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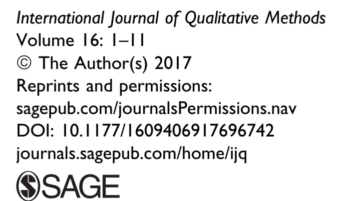

A Case Study of a Methodological Approach to Cocreating Perinatal Health Knowledge Between Western and Indigenous Communities

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Abstract

This article describes the methods taken to create an understanding of the perinatal health beliefs of elder Indigenous women of the Six Nations of the Grand River in Ontario, Canada. Our study paired constructivist grounded theory data collection and analysis methods with an Indigenous epistemological framework. We aimed to create knowledge that was specific to an Indigenous context, which was useful and resonant with both Indigenous and Western readers. The multidisciplinary research team included Indigenous and non-Indigenous members and worked with a common appreciation for multiple knowledge sources. We offer an account of our process and methodological principles to serve as an illustrative case study of bringing together diverse approaches when working with Indigenous communities.

Keywords

constructivist grounded theory, perinatal health, maternal health, Indigenous health, pregnancy, coding

What is already known?

Despite challenges from historical circumstances and present socioeconomic conditions, Indigenous knowledge has thrived and Indigenous peoples have demonstrated remarkable resilience, supported in part by their connection to traditional Indigenous worldviews and knowledge (epistemologies). The pluralism of Indigenous worldviews is a familiar perspective to qualitative researchers who are used to multiple ways of perceiving the world and making sense of the social landscape. In this respect, qualitative researchers are well positioned to respect alternative ways of seeing the world and adapting their research framework accordingly.

What this paper adds?

The purpose of this paper is to describe a collaborative research study and demonstrate a methodological approach that places precedence on Indigenous knowledge and worldviews, while maintaining qualitative research rigour. The scientific application of Indigenous knowledge that is both culturally relevant and upholds Western scientific principles is important because it results in the co-creation of health information that fulfills the needs of diverse communities.

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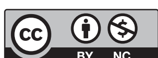

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Introduction

The purpose of this article is to describe a collaborative research study and demonstrate a methodological approach that places precedence on Indigenous knowledge and worldviews, while maintaining qualitative research rigor (remaining congruent to the aims, priorities, and understandings of both groups). The scientific application of Indigenous knowledge that is both culturally relevant and upholds Western scientific principles is important because it results in the cocreation of health information that fulfills the needs of diverse communities. Through the facilitated exchange of valuable practices and understanding, our approach achieves an integrated and culturally sensitive knowledge exchange with broader audiences. We show one way of working collaboratively to produce meaningful and impactful knowledge with an Indigenous community in Canada, through the incorporation of diverse ways of doing, thinking, and being.

The scientific objective of our qualitative study was to understand the perinatal health beliefs of elder Indigenous women as a supplement to the active longitudinal Aboriginal Birth Cohort (ABC) study (Wahi et al., 2013). We answered this question by speaking with 18 grandmothers who lived on the Six Nations reserve about their thoughts, advice, and understandings of health and well-being throughout pregnancy and the postpartum period. The research team involved in this study consisted of Indigenous and non-Indigenous members with clinical and research experience (medicine, midwifery, and qualitative health research methodology), community-level contextual experience, and artistic experience (poetry, filmmaking). The focus of this article is on the methods and processes carried out to conduct this qualitative study, not the results. A detailed description of the study findings is published elsewhere (Kandasamy et al., 2016).

We start with a review of our theoretical lenses and the perspectives we brought to this work and then detail the way that the study design and activities were carried out. The account of our research process also includes an explanation of some of the strategies that were used to enhance the experiences of nonresearchers who played an integral role in the data analysis and data dissemination phases. We conclude with a discussion of the importance of diverse strategies for knowledge communication.

Indigenous Peoples of Canada

Canada is a country of 35 million people, approximately 1.4 million of who identify as Indigenous (Statistics Canada, 2011). Although “Aboriginal” is the term recognized in the Canadian Constitution Act of 1982 to include people of Inuit, First Nations, or Metis ancestry, we will use the term “Indigenous” in order to acknowledge the preference of the community members we worked alongside.

The total population of Indigenous peoples is distributed over 600 different governments or bands and across urban/rural and on-reserve/off-reserve communities. Reserves are regions of land that are held under the legislation of the “Indian Act” and treaty agreements for the “exclusive use of an Indian band” (Government of Canada, Amended 2015). Across these groups, there is much heterogeneity in regard to culture, language art, and health practices.

