

Cultural Adaptation of a Shared Decision-Making Intervention to Address the Needs of First Nations, Métis and Inuit Women

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Abstract

Background

Little is known about shared decision-making (SDM) interventions with Aboriginal Peoples.

Purpose

To explore Aboriginal women's SDM needs and engage Aboriginal women in culturally adapting an SDM approach.

Methods

Three studies were guided by an advisory group, ethical framework and a postcolonial theoretical lens.

1. A systematic review of the literature to identify health decision-making interventions to support Indigenous Peoples.
2. An interpretive descriptive qualitative study using individual interviews with Aboriginal women to explore decision-making needs.
3. An interpretive descriptive qualitative study to culturally adapt and usability test the Ottawa Personal Decision Guide (OPDG) to support decision making by Aboriginal women.

Results

1. The only eligible intervention study was a randomized control trial conducted in the United States with 44 Indigenous students. Compared to baseline, post-intervention the students demonstrated increased knowledge and use of a four-step decision-making process.
2. Interviews with 13 Aboriginal women supported SDM. Shared decision-making needs were represented by four major themes and presented in a Medicine Wheel framework: *To be an active participant*; *To feel safe with care*; *Engagement in the decision process*; *Personal beliefs and community values*. Supports for each of the major themes focused on the relational nature of shared decision-making.
3. Aboriginal women participated in two focus groups (n=13) or usability interviews with decision coaching (n=6). For culturally adapting the OPDG seven themes were identified: *"This paper makes it hard for me to show that I am capable of making decisions"*; *"I am responsible for my decisions"*; *"My past and current experiences affect the way I make decisions"*; *"People need to talk with people"*; *"I need to fully participate in making my decisions"*; *"I need to explore my decision in a meaningful way"*; *"I need respect for my traditional learning and communication style."*

Conclusions

There is little evidence on SDM interventions with Indigenous Peoples. Although Aboriginal women support SDM, they may have unmet decision-making needs. The OPDG was culturally adapted to be combined with decision coaching and needs to be evaluated.

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Chapter 1

Introduction

Statement of the Problem

Shared decision-making (SDM) is a central feature of patient-centred care (Dagone, 2009; Weston, 2001). SDM approaches have been found to improve clinical decision-making processes (O'Connor & Jacobsen, 2007) and increase patient ("client") satisfaction (Kiesler & Auerbach, 2006). Available evidence and client preferences are influenced by personal circumstances, which include culture (Hajjaj, Salek, Basra, & Finlay, 2010). Current physician-client communication during clinical decision-making has been identified as inadequate (Couët et al., 2013). Client health information needs and clarification of preferences can, however, be met through the use of SDM approaches (Kiesler & Auerbach, 2006)

SDM is defined as a process that promotes collaboration between health care providers and the client making health care choices (Elwyn, Edwards, Kinnersley, & Grol, 2000). As well as structuring a collaborative, client-centred approach between health care provider and client, SDM promotes the sharing and use of information on the benefits and harms of health care options and integrates the values of the client into the decision process (Makoul & Clayman, 2006). The SDM process can be facilitated with the use of patient decision aids, which assist the client in making preference sensitive decisions (Stacey et al., 2014). Patient decision aids are adjuncts to practitioner counselling, and they have been found to increase people's involvement in their health care decision making, which can lead to more informed and values-based care decisions (Stacey et al., 2014). SDM approaches and tools are currently being developed and implemented within health care settings internationally (Elwyn et al., 2013; Stigglebout et al., 2012). Motivation to implement SDM in Canada appears to be linked to a focus on achieving client-centred care (Dagone, 2009).

Canadian health policy is committed to the delivery of client-centred care (Dagone, 2009; Romanov, 2002). Notwithstanding this commitment however, the delivery of health care services to Aboriginal¹ populations has been identified as often being ineffective or damaging, and contributing to their negative health experiences (Kelm, 1998; National Aboriginal Health Organization (NAHO), 2003; Smith, Edwards, Varcoe, Martens, & Davies, 2006; Smye & Browne, 2002). While SDM approaches and tools have been found to be effective in supporting clients to make informed health decisions, these approaches and tools have not yet been evaluated with Aboriginal populations. Although no single definition of health exists for Aboriginal populations (Graham & Stamler, 2010), a clear definition is articulated within the Royal College Indigenous Values and Principles statement (Royal College of Physicians and Surgeons, 2013). According to this statement, “health is holistically defined as a state of complete physical, cognitive, emotional, social and spiritual well-being and not merely the absence of disease or infirmity within a cultural context” (p.5). This understanding of health includes consideration of culture, which is an important feature of ensuring inclusive and accessible health services for Aboriginal populations.

Culture is “a dynamic and adaptive system of meaning that is learned, shared and transmitted from one generation to the next and is reflected in the norms, values, practices, symbols, ways of life and other social interactions of a given culture” (Kreuter & McClure, 2004). Recognition of culture is an important feature in considering the appropriateness of health interventions. Hence, culture should be considered when re-designing interventions that will be used within populations that differ from those for which the interventions were originally designed.

¹ In Canada, the term ‘Aboriginal’ is generally refers to Indigenous Peoples including First Nations, Métis, and Inuit (Royal Commission on Aboriginal Peoples, 1996).

Cultural adaptation refers to modifications that are culturally sensitive and tailored to a cultural group's traditional worldviews. These modifications move beyond changes to the surface structure (i.e., the appearance) and affect the deep structure of the health intervention itself, by addressing the core values, beliefs, norms of the particular group (Resnikow, Soler, Braithwait, Ahluwalia, & Butler, 2000). No definitive approach was identified in the literature for cultural adaptation of health interventions. There is, however, some emerging literature endorsing processes for development of culturally appropriate educational and mental health programs (Griner & Smith, 2006). As well, the literature on cultural adaptation is better established in the area of self-report instruments for measuring health outcomes (Beaton, Bombardier, Guillemin & Ferraz (2000). The 5 stage process developed by Beaton et al. (2000) is based on medical, sociological and psychological literature and it has been used subsequently in health instrument adaptations. This is a step-wise process for cross cultural adaptation of instruments used within health settings. The 5 step process has been tested for use in a range of settings, most prominently within the clinical areas of orthopedics and rheumatology. However, the focus is only on translation to other languages.

For this dissertation, the process aimed at exploring the health decisional needs of Aboriginal women and then engaging these women in culturally adapting an SDM tool, which was originally developed for use within white, Western populations. We aimed to do so in a way that could be defined by Aboriginal women as being useful and relevant. The dissertation was conducted in the form of a series of three studies. This chapter situates the series of three studies presented in this dissertation within current academic understandings of Aboriginal Peoples and SDM with a literature review. To understand the existing knowledge gaps for Aboriginal Peoples and SDM, this literature review describes the challenges experienced by Aboriginal populations as a result of colonialism, and in

particular, for Aboriginal women when they engage with health systems, including the inequities and power relations resulting from colonial influences. Then, approaches to safe and effective care are discussed followed by current understandings of Aboriginal Peoples and SDM, and identification of an evidence gap. Following the literature review, the theoretical framework, ethics, and methodology of this dissertation are presented and briefly discussed.

Literature Review

A general review of the literature to inform the background of this dissertation was initially conducted using electronic databases (e.g., MEDLINE, CINAHL, PubMed) as well major websites (e.g., National Collaborating Centre for Aboriginal Health, National Aboriginal Health Organization, A to Z Inventory of Patient Decision Aids, Cochrane Reviews), and journals and books known to focus on current and historical factors on Aboriginal social and health well-being. A reference librarian was consulted during the initial literature search.

Colonialism and Aboriginal Peoples

Within Canada, colonialism and racism have deleterious effects on the health status of Aboriginal populations. Aboriginal health is influenced by a complex colonial legacy that is reflected by limited health and social opportunities, and standards of living that are low in comparison to national standards (Commission on Social Determinants of Health (CSDH), 2008; Royal Commission on Aboriginal Peoples (RCAP), 1996). Despite the challenges of such history and its direct impacts, Aboriginal Peoples have demonstrated tremendous cultural resilience (Kelm, 1998), and they have worked to resist oppression caused by power inequities. Aboriginal Peoples are affected by relations of power in an environment that is both exploitative and unequal, and results in their endemic marginalization within all areas of

society, including health and social care systems (Kelm, 1998; RCAP, 1996; Smith et al., 2006). Further, while Canadian health care providers express commitments to practicing in a fair and equitable manner (Canadian Association of Occupational Therapists, 2007; Canadian Nurses Association, 2008; Canadian Medical Association, 2004), systemic and cultural barriers often prevent these commitments from being reflected in policy or health care delivery. The outcome is a large difference between the health statuses of Aboriginal people in relation to others living in Canada (RCAP, 1996).

Canadian health care programs and approaches have been criticized for reflecting oppressive values (Health Council of Canada, 2013; RCAP, 1996) and thereby contributing to and perpetuating inequities in relations of power stemming from colonialism (Nettledon, Napolitano, & Stephens, 2007). Health inequities are preventable systematic and socially produced differences in health within and between populations (World Health Organization (WHO), 2010). These inequities are particularly evident between Aboriginal and non-Aboriginal populations in Canada and can be understood from within the context of colonizing policies and their historical impacts on Aboriginal health (Kelm, 1998; Smith et al., 2006).

Marginalization, the Health Professions, and Aboriginal Women's Health

A historical legacy of colonialism exists within the health care system, including medical practices implemented for the purpose of assimilating Aboriginal Peoples and their culture with the colonizers of early Canada (Kelm, 1998). Aboriginal women have experienced particularly damaging impacts from colonial policies, which have resulted in the exploitation of Aboriginal land and resources and the violation of human rights, including issues with legislated identities, forced sterilization, and damaged family structures due to residential schooling (Aboriginal Healing Foundation, 2002).

Today, the literature documents the existence of a cultural divide in the provision of health care in Canada that deleteriously impacts Aboriginal Peoples' health, in particular, the health of Aboriginal women (Boyer, 2004). Researchers have argued that within health professions, Western-trained health care providers have an inadequate understanding of Aboriginal cultures (Browne, 2005; Browne & Fiske, 2001), which has had and continues to have a negative impact on Aboriginal people's health (NAHO, 2003). Experiences with Western-trained health care providers (NAHO, 2003; Papps, 2005) and biomedical models of health care delivery (Browne, Smye, & Varcoe, 2005; RCAP, 1996; Smith, Varcoe, & Edwards, 2005) have been described as leading to Aboriginal Peoples' choice to not use or to delay the use of health care services (Smith et al., 2006). Negative experiences with Western-trained health care providers have also been described as constituting interpersonal and institutional racism (NAHO, 2003; Papps, 2005) grounded in the conflicting cultural beliefs between those seeking health care and the beliefs and accepted practices of health care professionals.

The current approaches to care used within the Canadian health care system are alone insufficient to understand and address the needs of Aboriginal populations for health and wellbeing (Browne et al., 2005; RCAP, 1996; Smith et al., 2005) and fail to adequately support Aboriginal women. As people at risk for marginalization within health and social systems (CSDH, 2008), Aboriginal women may not have an opportunity to engage in a process of safe and effective care or to make meaningful decisions about their health. It is therefore crucial that approaches to SDM be explored by and with a population of Aboriginal women to facilitate processes of respectful and inclusive care.

Current Approaches to Safe and Effective Care: Cultural Safety

The concept of cultural safety was developed internationally within the health care field to improve the effectiveness and acceptability of care with Indigenous Peoples and to use attitudinal change to transfer power from health care provider to client (Gray & MacPherson, 2005). In culturally safe approaches, the client defines culturally safe practices, rather than the health care provider (Gray & MacPherson, 2005). Through a process aimed at identifying power imbalances within health care settings, culturally safe care upholds self-determination and de-colonization for Aboriginal Peoples (NAHO, 2006). The result is an empowered client and opportunities for decision-making and collaborative health care relationships. The outcome is more effective care (Brascoupé & Waters, 2009). SDM approaches and tools structure a collaborative process of decision making between health care provider and client, and therefore may be viewed as promoting the concepts of cultural safety.

SDM promotes collaboration between the health care provider and client in a process of making health decisions in ways that are reflective of the client's personal values, (Makoul & Clayman, 2006). Decisions most suitable for a SDM process are ones in which there is more than one reasonable option, including doing nothing or maintaining the status quo, and which should reflect the client's informed choice (Sepucha, Floyd, & Mulley, 2004). For decisions in which there is more than one reasonable option, the weighing of benefits and harms cannot be done without considering particular client values (Wennberg, 2002). Patient decision aids are tools that facilitate the SDM process (Stacey et al., 2014). Patient decision aids are booklets, videos, or online tools that complement practitioner counselling; they have been found to increase people's participation in making more informed and values-based care decisions. In some settings, studies describing the decision support needs of immigrant women and their health care providers have suggested that

patient decision aids may improve decision quality and empower women to make informed decisions based on personal values (Mitra, Jacobsen, O'Connor, Pottie, & Tugwell, 2006) or, have narrowed the gap between racial groups through engaging clients in a process to make decisions about health care services (Weng et al., 2007). These studies have been not yet been conducted with Aboriginal populations.

Current Understandings: Aboriginal Peoples and SDM

Literature reviews exploring concepts relating to SDM and health decisions and Aboriginal Peoples concentrate on describing health decision making in Aboriginal populations (Edgecomb, 2006; Kelly & Minty, 2007; Minore, Boone, Katt, Kinch, & Cromarty, 2004), health equity and the role of Indigenous Peoples within cancer care (Canales, 2004; Canales & Geller, 2004; Canales & Rakowski, 2006) or advanced care planning (Kaufert, Putsch, & Lavallee, 1998; Paulette, 1993; Thomas, Wilson, Justice, Birch, & Sheps, 2008). While health care interventions that incorporate concepts of SDM have been shown to be effective for translating research evidence to inform preference sensitive health decisions (Kiesler & Auerbach, 2006; Stacey et al., 2014), little is known about interventions to support SDM with Aboriginal Peoples.

Evidence Gap

Little is known regarding the processes or outcomes for Aboriginal women using SDM approaches in health settings or the cultural relevance of SDM approaches or tools, such as patient decision aids, within Aboriginal populations.

Theoretical Framework

Postcolonial theory was the main theoretical framework selected to guide this dissertation. Postcolonial theory encompasses a group of theories that share a social, political and moral concern about the history and legacy of colonialism and the role of colonialism in

continuing to shape peoples' lives (Young, 2001). Postcolonial theories are derived from diverse disciplinary perspectives (McEwan, 2009; Young, 2001) such as cultural studies, political science, literary criticism, and sociology, and have been informed by an array of scholars such as Gandhi, Bhaba, Said, and Spivak (Gray & MacPherson, 2005, Young, 2001). In the Canadian context, the "post" in postcolonial does not mean "after colonialism" (Smith, 1999), but instead refers to the idea of Canada "as a place of multiple identities, interconnected histories, and shifting and diverse material conditions. It is also a place where new racisms and oppressions are being formed" (Smye & Browne, 2002, p. 44). A postcolonial perspective provides a theoretical lens to show everyday experiences of marginalization that occur in day-to-day relationships and in the systems structuring human relations (Reimer-Kirkham & Anderson, 2002) such as the health care setting (Anderson, 2004; Reimer-Kirkham & Anderson, 2002). An essential feature of postcolonial theory, and of particular relevance to the work of this dissertation, is a focus on disrupting the thinking behind structural inequities that have been brought about by histories of colonization and ongoing neocolonial practices (Browne, 2005).

Scholars have identified the debate that exists within postcolonial theory about the inclusion and explicit identification of gender (Gandhi, 1998; Young, 2011). The result is that some scholars have included feminist theoretical perspectives to extend both postcolonial and feminist theory (Anderson, 2004; Brown, 2005). For this dissertation, the primary researcher (JJ) together with the advisory group agreed to focus on a postcolonial approach without inclusion of feminist theory. The chosen theoretical approach was supported by the complex and unresolved debate in the literature around the use of feminist theory as a basis from which to understand and address Aboriginal health issues (Huhndorf & Suzack, 2010).

Aboriginal scholars have made strong contributions to postcolonial theories; their perspectives have developed from Aboriginal epistemologies as a related and distinct endeavour (Battiste, 2000). Postcolonial Aboriginal thought has been described by Battiste (2000) as emerging from the need to accommodate the complexities of colonialism and its assumptions for Aboriginal Peoples. In this dissertation, which consists of a series of three studies, postcolonial theory as articulated by Battiste (2000) was identified as offering the most relevant perspective from which to view, understand, and seek to address the negative impacts resulting from the underpinning colonial forces that continue to negatively influence the lives of Aboriginal women living in Canada. Battiste (2000) proposed to “seek to initiate dialogue, advance a postcolonial discourse, and work actively for a transformation of colonization thought” (p. xxii). Using the Medicine Wheel, Battiste (2000) referred to the four directions from which to respectively map (west), diagnose (north), heal (east), and vision “the Indigenous renaissance” (p. xxiv) (south) within the processes of colonization. Battiste (2000) expressed postcolonial Indigenous thought, and placed Aboriginal Peoples as central to a process of change. The change process is inclusive of Aboriginal and non-Aboriginal participants, and is aimed at changing structures and the underpinning ideas in society, by collaboratively engaging all participants.

The generalized approach proposed by Battiste (2000) can be applied to the work presented in this dissertation, which was developed from within a research partnership between the researcher (of Euro-Canadian descent) and the advisory group which included representatives from the Aboriginal community. Battiste’s (2000) work informed the theoretical lens of this project and is evident throughout this dissertation. The concepts presented by Battiste (2000) provided a lens to frame the issues for Aboriginal people (in Chapter 2) and Aboriginal women (Chapters 3 and 4) and their experiences in making health

decisions (Chapters 2, 3 & 4) by situating their experiences within historical and social colonial society. For this dissertation, the postcolonial theoretical lens informed by Battiste's (2000) work provided ongoing opportunities for the researcher with the advisory group to reflect upon and understand the processes and outcomes of the research, so as to ensure that the work described in this dissertation promoted a decolonizing agenda.

Ethics

The work presented in this dissertation was developed to support a research agenda that was respectful of Aboriginal Peoples and responsive to the unique contextual and informational needs of an Aboriginal community. The Tri-Council Policy Statement (TCPS)(Panel on Research Ethics, 2012) and Ownership, Control, Access and Possession (OCAP)(First Nations Centre, 2007) strive to reflect the unique ethical issues involving research with Aboriginal Peoples, and they were used in the development of the protocol of this research presented in this dissertation as well as during the conduct of the study. The principles expressed in the TCPS and OCAP were implemented through the use of a meaningful research partnership with an advisory group, which included leaders from Minwaashin Lodge for two of the three studies presented in this dissertation. This included participation by the primary investigator (JJ) as a volunteer with Minwaashin Lodge. The first study presented in this dissertation is a systematic review of the literature, and which also included an advisory group with Aboriginal members. One advisory group member, who identified as Aboriginal, also acted as second reviewer on the systematic review. While this study did not require ethics approval from the University of Ottawa, we followed OCAP for the systematic review.

For the two studies that involved Minwaashin Lodge, administrative and ethical

approval was sought and obtained from Minwaashin Lodge and a memorandum of understanding was drafted to reflect the study agreement (Appendix A). Ethics approval was obtained from the University of Ottawa Research Ethics Board for the study, as well as from Minwaashin Lodge leaders and executive (Appendix B, Appendix C).

Study Methodology

Participatory Action Research

Consistent with the OCAP ethical framework, the principles of participatory action research (PAR) were applied as the overarching methodology for the series of three studies presented in this dissertation.

Community-based PAR methodologies acknowledge and aim to provide an alternative approach to the troubled history of research “on” Aboriginal peoples and have emerged from feminist (Anderson, 2004) and postcolonial approaches (Fletcher, 2002). PAR methodologies align with the theoretical foundations of postcolonial theory presented in this dissertation as they can accommodate a range of values and knowledge (Dodson & Schmalzbauer, 2010). PAR is a good fit for exploring the potentially varied knowledge, values and views of stakeholders such as health care recipients, community members, care providers, and policy makers (Macauley, 1999). There is no single method or approach for PAR; rather, it is characterized as adaptive to user needs (Fletcher, 2002).

PAR is identified within the literature as an appropriate approach for engaging in Aboriginal research partnerships (Fletcher, 2002). PAR has been demonstrated as being particularly successful in broader, interdisciplinary health promotion initiatives within Aboriginal populations (Smylie, Kaplan-Myrth, McShane, Métis Nation of Ontario-Ottawa Council, Pikwakanagan First Nation & Tungasuvvingat Inuit Family Resource Centre,

2009), including those involving multilevel interventions, such as addressing diabetes within a Mohawk community (Cargo et al, 2003). A research approach that supported the use of PAR principles was identified by the advisory group as appropriate for the research presented in this dissertation.

Objective and Research Questions

The overarching objective proposed for this study was to explore the health decision-making needs of Aboriginal women, and for Aboriginal women to culturally adapt an SDM approach. Each of the three studies focused on answering one of the following questions:

- 1) What are effective interventions to support Aboriginal Peoples making health decisions?
- 2) What are the experiences of Aboriginal women in making health decisions?
- 3) What is the usability of a culturally adapted Ottawa Personal Decision Guide for Aboriginal women?

The series of three studies is presented in the three papers comprising Chapters 2, 3 and 4 of this dissertation. The study protocol was published in an open-access journal, *BMC Medical Informatics and Decision Making* (Jull et al., 2012; Appendix D).

Chapter 2 is a systematic review of the international literature to determine effective interventions to support Aboriginal people making health decisions.

Chapter 3 is an interpretive descriptive qualitative study. Three specific research questions were answered in the study: 1) What are the health/social decision-making needs of urban Aboriginal women?; 2) What are the barriers to involving urban Aboriginal women in their health/social decision-making?; 3) What are potential supports to enhance the health/social decision-making experiences of urban Aboriginal women?

Chapter 4 is an interpretive descriptive qualitative study to culturally adapt and usability test a SDM intervention, the Ottawa Personal Decision Guide (OPDG), to support decision making by Aboriginal women. Cultural adaptation of the OPDG was conducted through a collaborative and systemic process. The adaptation process maintained the principles underlying the original OPDG.

Chapter 5 is an integrated discussion of the findings from the series of three studies and discusses their contribution to the field of population health.

Given the number of individuals involved in the various elements of the dissertation, Chapter 6 describes each collaborator's contribution. The Appendices provide the memorandum of understanding, ethics documents, study protocols, study posters, recruitment scripts, consent forms, interview guides and demographic data forms.

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Chapter 2

Interventions for Indigenous Peoples Making Health Decisions: A Systematic Review

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Abstract

Background: In general populations, shared decision-making (SDM) facilitates care provider and consumer collaboration for informed health decisions. This study identifies SDM interventions to support Indigenous Peoples making health decisions.

Methods: A systematic review developed in dialogue with an advisory group using the Cochrane Handbook. A comprehensive search was conducted of electronic databases including all dates to September 2012. Two independent researchers screened and quality appraised included studies. Findings were analyzed descriptively and reported using guidelines for equity focused systematic reviews.

Results: Of 1,769 citations screened, 1 study was eligible for inclusion. This study was a randomized control trial rated as low quality for randomization and unclear for the other risk of bias criteria (allocation concealment, performance, detection, attrition, reporting bias). The study was conducted in the US with 44 students ages 11 to 13, and members of Pueblo, Navajo, Hopi, and Jicarilla Apache Indian Nations. A culturally-relevant tool assessed student decision-making skills pre and post intervention. Students demonstrated increased decision-making knowledge and were able to apply a four-step decision-making process to health situations.

Conclusions: There is a lack of studies evaluating SDM among Indigenous Peoples. One study demonstrated that a culturally-relevant approach improved knowledge and application of decision-making skills. Further studies are needed.

Key Words: Indigenous Peoples, Aboriginal Peoples; children and youth; First Nations, Inuit, Métis; decision-making; intervention studies; equity; systematic review.

Background

Globally, Indigenous² populations are identified as experiencing significant inequities in health status (Commission on Social Determinants of Health [CSDH], 2008); Nettledon, Napolitano, & Stephens, 2007). Indigenous Peoples are disadvantaged in the social determinants of health and are among the most vulnerable populations in terms of poor health related to socioeconomic and environmental factors (CSDH, 2008). The results of these disadvantages are health inequities, defined as preventable, systematic and socially produced differences in health between and within populations (WHO, 2010). The evidence of health inequity is an indicator that Indigenous populations require opportunities to participate in health care that meets their self-identified needs. Shared decision-making (SDM) has the potential to decrease health inequities among Indigenous populations by facilitating participation in health care that better meets their self-identified need.

SDM is a process that promotes collaboration between healthcare providers and recipients in decisions affecting health (Elwyn, Edwards, Kinnersley, Grol, 2000; Towle & Godolphin, 1999) and it is a central feature of patient-centred care (Dagone, 2009; Weston, 2001). SDM has been found to both improve clinical decision-making and client satisfaction with their health care experience (Keisler & Auerbach, 2006; O'Connor & Jacobsen, 2007).

² The term “Indigenous peoples” refers to people that:

- Identify themselves and are recognized and accepted by their community as Indigenous.
- Demonstrate historical continuity with pre-colonial and/or pre-settler societies.
- Have strong links to territories and surrounding natural resources.
- Have distinct social, economic or political systems.
- Maintain distinct languages, cultures and beliefs.
- Form non-dominant groups of society.
- Resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities.

(United Nations Permanent Forum on Indigenous Issues, 2006)

Support for SDM approaches are emerging in health policy in Canada (Légaré, Stacey, Forest, Coutu, 2011) the U.S. (Senate and House of Representatives, 2010) and other international settings (Härter, van der Weijden & Elwyn 2011; McCaffery et al., 2011). Patient decision aids can facilitate SDM.

Patient decision aids, in the form of pamphlets, videos and web-based programs, are interventions that make explicit the decision being made, provide evidence based information on options, benefits and risks, and help patients determine a preference by clarifying what is most important to their particular situation (O'Connor, Llewellyn-Thomas & Flood, 2004). A review of studies looking at effectiveness of patient decision aids concluded that these tools help health consumers to improve knowledge about the decision to be made and increase understanding of possible risks and benefits of options. The result is that people make decisions which are more consistent with personal values and support their participation in decision-making with health care providers (Stacey et al., 2011). Other studies have found that health consumers' desire for involvement increases when patient decision aids are available; however, there has been limited evaluation of SDM tools and approaches used within a range of different populations (Frosch, Légaré & Mangione, 2008; McCaffery et al., 2012).

Although studies evaluating SDM strategies, such as patient decision aids used by Indigenous people are not yet evident within the literature, there are two non-randomized studies focused on diverse population subgroups. One study found that SDM interventions may improve decision quality and empower immigrant women to make informed decisions based on personal values (Mitra, Jacobsen, O'Connor, Pottie & Tugwell, 2006). The other study showed that patient decision aids narrowed the differences between racially distinct groups in surgical knowledge and expectations (Weng et al., 2007). Both of these studies

suggest that promoting SDM may also be acceptable and appropriate for facilitating more client-centred processes of clinical decision-making within Indigenous populations and thereby improve their control over health care decisions. To date, cultural relevance of SDM approaches or tools such as patient decision aids for Indigenous populations has not yet been established. By engaging with Indigenous partners in developing SDM approaches and tools, understandings of the unique care needs within this diverse group can be developed; evidence of such knowledge is not yet evident within Western health and social care networks. SDM creates opportunities for collaboration between health care providers and clients, from which systematic health and social changes may be facilitated to better reflect the perceptions of health held by Indigenous clients.

The overall purpose of this systematic review was to identify effective interventions to support Indigenous Peoples making health decisions. To achieve this purpose, the objective of the review was to search for published studies conducted with populations identified as Indigenous and making a decision affecting the health of themselves and/or a family member, using an intervention to influence health decision-making, and measuring decision-making outcomes.

Methods

Systematic reviews involve a process of searching, selecting, appraising, and synthesizing research studies to answer a specific question (Higgins & Green, 2011). They can help build an evidence base about effective interventions for improving health outcomes (Kelly, Morgan, Bonnefoy, Butt & Bergman, 2007). Within the area of Indigenous health this review will contribute to an evidence base that can be used to promote practices, such as SDM interventions, that may minimize health inequities between Indigenous and non-Indigenous populations. This systematic review was based on the Cochrane Handbook

(Higgins & Green, 2011). The Cochrane Handbook provides reporting guidelines that promote completeness and transparency in the research methods and how the results are reported. The Assessing the Methodological Quality of Systematic Reviews (AMSTAR) (Shea et al., 2007) criteria were used in the development of this systematic review. As well, the Preferred Reporting Items for Systematic Reviews and Meta-analysis Equity 2012 (PRISMA-E) (Welch et al., 2012) were used for reporting the results of the systematic review. A study protocol for this systematic review was previously published (Jull, Stacey, Giles, Boyer & Minwaashin Lodge, 2012/Appendix D), and includes details on the methods used. The only change in study methods was the use of the PRISMA-Equity 2012 (Welch et al., 2012) instead of PRISMA (Moher, Liberati, Tetzlaff, Altman, The Prisma Group, 2009), as the PRISMA-E includes criteria to assess for intervention effects on health equity (Figure 2.3). The following provides a brief summary of the study methods.

