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Development of a Collaborative Research Framework: An Example of a Study Conducted By and With a First Nations, Inuit and Métis Women's Community and Its Research Partners

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Abstract

The lack of research that effectively addresses inequity within Canadian society is an indicator of the failure of mainstream research approaches and practices to engage with all populations. This paper describes the development of a collaborative framework defined by a First Nations, Inuit and Métis women's community members and its research partners as ethical, useful and relevant. There were two essential phases in negotiating a collaborative framework for a community-research partnership and the steps in a community-based participatory approach described: 1) establish guiding features of a collaborative framework by forming an advisory group, developing ethical guidance, agreeing upon underlying theoretical concepts for the research study; and 2) engage in research actions that support co-creation of knowledge throughout study processes. The case study example used to illustrate the collaborative framework was conducted by and with a First Nations, Inuit and Métis women's community and research partners to culturally adapt a health decision-making strategy. A community-based participatory research approach fostered engagement among community and research participants and directed community-research collaboration. The collaborative framework structured ongoing negotiations within the community-research partnership to ensure that ethical obligations to research participants and the broader community were met and goals of the study achieved.

Keywords

Research; collaborative; community; First Nations, Inuit, Métis; decision making; equity; ethics

Introduction

Policy and decision makers need evidence to inform and/or influence systems-level decisions that affect inequities (Bosch-Capblanch et al., 2012). Health inequity is defined as avoidable and unfair differences in health within and between populations (Whitehead, 1992). Health equity is achieved when there are equitable opportunities to achieve health (Sen, 2002). In Canada, inequity is evident for First Nations, Inuit and Métis (FNIM)[1] groups who have historical, legal, cultural and socioeconomic circumstances that set them apart from general populations due to unique challenges and that are founded in colonization. For example, health indicators in Canada show that FNIM groups have the highest rates of health burdens (such as poverty, substance abuse, and poor health status), in relation to other general populations living in Canada (Health Council of Canada, 2005; Reading & Wien, 2009), and this poor health status is particularly notable for FNIM women (Brennan, 2009; Canadian Institutes of Health Information, 2003; Halseth, 2013). Health and socioeconomic indicators demonstrate that in Canada, FNIM women have the highest rates of poor health status, poverty and substance abuse (Canadian Institutes of Health Information, 2003; Halseth, 2013). In urban settings FNIM women face extreme socio-economic marginalization in relation to FNIM men and non-FNIM general populations and are over-represented among those who experience homelessness (Native Women's Association Canada,

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[1] The term *Aboriginal Peoples* refers to the Indigenous inhabitants (First Peoples) of Canada when describing in a general manner the *First Nations, Inuit*, and *Métis* people, without regard to their separate origins and identities. For this reason, we choose to use the term "FNIM" to convey the distinct origins and identities of First Nations, Inuit and Métis groups.

2007) or housing in need of major repairs (Browne, McDonald, & Elliot, 2009; Native Women's Association Canada, 2007; Statistics Canada, 2011). As FNIM women contribute to the strength and continuity of FNIM societies (National Collaborating Centre for Aboriginal Health, 2012), the health burdens of this group have significant implications for community structure and resilience.

The lack of research about how to effectively address inequity within Canadian society is an indicator of the failure of mainstream (that is, Western-informed) research approaches and practices to engage all populations and, in particular, those for which research evidence to inform policy change is most needed. As contextual factors structure and contain social relations as well as physical resources, consideration of the interplay of space and place is critical for understanding the health of populations, and in particular, the mutually reinforcing relationships between people and place (Cummins, Curtis, Diez-Roux, & Macintyre, 2007). The need for research that is decolonizing and focused on 'Indigenous geographies' (Shaw, Herman, & Dobbs, 2006, p. 267) has been identified and is evident in the poor health of FNIM populations.