Indigenous peoples in Canada face great health disparities in regard to chronic health conditions (cardiovascular disease, cancer, arthritis, kidney disease, diabetes, asthma, bronchitis; e.g., Anand, Yusuf, Jacobs, & Davis, 2001; Shah, Hux, & Zinman, 2000; Sin, Wells, Svenson, & Man, 2002; Yusuf, Reddy, Ounpuu, & Anand, 2001). Those living on-reserve have a higher prevalence of chronic conditions than those living off-reserve, especially in the case of cardiovascular diseases and diabetes (Loppie Reading & Wein, 2009). However, both on-reserve and off-reserve rates of chronic disease are generally higher than they are for non-Indigenous Canadians (Loppie Reading & Wein, 2009). In regard to the predispositions of these chronic conditions, it is widely accepted that prenatal origins and childhood circumstances can shape the course of one’s adult health (Boyce & Keating, 2004). For example, McEwen (2006) report that adverse social environments during early life can trigger recurrent stress responses that initiate the enduring physiological changes that underlie chronic diseases.

The contemporary lives of Indigenous peoples living in Canada have been tremendously influenced by colonial history. The policies of the Canadian government dating back to 1876 have left the majority of Indigenous peoples living in poor socioeconomic circumstances, with high rates of substance abuse (Chansonneuve, 2007), and increased interaction with the criminal justice system (Rudin, 2005). These factors are closely intertwined with intergenerational trauma related to residential schooling (Wesley-Esquimaux & Smolewski, 2004) and other colonial policies that led to the removal of children from their homes. This has led to the deeply rooted loss of language, culture, and traditional ways of living (McIvor, Napoleon, & Dickie, 2009), resulting in widespread perceptions of loss and grief (Cull, 2006).

Principles Informing Our Research Framework

Despite challenges from historical circumstances and present socioeconomic conditions, Indigenous knowledge has thrived and Indigenous peoples have demonstrated remarkable resilience, supported in part by their connection to traditional Indigenous worldviews and knowledge (epistemologies). The pluralism of Indigenous worldviews is a familiar perspective to qualitative researchers who are used to multiple ways of perceiving the world and making sense of the social landscape (Hart, 2010; Olsen, Lodwick, & Dunlap, 1992). In this respect, qualitative researchers are well positioned to respect alternative ways of seeing the world and adapting their research framework accordingly.

Adopting a pluralistic Indigenous worldview can be seen as a decolonizing act, working to advance the interests of Indigenous peoples in the face of traditional Western understandings of science and knowledge. Decolonizing acts are critical responses to colonialism that empower Indigenous ways of knowing, being, and doing (Smith, 1999). Adopting an

Indigenous worldview includes the valuing of knowledge that comes from diverse sources, including traditional, spiritual, and empirical sources (Dei, Hall, & Rosenburg, 2000).

> Decolonization is not 'integration' or the token inclusion of Aboriginal ceremony. Rather, it involves a paradigm shift from a culture of denial to the making of space for Aboriginal political philosophies and knowledge systems as they resurge, thereby shifting cultural perceptions and power relations in real ways. (Regan, 2010, p. 189)

Indigenous knowledge involves a holistic paradigm that recognizes the emotional, spiritual, physical, and mental well-being of a community. An Indigenous knowledge framework is developed to address critical issues of colonialism appropriating Indigenous authority, of misrepresentation, and of using Western cultural constructs of "valid empirical research" to marginalize Indigenous ways of knowing (Dei et al., 2000; Smith, 1999).

Multiple theoretical and social perspectives brought by the multidisciplinary team of Indigenous and non-Indigenous academic and nonacademic collaborators informed this study. We worked within a shared understanding of the sociohistorical context of Indigenous peoples in Canada, and a mutual commitment to flexibility and inclusivity of each other's perspectives.

Our study focuses on the knowledge of grandmothers and great-grandmothers, recognizing their special place in Six Nations culture as key leaders in the transmission of linguistic and cultural knowledge, especially to subsequent generations. Many Indigenous communities, including Six Nations, are based on a matrilineal structure (Ramsden, 2006), where women in their roles as mothers, sisters, aunties, daughters, and grandmothers play pivotal roles in ensuring the well-being of children, families, communities, and cultures (Lavell-Harvard & Lavell, 2006). This cross-generational transmission of teachings and cultural beliefs among women has maintained the stability of Indigenous societies, despite the fragmentation, loss, and grief caused by colonial policies (Cull, 2006). Thus, women are a key source of strength and resiliency for their communities (Lavell-Harvard & Lavell, 2006); the strength to move forward from the impacts of colonialism depends on women in their roles of nurturing and raising children (National Collaborating Center for Aboriginal Health, 2012). To build on this, recent studies have also reported on the immense value in engaging elders within the research process (Flicker et al., 2015). This is important because it serves as a way of encouraging and respecting Indigenous ways of knowing and can help researchers understand and amend study protocols to ensure that cultural values and practices are upheld (Baydala et al., 2013).

