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Viewpoint

Community-based participatory research with Indigenous communities: The proximity paradox

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ABSTRACT

Community-based participatory research (CBPR) is a promising approach used with increasing prevalence in health research with underserviced Indigenous communities in rural and remote locations. This case comparison used CBPR principles to examine the characteristics of two collaborative research projects in Canada. Both projects reflected CBPR principles in unique ways with particular differences related to community access and proximity of collaborating partners. CBPR principles are often used and recommended for partnerships involving remote underserviced communities, however many of these principles were easier to follow for the collaboration with a relatively well serviced community in close proximity to researchers, and more challenging to follow for a remote underserviced community. The proximity paradox is an apparent contradiction in the increasing application of CBPR principles for use in distal partnerships with remote Indigenous communities when many of these same principles are nearly impossible to follow. CBPR principles are much easier to apply in proximal partnerships because they afford an environment where collaborative relationships can be developed and sustained.

1. Introduction

New research paradigms are evolving to meet the health needs of Indigenous communities, and it is important to understand the implications of these approaches. According to the World Health Organization (2007), the global Indigenous population comprises over 370 million people in 70 different countries. The term Indigenous usually characterizes people who self-identify with a shared territory and heritage that predates colonial and settler societies (World Health Organization, 2007).

Over 1.4 million First Nations, Inuit and Métis people from Canada's Indigenous population (Statistics Canada, 2013)[1], many of whom live in rural and remote communities or reserves dispersed across Canada's expansive geography. There are 617 First Nation communities in Canada representing a wide variety of cultural groups with 50 distinct languages (Aboriginal Affairs and Northern Development Canada, 2013). Most of these communities are located in their traditional geographic territories which predates colonization and mass immigration from Europe and other regions of the world. In the province of Ontario, nearly 25% of the 133 First Nation communities are located in the isolated Far North region of Ontario (Chiefs of Ontario Office, 2013; Ministry of Natural Resources, 2013). The Far North region is a relatively new designation used by the Ministry of Natural Resources in Ontario to describe the vast northern region of the province. Most of the communities in this region are only accessible by air or ice road in winter. Thus, access to mainstream health services, programs, and resources is a significant challenge for many remote Indigenous communities.

In order to reflect a broader international perspective, we use the terms Indigenous in place of the terms Aboriginal, First Nations, Native American Indian, and Tribe. Similar to other colonial countries such as Australia, New Zealand, and the United States, there is a long history of imperialism and discriminatory policies in Canada that have marginalized many Indigenous people and communities. The 1996 Report of the Royal Commission on Aboriginal Peoples

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[1] Indigenous people in Canada are collectively referred to as Aboriginal peoples, and the Canadian constitution recognizes three distinct groups of people: Indian (commonly referred to as First Nations), Métis and Inuit (Aboriginal Affairs and Northern Development Canada, 2013).

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represented a turning point in Canada, since it identified many of the historical policies and practices of "domination and assimilation", such as treaty making, establishment of reserve lands for communities, and developing a network of residential schools Royal Commission on Aboriginal Peoples in Canada (1996). Research practices related to Indigenous people worldwide have followed a similar legacy of imperialism (Smith, 2012). In recent years in Canada, there has been a positive shift and evolution in ethical guidelines involving research with Indigenous people to redress earlier deficiencies (Brant-Castellano, 2004; Canadian Institutes of Health Research, 2010, Chapter 9; Martin-Hill and Soucy, 2005; Schnarch, 2004). Castleden et al. (2012, p. 166) summarized this evolution and concluded that "partnership approaches informed by community collaboration is [are] clearly necessary".