To assist in the development and implementation of the review, an advisory group was formed, and that consisted of the authors and those acknowledged on the paper. This group included experts in the area of Indigenous health issues, health equity, information services, decision-making tools and approaches, knowledge translation, systematic review methodology, collaborative research approaches with Indigenous people, quantitative and qualitative methodologies, and library sciences. The following key databases were searched with no start date limitation, i.e., from the earliest data sources on each database, e.g., 1947 or earlier, and up to September 16, 2012: MEDLINE, OVID, EMBASE, PsychInfo, CINAHL, Proquest Nursing and Allied Health, ERIC, Cochrane, and Sociological Abstracts, as well as a planned hand search of grey literature. The search strategy used by the librarian to conduct the database searches is shown in Figure 2.1. Details on the inclusion/exclusion

criteria used to guide selection of studies may be found in Table 2.1. The search and selection details are also available elsewhere (Jull et al., 2012/Appendix D).

Data Collection

The one included study had its data extracted using an explicit checklist, as recommended in the PRISMA-E 2012 guidelines (Welch et al., 2012), and included author, setting, and characteristics of the intervention study design, characteristics of the participants, and findings relevant to outcomes for this review. The data extraction process was conducted by the first reviewer (JJ), and a second reviewer (JC) verified the accuracy of extracted data.

Study Quality

Two reviewers (JJ, JC) independently assessed the included study for quality using the Cochrane Collaboration Risk of Bias Tool to examine internal validity (Higgins & Green, 2011). Due to the insufficient number of studies, sensitivity analysis was not possible.

Analysis

Characteristics of the included study were analyzed descriptively and situated within a colonial historical and social context.

Results

Of the 1,769 citations identified, 1 study was eligible for inclusion (Figure 2.1). Of the 34 studies that were eligible for full text review, 33 were excluded: 2 did not include participants specifically defined as Indigenous and as making a health or social decision for themselves or another family member; 15 did not report on decision making interventions, but focused instead on educational interventions; 16 did not report on primary outcomes relating to attributes or the process of decision-making but rather on the learning of other behaviours or knowledge (Figure 2.1, Table 2.2).

Characteristics of the Included Study

The included study was a randomized control trial (see Table 2.3). The study enrolled 44 male and female adolescents and final results were reported in the study for 43 adolescents. One participant from the intervention group withdrew from the study but no rationale was provided. In the study, participants were described as randomly assigned by computer to the intervention group (daytime health class learning decision-making skill; n=23) or control group (evening class no learning about decision-making skill; n=21).

Study participants had a mean age of 12.6 years and were described as of American Indian descent and representing the Pueblo, Navajo, Hopi and Jicarilla Apache Indian Nations. The study setting was described as a boarding school exclusively for American Indian youth and that promoted academic excellence. The school, operated under the Indian Self-Determination Act (P.L. 93-638), was not intended for children with emotional, psychological or social problems (Okwumabua & Duryea, 1989)

Quality assessment of the study using the Cochrane Risk of Bias tool revealed low risk of bias for randomization and unclear for the other five criteria (allocation concealment, performance, detection, attrition and reporting bias) due to inadequate reporting (Table 2.4).

Characteristics of Interventions

The study intervention consisted of teaching a four step decision-making process to participants, as described in Table 2.3. A modified version of the decision-making tool (Centres for Disease Control, 1984) was used to assess the students' baseline and post-intervention decision-making skill level. The decision-making tool was modified to be culturally relevant by incorporating realistic aspects of American Indian culture and social environments in each decision scenario. The tool was also reduced from five to four steps (Okwumabua, Okwumabua & Duryea, 1989).

Characteristics of Outcome Measures

Outcome measures of the decision-making tool included the students' knowledge and application of the four-step decision-making process at pre- and post-intervention. The tool consisted of a series of scenarios describing a person in the act of making a decision with health implications. For each scenario, selections from the four-step decision-making intervention were provided, either in the scenario or in a series of choices that followed the scenario. Students were expected to read the scenario, determine which steps had been taken, and select the next step that should be taken to make a 'wise' decision. The decision-making tool was modified by curriculum specialists and participating teachers to ensure that the tool was easy to understand and culturally relevant, and it was adapted from being a five step to a four step process (define decision, identify alternatives, weight costs/benefits, make a decision) with the fifth step (self-evaluation of the decision) removed as it was identified as not appropriate for the purpose of the study. Reliability of the decision-making tool was assessed at 0.81 using test-retest procedure; face validity was judged as 'significant' by a panel of experts from the University of New Mexico, local curriculum experts and participating teachers at the study school (Okwumabua, Okwumabua & Duryea, 1989).

Study Results

Pre-intervention results reported no significant differences between or within the control and intervention groups for knowledge of the four steps of decision-making (Table 2.3). Post-intervention between-group analyses showed that the experimental group demonstrated higher knowledge scores (Table 2.3). Within-group analyses demonstrated no significant differences in score distribution post-intervention for the control group; however, the experimental group demonstrated significant improved knowledge ($\chi^2 = 19.49$ $p < 0.001$) from pre- to post-training.

Post-intervention, between-group evaluation showed that the experimental group had significantly increased knowledge with a greater number of correct responses for decision-making ability than the control group (Table 2.3). Likewise, a post-intervention within-group analysis showed no differences in scores for the control group, while the experimental group had significant differences in score distribution ($X^2=13.63$ $p< 0.01$) from pre- to post-training, indicating improved application of decision-making process within the experimental group.

Qualitative Outcomes

The participants from the experimental group and the health teacher reported that role play and question and answer panel sessions were the most helpful intervention components for generating participation, open discussion, and facilitating understanding of the sequential decision-making process. During these sessions, information on the most frequent health compromising decision-making situations confronting students were revealed.

Discussion

Summary of Main Results

The objective of this systematic review was to determine effective SDM interventions to support Indigenous Peoples making health decisions. Despite extensive searching of published and unpublished research, only one relevant study was identified, which demonstrates a significant gap in the literature.

While quality assessment results were low (one criteria) and unclear (5 criteria), the authors concluded that in comparison to usual activities, students of Pueblo, Navajo, Hopi and Jicarilla Apache Indian Nations exposed to a highly supported program of training for 5 weeks had improved knowledge and ability to apply a four step decision-making process. Culturally relevant scenarios were used for applying the decision-making process. The study

findings are consistent with work that has been done within non-Indigenous populations, as SDM tools and approaches have been found to improve knowledge and enhance participation in decision-making (Stacey et al., 2012), and thereby provide clients with effective strategies to make informed decisions about health (Keisler & Auerbach, 2006; O'Connor & Jacobsen, 2007). As well, the four-step decision process (define the decision, identify alternative, weigh costs/benefits, make the decision) taught to students in the study aligns with four of the nine essential elements identified for client – health provider SDM (define problem, present options, pros and cons, clarify client values/preferences, client ability to follow through on plan, health care provider presents what is known and makes recommendations, check/clarify client understandings, make decision, arrange follow up) (Makoul & Clayman, 2006). This study not only suggests that students from Pueblo, Navajo, Hopi and Jicarilla Apache Indian Nations can learn and apply a four-step decision-making process; it also introduces a potentially feasible cognitive tool that can be used to train people to manage decisions affecting their health (Okwumabua, Okwumabua & Duryea, 1989).

Training for People Making Decisions about Their Health

Currently, within the broader literature on health decision-making, the focus has been on interventions supporting the training of health care providers for SDM skill development (Stacey & Hill, 2013). Interventions that train health care consumers or members of the general population (i.e., those that are not in a care provider role) to manage decisions that affect their health are not yet evident in the published literature.

The one included study in this review, now more than 20 years old, employed a role-playing strategy for teaching the four-step decision-making process to participating students. The use of a role-playing approach for training in SDM is consistent with more recent and on-going work that has been found to be effective within healthcare provider populations

(Stacey & Hill, 2013). Role-playing has been found to link with behaviour change in care providers and is a key part of the decision coaching curriculum (Ottawa Hospital Research Institute, 2012).

These findings indicate that despite the diversity found between participants in the one included study (students, care consumers, Indigenous) and the broader literature about training in SDM approaches (adult, Western trained care providers, unspecified cultural backgrounds), there may be commonalities in SDM training interventions. Techniques that have been found to successfully promote SDM behaviours within adult care provider populations may also be used effectively within a range of care consumer populations. The important role played by culture in initiatives promoting behaviour change, however, cannot be neglected.

Importance of Culturally Appropriate Support for Making Health Decisions

Exploration of concepts relating to SDM, health decisions, and specific subgroups of Indigenous populations in the literature emphasize the role that culture plays in health settings, and highlights a gap in intervention studies for Indigenous people making health decisions. The broader literature concentrates on generating descriptions of health decision-making within Indigenous populations (Edgecomb, 2006; Kelly & Minty, 2007; Minore, Boone, Katt, Kinch, & Cromarty, 2004), in advanced care planning (Kaufert, Putsch, & Lavalley, 1998; Paulette, 1993; Thomas, Wilson, Justice, Birch, & Sheps, 2008), as well as health equity issues and the factors influencing participation of Indigenous women in routine medical screening (Canales, 2004; Canales & Geller, 2004; Canales, & Rakowski, 2006). In particular, these studies place an emphasis on describing the ways in which culture influences individual choice within the health care system rather than focusing on how effective interventions are for the populations of interest.

While the influence of culture is a critical factor that effects the way in which health decisions are made, there is evidence that interventions using decision-making approaches may successfully be modified to accommodate non-white, Western cultural needs. For example, in one study conducted with a mixed group of Native American and Latina women, it was concluded that while cultural adaptation to a process of consultation planning (creation of a question list before physician visit) was necessary, the use of strategies typically applied within those of non-minority groups was effective (Belkora, Franklin, O'Donnell, Ohnemus, & Stacey, 2009). These findings align with those in this systematic review in which the one included study employed a decision-making approach developed for non-Indigenous children and youth, which was culturally modified for use with the Indigenous student population (Okwumabua & Duryea, 1989).

Despite findings that suggest SDM approaches may be adapted for use within Indigenous populations, intervention studies that employ decision-making strategies with this population have focused on compliance, rather than recognizing or building skills for making health decisions. This is evident in the literature exploring what is presented as health decision-making with Indigenous populations.

Focus on Compliance Versus Decision-Making Skills

Although some of the studies excluded at level 3 screening (Table 2.2) promoted decision-making in lifestyle choices, these studies were excluded because the focus was on promoting compliance. Specifically, these intervention studies employed decision-making strategies aimed at educating Indigenous participants to comply with particular health behaviours, such as self-management in cardiac care (Cook, Grothaus, Guitierrez, Kehoe, & Valentin, 2010), tobacco use cessation (Montgomery, Manuelito, Nass, Chock, & Buchwald, 2012) and preschool dental care practices (Lawrence, Romanetz, Rutherford, Cappel,

Binguis, & Rogers, 2004). These approaches were directed at educating participants to make the ‘right’ choice, rather than to acquire skills to negotiate the challenges of making preference sensitive decisions.

Instead of directing people in their choices, SDM practitioners should aim to uphold the principle of autonomy in health settings, and to support people to participate in making decisions about their health (Makoul & Clayman, 2006). Educational approaches that encourage compliance fail to align with the principles of client-centered care and undermine client-centred, informed choice. Moreover, a focus on compliance will not help clients to manage decisional conflict, a state commonly associated with making difficult preference sensitive decisions (Légaré et al., 2010).

Within the mental health literature, a focus on compliance has been criticized as failing to help people negotiate difficult decisions that have long-term implications for health and well-being (Deegan & Drake, 2006). Additionally, adolescent health literature exploring issues of compliance in disease treatment promotes strategies that facilitate relationships between the care provider and client, encouraging healthcare providers to engage with and develop understandings of the adolescent and to tailor information to meet the adolescent’s needs – essentially encouraging an SDM approach (Dinwiddie & Müller, 2002; Niggeman, 2005). Within the educational literature, ‘critical thinking skills’ training, described as training for adolescents in decision skills, are described as important for academic success, and are also promoted as crucial for making good decisions that influence health (Elias & Kress, 2009). These views align with the approach taken in the included study in which students were trained in skills that promoted their autonomy in making decisions that would be beneficial for their health (Okwumabua, Okwumabua & Duryea, 1989).

For populations identified as vulnerable to oppression, promoting approaches that facilitate participation in health decisions is of particular relevance. The findings in this review demonstrate that there is a need for further research to promote skills in decision-making, and to equip people to negotiate the complexities associated with difficult choices that have implications for health and well-being. SDM is a collaborative process that engages health care provider(s) and the health care client in making health decisions and is fundamental for informed consent and patient-centred care. More and better designed intervention studies will contribute to building evidence for Indigenous communities and their representatives, as well as policy and decision makers, to better address issues related to health decision-making within Indigenous populations

Limitations and Strengths

The potential limitations of this review included poor indexing of studies in databases and a lack of tested protocols for conducting systematic reviews in the area of Indigenous health. Given the poor indexing of studies in electronic databases, it is possible that some studies were missed; however, there is transparency in the extensive search strategy used. While the systematic reviews of the literature addressing Indigenous issues are not yet well established and have been challenged as potentially irrelevant to Indigenous health (MacDonald, Priest, Doyle, Anderson & Waters, 2010) there is a growing evidence base supporting the role of systematic reviews for conducting and promoting health equity.

Strengths of this review included the comprehensive search strategy developed in collaboration with an academic librarian, the use of two independent reviewers at each screening stage, and the iterative and ongoing consultation with an interprofessional team of researchers with expertise in Indigenous health, health decision-making, and systematic review methods. Additionally, the use of the PRISMA-E in this review to structure the

reporting of findings provides a standardized approach to the review, and will enable this review to contribute to building evidence on best standards for systematic reviews supporting equity in health (Welch et al., 2012).

Conclusions

Little is known about effective interventions for supporting Indigenous Peoples to participate in health decisions. The findings of this systematic review indicate that more and well-designed studies are needed in the area of interventions promoting SDM for Indigenous populations, and that specific studies must be developed which engage the communities for which the SDM interventions would be relevant.

While Indigenous populations are systematically disadvantaged in the area of health, the evidence of health inequity shows that Indigenous Peoples could benefit from opportunities presented through the use of SDM to participate in making decisions about their unique health needs. This study identified one randomized control trial study, which, while conducted over 20 years ago, demonstrated that a culturally-relevant approach to SDM could improve knowledge and application of decision-making skills affecting health of youth representative of Pueblo, Navajo, Hopi, and Jicarilla Apache Indian Nations. While cultural relevance of SDM approaches or tools have not yet been established within Indigenous populations, the one included study in this review is evidence that builds on two other studies conducted within diverse, although non-Indigenous, populations. Together, these studies suggest that promoting SDM may be acceptable and appropriate for facilitating client centred processes of decision-making and thereby improving control over health decisions in diverse populations. These studies must be interpreted together cautiously, as the issues underpinning the poor health of Indigenous populations is situated in a unique colonial social

and historical context and interventions found to be effective within one population cannot be assumed to be generalizable.

This review identified a significant gap in the literature for studies evaluating SDM among Indigenous Peoples. Better designed and inclusive intervention studies will contribute both to building an evidence-base, as well as developing effective approaches to further identify theoretical and methodological issues in health decision-making for Indigenous populations. In this way effective SDM contributions may be made for addressing health equity issues within Indigenous populations. Systematic review methods in the area of Indigenous health must continue to be developed in a collaborative manner that best meets the needs of those that use them – decision makers, health care providers, and most importantly, that of health care clients.

Figure 2.1. Flow Chart for Included and Excluded Studies

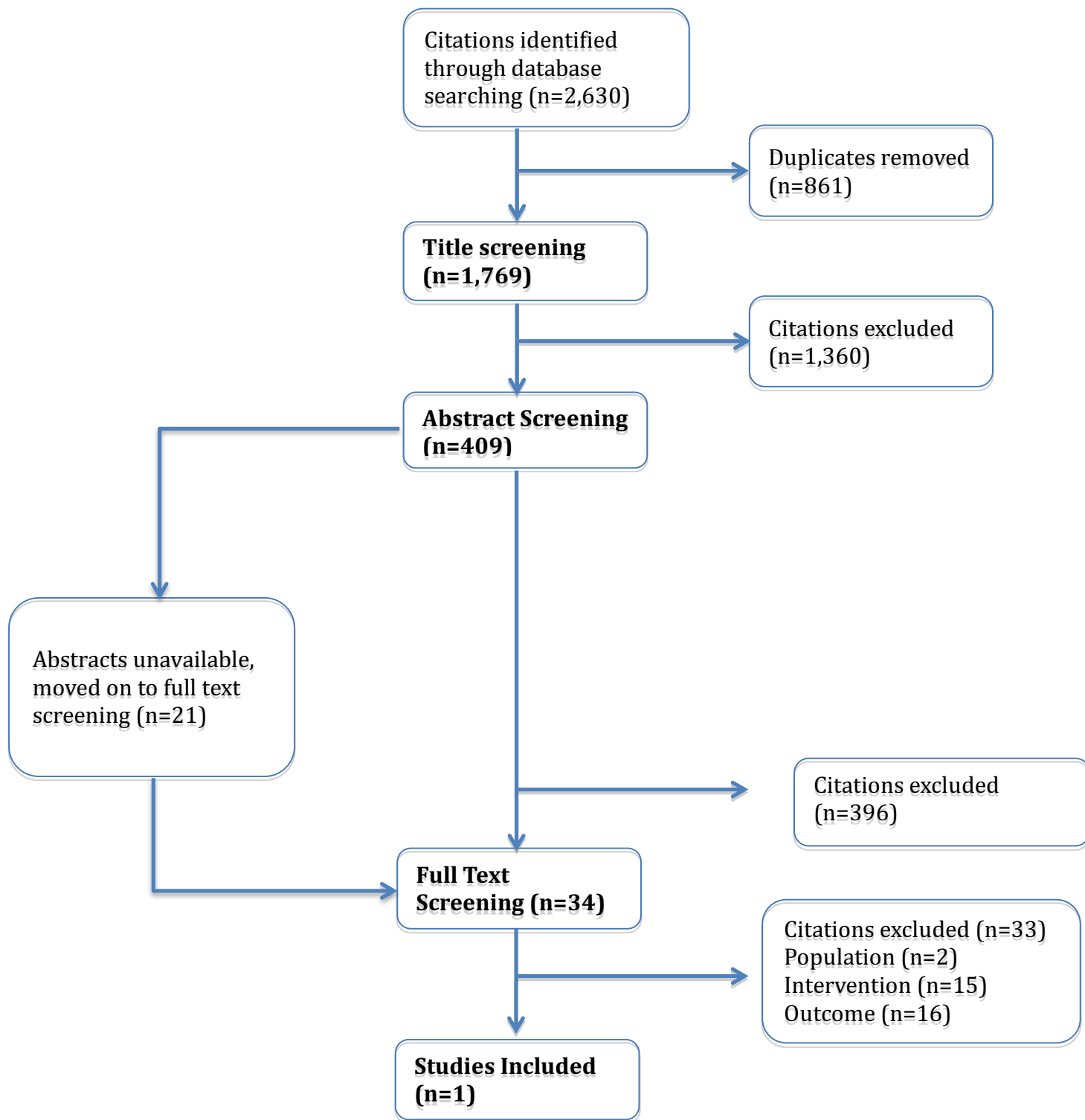


Figure 2.2. Search Strategy

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

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1  Choice Behavior/
2  Decision Making/
3  Decision Support Techniques/
4  Educational Technology/
5  exp Risk Reduction Behavior/
6  (decision adj3 aid$.tw.
7  (decision adj3 tool$.tw.
8  decision support.tw.
9  decision making.tw.
10 or/1-9
11 (decision$ or choic$ or preference$.tw.
12 exp Attitude to Health/
13 exp Health Behavior/
14 exp Health Education/
15 informed consent.mp.
16 or/12-15
17 11 and 16
18 ((personal or interpersonal or individual or parent$) adj1 (decision$ or choice$ or preference$)).mp.
19 ((patient$ or consumer$ or client$) adj1 (decision$ or choic$ or preference$)).mp.
20 informed choice$.tw.
21 informed decision$.tw.
22 or/18-21
23 10 or 17 or 22
24 exp american native continental ancestry group/ or oceanic ancestry group/
25 aborigin$.tw.
26 indigenous.tw.
27 native indian$.tw.
28 maori$.tw.
29 inuit$.tw.
30 first nation$.tw.
31 amerindian$.tw.
32 metis.tw.
33 pacific islander$.tw.
34 eskimo$.tw.
35 aleut$.tw.
36 (native adj1 hawai$.tw.
37 (native adj1 american$.tw.
38 (native adj1 alaskan$.tw.
39 american indian$.tw.
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40 or/24-39
41 23 and 40

Table 2.1. Criteria for Study Eligibility

Criteria:	Included:	Excluded:
Population:	People defined as Aboriginal/Indigenous and as making a health or social decision for themselves and/or a family member.	Aboriginal/Indigenous people are not identified as a distinct group.
Intervention:	Interventions to influence health or social decision-making.	Intervention does not involve a decision that affects health.
Comparator:	Any comparator.	
Outcomes:	Attributes of the decision and attributes of the decision process.	Primary outcomes not related to attributes of decision (knowledge, risks, value-based choice) and attributes of decision-making process (informed, clear about values).
Study Design:	Experimental designs (e.g. RCT, interrupted time series, pre/post-test)	Not an experimental (intervention) study design.

Table 2.2. List of Excluded Studies

Reason for Exclude: Population (n=2)
Anderson, L.M., Adeney, K.L., Shinn, C., Krause, L.K., Safranek, S. (2012). Community coalition-driven interventions to reduce health disparities among racial and ethnic minority populations. <i>Cochrane Database of Systematic Reviews</i> . 6.
Satterfield, D.W., Volansky, M., Caspersen, C.J., Engelgau, M.M., Bowman, B.A., Gregg, E.W., Geiss, L.S., Hosey, G.M., May, J., Vinicor, F. (2003). Community-based lifestyle interventions to prevent type 2 diabetes. <i>Diabetes care</i> , 26(9), 2643-2652.
Reason for Exclude: Intervention (n=15)
De Ravello, L., Rushing, S.C., Doshi, S., Smith, M.U., Tulloch, S. (2011). Evaluating native stand: A peer education curriculum for healthy decision-making for native youth. Sexually Transmitted Infections Conference: 19th Biennial Conference of the International Society for Sexually Transmitted Diseases Research Quebec City, QC Canada. Conference Start: 20110710 Conference End: 20110713 Conference Publication: (var pagings). 87:A226.
Foley, K., Duran, B., Morris, P., Lucero, J., Jiang, Y., Baxter, B., Harrison, M., Shurley, M., Shorty, E., Joe, D., Iralu, J., Davidson-Stroh, L., Foster, L., Begay, M., Sonleiter, N. (2005). Using motivational interviewing to promote HIV testing at an American Indian substance abuse treatment facility. <i>Journal of psychoactive drugs</i> , 37(3), 321-329.
Garro, L.C. (1998). On the rationality of decision-making studies: Part 2: Divergent rationalities. <i>Medical anthropology quarterly</i> , 12(3), 341-355.
Geller, K.S., Mendoza, I.D., Timbobolan, J., Montjoy, H.L., Nigg, C.R. (2012). The decisional balance sheet to promote healthy behavior among ethnically diverse older adults. <i>Public Health Nursing</i> , 29(3), 241-246.
Gellert, K.S., Aubert, R.E., Mikami, J.S. (2010). Ke 'Ano Ola: Moloka'i's community-based healthy lifestyle modification program. <i>American Journal of Public Health</i> , 100(5), 779-783.
Hites, L.S., Granillo, B.S., Garrison, E.R., Cimetta, A.D., Serafin, V.J., Renger, R.F., Wakelee, J.F., Burgess, J.L. (2012). Emergency preparedness training of tribal community health representatives. <i>Journal of Immigrant & Minority Health</i> , 14(2), 323-329.
Ho, J.S., Gittelsohn, J., Rima, I. R., Treuth, M.S., Sharma, S., Rosecrans, A., Harris, S.B. (2008). An integrated multi-institutional diabetes prevention program improves knowledge and healthy food acquisition in northwestern Ontario First Nations. <i>Health Education & Behavior</i> , 35(4), 561-573.
Kaufman, C.E., Litchfield, A., Schupman, E., Mitchell, C.M. (2012). Circle of Life HIV/AIDS-prevention intervention for American Indian and Alaska Native youth. <i>American Indian & Alaska Native Mental Health Research (Online)</i> , 19(1), 140-153.
Lawrence, H.P., Romanetz, M., Rutherford, L., Cappel, L., Binguis, D., Rogers, J.B. (2004). Effects of a community-based prenatal nutrition program on the oral health of Aboriginal preschool children in northern Ontario. <i>Probe (08341494)</i> 38(4), 172.
Martens, P.J. (1997). Prenatal infant feeding intent and perceived social support for breastfeeding in Manitoba first nations communities: a role for health care providers. <i>International journal of circumpolar health</i> . 56(4), 104-120.
Rios, R. , Fernández, L. (2007). Empowered women from rural areas of Bolivia promote community development. <i>Promotion & education</i> , 14(2), 83-84.

Robinson, S.C., Blackwood, I., Jognson, S. (2010). Increasing liver health knowledge in pediatric, adult and at risk populations. Hepatology Conference: 61st Annual Meeting of the American Association for the Study of Liver
Roubidoux, M.A. (2005). Breast Cancer Detective: a computer game to teach breast cancer screening to Native American patients. <i>Journal of Cancer Education</i> , 20(1), 87-91.
Schinke, S.P., Moncher, M.S., Singer, B.R. (1994). Native American youths and cancer risk reduction: Effects of software intervention. <i>Journal of Adolescent Health</i> , 15(2), 105-110.
Scrimgeour, D., Rowse, T., Knight, S. (1994). Food-purchasing behaviour in an Aboriginal community. 2. Evaluation of an intervention aimed at children. <i>Australian Journal of Public Health</i> , 18(1), 67-70.
Reason for Exclude: Outcome (n=16)
Albright, C., Dela Cruz, M.R., Kadowaki, J., Sagayadoro, T., Wong, L. (2010). Educating ethnic minority teens to be a designated organ donor on their first driver's license: Hawaii's idecide project. American Journal of Transplantation Conference: American Transplant Congress 2010, ATC 2010 San Diego, CA United States Conference Start: 20100501. Conference End: 20100505 Conference Publication: (var pagings). 10:287.
Allen, P., Thompson, J.L., Herman, C.J., Whyte, A.N., Wolfe, V.K., Qualls, C., Helitzer, D.L. (2008). Impact of periodic follow-up testing among urban American Indian women with impaired fasting glucose. <i>Preventing Chronic Disease</i> , 5(3):A76.
Beckham, S., Washburn, A., Ka'aha'aina, D., Bradley, S. (2007). Filling the void: a multi-component, culturally adapted smoking cessation program integrating Western and non-Western therapies. <i>American Journal of Health Education</i> , 38(4), 208-211.
Carson, K.V., Brinn, M.P., Labiszewski, N.A., Peters, M., Chang, A.B., Veale, A., Esterman, A.J., Smith, B.J., (2012). Interventions for tobacco use prevention in Indigenous youth. <i>Cochrane Database of Systematic Reviews</i> . 8.
Cook, A., Grothaus, C.T., Gutierrez, C.E., Kehoe, K.A., Valentin, M.R. (2010). Closing the gap 'Disparity in Native Hawaiian cardiac care'. <i>Hawaii medical journal</i> . 69(5 Suppl 2), 7-10.
Fahrenwald, N.L., Belitz, C., Keckler, A. (2010). Outcome evaluation of 'sharing the gift of life': an organ and tissue donation educational program for American Indians. <i>American Journal of Transplantation</i> , 10(6):1453-1459.
Ho, L.S. (2007). Diabetes prevention in northwestern Ontario First Nations: A multi-institutional program to improve diet and increase physical activity. Baltimore, MD: Department of International Health, Johns Hopkins Bloomberg School of Public Health.
Hunt, A.L., Jenkins, D.(2008). Knowledge of and preferred sources of assistance for physical activity in a sample of urban Indigenous Australians. <i>Marshall International Journal of Behavioral Nutrition and Physical Activity</i> . 5.
Mella, K. (2007). The impact of social group identity, message source, and cultural frame on reactance to persuasive health messages: Implications for communication theory and practice.; Dissertation Abstracts International, A: The Humanities and Social Sciences. 1203-1203.
Montgomery, M., Manuelito, B., Nass, C., Chock, T., Buchwald, D. (2012). The Native Comic Book Project: native youth making comics and healthy decisions. <i>Journal of Cancer Education</i> . 27(Suppl 1), S41-S46.
Moran, J.R., Bussey, M. (2007). Results of an alcohol prevention program with urban

American Indian youth. <i>Child & Adolescent Social Work Journal</i> , 24(1):1-21.
Owan, T.C. (1987). School/Community-Based Alcoholism/Substance Abuse Prevention Survey. 107-107. (on-line).
Rinderknecht, K., Smith, C. (2004). Social cognitive theory in an after-school nutrition intervention for urban Native American youth. <i>Journal of Nutrition Education & Behavior</i> , 36(6), 298-304.
Schinke, S.P., Singer, B., Cole, K., Contento, I.R. (1996). Reducing cancer risk among Native American adolescents. <i>Preventive medicine</i> , 25(2):146-155.
Stevens, J., Story, M., Ring, K., Murray, D.M., Cornell, C.E., Juhaeri, Gittelsohn, J. (2003). The impact of the Pathways intervention on psychosocial variables related to diet and physical activity in American Indian schoolchildren. <i>Preventive medicine</i> . 37 (6 Pt 2), S70-S79.
Sosa-Rubi, S.G., Walker, D., Servan, E., Bautista-Arredondo, S. (2011). Learning effect of a conditional cash transfer programme on poor rural women's selection of delivery care in Mexico. <i>Health Policy & Planning</i> , 26(6), 496-507.