In Canada, researchers typically look to and follow Western-informed study approaches and practices; this extends to the use of standard research ethics guidance that in Canada is provided through the Tri-Council Policy Statement (TCPS) (Panel on Research Ethics (PRE), 2015). Standard research ethics guidance may, however, neither adequately reflect views on ethical conduct that resonate with community members nor create opportunities to advance research agendas that are valued by communities and their members. Ethics guidance must be applied with consideration of the unique context and needs of those participating in the research processes (PRE, 2015). If we aim to achieve health equity and to address the contextual and individual factors that affect health equity, it is imperative that research protocols and practices be framed in ways that are defined as ethical, useful and relevant by participating community members themselves. Further hindering the development of evidence concerning the effectiveness of interventions for community members are the under-acknowledged differences between Western-informed research traditions and the beliefs, values and cultural perspectives of FNIM communities. This has led to the undermining and/or marginalization of community members as full and active participants in research (Ermine, Sinclair, & Jeffery, 2004).

The purpose of this paper is to use a case study approach to describe a process of negotiating a collaborative framework defined by community members and their research partners as ethical, useful and relevant. We describe in detail the steps in a study that used a community-based participatory approach, postcolonial theory, and ethical processes that met the unique community-research needs. The study was conducted by and with an FNIM community to culturally adapt a health decision-making strategy for FNIM women.

An approach to research with FNIM community

FNIM people in Canada are a growing population and continue to contend with health inequities, with underlying causal issues that are rooted in colonial practices that permeate social, political and historical systems (Reading & Wien, 2009). The delivery of Western-informed healthcare services to FNIM people is often ineffective or damaging, and is an important factor in many FNIM peoples' negative health experiences (Browne, 2005; Browne & Fiske, 2001; Jull, Giles, Minwaashin Lodge, Boyer, & Stacey, 2015; Kelm, 1998; National Aboriginal Health Organization, 2006). Successful strategies for addressing the health challenges faced by FNIM populations will require our health systems to address the structural and historical factors that affect health interventions and engage health systems users as partners in their care.

Shared decision making is defined as a process that promotes collaboration between healthcare providers and clients who are making choices about their healthcare (Elwyn, Edwards, Kinnersley, & Grol, 2000). There is evidence that shared decision making can improve outcomes for people who experience inequity. For example, in a review of the literature evaluating the impact of shared decision making interventions, people who experience inequities due to lower socioeconomic status showed significantly improved outcomes (i.e., increased knowledge, informed choice, participation in decision making, decision self-efficacy, preferences for collaborative decision making, reduced decisional conflict) in relation to those with higher socioeconomic standing (Durand et al., 2014). Shared decision making has also been found to improve health decision making processes for clients (O'Connor & Jacobsen, 2007) and to increase their satisfaction in health systems (Kiesler & Auerbach, 2006). Nevertheless, there is limited research about the potential efficacy of shared decision making interventions for improving the healthcare of FNIM people (Jull et al., 2013), and a need for evidence about these interventions that can be defined as useful by health systems users.

A community-based participatory research (CBPR) approach was used to meaningfully engage community members of a women's FNIM group, Minwaashin Lodge located in Ottawa, Ontario, Canada, in a research project focused on developing a shared decision making intervention. A key tenet of CBPR is the attempt to establish a power structure whereby the researcher's "expertise" is decentred and community members' knowledge is held as legitimate and expert in nature (Fletcher, 2002). Typically, CBPR involves the use of an advisory committee, which is made up of community members and a multi-disciplinary team of researchers drawn from universities or other institutions (Dubois et al., 2011). A memorandum of understanding or a research agreement may also be used to define rules of engagement for the research (Plough & Olafson, 1994). While formal measures such as advisory committees, memoranda of understanding and research agreements serve to set overall guiding principles for the process of CBPR, they do not capture the day-to-day negotiations that occur to ensure that all members of the research partnership view the research as meeting the ethical obligations both to the research participants as well as to the broader community it is meant to serve. Additionally, these formal measures are not particularly informative on the mechanics of the routine negotiations and dialogues that are essential to successful CBPR studies. This paper describes the steps taken with a CBPR approach to ensure ethical and mutually-agreed upon processes to co-create knowledge and that results in the establishment and conduct of the research process: a) engagement: find common ground, b) form an advisory group, c) commit to guiding principles, d) adopt a theoretical approach, and e) conduct research.