Building on Wilson's (2003) outline of the principles for Indigenous research, Hart (2010) identified important several values to guide such research, as well as some actions that would reflect these values. The values, along with how they were translated into research-oriented actions within the context of this study, are summarized in Table 1 and explained in detail in subsequent sections of this article.

Research Context and Aim

This project's community partner is the Six Nations of the Grand River, a Southern Ontario reserve of approximately 25,000 Haudenosaunee people, of which about 12,000 live within the borders of the reserve. Our research team has maintained a strong, positive relationship with Six Nations since 1999 and we have worked on several collaborative studies (e.g., Anand et al., 2001; Oliviera et al., 2013). To build upon this foundation, the primary researcher (SK) spent substantial time engaging with the community and taking a vested interest in learning more about Six Nations culture and heritage. SK visited the Six Nations reservation on a weekly basis and fostered positive relationships with community leaders, including elders. She also participated in an 8-day exchange program on the Six Nations reserve to learn about and reflect upon Six Nations history (including the residential school system), health services, local businesses, art, recreation, and literature. These extra initiatives helped the primary researcher reflect upon and maintain self-awareness and understand personal biases and subjectivity throughout the research process.

The scientific goal of this study was to understand the current perinatal health beliefs of elder Six Nations women and to create a culturally meaningful vehicle to disseminate findings to key stakeholders. This goal was built upon a growing understanding about the ways in which perinatal health behaviors impact health outcomes related to cardiovascular disease, diabetes, and obesity. Indeed, the improvement of prenatal health is an area that is currently a priority for the Six Nations Peoples (Oliviera et al., 2013).

Understanding the perinatal health beliefs of Six Nations people is an important step in translating the clinical knowledge about health outcomes so that culturally meaningful knowledge and interventions can be cocreated to improve cardiovascular disease, type 2 diabetes, and obesity rates in this group. For example, this could include the use of elder women as a vehicle to transmit clinical knowledge to the community. With these two sets of congruent priorities in mind, this qualitative study was designed to elicit understandings and beliefs from Six Nations grandmothers about optimal health in the perinatal period. As a result, the guiding research question of this study was: What are the perinatal health beliefs of Six Nations grandmothers?

The Research Team

Joint membership between McMaster University and Six Nations allowed for cooperative involvement in project planning, interview guide design, data analysis, the planning and execution of the knowledge translation project, and data dissemination. The McMaster team members had experience in the areas of cardiovascular medicine, qualitative health research methodology, epidemiology, knowledge translation, pediatrics, and psychiatry. They provided special assistance on the clinical background and research methodology. The Six Nations team members were opinion leaders who had experience working

Table 1. Values of Indigenous Research and How Each Value Was Applied in This Research.

Values	Examples of Actions That Uphold Values	Summary of How Values Were Specifically Upheld in This Study
Indigenous control over research	Having Indigenous people developing, approving, and implementing the research	• Active involvement of Indigenous community members in: (1) Research question design (2) Protocol development (3) Participant recruitment and scheduling (4) Data analysis (via community coder) (5) Knowledge translation (6) Data dissemination
Respect for individuals and community	Researcher being considerate of the diversity found within a community	• Thorough effort to explore the cultural, artistic, economic, and political diversity of the Six Nations community: (1) Several years of relationship building with the community (2) Active participation in a reflective 8-day immersion program on the Six Nations reserve (e.g., spending time with different community opinion leaders, writers, artists, healthcare professionals) • Relationship building and participation in supplementary programs: (1) More in-depth learning (2) Created opportunities to share this study with a diversity of people and community organizations
Reciprocity and responsibility	Researcher sharing and presenting ideas with the genuine goal of supporting a community	• Several meetings held with the community advisory group to plan and execute study for maximum community benefit
Respect and safety	Variety of methods taken to help research participants feel safe (e.g., addressing confidentiality in a manner that is comfortable)	• Significant time spent on preinterview conversations (e.g., detailed introductions between the researcher the interviewee) • Much time spent on the informed consent process to ensure participants received full disclosure of the research aims • Ample time given to answer questions and address concerns • Interviews held in a location selected by the research participant to ensure a maximum comfort
Deep listening	Carefully listening and paying attention to emotional content	• Completion of postinterview audio reflections on personal behaviors during the interview
Reflective nonjudgment	Researchers considering what is seen and heard without immediately placing a sense of right or wrong	• Additional discussions with Six Nations community members to maintain reflexivity • Taking note of emotions/intonations during coding
Self-awareness	Researcher listening to and observing themselves in relation to others during the research process	• No note-taking during interviews/focus groups • Continual self-awareness used to improve reflective nonjudgment and deep listening
Subjectivity	Acknowledgment of personal subjectivities to the research process and engagement in open and honest discussion of the subjectivity	• Maintaining notes and memos regarding personal biases and subjectivities • Files summarized in a document that is publically available (Appendix B)
To honor what is shared	Upholding the obligation to act with fidelity to the relationship between the participants and the researcher and to what has been heard, observed, and learned	• Upholding participant confidentiality during all post-data collection stages • Use of in vivo codes • Sharing the knowledge gained from this study with the community in a culturally meaningful way • This obligation propelled the design of the integrated knowledge translation project with a community artist