Community-based participatory research (CBPR) has emerged as a collaborative approach to health research well suited for diverse populations in many underserviced areas, such as those in rural and remote locations (Israel et al., 2005b; Minkler and Wallerstein, 2008a). Often remote populations have a "disproportionate burden of morbidity and mortality… with few economic and social resources" (Israel et al., 2008, p. 48). The literature recommends collaborative research in geographically isolated communities, as it is essential to address local research questions and needs (Israel et al., 2008; Lightfoot et al., 2008). CBPR approaches vary from project to project to adapt to the unique contextual challenges and rewards that are often encountered with Indigenous populations (Lardon et al., 2007; LaVeaux and Christopher, 2009; Maar et al., 2011; Mohammed et al., 2012; Peterson, 2010). Understanding the nature of these adaptations is essential to guide research with Indigenous populations in Canada and beyond.

The purpose of this paper is to compare two CBPR projects with two different Indigenous communities in northern Ontario, Canada, both of which are geographically isolated, but to a different degree. This comparison has global significance, since it profiles CBPR approaches with respect to the proximity of collaborating partners.

The first project was the integrated development and evaluation of an Outdoor Adventure Leadership Experience (OALE) using a mixed methods design. The collaboration involved community leaders from Wikwemikong Unceded Indian Reserve and researchers from Laurentian University. The OALE is an intervention designed to promote resilience and well-being for adolescents from the Wikwemikong community (Ritchie et al., 2010, 2012). Wikwemikong (population 2592) is a rural Indigenous community with road access. The second project was the integrated program development and evaluation of the Sachigo Lake Wilderness Emergency Response Education Initiative (SLWEREI), using qualitative methods. The SLWEREI is a community-based first aid training program with adapted curriculum for lay members in remote locations (Born et al., 2012; Orkin et al., 2012). The collaboration included community leaders from Sachigo Lake First Nation along with researchers from Laurentian University and the Northern Ontario School of Medicine. Sachigo Lake (population 450) is a remote Indigenous community with no permanent road access.

The first author (SR) was directly involved in both research projects, and was therefore in a position to coordinate the comparative analysis in collaboration with colleagues from both teams (OALE and SLWEREI). We use this comparison to advance what we dub the proximity paradox – the observation that the geographically isolated communities that might benefit most from involvement in CBPR initiatives are the very communities where a CBPR approach also becomes most challenging.

2. Community-based participatory research (CBPR)

CBPR is a collaborative approach to research that is usually characterized by community leaders partnering with university-based researchers to address a mutual health concern. There is a need for CBPR approaches when "researchers, practitioners, and community members are to address the growing disparities in health status between marginalized communities and those with greater social and economic resources" (Israel et al., 2008, 61). Maiter et al. (2008) used the term reciprocity to describe the foundational trust and respectful relationships that are essential to effective CBPR. Israel et al. (2005a) emphasized the process of sharing expertise, decision-making, and ownership through equitable involvement of partners in all phases of the research from inception through to implementation and dissemination. Minkler and Wallerstein (2008b) differentiated research that is community-based from that which is simply community placed, suggesting that the CBPR process is a cooperative alliance characterized by research, action, and education within the community.

There are many principles and guidelines for effective CBPR, however one of the most cited was originally synthesized as eight principles (Israel et al., 1998), and then later expanded to nine principles (Israel et al., 2005a, 2008). These are outlined in Table 1. Since CBPR has been used in many projects involving Indigenous communities, it may offer a decolonizing methodology (Smith, 2012) that is responsive to ethical concerns concordant with recommended approaches for community engagement (Canadian Institutes of Health Research, 2010). LaVeaux and Christopher (2009) offered nine additional recommendations for consideration by researchers endeavoring to collaborate with Indigenous communities, and these were later applied as principles in the evaluation of seven CBPR partnerships with Native American communities (Christopher et al., 2011). These are outlined in Table 2. We used the nine CBPR principles outlined by Israel et al. (2005a, 2008) and the nine CBPR recommendations identified by LaVeaux and Christopher (2009), as the basis for comparing the OALE and SLWEREI projects.

Table 1
Principles of CBPR for health[a].

