an opportunity for an on-going dialogue regarding dementia in their communities.

Creating community-based participatory partnerships. In order to avoid intentional or accidental exploitive research towards Indigenous communities, it is important to cultivate community-based partnerships alongside and directed by Indigenous communities (Walters et al., 2009). Studies have shown that it is beneficial to begin research with community engagement information sessions regarding the research project, whereby community members gather with researchers to highlight issues and discuss possible research pathways (Smylie et al., 2009). This can also be a catalyst for recruiting community researchers and participants. In order to facilitate ethically and culturally safe community meetings, there are several key elements that must be present, including face-to-face interactions, storytelling, and Knowledge Keepers holding roles in decision making. Knowledge Keeper, instead of Elder, is the preferred term used by many within Treaty Four Territory. Todd Cappo, the community health program coordinator at FHQTC Health Services, explained this role as: "One that understand[s] our ceremonies, the value of our culture, and our medicines." Knowledge Keepers provide a link between the past and present, creating a sense of cultural continuity despite ever-changing community health needs and responses (Hulko et al., 2010).

Engaging with the FHQTC area and its 11 diverse nations requires a keen understanding of the collective history these First Nations share as well as the distinctive, unique history each of the communities possess. In addition, engagement must align with FHQTC values and follow their plans for building strong communities. In the case of this dementia research project, engagement started with exploratory discussions between the health directors of the FHQTC and the co-researchers. Once the directors saw the value in and endorsed the project, they followed the appropriate community-based research protocols and sought approval through the Executive Council and Chiefs. After all of the members of the FHQTC were engaged, they created a community research assistant (CRA) position. The members then recruited the Community Research Advisory Committee (CRAC), which is a group comprised of Knowledge Keepers, frontline health workers, community members, and health directors who drive and guide the research. This project also sought to ensure both community researchers (who were referred to as knowledge brokers) and Knowledge Keepers were an integral part of the research team. In order for ethical engagement to work effectively in research, both Knowledge Keepers and invested community members require designated roles and responsibilities and equal opportunity to design and direct the project.

Community members were utilized in many ways. For example, the CRA was the primary contact for the CRAC and for individual community members. This role allowed the community to employ one of their own as a researcher and, in this role, ensure the project was conducted in an ethical and culturally safe way. In addition, the CRA ensured community engagement by attending events such as Treaty Days, health fairs, education sessions, and wellness clinics, as requested by the communities. The CRA further facilitated the focus groups in order to engage knowledge brokers and open up a community dialogue about dementia, which was previously absent.

Community members were also engaged through the creation of the CRAC. This committee was comprised of a diverse group of community Knowledge Keepers, frontline health workers and directors, and community members from all of the FHQTC communities. The Committee was open to whoever had a passion for dementia research and was either a member of one of the eleven communities or was a front-line health care professional working in these communities. The initial members were recruited during the FHQTC health directors meeting following a recommendation from a health director. Recruiting for the CRAC was an on-going process. The CRAC met with the CRA and research team members on a bi-monthly basis. The CRAC played an integral role throughout the research project. They provided insight into working within the community and helped to drive the research by drafting and finalizing the research questions. They reviewed and approved research materials and were able to determine what could and would be done as part of the research project. Currently, there are 12 CRAC members, each with their own strengths and offering a unique perspective related to the project.

Our focus on creating trusting and authentic relationships with community members also enabled the opportunity for long-term research partnerships with the FHQTC and community members. Furthermore, by using a CBPR research model, we were able to ensure higher rates of participation than is typical when researchers attempt to engage with community members without the inclusion or direction of the FHQTC. Creating this community-based participatory partnership with the FHQTC is a step in the direction of self-determination for this tribal council and many others. The FHQTC has created an opportunity to spearhead further research on this and other emerging health issues, without waiting for issues to be identified by outside medical agencies or the federal government (for example, during census enumeration). The FHQTC maintains the control over how dementia is researched in the community, how the findings are presented, and how to best implement and advocate for care and supports.

Creating dementia programs that are culturally safe and appropriate for First Nation communities and their membership requires work and continuous reciprocal learning. It is beneficial for all of those involved because it is rooted in the values and cultural understandings that First Nation Peoples know. It is important to note that a successful program that works well in one particular First Nation community does not automatically mean that same type of success will be replicated in a different First Nation community. Furthermore, past studies have revealed the importance of community leadership and self-determination regarding community programs and services in relation to Indigenous-specific health information education (Smylie et al., 2009).

