

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 stakeholders using the Cochrane Handbook. A comprehensive search was conducted of electronic databases including all dates to present. 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 11–13, and representative of Pueblo, Navajo, Hopi, and Jicarilla Apache Indian Nations. A culturally relevant tool assessed student decision-making skills before and after 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.

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BACKGROUND

Globally, Indigenous populations are identified as experiencing significant inequities in health status (Commission on Social Determinants of Health [CSDH], 2008); Nettledon et al., 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 (World Health Organization [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 health care providers and recipients in decisions affecting health (Elwyn et al., 2000; Towle and Godolphin, 1999) and it is a central feature of patient-centred care (Dagone, 2009; Weston, 2001). SDM has been found to improve clinical decision-making and client satisfaction with the health care experience (Keisler and Auerbach, 2006; O'Connor and Jacobsen, 2007). Support for SDM approaches are emerging in health policy in Canada (Légaré et al., 2011) the US (Senate and House of Representatives, 2010), and other international settings (Härter et al., 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 to be 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 et al., 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 diverse populations (Frosch et al., 2008; McCaffery et al., 2012).

Although studies evaluating SDM strategies, such as patient decision aids used by Indigenous people, are not yet evident in the literature, there are two nonrandomized 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 et al., 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 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 apparent in Western health and social care networks. SDM creates opportunities for collabora-

tion 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 health or social decision for 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 and Green, 2011). They can help build an evidence base about effective interventions for improving health outcomes (Kelly et al., 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 among Indigenous populations. This systematic review was based on the Cochrane Handbook (Higgins and Green, 2011), which provides reporting guidelines that promote completeness and transparency in the research methods and reporting of results. The Assessing the Methodological Quality of Systematic Reviews (AMSTAR) (Shea et al., 2007) criteria were used in developing this systematic review. The Preferred Reporting Items for Systematic Reviews and Meta-analysis Equity 2012 (PRISMA-E) (Welch et al., 2012) was used to report the results. A study protocol for this systematic review was previously published (Jull et al., 2012), and includes details on methods used. The only change in study methods was the use of the PRISMA-Equity 2012 (Welch et al., 2012) instead of PRISMA (Moher et al., 2009), as the PRISMA-E includes criteria to assess for intervention effects on health equity (Appendix A). The following provides a brief summary of the study methods.

To develop and implement the review, a reference group was formed, consisting 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 16 September 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 1. Details on the inclusion/exclusion criteria used to guide selection of studies may be found in Table 1. The search and selection details are also available elsewhere (Jull et al., 2012).

Figure 1. Flow Chart for Included and Excluded Studies

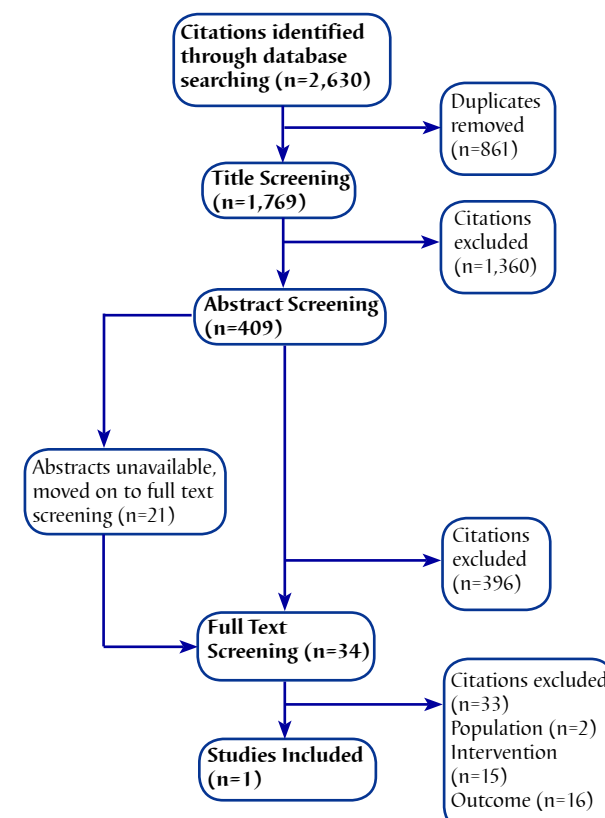


Table 1: Criteria for Study Eligibility

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.

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 (Janet Jull), and a second reviewer (James Crispo) verified the accuracy of extracted data.