(continued)

Table 1. (continued)

Values	Examples of Actions That Uphold Values	Summary of How Values Were Specifically Upheld in This Study
An awareness and connection between the logic of the mind and the feelings of the heart	Incorporation of both the emotional and cognitive experiences within one's actions	• Primary researcher (SK) conducted all interviews, transcribed, and participated actively in analysis and knowledge translation • Involvement of a community coder • Several meetings held between the primary researcher and the artistic collaborators to translate the participants' emotional experiences into the final integrated knowledge translation piece (a poetic digital story-based film)

with pregnant women, providing postnatal support, midwifery care, and are involved actively in the community (including two grandmothers). They provided special assistance with the design of a community feasibility plan, participant recruitment, and support with contextualized data analysis.

Project Planning

The initial project planning consisted of individual face-to-face meetings with the Six Nations team. All individuals made important contributions in designing and implementing the research protocol, particularly in the areas of feasibility, relevance, and impact—as related to conducting research in an Indigenous context. During protocol development, the primary researcher also approached artists from the Six Nations community to develop relationships with individuals who could produce the final knowledge translation piece (a short digital story film that highlights the research findings). This study obtained ethical approval from both the Hamilton Integrated Research Ethics Board (REB ID #: 12-152) and the Six Nations Ethics Board. The Six Nations ethics approval consisted of an application that acknowledged the principles of Ownership, Control, Access, and Possession (OCAP; First Nations Center, 2007). OCAP is motivated by the notions of self-determination and the preservation of culture. OCAP protects First Nations communities' rights to own, control, access, and possess information about their peoples.

Description of Research Design and Methodology

With the aim of cocreating knowledge about perinatal health beliefs, we decided that a qualitative research framework that was flexible and able to accommodate various ways of sharing knowledge was most appropriate. With that in mind, we selected a constructivist grounded theory approach (Charmaz, 2014) and worked closely with each individual grandmother to understand her beliefs, priorities, and preferences using an open-ended interview that was conducted in an environment of her choice. This design capitalized on the early finding that the knowledge shared by the elder women frequently came in the form of storytelling. Long, loosely structured interviews gave the opportunity for women to share their knowledge in a comfortable manner and gave the researcher an opportunity to understand how and why participants were placing value on certain health behaviors (e.g., by the emotional attachment to their stories, the importance of each story's moral). In addition, the design allowed the research participant to engage in what they found to be important aspects of the research question using various vehicles (stories, family photographs, newspaper articles, personal experiences, etc.).

Recruitment

The core group of Six Nations community advisors assisted with locating potential participants, contacting them, and scheduling interview appointments. In addition, SK and TH attended several local health fairs and community gatherings to meet additional potential participants. Participation in such gatherings created supplementary opportunities to speak to the community about this research project, answer questions, and begin a sustainable dialogue about perinatal well-being. All interviews were scheduled by an advisory committee member (AD) to help participants feel at ease with the research process.

As constructive grounded theory uses an iterative and dynamic framework (Charmaz, 2014), it was mutually agreed that AD, the community advisor who scheduled all interviews, would space the interviews far enough so that there was sufficient time to transcribe and code the previous one. For this to be successful, it required frequent communication between all members of this multidisciplinary team.

Initially, a wide variety of grandmothers were recruited to obtain a general understanding of perinatal health beliefs. As data analysis generated specific themes and questions, we decided to purposively sample a targeted group of grandmothers who could address our queries. For example, when analysis revealed a need for more interviews with older grandmothers and grandmothers who had great-grandchildren, we attended community gatherings and worked closely with key community leaders to obtain personal referrals to women who met these criteria.

Knowledge Collection

Knowledge collection consisted of in-depth individual and group interviews with elder Six Nations women who self-identified as

grandmothers. This group included elder women without biological grandchildren, but who still took responsibility for caring for the younger generation and considered themselves to be "grandmothers" according to the traditions of the community.

