

SHARED DECISION MAKING WITH ABORIGINAL WOMEN FACING HEALTH DECISIONS

**A qualitative study identifying needs,
supports, and barriers**

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Abstract

Shared decision making (SDM) may narrow health equity gaps by engaging clients with their health care providers in decision making; little is known about SDM interventions with Aboriginal people. This study describes the health decision-making experiences of Aboriginal women by identifying decision needs, supports, and barriers. An interpretive descriptive qualitative study was conducted from January to June 2013 with an advisory group using a mutually developed ethical framework, participatory research principles, and postcolonial theory. Aboriginal women

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at Minwaashin Lodge were interviewed in semi-structured interviews and transcripts were coded using thematic analysis. Participants were 13 women between 20 and 70 years of age, and of Inuit, Métis, or First Nations descent. SDM needs and supports are represented by themes focused on relational features of SDM, and presented in a Medicine Wheel framework. Findings indicate that to be relevant for Aboriginal women, SDM tools and approaches may need to be adapted, and participatory approaches must be used.

Keywords

health equity, women, Aboriginal, shared decision making,
cultural safety, health literacy

Introduction

While First Nations, Inuit, and Métis women (“Aboriginal women”) share similarities with non-Aboriginal women living in Canada, their historical, legal, cultural, and socioeconomic circumstances set them apart as experiencing unique challenges. Aboriginal women’s health and socioeconomic indicators demonstrate that this group generally has the highest rates of health burdens, including poor health status, poverty, and substance abuse, in Canada (Canadian Institute for Health Information, 2003; Halseth, 2013). Aboriginal women are also more likely than non-Aboriginal women to experience domestic violence and to be the sole caregiver for their children (Native Women’s Association of Canada, 2009; Public Health Agency of Canada, 2003; Statistics Canada, 2011). Traditionally, Aboriginal women have contributed to the strength and continuity of Aboriginal societies (National Collaborating Centre for Aboriginal Health, 2012). The health status of Aboriginal women has a broad effect on the collective health of their communities and must be understood as having far-reaching consequences that extend beyond that of individuals. Mainstream health care approaches are designed for a population that does not experience the same degree or type of health care needs as those of the Aboriginal population (Royal Commission on Aboriginal

Peoples, 1996). These are strong indicators that current health care systems in Canada fail to adequately support the health of Aboriginal women.

Aboriginal women have limited opportunities to engage in a process of safe and effective health care. Shared decision making (SDM) promotes collaboration between health care providers and clients in health decisions in ways that are meant to be reflective of the client’s personal values (Makoul & Clayman, 2006). Research with general populations has shown that there are potentially modifiable barriers at the level of the health care client, provider, and organization that hinder participation of clients in health systems (Joseph-Williams, Elwyn, & Edwards, 2014). SDM may, however, be facilitated by patient decision aids (for example, booklets, videos, online tools; Stacey et al., 2014) and decision coaching (Stacey et al., 2012). SDM has been found to improve both clinical decision-making processes (O’Connor & Jacobsen, 2007) and client satisfaction with health services (Kiesler & Auerbach, 2006). Moreover, increased client skill and confidence in health care processes have been associated with better health experiences and outcomes, including for those with varied socioeconomic status (Hibbard & Greene, 2013). Within some populations, SDM has contributed to narrowing health inequity (Frosch, Légaré, & Mangione, 2008) and research has suggested that patient

decision aids can improve decision quality and empower women to make informed decisions based on personal values (Mitra, Jacobsen, O'Connor, Pottie, & Tugwell, 2006). A systematic review of the literature showed that SDM interventions significantly improve health outcomes for those with lower socioeconomic status, education, and literacy (Durand et al., 2014). As a result, the adaptation of SDM interventions for use by Aboriginal women may be a useful approach for addressing health inequity for this population.

Our study is a qualitative investigation of SDM with Aboriginal women. Currently, there is limited literature within mainstream Western-informed research about the use of SDM approaches with Aboriginal peoples in Western health care settings (Jull, Stacey, Giles, Boyer, & Minwaashin Lodge, 2012). Instead, the literature has been focused on education rather than the collaborative SDM approach to making health decisions within the area of Aboriginal health and has neglected to identify and address the barriers imposed by colonial structures on Aboriginal people who must negotiate Western-informed systems of care (Jull et al., 2013). Therefore, to date, it has not been possible to determine how SDM may contribute to health care experiences for Aboriginal populations. The purpose of this study was to describe the experiences of Aboriginal women when making health decisions by identifying decision-making needs, supports, and barriers. For this study, participants identified health decisions as those that affected the mental and physical health of themselves and their families. The research questions addressed in this study were two-fold: 1) What are the health decision-making needs and supports of Aboriginal women? 2) What are the barriers to involving Aboriginal women in their health decision making?

Theory

As a theory derived from diverse disciplines (McEwan, 2009; Young, 2001), postcolonial

theory was selected for use in this study to provide a theoretical lens to view the everyday experiences of marginalization that Aboriginal women often experience in health care settings (Anderson, 2002; Reimer-Kirkham & Anderson, 2002). An important quality of postcolonial theory is a focus on identifying and disrupting the thinking that underpins structural inequities in society and that are the result of colonial practices. Aboriginal scholars, such as Battiste (2000), have made strong contributions to the development of postcolonial theories that have emerged from Aboriginal ways of knowing. Consistent with this approach, and with input from Minwaashin Lodge, it was decided that postcolonial theory principles as described by Battiste (2000) offered the most relevant perspective from which to view, understand, and seek to address colonialism's impact on Aboriginal women's health decision-making needs. In this perspective, Aboriginal peoples are positioned as being central to a collaborative process of societal change, which is also inclusive of non-Aboriginal people. Such an approach is fitting for this study, which was developed from a research partnership. Battiste's (2000) postcolonial approach was used to frame the issue of Aboriginal women's experiences in making health decisions and to situate their experiences within a particular sociohistorical context. Battiste (2000) utilized the Medicine Wheel as a way to conceptualize, map, diagnose, heal, and vision "the Indigenous renaissance" (p. xxiv) within the processes of colonization.