1. Recognize community as a unit of identity
2. Build on strengths and resources within the community
3. Facilitate collaborative, equitable partnerships in all research phases and involve an empowering and power-sharing process that attends to social inequalities
4. Promote co-learning and capacity building among all partners
5. Integrate and achieve a balance between research and action for the mutual benefit of all partners
6. Emphasize public health problems of local relevance and also ecological perspectives that recognize and attend to the multiple determinants of health and disease
7. Involve systems development through a cyclical and iterative process
8. Disseminate findings and knowledge gained to all partners and involve all partners in the dissemination process
9. Focus on a long-term process and commitment to sustainability

[a] Adapted from Israel et al., 2008.

Table 2
Principles of CBPR with Aboriginal communities[a].

1. Acknowledge historical experience with research and health issues and work to overcome the negative image of research
2. Recognize traditional sovereignty
3. Differentiate between band and community leadership
4. Understand community diversity and its implications
5. Plan for extended timelines
6. Recognize key gatekeepers
7. Prepare for leadership turnover
8. Interpret data within the cultural context
9. Utilize indigenous ways of knowing

[a] Adapted from LaVeaux and Christopher, 2009; and Christopher et al., 2011.

3. CBPR and the OALE project

The OALE project was developed over several years (2008–2011) using a CBPR approach (Ritchie et al., 2012, 2010). The OALE addressed a compelling community need to promote adolescent resilience and well-being, using outdoor adventure leadership as the medium. It was developed for Wikwemikong adolescents ages 12–18 yr as an immersive experience in the natural environment. Principles of wilderness adventure therapy were used to develop and implement a proprietary 10-day training program unique to the local context and geography. The program was implemented entirely in the wilderness during a canoe excursion homeward in the community's traditional territory.

Close proximity between collaborating partner locations (Sudbury and Wikwemikong, Ontario) facilitated relatively easy access (170 km/2 h drive). OALE development meetings, presentations, workshops, and training occurred frequently through face-to-face interactions in Wikwemikong and at Laurentian University in Sudbury. Research data validity processes included numerous member check meetings, and co-analysis and review of results by a Community Research Steering Committee with Elder oversight. Well-developed and committed relationships emerged amongst most members of the interdisciplinary team.

Institutional (university) ethics approval was received and maintained throughout the project. Local ethics approval in Wikwemikong was granted through an independent regional committee (Manitoulin Anishinabek Research Review Committee), endorsed by the Health Services Committee in the community, and supported by Chief and Council. Unfavorable historical experiences with research in Wikwemikong has led to well established protocols Blodgett et al., 2010. Findings were disseminated via co-presentation at conferences, co-authorship on papers, and ongoing collaborative program review and development. The OALE program is currently well established, sustainable, owned, and managed entirely by the community. Capacity building is focused on train-the-trainer, summer student training, and community researcher training.

4. CBPR and the SLWEREI project

The Sachigo Lake Wilderness Emergency Response Education Initiative (SLWEREI) was developed over several years (2009–2012) using CBPR (Born et al., 2012; Orkin et al., 2012). The SLWEREI addressed a compelling community need for pre-hospital first response, since there is no paramedic service in Sachigo Lake. It involved a system of curriculum development and training for lay community members so they have the capacity to respond appropriately to medical emergencies on-scene, and gain skills in emergency health management through direct interaction with experienced professional paramedic and physician providers. Principles of wilderness emergency management were used to develop and implement 5-day training program well suited to the local context and community. For instance, the program was modified to include a module on mental health first aid and an enhanced focus on CPR with AED (automatic external defibrillator) support.

As a remote fly-in community, Sachigo Lake presented many challenges related to access (minimum 425 km/costly flight). With the exception of an on-site needs assessment early in the program's development, nearly all SLWEREI planning meetings occurred via telephone and usually involved channeling communication through one or two individuals from the community and research teams. Research data validity processes were very challenging due to lack of proximity of collaborating partners. Relationship building and project development was challenged by the lack of face-to-face meetings. Sustained commitments from technical experts and key champions in the community and on the research team were essential to ensure project continuity and sustainability.