Table 2.3. Characteristics and Results of Included Trial (n=1)

Study Identification	Participants	Intervention	Methods	Study Outcomes	Results
Okwumbua & Duryea (1989)	- U.S.A. - 23 male and 21 female students, 11- 13 years old; Intervention n=23; Control n=21	- Educational program vs. none, conducted during 5 week student health class. - Delivered by trained teacher (2 days). - Education program included: 1) slide show, formal instructions about four step decision making process; 2) question/ answer, role play on how to evaluate costs /benefits in making decisions; 3) role play/film on application of decision making process to daily situations involving health choices.	- Randomized control trial. - Pre/post assessment of student decision making skill. - Modified version of the Decision-Making Instrument used (ref), - Consisted of 10 culturally appropriate decision scenarios	1) Knowledge of the four step decision making process 2) Application of the four step decision making process.	- Compared to controls intervention group had increased knowledge ($x^2=11.17$ $p<0.03$). - Compared to controls intervention group had increased skill ($x^2=18.51$ $p<0.001$).

Table 2.4. Quality Rating – Cochrane Risk of Bias Tool

Bias	Author judgment and evidence for judgment
Selection bias: Random sequence generation Allocation concealment	Low: Randomization done by computer. Unclear: Not described – insufficient information to permit judgment.
Performance bias: blinding of participants and personnel	Unclear: Not described – insufficient information to permit judgment.
Detection bias: Blinding of outcome assessment	Unclear: Not described – insufficient information to permit judgment.
Attrition bias: Incomplete outcome data	Unclear: Missing participant in outcome measures not accounted for in study.
Reporting bias: Selective reporting	Unclear: Not described – insufficient information.
Other sources of bias	Unclear: Lack of detail – insufficient information to assess if important risk of bias exists.

Figure 2.3 PRISMA-E 2012 Checklist

			Checklist of Items for Reporting Equity-Focused Systematic Reviews		
Section	Item	Standard PRISMA Item	pg	Extension for Equity-Focused Reviews	Pg #
Title					
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1	Identify equity as a focus of the review, if relevant, using the term equity	Yes, Indigenous Peoples.
Abstract					
Structured summary	2	2. Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2	State research question(s) related to health equity.	N/A: word restriction limits.
	2A			Present results of health equity analyses (e.g. subgroup analyses or meta-regression).	N/A
	2B			Describe extent and limits of applicability to disadvantaged populations of interest.	2.
Introduction					
Rationale	3	Describe the rationale for the review in the context of what is already known.	5	Describe assumptions about mechanism(s) by which the intervention is assumed to have an impact on health equity.	5,6
	3A			Provide the logic model/analytical framework, if done, to show the pathways through which the intervention is assumed to affect health equity and how it was developed.	5,6
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	6	Describe how disadvantage was defined if used as criterion in the review (e.g. for selecting studies, conducting analyses or judging applicability).	6
	4A			State the research questions being addressed with reference to health equity	6
Methods					
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	6		
Eligibility criteria	6	6. Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Table 2.1.	Describe the rationale for including particular study designs related to equity research questions.	No difference.
	6A			Describe the rationale for including the outcomes - e.g. how these are relevant to reducing inequity.	N/A
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7 & Original published protocol.	Describe information sources (e.g. health, non-health, and grey literature sources) that were searched that are of specific relevance to address the equity questions of the review.	7
Search	8	Present full electronic search strategy for at least one	Figure 2.1	Describe the broad search strategy and terms used to address	Focus on Indigenous;

		database, including any limits used, such that it could be repeated.		equity questions of the review.	Figure 2.1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	7		
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	8		
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7; All information on variables reported.	List and define data items related to equity where such data were sought (e.g. using PROGRESS-Plus or other criteria, context).	7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	8		
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	10 & Table 2.3		
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	N/A	Describe methods of synthesizing findings on health inequities (e.g. presenting both relative and absolute differences between groups).	N/A
Risk of bias across studies	15	15. Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	Table 2.4		
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	None	Describe methods of <u>additional</u> synthesis approaches related to equity questions, if done, indicating which were pre-specified	N/A
Results					
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Figure 2.1		
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	8 – 11; Table 2.3	Present the population characteristics that relate to the equity questions across the relevant PROGRESS-Plus or other factors of interest.	7; 8 – 11; Table 2.3
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Table 2.4		
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Table 2.3		
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A	Present the results of synthesizing findings on inequities (see 14).	N/A; 1 study.
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A; 1 study.		
Additional	23	Give results of additional analyses, if done (e.g., sensitivity	N/A; lack of	Give the results of <u>additional</u> synthesis approaches related to	N/A

analysis		or subgroup analyses, meta-regression [see Item 16]).	data.	equity objectives, if done, (see 16).	
Discussion					
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	11,12		
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	15,16		
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	11 – 17	Present extent and limits of applicability to disadvantaged populations of interest and describe the evidence and logic underlying those judgments.	17
	26A			Provide implications for research, practice or policy related to equity where relevant (e.g. types of research needed to address unanswered questions).	18
Funding					
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	1		

From: Source: Welch V, Petticrew M, Tugwell P, Moher D, O'Neill J, Waters E, White H, and the PRISMA-Equity Bellagio Group. (2012) PRISMA-Equity 2012 Extension: Reporting Guidelines for Systematic Reviews with a Focus on Health Equity. PLoS Med 9(10): e1001333. doi:10.1371/journal.pmed.1001333

For more information: <http://equity.cochrane.org/equity-extension-prisma>

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Chapter 3

Shared Decision-Making with Aboriginal Women Facing Health Decisions: A Qualitative Study Identifying Needs, Supports, and Barriers

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Abstract

Introduction: When compared with general populations in Canada, Aboriginal women are more likely to experience health inequity. Shared decision-making may narrow health equity gaps by engaging clients with their health care providers in making health decisions; however, little is known about shared decision-making interventions with Aboriginal Peoples. This study describes the experiences of Aboriginal women when making health decisions by identifying decision-making needs, supports, and barriers.

Methods: An interpretive descriptive qualitative study was conducted in collaboration with an advisory group and using a mutually agreed upon ethical framework. Participatory research principles incorporating postcolonial theory were utilized. Aboriginal women at Minwaashin Lodge were interviewed using a semi-structured interview guide; transcripts were read and then coded using thematic analysis. Themes were refined and confirmed by Minwaashin Lodge leaders, and confirmed with the rest of the advisory group.

Results: Thirteen women 20 to 70 years of age of Inuit, Métis, or First Nations descent participated in this study. Shared decision making needs are represented by four major themes that are focused on the specific relational features of shared decision-making: To be an active participant; to feel safe with health care; engagement in the decision process; and personal beliefs and community values. Supports for each of the major themes focused on the relational nature of shared decision-making, including women's views and roles and perceptions of health care providers' roles. These features are presented in a Medicine Wheel framework. Barriers were identified at interpersonal and systems levels.

Conclusions: Our findings indicate that although Aboriginal women support SDM, they may have unmet decision making needs.

Key words: Equity, women, Aboriginal, First Nations, Inuit, Métis, shared decision-making, health, 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 socio-economic 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 (NWAC), 2009; Public Health Agency of Canada (PHAC), 2011; PHAC, 2003). 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 (RCAP), 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). Patient decision aids (e.g., booklets, videos, online tools) facilitate a process of SDM (Stacey et al., 2014) along with decision coaching (Stacey, Kryworuchko, Bennett, Murray, Mullan, & Légaré, 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, Carpenter, Dolan, Bravo, Mann, Bunn, & Elwyn, 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 the first known qualitative investigation of SDM with Aboriginal women. Currently, little is known about the use of SDM approaches with Aboriginal Peoples in Western health care settings (Jull et al., 2013). Instead, the literature has been focused on an educational rather than the collaborative SDM approach to making health decisions within the area of Aboriginal health (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 urban

Aboriginal women?; 2) What are the barriers to involving urban Aboriginal women in their health decision-making?

Theory

Postcolonial theory was used 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 & McCann, 2002; Reimer-Kirkham & Anderson, 2002). Aboriginal scholars, such as Battiste (2000), have made strong contributions to the development of postcolonial theories that have emerged from Aboriginal ways of knowing. 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 (e.g., shelter, counseling, 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 viewed this study as of potential benefit to its community. 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.

Battiste (2000) situated Aboriginal Peoples 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 socio-historical context. Battiste (2000) described the four directions of the Medicine Wheel as a way to

conceptualize and 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, Stacey, Giles, Boyer and Minwaashin Lodge – The Aboriginal Women’s Support Centre, 2012/Appendix D) 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 (TCPS) (Panel on Research Ethics, 2012) and Ownership, Control, Access and Possession (OCAP) (First Nations Centre, 2007) criteria. The ethical framework was supported by the use of participatory research principles, with defined agreements between and roles for the research partners.

Methods

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

Design

An interpretive descriptive qualitative study was conducted in collaboration with Minwaashin Lodge. The interpretive descriptive method is an effective research approach for describing and understanding 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 and lead to the generation of new and unique links within the data not yet identified within the decision-making literature and foster understandings about Aboriginal women's health decision-making experiences.

Setting

Urban 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.

Participants

The 13 participants self-identified as Aboriginal, and described having been a part of a decision affecting the health of herself or a family member in the past 6 months.

Procedure

A semi-structured interview guide was developed in collaboration with Minwaashin Lodge (Table 3.1). 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.

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 analyzed using a method of 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 analyzed and generated codes (e.g., "safety," "values") within each transcript, and themes were generated; 3) initial themes were confirmed or adjusted ("to feel safe with care," "personal and community values") in collaboration with a second reviewer (CD), 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 (i.e., needs, supports, and barriers). Finally, participants' experiences with decisions were analyzed through a postcolonial theoretical lens (Battiste, 2000).

Findings were reviewed, revised and confirmed with Minwaashin Lodge and then confirmed with members of the advisory group. To enhance understanding of the findings, a decision was made (ML, JJ) to present the results (decision making needs and supports) as

part of a Medicine Wheel framework (Figure 3.1). The descriptions of participants' decision-making needs were grouped into four overarching themes. Their accompanying four areas of support are shown in the Medicine Wheel (Figure 3.1). 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

Participant Characteristics

Thirteen Aboriginal women with a range of personal characteristics participated in the study (Table 3.2). Eleven 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 (e.g., housing) or the health of a family member (e.g., the health of a child). Participants' names and identifying characteristics have been changed to preserve 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 member's 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 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 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 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. 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.

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 [health care provider] 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.

Theme #3: Engagement in Decision Process

The Western part of the Medicine Wheel, “Engagement in the decision process,” is situated in the mental domain and reflects participants’ need 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 fulfill 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, 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 decision-making. The participants described their SDM needs, supports, and barriers and in doing so provided their perspective on SDM. SDM was presented in the Medicine Wheel framework as consisting of four domains: 1) Physical: Be an active participant; 2) Emotional: 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. Barriers to SDM were identified at the interpersonal and systems levels. The relational nature of SDM, the role of SDM in culturally safe care, and health literacy were identified for a health care experience identified by participants as 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. 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.

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 (Brascoupé & Waters, 2009). By identifying power imbalances within health care settings, culturally safe care upholds self-determination and decolonization for Aboriginal peoples (National Aboriginal Health Organization (NAHO), 2006). This approach to care 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 (NAHO, 2008), which results in client opportunities to participate in decision-making (Brascoupé & 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 the potential to foster a health care relationship that the client defines as culturally safe. To our knowledge, this paper makes the first known link between cultural safety and SDM; as such, further exploration of SDM concepts with Aboriginal clients 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, 2007). 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 (WHO), 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 (WHO, 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, Carpenter, Dolan, Bravo, Mann, Bunn, & Elwynn, 2014). It is of importance, however, to be cognizant that SDM has been developed within mainstream (i.e., 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 and thus have the potential to enhance/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 socio-historical 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 framework reflecting the women's descriptions of SDM. SDM needs and supports were represented in four major themes 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. Although Aboriginal women support SDM, they may have unmet SDM needs. Health care providers must re-examine their approach to the relational aspects of care provision and do so from within the colonial contexts that have informed the development of Western health care systems. With their clients, health care providers may then 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 cultural adaptation of SDM tools and approaches to support the further engagement of Aboriginal women in making health care decisions they define as meaningful.

Table 3.1 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] 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?
-

Table 3.2 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
Metis, 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 that she was involved with Aboriginal community in a caregiving capacity.

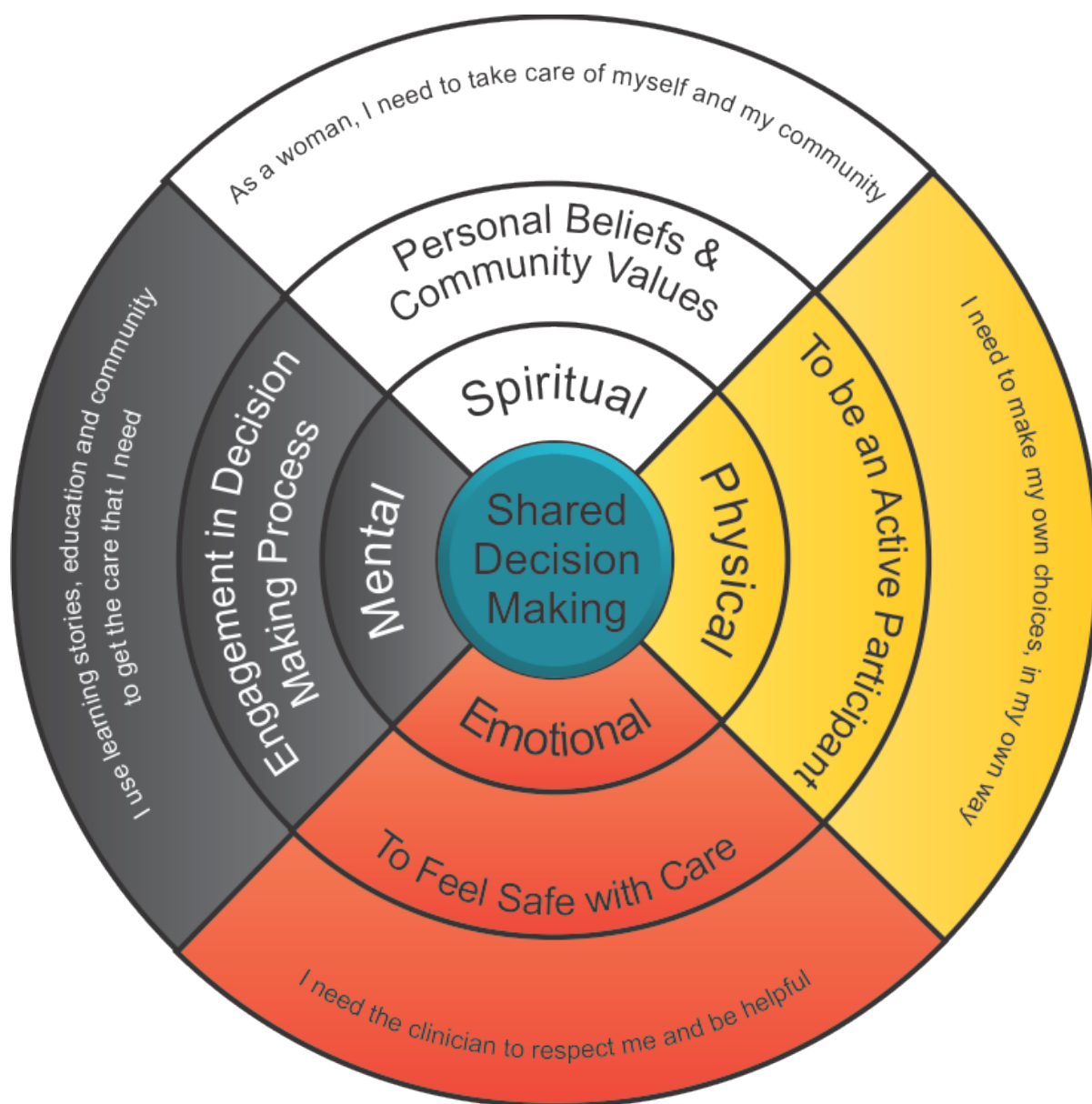


Figure 3.1 Shared Decision Making Medicine Wheel Framework

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Chapter 4

Cultural Adaptation of a Shared Decision-Making Tool with Aboriginal Women: A Qualitative Study

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Abstract

Introduction: Shared decision-making (SDM) may narrow health equity gaps experienced by Aboriginal women. SDM tools such as patient decision aids can facilitate SDM between the client and health care providers; SDM tools have not yet been developed for and with Aboriginal Peoples. This study describes the adaptation and usability testing of a SDM tool, the Ottawa Personal Decision Guide (OPDG), to support decision-making by Aboriginal women.

Methods: An interpretive descriptive qualitative study was structured by the Ottawa Decision Support Framework and used a postcolonial theoretical lens. An advisory group was established with representation from the Aboriginal community and used a mutually agreed-upon ethical framework. Eligible participants were Aboriginal women at Minwaashin Lodge. First, the OPDG was discussed in focus groups using a semi-structured interview guide. Then, individual usability interviews were conducted using a semi-structured interview guide with decision coaching. Iterative adaptations to the OPDG were made during focus groups and usability interviews until saturation was reached. Transcripts were coded using thematic analysis and themes confirmed in collaboration with Minwaashin Lodge leaders and advisory group.

Results: Aboriginal women 20 to 60 years of age and self-identifying as First Nations, Métis, or Inuit participated in two focus groups (n=13) or usability interviews (n=6). Seven themes were developed and reflected or affirmed OPDG adaptations. The themes were as follows: 1) “This paper makes it hard for me to show that I am capable of making decisions”; 2) “I am responsible for my decisions”; 3) “My past and current experiences affect the way I make decisions”; 4) “People need to talk with people”; 5) “I need to fully participate in

making my decisions”; 6) “I need to explore my decision in a meaningful way”; 7) “I need respect for my traditional learning and communication style”.

Conclusions: Adaptations resulted in a culturally adapted, lower health literacy version of the OPDG that better met the needs of Aboriginal women participants. Decision coaching was identified as required to enhance their engagement in the decision-making process and using the adapted OPDG as a talking guide. Feasibility and efficacy studies of the adapted OPDG with coaching are needed.

Key words: Equity, Aboriginal, Indigenous, women, shared decision making, cultural adaptation, usability testing, health literacy.

Introduction

Delivery of care from within traditional Western healthcare models often undermines Aboriginal peoples' health and well-being as these care models reflect values that may not align with the values of Aboriginal Peoples (Browne & Fiske, 2001; Jull & Giles, 2012). Western-trained health care providers typically lack understandings of Aboriginal cultures (Browne, 2005; Browne & Fiske, 2001), which has had, in particular, a negative impact on the health of Aboriginal women (Boyer, 2004) and affected their participation in care settings (Smith et al., 2006).

Aboriginal women have a right to safe and effective care practices, including participation with health care providers in making meaningful decisions about their health. Shared decision making (SDM) is a process of collaboration between health care providers and clients (Makoul & Clayman, 2006). SDM has been found to increase the client's level of satisfaction with care decisions by better meeting client's information needs and incorporation of client's values into care decisions (Hibbard, 2013; Kiesler & Auerbach, 2006). In summary, SDM is central to patient-centred care (Weston, 2001). Evidence for SDM is very limited with Aboriginal populations in care settings (Jull et al., 2014). Our previous study indicates that Aboriginal women view SDM as including relational features, and which are identified as core competencies for SDM (Légaré et al, 2013), although these views are not yet evident in mainstream models of SDM or in SDM tools and approaches (Jull et al., under review).

SDM is facilitated by patient decision aids and decision coaching to support decision making that is shared between health care providers and client (Elwyn, Kinnersley, & Grol, 2000). A client-centred approach to decision making may be structured between health care providers and client by patient decision aids, which facilitate the sharing of information, and

on the benefits and harms of care options, and can contribute to help the client make preference sensitive decisions (Stacey et al., 2014). Patient decision aids are booklets, videos, or online tools that complement practitioner counseling; they have been found to increase people's involvement in making more informed and values-based care decisions. Although there are over 300 publicly available decision aids, there is much overlap on topics and there remain many decisions for which patient decision aids have not yet been developed. In addition, none of these decision aids have been deemed culturally appropriate or defined as adequate for all Aboriginal populations.

Decision coaching supports SDM and coaches are trained to be non-directive, provide evidence, and support people rather than offer advice, so that people make choices consistent with their own values and beliefs (O'Connor, 2008; Stacey et al., 2012). In addition, decision coaching tailors decision-support to be relevant to each situation and is aimed at building decision-making skills so that people can use these skills in other situations. Used alone, decision coaching has been found to improve knowledge for clients and, when used with a patient decision aid, to increase knowledge and participation in care (Stacey et al., 2012).

Participation in care requires health literacy skills, which are described as the ability to access and use care, understand and use information for health and well-being, and the capacity to use information effectively. High levels of health literacy result in empowerment and the capacity to make decisions that support favourable health outcomes for the individual participating in care systems (World Health Organization (WHO), 2014). Health literacy issues have been identified as barriers to participation in decision making and to attaining the best outcomes with health services (Institute of Medicine, 2004; Rootman & Gordon-El-Bihbety, 2008). They have also been identified as problematic issues within a range of

populations that includes Aboriginal women (Public Health Agency of Canada (PHAC), 2014). For instance, due to historical factors that have created societal inequities and/or limited access to educational resources, Aboriginal learners have lower graduation rates and are less likely to be in age appropriate grades (Battiste, 2005). As well, Aboriginal Peoples in Canada must deal with the complexity of cultural identity legislation and other challenges that hamper their ability to negotiate systems of care; this often leads to limited access or exclusion from health and social programs (Smylie, 2010). These are some of the factors that challenge the health literacy of Aboriginal people and may ultimately disrupt their ability to be equitable participants in decision making.

Currently, there are no studies of SDM tools that have been developed for and with Aboriginal Peoples. Given the social systems and structures that undermine health and well being of this population, it is imperative that research be conducted in collaboration with Aboriginal people as equal partners to explore and adapt current approaches to SDM that are culturally relevant for Aboriginal populations. While guidelines that outline the cross-cultural adaptation of self-report measures exist (Beaton, Bomardier, Guillemin, & Ferraz, 2000), for our study we chose to support the adaptation of a patient decision aid from within a mutually agreed upon partnership and ethical framework, and using a process aligned with the socio-cultural values of those in the partnership. This study is the result of a partnership with an Aboriginal women's organization, Minwasshin Lodge, and was conducted in complete collaboration with members of the study's advisory group, all of whom were decision makers in the study and are co-authors of this paper. Minwaashin Lodge is a community-based organization that provides services (e.g., shelter, counseling, 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 viewed this study

as of potential benefit to its community of women and children. The purpose of this study is to describe the adaptation and usability testing of the Ottawa Personal Decision Guide (OPDG) to support decision making by Aboriginal women.

Theory

Two theoretical perspectives were selected to support and/or align with the ethical framework and used to inform this study: the Ottawa Decision Support Framework (O'Connor, Stacey & Jacobsen, 2011) and postcolonial theory (Battiste, 2000).

The ODSF is an evidence based, practical, midrange theory developed to guide people through health and social decisions and incorporates three key elements: decisional needs, decision support, and decision quality (O'Connor, Stacey, & Jacobsen, 2011). According to the framework, unresolved decisional needs will negatively influence decision quality. While it has not been used specifically with Aboriginal populations, the ODSF has been successfully used to structure the assessment of decisional needs within a range of populations in Canada and internationally (O'Connor et al., 2011) and specifically with women (Murray, Miller, Fiset, O'Connor, & Jacobsen, 2004; O'Connor, Tugwell, Wells, Elmslie, Jolly, & Hollingworth, 1998). In this study, the ODSF provided the theoretical foundation for the patient decision aid adapted in this study and was used with postcolonial theory to guide the creation of key questions and prompts for focus groups and usability interviews.

Postcolonial theory encompasses a group of theories that share a social, political and moral concern about the history and legacy of colonialism and are derived from diverse disciplinary perspectives (McEwan, 2009; Young, 2001). Aboriginal scholars have made strong contributions to postcolonial theories; these theories have developed from Aboriginal epistemologies (Battiste, 2000). A postcolonial perspective provides a theoretical lens to

show how marginalization occurs in day-to-day relationships and in the systems that structure human relations, such as the health care setting (Anderson & McCann, 2002; Reimer-Kirkham & Anderson, 2002).

The approach for this study is underpinned by Battiste's (2000) articulation of postcolonial theory. Battiste (2000) situated Aboriginal Peoples as central to a collaborative process of societal change with non-Aboriginal people, a perspective which aligns with this study as it was developed from a research partnership between the study's first author (of Euro-Canadian descent) and Minwaashin Lodge, an Aboriginal led organization that serves Aboriginal women. Battiste's (2000) postcolonial theory principles were adopted for this study as the most appropriate lens through which to view and address the complex intersections of colonialism's impact on the lives of the Aboriginal women who participated in the study (Anderson & McCann, 2002; Reimer-Kirkham & Anderson, 2002). Battiste's (2000) use of the postcolonial lens ensured that those conducting the study worked towards implementing research processes that promoted a decolonizing agenda. For instance, there was ongoing reflection on study practices and adherence to the ethical framework by the primary researcher and the advisory group throughout the study. The postcolonial lens was also used during data analysis to evoke the complex and interacting political, social, and historical factors that influence women's use of a shared decision making tool like the OPDG.

Methods

Design

Identified as effective for describing health events, an interpretive descriptive qualitative study design was selected (Thorne, Riemer Kirkham, & O'Flynn-Magee, 2004). For this study, the interpretive descriptive approach supported an iterative process that

occurred between data collection and data analysis; the use of informed questioning of participants by the researcher; participant and researcher reflection and examination of ideas; and the creation of an interpretive account of what was studied (Thorne et al., 2004). The interpretive descriptive process directed the study and the adaptations made to the OPDG. This qualitative approach also supported the generation of new ideas during the study (Thorne et al., 2004) and aligned with postcolonial theory and the ethical framework used to structure this study. Further, it supported the development of new understandings about Aboriginal women's preferences for an SDM tool. This study was approved by the University of Ottawa's Research Ethics Board, and it also received ethical approval from Minwaashin Lodge Executive and leaders. An ethical framework was developed by the study advisory group, whose membership included those of Aboriginal and of Euro-Canadian descent, and was structured by guidelines for ethical research with Aboriginal people (First Nations Centre, 2007; Panel on Research Ethics, 2011). The ethical framework was designed to support a research agenda respectful of the diverse needs of a population of Inuit, First Nations and Métis women. The study protocol was published a priori (Jull, Stacey, Giles, Boyer & Minwaashin Lodge, 2012/Appendix D).

Setting and Participants

Minwaashin Lodge representatives directed potential participants to recruitment posters and/or provided contact information to solicit information from the first author (JJ), and in this way participants were purposefully recruited for the study. Women who participated in the focus groups were not eligible for participation in the usability interviews. Participant inclusion criteria were those who self-identified as an Aboriginal women, were 18 years or older, who were clients of Minwaashin Lodge and were able to participate in an interview conducted in English.

Intervention to be Adapted: The OPDG

The OPDG is a generic tool that was developed according to the ODSF and is used to help people self-assess decisional needs, summarize knowledge, clarify values, and plan next steps when making any social or health decision. It can also be used as an adjunct to coaching by a care provider (O'Connor, Stacey, & Jacobsen, 2004). In response to focus group feedback, it was used with decision coaching during usability testing interviews. Although not yet evaluated for use by Aboriginal populations, the OPDG has been validated for use with general populations (O'Connor, Stacey, & Jacobsen, 2004), as well as with Japanese and American women considering treatment options (Arimori, 2006; Solberg, 2010).