The Medicine Wheel depicts the four aspects of self (Physical, Emotional, Mental, and Spiritual). It is strengths-based and focused on restoring life balance by attending to the four directions: East, South, West, and North. It has been found to be an appropriate methodological and categorization tool in health research, as it integrates Western and Indigenous ways of knowing and is an approach to knowledge generation (Graham & Leeseberg, 2010; McDonald, 2008). The Medicine Wheel is a

tool commonly used by the women while living and/or attending programs at Minwaashin Lodge. For the purpose of this study, we used a version that included colours traditional to the Algonquin peoples' Medicine Wheel (yellow, red, black, and white). Minwaashin Lodge is situated on Algonquin territory and these colours were used to honour this fact.

Relationship

The details on the research relationship (ethics) have been published in detail elsewhere (Jull et al., 2012) and are briefly summarized here. This study was designed and implemented to support a research agenda respectful of the diverse needs of a population of Aboriginal women and structured to meet the Tri-Council Policy Statement (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2014) and Ownership, Control, Access, and Possession (OCAP) (First Nations Centre, 2007) development, implementation, and criteria. The ethical framework was supported by the use of participatory research principles, with defined agreements between and roles for the research partners. The study received ethical approval from the University of Ottawa Research Ethics Board.

Methods

The details on the methods for this study have been published elsewhere (Jull et al., 2012) and are summarized below.

Design

An interpretive descriptive qualitative study was conducted from January to June 2013 in collaboration with Minwaashin Lodge. The interpretive descriptive method is an effective research approach for describing health

events (Thorne, Riemer Kirkham, & O'Flynn-Magee, 2004). It facilitates an iterative process between data collection and data analysis, and this process both directed the study and was used to generate new ideas during the study. With the interpretive descriptive approach, the researcher engages in a process of informed questioning; with the use of researcher and participant reflection and examination of ideas, the researcher creates an interpretive account of what is being studied (Thorne et al., 2004). The use of the interpretive descriptive methodology aligns with the postcolonial theory and participatory research principles used in this study by ensuring that the participants' thoughts and views on health decision making are key aspects of the data analysis process. It also facilitates the generation of new and unique links within the data not yet identified within the decision-making literature and fosters understandings about Aboriginal women's health decision-making experiences.

Setting

This study was conducted in partnership with an Aboriginal woman's organization, Minwaashin Lodge, whose leaders served as members of the study's advisory group and who are co-authors of this paper. Minwaashin Lodge is a community-based organization that provides services (for example, shelter, counselling, training programs) to First Nations, Métis, and Inuit women and children who are survivors of family violence and/or the residential school system. Minwaashin Lodge leaders and members viewed this study as of potential benefit to its community. Aboriginal women were purposefully recruited through posters (Fossey, Harvey, McDermott, & Davidson, 2002) for participation in an interview conducted in English. Minwaashin Lodge representatives directed women to the study posters or to the first author for information. Recruitment and 13 individual semi-structured interviews took place at Minwaashin Lodge.

TABLE 1 Interview questions used to explore participant decision-making needs, supports, and barriers

1. Thinking about your last visit—to a counselor, social worker, doctor or nurse, or some other care provider—can you tell me about the reason you were there and how the decision was made for managing the issue?
2. Now, I would like you to tell me how you were or were not involved in choosing an option for managing your [health/social] issue.
3. Was anyone else involved in helping you to make the decision?
4. Do you have any ideas on what might help you to be more involved in decisions and choose what you think are better options?

Procedure

A semi-structured interview guide was developed in collaboration with Minwaashin Lodge (Table 1). Participants reviewed and signed the study’s consent form, after which participants were interviewed for 45 to 90 minutes. The interviews were digitally recorded and transcribed verbatim. Participants’ names and

identifying characteristics were changed and/or removed to preserve anonymity.

Data analysis

Each participant was given the opportunity to review and revise her transcript; however, no participant elected to revise the text. Transcribed interviews were analysed using a method of