During the early study design phase, we planned to conduct individual interviews using a semi-structured interview guide. Our earliest interview guide consisted of very specific questions about perinatal health (focused primarily on nutrition, exercise, and psychological well-being categorized into pregnancy, first 6 weeks of life, first 6 months, and first year). After completing preliminary piloting of this interview guide with community advisors and community members, it became clear that questions needed to be revised to reflect the way in which participants were naturally inclined to engage: storytelling. The use of specific questions was inherently limiting the richness of knowledge that participants could share. This realization prompted the research team to redesign the interview to include broad, loose questions that were compatible with participants' preferred mode of storytelling.

The redesigned interview guide was developed in two stages. First, the lead researcher (SK) worked with the McMaster team to create skeleton questions. Second, SK met with Six Nations community advisors to refine the skeleton guide. Once agreed upon by all, subsequent interviews used the newly designed questions. This framework was conducive to allowing each participant to speak freely in narrative form about the aspects of perinatal health that were important to them.

It was collectively agreed upon by the research team that the decision to participate in an individual interview or a group session (focus group) was at the request of the participant(s). Depending on the preference of the participant, the interviews were held within their home or in a room at the Six Nations Birthing Centre. This allowed for all participants to feel comfortable in where and how they decide to share their knowledge. In addition, although language was not used as a criterion for eligibility, all participants requested that their interview be held in English. SK, who conducted all interviews, is not a speaker of Indigenous languages but was prepared to make arrangements to facilitate the session in another language, had it been required. All interviews and focus groups were completed between February 2014 and May 2015.

Data Analysis

Data analysis included grounded theory coding techniques including initial coding, focused coding, and thematic analysis, all of which were completed in triplicate (SK, GW, and TH). First, SK and GW coded one interview together prior to independently coding all subsequent interviews. Interviews were coded manually and organized in NVIVO-9. GW is a pediatrician with experience working alongside Indigenous communities across Canada, including Six Nations. SK and GW gathered for periodic coding meetings to discuss the results in detail. Second, SK worked with a community member from Six Nations (TH) to code interviews collaboratively, often engaging in deep discussions around vocabulary and language use. TH is a community member who worked on the ABC study team but did not have any previous experience with coding or qualitative data analysis. Preceding these coding meetings, SK and TH engaged in face-to-face meetings to discuss the coding process in detail and plan out a strategy for the joint-coding process. The strategy consisted of going through each line together, assigning the codes together, and discussing any issues or incongruities.

After the initial rounds of coding, important codes were identified through discussion between the three coders as the ones that were most common/recurrent and most culturally significant. For this particular study, determining codes that reflected cultural significance and/or had contextual meanings were vital to ensuring that relevant and appropriate conclusions were/are drawn from the data. For example, a grandmother telling a story about the suffering that her niece experienced during pregnancy was speaking to the importance of maintaining a sense of balance (physical, emotional, spiritual, and mental) for optimal health during the perinatal period (e.g., a sample is offered in Appendix A). This clarification was made with assistance from the community coder. Also through discussion, equivalent codes were identified and grouped together to have equivalent meanings. For example, "not laying around" and "remaining active" were grouped as two different action codes that had equivalent meanings.

At this point, the most significant and frequent codes were used to perform focused coding. This process also included an active comparison phase to group and categorize related codes into larger themes. The categories helped to inform the overall theory: an interpretation of how/why participants construct meanings and actions in specific situations.

The entire coding process encompassed frequent discussion between the coders, additional clarifying interviews with grandmothers, memo writing, diagramming, and audio reflections. The primary researcher reinterviewed several participants to clarify and better understand their stories. To maximally honor what is shared, we used in vivo codes and statements as frequently as possible (including in the memo writing and diagramming). It is important to note that oftentimes discussions between the coders would lead to insight on previously analyzed data, encouraging the team to revisit sections of the interview transcript multiple times. Some participants ($n = 3$) used family photographs and newspaper clippings to share their perspectives on the role they play within their family and their values associated with health and well-being. These sources of data were recorded within field notes and used to provide context during data analysis.

Employing all of these vehicles allowed for active, reflexive analysis that allowed the researchers to maintain self-awareness of their subjectivities and biases. In order to openly share this personal reflection, the primary researcher compiled a memo about her personal perspective and social location, and how they informed her understanding of the data (Appendix B). The contents of this memo reflect the researcher's understanding of her own social standpoint, something she discussed openly and honestly with all participants during the interview sessions. This exchange of knowledge would occur throughout

the interview, mostly when requested by the interviewee. However, prior to the start of the interview, we would spend time learning about one another, which typically resulted in the disclosure of many of these personal perspectives. The memo was also shared during presentations (written and oral) of this study. In addition, many of the participants expressed an interest in learning more about the primary researcher (specifically in regard to how she felt about a Western perspective of medical care, if she had experienced any personal loss that has impacted her perspective on life, etc.). While this sort of discussion of the researcher's life experiences during an interview may be unconventional in most Western qualitative research traditions, it is an important aspect of Indigenous worldviews that relate to building relationships and common understanding. The primary researcher openly and honestly addressed all participant questions and concerns. Overall, this reciprocity in sharing information contributed to the building of trust and respect between the participants and the researcher and increased self-awareness during data collection and analysis.