Procedure

The procedure for OPDG adaption and usability testing is presented in Figure 4.1. The first author (JJ) and a research assistant (CD) facilitated 2 focus groups. Then, the usability testing was conducted with decision coaching by the first author (JJ), who is also a trained decision coach. The semi-structured interview guides were developed using the ODSF and postcolonial theory and in collaboration with Minwaashin Lodge. An example decision about a return to school was selected as a neutral, non-distressing social decision, identified as common by Minwaashin Lodge representatives (Table 4.1, Table 4.2). At the completion of the usability interviews, the final version of the adapted OPDG was reviewed by the first author (JJ) and with an OPDG developer (DS) to ensure concept equivalence between the original and adapted OPDG, and then with representatives of Minwaashin Lodge for population relevance.

Data Analysis

Transcripts of focus group and usability interviews underwent thematic analysis. A six phase process was used for thematic analysis (Braun & Clarke, 2006): 1) familiarization with data; 2) generation of initial codes within each transcript (e.g. “hard to read/understand”; “responsible for decisions”; 3) search for themes (e.g. “paper is hard to understand”; “I take my decisions seriously”; 4) review of themes; 5) define and name themes, which were further confirmed or adjusted by a second reviewer (CD); 6) reporting of themes in a way that reflected the rationale for the adaptations to the OPDG.

Throughout the thematic analysis, findings were examined using a postcolonial theoretical lens by situating them in a social, historical, and political perspective (Battiste, 2000). At the completion of the usability-testing interviews, and following final confirmation by interview participants of the adapted OPDG acceptability, the adapted OPDG and final findings were reviewed and confirmed in collaboration with Minwaashin Lodge leaders and with the rest of the advisory group.

Results

Participant Characteristics

Nineteen Aboriginal women participated in the study in 2 focus groups (n=13) or usability interviews (n=6) (Table 4.3). Participants self-identified as First Nations, Métis and Inuit women, between the ages of 20 and 60 years and with education ranging from grade 8 to university and/or college levels. Many have children as well as Elders or extended family for whose care they are responsible. The names and identifying characteristics of the study participants have been changed to preserve anonymity.

OPDG Adaptation

Focus groups and usability interview participants suggested OPDG adaptations (Themes 1 through 4, Table 4.4) and confirmed the relevance of the adapted OPDG when used with decision coaching (Themes 5 through 7). The adapted OPDG is presented in Figure 4.2.

Theme 1: “This paper makes it hard for me to show that I am capable of making decisions.”

The theme reflects the OPDG adaptations to support participants’ ability to obtain, understand, and use factual information. The theme reflects the needs of participants to have accessible, user-friendly tools. As several participants reported, their experience with Western care systems and settings did not foster their full participation when accessing and using care. During the initial iterations of the OPDG adaption, participants were observed to often look silently at the paper until asked their views on the readability of the OPDG. Myrna described her difficulties with the OPDG when she stated, “It’s a little confusing, okay. The lists – it does not make sense.” Others voiced similar issues, with comments such as “I am not sure of what this means” or sometimes simply asking the facilitator, “what should I put?” To address these issues, participants identified several essential adaptations: a) use of plain language; b) adjustments to print size to better identify transitions to each new section; c) decreases to concept density (creation of extra white space by decreases in text density throughout text; provision of space for notes in section 4; removal of repetitive wording in section 4); d) a more logical layout of the OPDG text (alignment of the section 3 list with section 4, boxing lists in section 4 together to make information appear more manageable).

Theme 2: “I am responsible for my decisions.”

The theme reflects adaptations aimed at enhancing participants’ understanding of facts and enabling meaningful communication with health care providers, and to help participants to use information to meet their particular needs. Participants were found to be sensitive to the wording in the OPDG; they explained that some of the wording undermined their autonomy in care settings. In Section 2, participants identified the concept of ‘support’ as problematic and as implying that others should be making the decision for them. As Leah stated, “the decision is mine alone to make.” Some participants, such as Dana, related challenges to ensuring that she was not obstructed in her decision-making processes: “I have some people that I know that are doing that [are trying to tell me what to do] - and I say you cannot make my choice. I am the one who has to make my own choice.” Miriam provided some additional insight into the concept of support: “Support – who is involved? There is no one but me. I would like someone...but I don’t have anyone; everyone’s gone.” Participants also recognized that others could or should sometimes be involved in their decision-making processes, and that in every situation their decision making affected others. For this reason, an extra line of text was added to broaden the concept of support and to make it potentially more culturally relevant to participants (Section 2: ‘Who else can support you?’).

Participants also indicated that the language of the OPDG was sometimes negative and was not aligned with the way or the attitude they approached decision making. Further, some participants stated that the language seemed to reflect the discrimination they often perceived in care settings. For instance, the statement that defines the results of test questions that screen for decisional conflict in Section 3 (the “SURE test”) was perceived to blame the person using the form for not having enough certainty, knowledge, values, or support when decision making. Therefore, this statement was removed (‘People who answer “No” to one

or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or to blame others for bad outcomes.’) The changes reflected preferences expressed by participants to avoid feeling that they were being directed in their decision making. Instead, participants indicated that their preference was to participate in a self-directed process of decision making that supported the processes of problem solving commonly used within their community. For instance, Sarah said, “When I want something...need to get information, I have options, there is always a way...I can figure it out. I don’t need someone else telling me what I can’t do, don’t know.”

In addition, phrases were reframed using positive language, evident in a list of choices in Section 4 (for example, participants suggested ‘If you need to know more’ in place of ‘If you feel you do NOT have enough facts’ et cetera). Section 4 of the OPDG was further reworded during interviews to reflect the role of trusting oneself and others during decision making, for participants expressed concern about assumptions within care relationships, as Anna described: “I just balked at being told to ‘share your guide with others’ and ‘ask others to complete this guide’. And - I have heard that you can go to a neutral person, but how can you know them well enough? You have to build trust.” The language was also made more reflective of Aboriginal women’s approach to decision making. For instance, changes were made to make the language less directive (for example, ‘Ask others’ became ‘You can ask others’) and more personable (for example, ‘Find a neutral person’ became ‘Find a trusted person’).

Theme 3: “My past and current experiences affect the way I make decisions.”

The third theme represents adaptations to the OPDG to support reflection by participants on information or advice received, including the influence of wider social determinants of health. The factors that influence people’s access and use of care services

cannot be separated from the socio-historical contexts in which they are situated; participants identified this during the OPDG adaption. Changes to the OPDG were several-fold: using language defined by participants as meaningful, the addition of four decision implementation questions to Section 2, and tailoring the look of the OPDG to appeal to the participant population. Participants talked about how the use of language was important not just for readability, but for feelings of engagement with the decision-making process for, as Eliza-Jane said, “The words that are used here – it sounds just like another survey. We don’t need any more surveys – we need resources that we can actually use to actually help.” Changes to language throughout the text were made to not only reflect use of plain language, but also to language familiar to the women (for example, removing language perceived by participants as more technical and directive throughout the OPDG, and substituting more personable and familiar terms such as that of ‘care provider’ instead of ‘health provider’ in section 4).

The addition of four lines to the OPDG to include questions identifying implementation needs (Section 2) was affirmed by participants who talked about resource and personal barriers to carrying out decisions (The extra four lines included the following: ‘How motivated are you to take action’; ‘How confident are you that you can take action’; ‘List things that may get in the way of doing this’; ‘List things that may help you to do this’). Maeve stated, “making the decision is one thing; doing it is another” when talking about how health care providers rarely seemed to want to talk about or understand the situational barriers experienced by Aboriginal women making care decisions (e.g., lack of childcare, funding, transportation). Participants viewed the ‘doing’ of the decision as an integral part of the ‘making’ of the decision and described the process of decision making as situated within social, historical, political systems which often acted as barriers to implementation of their decisions.

The OPDG was also critiqued as looking like a ‘government form’. One participant noted that Aboriginal women “have had forms used against them” within social, historical and political systems. Participants suggested showing Aboriginal affiliation on the form (for example, Minwaashin Lodge’s logo and name), as well as further colour and spacing changes, and with potential for further tailoring (e.g., additional graphics, affiliations) in order to make the form more appealing to other clients of Minwaashin Lodge.

Theme 4: “People need to talk with people.”

Participants identified that they wanted a person knowledgeable with the OPDG to play a role in their use of the OPDG. This theme describes the impact that supportive interactions can have on people that experience marginalization within care and social systems. As described by Melissa, “this would not work as it is, as a paper you give to someone. To make a decision, it’s personal...for example, my aunty would not use this – older people, others who do not use forms much – they like to talk. That is how they make their decisions.” Participants described their views that the OPDG should be a supporting element of a broader strategy involving a trained person (decision coach) who could assist women in obtaining and understanding information and to provide support and build confidence with women such that they could use the information in a way they defined as meaningful and which accurately reflected their context. Sixteen of the 19 participants said that they would consider using the adapted OPDG in the future, but significantly, only 1 of the sixteen stated that they would consider using it *without* a coach. For those (n=3) who said they would not use the adapted OPDG, their reasons were that they felt it was too much like a government form (one participant), and that decisions are too personal to make using a form (two participants).

Theme 5: “I need to fully participate in making my decisions.”

This theme reflected the participants’ engagement in the decision-making process and reflected their growing confidence as they became more proficient in the use of the adapted OPDG with the support of their decision coach. During interviews, participants related experiences in which they expressed frustration and anxiety leading to low confidence about being able to receive help needed from health care providers, and their low expectations about positive care experiences. For instance, following the coach’s introduction of the adapted OPDG, one participant, Alicia, was silent, and when asked by the coach if it was okay to start, Alicia stated, “I am a good reader” and continued to remain silent. This was interpreted by the coach to mean that the participant required additional support. The coach assisted Alicia with the adapted OPDG, and Alicia responded and became progressively more confident in directing the coach in the use of the adapted OPDG, and to make comments to help with further adaptation. She explained why she wanted this support: “It’s just hard to answer – I’ve never done anything like this before – a paper or making a decision like this.”

Participants affirmed the readability of the adapted OPDG, easily engaged with the text, and did not suggest further changes to influence the readability of the adapted OPDG. They also identified the coaching role as an integral part of using the adapted OPDG. One participant, Samantha, explained: “[there is] the need to see that you [coach] are on my side, ready to work with me – it is a consensus process. Some people are more visual learners, and these words - they are not going to work for them. You have to be ready to make this work for everyone.”

Theme 6: “I need to explore my decision in a meaningful way.”

Participants identified the need for the adapted OPDG and decision coach to facilitate the meaningful acquisition and use of information. While participants viewed themselves as making care decisions, they indicated that in typical care settings their role(s) and way(s) of making decisions went unacknowledged and were undermined by dominant systems and social norms. The coach played a strong role in tailoring the way in which the adapted OPDG was used to foster respectful decision-making processes. For instance, participants questioned the system for rating option preferences that involved scoring the values of options in relation to each other (Section 2). Glenda described the dilemma: “I cannot put stars to differentiate – they all mean a lot to me. I would want to talk about it instead.” Samantha also emphasized the importance of a conversation with a decision coach rather than making relative rankings of options: “Without this [coach-participant] conversation...this paper is just ‘do you want to do this or that’ – not the ‘why’.” These responses showed that it was undesirable for users to quantify the meanings attached to different options along with their pros and cons. Participants preferred to focus on talking through the meanings of options with the coach. When used in this new format, the participants affirmed that the adapted OPDG fostered respect for their preferred approach to decision making.

Theme 7: “I need respect for my traditional learning and communication style.”

The final theme reflects the awareness of participants for the ways in which determinants of health (for example, income, education, culture) (Public Health Agency of Canada, 2011) influence their participation in decision making. During the interviews, all of the participants described how complex and interacting historical, political, and social issues influenced their care experiences. For instance, Chloe described language barriers and the

complexity of past historical factors (residential schooling) as influencing older community members and creating barriers to participation by community members when working with health care providers: “In my [community], how we use language is different...and if we use it, we are considered unintelligent [gives example of how language translates into a different structure in English]. Others who are not from our community make fun of this and then...they [community members] are demeaned.” Elizabeth explained how she had experienced barriers to care, as the health care system seemed to discount or discredit Aboriginal peoples’ traditions, knowledge or perspectives: “The person with the most knowledge within an Aboriginal community may have no education, but they are much smarter than you or I.”

Participants encouraged the decision coach in a process of learning *with* them as well as *about* them and their decision-making needs, for, as Samantha stated, “If you are asking for ways to make decisions with an Indigenous person, then you have to acknowledge that these social problems are there.” Participants viewed the decision coach as a person prepared to accompany them in a journey of decision making, and the decision coach was seen as a critical facilitator of decisions, one that was inseparable from the adapted OPDG form.

Discussion

The adapted OPDG is the first known patient decision aid designed by and with Aboriginal people; in this study adaptations were conducted by a diverse (First Nations, Métis and Inuit) group of Aboriginal women from various parts of Canada and who are clients of Minwaashin Lodge. Focus groups and usability interviews with Aboriginal women were used to adapt, refine, and affirm the OPDG for use by decision coaches. Seven themes were identified that reflected the adaptations made by the participants to the original OPDG (Themes 1 through 4) or affirmed the adapted OPDG (Themes 5 through 7). Our findings

demonstrated that adaptations resulted in a more culturally sensitive and lower health literacy version of the original OPDG that were identified by Aboriginal women participants as better able to meet their decision making needs. Additionally, decision coaching was identified by participants as able to enhance their engagement in the decision making process using the adapted OPDG. Further, our study suggests that current health literacy frameworks may require expansion to accommodate more inclusive understandings of health literacy within various Aboriginal populations. A postcolonial theoretical lens was used to show how the adapted OPDG with coaching can support Aboriginal women as they negotiate societal disadvantages that are influenced by the political, social, and historical systems in which they must function.

Adaptations that Better Meet Participant Needs

Our findings indicated that the adapted OPDG with coaching resulted in a lower health literacy version of the original OPDG that was identified by participants as better able to meet their decision making needs. The first four themes identified adaptations to the OPDG and align with Nutbeam's (2000) three tier model of Health Literacy: Theme 1 ("This paper makes it hard for me to show that I am capable of making decisions") identified the need to enhance functional literacy skills through increasing the readability of the OPDG; theme 2 ("I am responsible for my decisions") identified the need to facilitate the meaningful use of the OPDG, which relates to interactive health literacy skills; theme 3 ("My past and current experiences affect the way I make decisions") identified opportunities for critical reflection and incorporation of contextual features into the OPDG; and theme 4 ("People need to talk with people") supported health literacy at all three levels by engaging the decision coach in a supportive role with Aboriginal women using their functional, interactive and critical health literacy skills. As Nutbeam's (2000) model described health literacy as the result of complex

sociocultural factors, it is appropriate for use within Aboriginal contexts; understanding and building literacy for/with Aboriginal Peoples has been identified as requiring the accommodation and integration of sociocultural factors, including Aboriginal views and beliefs (Smylie, Williams, & Cooper, 2006). Addressing lower levels of health literacy has been defined as crucial for decreasing disparities in health status experienced by populations (Rootman & Gordon-El-Bihbity, 2007); our findings show one potential user groups approach to fostering and supporting health literacy skill.

The remaining three themes were also found to align with health literacy as defined by Nutbeam (2000) and reflected the role played by the decision coach to support health literacy: Theme 5 (“I need to fully participate in making my decisions”) reflected the participants’ functional health literacy skill, reflected by their ability to engage in the decision-making process and use the adapted OPDG with the decision coach; theme 6 (“I need to explore my decision in a way that is meaningful to me”) identified participants’ interactive health literacy skill by using the adapted OPDG with coaching to foster decision-making processes they defined as meaningful; and theme 7 (“I need respect for my traditional learning and communication style”) relates to participants’ critical literacy skills and their awareness of contextual features factoring into their decision-making process when using the adapted OPDG with decision coaching. In our study, the addition of decision coaching addressed health literacy skills (functional, interactive, critical), leading to a better understanding and use of information.

The adapted OPDG, of which decision coaching is a critical part, suggests an SDM strategy for Aboriginal women and aligns with Battiste’s (2000) postcolonial approach in which social interactions that underlie oppression of Aboriginal people and contribute to undermining health literacy are resolved from within a partnership. Further, this strategy may

have broader potential applicability to other disadvantaged populations who face similar challenges with health literacy and inequitable barriers to access and negotiate systems of care.

Coaching is an Essential Element of the Adapted OPDG

Patient decision aids, such as the adapted OPDG, facilitate SDM between health care providers and clients (Elwyn et al, 2000). Research has found that the use of patient decision aids needs to be integrated into the process of care (Joseph-Williams, Elwyn, & Edwards, 2014; Légaré et al., 2010), and increased participation in care can be attained when coaching accompanies the use of patient decision aids (Stacey et al., 2012). Additionally, health care providers have been encouraged to discuss evidence-based information and to support clients' chosen level of participation (Politi, Dizon, Frosch, Kuzemchak, & Stigglebout, 2013).

In our study, Aboriginal women wanted to participate in shared decision making and identified coaching as an essential element in their decision-making process. Coaching used in the individual interviews enabled participants to more fully integrate the adapted OPDG into their decision-making process: specifically, they used the OPDG as a talking guide, used the dialogue with the decision coach as a means to bridge health literacy issues, and found the oral interaction with the decision coach to resonate with their own cultural approach to problem solving. Participants reported that the adapted OPDG with accompanying decision coaching support permitted them to choose their level of involvement in the decision-making process and supported a more fulsome engagement in decision making. Equally important, our study also found that participants must feel empowered to indicate the *ways* in which they want to be involved. We found that participants expressed a need for an approach that was reflective of their own unique cultural approach to decision making and reflective of

who they are as Aboriginal people (that is, First Nations, Métis or Inuit), and which may place emphasis on dialogue, community based decision support and consultation, and the need for a trusted source of information/support. Participants emphasized the importance of the coaching role as a central feature of an effective decision-making process, which reflects the cultural importance of mutual learning and building of knowledge together. This need for expansion of the coaching role to support women in ways that address the broader context in which they are making health decisions, including empowerment, support, and access to resources, has been identified elsewhere (Doull et al., 2006).

For our study, participants shaped the decision tool and accompanying processes to better support them in their efforts to seek, understand, and use health information to meet their care needs. The approach used in this study was also designed to be culturally resonant by engaging the coach in a collaborative process, to be a ‘trusted’ rather than ‘neutral’ source of support, and act as an agent with a stake in the process of decision making. There is currently little literature about the health literacy skills of health care providers (Institute of Medicine, 2004), however, health care providers have the potential to create positive change at a systems level through the critical exploration of assumptions underlying care systems in collaboration with their Aboriginal clients (Jull & Giles, 2012). Using a postcolonial theoretical lens (i.e., situating the findings in social, historical, political contexts) showed how the experience of health literacy could be influenced by the adaptations to the OPDG (which included decision coaching). These changes could possibly influence participants at the three levels of health literacy: functional, interactive and critical (Nutbeam, 2000). As a tool supporting SDM, the adapted OPDG features the decision coach (a role which may be assumed by trained health care providers) as an essential feature of its use, and as an interactive tool may lead to changes in critical health literacy of health care providers. If so,

the result would be additional opportunities to address the unfair processes and issues in existence within care delivery systems, which for Aboriginal people are the results of colonization, and align health care providers with them as equitable partners in reorganizing healthcare.

Expanding Understandings of Health Literacy

Our findings suggest that standard understandings of health literacy – as a set of skills possessed by an individual (WHO, 2014) – may be influenced by relational factors in the care environment, specifically, by the relationship with the decision coach. Our work has demonstrated the limitations of application of normative approaches to decision making in which decision makers are encouraged to arrive at health care decisions after a period of self-reflection and an introspective weighing of the personal preferences associated with various options. Instead, our study has demonstrated that participants often prefer to engage in a process of dialogue during which they have the opportunity to articulate the factors underlying their decision making. This dialogue, facilitated by a decision coach, can lead to collaborative and more meaningful discussions and better support decision-making solutions that are founded on greater health literacy skills. While our findings show promise for the potential use of SDM tools and approaches for use by and with Aboriginal women, they also suggest that health literacy models may require further examination and expansion. These changes would more accurately reflect the features of health literacy identified as relevant by users, in our case Aboriginal women, and which were reflected in adaptations to the OPDG and that are evoked/influenced in the relationship with the decision coach.

Limitations and Strengths

There are a mix of limitations and strengths to be considered. The use of focus groups may not have been most appropriate for a group with members who may have experienced

stigma associated with lower health literacy (Easton, Entwistle, & Williams, 2013). To minimize the potential limitation associated with past experiences of stigma, our focus groups were conducted in a setting familiar to the participants and findings from the focus groups were reviewed and confirmed during individual usability testing. As well, findings from the focus groups and usability interviews were from a small group of Aboriginal women; however, participants did self-identify as First Nations, Métis, and Inuit, and thus represented a very diverse group. Therefore, these findings may have some transferability to other groups. To strengthen the study, the ethical framework, tools and approaches used in the study were developed and approved by and with members of the advisory group that included representatives of the Aboriginal research partner community.

The approach to the adaptation of the OPDG was tailored to meet the needs of those participating in and using the information for the study. The study design incorporated the socio-cultural context of the OPDG users into the process of adaptation and usability testing, an important feature in cross-cultural questionnaires (Willis & Zhanid, 2007). An additional strength of this study included maintaining the principles underlying the OPDG and therefore the fidelity of the culturally adapted tool (Beaton et al., 2000). Finally, the second reviewer and members of the advisory group are familiar with the women of Minwaashin Lodge, and were able to verify the study process and findings as relevant to women of Minwaashin Lodge.

Conclusion

This study described adaptation and usability testing of the OPDG to support decision making by and with Aboriginal women, and conducted from within a research collaboration inclusive of a particular population of Aboriginal people. Following a process of OPDG adaption using focus groups and then usability interviews, seven themes were developed,

reflecting the OPDG adaptations and affirmed the relevance of the adapted OPDG with coaching for this population of Aboriginal women. The major conclusions of our study were that: adaptations by Aboriginal women to the OPDG resulted in a lower health literacy version of the original OPDG that was defined by participants as better able to meet their decision making needs; decision coaching was identified as being important to enhance interaction in the use of the adapted OPDG and resulting in the use of the adapted OPDG as a talking guide, and further research of the adapted OPDG with coaching is required.

A postcolonial theoretical lens was used to show how the adapted OPDG with coaching aligns with the experiences of Aboriginal women as they negotiate complex government or private care institutions. In creating a user-meaningful approach to adaptation of the OPDG, the resulting SDM strategy (adapted OPDG with decision coaching) prominently features user-values as an integral feature. The adapted OPDG with coaching was designed to further support participants' strengths in the area of health literacy by emphasizing the importance of mutual learning and building of knowledge together with care partners. Our findings show promise for the potential use of SDM tools and approaches for use by and with Aboriginal women; they also suggest that health literacy models may require further examination and expansion to more accurately reflect the features of health literacy identified as relevant by users during the adaptation process, and that are evoked/influenced by the decision-coach relationship.

In summary, our study has demonstrated a process of adaptation and usability testing of a lower health literacy SDM tool (the adapted OPDG) with decision coaching as an integral feature of its use for fostering engagement in the decision-making process. Further collaboration with Aboriginal community partners is needed for research to explore and

identify the feasibility and efficacy of using the adapted OPDG with decision coaching as part of effective SDM strategies within Aboriginal populations.

Figure 4.1 Procedure for Cultural Adaptation of SDM Intervention.

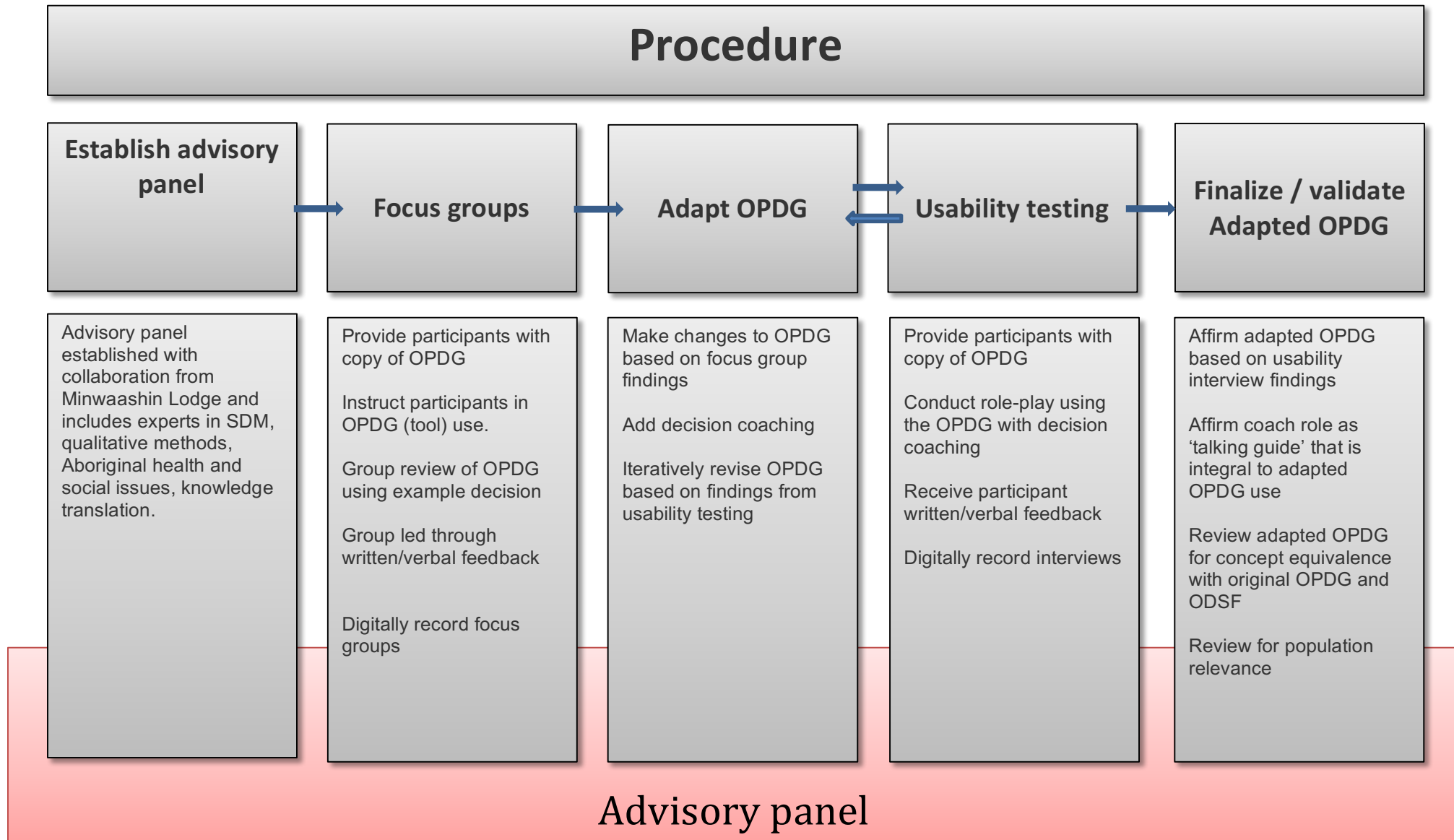


Figure 4.2 The Adapted Ottawa Personal Decision Guide (OPDG).

Adapted Ottawa Personal Decision Guide: For People Making Health or Social Decisions

There are four steps: ① ② ③ ④

① Clarify your decision

What decision do you face?

Why are you making this decision?

When do you need to make a choice?

Where are you with making a choice?

