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Community-based participatory research with Aboriginal children and their communities: Research principles, practice and the social determinants of health

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Article abstract

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An Interdisciplinary Journal

*Honouring the Voices, Perspectives and Knowledges
of First Peoples through Research, Critical Analyses,
Stories, Standpoints and Media Reviews*

Community-based participatory research with Aboriginal children and their communities: Research principles, practice and the social determinants of health

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Abstract

Conventional health and social science research has contributed to advances in public well-being over the past century. Despite these advances, a significant gap exists in the health of Aboriginal children as compared to non-Aboriginal children in Canada. This has occurred, in part, as a result of the failure of conventional research to acknowledge the worldview of First Nations, Inuit, and Métis peoples, to fully take into account their experience of the social determinants of health (SDOH) and to address the intergenerational impact of colonization. In this article we review and discuss the social determinants of health (SDOH) with a specific focus on Aboriginal children and youth. Motivated by our experience in carrying out community based participatory research (CBPR) with children and families from First Nations and Métis communities in Alberta, Canada we review how use of CBPR approach to research with Aboriginal children and communities can serve to enhance research results, resulting in greater relevance to community identified questions. We will address these issues in the context not only of good research practice but as an aspect of "wise practices" (Wesley-Esquimaux & Calliou, 2010) occurring within an "ethical space of engagement" (Ermine, 2007). We conclude that CBPR allows for meaningful and equitable research partnerships to occur in an ethical space without reinforcing colonial processes of knowledge construction and translation while marginalizing Indigenous knowledge.

Key Words: *Aboriginal children, health, CBPR, SDOH, research approaches, ethical space*

Introduction

Aboriginal peoples are diverse in cultures, perspectives, and languages; however, all agree that the health of their children is essential to their futures. Elders' teachings express the belief that Aboriginal children need to be welcomed and supported by family and community while engaged in healthy learning

and spiritual practices. Children are understood to develop through relational and experiential learning within frames of identity, kinship, relationship with all beings, language, and culture—a process referred to by Mi'kmaw scholar Marie Battiste, as “nourishing the learning spirit” (2010, p.14). Knowledge is authenticated through observation, respect for the knowledge holder, and accounts of learning through personal experience. Throughout life, one's own experience adds to this body of shared empirical, experiential and revealed knowledge (Castellano, 2000). Decisions are made while keeping in mind the needs of future generations who are also connected with past and present, ancestors and descendants. From this view, well-being takes place through a holistic approach to individual, family, community, and environmental health. Sources of illness and appropriate interventions are understood not only physically but in the context of relationships of spirit (Malloch, 1989). Knowledge of health, medicines and healing processes are available through use of proper protocol, actions and thought.

The health of Aboriginal children in Canada

Canada's Aboriginal population is made up of First Nations, Métis, non-Status and Inuit peoples. Personal, community, and cultural identities are important to the well-being of Aboriginal peoples. The effect of colonization, including particular efforts aimed at children and families, resulted in devastating effects on community well-being. Loss of land and mobility, legal definitions of membership, legal restriction and differential rights for particular Aboriginal peoples intersect to compound this ongoing process. These limitations are enshrined in Canadian law, principally the *Indian Act* (Imai, 2002) and reinforce legal, economic, and sociocultural factors that produce and reinforce health inequity (Adelson, 2005; Bombay, Matheson & Anisman, 2010; Smylie & Adomako, 2009).

Aboriginal children lag behind their non-Aboriginal counterparts on almost every standard measure of health (Smylie & Adomako, 2009). There are numerous areas for improvement in Canada's performance on Aboriginal child health and wellness, including addressing the social determinants of health (SDOH) which are especially relevant to the experience of Aboriginal children and their families. As Reading and Wien (2009) note, “Aboriginal children, youth and adults are distinctly, as well as differentially, influenced by a broad range of social determinants ... includ[ing] circumstances and environments as well as structures, systems and institutions that influence the development and maintenance of health” (p.1). For example, one in four Aboriginal children in Canada live in poverty, with historical and systemic roots manifest in children's health, as compared to one in nine for the overall population (Greenwood, 2009; Greenwood & de Leeuw, 2012).