Findings

Although the results of this study are published elsewhere (Kandasamy et al., 2016), to illustrate the way that our findings met the goals of both the researchers and their Six Nations partners, we provide a concise summary of the study findings here.

Three primary perinatal health beliefs and six community-level responsibilities were believed to be important for the health and well-being of future generations. The three primary perinatal beliefs were: (1) Pregnancy is a natural phase of the life course that is not an illness, a medical condition, nor a comfort zone; (2) Pregnancy is a sacred period where a state of balance is key; (3) Babies should be given a chance to be healthy through the promotion of immunity, security, comfort, social development, and parental responsibility. In addition, the grandmothers identified local community responsibilities required to uphold optimal health (better access to healthy food options, availability of support systems that encourage healthy partnerships, improved family-based postnatal care, promotion of physical activity for children, more teachings around the impact of parental behaviors, and more teachings around spirituality and positive thinking). These six factors were viewed as communal efforts that are important to securing the well-being of current and subsequent generations.

With a collective goal of improving the maternal and child health of the Six Nations community, we will continue our work with local health partners to cocreate appropriate interventions that apply these results in a beneficial manner. Meetings to discuss this further will be held in the near future.

Knowledge Dissemination

It was important to employ a culturally meaningful (and innovative) vehicle to connect with and translate the research findings to community stakeholders (including but not limited to Six Nations women of childbearing age). To achieve this goal, a digital story was produced in collaboration with a Six Nations Spoken Word artist, Tahnee Wilson and a filmmaker, Bhavna Samtani. Spoken word is a style of performance that uses poetry/poetic elements (e.g., rhyme and repetition), word play, and storytelling to convey a message.

To ensure the communication of the research knowledge was culturally meaningful and significant, it was vital that the distilled research findings were crafted and communicated through the voice of a Six Nations person. Subsequently, a community-based search for the most suitable artistic candidate was held. In January 2015, the candidate was selected after a face-to-face discussion with the primary researcher to jointly discuss intention, experience, and outcomes of the project. In February 2015, a filmmaker who had previously worked with the primary researcher to create training modules and information videos for the ABC study, was brought onto this project.

Once all parties agreed on the overall goal of the project, the primary researcher and the artists devised a timeline to ensure that the film could be completed before August 2015. Between February and August, the artists and the primary researcher held several face-to-face meetings and phone calls to discuss the research findings. The analyzed data were provided to the collaborators in three different formats: written summaries, drawings, and several oral presentations during face-to-face meetings and phone calls. These meetings were especially important to ensure that the research participants' expressions of the connection between the logic of the mind and the feelings of the heart were honored and showcased in the words and imagery of the film.

The spoken word artist is a young mother from the Six Nations community with a wealth of experience in creative writing and live performances. She composed and performed a 4-min poem by incorporating a personal thread to the research findings. The filmmaker selected visual scenes that accompanied the poem in a way that reiterated the poignant words. It was important to create content that would align with the young women of this First Nations community, a value that propelled the style of the film. Full creative control was given to the artists; the primary researcher remained an active participant charged with ensuring that the results were captured and presented with integrity.

To raise the funds to cover the costs of this integrated knowledge translation project, the research team partnered with the Six Nations Health Foundation. The Six Nations Health Foundation is a registered charity committed to supporting health/medical services for all band members, achieved particularly through raising funds for services that are not covered by Ministerial programs and funding. To initiate this partnership, the primary researcher was invited to attend a Board of Directors meeting in March of 2015 to mutually brainstorm ideas for the fund-raising campaign and to finalize the logistics of handling funds. The decision of participating in this project was unanimously supported by all the individuals on the Board.

A fund-raising campaign was launched for a 6-month period (March to August 2015) and was active at Six Nations (home base at the Six Nations Birthing Centre and the White Pines Wellness Center) and in Hamilton (home base at the Michael DeGroote Center for Learning and Discovery, McMaster University). Throughout the fund-raising period, administrative staff at McMaster University

and the members of the Six Nations Health Foundation provided logistic and promotional support. The entirety of the funds (total of CAD$900.00) was raised through philanthropic donations and a large-scale 50/50 draw. All of the funds were used to cover artistic fees (honorarium for the spoken word artist and filmmaker, costs incurred with photography/filming).