Ownership, Control, Access & Possession (OCAP®). Recently there has been an increase in the funding of community-based research projects in Canada (Gibson & Lund, 2012). When initiating research projects that include both non-community- and community-based researchers, it is important that power and ownership are shared equally. One example of how this can be done successfully is data sharing agreements, which help to establish effective partnerships and highlight the changing research world in which non-community researchers become research facilitators and community partners become researchers (Gibson & Lund, 2012). A number of different research terms have emerged for this type of partnership, including community-based participatory research and action research. Regardless of the term used, the concept is the same; it is a respectful partnership that honours the autonomy of the community being researched (Gibson & Lund, 2012).

Indigenous Peoples in Canada strive towards self-determination, and the principles of Ownership, Control, Access, and Possession (OCAP®) can help achieve it, particularly with research focusing on and taking place within Indigenous communities (Schnarch, 2004). OCAP® identifies who owns the information gathered, who has control in the research, who can access and use the information and data gathered, and, lastly, who will be in possession of the data in the short- and long-term. It is important to note that OCAP® principles are not static; it is not a one-size-fits all process. OCAP® is a starting point for Indigenous communities to achieve self-determination throughout the research process within their communities by providing the opportunity for communities to make these decisions during the research process (Schnarch, 2004).

Historically, health research has demonstrated a disregard for Indigenous communities, their beliefs, and their needs. Harmful research practices involving Indigenous Peoples in Canada include a lack of consultation, communities and individuals being over researched, research undertaken without the proper consent, and participants being pressured during data collection. An absence of ethical engagement within research has resulted in Indigenous Peoples being resistant to research in their communities (Schnarch, 2004). Researchers need to understand and support the goals of the Indigenous communities that they work with and collaboratively build healthy relationships. There is a need to focus on community involvement, participation, respect, and consultation, as well as capacity development. This style of research challenges research norms and allows researchers to question what constitutes proper research, and the abilities and biases of existing gatekeepers (e.g., academic peer review committees, funding agencies) who evaluate Indigenous research (Schnarch, 2004). It ensures that researchers will reflect the research findings back to the communities to ensure that what comes out of these projects aligns with the communities' intentions and goals (Schnarch, 2004).

Creating ethical engagement is a dynamic process that must be rooted in the needs and strengths of the community. Fortunately, a relationship of trust and honour was already built between the FHQTC and the principal researchers. Creating the research agreement was a collaborative effort that ensured a community-based participatory partnership, instead of the traditional researcher and research subject dynamic that has often dictated previous research projects within the FHQTC. As such, both research partners are considered co-researchers and co-authors of the project. Moreover, the collaborative effort ensured OCAP® principles were followed and data collection and sharing arrangements were implemented. All consent forms, data, and research materials would be stored at a mutually agreed upon local research lab; however, the data would remain the property of the FHQTC. Furthermore, the research agreement also states that "all data (electronic or paper) will be given to FHQTC at the end of the project for storage or destruction." In addition, there were specific protocols and procedures outlining how the participants and the community would be protected throughout data collection, analysis, storage, and dissemination (e.g., research materials, surveys, datasets, paper records, electronic records, visual aids). It was determined that the FHQTC would be considered the primary decision-maker regarding future data sharing and authorship. Outlining the specific data collection, ownership, and storage details was essential in guaranteeing that a reciprocal relationship existed and provided a solid foundation to move the research project forward.

Knowledge brokers: Community members as researchers. When conducting community-based research, it is also important to facilitate room for dialogue between researchers and Indigenous communities, creating a safe space for commonalities and differences to be addressed (Canadian Institute of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], & Social Sciences and Humanities Research Council of Canada [SSHRC], 2014). The core commonality between Indigenous communities and non-community-based researchers is reciprocity. Reciprocity is necessary for ethically engaged research in order to maintain relationships and strengthen mutual trust. Trust is built when community researchers fulfil their roles as "knowledge brokers" who have the ability to transform knowledge from the research project in ways that benefit the communities involved in the study (Fornssler, McKenzie, Dell, Laliberte, & Hopkins, 2014, p. 180). An integral part of the knowledge-broker process is this ongoing dialogue with the communities and the recognition of the socioeconomic barriers and structural determinants specifically unique to Indigenous communities (Ford et al., 2015).