Institutional (university) medical research ethics approval was received and maintained throughout the project. Local ethics review in Sachigo Lake involved verbal approval by Chief and Council, and regional approval from the Nishnawbe Aski Nation and Sioux Lookout First Nations Health Authority. This process reflected previous favorable local experiences with research in Sachigo Lake. Findings were disseminated locally and through academic fora by the university research team. The SLWEREI program is currently well established and managed primarily by committed clinicians and researchers from outside the community. Current capacity building is focused primarily on front-line workers and lay community members through delivery of the SLWEREI program by researchers from outside the community.

5. Comparative results

The OALE and SLWEREI were unique projects, but their similarities permitted a comparison of CBPR approaches. Both projects were multi-day experiential education training programs that evolved over several years. Each program included design, implementation, and evaluation phases, and development was iterative and focused on community systems (health services and education). Resources and strengths within each community directly influenced the projects and programs of research. For instance, community leaders at the Waasa Naabin Community Youth Services Centre in Wikwemikong provided the staff, equipment, meeting location, and resources necessary to manage and develop the OALE. In Sachigo Lake, members of the Emergency Response Team, Crisis Response Team, and Canadian Rangers participated and promoted the SLWEREI within their community. Both projects were characterized by a culture of co-learning and equity, and this resulted in genuine and committed relationships between collaborators extending beyond the research context. This sensitized researchers to varied Indigenous ways of knowing (such as the importance of experiential learning) which influenced program development and delivery. Both projects experienced leadership turnover, delayed timelines, and changing gatekeeper roles; these experiences challenged project development.

Important differences between the two CBPR approaches are outlined in Table 3. The most noteworthy differences were related to the degree of geographical isolation. Sachigo Lake is a small remote community located in Ontario's far north, with very limited Internet connectivity and difficult access due to long costly flights that are only possible in favorable weather. Naturally, the SLWEREI project collaborators had few opportunities for face-to-face interaction. Other research teams using CBPR approaches with Indigenous communities have highlighted challenges, learnings, and recommendations (Caldwell et al., 2005; Holkup et al., 2004; Lardon et al., 2007; Maar et al., 2011; Minore et al., 2004;

Table 3
Key differences related to CBPR.

	OALE (Wikwemikong)	SLWEREI (Sachigo Lake)
History of research	Extensive with many negative experiences[a]	Few experiences; most were favorable
Issue of local relevance	Adolescent mental health	Pre-hospital emergency response
System development to address local issue (need)	Health promotion focus using principles of wilderness adventure therapy to develop a culturally relevant program and medium (nature) for delivery	Health systems focus using principles of wilderness emergency first aid to develop community and context specific curriculum and training
Project approval and review process (ethics)	Review and written approval by regional Manitoulin Anishinabek Research Review Committee Motions of support by Health Services Committee and Chief and Council Community Research Steering Committee provided oversight and guidance Signed formal research agreement	Formal verbal assent by Chief and Council[b] Written support from Nishnawbe Aski Nation and Sioux Lookout First Nations Health Authority Research agreement used as a tool to clarify relationships and expectations
Access and proximity	Primary access by road which is open year round Distance (by road) is 170 km between Wikwemikong and Laurentian University	Primary access by air (flight) in fair weather conditions only; winter road is open a few weeks each year Distance (by air) from Sachigo Lake to Northern Ontario School of Medicine (West Campus) is 640 km and to Laurentian University is 1145 km
Nature of collaboration	Numerous phone calls, e-mails, and face-to-face meetings and presentations in community and at university Numerous dissemination activities within community including invited presentations, open community wide update meetings, and informal ad-hoc meetings	Telephone and e-mail was primary mode of communication usually channeled through one or two key members of the collaborative team Very few face-to-face meetings or presentations in community other than initial onsite needs assessment (in May 2010) and program delivery (in November 2010 and May 2012)

[a] See Blodgett et al., 2010 for a historical perspective of research in Wikwemikong.
[b] Chief and Council preferred providing project support and approval verbally rather than through a motion of support, written resolution, or signed agreement.