The final piece is published online for public viewing and is available in an accessible format for hearing impaired viewers (https://goo.gl/rCvOYb and https://goo.gl/J1aYiE). During the first 6 months it was available, several thousand people viewed it across North America, Europe, and Australia. The film has received acclaim from both Indigenous and Western scientific communities. The Six Nations community praised the film for its ability to showcase study results in a way that highlights the emotions associated with a colonial past. In January 2016, the film received one of the "Video Talks Prizes" from the Canadian Institutes of Health Research (Institute of Human Development, Child and Youth Health; CIHR, 2016). This national recognition celebrates excellence in the communication of rigorous research from a Western scientific perspective. In addition to the film, the primary researcher prepared lay-language study information packages to distribute to community members. The packages included DVD copies of the film for those who were unable to access it via online platforms. These packets, serving as another level of knowledge translation, were reviewed and approved by the joint research team prior to distribution.

Supporting Indigenous control during the dissemination process not only helps the community connect with the research findings on a deeper level, it also displays respect for individuals and community (researchers being considerate of community), reciprocity and responsibility (the researcher sharing and presenting ideas with the intent of supporting a community), and respect for the importance of storytelling in Indigenous cultures.

Lessons Learned and Limitations

The strengths of this study include the comprehensive community-level applicability of the research methodology, the methodological rigor of a constructivist grounded theory approach, use of an Indigenous knowledge translation framework, and the diverse expertise brought in by the multidisciplinary research team. In addition, many measures were used to ensure participant respect and comfort. The achievement of a comfortable and safe interview environment was indicated by participants initiating discussion of many sensitive topics (such as racism in the healthcare system, traditional practices, and personal challenges with motherhood). SK also kept detailed notes and maintained oral reflections about what she heard and felt during the interviews, which assisted in a more holistic understanding of the complexity of knowledge that was exchanged during the interview process.

Further data collection that builds upon the knowledge translation pieces could assist with cocreating a future direction for this project. For example, facilitating focus groups that commence with the film and then leads to discussion around the health advice that resonated with each participant could help direct long-term community-level implications. In addition, although the primary researcher welcomed research participants to use multiple sources of knowledge beyond the oral conversations (e.g., family photos, newspaper articles, magazine publications, etc.), only three participants used these alternative sources during the interview (two used photos and one used newspaper clippings). Thus, a recommendation for future studies could include directly speaking to research participants about these options. This would ensure that data collection actively incorporates the multiplicity of knowledge sources, allowing for participants to feel more comfortable and safe. For example, if a participant wanted the interview to be based upon a photograph of their grandchild (instead of answering the interview questions), that should be welcomed, appreciated, and celebrated. This step shows additional respect for an individual's and community's heterogeneity, respect/safety for participants, and openly shares the perspective of a research team that is reflective and nonjudgmental. To further support this, future studies could be led by a Six Nations interviewer and efforts could be made to offer a collaborative training program for Six Nations members who are interested in pursuing research.

Conclusions

This study represents the contribution of the voices of elder women in an important dialogue of maternal and child health in Indigenous communities. The amplification of these voices highlights the integration of Indigenous and Western epistemologies, the benefits of utilizing the plurality of knowledge sources, deep listening, establishing a research team that allows Indigenous peoples to develop, create, and disseminate the research findings, and the gravity of a research relationship that is built upon mutual respect, relevant research objectives, and reciprocity.

Moving forward, it is important to consider the methodological fusion of different worldviews so that knowledge can be cocreated for the benefit of the communities that we work with. It is vital to take the time to build strong research relationships, develop a jointly relevant and feasible protocol, negotiate mutually respectful recruitment and data analysis, and to develop an integrated plan of involving community collaborators in the research process. In addition, actively promoting that research participants share their knowledge using a method that is most comfortable for them further acknowledges respect for participants and concern over their comfort and safety. Taking these steps will ensure that the community benefits maximally from the project, which should be the most important goal of health research.

Appendix A

Interview Excerpt and Memo Sample

> Coz my niece kept complaining of heart burn. She was only 33 and she had severe heart burn but she just thought it was heart burn, she kept taking antacids and stuff like that. She had a cardiac arrest and died. That was two years ago and she lost her baby too. The baby was born. She had six weeks to go to her delivery and then it happened.