Having community partners that are passionate about the research avoids research fatigue while simultaneously building trust with the non-community researchers and the communities (Gibson & Lund, 2012). Indigenous community-based research acknowledges the value of profound local knowledge and experience, as it is fundamental to have community members actively involved in the creation of the research questions that the community will engage with and benefit most from (Gibson & Lund, 2012). In addition, there is a need to define roles within the research partnerships. Ideally, minimal turnover among both non-community and community researchers is best for the project; this also ensures the language used to define the research and the research partnership is accessible to community members. Often times, when research partnerships change, and new non-community members join already existing research projects, there is a shift in the research language used, which may or may not align with that used by the community members. Decreasing the chances of turnover by ensuring both non-community and community members are equally invested and committed lessens the likelihood of confusion or misunderstandings to occur during the research process (Gibson & Lund, 2012).

Each meeting began with presenting tobacco to a Knowledge Keeper for opening prayers to ensure proper protocol and to fully ground the project in the cultural practices and traditions necessary for the project to continue in a good way. Beginning each meeting in this way also established that the Knowledge Keepers were essential members of the research team who offered valuable insights and grounded the project in the spiritual, cultural, and traditional ways of the community. This also symbolizes the project's commitment to preserve the integrity and value the input of these First Nations communities. It is a significant step towards creating a culturally safe model of dementia health research in the tribal council area because it demonstrates the value placed on Knowledge Keepers as leaders, teachers, healers, and protectors of the people.

Knowledge translation & reciprocal learning. The ultimate goal of ethically based Indigenous research is to gather and preserve Indigenous knowledge using a community-driven approach. Research has created a space for mutual learning between institutional-based researchers and community members, despite possible resistance from non-community researchers in admitting that they can learn from community members (Smith & Blumenthal, 2012). Traditional Western research is done *to* communities, rather than *with* communities. Research based on Indigenous ethics, in contrast, is collective and collaborative, creating a space where reciprocal learning happens (Smith & Blumenthal, 2012). By utilizing community-based participatory research practices, these projects enable capacity building, respect the ethics of the community, and empower community members through employment and engagement. These reciprocal acts leave a lasting positive impact (Smith & Blumenthal, 2012).

Indigenous knowledge translation (KT) is an emerging concept defined as the process(es) through which knowledge is transformed into strategic action (Estey, Kmetic & Reading, 2008). Indigenous KT is rarely written about; yet, it is critical to consider within the parameters of Indigenous research because of the disproportionate burden of ill health experienced by Indigenous populations compared to the general population of Canada (Estey et al., 2008). KT provides an alternative model to research that problematically puts forward invalid pan-Indigenous experiences and presents the Indigenous health model and the Western health model as two mutually exclusive perspectives (Ermine, 2007; Estey et al., 2008). In order to bridge the divide between these models, academic researchers must work with Indigenous communities in a more complex way so that both parties can engage in a safe discussion and feel validated (Estey et al., 2008).

Finally, Indigenous ways of knowing accept everyone's knowledge, as it is only through acknowledging multiple perspectives that the world can be understood in its entirety (Martin, 2012). It is here that the concept of reciprocal learning emerges, which is a way of understanding the world from both Western and Indigenous perspectives (Martin, 2012). Reciprocal learning recognizes the need to respect the diversity of all knowledge presented in research by merging Indigenous knowledge and contemporary Western academic research systems and beliefs. It is particularly beneficial within health research, as it can be used to properly address major health issues that Indigenous populations face (Martin, 2012). Furthermore, in addition to focusing on KT and reciprocal learning, researchers must ensure that their end result or final goal is to leave the communities with attainable, effective action-based measures, which then strengthen the communities as a whole (Estey et al., 2008).

After recruiting the CRAC, we began engaging the community by offering educational sessions on dementia in cooperation with the Alzheimer's Society of Saskatchewan. In the spring, we hosted two educational sessions in Fort Qu'Appelle. All who attended were provided with a meal, and travel honorariums were given to show appreciation for those who travelled from out of town. The CRA went to the local health centres to recruit for these sessions and, as a result, both of the sessions were well-received and attended. Word travelled to the community of Peepeekisis, and the members requested the CRA come out to provide an educational session for their community during one of their monthly wellness clinics. The Alzheimer's Society of Saskatchewan gave the CRA the necessary training on presenting and offered their continued support for the project in any capacity. The project began by taking dementia information to the people, then allowing other communities to identify the sessions they needed. We then provided the opportunity for these other communities to determine when, where, and in what capacity the research team should come and provide information. This demonstrates cultural safety and community members as co-researchers in action.