STUDY QUALITY

Janet Jull and James Crispo independently assessed the included study for quality using the Cochrane Collaboration Risk of Bias Tool to examine internal validity (Higgins and Green, 2011) (Table 3). The insufficient number of studies made sensitivity analysis impossible.

ANALYSIS

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

RESULTS

Of the 1,769 citations identified, 1 study was eligible for inclusion (Figure 2). Of the 34 studies which

Table 2. List of Excluded Studies

Reason for Exclusion: Population (n=2)	Reason for Exclusion: Outcome (n=16)
Anderson, L.M., Adeney, K.L., Shinn, C., Krause, L.K., and 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.	Scrimgeour, D., Rowse, T., and 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.
Satterfield, D.W., Volansky, M., Caspersen, C.J., Engelgau, M.M., Bowman, B.A., Gregg, E.W., Geiss, L.S., Hoseney, G.M., May, J., and Vinicor, F. (2003). Community-based lifestyle interventions to prevent type 2 diabetes. <i>Diabetes Care</i> , 26(9), 2643-2652.	Albright, C., Dela Cruz, M.R., Kadowaki, J., Sagayadoro, T., and 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: 2010/05/01. Conference End: 2010/05/05 Conference Publication: (var pagings). 10:287.
De Ravello, L., Rushing, S.C., Doshi, S., Smith, M.U., and 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: 2011/07/10 Conference End: 2011/07/13 Conference Publication: (var pagings). 87:A226.	Allen, P., Thompson, J.L., Herman, C.J., Whyte, A.N., Wolfe, V.K., Qualls, C., and 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.
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., and 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.	Beckham, S., Washburn, A., Ka'aha'aina, D., and 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.
Garro, L.C. (1998). On the rationality of decision-making studies: Part 2: Divergent rationalities. <i>Medical Anthropology Quarterly</i> , 12(3), 341-355.	Carson, K.V., Brinn, M.P., Labiszewski, N.A., Peters, M., Chang, A.B., Veale, A., Esterman, A.J., and Smith, B.J. (2012). Interventions for tobacco use prevention in Indigenous youth. <i>Cochrane Database of Systematic Reviews</i> , 8.
Geller, K.S., Mendoza, I.D., Timbobolan, J., Montjoy, H.L., and 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.	Cook, A., Grothaus, C.T., Gutierrez, C.E., Kehoe, K.A., and Valentin, M.R. (2010). Closing the gap: 'Disparity in Native Hawaiian cardiac care'. <i>Hawaii Medical Journal</i> , 69(5 Suppl 2), 7-10.
Gellert, K.S., Aubert, R.E., and 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.	Fahrenwald, N.L., Belitz, C., and 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.
Hites, L.S., Granillo, B.S., Garrison, E.R., Cimetta, A.D., Serafin, V.J., Renger, R.F., Wakelee, J.F., and Burgess, J.L. (2012). Emergency preparedness training of tribal community health representatives. <i>Journal of Immigrant & Minority Health</i> , 14(2), 323-329.	Ho, L.S. (2007). <i>Diabetes Prevention in Northwestern Ontario First Nations: A Multi-institutional Program to Improve Diet and Increase Physical Activity</i> . Baltimore, MD: Department of International Health, Johns Hopkins Bloomberg School of Public Health.
Ho, L.S., Gittelsohn, J., Rima, L.R., Treuth, M.S., Sharma, S., Rosecrans, A., and 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.	Hunt, A.L. and 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.
Kaufman, C.E., Litchfield, A., Schupman, E., and 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.	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. <i>Dissertation Abstracts International, A: The Humanities and Social Sciences</i> , 1203-1203.
Lawrence, H.P., Romanetz, M., Rutherford, L., Cappel, L., Binguis, D., and 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.	Montgomery, M., Manuelito, B., Nass, C., Chock, T., and 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.
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.	Moran, J.R. and 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.
Rios, R. and Fernández, L. (2007). Empowered women from rural areas of Bolivia promote community development. <i>Promotion & Education</i> , 14(2), 83-84.	Owan, T.C. (1987). School/Community-based Alcoholism/Substance Abuse Prevention Survey. 107-107. (on-line).
Robinson, S.C., Blackwood, I., and Jorgenson, 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.	Rinderknecht, K. and 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.
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., Singer, B., Cole, K., and Contento, I.R. (1996). Reducing cancer risk among Native American adolescents. <i>Preventive Medicine</i> , 25(2), 146-155.
Schinke, S.P., Moncher, M.S., and 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.	Stevens, J., Story, M., Ring, K., Murray, D.M., Cornell, C.E., Juhaeri, and 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., and 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.