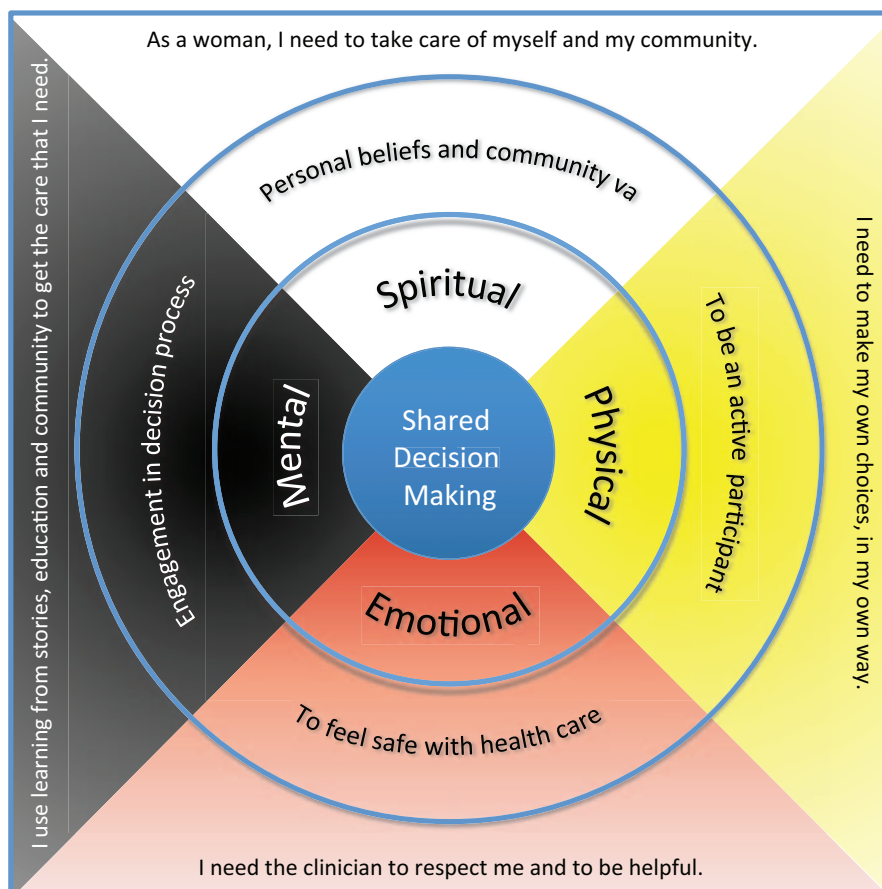


FIGURE 1 The shared decision making Medicine Wheel framework

data reduction, data display, and drawing conclusions with verification (Huberman & Miles, 1994). The process of qualitative data analysis was iterative and included five steps: 1) preliminary exploration of manuscripts by reading transcripts and writing memos (JJ); 2) JJ analysed and generated codes (for example, “safety”, “values”) within each transcript, and themes were generated; 3) initial themes were confirmed or adjusted (“to feel safe with health care”, “personal and community values”) in collaboration with a second reviewer (CL), who was familiar with the women of Minwaashin Lodge; 4) the inductively derived codes and themes were organized and sorted into categories that reflected the research questions (that is, needs, supports, and barriers). Finally, participants’ experiences with decisions were analysed through a postcolonial theoretical lens (Battiste, 2000).

Findings were reviewed and revised with members of the advisory group. To enhance understanding of the findings, a decision was made to present the results (decision-making needs and supports) as part of a Medicine Wheel framework (Figure 1). The descriptions of all participants’ decision-making needs were grouped into four overarching themes. Their accompanying four areas of support are shown in the Medicine Wheel. Barriers to meeting decision-making needs were also identified by the participants and are described for each quadrant of the Medicine Wheel. Each theme was viewed as aligning with one direction of the Medicine Wheel. An Elder from Minwaashin Lodge reviewed the Medicine Wheel framework and agreed with the final format.

Results

Participants

Thirteen women with a range of personal characteristics who self-identified as Aboriginal and as having been a part of a decision affecting the

health of herself or a family member in the past six months chose to participate in the study (Table 2). Additional participant characteristics are not included in the table to protect anonymity. Eleven participants indicated having ongoing caregiving responsibility of a family member. Most of the women told stories about their experiences in making health decisions with some who discussed social decisions that affected their health (for example, housing) or the health of a family member (for example, the health of a child). Pseudonyms have been used to protect participant anonymity.

Theme #1: To be an active participant

The Eastern side of the Medicine Wheel is the Wheel’s entry point, and “To be an active participant” represents a decision-making need identified by participants. This decision-making need was situated in the physical domain of the Medicine Wheel as participants described taking action to care for the physical well-being of themselves or a family member by seeking health care to improve health. Participants viewed being an active participant in their decision making as linking their physical health to their overall well-being, and they often talked about seeking care as part of treating their “whole” selves. As described by Day, “Keeping that balance for the body, it helps the mind, they go together.”

All participants described themselves as active decision makers in their or their family members’ health care. They identified a key component for being an active participant in decision making as “needing to make my own choices, in my own way”. For instance, Sophie explained how she decided to make a decision to control her child’s significant and worsening health issues attributed to deplorable housing conditions:

I gave up when I found out that I wasn’t on the housing list, and I just left [community]. Well, not like that—took me a few months

TABLE 2 Participant characteristics: Demographic data

Aboriginal identity	Decision	Decade of birth	Children Yes/No, #	Others to care for	Education
Aboriginal woman	Lifestyle changes (smoking/diet)	1940	Yes: 3	No	Grade 8
Inuk	Where to move	1980	Yes: 2	No	Grade 10
First Nations	Return to school	1980	No	Yes*	College
Aboriginal woman	To have a mammogram	1950	Yes: 2	No	University
Aboriginal woman	Pain in knee	1960	Yes: 4	Yes*	College
Inuk	Treatment for tuberculosis	1970	Yes: 2	No	Grade 7
Aboriginal woman	Treatment for substance abuse	1960	Yes: 3	No	College
Ojibwe	Choosing a care provider	1960	Yes: 2	Yes*	University
Anishnawbe	Treatment for substance abuse	1950	Yes: 3	No	University
Métis, Algonquin	Treatment for chronic disease	1970	Yes: 1	Yes*	College
Aboriginal woman/First Nations	Finding a place to live	1980	Yes: 5	No	Grade 10
First Nations	Treatment for fracture	1990	No	No	Grade 12
Inuk	Return to school	1970	No	No	Grade 10

* Indicated involvement with Aboriginal community in a caregiving capacity.

to plan it out, think about it and all that. Thinking about my kids, how they were doing there and just didn't like it. It was hard too . . . really hard. I just wanted to leave and get more options out here.

