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Original Article

Everyday ethics of participation: a case study of a CBPR in Nunavik

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Abstract

Introduction: Multiple reports highlight the need for community-based family-oriented prevention services for Aboriginal peoples in order to address important health and social inequalities. Participatory, empowerment-based approaches are generally favoured for these means. Faced with important social issues, in a context of colonisation and complex power dynamics, we question how community members experience participation, as well as the everyday dynamics that take place when attempting to create community-level change.

Context: The initial steps of this community-based participatory research (CBPR) took place over a two-year period in a community of Nunavik, a large northern region of the province of Quebec. The objective of the CBPR was to develop a community-driven project aimed at supporting families to be able to keep children within their homes or communities, rather than having to be placed under child welfare services.

Method: We participated in, and documented, various group meetings, community workshops, informal reflexive discussions, and formal interviews with community partners to explore their everyday experiences of participation in community-based change.

Results: We describe some of the initial actions taken in this project. We describe how certain social and power dynamics infiltrated into the process of participation leading to various tensions, personal and interpersonal experiences and needs.

Discussion: We discuss how these experiences led to everyday ethical dilemmas regarding participation. We conclude that although participatory approaches towards community change may be effective, they are also ethically challenging and at times disempowering for those who participate. We describe some of the approaches used to work with these ethical challenges. (Global Health Promotion, 2018; 25(1): 82–90)

Keywords: community development, children, empowerment, power, Aboriginal wellbeing, needs assessment, ethics

Introduction

A recent report from UNICEF suggests that 'Inuit live in some of the worst conditions in Canada, which negatively affect the health of Inuit children' (1). Many have highlighted the need for community-based empowerment approaches in order to reduce health and social inequalities experienced by Aboriginal peoples, including Inuit (2–5).

Community-based participatory research (CBPR) is socially motivated research that generally includes an intervention strategy (6). It is oriented towards

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social justice, reduction of social inequalities, empowerment and change (5,7). The principles of CBPR include, but are not limited to, inclusion of multiple stakeholders, recognising the uniqueness and strengths of all partners, development of trust, collaboration and shared decision-making, promoting capacity building and empowerment (8, 9). CBPR has been used with success in First Nation and Inuit communities of Canada and abroad (10–15), as part of ongoing attempts to decolonise research in the field of Aboriginal health (16). Buchanan *et al.* suggest that CBPR is an ethical research position (17), a posture of respect for communities in their ability to address their social and health concerns through actions. Community-oriented approaches are often assumed to be empowering. In our own experience of community intervention, in a specific Inuit community, we were often faced with feelings of disempowerment and ethical dilemmas regarding participation and expectations of change.

Ethics, CBPR and Aboriginal research

Very broadly, research ethics is about reflecting on standards of 'doing right' for individuals and collectivities. Ethical practice has been a major concern in Aboriginal research (14,18). The difficult history of research in Aboriginal communities has led to the development of ethical guidelines and principles such as OCAP (Ownership, Control of data, Access to data and Possession of data), the Tri-council Policy Statement and the 4Rs (Respect, Reciprocity, Relevance, Responsibility) (19,20). Similarly, the multiple challenges associated with conducting CBPR in general have also led to outlining and promoting principles, guidelines and codes of ethics (14,21–24). These have largely explored the complex dynamics between researcher and community (14,17,21,25). In their literature review on ethics and CBPR, Banks *et al.* identified six recurrent themes (26), all of which are directly related to the role of researcher and possible tensions between research and community.

This case study is an illustration of the dynamics, experiences and processes that can take place when partnering in community change. Macaulay and Nutting suggest that such case descriptions of both the 'successes' and 'setbacks' allow communities and researchers to engage in a meaningful dialogue on methods and practice of CBPR (27).

The context and community

Faced with social issues and lack of adequate services, the Regional Partnership Committee (RPC) composed of Inuit leaders representing all institutions and organisations of Nunavik, requested the support of a group of researchers and non-for-profit organisations in the development of community programs for young children and their families. The long-term goal was to reduce the number of reports and placements under child welfare services. In 2009, one of the fourteen communities of Nunavik volunteered to pilot the project. In 2012, the RPC passed a resolution registering the project as a regional priority. The community of Kuujjuaraapik was invited by the RPC to be the first community to take on this project.