- ☐ Not yet thought about the options
- ☐ Thinking about the options

- ☐ Close to making a choice
- ☐ Already made a choice

② Explore your decision

	Reasons to Choose this Option (Benefits / Pros)	How much it matters Use 0 to 5 ★s	Reasons to Avoid this Option (Risks / Cons)	How much it matters Use 0 to 5 ★s
Option #1				
Option #2				
Option #3				

Which option do you prefer?	☐ #1	☐ #2	☐ #3	☐ Unsure
-----------------------------	-----------------------------	-----------------------------	-----------------------------	---------------------------------

How motivated are you to take action	<i>Not Motivated</i>	0	1	2	3	4	5	<i>Very Motivated</i>
--------------------------------------	----------------------	---	---	---	---	---	---	-----------------------

How confident are you that you can take action?	<i>Not Confident</i>	0	1	2	3	4	5	<i>Very Confident</i>
---	----------------------	---	---	---	---	---	---	-----------------------

List things that may get in the way of doing this:

List things that may help you to do this:

Support

Who is involved?	
Who else can support you?	
Which option do they prefer?	
Is this person pressuring you?	
How can they support you?	
What role do you prefer in making the choice?	☐ Share the decision with _____ ☐ Decide myself after hearing views of _____ ☐ Someone else decides _____

3 Identify your decision making needs

Certainty	Do you feel sure about the best choice for you?	☐ Yes	☐ No
Knowledge	Do you know the benefits and risk of each option?	☐ Yes	☐ No
Values	Are you clear about which benefits and risks matter most to you?	☐ Yes	☐ No
Support	Do you have enough support and advice to make a choice?	☐ Yes	☐ No

4 Plan the next steps based on your needs

✓ Things you would like to try

A. Certainty	
If you feel unsure about the best choice for you:	☐ Working through the steps below may help.
B. Knowledge	
If you need to know more:	☐ Find out more about the options and the chances of the benefits and risks. ☐ List your questions. ☐ List where to find the answers (e.g. library, care provider, counsellor)
C. Values	
If you need to think about what matters most to you:	☐ Review the stars in the balance scale to see what matters most to you. ☐ Talk to others who have made the decision. ☐ Read stories of what mattered most to others. ☐ Discuss with others what mattered most to you.
D. Support	
If you need support:	☐ Discuss your options with a trusted person (e.g. care provider, counsellor, family, friends). ☐ Find help to support your choice (e.g. funds, transport, child care).
If you feel pressure to make a certain choice:	☐ Focus on the views of others who matter most. ☐ You can share your guide with others. ☐ You can ask others to try this guide. See where you agree. If you disagree on facts, agree to get more facts. If you disagree on what matters most, consider each other's view. ☐ Find a trusted person to help you and others involved.
Other ideas and plans:	

Table 4.1 Examples of Questions Asked by Interviewer of Focus Group Participants

1. In general, what did you like or not like about this form?
(prompt: Made sense? Seems well organized? Useful? Why/why not?) Was anything confusing about it? Or not sure of how to use it?
2. Now, thinking about you as an Aboriginal woman, do you think that this form would be useful when considering a decision about your health and well being, or about something like whether to go to school?
(prompt: Do they seem to ask the right questions? Do the topics/ideas seem right?)
3. We will now go through each question on the form. Do you think that #_ makes sense?
(prompt: if a concern is raised: What do you like/not like? What would you change?)
4. Do you have any other comments or suggestions that we should consider that would make the form easier for Aboriginal women to use?
(prompt: Topics/ideas; particular words; pictures?)
5. Those are all the questions we were going to ask; would you like to ask us about anything? Is there anyone else you think we should talk with about this topic?
6. Do you feel that we have created a tool that could be useful for making a health or social decision?
7. Would you try it out again/for making a real decision?
(prompt: Why or why not? What was it like to use it? What could make it better?)
8. Do you think that this could help you to make a decision that you think is good?
(prompt: Clarify the choice options? Figure out the benefits and harms? The chances that the benefits or harms might happen?)

Table 4.2 Examples of Questions Asked by Interviewer of Usability Participants

Background Statement (interviewer speaking to participant): ‘This is your decision scenario – so I am asking you to pretend to be preparing to go in to see your care provider, a counselor, social worker, doctor/nurse, to make a decision about a return to school’.

The participant talks through how she would use the OPDG to prepare for her meeting with a care provider, and answers some brief questions at the end of the role-play on her views towards using the OPDG.

1. Was the OPDG easy to use?

(prompt: Did it make sense the way it was organized? Was it clear?)

2. Would you try it out again/for making a real decision?

(prompt: Why or why not? What was it like to use it? What could make it better?)

3. Do you think that this could help you to make a decision that you think is good?

(prompt: Clarify the choice options? Figure out the benefits and harms? The chances that the benefits or harms might happen?)

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?

Table 4.3 Demographic Data for Focus Groups and Usability Interviews

Demographic Data	Participants (N=19)
Inuk	2
First Nations	7
Métis	10
Age Range	
20 to 29	7
30 to 49	9
50 to 50	3
Number of children:	
0	2
1	2
2	6
3	4
4	3
5	2
Education:	
<Grade 8	2
Grade 8 to 12	13
College	1
University	3

Table 4.4 Themes Informing OPDG Adaptations

Theme	Adaptation to OPDG	Focus Groups	Usability Testing
“This paper makes it hard for me to show that I am capable of making decisions”	• Plain language • Print size • Decreased concept density • Logical layout	☒ ☒ ☒ ☒	☒ ☒ ☒
“I am responsible for my decisions.”	• Addition of text in ‘Support’ (section 2) • Removal of extra text (section 3) • Positive language (section 4)	☒ ☒ ☒	 ☒ ☒
“My past and current experiences affect the way I make decisions.”	• Use of neutral language and/or meaningful language • Addition of 4 lines for decision implementation (section 2) • Tailored to population – less like ‘government form’	☒ ☒ ☒	☒ ☒
“People need to talk with people”	• Coach facilitates access of OPDG, meaningful use of OPDG, integrates context into use of OPDG process	☒	☒

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Chapter 5

Integrated Discussion

Introduction

This chapter provides an integrated discussion of the findings described in this dissertation. First, the unique contributions of each are briefly described. Then, the dissertation's findings are discussed as they relate to the cultural adaptation of the Ottawa Personal Decision Guide (OPDG) with decision coaching, and the cultural adaptation process is proposed as 5-steps titled "A Participatory Approach to Cultural Adaptation of Healthcare Interventions". Next, there is a discussion focused on the essentialness of relational features in shared decision making (SDM) interventions (that is, tools and approaches promoting a process of SDM) and that for the findings of this dissertation include the context of Aboriginal women's health decision making. The chapter concludes with the potential contributions of the dissertation findings to Aboriginal Peoples' population health, and implications for clinical practice, education, and research.

Summary of Dissertation Findings

This dissertation is structured as a series of three studies determined a priori (Appendix D). Each focused on one of the following research questions: a) What are effective interventions to support Aboriginal Peoples in making health decisions (Chapter 2); b) What are the experiences of Aboriginal women in making health decisions (Chapter 3); c) What is the usability of a culturally adapted Ottawa Personal Decision Guide (OPDG) for Aboriginal women (Chapter 4)? The contributions from each of these studies will be briefly summarized.

Study One

The first study was a systematic review titled "Interventions for Indigenous Peoples Making Health Decisions: A Systematic Review" (Chapter 2; Jull et al., 2013). The systematic review sought to identify SDM interventions that support Indigenous Peoples in

making health decisions. Findings revealed only one eligible study indicating a lack of studies evaluating SDM among Indigenous Peoples. The included study was unique as it was developed in a partnership with researchers and educators that included representatives of American Indian groups and who provided services in an academically focused school for Native American children, and specifically with grade 7 students. The adapted SDM intervention, however, is no longer available for review or use. Findings from the systematic review were used to inform the subsequent studies in this dissertation by providing context for the ways in which decision making was conceptualized within the literature.

Study Two

The second study of this dissertation was titled “Shared Decision-Making with Aboriginal Women Facing Health Decisions: A Qualitative Study Identifying Needs, Supports, and Barriers” (Chapter 3). This interpretive descriptive qualitative study described the experiences of Aboriginal women when making health decisions by identifying decision-making needs, supports, and barriers. The study concluded that the use of SDM with Aboriginal women is appropriate and their perspectives on the SDM approach were articulated using the Medicine Wheel. The findings from this study were used to inform the third study in this dissertation by ensuring more emphasis on relational and contextual features of SDM.

Study Three

The third study of this dissertation was titled “Cultural Adaptation of a Shared Decision Making Tool with Aboriginal Women: A Qualitative Study” (Chapter 4). An interpretive descriptive qualitative study was structured using the Ottawa Decision Support Framework and employing a postcolonial theoretical lens. The study created an adapted

version of the OPDG that was identified by participating Aboriginal women as being better able to meet their decision making needs. As well, the culturally adapted OPDG was a lower health literacy version of the original OPDG, and it was identified by participants as being more likely to support the participation of Aboriginal women in SDM. The Aboriginal women participants also identified a trained decision coach as an essential requirement to using the OPDG as a ‘talking guide’.

The Cultural Adaptation of a SDM Intervention

The cultural adaptation of the SDM intervention (the OPDG) used in this dissertation was a 5-step process titled “A Participatory Approach to Cultural Adaptation of Healthcare Interventions (P-CAHI)” (see Figure 5.1). The 5-step process consisted of a series of linked steps: 1) Define the issue, 2) Population needs assessment, 3) Intervention adaptation, 4) Usability testing, 5) Evaluation of adapted intervention. For this process of cultural adaptation, it was essential to collaborate using a participatory action research (PAR) approach with individuals from within the community for which the intervention is meant (Castro, Barrera & Martinez, 2004). The following provides more details on the 5-steps.

P-CAHI Steps

Step 1: Define the issue

In step one, external evidence is identified to provide background information and contextualize the issues affecting the health of a community. The issue is identified by the community, or, if identified by those outside of the community (e.g., by a health care provider or researcher), agreed to by the community as warranting further investigation.

For example, for this dissertation, the issue was a lack/inadequacy of existing SDM interventions developed by and for Aboriginal populations, and indicated by a general literature review, consultation with experts in the area of decision making and

Indigenous/Aboriginal health, community leaders at Minwaashin Lodge, SDM tool inventories, and a systematic review to identify SDM interventions. The findings provided background information on health decision making within Aboriginal populations.

Step 2: Population needs assessment

In step two, data are collected to estimate the decision making needs of the population (i.e., community), existing resources, identified key target users, and options for making changes to the intervention to best meet health needs. To address specific health issues, the population needs assessment process may require tailoring. For identification of the decisional needs of a population, the focus would be on identifying what a community needs for making better decisions, and this could extend to assessing the needs of health care providers to best support decision making within the particular community. The assessment could be conducted using individual interviews, focus groups, survey, chart audits, and/or observation of clinical encounters (Jacobsen, O'Connor, & Stacey, 2009). Specific to the P-CAHI is the inclusion of data collected on the cultural needs of the community, which could include information on the ways in which cultural needs of community members have been influenced by political structures, historic or more recent health care system experiences, or social expectations about client and/or health care provider roles in the health care system. Theoretical frameworks can be used to guide needs assessment. The Ottawa Decision Support Framework is an example of a theoretically informed framework that can be used to guide a decisional needs assessment (Jacobsen et al, 2009), and there are other examples of population needs assessments that are guided by theoretically informed frameworks (Christanson et al, 2013; Stevens & Gillam, 1998).

For example, in this dissertation, individual interviews were used to identify the decision making needs of Aboriginal women. More specifically, the needs assessment

identified that they wanted an intervention designed to guide an interactive dialogue of decision making, rather than in a solitary, paper-based form. Opportunities for interaction and mutual learning between the Aboriginal women and their health care providers was emphasized by participants during the needs assessment.

Step 3: Intervention adaptation

For step three, an existing intervention is reviewed by and with representative community members for which the intervention is being adapted, to assess for relevance, pragmatics (how and when it could be used), and potential modifications. As the culture of a community is defined by socially constructed processes and made evident in social interaction (Aneas & Sandin, 2009), a qualitative approach is ideal for obtaining information on context and the social processes that shape culture. The process of gathering feedback on the intervention can be conducted using individual interviews and/or focus groups; the resulting information can support and lead to the adaptation of the health intervention by and with the community. Focus groups, for instance, have been shown to be appropriate for generating data with a range of cultural and linguistically diverse groups, including Aboriginal groups (Halcombe, Gholizdeh, DiGiacomo, Phillips, & Davidson, 2006; Ruppenthal, Tuck, & Gagnon, 2005; Willgerodt, 2003).

In this dissertation, focus groups with community members were used to identify culturally appropriate modifications to the OPDG. Aboriginal populations may view focus groups as acceptable as they facilitate a culturally respectful and equitable forum for sharing ideas (Berthelette, Raftis, & Henderson, 2001; Kirby, Levesque, & Wabano, 2007). Further, Minwaashin Lodge leaders indicated that a focus group approach was preferred. Findings from the focus groups were used to modify the OPDG in ways that participants viewed as useful and relevant to them and potentially also to their community. These modifications

were agreed upon by members of the advisory group, and they resulted in the adapted OPDG with decision coaching.

Step 4: Usability testing

Step four involves the usability testing of the adapted intervention by and with members of the community for which the intervention is being adapted, and with potential for further, iterative changes to the intervention. As 80% of usability problems have been found within four to five participants (Virzi, 1992), five to six participants have been proposed as necessary for establishing and refining data during usability testing with decision tools (Brehaut, Lott, Fergusson, Shojania, Kimmelman, & Saginur, 2008).

For example, in the dissertation this step was conducted using individual interviews with six Aboriginal women participants who used the “think aloud” technique (Skaner, Backlund, Montgomery, Bring, & Strender, 2005) to test the use of the adapted OPDG. Iterative changes were made to the adapted OPDG during the interviews until there were no further changes to the OPDG identified, and final interviews confirmed the adapted OPDG with coaching. The advisory group was involved throughout the process of the usability testing, from the development of the process, providing feedback throughout the data collection, and who also confirmed the final findings.

Step 5: Evaluation of adapted intervention

In step five, the evaluation of both feasibility and efficacy of the adapted intervention are conducted. A feasibility study identifies factors related to the recruitment, randomization, retentions, assessment, and implementation of a new intervention (Leon, Davis, & Kramer, 2012). This information is used to design a larger scale study aimed at evaluating the efficacy of the intervention. Evaluation of the intervention efficacy determines the impact of

the intervention on outcomes identified as important (Flay et al., 2005) and within the P-CAHI is conducted and evaluated by and with the user population.

For example, building on the work presented in this dissertation, a pilot study could be developed in collaboration with Minwaashin Lodge or other organizations that support Aboriginal women to determine the feasibility of the culturally adapted OPDG with coaching in health settings with Aboriginal women. This, in turn, could guide the design and implementation of a larger scale study to evaluate the efficacy of the culturally adapted OPDG with coaching with Aboriginal women.

Guiding Features Structuring the Cultural Adaptation Process

The 5-step process of cultural adaptation is structured within the context of a PAR approach that involves 1) the formation of an advisory group, 2) creation of an ethical framework, and 3) selection of a theoretical perspective. PAR is defined as a systematic and collaborative enquiry with those affected by an issue. It is aimed at education, taking action, and/or social change (Green, George, Daniel, Frankish, Herbert, Bowie, & O'Neill, 1995). PAR addresses social change through action-oriented strategies that have the potential to both generate knowledge and to bridge gaps between research and practice (Cargo & Mercer, 2008). Within research settings that involve Aboriginal people, the use of PAR has been identified as contributing to the decolonization of research (Warry, 2007). PAR is an essential part of engaging knowledge users with researchers with the objective of developing and implementing the adaptation processes described in P-CAHI.

An advisory group for the P-CAHI includes researchers and knowledge users, or potential knowledge users from the community for which the intervention is being adapted, consisting of experts on the issues to be addressed in cultural adaptation process. When users/potential users of the study outcomes are involved with the researchers in a formal

partnership, this increases the likelihood that the objectives of the project will be met (Levy, Baldyga, & Jurkowski, 2003). For example, in this dissertation the advisory group first developed and agreed to a memorandum of understanding to structure the researcher-community partnership, and collaboratively developed and published a study protocol that described the objectives of the research project.

Next, having a structured and clearly articulated ethical framework is key feature of the P-CAHI. The importance of ethical conduct in research with humans is emphasized in the Tri-Council Policy Statement (Panel on Research Ethics, 2011). For community groups, there may be additional ethical guidelines to consider and these may be accommodated in the P-CAHI framework. For example, in this dissertation, the advisory group developed and agreed to an ethical framework, which included approval from Minwaashin Lodge, the use of the Ownership, Control, Access, and Possession (First Nations Centre, 2007) approach, and the Tri-Council Policy Guidelines (Panel on Research Ethics, 2011). The ethical framework was used to guide the entire cultural adaptation process. The creation of a relevant and useful ethical framework was viewed as essential as there is a history of research being done “on” Aboriginal Peoples, that has led to important guidelines to protect and promote their interests (First Nations Centre, 2007; Panel on Research Ethics, 2011).

Finally, the selection of a theoretical perspective in the P-CAHI is important as the theoretical perspective situates and makes explicit the underlying worldviews that inform the study. The selection of theory must be done with the input and agreement of the advisory group members. This is done so that the collaborative, interdisciplinary, and user-oriented approach to research in the cultural adaptation process is perceived as coherent, understandable, and useful (Giacomini, 2010). For example, in this dissertation, with input from all advisory group members, it was agreed that postcolonial theory offered the most

relevant perspective from which to view, understand, and seek to address the negative impacts resulting from the underpinning social, historical, and political forces (Battiste, 2000) affecting Aboriginal women. In particular, postcolonial theory is useful for understanding how colonialism continues to negatively influence the everyday lives of Aboriginal women living in Canada through social and economic structures, and including access to resources for health (Browne et al, 2005).

Assumptions of the P-CAHI Approach

The P-CAHI will not be useful or relevant to users without accepting three underpinning assumptions. First, that using a PAR approach will result in interventions more sensitive to the cultural norms of the population for which the intervention is meant, and generation of knowledge that is defined as both useful and relevant by those for which the intervention is meant. Second, the use of a systematic and iterative process with various data sources will enhance the transparency of the adaptation process. Third, that the participating community members view research and/or a collaborative relationship with researchers (or others who are potentially external to their group) as a benefit in the adaptation of a health intervention for their community. These assumptions and the use of a PR approach are fundamental to the P-CAHI.

Limitations and Strengths

The limitations of the P-CAHI as it is presented in this dissertation are that it does not address the translation of a health intervention, and only suggests but does not demonstrate how to conduct feasibility and efficacy studies. A strength and a major contribution is that the P-CAHI suggests a novel approach to the collaborative adaptation of a SDM intervention from within a mutually agreed upon partnership, ethical and theoretical framework, and using a systematic and transparent process. As a result, the end product of this dissertation,

the adapted OPDG with decision coaching, was acceptable to advisory group members and found by Aboriginal women participants to be both useful and relevant to them, and to facilitate what they identified as relational features of SDM.

Discussion

Although there are numerous interventions available to facilitate SDM, there is little literature available to inform the cultural adaptation of health interventions, such as SDM tools in health settings, and particularly in ways that are defined as useful and relevant by the populations for which they are meant to serve. Cultural adaptation refers to “a process that looks at both language (translation) and cultural adaptation issues in preparing a questionnaire for use in another setting” (Beaton, Bombardier, Guillemin, & Ferraz, 2000, p. 3186). While guidelines that describe cultural adaptation of health interventions were not located to inform the work presented in this dissertation, guidelines do exist to facilitate the cross-cultural adaptation of self-report measurement instruments (Beaton et al., 2000).

Beaton et al. (2000) outlined a 5-stage process of adaptation for health status questionnaires that is aimed at retaining psychometric properties of the original questionnaire in the adapted version. This five stage process includes 1. translation by two translators, 2. synthesis of translations into one document, 3. back translation of document into original language, 4. expert committee review to reach consensus on discrepancies and produce pre-final version and, 5. pretesting of complete questionnaire with users. That said, these translation guidelines “do not automatically provide a valid measure of another culture’s health” (Beaton et al., 2000, p. 3190) nor do they use processes that examine the underlying assumptions in the measures or assumptions used to adapt measures. While alignment with the socio-cultural values of the user population in cross-cultural questionnaires has been identified as important (Willis & Zhanid, 2007), the need to achieve alignment with the

socio-cultural values of users has been identified as being particularly important for health issues within the Aboriginal context (Ellison, 2014). This dissertation presents work completed with advisory group members who valued the alignment of the intervention adaptation process and product with the socio-cultural views of intervention users. The processes developed and used during the cultural adaptation of the OPDG reflect these values.

Tensions exist between maintaining the fidelity of interventions while also ensuring their responsiveness to the cultural needs of the community (Castro, Barrera, & Martinez, 2004). One strategy is to design an evidence-informed intervention that is also culturally relevant, and with a collaborative and iterative process between the researcher, advisory group, and study participants during the cultural adaptation process. The overarching aim of the P-CAHI is to refine, affirm and finalize the adaptation of an intervention that is defined as both useful, and as maintaining the fidelity of the original intervention. For example, in this dissertation, the adaptation process involved the intervention experts as well as those of the population for which the intervention is meant, in an iterative process of suggesting and then confirming modifications to the OPDG, until all were in agreement with the end product (the adapted OPDG with coaching).

Relational Features as Essential in SDM Interventions: The Context of Aboriginal Women

Another theme identified in this dissertation was how the relational features of SDM have potential to support a decision making approach that makes evident and is concerned with the complex social, historical, and political factors, which undermine the health of Aboriginal women. The relational features of SDM refer to the interpersonal relations between the client and her/his health care provider (Entwistle & Watt, 2006). The importance

of the relational features of SDM have been identified by health care providers, who have identified risk communication and relational core competencies as essential for SDM training (Légaré, 2013). There is little evidence identifying the relational features of SDM within Aboriginal populations. In the literature, only one study was identified as conducted by and with an Indigenous population and which supported SDM as a dialogue and in an interactive and culturally sensitive way (Okwumabua & Duryea, 1989), although the relational features of the SDM process were not discussed; other studies were found to be directive and focused on the compliance of Indigenous populations in health care. These findings show how assumptions about Aboriginal people and their presumed differences are an integral feature of health care practice and research, and the limited information on the relational features of SDM in Aboriginal populations.

In this dissertation, the relational features of SDM were first identified by and with a group of Aboriginal women, and then used to inform the adaptation of the OPDG that also involved a decision coach. Aboriginal women participants emphasized the importance of contextual factors (i.e., social, historical, political) as influencing their views and experiences with SDM. They identified that the impact of these factors on their lives had to be made evident in health care encounters so that they could participate in making decisions with their health care providers. The adapted OPDG was used in a novel way and in what we described as a talking guide, and provided structured guidance for an SDM process between the decision coach and participant. Used in this way, the adapted OPDG was viewed by the Aboriginal women participants as fostering opportunities for engagement in making health decisions through the use of an interpersonal relationship.

Mainstream decision making models emphasize a series of steps for SDM, and the complexity and features of interpersonal relationships are not well identified. There is one

conceptual framework that increased awareness of and drew importance to the need for understanding the relational context in which decision making occurs between health care provider and client (Entwistle & Watt, 2006). The perspective on SDM shown by this framework is important, as negative social assumptions within society have been shown to extend to health settings and influence the participation of Aboriginal women in health care services (Brown, 2007; Kurtz, Nyberg, Tillaart, & Mills, 2008). Further, mainstream approaches to SDM are challenged by research that has indicated that even when (non-Aboriginal) clients have engaged with health care services and are considered informed, they may not be able to participate in the health care-provider relationship due to interpersonal power imbalances (Joseph-Williams, Elwyn, & Edwards, 2014). For Aboriginal women, relationship building with a health care provider was identified as requiring the mutual understanding of the historical and contemporary social relations of Aboriginal Peoples and the members of the dominant (ie, Euro-Canadian) group (Browne & Smye, 2002). The views of Aboriginal women presented in this dissertation have shown that they value active participation in their health care decision making and require opportunities to be active participants in their care. The findings of this dissertation suggest that using the adapted OPDG as a talking guide with a decision coach may potentially be useful for Aboriginal women who want to participate in making health decisions with health care providers. The findings also suggest that further work in the area of the relational features of SDM is required to develop better understandings of how SDM may be able to influence the underpinning social forces that shape the dynamics within health care settings, and between health care providers and Aboriginal populations.

Contributions to Aboriginal People's Population Health

A population health approach is focused on the health and well-being of populations

through examination of the interrelated factors that influence health over the life course (Public Health Agency of Canada (PHAC), 2011). There are three categories of determinants of health that influence Aboriginal populations in Canada: proximal (e.g., health behaviours, education, food insecurity), intermediate (e.g., health care systems, educational systems, cultural continuity), and distal (e.g., colonialism, racism and social exclusion, self determinism). Using these categories, the findings presented in this dissertation may have potential to influence “health behaviours” (proximal), “health and social systems” (intermediate), and “colonialism” (distal) (Reading & Wein, 2009) (PHAC, 2013).

Health Behaviours as a Determinant of Aboriginal Population Health

“Health behaviours,” as a proximal social determinant of Aboriginal health, is described as influencing health through decisions to participate in particular health behaviours (e.g., participation in prenatal care, cancer screening) (Reading & Wein, 2009). SDM may influence participation in particular health behaviours, as SDM promotes the use of specific knowledge and skills to support participation in decisions by defining the decision, becoming informed on the decision options (including benefits and harms), clarifying values for outcomes of options, defining client ability to follow through on decision plan, considering opinions of those who matter most (including communication with the care provider), and communicating preferences for a decision and with decision follow up (Makoul & Clayman, 2006). Participation in SDM has been found to increase client skill and confidence in health care processes and has been associated with better health experiences and outcomes, including for those with lower socioeconomic status (Hibbard & Green, 2013; Durand, Carpenter, Dolan, Bravo, Mann, Bunn, & Elwyn, 2014). This dissertation has presented the development of a culturally appropriate strategy (the adapted OPDG with coaching) that may have potential to influence the participation of Aboriginal

women in a process of making health care decisions with their care providers.

As a proximal determinant of health, health behaviours have also been described as being influenced by the socio-political context of Aboriginal health (Reading & Wein, 2009), a view that aligns with those expressed in this dissertation and reflected by the choice of the advisory group to use postcolonial theory. For instance, due to systemic socio-political issues within Canadian society, Aboriginal women are more likely than non-Aboriginal populations to have low health literacy (PHAC, 2014). This dissertation presents a culturally adapted and lower health literacy version of the original OPDG, which has potential to facilitate greater participation of Aboriginal women in making care decisions with their health care provider(s). This finding is corroborated in the broader literature that evaluates the role of SDM in fostering health literacy. This literature identified that decision aids that enhanced health literacy resulted in increased knowledge and better-informed choice; additionally those with lower health literacy had greater gains (McCaffery, 2013).

Health Care Systems as a Determinant of Aboriginal Population Health

As another Aboriginal determinant of health, “health care systems” is an intermediate determinant of health and also influences the proximal determinants of health (Reading & Wein, 2009). For instance, inequitably structured health care systems may prevent or undermine Aboriginal Peoples from “accessing or developing health promoting behaviours, resources and opportunities” (Reading & Wein, 2009, p. 18). Those with low socioeconomic status are more likely to have low knowledge about treatment efficacy (Ebrahim, Anderson, Weidle, & Purcell, 2004); this has also been found in a population of Aboriginal women with chronic illness (McCall, Browne, & Reimer-Kirkham, 2009). Studies have identified Aboriginal clients as undermined in their participation in routine clinical care due to their disengagement in relations with health care providers (Browne, 2007; Smith, Edwards,

Varcoe, Martens, & Davies, 2006). These findings were affirmed in the work presented in this dissertation in which women described the barriers to participation in SDM within health settings and in relationships with their health care providers.

In this dissertation, Aboriginal women's health decision making needs were explored and Aboriginal women were engaged in adapting an SDM approach to support their information and decisional needs within health care systems. Aboriginal women defined their needs for SDM experiences within health care systems and this was presented in a Medicine Wheel framework. This framework could be used to inform and possibly restructure the relational features of health care settings to facilitate the participation of Aboriginal women in their health care decisions. For example, health setting managers/care providers could partner with an Aboriginal women's organization to develop and implement policies that create environments and opportunities for Aboriginal women to feel safe with care, such as clinical routines promoting safety and privacy and health care provider communication skills training. The understandings of SDM presented in this dissertation by Aboriginal women has potential to foster changes in health care systems, and could lead to more accessible and equitable use of health systems by Aboriginal populations.

Colonialism as a Determinant of Aboriginal Population Health

"Colonialism," as an Aboriginal determinant of health (Reading & Wein, 2009), was identified by Aboriginal participants as an issue underpinning their overall health and social well-being. It influences the intermediate and proximal determinants of health (Reading & Wein, 2009). Participants adapted the SDM intervention (adapted OPDG with coaching) to create opportunities for understanding and integration of context into the processes of decision making. The SDM intervention was designed to engage participants in what they defined as a meaningful and productive relationship with health care providers.

The findings of this dissertation suggest that a culturally sensitive and interactive SDM approach has potential to alter the decision making experiences of Aboriginal women with their health care providers, and to expand health care provider understandings of how colonial socio-historical issues impact Aboriginal clients. This, in turn, could possibly lead to systematic changes to care delivery, such as policy in support of health care provider training to promote more culturally appropriate/competent/safe respectful and inclusive care approaches. Greater awareness by health care providers of their clients' context would inform and dispel negative views of Aboriginal clients (e.g., "non-compliant"), and support the identified need for care environments that are more responsive to their Aboriginal clients (Browne, Smye, Rodney, Tang, Mussell, & O'Neil, 2010). For Aboriginal clients, interactive SDM approaches may create an opportunity for engagement with health systems and health care providers who are more sensitive to and understanding of the impacts of colonization.

Implications for Practice, Education, and Future Research

Findings from the series of three studies in this dissertation have several implications for the areas of practice, education, and further research (Table 5.1).