Engagement: Find common ground

The principal investigator (PI) (Jull) engaged in a series of meetings within FNIM communities and academic settings to identify potential collaborators who shared concerns about equity in health systems. Through these consultations, Minwaashin Lodge was identified as a potential research partner with an interest in exploring health equity issues and how shared decision making could better support their clients. Minwaashin Lodge is an organization dedicated to providing intervention services and programs to First Nations, Inuit and Métis women, children and youth who are survivors of family violence and/or the residential school system, including the intergenerational impacts of violence against FNIM people in Canada. The PI also met researchers who had knowledge of shared decision making (Stacey), health and CBPR (Giles) and who understood the issues faced by FNIM women within health and social systems (Giles, Boyer, Minwaashin Lodge). The PI fulfilled a series of volunteer and invited opportunities to build early and critical relationships and trust with Minwaashin Lodge and links within the community-research relationship. The process enabled the PI to understand important features of relationships with the community. This early engagement was essential to laying the foundation for implementation of ethical principles, as it enabled the PI to find common ground within the collaboration and build shared understandings on issues of mutual concern; namely, the health inequity experienced by FNIM women in Western-informed health systems. Early engagement assisted the research collaborators with scoping the objectives of the study and establishing the parameters of the community-research relationship (Box 1).

Box 1: Engagement: Finding common ground

Approach	**Example: Tasks completed by primary researcher (PI)**
1. Define communities/individual stakeholders and their common concerns/interests	Engaged in meetings with individuals in communities and academic settings to identify shared concerns about equity in health systems
2. Identify a potential community research partner with knowledge and concerns about the issues	Identified a potential community research partner with an interest and knowledge of exploring health equity issues and ways to improve support for community members in health systems
3. Identify other individuals who hold relevant knowledge	Met researchers who collectively had knowledge of topics relevant to the particular research study (e.g. decision making, health and CBPR, and understandings of the issues faced by FNIM women within health and social systems); began relationship building between community research partner leaders and researchers
4. Build trust within and between community-research stakeholders	Fulfilled a series of volunteer and invited opportunities to build relationships and trust with the community and strengthen links within the community-research partner relationship. Honoured traditions, preferences of community partners during this process (e.g. honour Elders, sharing meals). Facilitated inclusive, respectful relationships among community-research partner stakeholders
5. Define parameters of the community-research relationship among stakeholders, find common ground	Facilitated participation and mutual-knowledge building: Community-research partner collaboration scoped the objectives of the study, established the parameters of the community-research partner relationship and built shared understandings on issues of mutual concern (e.g. the health inequity experienced by FNIM women in Western-informed health systems)

Form an advisory group

The PI identified and invited members from the FNIM and academic research community to act as an advisory group for a research study focused on shared decision making, health equity, and FNIM women. The advisory group members (Boyer, Giles, Stacey, and four Minwaashin Lodge senior staff) agreed upon the research study's overarching goals: 1) Conduct research that is defined by and with the FNIM community as important and ethical; 2) Develop pragmatic research outcomes for users (FNIM people/communities; healthcare providers, academics, decision/policy makers); 3) Use shared decision making to address health systems equity issues.

In addition, the advisory group, which consisted of FNIM and non-FNIM members, created opportunities to explore the tension between FNIM approaches to knowledge acquisition and Western research approaches, which facilitated mutual learning to build evidence in ways that were identified by advisory group members as ethical and of relevance to FNIM and non-FNIM people. For example, the advisory group members actively debated and collaborated on the development of the ethical framework to guide the study, which consisted of both Western informed and Indigenous principles (Jull, Stacey, Giles, Boyer, & Minwaashin Lodge, 2012). The advisory group also maintained a pragmatic focus on meeting the needs of the Minwaashin Lodge community in ways that were directed by, respectful and inclusive of Minwaashin Lodge members.