She described her decision making as follows: "I try thinking about myself, what I need to do for family, instead of what [others] say." Like Sophie, other participants explained that making decisions in their own way was the best approach to negotiating complex health care systems. During interviews, the participants described their efforts to be in active decision-making roles as crucial, as ultimately they found they could only rely on themselves to ensure that they were doing all that they could to be healthy or to ensure the health of the person for whom they cared. As August said, "When I make a decision, I own it . . . I'm the one that has to own up to it."

Barriers to being an active participant in health decision making

Participants described family and community-based situations they had to overcome as barriers to being active in health decisions. Renee referred to a time of family disruption when explaining her reasons for a delay in making her decision to participate in health screening: "I was supposed to follow-up, which I didn't do 'cause my life just kind of went upside down." Likewise, many other participants related that troubles in their personal lives challenged their ability to be active in making health-related decisions. These challenges were described as extending to the broader community and included situational barriers to accessing resources for the treatment of health issues. For instance, Mary-Jane spoke of living in a community with limited health care resources: "[Health care providers] are

always in a hurry. Seems like they don't have the patience for anything." Mary-Jane explained how these experiences with health care providers were paired with social tensions that related to "people not talking . . . so many suicides", all of which limited her ability to participate in important health care decisions and led her to seek treatment outside of the community. All participants related their experience of having to first overcome barriers as having an impact on their ability to engage in decision making.

Theme #2: To feel safe with health care

The Southern part of the Medicine Wheel, "To feel safe with health care", is situated in the emotional domain and reflects that participants have to have their emotional needs met when making health decisions. The need to feel safe with health care was described as participants' views towards their health care providers and the health care setting. Day described her positive feelings about the environment in which she accessed care as resulting from the health care provider who consistently used a strengths-based approach for support during her decision-making process: "It's a good place, a safe place, where we are allowed to express who we are." Susan also described how being in "a safe place" allowed her to participate in making health care decisions with health care providers who actively worked to ensure that she felt comfortable.

Participants described the support they needed to feel safe with health care: "I need the care provider to respect me and be helpful." Helpful health care providers were described as those who built trust with the participants by demonstrating genuine interest and effort to communicate. This gave the impression that the health care provider was "there" for them. Irene, who described her visit to an emergency room, said the health care provider listened to her and then included her in an active process of making a treatment decision. She described

the health care provider's actions: "He was doing everything he could to make me feel comfortable and stuff. So it was good." She related details about her health care experience and how her health care provider worked through treatment options with her and used his networks to help her. Irene's story shows how perceiving clinicians as respectful and genuine in their desire to engage in a collaborative decision-making process can support a good health care experience.

Barriers to feeling safe with health care

Participants described barriers to feelings of safety in health care situations as occurring when providers were not perceived as doing their job. Beth described her experience with a hospital health care provider and her humiliation around the lack of say she had in her health care decision:

It wasn't really my choice . . . they just took care of things . . . [the health care provider] wasn't doing their job. [The health care provider] just told me to call [place] and gave me a bus ticket after and told me to go.

These barriers show the powerful role of health care providers and how their approach to either foster or undermine trust and communication can influence the recipient's perceptions of safety in health care settings.

Further, limited access to or limited choice in selecting a health care provider was described as compounding the issue. Sylvie described her troubles with a health care provider:

She didn't ask if I was able to do what she was asking . . . it was like "do this". [It was] kind of like I was in a marriage—I don't want to make [her] mad because I didn't *not* want to get that [health care intervention]. I'd better be nice to [health care provider] because I'm stuck with [her].

Similarly, Irene, recounted previous health care experiences and the fear and frustration she experienced at each new clinic appointment when she had to again explain her history and wonder how it would affect her care: “They’re so dismissive about your issues—like—my issues are a non-issue because I was—what—assaulted?” Every participant expressed familiarity with the feeling of perceiving conflict between receiving health care and personal safety.

Theme #3: Engagement in decision process

The Western part of the Medicine Wheel, “Engagement in decision process”, is situated in the mental domain and reflects participants’ needs for thoughtful and deliberative participation in making health care decisions. The importance of this was reflected on by Melody: “How I was living was not living . . . now I’m responsible. I know what I want and what I need.”

All participants talked about the need for engagement in the health decision process, and obtained this from a number of sources, such as “learning from stories, education, and community”. One participant talked about growing up with a family member who was a health care provider (nurse) and the influence this had on her expectations in health decisions. Others talked about learning from online sources and through social media.

Participants spoke of their community networks as valued sources for learning. Susan noted, “friends, workers, people . . . they are really helpful”, as she emphasized the importance of engaging with others to support her decision making. Most participants viewed health care providers as part of their information networks and as valuable sources for learning. Chantel described how she used the information from health care providers to make decisions about a chronic health issue: “I just came from the hospital so they told me stuff. I like it. I [saw] my doctor, nutrition, pharmacy

. . . I [saw] all of them. I have to listen to them because if I don’t things will really go downhill.” Opportunities for learning were valued, as the participants described having to think through and adapt to the new care challenges.