Nunavik is the northern region of the province of Quebec, Canada and home to approximately 12,000 Inuit. Kuujjuaraapik is the southern-most of 14 communities of the region, and is over 1000 km from Montreal. 'Communities' of Nunavik started developing in the 1930s–1950s, following forced settlement of nomadic peoples who traditionally lived uniquely with immediate and extended family. In the 1950s, school became mandatory. Kuujjuaraapik, also known as Great Whale, was the location of a trading post in the early nineteenth century, and later became a military base and airport. Families aggregated around this area, which became what is now called Kuujjuaraapik. Today, the Inuit population of Kuujjuaraapik is less than 700. It is unique in the sense that Kuujjuaraapik shares geographical space with the Cree community of Whapmagoostui, population of approximately 900. Kuujjuaraapik has a municipal office, a day care centre, a school, a health clinic, a social services clinic, a youth protection centre, a church, a gym, two general merchandise stores and a governmental building that includes administrators from the school board and the regional government. There are approximately 160 housing units in the community for Inuit. Under the James Bay and Northern Quebec Agreement, medical, social and education services for people of Nunavik are under provincial legislation.

The coordinator of the RPC, who is originally from Kuujjuaraapik, was appointed by the RPC as main regional collaborator for the project. She was in charge of linking with regional organisations,

making the liaison with the community, and participating in all decision-making. A local *core agent* was hired in Kuujjuaraapik to create links with all community services, to communicate with the community, participate in decision-making and help coordinate community activities. A local advisory board was created from a list of potential leaders based on informal discussions with key informants during community visits. A total of five residents from the community, aged 28–55, took on the mandate. Four had steady jobs in different sectors in the community. Their role was to act as community consultants and decision-makers for most community level decisions. After 2 years, the advisory board members reached out to community members inviting them to join the group. The board currently consists of 10 individuals between the ages of 20 and 75; two youth and two elders.

The research group was led by a non-Aboriginal researcher who had worked in the field of aboriginal youth protection and Inuit health for approximately 5 years. Three co-investigators were invited to act as external 'research consultants' to the main researcher. Two are non-Aboriginal and one is Aboriginal. Three graduate level students joined the team. They played an active role in both community actions and documentation for research purposes. All are non-Aboriginal. RPC asked that this research group support the community of Kuujjuaraapik by providing guidance and resources, recording the program's development and implementation and participating in knowledge transfer activities.

The community had previously received support and financial resources from an NGO, 'Quebec en Forme'. Their mission was to support healthy living. The first author was asked by the regional partners to co-write, with the coordinator, a grant proposal to an NGO specialised in community mobilisation for the wellbeing of young children, 'Avenir d'enfants' (AE). AE offered financial resources over a 5-year period and a part time agent who would support local initiatives. This agent had previously worked one year in another northern Inuit community.

A memorandum of understanding was developed in the first year and signed by representatives of the regional partners, local partners, non-profit organisation and the University of Montreal. All steps and methods of the project were decided upon collaboratively with regional and local partners.

Action research methods and data analysis

All actions were planned and conducted based on criteria of trustworthiness in naturalistic settings, as described by Holkup *et al.* and based on Guba and Lincoln (28,29). Methods included workshops for the advisory board as well as for the entire community, community indoor and outdoor events for mobilisation, door-to-door surveys to document family needs and visions for a community family prevention program, individual interviews and more. Results from all activities were documented and returned to the community via newsletters, public radio, evening workshops, and white boards on the community centre walls to show how results can be translated to concrete actions. During all group meetings, workshops and interviews, the PI and research assistants took detailed notes.

For the analysis of this study, we read over field notes, meeting notes and interviews. We jotted down themes and reflections related to ethical or moral dilemmas as well as general themes related to community member participation. We engaged in reflective and reflexive sessions with research students, local and regional partners throughout a one-year period. By reflective, we refer to a circular questioning of situations, events and actions in an attempt to see different possibilities of why and how they are taking place.

Questions included: What are the relational and social dynamics that take place? What could be reasons for these dynamics? How do partners negotiate these dynamics? And what are some ethical dilemmas that arise? By reflexive we mean being aware that we, partners, are part of the social world that we are observing and therefore emotionally involved. We were attuned to our own reactions and reflections, as well as to the impact of these reactions on the interactions that take place with different partners. We challenged and questioned our own reactions and those of our partners in a respectful manner. All reflexive sessions were documented. After the first 18 months of the project the recurring themes related to ethics and participation were organised by the first author and shared with the local and regional partners for approval. Then the first author went back to the data and extracted verbatim examples that corresponded to the themes. The article was written

in collaboration with two co-investigators (authors 2 and 3) and a community partner (author 4).