That Indigenous health inequities world-wide rise from the interaction of the SDOH with “culturally and historically specific factors particular to the peoples affected” (King, Smith & Gracey, 2009, p. 76) is generally agreed upon. In Canada, these factors not only influence health status, per se, they are implicated in historical and ongoing colonial processes, inherently undermining the health of Aboriginal children and communities (Adelson, 2005; King et al., 2009; Reading & Wein, 2009; Smylie & Adomako, 2009). Aboriginal health researchers agree that the colonization process and its continuing impact is the most influential determinant of health for First Nations, Inuit and Métis peoples (Greenwood, 2009; King, Sanguins, McGregor & Leblanc, 2007; King et al. 2009; Macaulay & Saylor, 2009; Reading & Wein, 2009; Smylie & Adomako, 2009). For instance, almost every one of the SDOH is influenced by residential school attendance by self or family members (Reading, J. & Elias, 1999); children experience the ongoing cumulative effects (Blackstock, 2007; Bombay, Matheson & Anisman, 2009). In

Canada, access to equitable health services along with discriminatory processes experienced by Aboriginal children and youth in schools and communities has a significant effect on their prospects for adult well-being (McQuaid, Bombay, McInnis, Matheson & Anisman, 2014).

Aboriginal peoples in Canada have shown significant resilience in light of these dynamics. They have faced historical and current challenges to health sustaining relationships with relatives, lands, economic systems, rights, and sovereignty. However, traditional ways of spiritual expression, healing, ecological knowledge and relationship to the land, and methods of collective governance have faced opposition from Western society and governments. The overall health impact of colonial assumptions, legal processes and regulatory practice and the resulting decrease in both individual and collective autonomy on Indigenous peoples cannot be understated.

Western health and social research was, and is, a part of this process. Understanding how and why these disparities are created and maintained is an important first step in developing and implementing appropriate interventions and policy to improve the health and well-being of children, families and communities. Researchers have not focused, to any great degree, on cultural strengths or on the SDOH and their cumulative effects as experienced by Aboriginal communities, but rather on identifying and reducing specific disease and social factors. Disparity in the health status of First Nations, Inuit, and Métis children in Canada and Indigenous peoples worldwide can, in part, be understood as a result of the failure of conventional research to address both Indigenous worldviews and the ongoing impact of the SDOH (King et al., 2009).

Challenges to current approaches to research with Aboriginal children and communities

Aboriginal peoples in Canada tend to rely on models of well-being that view health as not just related to the health of the individual but of the entire community. Saylor and Blackstock (2005) explain that:

Aboriginal peoples believe that health goes beyond the physical body to the spirit, emotions, and the mind. It goes beyond the individual to encompass the relations one has with family, the community, the world, the spirit and the land. It exists in the past and future as much as it does in the present, so decisions regarding health must be reflective and prognostic at the same time (p.523).

Maintenance of cultural knowledge promotes growth and well-being and increases health equity. For Aboriginal children, “the importance of culture is that it contains many teachings that children need at an early age to establish the foundation for both emotional and holistic health” (L. Brown, personal communication, Oct. 4, 2012).

Western definitions of health and Western models of research, service delivery, and health promotion are frequently ineffective in communities that rely on holistic understandings, serving to destabilize rather than enhance cultural foundations, contributing to the undermining of the health of Aboriginal children (King et al., 2009; Reading & Wein, 2009; Smylie & Adomako, 2009). Further, Aboriginal beliefs regarding ethical behaviour and good ways of learning may not always be compatible with evidence-based research or best practices based in Western traditions (Castellano, 2004; Battiste, 2010;

Fletcher et al., 2011; Wesley-Esquimaux & Calliou, 2010).