Barriers to engagement in the decision process

Participants identified numerous barriers in finding the right people to help them to negotiate health care systems and participate in decision making. Renee talked about being unable to find a regular health care provider as a barrier to making a screening decision: “That’s my problem now, I don’t have a doctor now, again . . . [it] took me five years to find one.” Melody also shared another experience: “The [care provider] kept mixing me up with other Native people that were coming to see [care provider], mixing up my story with other people.” Charlotte described her decision to not follow through with specialist care, as the specialist had not explained the intervention and did not seem to care that she had conflicting appointments: “I suppose he might have done that [explained the actions of the prescribed medications] if I went to a follow-up appointment. But I didn’t do that because I had to meet with my [financial aid] worker.” Many of the participants described situations in which they had not followed through on health care as they had felt that the health care providers were unable to help them to negotiate the complex health care system they were in and to provide feasible ways to address the issues for which they were seeking help.

Theme #4: Personal beliefs and community values

The Northern part of the Medicine Wheel, “Personal beliefs and community values”, is situated in the spiritual domain and reflects participants’ needs for engagement in decision making in ways they define as meaningful.

Charlotte described why she made a decision to quit smoking based on her beliefs about caring for herself and others: “I don’t smoke much and I would rather be a role model.” Charlotte talked about how she started a support group for others who wanted to stop smoking and make healthy lifestyle choices. Like Charlotte, many other participants in this study talked about decision making as a process in which they could take action towards health based on their personal beliefs to benefit themselves and their communities.

Participants identified personal beliefs and community values as integral features of decision making: “I need to take care of myself and my community.” For instance, in making a health care decision, Mary-Jane considered how she could best care for herself and her community. Ultimately, she decided to avoid health care in a particular setting as she felt that she was not able to receive good health care or fulfil her caregiver role: “I [didn’t] want my [child] to be around those kinds of people . . . drunk and booze and a lot of cigarettes . . . negative people.” She talked about how it was important for her to be part of a community in which people value themselves and treat one another with respect, and in which she could contribute in a positive way. All participants described that feeling like a valued part of a community provided the setting for engagement in decision making, as it allowed them to take on active roles as community members.

Participants also described the benefits of decision making that was congruent with their personal beliefs and community values. For instance, Sylvie talked positively about one aspect of her treatment plan, as she perceived it to align with her personal beliefs of caring for herself:

It also connects me with Native things that I’m doing and reconnecting with my heritage because . . . its making you—like, whole, and if there’s a reason and it’s all balanced . . . I don’t know, it’s cool.

These values extended to community obligations and leadership roles. Like many of the participants, August also spoke of how a commitment to herself, her community, and her beliefs and values all helped in her decision making: “I know that to have other women behind you—to have women with you—when you make these major decisions in your life . . . has been very beneficial—for me.”

Barriers to personal beliefs and community values

The barriers to the implementation of personal beliefs and community values in decision making were described by most participants as resulting from discrimination. Irene explained why she had rarely been able to collaborate with health care providers in decisions about her care: “They’ve treated me like . . . really disrespectfully, and, like [pause], I’ve just had really bad experiences at hospitals—yeah. For the most part, [it’s] because I’m a woman and I’m Native.” Renee summarized her views on treatment of Aboriginal women within health care systems:

It’s almost like being Aboriginal you have to work twice as hard at being “normal”, you know what I mean? Your house has to be twice as clean or like you have to dress twice as nice . . . I don’t know, sometimes you get that feeling.

Discussion

This study presented Aboriginal women’s views about their experiences with health decision making. The participants described their SDM needs, supports, and barriers, and in doing so provided their perspectives on SDM. SDM was presented in the Medicine Wheel framework as consisting of four domains: 1) Physical: To be an active participant; 2) Emotional: To feel

safe with health care; 3) Mental: Engagement in decision process; and 4) Spiritual: Personal beliefs and community values. The Medicine Wheel framework was used to present participants' descriptions of both their roles in SDM and perceptions of their health care providers' role within SDM. The relational nature of SDM, the role of SDM in culturally safe care, and health literacy were identified as components that are necessary for a health care experience that participants consider meaningful.

Placing an emphasis on the relational nature of SDM

The relational nature of SDM emerged in our research as the most important feature of decision making for participants. SDM is typically defined as a collaborative series of events that occur between the health care provider and client: identification and agreement upon a problem, information sharing, review of options and their risks and benefits, and the integration of client values (Charles, Gafni, & Whelan, 1997; Makoul & Clayman, 2006). In this study, participants spoke about themselves in relation to their health care providers and the importance of their interpersonal relationships with health care providers in decision making. The relational nature of SDM is an emerging area of study, and there are evolving understandings of the importance of relational aspects of health care (Mead et al., 2013). For example, Entwistle and Watt (2006) developed a broad conceptual framework aimed at reflecting the complexity of SDM and the concepts of involvement between health care client and provider. There is still, however, limited knowledge on the relational nature of SDM.