A brief summary of the project and vision

The vision that was established was as follows: *reconnecting families by sharing, being positive and non-judgmental, and bringing culture into people's lives*.

The vision led to the organisation of three broad goals: 1) develop community capacity and mobilisation via the opening of a community space for all families; 2) improve links and collaboration between community members and services, both local and regional, in a way that empowers communities and respects Inuit ways; 3) develop a regional working group that would be of assistance in program development to transfer the acquired knowledge to other communities.

Actions were organised to initiate the community mobilisation, make a building accessible for the project and start planning the project around goals and activities. This included meetings with the municipal council and regional institutions, renovating the building, having a cultural and social activities coordinated by community members, developing a monthly activity calendar, opening a Facebook page and going on the radio to ensure constant communication with the community. To date there has been a very positive response from the region, both from individuals from other communities and from institutions. First activities started approximately 1 year after the first advisory board meeting and immediately attracted between 2 and 20 community members. Local and regional organisations have offered to support different facets of the project and have created policy level changes such as developing funds specifically for family-oriented community-based projects and explicitly making these projects a top priority for their organisation. The most general positive comment heard from both Inuit and non-Inuit community members is 'it gives us hope'. That being said, the challenges have been great. These are described below.

The process

Integrating multiple voices

The use of activities and workshops allowed for quick mobilisation; however, they naturally pulled together individuals who were already quite involved in the community, people who were generally used to working together and who already had a certain sense of belonging. In a first 3-day community workshop, 15 community members participated. Participants included one elder, four youth, two Cree women from the community and Inuit men and women working in different organisations in the community. The absence of more disadvantaged and marginalised individuals within these workshops was not necessarily observed or discussed by the participants. On the contrary, the absence of individuals with specific roles within organisations and institutions was noted by the attendees and left people reflecting on the meaning of their non-participation: did they feel that the project was not important enough? It created a feeling of disempowerment, as though the absence of these people said something about the importance of Inuit voices. Many have written about the complexity of determining what 'community' represents and who 'represents community' (27,30,31). However, in this case the questions elicited included: Whose voices do community members expect to hear from? And how do we create change in power hierarchies when those with most power are often looked-up to with expectations? Some have suggested purely bottom-up approaches may not be sufficient for effective outcomes and empowerment. It has been suggested that initiatives that include both bottom-up and top-down may be most promising, as they increase feelings of marginalised individuals being heard by those who actually have decision-making power (27,32).

Power of exposure, power of exchange and spaces to elicit visions

Using different methods to hear the community members' vision for the project, it became clear that people have different abilities in imagining and in expressing a vision. This led to disadvantages in being able to participate in creating a common vision. Those who described the clearest and most detailed vision for a centre were those who had the most prior exposure to external resources including RPC members who have travelled, been to conferences, and have seen a variety of organisations and services. However, being of higher administrative ranks and from other communities, they would not

be the ones doing the everyday decision-making and actions for the centre.

To enhance experiences and exposure to different possibilities, the advisory board requested to visit community-based organisations from other regions to create their own vision. Similarly, during the needs assessment interviews, we noticed an important evolution in the development of visions for the project as the conversation took place. Participants were asked what they thought of when they heard the words 'family-house'; what they felt would help the community. Only two individuals had clear visions from the beginning of the interview. These two individuals had previously visited community centres with similar goals. For all participants who had not visited family centres or community centres, the first answers to our questions were almost systematically: I really don't know. This would then be followed by a one-liner such as: 'a place for families to go and be together'. The participant would generally develop a more and more detailed vision of the centre as the interview evolved.

This brought a long-standing and evolving reflection amongst partners regarding exposing people to other projects and resources. On the one hand, we were concerned that these exposures could influence the vision making, and therefore exert a certain 'power over'. On the other hand, without these spaces of exposure and exchanges, individuals often felt overwhelmed or unable to imagine something different from what they knew. One of the advisory board members told the external supporters: 'Give us something to work with, to bounce ideas off of each other. If we don't like it, we'll tell you. Without ideas, we can go on forever, not knowing where we're going'.

Over time, we found that exposure to possibilities was useful in mobilisation during the first stages of development. When external ideas, projects and resources were exposed as 'possibilities', without being qualified, people seemed to take in what made sense to them and leave out, as if not hearing, other resources or ideas. However, at times, external individuals came into the community, or the project, proposing resources or activities, and when faced with 'non-answers' (people not directly responding to their proposition), they would push their idea even more, or make it happen themselves. This was discussed by community members as being quite stressful and frustrating. Presenting external resources may be interesting, perhaps necessary in certain contexts, but it is also delicate.