Mohammed et al., 2012), but few have explored ways to adapt CBPR practices and principles when partnership communities are located in isolated areas, or distant from research centres.

Castleden et al. (2012) surveyed 15 CBPR researchers involved in collaborations with Indigenous communities, and they identified financial and time constraints as significant barriers, especially for respondents engaged in partnerships with northern and remote communities. Lardon et al. (2007) described the tremendous challenges of CBPR related to their project in remote Indigenous villages in the Yukon–Kuskokwin river delta in Alaska:

> *The geographical remoteness of these villages, combined with weather conditions in the region, an underdeveloped telecommunications infrastructure, a less than reliable power supply, and a host of other factors present researchers with significant challenges that increase costs and time needed to complete research. Since strong kinship and personal, face-to-face communication is the social norm, researchers must spend additional time in villages to make themselves known, trusted, and accepted.* (Lardon et al., 2007, 135)

Despite these challenges, Lardon et al. (2007) went on to describe a committed CBPR strategy that included ongoing e-mail, weekly phone conferences, and village visits eight times per year. Other researchers have indicated that CBPR approaches with smaller Indigenous communities may not be respectful processes of their members' availability to engage in collaborative activities requiring significant time commitments (Castleden et al., 2012; de Leeuw et al., 2012).

In the introductory chapter of their edited text on CBPR, Minkler and Wallerstein (2008b, p.12) stated that "the fight against disparities can be won only if the most oppressed communities can be fully engaged as research partners…". For many researchers this imperative reflects an implicit directive to head north to remote Indigenous communities, armed with CBPR principles, and perhaps oblivious to the challenges of distance. Researchers have identified the importance of building close trusting relationships as an integral part of the CBPR process (Christopher et al., 2011; Maiter et al., 2008; Minkler and Wallerstein, 2008b), yet developing these relationships requires a significant commitment that seems to be confounded by access and distance between collaborating partners. It is clear that such an approach, and the associated financial and convenience factors, favor the implementation of CBPR projects in underserviced communities in close proximity to large academic research centres. Methodologies requiring impractical or unfeasible investments over long distances may result in the exclusion of remote communities from CBPR undertakings, and serve to magnify existing health inequities and research gaps (Born et al., 2012).

5.1. Key learnings

There were five key learnings that emerged from comparing the two CBPR projects.

1. Key community champions and strong relationships with researchers ensured continuity and sustainability in both projects.
2. Core values such as integrity, trust, reciprocity, and mutual respect were foundational elements in both projects.
3. The ethical review and project approval process were unique and vastly different for each community.
4. Communication and face-to-face interaction were necessary for relationship development in both projects, yet they were much more challenging in Sachigo Lake.
5. Geographic distance between collaborating partners, time commitment required, travel and logistics planning, uncertainty related to weather, and extensive costs were major

Fig. 1. Proximity map of collaborating partners and other remote communities.

challenges to CBPR in Sachigo Lake. This required the adaptation of CBPR principles to create a unique methodological approach appropriate for the specific context and collaboration (see Table 3).

It was clear that following CBPR principles and recommendations was much more challenging for research in a remote location such as Sachigo Lake. Although variability in CBPR principles is expected for different projects (Israel et al., 2008), the varied approaches in these two cases highlighted the need for pragmatic and often difficult adaptation to guide the partnerships appropriately.