Commit to guiding principles

The advisory group defined ethical guidance to support the community-research collaboration. While all health research in Canada is guided by ethical standards in the TCPS, the researchers also identified ethical principles developed by the First Nations Centre in National Aboriginal Health Organization (First Nations Centre, 2007) as being particularly relevant. These principles govern Ownership, Control, Access, and Possession (OCAP) of research, stipulate ethics in research, and protect the inherent right of self-determination by FNIM communities within research studies (Plough & Olafson, 1994). Being applicable to all stages of the research process, OCAP principles were designed and implemented throughout the development of the study protocol and implemented and evaluated during the entire conduct of the study. The successful integration of OCAP required meaningful engagement and reciprocity between the researchers and Minwaashin Lodge, and included many initiatives focused on ownership and inclusivity. One such initiative involved ensuring that data collection, storage and use met the approval of Minwaashin Lodge senior staff. As well, representatives for the Minwaashin Lodge community were included and acknowledged as full research members by the University of Ottawa Research Ethics Board, which positioned Minwaashin Lodge as having full access to all data and consideration in all matters related to the study design, conduct, and dissemination of results (Table 1). Approval for the research study was obtained from Minwaashin Lodge as well as from the University of Ottawa Research Ethics Board.

Table 1. Guiding principles: application of Ownership, Control, Access and Possession (OCAP) (First Nations Centre, 2007)

OCAP Principles	Examples of Application within Studies
Ownership: An FNIM community owns information collectively in the same way that an individual owns their personal information	Minwaashin Lodge ("ML") acknowledged as a full research partner by the University of Ottawa Research Ethics Board; full access and consideration for participation in design, conduct, dissemination activities including authorship
Control: FNIM communities are within their rights in seeking to control all aspects of research and information management processes that impact them	ML representatives included during development of the study protocol, co-producers and coauthors of knowledge during data collection, interpretation, and dissemination
Access: The right of FNIM people to information and data about themselves and their communities, and right to manage and make decisions regarding access to their collective information	Collected data stored in a mutually agreed upon way to ensure the privacy and confidentiality of participants, with the data sets accessible by representatives of ML
Possession: Stewardship of data is a mechanism by which ownership can be asserted and protected	Community-academic collaboration of ML representatives with academic partners. Dissemination of research by and with ML to stakeholders identified and/or approved by ML, including publication of papers in mutually agreed upon journals

Adopt a theoretical approach

The selection of a theoretical framework for this research study involved intensive and detailed negotiations as the community-research collaborative partnership included individuals with varying worldviews. The source of inequity for FNIM people in Canada has been identified as residing in colonial relations of power that have been and continue to be enacted by those who are in possession of worldviews that differ from that of FNIM population (Alden, 2005; Reading & Wien, 2009). Therefore, it was of particular importance that the underlying assumptions of the study be stated explicitly, grounded in worldviews that were acceptable to the community-research collaboration, and aimed at disrupting standing practices in health systems that are situated in colonial relations of power.

Postcolonial theory principles as described by Battiste (2000) positions FNIM people as being central to a collaborative process of societal change, which is also inclusive of those who do not identify as FNIM. The use of the postcolonial theoretical perspective was identified as relevant for the study as it describes a process of identifying and addressing the underlying tensions within colonial relations, and making it suitable for use as a lens through which to view the research processes (Table 2). Battiste (2000) utilized the Medicine Wheel as an approach to address colonization and the Medicine Wheel is described elsewhere as an appropriate methodological and categorization tool in health research, as it integrates Western and Indigenous ways of knowing and is an approach to knowledge generation (Graham & Leeseberg, 2010; McDonald, 2008). The Medicine Wheel is strengths-based and focused on restoring life balance by attending to the four directions: East, South, West, and North. These cardinal points align with and also depict, respectively, the four aspects of self: Physical, Emotional, Mental, and Spiritual, and aligned philosophically and pragmatically with the theoretical focus of our study.