The social context of dreaming

Partners, including the researchers, were told by non-Inuit individuals, who live in the north, that the project would be impossible, that people would never participate. We heard comments such as: 'Good luck! Inuit will never volunteer' or 'Inuit will never remain involved in the project'. In this project we felt that prejudices could dissuade people from creating or putting their visions into action. Similarly, when Inuit participated, made decisions or took action, some individuals, both Inuit and non-Inuit would at times speak negatively in their back. Their involvement was at times assessed as not being sufficient, or not exactly what was expected. This again created negativity by discrediting their actions and at times led to feelings of disempowerment.

> I see people don't know that it's a good thing, they don't know what to do, they don't know how to get it going, I sometimes don't know what to do, where to go and the only thing to do is move forward and try something.
>
> Advisory board member

Moreover, there were important structural barriers to making visions real. During the advisory board's visit to a Montreal-based community centre, the representatives of the centre discussed their roles with 'at-risk' families, families who for different reasons are at risk of being signalled or having children placed in child welfare services. They explained to the advisory board that they would often represent families in court; they would do assessments and actively fight for the best interest of the children. Amazed, one of the members of the advisory board inquired: 'and does the court system take you into consideration when they make their decisions?' to which the enthusiastic community-centre representative answered: 'of course, we are lawyers, doctors and psychologists'. This answer provoked reflection and exchanges between researchers and the advisory board members who realised that when Inuit children were placed within a family or a centre, not only did family members

not have a say, they may not even realise that they might be allowed to have one.

Finally, perhaps one of the most difficult challenges we experienced was shared decision-making at the community level. Who would make decisions and take action? We experienced what many partners described as a social phenomenon: not speaking directly to one another about different points of views and frustrations. It became difficult to have group meetings. Individuals were encouraged to speak their mind, but they felt guilty about opening up while others felt attacked by reflections and comments that might be different from their own. This has been observed by others (33), and may be related to a traditionally adaptive way of interacting in a context where few individuals lived together and were incredibly dependent on one another. The literature on aboriginal health has also described how a history of colonialism and ongoing experiences of discrimination have led to intergenerational trauma, which impacts interpersonal relations and communications within families and communities (34–36). Above and beyond the causes, shared decision-making, conflict resolution and problem solving are key ingredients to group efficiency, and are also identified as essential factors for community readiness (37–39). Without these ingredients, group members generally will not feel group satisfaction, feelings of effectiveness and of belonging (40,41), nor will there be positive outcomes.

The partners involved in the project felt that before requesting shared decision-making, people had to feel safe. To develop this safety, people had to get used to spending time together, with no expectations and a positive atmosphere. Activities that allowed for this included arts and crafts and cooking, activities that are not focused on solving problems but rather on spending time together. A year into these art and culture activities, a group of 10 people have accepted to take on shared decision-making, to develop a more formalised team functioning and to develop common objectives, and this, with very little external support, calling upon support when the need is felt.

The process of disempowerment and empowerment

The workshops as part of the needs assessment were particularly uplifting to people, as were the return sessions where their needs were written out and shared. People described a sense of having been heard, of achievement and being closer to the project goals. However, the weeks following the workshops were often accompanied by what was described by community partners as a sense of loss and loneliness. Faced with negativity from the individuals who had not participated in the needs assessments, lack of resources to transform the vision into actions, and the presence of important structural and hierarchical barriers, partners described mounting frustration and disempowerment.

> It's been most difficult to go through what we've gone through (in the project)…. We all know that we are suffering people and we have been talking about how to better ourselves, and what we can do, … and I strongly feel we have one (solution) but yet when we really try to work at it we face so many difficulties. We have to remind ourselves why we are doing this, because if we don't it is very easy to quit, very easy to quit…. It's very heavy, it's a burden.
>
> Advisory board member

> This project reminds me that Life is like a sailboat, we are all on a boat together going in a direction that we are not completely sure of, there are days when the weather is great and the sailing is smooth, there are days when it gets rainy and there are other days when the Storm gets so strong you just want to jump off the boat and swim towards the shore.
>
> Advisory board member

The community partners most involved in the project experienced many difficulties working as a group, which led to feelings of disempowerment and the need to distance oneself from the project. All partners engaged in the project, had recurrent periods of distancing where they became completely unreachable. However, this would often be accompanied by feelings of guilt.