Figure 2. Results: 1

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

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 attrib-

utes or the process of decision making but rather on the learning of other behaviours or knowledge (Figure 2, Table 2).

CHARACTERISTICS OF THE INCLUDED STUDY

The included study was a randomized control trial (see Table 3). The study enrolled 44 male and female adolescents and final results are 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 not 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 promoting academic excellence. The school, operating under the *Indian Self-Determination Act* (P.L. 93-638), was not intended for children with emotional, psychological, or social problems (Okwumabua and 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 4).

CHARACTERISTICS OF INTERVENTIONS

The study intervention consisted of teaching a four-step decision-making process to participants, as described in Table 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 and Duryea, 1989).

Table 3: Characteristics and Results of Included Trial (n=1)

Study Identification	Participants	Intervention	Methods	Study Outcomes	Results
Okwumbua and Duryea (1989)	<ul style="list-style-type: none"> U.S.A. 23 male and 21 female students, 11-13 years old, mean age 12.6, American Indian descent, representing the Pueblo, Navajo, Hopi, and Jicarilla Apache Indian nations; Intervention n=23; Control n=21 	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> Randomized control trial. Pre/post assessment of student decision making skill. Modified version of the Decision-Making Instrument used. Consisted of 10 culturally appropriate decision scenarios 	<ol style="list-style-type: none"> Knowledge of the four step decision making process Application of the four step decision making process. 	<ul style="list-style-type: none"> Compared to controls intervention group had increased knowledge ($\chi^2=11.17$ $p<0.03$). Compared to controls intervention group had increased skill ($\chi^2=18.51$ $p<0.001$).

Table 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.

CHARACTERISTICS OF OUTCOME MEASURES

Outcomes 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. 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 it was easy to understand and culturally relevant, and adapted from being a five-step to a four-step process (define decision, identify alternatives, weigh costs/benefits, make a decision) with the fifth step (self-evaluation of the decision) removed as it was identified as inappropriate 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 (Okwumbua and 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 3). Post-intervention between-group analyses showed that the experimental group demonstrated higher knowledge scores (Table 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 signifi-

cantly increased knowledge with a greater number of correct responses for decision-making ability than the control group (Table 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 ($\chi^2=13.63$ $p<0.01$) 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, demonstrating a significant gap in the literature.

While quality assessment results were low (one criteria) and unclear (5 criteria), the study 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 to apply the decision-making process. The study findings are consistent with work that has been done in non-Indigenous populations, as SDM tools and approaches have been found to improve knowledge and enhance participation in decision-making (Stacey et al., 2011), and thereby provide clients with effective strategies to make informed decisions about health (Keisler and Auerbach, 2006; O'Connor

and 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 professional SDM (define problem, present options, pros and cons, clarify client values/preferences, client ability to follow through on plan, health care professional presents what is known and makes recommendations, check/clarify client understandings, make decision, arrange follow up) (Makoul and 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 and the health of others, such as family members (Okwumbua and 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 professionals for SDM skill development (Stacey and 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 effective in health care provider populations (Stacey and 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 in adult care provider populations may also be used in 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 in Indigenous populations (Edgecomb, 2006; Kelly and Minty, 2007; Minore et al., 2004), in advanced care planning (Kaufert et al., 1998; Paulette, 1993; Thomas et al., 2008), as well as health equity issues and the factors influencing participation of Indigenous women in routine medical screening (Canales, 2004; Canales and Geller, 2004; Canales and Rakowski, 2006). In particular, these studies emphasize the ways in which culture influences individual choice in the health care system rather than focusing on how effective interventions are for populations of interest.

While the influence of culture is a critical factor which affects the way health decisions are made, there is evidence that interventions using decision-making approaches may successfully be modified to accommodate 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 nonminority groups was effective (Belkora et al., 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 and Duryea, 1989).

Despite findings that suggest SDM approaches may be adapted for use within Indigenous populations, intervention studies which employ decision-making strategies with this population have focused on compliance, rather than 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) promoted decision-making in lifestyle choices, these studies were excluded because the focus was on promoting compliance. Specifically, these intervention studies used decision-making strategies aimed at educating Indigenous participants to comply with particular health behaviours, such as self management in cardiac care (Cook et al., 2010), tobacco use cessation (Montgomery et al., 2012) and preschool dental care practices (Lawrence et al., 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 aims to uphold the principle of autonomy in health settings, and to support people to participate in making decisions about their health (Makoul and Clayman, 2006). Educational approaches encouraging compliance fail to align with the principles of client-centred 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).