Additional ongoing research is needed to address Aboriginal child health considering the significant gaps in needs, prevention, service delivery and under-representation in research data reflecting community-identified research questions (King et al., 2009; Smylie & Adomako, 2009). As well, academic research is often carried out in a manner that fails to maximize value to the community (Schnarch, 2004). As a result, reliance on the principles of ownership, control, access and possession (OCAP) (First Nations Centre, 2007) was adopted as a research guideline by Aboriginal organizations and by the Tri-Council of Canada (2014). The principles recommend addressing these issues with communities and research ethics boards prior to the start of research and note that omission may create risk to participants and their communities (Canadian Institutes of Health Research et al., 2014; Schnarch, 2004; Travers, Guta, McDonald and Meagher, 2007). From Indigenous community frameworks, risk applies not only to individuals but also to communities (Baydala et al., 2011; Fletcher et al., 2011). For example, “participants may be placed at risk when research design and data collection procedures, including informed consent, are inappropriate for the specific research context” (Tilley & Gormley, 2007, p. 273). This process may, as a result, stigmatize entire communities.

Given concerns regarding past inaccurate and harmful misrepresentation, misuse of research, and failure to produce tangible benefits, “research is not a word that is taken lightly by Aboriginal peoples” (Pidgeon & Hardy Cox, 2002, p. 96). Aboriginal communities have reported feeling both over-researched and, also, under-represented in research that responds to community-identified needs (Castellano, 2004; Schnarch, 2004). This research history perpetuates the historical failure of Western institutions to keep their word in signed agreements including treaty, medical, and human rights (Ruttan, 2004), and failure to produce tangible benefits to communities is raised frequently (Castellano, 2004). Some communities have expressed the sentiment that they have been researched ‘to death’ (Castellano, 2004; Pigeon & Cox 2002). In response, Ermine, Sinclair & Jeffery (2004) call for a “decolonization agenda that has as a principal goal, the amelioration of disease and the recovery of health and wellness for Indigenous populations” (p.9). We suggest that a community-based participatory research (CBPR) approach is a good place to start.

Community-based participatory research: What is it?

CBPR is a philosophical approach to research which looks beyond questions of individual health care and health risk to those of community health and well-being. CBPR is defined as a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. Beginning with a research project of importance to the community, CBPR aims to integrate knowledge generation and action in order to advance community health and eliminate inequity. The key to CBPR success in Aboriginal communities is the participation of community representatives in all stages of the research, including identification of the research question, research design, advice on appropriate community protocol, data interpretation, and the application and dissemination of findings (Israel, Eng, Schulz, & Parker, 2005). CBPR is especially useful in research with “marginalized communities that experience a disproportionate burden of environmental, health, and other problems and that typically have not been included in deciding what types of research and interventions are most appropriate for and likely to be most effective in their communities” (Israel et al., 2005, p.1469).

By maintaining a focus on research that addresses community concerns, and while developing ownership and pride in the project, CBPR enhances community capacity while engaging in research aimed at reducing health disparities (Cochran, Marshall, & Garcia-Downing, 2008; Baydala, A., Plasco, Hampton, Bourassa & McKay-McNabb, 2006). To build the integrity and trust needed, CBPR relies on a set of guiding principles to guide research relationships, ethics, and decision-making. Developed by Israel and her colleagues, these principles are particularly applicable to the context of Aboriginal communities (Israel, Schulz, Parker, Becker, 1998; LaVeaux & Christopher, 2009). They include:

- 1) Acknowledgement of 'community' as a unit of identity.
- 2) Building on strengths and resources within the community.
- 3) Collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities.
- 4) Co-learning and capacity building among all partners.
- 5) A balance between knowledge generation and intervention for the mutual benefit of all partners.
- 6) Emphasis on the local relevance of public health problems and on ecological perspectives that attend to the multiple determinants of health.
- 7) Systems development using a critical and iterative process.
- 8) Dissemination of results to all partners and involving them in the wider dissemination of results.
- 9) Understanding of the need for long-term processes and a commitment to sustainability (Israel et al., 1998, p.178-180).