They said she had a massive heart attack. So, (clears throat) I think her symptom was that. So, I think anything excessive should be monitored. Anything out of the ordinary should be monitored, not taken lightly. Plus we didn't know how she felt because she didn't say anything besides that. Like if she was having any other symptoms. But her feet started to swell because she was a pharmacy assistant. So thinking back I think maybe in her regular visits with her doctor if she had told them, they could have taken the baby and done a bypass or something. I was talking to her mother that day. She and her girls were already there ready to go to the Longhouse. She has two other girls. (cough). She said I'm not going to after she got them all ready because she feels sick. She went up to her bedroom and flopped over and went into arrest and the girls started screaming. The girl that died's mother—I was on the phone with her. She said call 911 something terrible has happened. I didn't know what had happened but I called 911 and (clears throat) and that something drastic has happened, something very bad that they need help with. A mother doesn't just get upset like that. And I said please get there, she needs your help. I got ready and raced there myself, the ambulance was there. They got her pulse back for a bit and they took the baby but there was too much damage. So she died. And that was her symptom. But I don't know any other symptoms so I would say anything out of the ordinary that she thinks is different should be checked out.

Brief Memo (Written by the Primary Researcher in April 2015)

Initially, I thought the participant was speaking quite literally to being cautious around out-of-the-ordinary symptoms during pregnancy, particularly heartburn. After discussions with the community, I came to realize that she was conveying a broader idea: the importance of knowing yourself, trusting yourself, and truly maintaining a sense of balance—all of which is what helps us adequately judge and take action against out-of-the-ordinary symptoms. Being able to form an action plan against these symptoms is not only crucial to survival but also to being able to thrive throughout life (as this 'skill' is also important to optimal health post-pregnancy). The community member explained these intricacies (among other sections of this interview) using personal examples from her own life. Discussion also lead to completing a clarifying interview with the interviewee for member-checking.

Appendix B

Research Memo

My Position Throughout This Research Journey (Compiled August 2015)

I am a non-Indigenous minority woman of color who was raised in Ontario, Canada in a four-person nuclear family. Although I grew up in the security of a free country, my ancestral roots intertwine in politically-unstable soil where Indigenous peoples faced a string of broken promises. I am no stranger to understanding what it feels like to have ancestral lands destroyed by the arrows of a historically patriarchal government. Nor am I stranger to the feeling of familial loss and grief. At the age of 21, I lost my younger sister in a tragic accident, leaving my family torn with emotion. This life-changing hurdle left everything I knew in a state anguish and I saw my parents face the unbearable punishment of having a child taken away from them far too soon.

I hope that sharing this story helps to illustrate that this project's roots run deeper than the vein of its written existence. It also runs through the person who conducted the heartfelt interviews, transcribed each word, and shared the knowledge through the lens of a unique life perspective—a perspective that empathizes with the challenges that Indigenous peoples have faced and of course, the resilience that an individual (and collective) spirit can show.

During one of the earliest interviews that I conducted for this project, a grandmother asked me if I knew what it felt like to have my sovereignty taken away. I quickly realized that although I was asking questions about prenatal and postnatal health beliefs, the discussion would undoubtedly be a reflection of socio-political realities. From that point onwards, I made a promise to myself that I would be conscious toward ensuring that it was indeed the voice of the participants that came fourth in the data analysis. After all, Charmaz does say that data should be 'collected and analyzed to make participants' actions, interpretations, and influences explicit'. In addition, it was also a re-iteration that working with Indigenous communities is a life-long commitment to upholding a reciprocal, active, collaborative relationship.

I am also closer in age to the mothers of this community than to the grandmothers I interviewed, which places me in an interesting position during data collection and analysis. Truly and surely, I was the one that was doing all the learning. The grandmothers that I interviewed taught me so much about how to approach difficult life situations and how to prepare myself for the challenges of bringing new lives into this world. I genuinely felt they were the experts in this content area, which is something I strived to illustrate in the presentation of this thesis.

My Hindu background and South Asian culture has shown me a different perspective of perinatal health than I observed from the Six Nations grandmothers. In fact, I expected to hear an abundance of culturally unique prenatal health advice (as I did when I completed a similar study with South Asian grandmothers). Instead, I heard personal stories and life experiences that came with pregnancy and caring for a newborn. I found it beautiful but challenging at times to comprehend the meaning of some of the stories. But, I soon realized that the splendor in sharing knowledge through stories is that it allows the listener to take what they need and apply what makes sense to their own unique situations. It is a very respectful way of sharing information and advice, thus probably more relevant to a younger generation living in times that are quite different from what the grandmothers were used to. This is the principle that was used as the underpinning for the knowledge translation piece in this thesis. Stories have immense power. It is my hope that we can use that power to share the necessary knowledge for the benefit of the Six Nations community.

My hope is also that we will be able to co-create interventions to help support the re-building of a community in a way that intergenerational knowledge can be shared and celebrated in a way that women can have the power to raise healthy future generations.

I present the following research findings to you in cross-cultural solidarity with the Six Nations community, the original inhabitants of the land that I am so lucky to call my home.

Authors' Note

The views expressed in the article are the views of the authors and should not be taken to represent the views of the Ontario Ministry of Health and Long-Term Care.

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