Table 2. Application of a postcolonial theoretical lens (Battiste, 2000)

Medicine Wheel Door	Lens/Perspective	Action: our study
West (autumn): Colonization as "the ideas that have shaped the last era of domination underpinning modern society and the varied forces" (p. xxii)	Understand colonization as a system of oppression which continues to shape the lives of people	A partnership between FNIM people and those of Euro-Canadian ancestry in a community-academic collaboration
North (winter): Opportunity to learn endurance and wisdom from challenge; thereby diagnosing of colonization	Challenge assumptions and the creation of patterns of inclusion and exclusion within healthcare settings	A collaborative research study ultimately aimed at the disruption of colonial practices in Western-informed health systems
East (spring): Seek new ways, healing colonized Indigenous peoples	Engagement in processes (intellectual, practical) to rebuild/heal	Collaborative, co-creation of knowledge useful for health systems change, resulting in research processes and products
South (summer): Visioning of "the Indigenous renaissance" (p. xxiv) based on Indigenous knowledge and heritage	Appreciation for Indigenous and other forms of knowledge; critical analysis of discourses for masked neocolonial practices	Relationships, research processes and new knowledge meaningful to collaborators (publications, presentations, culturally-appropriate shared decision making strategy)

Conduct research

The sequencing of the research study was reflected in a published protocol developed by and published with members of the community-research collaboration (Jull et al., 2012). First, the advisory group decided that it was important to define the issue. To do so, external evidence was collected to provide background knowledge and to identify ways in which the evidence could be used to contextualize issues for FNIM women who are seeking to participate in health systems, and that align with issues identified by Minwaashin Lodge. For example, the advisory group consulted additional external expertise and a systematic review of the literature was conducted (Jull et al, 2013). The findings echoed the experiences of Minwaashin Lodge senior staff, who expressed concern over the lack of support for FNIM women who faced decision making in care settings. The information collected in this phase served to inform all subsequent research in our study.

Next, using a qualitative study the shared decision making needs of the Minwaashin Lodge community were identified, as well as the availability of supporting resources such as the options available for meeting those needs (Jacobsen, O’Connor, & Stacey, 2013). This population needs assessment provided valuable insight into FNIM women’s recent experiences when making decisions affecting their health or the health of someone for whom they cared (Jull et al., 2015). The findings informed the need to adapt a shared decision making tool, the Ottawa Personal Decision Guide (OPDG) (O’Connor, Stacey, & Jacobsen, 2004), to meet the needs of this population.

The adaptation of the OPDG that was defined by participants as being useful, while remaining true to the evidence-base from which it was originally derived, was the overarching aim of the shared decision making process for FNIM women. For this part of the study, researchers engaged in focus groups modeled on an approach described by Minwaashin Lodge’s senior staff as a “kitchen table” talk approach. This format for conversation enabled FNIM women who are members of the Minwaashin Lodge community to be comfortable in a communal place where they were able to direct and contribute to the conversation in ways that were defined as meaningful to them. Following analysis, the advisory group created an adapted version of the OPDG and a process for using it that met the health literacy needs of the population.

The usability portion of the study tested the adapted shared decision making tool to determine whether or not participants defined the adapted tool as useful. FNIM women participated individually in an iterative process of testing the adapted shared decision making tool. The advisory group conducted a review for concept equivalence and population relevance and the final tool was assessed by FNIM participants, their community and the advisory group to be an effective, adapted shared decision making strategy to facilitate the participation of FNIM women of Minwaashin Lodge in shared decision making and is described in detail elsewhere (Jull, Giles, Boyer, Stacey, & Minwaashin Lodge, 2015). Led by advisory group members, findings have been published and presented in agreed-upon papers and presentations and is being carried forward in further studies to test applicability and further develop the research intervention.