Often associated with qualitative research and public health questions, CBPR can and is being used in a variety of research studies. For example, environmental health studies measuring the effects of contaminants on children benefitted from this approach (Israel et al., 2005; Kwiatkowski, 2011). Other examples include research on substance abuse prevention for First Nations children and youth (Baydala, et al., 2014; Baydala et al., 2009), diabetes prevention with First Nations school children (Macaulay et al. 1999), health and genetics research (Boyer, Mohatt, Pasker, Drew, & McGlone, 2007) along with food security and diet studies (Wesche, Schuster & Tobin, 2011).

There are challenges common to the use of CBPR, including the additional time typically required and the need to build both community capacity, as well as, researcher capacity in the skills required to work with Aboriginal communities. One of the major benefits of CBPR is that community involvement contributes to a more thorough understanding of data and design of culturally relevant interventions (Leung, Yen & Minkler, 2003; Williams, Bray, Shapiro-Mendoza, Reisz & Parenteau, 2009; Wallerstein et al., 2008). CBPR enhances an ethical and valid approach to the conduct of research with and by Aboriginal communities and their children (Wallerstein & Duran, 2006). We believe that CBPR research increases the probability that research takes place in an ethical space

Carrying out research in an ethical space

To address some of the historical and ethical challenges inherent in this research context, Ermine,

Sinclair and Jeffery (2004) recommend the use of a less objectifying research paradigm developed as “a result of the decolonization agenda” (p. 9). It has “as a principal goal, the amelioration of disease and the recovery of health and wellness for Indigenous populations” (p.9). If future health research partnerships are to produce results based in the principles of justice and beneficence for Aboriginal communities and children, the dialogue and practices that establish these relationships must take place in the space between Western and Indigenous knowledge systems (Ermine, 2007, Ermine et al., 2004). Working with philosopher Roger Poole’s original concept, Ermine (2007) advances the concept of ethical space by using “an analogy of a space between . . . Indigenous and Western thought worlds” (p. 194) where the “encounter and interaction of two entities with different intentions” may take place (Ermine, Sinclair & Jeffery, 2004, p.19). This found space, located between Indigenous and Western knowledge systems, presents itself as one with the potential for exploration of interests through engaged dialogue. This dialogue has the potential to lead to ethical and collaborative research practice and enhanced research outcomes, importantly ensuring that the “ethics of the research process not only comply with academic standards but with the ethical values of the community where the research will be conducted” (Fletcher et al., 2010, p. 324).

CBPR is intended, similarly to the OCAP principles, to situate research with Indigenous peoples within this ethical space. In our experience, community research team members from the Alexis Nakota Sioux Nation located in central Alberta (Baydala, 2014), stressed that the principles of CBPR come close to their own value systems and the teachings of the Elders. They indicated that CBPR research took place at a more meaningful level than earlier research projects carried out in their community; one with greater spiritual significance, creating more useful outcomes (S. Letendre, personal communication, 12/8/2014). Similarly, they noted that a CBPR approach was particularly effective because it mirrors kinship relations. The acquisition of knowledge through equitable research partnerships, which value the varied skills that each team member brings to the work, is a critical dynamic. This process can be as critical to community health and empowerment as the health knowledge produced (Cochran et al., 2008).

Working from this perspective, researchers may begin to develop relationships by stepping into this ethical space. This action allows community members to initiate active involvement to meet them there and begin the trust building essential to successful CBPR. All team members benefit from the capacity building inherent in this approach. Humility is required; in order to succeed, academic researchers must be as willing to learn as to teach, to listen as to speak, and to share, rather than control, power and decision making. Drawing from Aboriginal knowledge systems rather than solely from Western knowledge systems is also mandatory. Given the history and perception of research outlined above, if academic researchers cannot engage in legitimate partnerships within this space, they may be told not enter this place of research at all.