Practice

Findings from this dissertation indicate that Aboriginal women in clinical consultations need to have their unique SDM needs addressed, and to have access to decision coaching to guide them in preparing for SDM. Research with clients in care settings affirms the benefits of SDM for clinical outcomes (Stacey et al., 2014); however, understandings of SDM have been identified in this dissertation as needing to be expanded to recognize the unique needs of Aboriginal populations. SDM research to inform practice to date has been limited to predominantly Euro-Canadian settings and populations (Alden, Friend, Schapira & Stiggelbout, 2014) and has not been adequately explored in Aboriginal populations.

Although we found that Aboriginal women participants agreed that SDM was relevant to them and their decision making needs, we also identified that better understandings of relational features in the development and use of SDM tools and approaches are required so that they can be enacted in practice. For example, in our needs assessment study, participants used relational methods (stories) to relate their experiences and then identified the need for a decision coach to discuss the decision with them during use of the adapted OPDG. They also described the approaches they used to make useful and relevant decisions about their health, reflected in the Medicine Wheel framework, and focused on the relational nature of SDM. The participants described their views and roles about themselves with SDM, and their perceptions of care providers' roles in SDM. The work in this dissertation affirms work done elsewhere, which has identified the value and potential contributions to practice by health

care providers who learn decision coaching skills, and who engage with their clients and support the use of SDM in clinical settings (Légaré et al., 2010).

While current decision coaching programs are not specifically focused on culturally relevant issues, the findings of this dissertation further emphasizes the importance of decision coaching training, already identified as important for clinical practice settings (Stacey, Kryworuchko, Bennett, Murray, Mullan, Légaré, 2012). This is of particular importance, as training in decision coaching may support health care providers to better support clients with a diversity of decision making needs. The results presented in this dissertation indicate that a client population (Aboriginal women of Minwaashin Lodge) identified the decision coach as an integral feature of the SDM intervention, a finding of particular relevance for health care providers who work with clients needing additional support due to challenging health and/or social issues. Elsewhere, competencies in communication skills have been identified as essential for practitioners (Laughlin, 2012). This dissertation introduces new knowledge that can be used to contribute to the evolving area of SDM and emphasizes the essential features of the health care providers' skills, findings that are applicable to the education of care providers.

Education

The findings of this dissertation suggest that using the adapted OPDG with coaching may not only provide a way in which to engage Aboriginal women in SDM, but to also indirectly educate care providers. Approaches that aim to change health care providers' behaviour through client-provider interactions are called 'patient mediated interventions' and are defined as "any intervention targeting patients that aims to influence the uptake of evidence by health care professionals" (Stacey & Hill, 2013, p. 205). In our study, we noted that the Aboriginal women in our study preferred that the decision coach engage in a process

of learning with them as well as about them. Rather than engaging alone in the use of the OPDG, participant adaptations to the OPDG were made so as to enhance the relationship and mutual learning between decision coach and client. In this way, participants viewed the decision coach (a role that could be assumed by a trained health care provider) as genuinely engaged and learning about them (the Aboriginal client) and therefore able to engage in making collaborative health care decisions.

The OPDG adaptations directed the client-coach relationship in a way that was aimed at reducing the barriers, such as those imposed by health literacy issues in the clinical setting. For instance, there is little information on the health literacy skill of health care providers (National Institute of Literacy, 2011). The approach fostered by the adapted OPDG with coaching could have potential to also support changes in the environment in which the care is provided by contributing to better defining the meaning of client-centred concepts (Sumsion & Law, 2006) and leading to understandings of care system requirements to support client-centred care. For example, this could be done by training health care providers to support clients in their health literacy and participation in SDM through the use of SDM interventions, such as the adapted OPDG with decision coaching. Health care provider education to use the SDM strategy would be supported by training in essential SDM competencies.

Consensus on competencies for training of care providers in SDM is emerging and our findings focused on relational features of SDM, which are consistent with and support one of two sets of core competencies identified for training care providers in SDM (i.e., relational and risk communication) (Légaré et al., 2013). The findings presented in the Medicine Wheel framework emphasize the importance of relational skills in SDM and in this way align with the relational core competencies for care practitioner training. The findings

also suggest that there may be a need for a focus on SDM communication skills training within the relational core competencies so that practitioners have the skill to engage with clients and thereby enable the incorporation of Aboriginal womens' context into the SDM process.

Aboriginal women indicated that SDM requires understandings of their context by health care providers which is acquired through interpersonal communication. The findings of this dissertation suggest that there is a need to further explore communication skills as part of developing relational SDM competencies. The development of the OPDG as a talking guide in this dissertation indicates that for Aboriginal women participants, communication with a trained decision coach fosters their participation in a SDM process. While communication skills have been identified as important for health practitioners who facilitate SDM (Guidmond et al., 2002), there has not been an emphasis on communication skills development within the area of SDM similar to that found in other areas of health care. For instance, the need for and components of communication skill competency training have been defined in some health professions (Laughlin, 2012) as a way to foster productive relationships in health care encounters. Future studies could contribute to developing the area of SDM competencies by further defining and promoting the uptake of communication skills training as a part of SDM competencies and thereby supporting understandings of clients' contexts. This work could begin by building a program of research based on the findings of this dissertation.

Research

More research is required for developing feasible and effective SDM interventions, such as the adapted OPDG with coaching, for use within Aboriginal and other populations. This study provides a starting point for building such a program of research, and can be

replicated and expanded to other settings with a larger number of clients and health care providers. For instance, this dissertation provides a foundation for the testing of the feasibility and efficacy of the adapted OPDG plus decision coaching with Aboriginal women. A pilot study could be developed to determine the feasibility of evaluating the culturally adapted OPDG with coaching in health settings with Aboriginal women. Then, the feasibility study findings could guide the design and implementation of a study to evaluate the efficacy of the culturally adapted OPDG with coaching with Aboriginal women, and with outcomes related to SDM. Such studies would further inform community-researcher partnerships in planning, testing, and further refining of the adapted OPDG with coaching as an SDM intervention.

The findings of this dissertation propose a research-based approach to the adaptation of a SDM intervention, resulting in the adapted OPDG with coaching and depicted in a proposed model (P-CAHI, Figure 5.1). This proposed research-based approach to intervention adaptation may be of relevance to other populations, and could support those populations in identifying and then addressing barriers to their members' participation in making health decisions. For example, this dissertation presents a research process in which the culturally adapted, lower health literacy version of the original OPDG was developed. This is important for the women of Minwaashin Lodge as it met their self-identified needs, and may be of relevance to other populations, such as other groups of First Nations, Métis or Inuit women. Health literacy has been identified as an issue for Aboriginal women (PHAC, 2014) and has been found to predict the level of engagement by clients in health care and enables their participation in making health care decisions (Hoffman-Goetz, Donelle, & Ahmed, 2014). In addition, the findings of one systematic review suggest that SDM interventions may more significantly improve health outcomes for clients with lower literacy

than for those with higher socioeconomic, education, and literacy status (Durand, Carpenter, Dolan, Bravo, Mann, Bunn, & Elwyn, 2014). In our study, there are indicators that the adapted OPDG with coaching may have potential to enhance the health care decision making experiences of Aboriginal women at Minwaashin Lodge, and studies are required to demonstrate the potential role of the adapted OPDG with coaching. Other populations may also benefit from the proposed approach to intervention adaptation described by the P-CAHI model, presented in this dissertation. The findings of this dissertation contribute to the emerging knowledge about the role and development of SDM within populations who experience barriers to their participation in health care, an as yet underexplored area.

This dissertation has described a process for SDM intervention adaptation that could also be used for another SDM intervention within the same population (e.g., the Aboriginal women of Minwaashin Lodge). For instance, a decision aid that has been developed and used with women of Euro-Canadian descent could be culturally adapted for use with members of the Minwaashin Lodge community, and undergo the process of adaptation described in this dissertation (Figure 5.1).

Conclusion

The findings presented in this dissertation add new knowledge to the SDM literature. The series of three studies in this dissertation were focused on adapting an SDM intervention to address Aboriginal women's decision making needs and makes three significant contributions. First, prior to the work presented in this dissertation, there is no evidence on interventions about SDM with Aboriginal women. Second, the decision making needs of Aboriginal women focused on and emphasized the need for relational approaches in SDM. Third, a culturally relevant intervention (adapted OPDG with decision coaching) may have potential to facilitate a process of SDM within a population of Aboriginal women.

The use of the PAR approach within the series of three studies in this dissertation facilitated an SDM intervention adaptation process that emphasized the importance of early and sustained engagement of advisory group participants, the need for structured and clearly articulated ethical guidelines and theoretical framework, and a process of research focused on meeting pragmatic knowledge needs of user (i.e., client) populations. The cultural adaptation process is proposed as a 5-step process titled “A Participatory Approach to Cultural Adaptation of Healthcare Interventions”. As well, the essential relational features of SDM interventions that includes the context of Aboriginal women’s health decision making was emphasized. The dissertation was focused on the use of SDM to meet decisional needs of Aboriginal women and may potentially contribute to addressing determinants of health that influence Aboriginal population health in Canada, and with implications for the areas of practice, education, and further research. The findings of this dissertation may contribute to fostering the participation of Aboriginal women with their health care providers in processes of decision making, and thereby make a contribution to the population health of Aboriginal communities.

Table 5.1 Implications for Practice, Education, and Research

Category	Implications
Practice	• Recognize the unique needs of Aboriginal populations in SDM. • Provide decision coaching in clinical practice to facilitate SDM with Aboriginal women.
Education	• Educate health care providers to use the adapted OPDG + coaching to prepare for SDM participation. • Ensure training focuses on relational core competencies in SDM and the influence of context for Aboriginal women (e.g., using the OPDG as a talking guide).
Research	• Evaluate 1) feasibility and 2) efficacy of adapted OPDG + decision coaching with Aboriginal women. • Evaluate the proposed intervention adaptation process (P-CAHI) with another culturally diverse population to facilitate SDM. • Validate the proposed intervention adaptation process with a different intervention.

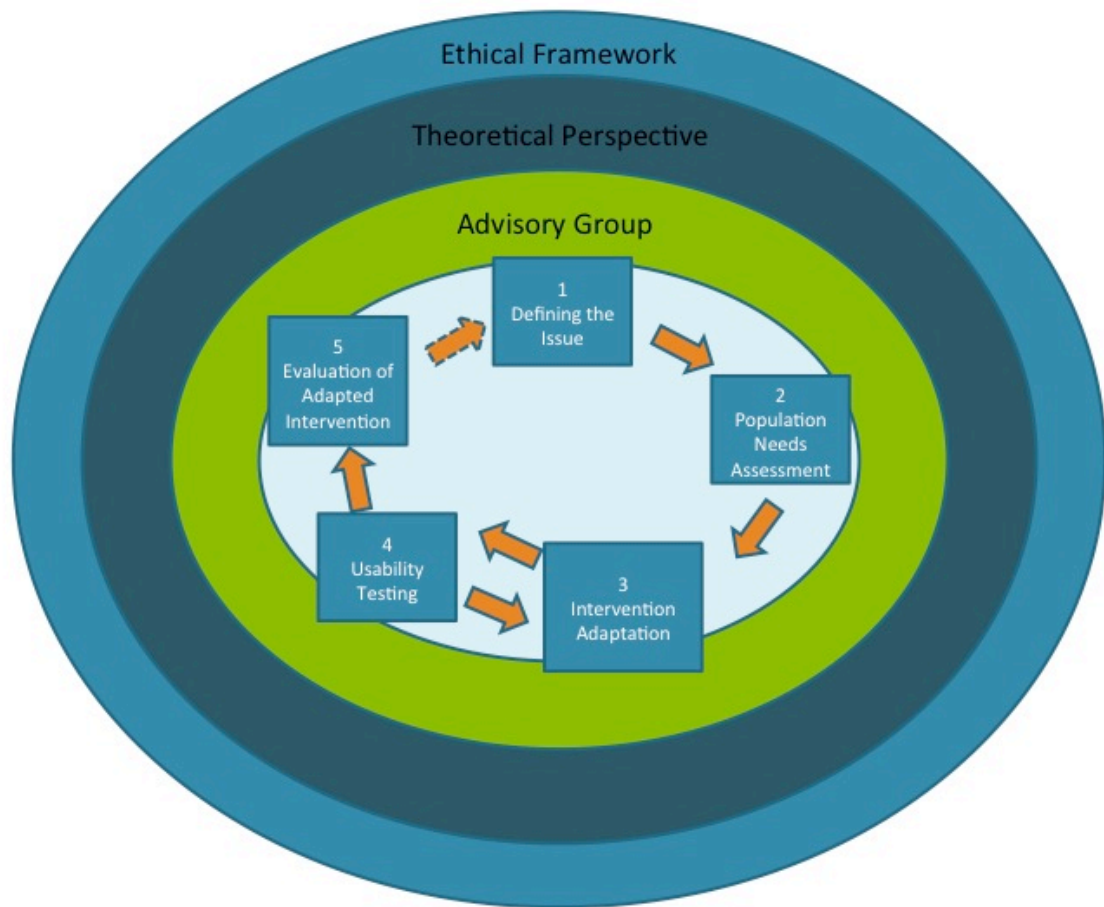


Figure 5.1

A Participatory Approach to Cultural Adaptation of Healthcare Interventions (P-CAHI)

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Chapter 6

Contributions of Collaborators

This section of the dissertation provides a statement of the contributions of collaborators and was written in accordance with the guidelines of the Faculty of Graduate and Postdoctoral Studies at the University of Ottawa (2012). Contributions are discussed as they relate to those who were involved as part of the research team as well as co-authors on the manuscripts.

Research Team Collaborators

Janet Jull OT, MSc(OT), PhD(c) (JJ) conceived of, participated in and led all aspects of the research study presented in this dissertation. This work was done as part of the fulfillment to meet the requirements for the degree of Doctorate in Philosophy at the University of Ottawa. Collaborators were selected in order to gain a transdisciplinary perspective on the development of new knowledge in the area of shared decision making, health and Aboriginal women. Transdisciplinarity is defined as an approach in which members from varying fields of knowledge collaborate in development of a shared conceptual framework and is founded upon shared disciplinary concepts, theories, and methods, all aimed at defining, addressing, and resolving complex real-world problems (Higginbotham, Albretch, & Connor, 2001; Rosenfield, 1992; Stokols, Hall, Taylor, & Moser, 2008). As such, a transdisciplinary approach is viewed as most likely to address issues in the area of population health (Institute of Population Health, 2013). As conflicting understandings of knowledge found between Western-generated understandings of health and Indigenous understandings have been identified within research settings (Durie, 2004), the inclusion of collaborators from multiple backgrounds including that of Aboriginal communities was viewed as critical for conducting the work presented in this dissertation.

JJ is an occupational therapist and has worked in community and institutional settings, including rural and remote areas of Canada, and with expertise in population health,

decision support, informed consent, client and care provider education, and healthcare and policy systems. In addition to completing doctoral studies in the Population Health Program at the Institute of Population Health, University of Ottawa, she also obtained a Graduate Diploma in Health Services and Policy Research at the University of Ottawa (2012). JJ received a two year Knowledge Translation Canada Strategic Training Initiative in Health Research award, a two year Knowledge Translation Canada Research Project Stipend, an Ontario Training Centre in Health Services and Policy Research bursary, and a four year admission scholarship from the University of Ottawa.

Thesis committee supervisor, Dawn Stacey, RN, PhD (DS) and committee members, Professors Yvonne Boyer, PhD, LLD (YB), Audrey Giles, PhD (AG), collaborated in the development of the proposal, provided consultation throughout the research process, and participated in the analysis and interpretation of findings, and contributed to the intellectual content of the drafted and final manuscripts. Outside of the thesis committee there were also additional collaborators, of which Minwaashin Lodge, the Aboriginal women's support centre (ML), was also a part. ML collaborated in the development of the proposal, provided consultation throughout the research process, participated in the analysis and interpretation of findings, and contributed to the intellectual content of the drafted and final manuscripts. Thesis committee members (YB, AG, and DS) with ML executive members were included on ethics (Appendix B), constituted the primary advisory group during the study with all members participating during the studies presented in Chapters 3 and 4 (see Table 6.1).

DS holds a Research Chair in Knowledge Translation to Patients and is Professor, School of Nursing at the University of Ottawa. She is a Scientist at the Ottawa Hospital Research Institute where she is Director of the Patient Decision Aids Research Group. She is the principal-investigator for the Cochrane Review of Patient Decision Aids, co-chair of the

Steering Committee for the International Patient Decision Aid Standards Collaboration (IPDAS), and co-investigator for the Cochrane Review of Interventions to Improve the Adoption of Shared Decision Making. Her research includes: knowledge translation to patients; patient decision aid development, evaluation and appraisal; decision coaching; implementation of decision aids and decision coaching into practice; telephone-based care, and interprofessional approaches to shared decision making.

YB is Métis from Saskatchewan who received her Doctorate in Law at the University of Ottawa in 2011, Master of Laws in 2003 and Juris Doctorate in 1997. She is a member of the Law Society of Saskatchewan and the Law Society of Upper Canada and specializes in Aboriginal health and the law. She has been a member of the board of Minwasshin Lodge since 2006 and has acted as the guardian of the Ownership, Control, Access and Possession requirements between the Lodge and this important work on shared decision-making. YB holds a Canada Research Chair in Aboriginal Health and Wellness at Brandon University.

AG is an Associate Professor in the School of Human Kinetics at the University of Ottawa. She is an applied cultural anthropologist who conducts qualitative research with Aboriginal communities in the Canadian Arctic and Sub-Arctic. Her research focuses on the intersections of culture, gender, physical activity, injury prevention, and health promotion.

ML is a residential and community service organization in Ottawa, Canada. ML is an organization dedicated to providing intervention services and programs to First Nations, Métis and Inuit women, children and youth who are survivors of family violence and/or the residential school system, including the inter-generational impacts of violence against Aboriginal Peoples in Canada.

Additionally, for Chapter 2, for which University of Ottawa Research Ethics Board approval was not required, there were collaborators both within (YB, DS) and external to the

thesis committee: James Crispo, MSc, PhD(c) (JC), Vivian Welch, PhD, (VW), Simon Brascoupé, MA, (SB), Heather MacDonald, MLIS (HM). These collaborators formed the advisory group for the study of Chapter 2 and participated in the development of the proposal, provided consultation throughout the research process, participated in the analysis and interpretation of findings, and contributed to the intellectual content of the drafted and final manuscripts (see Table 6.1, Chapter 2).

JC Born is of Métis ancestry, completed his Honours BSc Biochemistry and MSc Chemical Sciences at Laurentian University/Northern Ontario School of Medicine (Sudbury, ON) before beginning his PhD in Population Health at the University of Ottawa. His current doctoral research focuses on pharmaceutical use and safety, specifically on cardiovascular risks associated with the use of antiparkinson agents. Additionally, JC is interested in leveraging administrative health databases to better understand and mitigate population health risks.

VW is a scientist at the Bruyere Research Institute, University of Ottawa. Her research interests include methods to consider health equity in systematic reviews, clinical guidelines and primary research. She is also interested in knowledge translation tools such as decision aids and policy briefs. VW is a co-convenor to the Campbell and Cochrane Equity methods Group, a member of the international Grading Recommendations Assessment, Development and Evaluation (GRADE working group), and a member of the International Clinical Epidemiology Network (INCLEN). As part of her work on methods for considering health equity, VW led the development of a reporting guideline for equity-focused systematic reviews, as an extension to the PRISMA statement (Preferred Reporting items for Systematic reviews and Meta-Analyses).

HM has worked in academic libraries and with various research groups in the areas of

knowledge synthesis and knowledge translation. She currently works with the Knowledge Translation group at the Li Ka Shing Knowledge Institute in Toronto.

SB, Anishinabeg/Haudenosaunee – Bear Clan is a member of Kitigan Zibi Anishinabeg First Nation, Maniwaki, Quebec. SB is Adjunct Research Professor at Carleton University Adjunct Professor in the Department of Indigenous Studies at Trent University in Peterborough, Ontario. He was recently awarded a Certified Aboriginal Professional Administrator (CAPA) from the Aboriginal Financial Officers Association of Canada (AFOA). He has a B.A. and M.A. from State University of New York at Buffalo, where he is also completing his Ph.D. He has a research interest in land based healing, traditional medicine and traditional knowledge, and conducts research and writes on cultural competency and safety. SB teaches Indigenous Studies at Carleton University. Previously, SB was Chief Executive Officer, National Aboriginal Health Organization; Director, Primary Health Care Division, First Nations and Inuit Health Branch, Health Canada; and Director, Aboriginal Affairs Branch, Environment Canada. He has written and worked in the field of traditional knowledge and intellectual Property Rights and is on Trent University's Ph.D. Indigenous Knowledge Council.

Additional support was provided by Anton Saarimaki, the database, website and technical administrator and analyst for the Patient Decision Aids Research Group. He set up and managed an on-line data management system to facilitate an independent on-line screening of studies by two reviewers during the Chapter 2 study.

Table 6.1 Summary of Author Contributions

	Chapter 1 Introduction	Chapter 2 Systematic Review	Chapter 3 Needs Assessment	Chapter 4 Cultural Adaptation	Chapter 5 Integrated Discussion
Envisage and design	JJ	JJ, DS, HM, SB	JJ, YB, AG, DS, ML	JJ, YB, AG, DS, ML	JJ
Collect data	JJ	JJ, HM, JC	JJ, ML	JJ	JJ
Analyze and interpret data	JJ	JJ, DS, JC	JJ, AG, DS, ML	JJ, AG, DS, ML	JJ
Draft manuscript	JJ	JJ	JJ	JJ	JJ
Revise manuscript for important intellectual content	JJ, YB, AG, DL	JJ, YB, DS, JC, VW, SB, HM	JJ, YB, AG, DS, ML	JJ, YB, AG, DS, ML	JJ
Approve final version to be published	JJ, YB, AG, DL	JJ, YB, DS, JC, VW, SB, HM	JJ, YB, AG, DS, ML	JJ, YB, AG, DS, ML	JJ, DS
Responsible for overall content	JJ	JJ	JJ	JJ	JJ

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Appendix A – Memorandum of Understanding

Principles of Research Collaboration

Between
Minwaashin Lodge [represented by [REDACTED], [REDACTED], [REDACTED]] And
[REDACTED] [and thesis committee: [REDACTED], [REDACTED], [REDACTED]]
Parties

This document constitutes a Principles for Research Collaboration (PRC) between **Janet Jull** and **Minwaashin Lodge**, a nongovernmental organization dedicated to providing, intervention services and programs to Metis, First Nations, and Inuit women, children and youth who are survivors of family violence and/or the residential school system, including the inter-generational impacts of violence against Aboriginal Peoples in Canada.

Minwaashin Lodge representatives will participate as a member of the research team under the terms identified below through **the University of Ottawa Research Ethics Board**.

The above listed Parties constitute the research team.

Purpose

The purpose of this PRC is to establish a set of principles that guide the conduct of the research project, **Shared Decision-Making and Health for First Nations, Metis and Inuit Women**. In short, this agreement acknowledges the importance of incorporating OCAP (Ownership Control Access and Possession), Aboriginal cultural values and perspectives into the research process.

Records

The Principal Investigator (PI or project coordinator), Janet Jull, will coordinate all administrative matters relating to the above named research project. The PI will provide each member of the research team with notes of meetings, including decisions made, within a reasonable time frame (i.e., 2 weeks).

Ethical Considerations

Ethical codes of conduct for research in Aboriginal communities have been articulated in the *Tri-Council Policy Statement* and OCAP principles. However, each member of the research team collectively shares the responsibility for raising ethical concerns and issues. Ethical dilemmas will be resolved on the basis of the research team striving for consensus.

Duration and Amendments

This PRC will be in effect throughout the entire research process, from the development of research questions through data collection and analysis phases into dissemination of findings. This PRC can be amended upon mutual consent by the research team.

Principles: Ownership, Control, Access and Possession

The research team acknowledges and supports the principles of ownership, control, access and possession as outlined below:

- Members of the research team acknowledge and respect the Aboriginal right to self determination, Including the jurisdiction to decide about research in their communities. In doing so, the research process shall be built upon meaningful engagement and reciprocity between the research team and Minwaashin Lodge (the Aboriginal community). Further, the research team members agree they will strive to respect the privacy, dignity, culture and rights of Aboriginal peoples.
- The research team will strive to include meaningful and equal participation from Aboriginal community members; therefore, the parties agree they will be jointly and equally involved

Appendix A – Memorandum of Understanding

from beginning to end in the research process, from research question formulation, through data collection, analysis and into dissemination of research findings related to the above named project.

- The research team members agree that they will collectively make decisions on research questions, in data collection, interpreting results, in drafting research reports and in dissemination of findings. In other words, the PI will not present a completed research design for approval, but rather will involve all other members of the research team in the process.
- The research questions must not only reflect academic interests, but must also be relevant and beneficial to Aboriginal women and communities.
- In dissemination strategies to Aboriginal women and communities, the research team agrees that the language and manner of sharing research will be appropriate, as defined by Minwaashin Lodge representatives.
- The parties agree to review findings in a timely manner (e.g. two weeks).
- Given that all members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation, any one member of the research team may not, particularly once initial dissemination has occurred, further analyze, publish or present findings resulting from the above mentioned research project unless the entire research team reaches a consensus.
- The PI is responsible for maintaining the integrity of all data collected, such as storing participant consent forms, etc. Once the datum has been anonymized, however, transcripts may be shared with all members of the research team. In cases of disagreement over transfer of datum (as described above), the research team will strive to achieve consensus.
- The research team agrees to provide meaningful and appropriate opportunities for research capacity-building, as indicated by Aboriginal community participants. For instance, by hiring research assistants recommended by Minwaashin Lodge representatives, presenting results to stakeholders/members as requested by Minwaashin Lodge.
- The research team agrees that it may be necessary for Aboriginal community members (investigators and participants) to seek advice and support from community Elders and other community leadership and will support this.

Authorship

Criteria outlined by Huth (1986) will be used as guidelines for authorship of publication based on the findings of the research. The criteria recommend that: (1) all authors must make a substantial contribution to the conception, design, analysis, or interpretation of data; (2) authors must be involved in writing and revising the manuscript for intellectual content; and (3) authors must approve the final draft and be able to defend the published work. Those who have made other contributions to the work (e.g. data collection without interpretation, etc.) or only parts of the above criteria should be credited in the acknowledgements, but not receive authorship.

Further,

- Research project staff may participate as authors provided that they fulfill the criteria outlined above.
- All members of the research team will be provided the opportunity to review and comment on findings prior to publication or presentation. Any one member of the research may further analyze, publish or present findings resulting from the above-mentioned research

Appendix A – Memorandum of Understanding

project with the agreement of the Principal Investigator and the other research team members.

- The explicit permission of an individual or organization must be sought prior to acknowledging their contribution in a paper or presentation.
- A research team member or a partner may chose to include a disclaimer if she does not agree with the content or views presented in a publication.

IN WITNESS WHEREOF, the parties hereto have executed this agreement.

(Date) _____ (Signature) _____
[Redacted Signature]

(Date) _____ (Signature) _____
[Redacted Signature]

(Date) _____ (Signature) _____
[Redacted Signature]

(Date) _____ (Signature) _____
[Redacted Signature]

(Date) _____ (Signature) _____
[Redacted Signature]

(Date) _____ (Signature) _____
[Redacted Signature]

(Date) _____ (Signature) _____
[Redacted Signature]

We gratefully acknowledge The Canadian Aboriginal Aids Network for allowing adaptation of their original document for our use.

Appendix B – Certificate of Ethics Approval

File Number: H05-12-05

Date (mm/dd/yyyy): 02/22/2013



Université d'Ottawa **University of Ottawa**
Bureau d'éthique et d'intégrité de la recherche Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement and other applicable laws and regulations in Ontario, has examined and approved the application for ethical approval for the above named research project as of the Ethics Approval Date indicated for the period above and subject to the conditions listed the section above entitled "Special Conditions / Comments".

During the course of the study the protocol may not be modified without prior written approval from the REB except when necessary to remove subjects from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the study (e.g. change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, information/consent documentation, and/or recruitment documentation, should be submitted to this office for approval using the "Modification to research project" form available at:

<http://www.research.uottawa.ca/ethics/forms.html>.

Please submit an annual status report to the Protocol Officer four weeks before the above-referenced expiry date to either close the file or request a renewal of ethics approval. This document can be found at:

<http://www.research.uottawa.ca/ethics/forms.html>.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Kim Thompson
Protocol Officer for Ethics in Research
For Daniel Lagarec, Chair of the Sciences and Health Sciences REB



ABORIGINAL WOMEN'S SUPPORT CENTRE
MINWAASHIN LODGE

424 Catherine Street, 2nd Floor • Ottawa, Ontario K1R 5T8
Tel: (613) 741-5590 • Fax: (613) 748-8311
www.minlodge.com

April 23, 2012

To Whom It May Concern:

Minwaashin Lodge authorizes Janet Jull to conduct a research project, titled "Urban Aboriginal Women, Shared Decision Making, and Health".

The project will explore Aboriginal women's health decision making needs and engage research participants in culturally adapting an approach to shared decision making. The anticipated outcome of this project will be the development of a tool, in collaboration with Aboriginal women, that can facilitate processes of respectful and effective care to support them in making meaningful decisions about health.