Lessons Learned

Using CBPR, in this study we set out to answer questions about the conduct of research to inform how healthcare systems should change for FNIM populations who have faced a history of research practices that undermine and/or marginalize community members as full and active members in research. We shared a common goal: to address inequity within healthcare systems by exploring the relevance and use of shared decision making tools and then adapting an intervention with a focus on building equity-relevant knowledge. This work required that the researcher, advisory group and community research collaborators establish common ground and commit to guiding principles, which for our study meant using OCAP principles to develop ethical guidance that would enable research to be conducted in transparent, useful and collaborative ways. There was careful consideration of and concern for the underlying assumptions inherent in Western-informed healthcare and research systems that perpetuate the colonial legacy that undermines FNIM people in society and led to the choice of (postcolonial) theory. Our solution was to engage in a process of relationship building, with the PI acting as a facilitator to foster the use of CBPR within community-research partnership, along with the full engagement of an advisory group throughout a defined two-phase research process: 1) establish guiding features of a collaborative framework by forming an advisory group, developing ethical guidance, agreeing upon underlying theoretical concepts for the research study; and 2) engage in research actions that support co-creation of knowledge throughout study processes.

A framework for community-research research collaboration

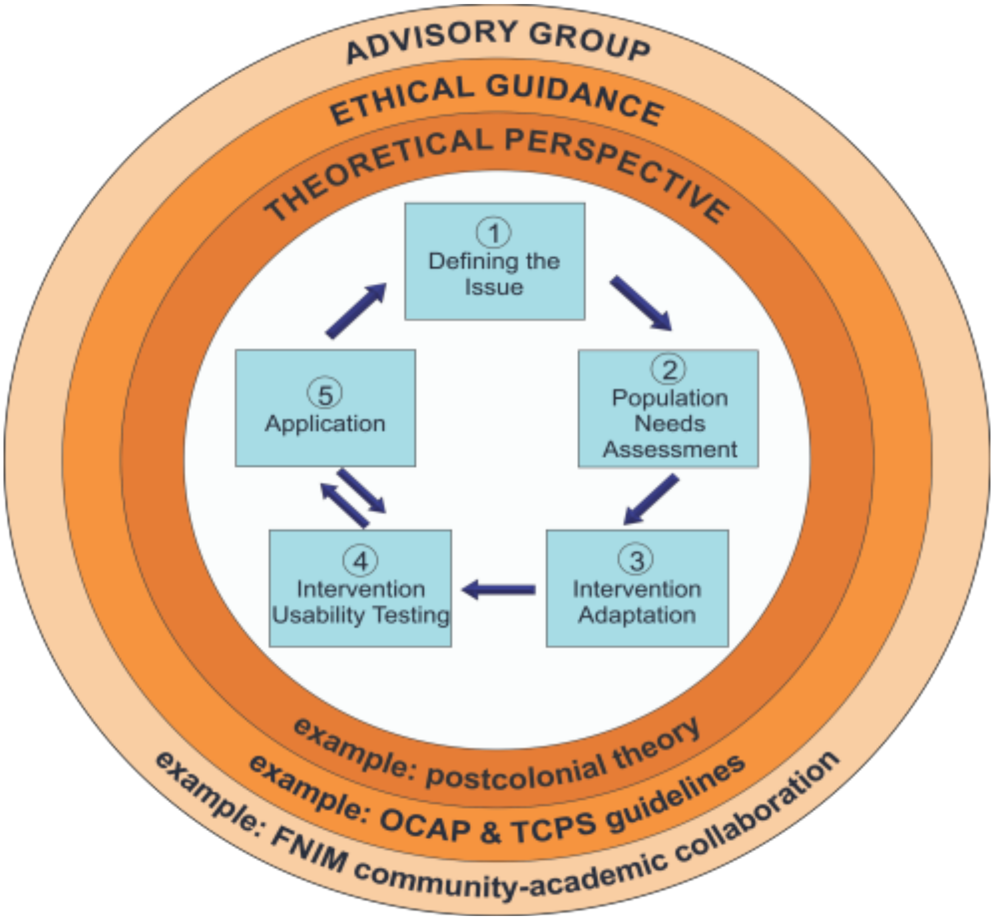
Prior to initiating the study, frameworks to guide community-research partnerships were assessed (Adams, Miller-Korth, & Brown, 2004; Baker, Homan, Schonhoff, & Kreuter, 1999; Cargo & Mercer, 2008; Israel et al., 2006; Macaulay et al., 2003; Metzler, et al., 2003; Ontario Federation of Indian Friendship Centres, 2012; Pinto, Wall & Spector, 2014), but none were found that met our purpose, as they did not describe clear and replicable steps that explicitly included consideration of ethical conduct and examination of underlying theoretical assumptions as integral to a participatory-focused approach. Based on the processes and findings described in our case study, we argue that there are two essential phases in negotiating a collaborative framework for community-research partnership (see Figure 1). The first phase, represented by the three outer rings of the figure, is formative, and represents the guiding features of the model describing the collaborative framework: advisory group, ethical guidance, and theoretical perspective.