5.2. *The proximity paradox*

Comparing these two projects highlights a proximity paradox. CBPR principles were easier to follow for the collaboration with a relatively well-serviced community in close proximity (Wikwemikong), and much more challenging to follow for an underserviced community that is not in close proximity (Sachigo Lake). An implicit assumption in the CBPR literature and principles, is that in less serviced communities where the needs are greatest, the use of CBPR approaches are even more appropriate and applicable. Thus, CBPR principles and methods seem to be uniquely suited and recommended for research with small Indigenous communities with distinct cultures; but they are contingent on strong relationships. When you impose geographic distance, challenging and costly travel, and uncertainties associated with climate, relationships are nearly impossible to develop and maintain in remote isolated communities. This highlights a conundrum for potential collaborators. The proximity paradox is the apparent contradiction between needs and ease of application. CBPR principles seem to be strongly encouraged for use in distant or underserviced Indigenous communities, yet they are more difficult to apply in these same communities. Conversely, they are much easier to apply in proximal partnerships where the needs may be less pronounced.

While we have these experiences in Northern Canada, we imagine the context is not unique. So too in other countries where academic hubs are in major urban areas, researchers travel variable distances from university campuses to work with communities with differential health services available. Fig. 1 portrays the effect of distance in a proximity map of collaborating partners (OALE and SLWEREI). Other remote First Nations communities identified on the map are located in the Far North region of Ontario (Ministry of Natural Resources, 2013).

There are potential ramifications to this paradox that lead to a dilemma for the future of CBPR-type research in the far north of Ontario as well as in other isolated Indigenous communities around the world. Aboriginal health researchers committed to CBPR principles and recommendations may: (1) avoid partnering

with remote underserviced communities even though these same communities may benefit or demonstrate the most compelling need for locally-appropriate health research interventions; or (2) partner with remote underserviced communities and navigate the additional challenges and difficulties related to adhering to principles and "best practices" that seem better suited for "convenient collaborations" in more urban areas. Community health leaders in remote locations may: (1) face difficulties attracting and sustaining partnerships with health researchers who may not have the time, resources, or dedication to tackle the methodological challenges related to implementing CBPR-type projects in remote regions; or (2) not have the time, resources, or dedication to invest in a demanding CBPR process with researchers from distant locations. Paradoxically, this situation may perpetuate and entrench the very research gaps and health inequities that CBPR researchers might otherwise seek to address. Best practices in CBPR and other collaborative research approaches must be as flexible and varied as the researchers and communities involved. They must reflect the place and proximity of the collaborating partners.

5.3. Conclusion

We are convinced that the challenge, rewards, commitment, and success of the OALE and SLWEREI projects were all inextricably linked to the foundational relationship development achieved through face-to-face interaction. The proximity paradox is not just about geographical distance and remoteness, but more concisely about the ways that proximity plays out in the social sphere through the foundational relationship building that makes CBPR so successful. New funding models need to recognize and provide financial support for these face-to-face interactions in order for effective collaborations to emerge.

The future of health research in isolated areas of the world requires new paradigms, custom approaches, and modified methods that work for the communities and collaborating partners involved. These approaches may or may not reflect conventional CBPR. For instance, communities may need to network together with large collaborative research teams to access more extensive funding for longer time periods. Emerging cost-effective communication technologies may also help by supplementing face-to-face interaction with web-based tools, social media, and video conferencing from a distance (Jones et al., 2008).

An important CBPR principle is to recognize community sovereignty (LaVeaux and Christopher, 2009; Christopher et al., 2011); this implies that Indigenous communities are heterogeneous. We must be cautious in applying homogeneous CBPR principles (and recommendations) to heterogeneous communities and research imperatives. The choices and approaches taken by committed CBPR researchers must differ across settings. Research methodologists must be equipped to identify, develop, and implement the most appropriate methodologies for unique settings and relationships, rather than seeking to apply a singular approach to all CBPR undertakings. The slogan "this is how we do research in our community" may better reflect a decolonizing approach, support a path towards self-determination, and carry more implicit credibility than the slogan "this project followed the principles of community-based participatory research".

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