The CRAC and FHQTC health directors suggested that attending the FHQTC Treaty Days in several communities would be an opportunity to engage the community and provide information on dementia services and supports available to First Nations people in the FHQTC area. Subsequently, project representatives attended Treaty Days in six communities: Piapot, Muscowpetung, Nekaneet, Pasqua, Carry the Kettle, and the File Hills (Okanese, Starblanket, and Little Black Bear First Nations). Two other communities in the FHQTC region—Standing Buffalo and Wood Mountain—did not enter into treaties and, therefore, do not host treaty days. In order to engage with these two communities, the research group found other opportunities during relevant community events. For example, they attended Wood Mountain's Health Fair during their annual summer gathering, for which many members travel back home to the community. To engage with Standing Buffalo, the project partnered with the Regional Health Survey and the School of Tobacco health programs to provide information about the programs during a lunch-and-learn. A lunch-and-learn is an informal information sharing strategy where community members are invited to learn about a particular project or idea, while also being able to share food in a socially comfortable setting.

This education outreach initiative accomplished three things: It allowed the community to become familiarized and have trust in the research assistants and vice versa; it helped recruit potential focus group and interview participants; and it exposed a need for greater awareness and education about dementia in Indigenous communities. These initial findings led the CRA to offer educational sessions to any community in the tribal council that requested them. For example, the All Nations Healing Hospital, an entity of FHQTC, contacted the team requesting to hear about dementia at their annual Women's Wellness Day. The feedback from the presentation was very positive and many people identified the presentation as the one they enjoyed the most at the conference.

Following these outreach initiatives, focus groups and interviews were facilitated in the communities by the CRA. These focus groups allowed community members to come together and share their knowledge, learn from one another, and access further information and supports regarding dementia. The groups were comprised of a dynamic group of individuals who were either dealing with dementia themselves or helping care for a loved one who was dealing with dementia or a related health condition. These focus groups moved away from traditional methodological practices where community members are interviewed in isolation and/or where a certain set of research questions are asked in a group context. Here, each group determined how dementia was addressed and some spoke of their own circumstances, while others shared broader thoughts or unrelated health concerns. During this time, the CRA facilitated, but did not direct community members in their sharing. This allowed community members to become knowledge brokers and co-researchers capable of shifting and focusing the research lens and scope.

Lessons Learned: Creating a Culturally Safe Model for Dementia Research

Best practices in ethically engaging communities are deeply rooted in culturally safe models of health research. This project was able to implement a culturally safe model for dementia research by focusing on four central tenets: (a) relationships between researchers and community members are essential; (b) the environment within which the research project takes place is important; (c) Knowledge Keepers play a vital role in dementia health research in First Nations communities; and (d) the reflection of the research team must be continuous. Relationships have been identified as critically important in previous dementia studies with First Nations communities. In this case, the FHQTC health directors and research team created a long-term reciprocal relationship. They then turned to the community Knowledge Keepers before engaging the community. These relationships focused on trust, bi-directional learning, personal reflection, and further addressed previous issues and concerns with dementia research in the communities. This very important relationship building piece occurred before the project was implemented, allowing the FHQTC and community Knowledge Keepers opportunities to design and determine the research questions, processes, and protocols used. For example, proper community protocols were followed when the health directors sought approval from the Executive Council and Chiefs to begin the research project, and they were continued through the hiring of the

CRA and formation of the CRAC. These protocols helped to solidify strong working relationships and connected the outside researchers to the FHQTC, the Knowledge Keepers, and the community.

For many First Nations community members, dementia and other hidden health issues are not discussed openly with health care providers outside of the community, and/or health care providers are not aware of the need for these services. Dementia is still viewed as both a natural part of the aging process and a condition with limited treatment and management options. While this may not necessarily be the case, it is important to value these insights and, instead of providing services and supports that challenge these ideas, to meet the community members where they are at and work with the knowledge they have of their bodies, their beliefs, and their decisions. Adopting this culturally safe CBPR research model, which was congruent with local Indigenous norms and research methodologies, allowed us to explore the impacts of dementia on the communities, while simultaneously implementing strategies to assist people. For example, in addition to collecting valuable information from participants about dementia, there were opportunities during the health fairs to provide dementia information and referrals to health services. As well, the focus groups acted as a place of information sharing among participants, while also providing a great sense of comfort for others who felt isolated because of this condition.