As the community partner for this project, Minwaashin Lodge has made significant contributions in the development of the project proposal. As well, Minwaashin Lodge plans to participate with Ms. Jull throughout the research process.

For further information, you may contact me at 613-741-5590 ext. 222 or ctroy@minlodge.com.

Sincerely

Castille Troy
Executive Director

Appendix D – Study Protocol

Shared decision-making and health for First nations, Métis and Inuit women: a study protocol

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* Corresponding author

Dawn Stacey²

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Abstract

Background

Little is known about shared decision-making (SDM) with Métis, First Nations and Inuit women (“Aboriginal women”). SDM is a collaborative process that engages health care professional(s) and the client in making health decisions and is fundamental for informed consent and patient-centred care. The objective of this study is to explore Aboriginal women's health and social decision-making needs and to engage Aboriginal women in culturally adapting an SDM approach.

Methods

Using participatory research principles and guided by a postcolonial theoretical lens, the proposed mixed methods research will involve three phases. Phase I is an international systematic review of the effectiveness of interventions for Aboriginal peoples' health decision-making. Developed in consultation with key stakeholders, proposed methods are guided by the Cochrane handbook and include a comprehensive search, screening by two independent researchers, and synthesis of findings. Phases II and III will be conducted in collaboration with Minwaashin Lodge and engage an urban Aboriginal community of women in an interpretive descriptive qualitative study. In Phase II, 10 to 13 Aboriginal women will be interviewed to explore their health/social decision-making experiences. The interview guide is based on the Ottawa Decision Support Framework and previous decisional needs assessments, and as appropriate may be adapted to findings from the systematic review. Digitally-recorded interviews will be transcribed verbatim and analyzed inductively to identify participant decision-making approaches and needs when making health/social decisions. In Phase III, there will be cultural adaptation of an SDM facilitation tool, the Ottawa

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Personal Decision Guide, by two focus groups consisting of five to seven Aboriginal women. The culturally adapted guide will undergo usability testing through individual interviews with five to six women who are about to make a health/social decision. Focus groups and individual interviews will be digitally-recorded, transcribed verbatim, and analyzed inductively to identify the adaptation required and usability of the adapted decision guide.

Conclusions

Findings from this research will produce a culturally sensitive intervention to facilitate SDM within a population of urban Aboriginal women, which can subsequently be evaluated to determine impacts on narrowing health/social decision-making inequities.

Keywords

First nations, Inuit and Métis women, Shared decision-making, Equity, Health equity, Participatory research principles, Cultural adaption

Background

Shared decision-making (SDM) is a central feature of patient-centred care [1,2]. SDM approaches have been found to improve clinical decision-making processes and increase health care client satisfaction [3,4]. Client preferences are inadequately addressed in physician – client communication; however, client values and needs for health information can be met through the use of SDM approaches [4].

SDM is enacted through health care delivery approaches and tools, and defined as a process that promotes collaboration between healthcare providers and recipients in decisions affecting health [5,6]. As well as structuring a collaborative, client-centred approach between practitioner and client, SDM promotes the sharing and use of information on the benefits and harms of care options in the form of patient decision aids, which assist the client in making preference sensitive decisions [7]. Patient decision aids complement practitioner counselling; they have been found to increase people's involvement in making more informed and values-based care decisions [7]. SDM approaches and tools are currently being developed and implemented in international settings and are evolving as standards of care [1,2].

While SDM approaches and tools have been found to be effective in supporting clients to make informed decisions about health, evaluation of these approaches with Aboriginal peoples^a has not occurred. In comparison to those living in Canada who are of Euro-Canadian descent, Inuit, Métis, and First Nations peoples experience relatively poor health [8,9], and are recognized as experiencing significant health inequities [10,11]. The health of First Nations, Métis, and Inuit peoples in Canada has been defined as poor, with shorter life expectancies, and higher rates of illness, injury, and suicide when compared to non-Aboriginal Canadians [12,13]. Moreover, Aboriginal women as a population have been identified as being in a far worse predicament. For example, while Inuit, Métis and First Nations populations are very diverse, there are general trends indicating that these groups experience significantly higher rates of chronic disease such as diabetes. Overall, Aboriginal women are more likely than those in the general population [14,15] or Aboriginal men [15], to be diagnosed with diabetes. Further, violence against women is also a significant issue within Canada, and violence against Aboriginal women has been documented as of particular concern [16]. Women in Métis, Inuit, and First Nations communities play important roles as caregivers,

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community leaders, and keepers of community knowledge; therefore, poor health of Aboriginal women is a significant issue for Aboriginal populations [17]. Aboriginal peoples, and in particular Aboriginal women, must have care that meets their needs – in effect, care that is client-centred.

Meanings of health are unique to individuals and populations, and a consensus on the meaning of the term ‘health’ does not exist [18]; it is therefore important to understand that the perception of decision-making needs for health varies between populations. Decision-making in health settings for Aboriginal peoples requires attention to cultural beliefs not yet evident within Western health and social care frameworks [19]. Little is known regarding the processes or outcomes for Aboriginal women using SDM approaches in care settings or the cultural relevance of SDM approaches or tools such as patient decision aids for Aboriginal populations.

Objective and research questions

The overarching objective proposed for this study is to explore health and social decision-making needs of Aboriginal women and to engage them in culturally adapting an SDM approach. The study will involve three phases, each focused on one of the following research questions:

1. What are effective interventions to support Aboriginal peoples making health decisions?
2. What are the experiences of Aboriginal women in making health or social decisions?
3. What is the usability of a culturally adapted Ottawa Personal Decision Guide for Aboriginal women?

Methods

A three phase mixed methods project was designed with the collaboration of Minwaashin Lodge (“the research partner”), located in Ottawa, Canada, and incorporates a postcolonial theoretical framework and principles of participatory research. Minwaashin Lodge is an organization dedicated to providing intervention services and programs to Métis, First Nations, and Inuit women, children and youth who are survivors of family violence and/or the residential school system, including the inter-generational impacts of violence against Aboriginal peoples in Canada.

A postcolonial perspective provides a theoretical lens to show everyday experiences of marginalization of First Nations, Inuit and Métis people that occur in day-to-day relationships and in the systems structuring human relations [20], such as the health care setting [20,21]. Postcolonial theory is particularly relevant for the proposed study, which places Aboriginal peoples as central to a process of change with non-Aboriginal partners [22]. The principal investigator for this study is of Euro-Canadian descent and has collaborated with the research partner using principles of participatory action research to produce this study protocol. The principles of participatory action research (PAR) are emerging in the literature as an appropriate approach for engaging in Aboriginal research partnerships [23], and have been demonstrated as particularly successful in broader, interdisciplinary health promotion initiatives within Aboriginal populations [24], including multilevel interventions [25]. The University of Ottawa Research Ethics Board granted ethics approval for this study in July 2012 (#H05-12-05).

This protocol describes a research study design consisting of three complementary phases. Each phase sequentially informs the next.

Phase I

Systematic review of Aboriginal peoples and health decision-making

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Research Question 1

What are effective interventions to support Aboriginal peoples making health decisions?

Background

Most literature exploring concepts relating to SDM, health decisions, and Aboriginal peoples, (internationally referred to as Indigenous peoples^b), concentrates on describing health decision-making [26-28], health equity issues and the role of Indigenous peoples within cancer care [29-31] or advanced care planning [32-34]. Studies have suggested that patient decision aids can improve decision quality and empower immigrant women to make informed decisions based on personal values [35] or have narrowed the gap between racially distinct groups through engaging clients in a process to make decisions about healthcare services [36]. While interventions that incorporate concepts of SDM have been shown as effective for translating research to inform preference sensitive health decisions [4,7], little is known about interventions to support SDM with Aboriginal peoples.

Method/design

A systematic review guided by the Cochrane Handbook [37], and structured to meet the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [38] criteria was developed. To assist in the development and implementation of the review, a reference group was formed of recognized experts in the area of Aboriginal health issues, information services, decision-making tools and approaches, knowledge translation, systematic review methodology, collaborative research approaches with Aboriginal/Indigenous peoples, quantitative and qualitative methodologies, and library sciences.

Study inclusion/exclusion criteria were framed in a systematic manner, using the elements of a clinical question and include population, intervention, comparator, and outcome (PICO) [39] (Table 1.). All studies evaluating interventions for SDM in health decisions with Aboriginal populations will be included: randomized control trials, cross-over, cohort, case controlled studies, and cross-sectional survey.

Search strategy

The search strategy protocol was developed collaboratively with an academic reference librarian, after consultation with subject experts on health, decision-making and Aboriginal peoples'. The search will focus on all major databases relevant to the subject matter: MEDLINE, EMBASE, PsychInfo, CINAHL, Proquest Nursing and Allied Health, ERIC, and Cochrane, and will include all years for the database, i.e., from the earliest data sources on each database, e.g., 1947 or earlier, and up to 2012. To supplement the database search, a planned hand search of grey literature for articles on PubMed and checking of reference lists of identified articles for relevant studies will be conducted [41]. As well, a planned hand search of journals found to be associated with the subject of the search will be conducted [37] from one year prior to the review end date.

Screening of studies

Following the identification of studies, duplicates will be removed and three levels of screening will be conducted by two independent reviewers, using standardized forms. Level one screening will be a title screen to determine study relevance to the overall objective of the systematic review. All studies identified as “included” and “unsure” will be retained for the level two screening; only studies excluded by both reviewers will be excluded. Level two screening will be a title and abstract screen based on the inclusion/exclusion criteria (PICO). All titles and abstracts identified as “included” or “unsure” by either reviewer will be retained for the level three full text screening; those that are identified by both reviewers as “excluded” will be excluded from further screening. Following level three screening, any disputes between reviewers will be resolved, including those articles identified as “unsure” and resulting in a final group of studies identified by both reviewers as meeting the inclusion criteria. If required, a third person will be available to assist with arbitration. During level two and three screening, rationale for exclusion will be documented.

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Data collection

All included studies will have their data extracted using a standardized form, which will be pilot tested prior to commencing data extraction. During the data extraction process, a second reviewer will verify the accuracy of extracted data. Data will include authors, setting, characteristics of the intervention, study design, characteristics of the participants, and findings relevant to outcomes for this review.

Study quality

Two independent reviewers will assess the quality of included studies using the appropriate critical appraisal skills programme (CASP) checklist [42]. If randomized control trials are found, the Cochrane Collaboration Risk of Bias Tool will be used in quality appraisal to examine internal validity [37].

Analysis

Characteristics of included studies will be analyzed descriptively. A decision to conduct meta-analysis versus a qualitative synthesis of findings will be determined once data are extracted and the heterogeneity between studies can be assessed. Should it be possible to combine the data between studies to determine an overall statistic on the effectiveness of the intervention on the experimental versus control groups, meta-analysis will be used (i.e., studies demonstrate that similar outcomes were used with similar interventions). A descriptive analysis of data findings will situate study findings within historical and social colonial society [22].

Bias

To minimize risk of bias [43] and to ensure that Assessment of Multiple Systematic Reviews (AMSTAR) criteria for methodological quality are met [44], the protocol for the systematic review was established a priori, and plans made for two researchers to screen identified literature, participate in data extraction, and to quality appraise included studies.

Phase II

Decision-making experiences of Aboriginal women.

Research question 2

What are the experiences of Aboriginal women when making health or social decisions?

Specific research questions include: 1) What are the health/social decision-making needs of urban Aboriginal women?; 2) What are the barriers to involving urban Aboriginal women in their health/social decision-making?; 3) What are potential supports to enhance the health/social decision-making experiences of urban Aboriginal women?.

Methods

An interpretive descriptive qualitative study will be conducted in collaboration with Minwaashin Lodge and with the clients of Minwaashin Lodge (urban dwelling Aboriginal women). As a qualitative approach effective for describing health care events, interpretive description is an inductive analytic approach [45]. For this study the events of interest will be Aboriginal women's recent experiences in making decisions affecting their health, or the health of someone they care for. The Ottawa Decision Support Framework (ODSF) has informed the study design.

The ODSF is a framework developed to guide people through health and social decisions and involves three key elements: decisional needs, decision support, and decision quality [46]. It is used to describe the

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hypothesis/assumption that unresolved decisional needs may negatively influence decision quality, and that decision support is aimed at addressing decisional needs. The ODSF can be used to structure the assessment of decisional needs within a range of populations [3] and is suitable for use within this study. The needs assessment interview guide is based on the ODSF and informed by published studies on other populations' decision-making needs [3,46]. Most importantly, this guide was developed to incorporate information conveyed by members of the research partner, Minwaashin Lodge, who indicated that Aboriginal women prefer opportunities to tell their stories, rather than respond to a highly structured process of questioning.

Participants and procedures

Participants will be female clients of Minwaashin Lodge, living in Ottawa and of Inuit, First Nations, or Métis descent, and identified as having recently (i.e., within the past 6 months) been a part of a health/social decision for herself or a family member. They will be asked to participate in an interview conducted in English. Women will be purposefully invited to participate in the study and are anticipated to represent a variety of ages (younger, middle aged, older) and family form (single, with/without children). Recruitment will continue until data saturation plus an additional three participants, to ensure that no new themes are identified. We anticipate reaching saturation with 10 participants, and therefore recruiting a total of 13 women [47].

Individual interviews were selected to support dialogue with the women about their experiences of how decisions affecting health are made with a professional. The women will be invited and informed about joining the study in accordance to Lodge protocol by Minwaashin Lodge representatives and with recruitment posters. After reviewing and signing the consent form with the researcher, participants will be interviewed for 60 to 90 minutes using semi-structured interviews, including a request for non-identifying demographic information. Any questions that the participant does not feel comfortable answering will be omitted. The interviews conducted with the women will be digitally-recorded, transcribed verbatim, and field notes from the researcher will be included as part of the gathered data.

Analysis

Demographic data will be entered into Excel database and analyzed descriptively by the researcher. NVivo software [48] will be used during the process to assist with organization of data during analysis. Transcribed interviews will be analyzed using the interpretive descriptive method [45]. The process of qualitative data analysis will use the three step method of data reduction, data display, and drawing conclusions/verification [49]. The data findings, guided by the three research questions, will be organized and evaluated using the postcolonial theoretical lens described by Battiste [22] to contextualize the data, and final findings developed with the Minwaashin Lodge advisory group. This approach to data analysis will support and increase the likelihood that meaningful health decision-making needs, barriers and supports are identified.

Findings from phase II will be used to inform phase III.

Phase III

Adaptation and usability testing of a culturally relevant patient decision support tool.

Research question 3

What is the usability of a culturally adapted Ottawa Personal Decision Guide for Aboriginal women ?

Design

Cultural adaptation of the Ottawa Personal Decision Guide (OPDG) will be conducted through a collaborative and iterative process between the researcher, Minwaashin Lodge, and Aboriginal women, and then followed by usability

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testing. The overarching aim of the OPDG adaptation process is to develop a tool defined by women as useful, and to support the fidelity of the culturally adapted OPDG [50].

Intervention for adaptation

The OPDG is a tool that has been validated for use in making any health-related or social decisions [51]. It can be used to help people assess their decision making needs, summarize their current knowledge (of options, benefits, and harms), clarify their values associated with option outcomes, plan the next steps, and track their progress in decision making. Although the OPDG has been used in a variety of care contexts and countries outside of Canada (e.g., Japan and U.S.) [52,53] the OPDG has not yet been evaluated for use within Aboriginal populations.

Participants – focus groups

Clients of Minwaashin Lodge that live in Ottawa, are of Aboriginal descent, and are able to participate in an English language interview will be purposefully selected by the research partner to participate in focus groups adapting the OPDG. Participants will be women representative of a range of ages and family form and will also be identified as having made a health/social decision in the past six months for themselves or a family member. In studies using focus groups to explore health issues, five to eight participants have been identified as ideal [54,55], and fewer participants identified as more effective for discussion of sensitive subjects [56]. For this reason, five to seven women will be recruited for participation in the OPDG adaptation focus groups.

Participants – usability testing

Participants for usability testing will be recruited separately from the focus group cohort, and will be clients of Minwaashin Lodge, living in Ottawa, of Aboriginal descent, and able to participate in an interview in English. The women will participate individually in an iterative process of testing the decision aid adapted by the focus group. As 80% of usability problems have been found within four to five participants [57], five to six participants will be recruited for establishing and refining data during usability testing with decision tools [58].

Procedures - focus group

The focus groups will be facilitated by the researcher and a research assistant. They are anticipated to take up to three hours each. Following informed consent by participants, non-identifying demographic information will be collected. Participants will then be guided as a group by the researcher through the use of the OPDG with an example decision. The group will be asked to provide general feedback on the tool (e.g., readability, organization). Then, the tool will be reviewed step by step to discuss specific adaptations to language and/or flow of ideas, and to document a rationale for changes. The focus groups will be digitally recorded and transcribed verbatim, and field notes from the researcher and research assistant will be included as part of the gathered data.

Procedure – usability testing

The usability testing will be conducted during a 60 to 90 minute role play in which the OPDG is used to prepare the participant for making a preference sensitive health/social decision. Following informed consent and collection of non-identifying demographic information, the participant will be instructed in the “think-aloud” technique for use during the role play. In the think-aloud technique, participants are instructed to say their thoughts out loud while performing a task, and the interview is digitally-taped then transcribed [59]. The aim of the think aloud technique is to gain an understanding of the women’s views and experiences using the adapted OPDG. During the initial interviews, the think-aloud technique will provide baseline measures for user satisfaction and performance, such as ease of readability and comprehension [58]. Information on the functionality of the design will be conveyed in later interviews [58], and contribute information on the usefulness of the OPDG for assisting women in making health/social decisions.

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The women will be asked to bring a decision that needs to be made OR provided with a health/social decision identified by Minwaashin Lodge as commonly experienced by clients. The think-aloud methods will be used while the participant uses the adapted OPDG (concurrent), and immediately after using the adapted OPDG (retrospective) while reflecting on the process of using the OPDG. Previous studies have found that using concurrent and retrospective think-aloud methods produce similar results with different perspectives (e.g., usability issues are more verbalized with retrospective methods and more observed with concurrent methods) [60]. The researcher will use a guide with prompts during usability testing. The role-play interviews will be digitally-recorded, transcribed verbatim, and field notes from the researcher included as part of the gathered data.

Analysis

For the focus group analysis, data will be transcribed by the researcher and NVivo software [48] used to assist with organization of data during thematic analysis. Data will be thematically organized to map the adaptation process; additionally, summaries of decisions made about the OPDG adaptation will be developed and analyzed for criteria indicating equivalence between the original and end product [50]. The findings will be reviewed with the Minwaashin Lodge advisory group and any additional information from the review will be incorporated into the adapted OPDG.

For the usability testing analysis, the data from the first two to three women users will iteratively inform further development of the OPDG, meaning that the taped and transcribed data from these initial interviews will be analyzed to provide baseline data and used to reveal major flaws in the OPDG. These findings will be brought back to the Minwaashin Lodge advisory group; based on the outcomes of the findings from the initial interviews any decisions to make changes to the OPDG will be made in collaboration with Minwaashin Lodge. The next two to three users will then use think-aloud methods with the iteratively adapted OPDG. Their sessions will also be taped, transcribed and analyzed to inform further changes to the OPDG. Again, findings will be reviewed by the Minwaashin Lodge advisory group and primary investigator, and, if necessary, changes made to the OPDG.

For focus group adaptations and usability testing, demographic data will be entered into an Excel database and analyzed descriptively. Nvivo software [48] will be used to assist with organization of data during thematic analysis, and data analyzed using the interpretive descriptive method [45]. The process of qualitative data analysis will include a three step process [49] described in section 2.2.4 of this protocol, and contextualized using the postcolonial theoretical lens provided by Battiste [22]. Final findings will be reviewed in collaboration with the Minwaashin Lodge advisory group and/or a town hall meeting, and conclusions developed on the feasibility of Aboriginal women using the OPDG within care settings.

Strengths and limitations

Common limitations in the use of interpretive descriptive methods include: the belief that it is possible to fully comprehend the experience of research participants; seeking to confirm conclusions too early in the analytic process; failing to move beyond merely describing phenomenon within the study; and the researcher attributing significance to something that is not significant to the participants [45]. Despite these potential limitations, during the phase II study, the interpretive descriptive approach creates an opportunity to generate links within the data about women's experiences, and thereby facilitate new understandings of urban Aboriginal women's experiences with health decision-making. The phase III study will lead to understandings about how the OPDG may be used by urban Aboriginal women in making decisions that affect health. Additional strengths of the phase III study include maintaining the principles underlying the OPDG and therefore the fidelity of the culturally adapted tool [50]. As well, the study design incorporates the socio-cultural context of the potential OPDG users into the process of adaptation and usability testing, an important feature identified in cross-cultural questionnaires [61].

For both the phase II and III studies, the primary investigator will use strategies to facilitate the evaluation of data synthesis and credibility processes and demonstrating an awareness of how the study findings may potentially be transferred, including: rich, thick description, journal keeping, member checking, an audit trail, identification of clear outcomes, contextualization of study findings.

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Ethics

This research protocol has been designed to support a research agenda respectful of the diverse needs of a population of urban Inuit, First Nations and Métis women. Within Aboriginal contexts, research ethics reflect views on ethical conduct as an integral part of a life which is interdependent with all living and material things. The Tri-Council Policy Statement (TCPS)[62] and Ownership, Control, Access and Possession (OCAP)[63] strive to reflect the unique ethical issues involving research with Aboriginal peoples, and were used in the development of this protocol.

OCAP principles identify and implement the inherent right of self-determination by Aboriginal communities within research studies, and are applicable to all stages of the research process. The principles of OCAP have been acknowledged and supported throughout the development of this protocol (Table 2). The research process has been built upon meaningful engagement and reciprocity between the principal investigator and her thesis committee, and Minwaashin Lodge, and is demonstrated in a letter of support from Minwaashin Lodge for the research process. Participatory research principals and postcolonial theory also contribute to support the principles expressed in OCAP.

Additionally, the primary researcher was invited by Minwaashin Lodge to participate in Minwaashin's Culture program and oriented to the Oshki Kizis shelter for women and children to gain a deeper understanding and knowledge of the people providing and seeking services at Minwaashin Lodge. Prior to initiating the research study, the primary researcher attended the Annual General Meetings and weekly culture events, as well as special educational initiatives, and including meals at Minwaashin Lodge. These opportunities allowed the primary researcher to meet with clients, Board members, program leaders, and other volunteers, and to become acquainted with the research partner. An on-going process of relationship building between the primary investigator and Minwaashin Lodge has resulted in the development of a protocol designed to be inclusive, meaningful, and respectful and in compliance with OCAP principles.

Discussion

There are few studies of interventions influencing the health status of Aboriginal populations [65]. This protocol outlines a strategy for urban Aboriginal women to develop a resource that can influence their participation within health and social systems. The study will make four significant contributions: 1) it will synthesize studies describing effective interventions to support Aboriginal people making health decisions; 2) explore and describe the health/social decision-making needs of a group of urban Aboriginal women and; 3) create a culturally relevant tool to facilitate SDM for urban Aboriginal women in health/social care settings; 4) evaluate the feasibility of an intervention (the OPDG) designed to narrow the health equity gap experienced by Aboriginal women. Moreover, the study has been designed with a focus on an integrated knowledge translation and dissemination strategy.

This protocol is the result of research partner and researcher collaboration. It was developed to meet the needs of the knowledge users to and engage the research partner and other key stakeholders throughout the research process. It can therefore be considered an integrated knowledge translation (KT) project [66]. Integrated KT describes an iterative cycle of knowledge acquisition and implementation; the results of this study will inform further development of decision tools and approaches to facilitate Aboriginal women in identifying and achieving goals they identify for SDM within health and health related settings. In conclusion, this protocol describes a study supporting development of community-research partnerships, and development of tools with the potential for promoting equity for Métis, First Nations and Inuit women in Canadian care settings.

Endnotes

^a "Aboriginal Peoples" is a collective name for all of the original peoples of Canada and their descendants. Section 35 of the Constitution Act of 1982 specifies that the Aboriginal Peoples in Canada consist of three groups – First Nations, Inuit and Métis. It is not used to describe only one or two of the groups (65).

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^b “Indigenous peoples” is an international term and refers to people who:

- Identify themselves and are recognized and accepted by their community as Indigenous.
- Demonstrate historical continuity with pre-colonial and/or pre-settler societies.
- Have strong links to territories and surrounding natural resources.
- Have distinct social, economic or political systems.
- Maintain distinct languages, cultures and beliefs.
- Form non-dominant groups of society.
- Resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities.

(United Nations Permanent Forum on Indigenous Issues, 2006) (66).

Competing interests

The authors declare that they have no competing interests.

Author contributions

JJ is the primary investigator, conceived, led and co-ordinated the development and writing of the manuscript; DS, AG, YB and ML participated throughout the development and writing of the manuscript by contributing intellectual content and feedback on drafts of the manuscript. All authors read and approved the final manuscript.

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Table 1. Phase I Study PICO Criteria

Population	Defined as Aboriginal and/or Indigenous peoples and as making a health or social decision for themselves and/or a family member. Studies in which Aboriginal and/or Indigenous peoples are included with non-Aboriginal/Indigenous people will be excluded unless the findings for each of the sub-groups are reported separately.
Intervention	Any intervention to influence health decision-making
Comparator	Any comparison including usual care.
Outcomes	Attributes of the decision [3] and attributes of the decision process [40].
Publication status	Published.

Table 2. Principles of OCAP [64] and Study Initiatives.

OCAP Principles	Study Initiatives
Ownership: An Aboriginal community or group owns information collectively in the same way that an individual owns their personal information.	Minwaashin Lodge is recognised as a full research partner by the University of Ottawa Research Ethics Board.
Control: Aboriginal communities/representative bodies are within their rights in seeking to control all aspects of research and information management processes that impact them.	Key stakeholders and Minwaashin Lodge have been included during development of the three-stage study protocol, and will be co-producers of knowledge during data collection, interpretation, and dissemination.
Access: The right of Aboriginal Peoples to information and data about themselves and their communities, as well as a right to manage and make decisions regarding access to their collective information.	Collected data is to be stored in a mutually agreed upon way to ensure the privacy and confidentiality of participants; the data sets will be accessible by representatives of the Minwaashin Lodge.
Possession: Possession, or stewardship, of data is a mechanism by which ownership can be asserted and protected.	The primary investigator and Minwaashin Lodge act in a collaborative manner e.g. creating opportunities for: meetings, informed questions about the study procedures, on-going email and in-person contact for dialogue. Data will be disseminated in collaboration with Minwaashin Lodge and to stakeholders identified and/or approved by Minwaashin Lodge.

Poster: Phase II individual interviews

[Date]

Do you have the power to make your own decisions?

Are you: 18 years or older? A client of Minwaashin Lodge? Living in [city]?
Fluent in English?

Have you made a health or social decision in the past 6 months?

**Your experiences are important for understanding how Aboriginal women can get the
help they need to make health decisions.**

If you agree to join the study, we would

- plan to meet with you for a 60 to 90 minutes at Minwaashin
- ask you about your experience in making a health or social decision
- be audiotaped during the interview
- give you \$25 to thank you for joining the study

Participants will be selected on a first come, first serve basis.

Please contact Janet Jull or Minwaashin Lodge for more information about the research study

“Urban Aboriginal women, shared decision making, and health”.

Janet can be reached at: xxx-xxx-xxxx extension y; email

Minwaashin Lodge: xxx-xxxx

Poster: Phase III focus groups

[Date]

Are you interested in helping Aboriginal women make good decisions for their health?

Are you: 18 years or older? A client of Minwaashin Lodge? Living in [city]?
Fluent in English?

Have you made a health or social decision in the past 6 months?

**Your views are important for developing a way to help Aboriginal women to get the help
they need to make health decisions.**

If you agree to participate in the study, you would:

- meet at Minwaashin with a group of women for 2 to 3 hours
- be asked questions about a tool that helps people make health decisions
- be audiotaped during the meeting
- get \$25 to thank you for participating in the group interview

Participants will be selected on a first come, first serve basis.

Please contact Janet Jull or Minwaashin Lodge for more information about the study “Urban
Aboriginal women, shared decision making, and health”.

Janet can be reached at: xxx-xxx-xxxx extension y, email
Minwaashin Lodge: xxx-xxx-xxxx

Poster: Phase III Usability interview

[Date]

Are you interested in helping Aboriginal women
make good decisions for their health?

**Interested in trying out a tool designed to help Aboriginal women make good health or
social decisions?**

Are you: 18 years or older? A client of Minwaashin Lodge? Living in [city]?
Fluent in English?

If you agree to participate in the study, you would:

- meet at Minwaashin for 60 to 90 minutes
- be try out a tool that helps people make health and social decisions
- be audiotaped during the meeting
- get \$25 to thank you for participating in the group interview

Participants will be selected on a first come, first serve basis.

Please contact Janet Jull or Minwaashin Lodge for more information about the research study

“Urban Aboriginal women, shared decision making, and health”.