The focus on developing understandings of the relational nature of SDM in our study is reflected in the Medicine Wheel framework. This approach is unique in that it was developed in collaboration with the user population. To date, there is no known framework that has been developed in collaboration with a

user population to reflect features of an SDM approach. The focus by the participants on the relational features of SDM depicts a strengths-based approach (Kelly, Dudgeon, Gee, & Glaskin, 2009). This is in contrast to the typical biomedical, deficit-based models that focus instead on what must be "corrected" (Pfeiffer, 2001). The Medicine Wheel framework outlines a relational SDM approach that the participants identified as being necessary to overcome the barriers experienced by Aboriginal women in Western health care settings. Such an approach may facilitate a culturally safe approach to care, and suggests that there is a dimension of SDM associated with women's roles and interpersonal relationships within their families and communities that has impacts on health decisions. The relational nature of SDM as it involves Aboriginal women's considerations of family and community might be viewed as situated within a collectivist culture, an area under exploration with other populations (Durey et al., 2012; Kruske, Kildea, & Barclay, 2006). This study indicates that there are a number of important factors and areas for consideration that influence SDM for Aboriginal women (Jull, Giles, Boyer, Stacey, & Minwaashin Lodge, 2015) and which extend beyond the relationship with the health care provider.

SDM and culturally safe care

Cultural safety featured in the participants' perspectives of SDM. The concept of cultural safety was developed internationally within the health care field to improve the effectiveness and acceptability of health care with Indigenous peoples. By identifying power imbalances within health care settings, culturally safe care upholds self-determination and decolonization for Aboriginal peoples (National Aboriginal Health Organization, 2006), engages the client in decision making in a respectful and inclusive way, and builds a health care relationship where the client and health care provider work together as a team to ensure maximum effectiveness

of health care (National Aboriginal Health Organization, 2008), which results in client opportunities to participate in decision making (Brascoupe & Waters, 2009). When designed in collaboration with Aboriginal partners, SDM approaches and tools may be viewed as promoting cultural safety.

The relational concepts of SDM identified by the participants and depicted in the Medicine Wheel framework may have the potential to facilitate the delivery of culturally safe care. Participants defined SDM in health care settings as being built on a health care provider–client relationship, through the fostering of communication, mutual respect, trust, and supporting women in their decision-making roles. SDM promotes collaboration between health care providers and clients in making health decisions in ways that are reflective of the clients' personal values (Makoul & Clayman, 2006), and this suggests that the use of SDM may have potential to foster a health care relationship that the client defines as culturally safe. This paper makes a link between cultural safety and SDM; as such, further exploration of SDM concepts with Aboriginal clients within Western-informed health care and research settings is required to assess the extent to which they can be used to promote or achieve cultural safety.

SDM and health literacy

The participants in our study are similar to other populations with respect to their desire for information and opportunities to participate in decision making; however, the participants may also be undermined in their decision making by the context of colonialism in which they live, which may in turn influence their health literacy. Health literacy has been identified as existing at multiple levels, including functional (reading/writing), interactive (communication/social) and critical (advanced functional/cognitive/social) levels (Nutbeam, 2000). It has been defined as the ability to access and use care, understand and use information for health and

well-being, and the capacity to use information effectively (World Health Organization, 2014). High levels of health literacy result in empowerment and the capacity to make decisions that support favourable health outcomes for the individual participating in health care systems (World Health Organization, 2014). In theory, any individual may be affected by lower levels of health literacy when functioning within an unfamiliar social, economic, or cultural context.

Literacy issues have been identified as being of particular concern for Aboriginal women, as the source of literacy issues lies in the colonial forces that shape the social and economic environment in which Aboriginal women live (Sankhulani, 2007). Most of the participants in our study may not have been familiar with being given choices or receiving support from health care providers. Consequently, they may have expressed ideas about SDM that differ from those referred to in the mainstream (non-Aboriginal populations) literature. Low health literacy and the stigma that is often associated with it have been found to impair both spoken interactions with health care providers and to reduce the benefits clients derive from health services (Easton, Entwistle, & Williams, 2013). Limited or lack of experience in collaboration with health care providers can influence participation in SDM and has been identified as an issue within non-Aboriginal populations (Entwistle, Prior, Skea, & Francis, 2007). SDM requires that the health care provider and client collaboratively engage in a decision-making process, and requires that barriers to health literacy be addressed to enable participation in the SDM process.

As a potential solution, SDM interventions have been found to improve knowledge and informed choice for those with lower health literacy (McCaffery et al., 2013). Further, SDM has been suggested as a means to significantly improve health outcomes for vulnerable groups, including those with lower health literacy (Durand et al., 2014). It is of importance,

however, to be cognizant that SDM has been developed within mainstream (that is, Western European) academic and health care settings; as such, it is inappropriate to assume that the underpinning cultural beliefs and values of SDM will reflect the views of all populations (Alden, Friend, Schapira, & Stigglebout, 2014) and thus have the potential to enhance and support the health literacy of every population. For this reason, it is imperative that understandings and supports of the SDM process be developed collaboratively with user populations as a way to identify and create potential opportunities to enhance health literacy.

The main limitations of this study were that participants were clients of Minwaashin Lodge and the findings reflect a particular set of views from a very diverse group of First Nations, Métis, and Inuit women. As well, participants may not have had experiences with health decision making that would have allowed them to express views in ways similar to other, non-Aboriginal populations. Finally, the participants are situated within a particular sociohistorical context, meaning that the findings may not be relevant to others who do not share similar backgrounds.