CBPR and the social determinants of health

The SDOH are described as the interacting social and economic factors (education, income, housing, employment etc.) that affect people’s health and the experience of well-being or lack of wellness (Mikkonen & Raphael, 2010). According to King et al. (2009), “Indigenous health inequalities arise from general socioeconomic factors [i.e. the social determinants] in combination with culturally and historically specific factors particular to the peoples affected” (p. 76). This interaction contributes to inequities in life experience and reinforces inequitable and unethical institutional structures along with

attitudes about moral responsibility for health (blame or credit) that serve as justification for the status quo. These factors not only influence health status, per se, but are also implicated in both past and ongoing colonial dynamics, inherently undermining the health of Aboriginal children (Smylie & Adomako, 2009; Greenwood & de Leeuw, 2012; King et al., 2009, Reading & Wein, 2009).

Willows, Hanley and Delormier (2012) recommend situating research and intervention with Aboriginal children “within the context of a history of colonization and inequities in the social determinants of health” (p.1). To explore these impacts several models were developed which expand on the SDOH model to take into account the particular circumstances of Aboriginal peoples in Canada. For instance, Smylie and Adomako (2009), stress the importance of employment, income, education, food security, and housing, as well as, kinship and support networks, communication technology, and language skills. Experiences of racism, language loss, reduction in connection with the land and environment, spiritual, emotional and mental dispiritedness and undermining of identity are added to the SDOH by King et al. (2009). Macaulay and Saylor (2009) refer to the impact of categories of loss, including land, language, rights, and traditions while also experiencing racism and discrimination.

Aboriginal scholars agree that the colonization process and its continuing impact is, in fact, the most influential determinant of health for First Nations, Inuit and Métis peoples in Canada (Greenwood, 2009; King et al., 2009; Saylor & Blackstock, 2005; Smylie & Adomako, 2009). According to Reading & Wein (1999), almost every one of the SDOH is influenced by residential school attendance of self or family members. This experience can have an intergenerational effect that, rather than being diluted by time, is exacerbated through ongoing systemic and interpersonal aggressions at collective and individual levels (Bombay, 2009). In Canada, health inequalities continue to have significant effects on growth, development and the adult prospects for well-being of Aboriginal children, often expressed as statistics without analysis of social, economic and historical factors (King et al., 2007).

Discussion

Economic, social, and political factors entailed in the SDOH have significantly affected the health of Aboriginal children in Canada. Failure to address the SDOH results in interacting cumulative effects that increase health inequities and restricts efforts to work in an ethical space. Finding ways to address the SDOH to enhance health promoting strengths, particularly cultural strengths, known for their importance to child development is essential (L. Brown, personal communication, Oct. 4, 2012; Greenwood, 2009). Early childhood, a critical developmental period, is marked by particular vulnerability to the impacts of the SDOH for Aboriginal children (Greenwood, 2005). Child welfare involvement in Aboriginal families is, also, influenced by the cumulative effects of the SDOH as a result of the historical context (Blackstock, 2007; Greenwood, 2005; de Leeuw, Greenwood & Cameron, 2010; Greenwood & de Leeuw, 2012; Saylor & Blackstock, 2005; Smylie & Adomako, 2009). For example, the inequity found in the interaction of poverty, social exclusion, access to health service and housing, along with limits to education and child welfare funding have roots in colonial and assimilationist processes (Blackstock, 2007; Trocme, Knoke, & Blackstock, 2005; Bombay, 2009). The resultant disparities have substantial effects on growth, development, and prospects for well-being (Greenwood, 2005; Smylie & Wein, 2009).