Janet can be reached at: xxx-xxx-xxxx extension y; email

Minwaashin Lodge: xxx-xxx-xxxx.

Appendix H – Recruitment Script: Individual Interviews

Script for telephone and/or email information for participation in individual interviews

DRAFT form: As this project is premised on principals of participatory research, the following script provides an outline of information that would be covered during the recruitment stage of the study. It is the plan of the researcher to respond to questions posed by participants. Therefore, this script relates information that will be covered to ensure that the participant meets study criteria, while there may also be additional discussion that occurs.

[If the study is full, let caller/email know that we were accepting participants on a first come, first served basis – if the study is full, a polite response will be given and the script will not be followed]

Thank you for calling/emailing for more information about the study “Urban Aboriginal women, shared decision making, and health”. Do you have any particular questions about the study? [Yes, then respond; no, then carry on with the script]

I would like to ask you a few questions to see if you are eligible for the study – is this okay?

First, are you 18 years or older? [yes – or no – and respond to comments]

Are you a client of Minwaashin Lodge?

Are you currently living in [city]?

The interview requires that participants speak and understand English – is this possible for you?

And, my final question – have you made a health or social decision in the past 6 months? It could be for you or for someone that you care for – for instance, going to the doctor and deciding for or against a treatment, or deciding to attend school.

[If the person seems to meet all the criteria, then we could move on to the next part of the script]

What I am doing is asking women if they would participate in one on one interviews, in which they are asked some questions about their recent experiences in making a health or social decision. These experiences are important for understanding how Aboriginal women can get the help they need to make health decisions, and the information would be collected by me using a tape recorder in the interview – your name would not go on anything. Then, I would write up the information and it would be published in an article.

So, if you were to agree to join the study, I would plan to meet with you for 60 to 90 minutes at Minwaashin Lodge. What are your thoughts about this? [okay? questions?].

Do you think that you would have time to meet with me during {name a time}. Minwaashin has arranged babysitting to help you if you have children that need to be cared for, and we can also pay for the bus/taxi drive to and from the interview. I know that it is a big trip to make to talk with us, and we wanted to make it possible for you to attend, if you were interested.

Appendix H – Recruitment Script: Individual Interviews

[if yes] that is great – you will receive \$25 to thank you for joining the study after we meet at Minwaashin. Also, there will be an Elder on site if you need to talk with someone during or after the interview.

We can meet then, at [x place] at [y] time and conduct the interview then. Would you like me to call you/email you the day before to remind you, or to make sure that it still works out for you?

Thanks again and look forward to talking soon.

Appendix I – Recruitment Script: Focus Groups

Script for telephone and/or email information for participation in focus group interviews

DRAFT form: As this project is premised on principals of participatory research, the following script provides an outline of information that would be covered during the recruitment stage of the study. It is the plan of the researcher to respond to questions posed by participants. Therefore, this script relates information that will be covered to ensure that the participant meets study criteria, while there may also be additional discussion that occurs.

[If the study is full, let caller/email know that we were accepting participants on a first come, first served basis – if the study is full, a polite response will be given and the script will not be followed]

Thank you for calling/emailing for more information about the study “Urban Aboriginal women, shared decision making, and health”. Do you have any particular questions about the study? [Yes, then respond; no, then carry on with the script]

I would like to ask you a few questions to see if you are eligible for the study – is this okay?

First, are you 18 years or older? [yes – or no – and respond to comments]

Are you a client of Minwaashin Lodge?

Are you currently living in [city]?

The interview requires that participants speak and understand English – is this possible for you?

And, my final question – have you made a health or social decision in the past 6 months? It could be for you or for someone that you care for – for instance, going to the doctor and deciding for or against a treatment, or deciding to attend school.

[If the person seems to meet all the criteria, then we could move on to the next part of the script]

What I am doing is asking women if they would participate in a group interview, in which they are asked their views about a paper that helps people to figure out how to make the best health or social decision for themselves or for someone that they care for. I will be working with a research assistant, and we will be showing you how this paper can be used, and asking you and the other members of the group to tell us how it might need to be changed so that Aboriginal women could use it. We would be asking for your views and listening to you talk.

The views of the group of women are important for developing a way to help Aboriginal women to get the help they need to make health decisions, and the information would be collected by me using a tape recorder in the interview – your name would not go on anything. Then, I would write up the information and it would be published in an article.

So, if you were to agree to join the study, we would have a meeting for 2 to 3 hours at Minwaashin Lodge with this group of about 6 women. What are your thoughts about this? [okay? questions?].

Appendix I – Recruitment Script: Focus Groups

Do you think that you would have time to meet with the group during {name the time and place}? Minwaashin has arranged babysitting to help you if you have children that need to be cared for, and we can also pay for the bus/taxi drive to and from the interview. I know that it is a big trip to make to talk with us, and we wanted to make it possible for you to attend, if you were interested.

[if yes] that is great – you will receive \$25 to thank you for joining the study after we meet at Minwaashin. Also, there will be an Elder on site if you need to talk with someone during or after the interview.

We can meet then, at [x place] at [y] time and conduct the interview then. Would you like me to call you/email you the day before to remind you, or to make sure that it still works out for you?

Thanks again and look forward to talking soon.

Recruitment script/letter: Phase III usability interviews

Urban Aboriginal women, shared decision making and health

Hello, and thank you for your interest in participating in the research project called “Urban Aboriginal women, shared decision making and health”. Your experiences are important for understanding how women can get the information they need to make health decisions they define as good for themselves or for their family.

You are invited for an individual interview, to try out the tool that was developed by Aboriginal women. We would ask you to meet with us and have you pretend to make a health or social decision using the tool. If you would be willing to meet with us and to do this, you can contact Janet or [Minwaashin contact].

We can meet at Minwaashin Lodge. If you would like a member of Minwaashin lodge to be present during the interview that is possible, and there will be an Elder available should you feel distress and want to talk with them. The interview will last for 60 to 90 minutes.

Our meeting would be audio recorded (no cameras). You can withdraw from the interview at any time. You can choose to be quoted but will remain anonymous whether you choose this or not, meaning that your name will **never** be used in the research.

Your participation will be a big help. The information you give us will help contribute to a better understanding of what women need to make good health decisions for themselves and their families.

If you do not want to participate in this research, you do not have to.

Thank you!

Janet Jull, PhD Candidate, University of Ottawa

Minwaashin Lodge

[contact information]



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Consent Form: Phase II individual interviews

[Consent Form \(individual interviews – phase II\)](#)

Title of the study: Urban Aboriginal Women, Shared Decision Making and Health.

Researcher: Janet Jull, Faculty of Graduate and Post-doctoral Studies, Institute of Population Health, Population Health PhD Program.

Telephone:

Email:

Research partner: Minwaashin Lodge

Telephone:

Thesis supervisor: Dr. Dawn Stacey, School of Nursing, Faculty of Health Sciences

Telephone:

Email:

Invitation to Participate: I am invited to participate in the research study conducted by Janet Jull and Minwaashin Lodge. This project is funded by KT Canada.

Purpose of the Study: The purpose of the study is to describe the decision making needs of Aboriginal women when making health decisions within any care setting. This will be done by interviewing women about their health and social decision making experiences. Information about decision making experiences will be collected, and this information will be also be used in publications.

Participation: My participation will consist essentially of attending one interview with the researcher, for up to 90 minutes, during which I will talk with researcher about a health decision. The interview has been scheduled for (*place, date and time of interview*). I will also be asked to provide some demographic information. I agree with having an observer from Minwaashin Lodge present, should Minwaashin want a representative there during my interview.

Risks: My participation in this study will entail that I volunteer personal information about a health experience and this may cause me to feel some emotional distress. I have received assurance from the researcher that every effort will be made to minimize

Appendix K– Consent Form: Individual Interviews

these risks in that I do not have to talk about anything that I do not want to talk about, that I can stop at any time, and that an Elder is available if I need more support.

Benefits: My participation in this study will contribute to helping Aboriginal women make good health and social decisions for themselves and their families.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for activities related to this study, that is describing the health decision making needs of Aboriginal women, and that my confidentiality will be protected. I will not be quoted or have any of my information used unless I have given written permission to use it (at end of document). Anonymity will be protected in the following manner: my real name will never be used, a code will identify my interview only and the researcher will be the only person that knows this code.

Conservation of data: The data collected by taping and notes, and the transcripts that are typed up from these tapes and notes and kept on a computer will be kept in a secure manner by the researcher on her password protected work computer and on a password protected disk – both of which will be wiped clean once the study is done. The Ottawa Hospital Research Unit will keep the data in a secure locked drawer for 10 years, after which they will destroy the data.

Compensation: I have been offered \$25 for participating in this study; I will still get this money if I choose to withdraw from the study. I will also be offered a type written copy of a summary resulting from this study.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences, and it will not affect the services I receive from Minwaashin. If I choose to withdraw, all data gathered until the time of withdrawal will be used only if I choose to allow it to be used. Should I choose to withdraw from the study and do not want my data used, my data will be removed and destroyed, and it will not be used in the study. The information linking me to my data will be destroyed at the completion of the research project.

My interview will be audio-recorded and I will have opportunities to review a synthesis of the interview findings.

Acceptance: I, (*Name of participant*), agree to participate in the above research study conducted by Janet Jull of the Faculty of Graduate and Post-Doctoral Studies, Institute of Population Health, Population Health PhD Program, and Minwaashin Lodge. The research is under the supervision of Dr. Dawn Stacey

Appendix K– Consent Form: Individual Interviews

If I have any questions about the study, I may contact the researcher, Janet Jull or her supervisor, Dr. Dawn Stacey.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5

Tel.:

Email: ethics@uottawa.ca

There are two copies of the consent form, one of which is mine to keep.

I give permission to be quoted: Yes___ No___

Participant's signature: *(Signature)* Date: *(Date)*

Researcher's signature: *(Signature)* Date: *(Date)*



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Consent Form: Phase III focus group

Title of the study: Urban Aboriginal women, Shared decision making and Health.

Researcher: Janet Jull, Faculty of Graduate and Post-doctoral Studies, Institute of Population Health, Population Health PhD Program.

Telephone:

Email:

Research partner: Minwaashin Lodge

Telephone:

Thesis supervisor: Dr. Dawn Stacey, School of Nursing, Faculty of Health Sciences

Telephone:

Email:

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Janet Jull and Minwaashin Lodge. The project is funded by KT Canada.

Purpose of the Study: The purpose of this study is the cultural adaptation of a personal decision tool, the Ottawa Personal Decision Guide. The aim is to develop a guide that can support Aboriginal women in making health or social decisions for themselves and their families. Information about the adaptation of the decision tool will be collected, and this information will also be used in publications.

Participation: My participation will consist essentially of attending one group interview with the researcher and an assistant, for up to 3 hours, during which I will talk with researcher about how the Ottawa Personal Decision guide can be changed to better meet the needs of Aboriginal women. The group interview has been scheduled for (*place, date and time of interview*). I will also be asked to answer some demographic information.

Risks: My participation in this study will entail that I volunteer personal views on how

Appendix L – Consent Form: Focus Groups

the Ottawa Personal Decision Guide could be changed; it may mean that I am offering examples from my own experience, and this may cause me to feel some emotional distress. I have received assurance from the researcher that every effort will be made to minimize these risks in that I do not have to talk about anything that I do not want to talk about, that I can stop at any time, and that an Elder is available if I need more support.

Benefits: My participation in this study will contribute to helping Aboriginal women make good health decisions for themselves and their families.

Confidentiality and anonymity: I have received assurance from the researcher that every effort will be made to ensure that the information I will share will remain confidential, and of the risks to confidentiality associated with focus group participation. I understand that the contents will be used only for activities related to this study, that is, to contribute to adapting the Ottawa Personal Decision Guide. I have been asked to not share what is talked about in the meeting with anyone outside of the meeting, and realize that it is beyond the control of the researcher and research partner to ensure that other members of the group honour this request. I will only be quoted if I give written permission (at the end of the form). Anonymity will be protected in the following manner: my name will never be used, a code will identify me in the group interview, and the researcher will be the only person that knows this code. I have been asked to not disclose the identity of other members of the group outside of the interview; however, I understand that it is beyond the control of the researcher and research partner to ensure that other members of the group honour anonymity of group members.

Conservation of data: The data collected by taping and notes, and the transcripts that are typed up from these tapes and notes will be kept in a secure manner by the researcher on her password protected work computer and on a password protected disk or stick – all of which will either be wiped clean or destroyed once the study is done. The University of Ottawa Hospital Research Institute will keep the data in a secure locked drawer for 10 years, after which they will destroy the data.

Compensation: I have been offered \$25 for participating in this study; I will still get this money if I choose to withdraw from the study. I will also be offered a type written copy of a summary resulting from this study.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences, and it will not affect the services I receive from Minwaashin. If I choose to withdraw, all data gathered until the time of withdrawal will be used only if I choose to allow it to be used. Should I choose to withdraw from the study and do not want my data used, every effort will be made to

Appendix L – Consent Form: Focus Groups

immediately remove and destroy my data. The information linking me to my data will be destroyed at the completion of the research project.

My interview will be audio-recorded and I will have opportunities to review a synthesis of the interview findings.

Acceptance: I, (*Name of participant*), agree to participate in the above research study conducted by Janet Jull of the Faculty of Graduate and Post-Doctoral Studies, Institute of Population Health, Population Health PhD Program, and Minwaashin Lodge. The research is under the supervision of Dr. Dawn Stacey. If I have any questions about the study, I may contact the researcher, Janet Jull or her supervisor, Dr. Dawn Stacey.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5 Tel.:

Email: ethics@uottawa.ca

There are two copies of the consent form, one of which is mine to keep.

I agree to be quoted: Yes___No___

Participant's signature: (*Signature*)

Date: (*Date*)

Researcher's signature: (*Signature*)

Date: (*Date*)



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Consent Form: Phase III Usability interviews

Title of the study: Urban Aboriginal Women, Shared Decision Making, and Health

Researcher: Janet Jull, Faculty of Graduate and Post-doctoral Studies, Institute of Population Health, Population Health PhD Program.

Telephone:

Email:

Research partner: Minwaashin Lodge

Telephone:

Thesis supervisor: Dr. Dawn Stacey, School of Nursing, Faculty of Health Sciences

Telephone:

Email:

Invitation to Participate: I am invited to participate in the abovementioned research study conducted by Janet Jull and Minwaashin Lodge. This project is funded by KT Canada.

Purpose of the Study: The purpose of the study is to conduct usability testing of a personal decision tool the Ottawa Personal Decision Guide. This guide was developed to support Aboriginal women in making health decisions. Information about how well the Ottawa Personal Decision Guide works will be collected, and this information will be used to evaluate the guide, and also used in publications describing the process.

Participation: My participation will consist of attending one interview with the researcher and an assistant, for 60 to 90 minutes, during which I talk through a role play about making a health decision using the Ottawa Personal Decision guide with the researcher. The interview has been scheduled for *(place, date and time of interview)*.

Risks: My participation in this study means that I volunteer personal views on how the Ottawa Personal Decision Guide works for me; it may also mean that I am talking about my own experience, and this may cause me to feel some emotional distress. I have received assurance from the researcher that every effort will be made to minimize

Appendix M – Consent Form: Usability Interviews

these risks in that I do not have to talk about anything that I do not want to talk about, that I can stop at any time, and that an Elder is available if I need more support.

Benefits: My participation in this study will contribute to helping Aboriginal women make good health decisions for themselves and their families.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential. I will not be quoted unless I give written permission for this (at the end of the form). I understand that the contents will be used only for activities related to this study, that is, to contribute to testing the adapted Ottawa Personal Decision Guide. Anonymity will be protected in the following manner: my name will never be used, a code will identify me in the interview, and the researcher will be the only person that knows this code.

Conservation of data: The data collected by taping and notes, and the transcripts that are typed up from these tapes and notes will be kept in a secure manner by the researcher on her password protected work computer and on a password protected disk – both of which will be wiped clean once the study is done. The Ottawa Hospital Research Institute will keep the data in a secure locked drawer for 10 years, after which they will destroy the data.

Compensation: I have been offered \$25 for participating in this study; I will still get this money if I choose to withdraw from the study. I will also be offered a type written copy of a summary resulting from this study.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences, and it will not affect the services I receive from Minwaashin. If I choose to withdraw, all data gathered until the time of withdrawal will be used only if I choose to allow it to be used. Should I choose to withdraw from the study and do not want my data used, my data will be removed and destroyed, and it will not be used in the study. The information linking me to my data will be destroyed at the completion of the research project.

My interview will be audio-recorded and I will have opportunities to review a synthesis of the interview findings.

Acceptance: I, (*Name of participant*), agree to participate in the above research study conducted by Janet Jull of the Faculty of Graduate and Post-Doctoral Studies, Institute of Population Health, Population Health PhD Program, and Minwaashin Lodge. The research is under the supervision of Dr. Dawn Stacey

Appendix M – Consent Form: Usability Interviews

If I have any questions about the study, I may contact the researcher, Janet Jull, or her supervisor, Dr. Dawn Stacey.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5

Tel.:

Email: ethics@uottawa.ca

There are two copies of the consent form, one of which is mine to keep.

I agree to be quoted: Yes____ NO____

Participant's signature: *(Signature)*

Date: *(Date)*

Researcher's signature: *(Signature)*

Date: *(Date)*

Interview Guide: Phase II Individual Interviews

DRAFT form: As this project is premised on principals of participatory research, the following interview guide provides an outline of anticipated interviews; it is the plan of the researcher to respond to and incorporate information identified as important by participants, therefore, it may not be possible to follow the interview guide exactly.

Interview Guide: Phase II Interviews

Date: _____

Time: _____

Place: _____

Interviewer: _____

Interviewee (Code #): _____

Introduction:

Hello, my name is Janet Jull and I am a student at the University of Ottawa – and this interview is for the study about Aboriginal women and health decision making that is being done by [the research partner] and me. [If observer present – introduce them, who they are and why they are there]. We wanted to talk with you today, as we are interested in hearing about your experiences in making health decisions. This interview will take 60 to 90 minutes – and if you need a break you can tell us at any time. Also, there is an Elder [identify who] available if you need to talk with them. We are going to audiotape the interview – and wanted to make sure that it is okay to take notes as well as we do not want to forget any important points. All the notes/tapes will be typed up by me and sent to you after so that you can tell us if we get it right.

Before we start, do you have any questions to ask us? Please ask questions during our talk, or let us know if you want to stop for a break.

Question 1.

Thinking about your last visit - to a counselor, social worker, doctor, a nurse, or some other care provider -, please can you tell me about the reason you were there and how the decision was made for managing the issue?

(prompt: Challenging situation? Get enough information to make a decision? Surprised that had to make a decision? Timing of decision – had to be made right away/later?)

Question 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]. (prompt: Anyone asked your views? Were you clear on what you wanted?)

Question 3. Was anyone else involved in helping you to make the decision? (prompt: doctor, friend, Elder? If yes: did they support you? Any pressure from others?)

Question 4. Do you have any ideas on what might help you to be more involved in decisions and choose better options? (prompt: Information? Support?)

Those are all the questions we were going to ask about making a health decision; would you like to ask us about anything?

Is there anyone else you think we should talk with about this topic?

There were a few final questions we had wanted to ask.

(Demographic information)

What is your year of birth? 19_____

Do you have any children? (circle) Yes No

How many?_____

Are they living with you now? Yes No

Are there any others, besides your children, that you have to care for?_____

What is your highest level of education?

finished elementary (grade 8)

high school

Appendix N – Interview Guide and Demographic Form: Individual Interviews

college or university

other training _____

How long you have lived in Ottawa? _____

How do you describe your Aboriginal identity? _____

Closing Statement:

Thank you so much for talking with us – it has been a really helpful. What we will do next is to take this tape recording and type it all up – then we will send the copies of this conversation to you and you can tell us if it is accurate. If it is not, then we can talk about it and you can add or take away anything that you think should be changed. Your name is not going to go on anything, I have assigned a code number to you and I am the only one who will know of this code number. Your name will not be on any of the papers.

Thanks so much again – it was a pleasure to meet with you!

Interview Guide: Phase III Focus Group

DRAFT form: As this project is premised on principals of participatory research, the following interview guide provides an outline of anticipated interviews; it is the plan of the researcher to respond to and incorporate information identified as important by participants, therefore, it may not be possible to follow the interview guide exactly.

Focus group questions to guide OPDG adaptation

Date: _____

Time: _____

Place: _____

Interviewer: _____

Interviewees (Code #): _____

[Include space to map out where participants sitting, so that later, transcription of participant comments are not confusing]

Introduction:

Hello my name is Janet Jull and I am a student at the University of Ottawa doing a research project with Minwaashin about Aboriginal women making health decisions. This is my assistant [introduce the assistant]. The assistant will be helping us today during the group.

Today we want to show all of you a tool used to help people make health decisions and get your views on it, and then find out how it could be changed to meet your needs. Our meeting will take 2 to 3 hours and will be audiotaped - and we will write notes on the paper [gesture to the paper in the front of the room].

Before we start, do you have any questions to ask us? Please ask questions during our talk, or let me know if you want to stop for a break. There is an Elder [introduce] available if you need support during or after the group.

Interview questions for the group:

This is a paper called the Ottawa personal decision guide. It was developed in 1990's for helping people make any health or social decision. It is being used by people in Canada, US, Chile, England but we have not tried it with Aboriginal people to find out if it works for them.

Appendix O – Interview Guide: Focus Groups

The Ottawa personal decision guide is something to help you get ready before going to talk with your doctor or nurse (or other health or social support person). It can help you to organize your ideas and be clear on what it is you need to know, and how you feel about the decision you have to make. To start, we are going to show how it works, and go through some examples.....for instance, if you were considering whether to get the flu vaccine for your child....another example which is social in nature, such as a decision to look for a place to live, or attend counseling [Minwaashin can provide some typical examples with which clients are faced].

Now that you have a sense of how this works, we would like to have you tell us what would make it work for you. What we would like to do is ask you some questions about the OPDG.

Question 1. *In general, what was your experience in reviewing this form? (prompt: Made sense? Seems well organized? Useful? Why/why not?)*

Question 2. *Now, thinking about you as an Aboriginal woman, do you think that this form would be useful when considering a decision about affecting your health and well being? (prompt: Do they seem to ask the right questions? Do the topics/ideas seem right?)*

Question 3. *We will now go through each question on the form. Do you think that #_ makes sense? (prompt: if a concern is raised: What do you like/not like? What would you change?)*

Question 4. *Do you have any other comments or suggestions that we should consider that would make the form easier for Aboriginal women to use? (prompt: Topics/ideas; particular words; pictures?)*

Those are all the questions we were going to ask; would you like to ask us about anything? Is there anyone else you think we should talk with about this topic?

Do you feel that we have created a tool that could be useful for making a health or social decision? [show of hands].

We are going to hand out a paper asking a few questions about yourselves...if you could fill it out it will complete the interview questions. [Demographic questionnaire]

Closing Statement:

Thank you so much for talking with us – it has been a really interesting and we appreciate your willingness to go through this paper. What will be done next is to take this tape recording and notes and type it up – then copies of this conversation will be sent to each of you and you can tell us if it is accurate. If it is not, then we can talk about it and you can add or take away anything that you think should be changed. Your name is not going to go on anything, we will assign a code number to each of you and I am the only one who will know of this code number. Your name will not be on any of the papers.

Interview Guide: Phase III Usability Testing

DRAFT form: As this project is premised on principals of participatory research, the following interview guide provides an outline of anticipated interviews; it is the plan of the researcher to respond to and incorporate information identified as important by participants, therefore, it may not be possible to follow the interview guide exactly.

Phase III: Usability testing – participant interview guide

Date: _____

Time: _____

Place: _____

Interviewer: _____

Interviewees (Code #): _____

Introduction:

Hello my name is Janet Jull and I am a student at the university of Ottawa doing a research project with Minwaashin about Aboriginal women making health decisions [introduce Minwaashin representative if present].

Today we wanted to interview you about the use of the tool that we developed in our last group meeting – the Ottawa personal decision guide, which is used to help people make health decisions. We wanted to have you pretend to use it and get your views on it while you are trying it out. Our meeting will take up to 90 minutes and will be audiotaped - and I will take notes, just as we discussed when we reviewed the consent form. You can tell me if you do not agree with anything okay?.

Before we start, do you have any questions to ask us? Please ask questions during our talk, or let us know if you want to stop for a break. There is an Elder [introduce] available if you need support during or after the group.

To start, I am going to show you how the Ottawa personal decision guide works, and go through an example decisions.....for instance, considering returning to school, or making a choice of where to live....Do you have a decision that you could try out today? We had talked about this when you called me about participating in this interview, and I was not sure [if you wanted to try it out still] [if you now had a decision that you wanted to try out]. [If yes], Great, if you are okay we could give it a try/[If not]. Good, well, we had talked about you trying out a decision that we could give you to try out here and see how the Ottawa personal decision guide works for you. This is an example scenario....[give example decision that Minwaashin describes as typical for clients]

First part: Instruction in think-aloud methods

The next step will involve you doing something called “think aloud”, which is just talking out loud while you use the decision guide. Think aloud while using the OPDG to help you figure out how to manage the decision about [decision example here]. Pretend I am not here. If you are quiet for a while, I will remind you to keep thinking aloud. Finally, remember that it is the OPDG, and not you, that is being tested.

Second part: Decision scenario role play

[Decision scenario is presented to the participant. It is read through with them. One possible scenario is making a decision to return to school. The other possible scenario is making the decision to move out of the shelter and to find their own place to live.] *This is your decision scenario – so I am asking you to pretend to be preparing to go in to see your care professional, a counselor, social worker, doctor/nurse, to make a decision about... (the details on the scenarios will be talked through with the research partner, Minwaashin Lodge. Each cohort of women has unique issues – for some, there are significant issues with housing, others, housing may not be the issue, but considering returning to school to develop work skills is a big focus. As well, there may be other issues which have not been anticipated here; however, given Minwaashin’s focus on the women being able to care for themselves and have longer-term safe shelter, these are possible scenarios.)*

Do you have any questions - or are you ready to talk through how you would use this to get ready for the interview?

The participant talks through how she would use the OPDG to prepare for her meeting with a care professional.

Third part: Final discussion with researcher

Question 1. *Was the OPDG easy to use?* (prompt: Did it make sense the way it was organized? Was it clear?)

Question 2. *Would you try it out again/for making a real decision?* (prompt: Why or why not? What was it like to use it? What could make it better?)

Question 3. *Do you think that this could help you to make a decision that you think is good?* (prompt: Clarify the choice options? Figure out the benefits and harms? The chances that the benefits or harms might happen?)

*Those are all the questions I was going to ask; would you like to ask me about anything?
Is there anyone else you think I should visit with and talk with about this topic?*

Closing Statement:

Thank you so much for talking with us – it has been a really interesting and we appreciate your willingness to share your views. What I will do next is to take this tape recording and type it up – then we will send the copies of this conversation to you and you can tell us if it is accurate. If it is not, then we can talk about it and you can add or take away anything that you think should be changed. Your name is not going to go on anything, we have assigned a code number to you and I am the only one who will know of this code number. Your name will not be on any of the papers.

Thanks so much again – it was a pleasure to meet with you!

Demographic Information: Phase III Focus Groups & Usability Testing

Demographic information

1. What is your year of birth? 19
2. Do you have any children?
 - ☐ No
 - ☐ YesIf yes, How many?
2. Are they living with you now?
 - ☐ Yes
 - ☐ No
3. Are there any others, besides your children, that you have to care for?
4. What is your highest level of education?
 - ☐ finished elementary (grade 8)
 - ☐ high school
 - ☐ college or university
 - ☐ other training, please specify
5. How long you have lived in Ottawa?
6. How do you describe your Aboriginal identity?



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Confidentiality Agreement

In my capacity of employment with Janet Jull (University of Ottawa PhD Candidate) as a research assistant, I understand and agree to the following, with respect to all confidential and/or personal information that I have access to or learn:

- I will comply with all privacy policies and procedures
- I will not access or use any confidential and/or personal information that I learn of or possess, unless it is necessary for me to do so in order to perform my job responsibilities
- I will not disclose or discuss confidential and/or personal information except with authorization and in accordance with the policies and procedures;
- I will keep any computer access codes (for example, passwords) confidential and secure, and protect physical access devices (for example, keys and badges). I will not lend my access codes or devices to anyone, nor will I attempt to use those of others; and I understand that alleged breaches will be investigated.

I agree and understand that my failure to comply with the above, or in my participation in a breach of privacy, may result in disciplinary action, including the termination of my employment or affiliation with the University of Ottawa and may also result in legal action being taken against me. By signing this agreement, I acknowledge that this agreement continues in effect following my employment or affiliation with the researcher Janet Jull, at the University of Ottawa.

Name _____

Title: Research Assistant

Signature: _____

Based on the confidentiality agreement at the Ottawa Hospital Research Institute, and the University of Ottawa Heart Institute CON 53(0)