Conclusion

Our study presented the needs, supports, and barriers to SDM as identified by a select group of women who access Minwaashin Lodge services. Results were organized into a strengths-based framework reflecting the women's descriptions of SDM. The SDM needs and supports described by the participating women were represented in four major themes and subthemes that describe the meanings of SDM held by participants from Minwaashin Lodge. These were framed in a culturally resonant Medicine Wheel framework. The participants emphasized the relational features of SDM in their health decision-making needs. Further, we found that there is a potential role for SDM to facilitate understandings

and approaches to culturally safe health care practices and practices that support Aboriginal women's health literacy needs. These findings suggest that health care providers must re-examine their approach to the relational aspects of care provision and must do so from within the colonial contexts that have informed the development of Western health care systems. With their clients, health care providers must choose to identify and then challenge these systems to function in a way that strives for equity in service provision. With such changes, health care relationships can better reflect processes of SDM and support health care that is defined by Aboriginal clients as both necessary and culturally safe. Research conducted in collaboration with Aboriginal partners is needed to explore current approaches to SDM within Aboriginal populations and the potential relevance and use of SDM tools and approaches to support the further engagement of Aboriginal women in making health care decisions they define as meaningful.

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References

- Alden, D. L., Friend, J., Schapira, M., & Stiggelbout, A. (2014). Cultural targeting and tailoring of shared decision making technology: A theoretical framework for improving the effectiveness of patient decision aids in culturally diverse groups. *Social Science and Medicine*, *105*, 1–8.
- Anderson, J. M. (2002). Towards a post-colonial feminist methodology in nursing research exploring the convergence of post-colonial and feminist scholarship. *Nurse Researcher*, *9*(3), 7–20.
- Battiste, M. (2000). Introduction: Unfolding the lessons of colonization. In M. Battiste (Ed.), *Reclaiming indigenous voice and vision* (pp. xvi–xxix). Vancouver, Canada: University of British Columbia Press.
- Brascoupe, S., & Waters, C. (2009). Cultural safety—Exploring the applicability of the concept of cultural safety to Aboriginal health and community wellness. *Journal of Aboriginal Health*, *5*(2), 6–41.
- Canadian Institute for Health Information. (2003). *Women's health surveillance report: A multidimensional look at the health of Canadian Women*. Retrieved from https://secure.cihi.ca/free_products/CPHI_WomensHealth_e.pdf
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2014). *Tri-council policy statement: Ethical conduct for research involving humans, 2014*. Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (Or, it takes at least two to tango). *Social Science and Medicine*, *44*(5), 681–692.
- Durand, M. A., Carpenter, L., Dolan, H., Bravo, P., Mann, M., Bunn, F., & Elwyn, G. (2014). Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. *PLoS One*, *9*(4), e94670. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3988077/>
- Durey, A., Wynaden, D., Thompson, S. C., Davidson, P. M., Bessarab, D., & Katzenellenbogen, J. M. (2012). Owing solutions: A collaborative model to improve quality in hospital care for Aboriginal Australians. *Nursing Inquiry*, *19*(2), 144–152.
- Easton, P., Entwistle, V. A., & Williams, B. (2013). How the stigma of low literacy can impair patient–professional spoken interactions and affect health: Insights from a qualitative investigation. *BMC Health Services Research*, *13*, 319. doi:10.1186/1472-6963-13-319
- Entwistle, V., Prior, M., Skea, Z. C., & Francis, J. J. (2007). Involvement in treatment decision-making: Its meaning to people with diabetes and implications for conceptualization. *Social Sciences and Medicine*, *66*(2), 362–375. doi:10.1016/j.socscimed.2007.09.001
- Entwistle, V. A., & Watt, I. S. (2006). Patient involvement in treatment decision-making: The case for a broader conceptual framework. *Patient Education and Counseling*, *63*(3), 268–278. doi:10.1016/j.pec.2006.05.002
- First Nations Centre. (2007). *OCAP: Ownership, control, access and possession. Sanctioned by the First Nations Information Governance Committee*. Ottawa, Canada: National Aboriginal Health Organization.
- Fossey, E., Harvey, C., McDermott, F., & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry*, *36*, 717–732. Retrieved from http://www.stes.apes.med.ulg.ac.be/Documents_electroniques/MET/MET-DON/ELE%20MET-DON%20A-8082.pdf
- Frosch, D. L., Legare, F., & Mangione, C. M. (2008). Using decision aids in community based primary care: A theory driven evaluation with ethnically diverse patients. *Patient Education and Counseling*, *73*(3), 490–496. doi:10.1016/j.pec.2008.07.040
- Graham, H., & Leeseberg, L. (2010). Contemporary perceptions of health from an indigenous (Plains Cree) perspective. *Journal of Aboriginal Health*, *6*(1), 6–17.
- Halseth, R. (2013). *Aboriginal women in Canada: Gender, socio-economic determinants of health, and initiatives to close the wellness gap*. Prince George, Canada: National Collaborating Centre for Aboriginal Health.
- Hibbard, J. H., & Green, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs*, *32*(2), 207–214.
- Huberman, A. M., & Miles, M. B. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.
- Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to

