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 Aboriginal\(^1\) 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
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 (Netledon, 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 colonization 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, Indigenous 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).

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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.

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 ($X^2 = 19.49 \ p < 0.001$) 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.
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, & Lavallee, 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 affects 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

Citations identified through database searching (n=2,630)

Duplicates removed (n=861)

Title screening (n=1,769)

Citations excluded (n=1,360)

Abstracts unavailable, moved on to full text screening (n=21)

Full Text Screening (n=34)

Citations excluded (n=396)

Abstract Screening (n=409)

Population (n=2)

Intervention (n=15)

Outcome (n=16)

Studies Included (n=1)
Figure 2.2. Search Strategy

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

--------------------------------------------------------------------
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.
40  or/24-39
41  23 and 40
Table 2.1. Criteria for Study Eligibility

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<th>Criteria:</th>
<th>Included:</th>
<th>Excluded:</th>
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<tbody>
<tr>
<td>Population:</td>
<td>People defined as Aboriginal/Indigenous and as making a health or social decision for themselves and/or a family member.</td>
<td>Aboriginal/Indigenous people are not identified as a distinct group.</td>
</tr>
<tr>
<td>Intervention:</td>
<td>Interventions to influence health or social decision-making.</td>
<td>Intervention does not involve a decision that affects health.</td>
</tr>
<tr>
<td>Comparator:</td>
<td>Any comparator.</td>
<td></td>
</tr>
<tr>
<td>Outcomes:</td>
<td>Attributes of the decision and attributes of the decision process.</td>
<td>Primary outcomes not related to attributes of decision (knowledge, risks, value-based choice) and attributes of decision-making process (informed, clear about values).</td>
</tr>
<tr>
<td>Study Design:</td>
<td>Experimental designs (e.g. RCT, interrupted time series, pre/post-test)</td>
<td>Not an experimental (intervention) study design.</td>
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Table 2.2. List of Excluded Studies

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<table>
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<tr>
<th>Reason for Exclude: Intervention (n=15)</th>
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**Reason for Exclude: Outcome (n=16)**


Moran, J.R., Bussey, M. (2007). Results of an alcohol prevention program with urban
<table>
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<th>Title</th>
<th>Author(s)</th>
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