Traditional health and social research are implicated in both past and present colonial practices. Finding solutions to address systemic factors which perpetuate health inequity for Aboriginal children

and communities is not simply a matter of doing more research. Effective research approaches are needed to conduct research that is significant, empowering and ensures that results drive policy and practice. CBPR research begins with the development of meaningful relationships between researcher/s and community/ies providing a base for making sure sound, ethical research is carried out. Wesley-Esquimaux and Calliou (2010) describe a “wise practices” approach to research with Aboriginal peoples. Based originally on a UNESCO concept and consistent with CBPR principles, wise practices are understood as highly contextual and build on and enhance community strengths, culture and efficacy (Wesley-Esquimaux & Snowball, 2010). The basic skills required for success in carrying out CBPR include: deep listening, establishing authentic and meaningful relationships, showing respect for each team member’s gifts/skills, revising taken-for-granted language and terminology, displaying belief in the process, and a willingness to make changes or respond to change as needed or as informed by the community.

Conventional approaches are often taken as a given, failing to take full advantage of the knowledge, insight and expertise that Aboriginal community members could contribute to framing and answering important research questions. Inequities in the health status of First Nations, Inuit and Métis children can, in part, be understood as a result of the failure of conventional health research to address the worldview of Aboriginal peoples and their experience of the SDOH. Understanding how and why these disparities are created and maintained in specific populations and communities is an important first step towards ethical research interaction aimed at developing and implementing appropriate interventions, practices and policies. Comprehending how the SDOH interact in a cumulative manner, adding not only to the health burden for an individual child but for entire communities of people in a cyclical process that increases over time is necessary.

Programs that address the SDOH and asset enhancing strategies for improving the well-being of marginalized groups are vastly underfunded, potentially undermining researcher’s intent and results. CBPR principles and practices, along with the ethics of Indigenous research and the skills needed to work with communities must be taught to students prior to beginning research. The use of collaborative research methods is not just legitimate but preferred in this context. The implications of ethical guidelines in research with Aboriginal and Indigenous peoples as discussed in OCAP and the Tri-Council policy must be understood. Commitment to incorporating these guidelines in an ethical space of dialogue and co-learning is required by researchers, academic institutions, research ethics boards, and funding agencies (Baydala, 2011). Research must meet ethical standards, respect contextual community-based processes, and ensure results appropriate to community use. Institutional change is needed to support the education needed to use CBPR appropriately, to open up research practice models, and prepare university ethics boards for assessing ethics in this research context. Funding bodies must also reflect the greater time and costs involved in CBPR research. In addition, change is needed in the institutionalized culture of how status is achieved and rewarded in order to validate CBPR and take into account the additional time required.

Conclusion and recommendations

Recently, Nigel Fisher, President and CEO of UNICEF Canada, reported that “the health conditions of Canada’s Aboriginal children are not what we would expect in one of the most affluent

countries in the world” (as cited in Greenwood, 2009, p. 2). Given this discrepancy, we hold that CBPR is an important approach to research which enhances our ability to address these issues. CBPR is centered in ethical and collaborative research partnerships that require that team members, both academic and community-based, engage in trust, co-learning and capacity building and avoid replicating colonial dynamics that have contributed to a guarded response to research and researchers. In seeking an ethical space to communicate and work together, CBPR allows for the bridging of community concerns regarding trust, while addressing self-identified community needs, protocol and methods.

We endorse the Canadian Paediatric Society’s position statement supporting CBPR as the first option for all research involving Aboriginal children and youth, especially research that encompasses the SDOH (Baydala & Starkes, 2014). Researchers must make certain that everyone involved whether as co-researchers, Elders and/or research participants are fully aware of their options for meaningful collaboration. To carry this out, research engagement and practice needs to take place within a dialogical and relational space where actions reflect regard for respective knowledge systems, experience, and principles of self-determination, protocol, and decision-making. Working together in this ethical space requires that researchers fully comprehend the historical, social, and culturally embedded factors that influence appraisal of child and community health and relevant ways to address them. Avoiding risk in research with all children must bear especial weight, given their vulnerability. In Aboriginal community’s research involving children needs to be based in context, in strengths and community assets and importantly in relationship. Given high needs, social and health research should not reify approaches that perpetuate inequities, however unintentional (Baydala, 2011). CBPR should be considered by all researchers working with Aboriginal children, families and communities as a means to meet these requirements.

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