- shared decision making. *Patient Education and Counselling*, 94(3), 291–301.
- Jull, J., Crispo, J., Welch, V., MacDonald, H., Brascoupe, S., Boyer, Y., & Stacey, D. (2013). Interventions for indigenous peoples making health decisions: A systematic review. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 11(3), 539–554. Retrieved from http://www.pimatisiwin.com/online/?page_id=1288
- Jull, J., Giles, A., Boyer, Y., Stacey, D., & Minwaashin Lodge. (2015). Cultural adaptation of a shared decision making tool with Aboriginal women: A qualitative study. *BMC Medical Informatics & Decision Making*, 15(1). doi:10.1186/s12911-015-0129-7
- Jull, J., Stacey, D., Giles, A., Boyer, Y., & Minwaashin Lodge. (2012). Shared decision-making and health for First Nations, Métis and Inuit women: A study protocol. *BMC Medical Informatics & Decision Making*, 12, 146. doi:10.1186/1472-6947-12-146
- Kelly, K., Dudgeon, P., Gee, G., & Glaskin, B. (2009). *Living on the edge: Social and emotional wellbeing and risk and protective factors for serious psychological distress among Aboriginal and Torres Strait Islander people*. Discussion Paper No. 10. Retrieved from https://www.lowitja.org.au/sites/default/files/docs/DP%2010_web_0.pdf
- Kiesler, D. J., & Auerbach, A. M. (2006). Optimal matches of patient preferences for information, decision-making and interpersonal behavior: Evidence, models and interventions. *Patient Education and Counseling*, 61(3), 319–341. doi:10.1016/j.pec.2005.08.002
- Kruske, S., Kildea, S., & Barclay, L. (2006). Cultural safety and maternity care for Aboriginal and Torres Strait Islanders. *Women and Birth*, 19(3), 73–77.
- MacDonald, C. (2008). Using components of the Medicine Wheel to develop a conceptual framework for understanding Aboriginal women in the context of pap smear screening. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 6(3), 95–108.
- Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in clinical encounters. *Patient Education and Counseling*, 60(3), 301–312.
- McCaffery, K., Holmes-Rovner, M., Smith, S. K., Rovner, D., Nutbeam, D., Clayman, M., . . . Sheridan, S. I. (2013). Addressing health literacy in patient decision aids. *BMC Medical Informatics & Decision Making*, 13(Suppl. 2), S10. Retrieved from <http://www.biomedcentral.com/1472-6947/13/S2/S10>
- McEwan, C. (2009). *Postcolonialism and development*. New York, NY: Routledge.
- Mead, E. L., Doorenbos, A. Z., Javid, S. H., Haozous, E. A., Alvord, L. A., Flum, D. R., & Morris, A. M. (2013). Shared decision-making for cancer care among racial and ethnic minorities: A systematic review. *American Journal of Public Health*, 103(12), e15–e29. doi: 10.2105/AJPH.2013.301631
- Mitra, D., Jacobsen, M. J., O'Connor, A., Pottie, K., & Tugwell, P. (2006). Assessment of the decision support needs of women from HIV endemic countries regarding voluntary HIV testing in Canada. *Patient Education & Counseling*, 63(3), 292–300.
- National Aboriginal Health Organization. (2008). *Cultural competency and safety: A guide for health care administrators, providers, and educators*. Ottawa, Canada: Author.
- National Aboriginal Health Organization. (2006). *Fact sheet: Cultural safety*. Retrieved from <http://www.naho.ca/documents/naho/english/Culturalsafetyfactsheet.pdf>
- National Collaborating Centre for Aboriginal Health. (2012). *The sacred space of womanhood: Mothering across the generations*. Retrieved from <http://www.nccah-ccnsa.ca/docs/child%20and%20youth/The%20Sacred%20Space%20of%20Womanhood%20-%20Mothering%20Across%20the%20Generations%20%28EN%20-%20web%29.pdf>
- Native Women's Association of Canada. (2009). *Violence against Aboriginal women in Canada (backgrounder)*. Ottawa, Canada: Author.
- Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15(3), 259–267.
- O'Connor, A. M., & Jacobsen, M. J. (2007). *Decisional conflict: Supporting people experiencing uncertainty about options affecting their health*. Retrieved from http://homeless.ehclients.com/images/uploads/W-2_Ottawa_Decision_Making_tool--_Reading-1.pdf
- Pfeiffer, D. (2001). The conceptualization of disability. In S. N. Barnartt & B. Mandell Altman (Eds.), *Research in social science and disability* (pp. 29–52). New York, NY: Elsevier Science.
- Public Health Agency of Canada. (2003). *Canadian incidence study of reported child abuse and*

- neglect, 2003: Major findings*. Ottawa, Canada: Minister of Public Works and Government Services Canada.
- Reimer-Kirkham, S., & Anderson, J. (2002). Postcolonial nursing scholarship: From epistemology to method. *Advances in Nursing Science*, 25(1), 1–17.
- Royal Commission on Aboriginal Peoples. (1996). *Report of the Royal Commission on Aboriginal Peoples*. Retrieved from <http://www.aadnc-aandc.gc.ca/eng/1307458586498/1307458751962>
- Sankhulani, L. (2007). *Gender issues in Aboriginal learning*. Saskatoon, Canada: Canadian Council on Learning.
- Stacey, D., Kryworuchko, J., Bennett, C., Murray, M. A., Mullan, S., & Légaré, F. (2012). Decision coaching to help prepare patients for making health decisions: A systematic review of decision coaching in trials of patient decision aids. *Medical Decision Making*, 32(3), E22–E33.
- Stacey, D., Légaré, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., . . . Wu, J. H. (2014). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, 2014(1), 1–265. doi:10.1002/14651858.CD001431.pub4
- Statistics Canada. (2011). *Violent victimization of Aboriginal women in the Canadian provinces 2009*. Retrieved from <http://www.statcan.gc.ca/pub/85-002-x/2011001/article/11439-eng.htm>
- Thorne, S., Riemer Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1–21. Retrieved from http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/thorneetal.pdf
- World Health Organization. (2014). *Health promotion. Track 2: Health literacy and health behavior*. Retrieved from <http://www.who.int/healthpromotion/conferences/7gchp/track2/en/>
- Young, J. C. (2001). *Postcolonialism: An historical introduction*. Oxford, England: Blackwell.