The second phase consists of sequential studies whose planning and conduct were bounded by the guiding elements (three outer rings) of the collaborative framework, and represented by the five boxed activities within the inner rings describes the actions taken during the study to engage in the co-creation of knowledge. These five steps are iterative, meaning that they build upon one another and are conducted in successive spirals and which in this case study were used to achieve an accepted shared decision making strategy that remains true to its underlying evidence-base. In other words, after following one cycle and adapting an intervention, subsequent spirals of adaptation and testing may occur.

Mutual learning and co-creation of knowledge

Our work resulted in the development of a mutually agreed-upon collaborative framework. In this research work, the advisory group first developed, then followed ethical guidance and, using postcolonial theory as a lens, focused on creating opportunities to promote equity within the research relationships, processes, and products. An emphasis on collective decision making, respect, and co-development of knowledge during each step of the research study fostered trust within the community-research collaboration. The literature identifies potential for CBPR to address social issues through both generating knowledge and bridging gaps between research and practice (Cargo & Mercer, 2008); however, the literature also describes the need for practical strategies to move research knowledge into action (Campbell, 2010). Our framework explicitly lays out steps and creates opportunities for community-research collaboration and that builds knowledge that is defined as ethical, useful and relevant by those in the partnership.

Figure 1. A collaborative framework for community-research partnership



There were multiple and ongoing opportunities for mutual learning during the research processes by creating opportunities for the co-creation of knowledge. For example, advisory group members were kept informed by the PI who played a coordinating role that was agreed upon at the start of the study; the PI facilitated the research processes through ensuring regular in-person meetings and email contact, and members contributed their strengths to the research study appropriately throughout the study stages. There were many opportunities for mutual learning, such as when the Minwaashin Lodge senior staff supported the PI and other collaborators during the process of data analysis with the result being a culturally resonant Medicine Wheel framework to depict study results (Jull et al., 2015). As well, the study processes led to relationships that are ongoing, and that extend and further build networks that foster community and academic research capacity.

The limitations of this work included the work and time constraints for those in the community-research collaboration and subsequent reliance upon one facilitator (the PI) for ensuring regular and productive contacts among members. The strengths include contributions to building mutual opportunities for community-research capacity. For example, individuals from the FNIM community met requirements for co-authorship in publications and the academic members furthered CBPR research skills, with all members of the community-research collaboration learning about building knowledge beneficial to society in ways that are ethical and equitable.

Conclusions

A collaborative framework is presented as a dynamic series of negotiations between community and researchers, and is conducted within a mutually agreed upon two-phased framework. The collaborative framework is demonstrated using the example of a cultural adaptation of a shared decision making intervention. In our work, an advisory group united by common concern and interests reached agreement, and then utilized a collaborative framework for the selection and application of theory for a multi-study research project that considers the mutually reinforcing relationships between people and place and the need for research that is decolonizing. The conceptual elements of a collaborative framework structured a process for the community-research collaboration to develop, conduct, and disseminate research, and in which co-created knowledge was used to inform an intervention - in our instance, a culturally adapted shared decision making strategy aimed at health equity.

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