Many of the findings emerging from the focus groups highlighted the difference between Indigenous ways of framing dementia as a natural part of the aging process and the traditional Western medical view of the disease model. For this reason, our researchers were careful not to imply that the participants should reframe or shift their perspective to align with mainstream medicine. However, we were able to convey that the two approaches, although different, still focus on health, establishing a good quality of life, and providing medical or healing interventions when applicable. While many participants did not wish to be thought of as sick or diseased, but rather as moving through a natural life cycle, they still acknowledged that pain and suffering for both themselves and their families was not desirable or necessary. The researchers, therefore, did not attempt to change or alter the participants' traditional beliefs or experiences; instead, participants were able to keep their beliefs while still accessing modern medical care and supports.

The environment where research occurs matters. Along with validating the unique knowledge of the community members, it was also important to value the community itself and its geographical location. Previous dementia research discovered that First Nations people are more likely to engage in dementia education and support services when the information and service delivery is brought directly to them. In this case, the research team brought the research directly to the communities during their education outreach and the subsequent focus groups. They acknowledged that this outreach should be done during already existing community events such as Treaty Days, health fairs, and other wellness events. Lack of transportation, unease navigating urban medical clinics, and non-Indigenous health care practitioners showing a lack of empathy and understanding prevents many First Nations seniors from accessing dementia services offered in nearby urban centres. It became essential, then, to tie service delivery to community events and have dementia education and awareness become a part of the already existing community conversation on health and well-being.

Knowledge Keepers are also an essential part of this project. Culturally safe projects foster trust and value the insights and opinions of community members. As there is frequently mistrust of outside health researchers and practitioners amongst community members, it was important to consult Knowledge

Keepers to create trusting relationships. It was also clear from previous dementia health research that, in order to create a *sharing dementia care knowledge* model, Knowledge Keepers must be more than simply consulted or considered after a project is designed. In this case, the FHQTC Knowledge Keepers were a part of designing the research questions, overseeing the project, and grounding it in cultural and spiritual traditions by performing necessary ceremonies to ensure cultural safety.

Finally, the continuous reflection of the research team is of the utmost importance. This includes acknowledging the possible personal biases, privileges, and authority of the researchers prior to engaging with the community. The team met regularly with the FHQTC health directors, the Executive Council and Chiefs, Knowledge Keepers, and community members prior to designing the research questions. This provided an opportunity to ensure all members agreed about the biases they might be bringing to the project and how to respectfully engage with community members. Each and every researcher was also tasked with self-reflection and bringing any issues, concerns, and questions they had to the team meetings. These open and honest meetings created the space needed for personal and group reflection and prevented harmful practices or culturally unsafe interactions from occurring once the initiatives were rolled out into the communities. They created a climate and culture that was proactive and based on healthy communication and reciprocal learning.

Using a culturally safe, CBPR research model created an opportunity to "research back to life" the needs and concerns of the participants in the FHQTC. Traditional Western approaches have typically silenced issues such as dementia and other neurological conditions in First Nations communities because they do not have a prevalence rate high enough to warrant research initiatives or intervention. Unlike well-known health issues such as substance abuse and diabetes, dementia often goes undetected and untreated, even when individuals do seek health care assistance. This research project created a space for the FHQTC to determine the needs of its community members and, before creating any programming or initiatives, allowed the community members to identify their concerns, beliefs, and health care needs. Unlike a Western medical approach (which would have identified the issue of increasing dementia rates through gathering data, implemented a program based on those findings, and, finally, surveyed participants when evaluating the success of the intervention), our research model connected us with the community members prior to even establishing the research questions.

Conclusion

It is clear when working with Indigenous communities that there is a need for implementing ethical, culturally safe research models. Canada's colonial history and practices continue to influence the ways in which health research is both framed and implemented today, resulting in devastating intergenerational impacts and health disparities for Indigenous people. Despite these barriers in health and health research, best practices in culturally safe health research are possible, and several working models exist in communities today. At the heart of these best practices is learning from past research mistakes, acknowledging and resisting colonial practices and beliefs, and implementing community-based participatory research principles. This model utilizes OCAP©®, knowledge transmission, and reciprocal learning, and positions communities as co-researchers, thus shifting destructive power dynamics that situate non-community members and researchers as the sole experts.

The tribal council and the associated research team demonstrated the promise and possibilities of using an Indigenous community-based participatory action research model to ethically engage with community members. This project centred on providing information and education on dementia to First Nations community members in the tribal council region and, in turn, sought the feedback and gained valuable insights from community members. We ensured cultural safety and ethical engagement by first approaching communities through meetings, then creating community advisory councils, which included Knowledge Keepers, and established community members as researchers. The project itself, along with the research protocols and practices used, demonstrate that ethical, action-based research is effective in restoring and healing the once fractured relationships between communities, health organizations, and health researchers.

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