In the mental health literature, a focus on compliance has been criticized as failing to help people negotiate difficult decisions with long-term implications for health and well-being (Deegan and 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 health care 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 and Müller, 2002; Niggeman, 2005). In the educational literature, “critical thinking skills” training, described as training for adolescents in decision skills, are considered important for academic success, and promoted as crucial for making good decisions that influence health (Elias and 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 and 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 with implications for health and well-being. SDM is a collaborative process that engages health care professional(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 (MacDonald, Priest, Doyle, Anderson & Waters, 2010), there is a growing evidence base supporting the role of systematic reviews for conducting and promoting health equity. Additionally, the use of the PRISMA-E

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

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

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.

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 the knowledge and application of decision-making skills affecting the health of youth representative of the Pueblo, Navajo, Hopi, and Jicarilla Apache Indian Nations. While cultural relevance of SDM approaches or tools have not yet been established in Indigenous populations, the one included study in this review is evidence that builds on two other studies conducted within diverse, although non-Indigenous, populations. This suggests that promoting SDM may be acceptable and appropriate for facilitating client-centred processes of decision-making, thereby improving control over health decisions. These studies must be interpreted together cautiously, as the issues underpinning the poor health of Indigenous populations are 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 in 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 who use them — decision makers, health care providers, and most importantly, that of health care clients.

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APPENDIX A. 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	1	Identify the report as a systematic review, meta-analysis, or both.	539	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.	539	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.	539
Introduction					
Rationale	3	Describe the rationale for the review in the context of what is already known.	540	Describe assumptions about mechanism(s) by which the intervention is assumed to have an impact on health equity.	539–540
	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.	539–540
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	540–541	Describe how disadvantage was defined if used as criterion in the review (e.g. for selecting studies, conducting analyses or judging applicability).	540–541
	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.	540		
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 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.	541 and 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.	541
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Figure 1.	Describe the broad search strategy and terms used to address equity questions of the review.	Focus on Indigenous Peoples Figure 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).	541		
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.	541		

Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	541; 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).	541
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.	541		
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	543 and Table 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.	Descriptive analysis	Describe methods of synthesizing findings on health inequities (e.g. presenting both relative and absolute differences between groups).	541; 543-545
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 4.		Table 4.
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	541	Describe methods of <i>additional</i> synthesis approaches related to equity questions, if done, indicating which were pre-specified	541
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 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.	543-544; Table 3.	Present the population characteristics that relate to the equity questions across the relevant PROGRESS-Plus or other factors of interest.	543-545; Table 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 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 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 analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A; lack of data.	Give the results of <i>additional</i> synthesis approaches related to equity objectives, if done, (see 16).	541; 545-547
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., health-care providers, users, and policy makers).	545-548		
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).	547; Table 4		

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](https://doi.org/10.1371/journal.pmed.1001333). 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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James A.G. Crispo MSc, PhD(c) contributed to study screening/selection and contributed to the writing of the final paper. He was born and raised in northern Ontario (Blind River) and is of Métis ancestry. He 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. James' current doctoral research focuses on pharmaceutical use and safety, specifically on cardiovascular risks associated with the use of anti-Parkinson agents. Additionally, he is interested in leveraging administrative health databases to better understand and mitigate population health risks.

Vivian Welch, PhD (Population Health) contributed intellectually and to the writing of the final paper. She 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. Vivian 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 (INCLIN). As part of her work on methods for considering health equity, Vivian 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), which was used in this paper.

Heather MacDonald, MSc, MLIS contributed intellectually, conducted the search of the literature and contributed to the writing of the final paper. She 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.

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Simon Brascoupe 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.

Yvonne Boyer, JD, LLM, PhD (LLD) contributed intellectually to the study and the writing of the final paper. She is a 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. Yvonne holds a Research Chair in Aboriginal Health and Wellness at Brandon University, and has been a member of the board of Minwaashin Lodge since 2006. She has acted as the guardian of the Ownership, Control, Access and Possession requirements between the Lodge and this important work on shared decision making.

Dawn Stacey RN PhD CON(C) contributed intellectually during the study development, study screening/selection, and writing of the final paper. She holds a Research Chair in Knowledge Translation to Patients and is Associate 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. She is collaborating with the Ministry of Health in Saskatchewan to implement shared decision making and patient decision aids across the province. She has over 100 publications and 80 invited national and international presentations. Her research program website is <http://decisionaid.ohri.ca>.