> When I'm not there I constantly feel guilty. I wonder why I'm not there. The project is part of me no matter what, but sometimes it is too much.
>
> Advisory board member

Generally the re-ignition of the common project vision via concrete actions or intense positivity on behalf of partners brought people back to an active state.

As partners in the projects, we continuously questioned whether decisions should be made when others were taking a break. Indeed, we noticed that decision-making halted when certain partners were busier or emotionally unavailable. During these periods the project was slow and certain partners felt disappointment from things not going as planned. The balance between ensuring all partners were active decision-makers and ensuring that the project moved forward for the community was difficult to attain.

Discussion

As partners in a community initiative, as active promoters of social change and of reflexivity, we felt an ethical obligation to explore ethics beyond our more traditional concerns related to research. In a context where community members participated in creating social change, we wanted to describe the complex dynamics that took place, and the ethics of these dynamics.

In contexts of social marginalisation and ongoing oppression, there may be added factors that influence dynamics in community mobilisation. Inuit, especially in such remote areas, do not always have access to economic, social, and political resources required to make the expected change. Moreover, longstanding oppressive practices have had impacts on lateral violence, mistrust, power dynamics and general wellbeing. This directly influences the ability to engage in discussions, problem solving, conflict resolution, and speaking one's mind, all of which are essential for group efficiency and positive outcomes (37–39). For community partners in northern communities this means engaging in intense processes with friends and family, with individuals they live with on a daily basis. Whether a project is part of CBPR or a non-research partnered community initiative, these actions can threaten individual and community feelings of wellness.

We, as partners, realised that developing community visions and programming, in a context of colonisation, and in small communities, can come at an emotional and social cost. Change is desired yet it is difficult. As described by others, in attempts towards change there is a split between hopes and reality. Promises confer hope but can also participate in reproducing social dynamics (42–44). Ayala suggests that inviting individuals to participate in change can bring both feelings of empowerment and vulnerability (43), especially when partners must go against complex social and political dynamics. Ayala cites Fine (43), who says that in such contexts we are 'asking them to expose the elephant in the room, knowing they may get trampled in the process'. Cooke and Kothari have called this the tyranny of participation (42). In this project all partners used the words: 'walking on eggshells' to express the complex dynamics.

We therefore continuously questioned ourselves: when is the process bringing more harm than benefits and to whom? Are certain individuals experiencing more harm for the benefit of others? And if it is their decision to participate in change, despite the immense personal and social challenges, how do we continue participating as partners knowing that certain people are feeling the burden of participation? We wondered whether requests for participation should stop despite the project not being completed. However, if the project was not maintained it would be a failure, which in itself is unethical in a context where partners felt that they had experienced a history of failed projects, and where failed experiences lead to a decrease in community readiness for future community projects (37,40,45). Moreover, Kesby *et al.* suggest that empowerment and ethical practice comes from perseverance, long-term outcomes and constant reflexivity (46).

Researchers, and other partners engaged in community change cannot naively assume that change will not be accompanied by important difficulties and that creating spaces for 'empowerment' and community participation is not without harm and conflict (46–49). Kothari reminds us that participatory approaches towards social change are in themselves exercises of power relations (42,50). We must assess the difficulties and readiness of partners and explore how to offer support to those who are experiencing the challenges of participating in such a project. Some of the mechanisms we naturally adopted were to support all partners when feeling the need to take a distance from the project, and maintaining a connection and relationship with the partners even when they were less engaged. This

way, they would hopefully understand that they were respected no matter their degree of involvement or non-involvement. This allowed for partners to disengage when needed. We also attempted to create possibilities for community partners to have one-on-one communication with an outside partner, so as to have the opportunity to speak their mind without the perceived risks of hurting a fellow local partner. As described by others, promoting shared decision-making in contexts of social marginalisation and unequal power dynamics can be threatening (42,46). It is important to be aware of the social dynamics and social experiences lived by those who are invited to participate in community change. As noted by Mantoura and Potvin (51), such spaces for dialogue are infused with power relations, needs, conflicts, and organisational contexts, all of which must be acknowledged and discussed by those proposing participation and change.

We feel that sharing this experience not only contributes to the literature on CBPR, but also to an understanding of the experiences and complexities of change in certain communities, where change may be most needed and hoped for.

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Conflict of interest

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