



Co-Developed Indigenous Educational Materials for Chronic Kidney Disease: A Scoping Review

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Lynn Jansen¹ , Geoffrey Maina¹, Beth Horsburgh², Maha Kumaran³, Kasha Mcharo², George Laliberte⁴, Joanne Kappel⁵, and Carol Ann Bullin²

Abstract

Background: Canadian Indigenous populations experience significantly more chronic kidney disease (CKD) than the general population. Indigenous people who live in rural and remote areas may also have difficulty accessing both information and care for their CKD. Informed decision making about treatment options for advancing kidney disease may be delayed, which can result in poor health outcomes and decreased quality of life. Moreover, Indigenous people may experience marginalization within Western health care systems.

Objective: The objective of this scoping review is to identify culturally appropriate and co-developed Indigenous educational tools that will ultimately support CKD learning and end-stage kidney treatment decision making.

Design: Scoping Review

Setting: Databases included Embase, CINAHL, Medline (OVID), ERIC, and the Canadian Agency for Drugs and Technology Gray Matters.

Study Participants: Community-based Indigenous patients, families, health care workers, and community members.

Methods: We systematically reviewed the literature to explore the availability of co-developed Indigenous educational tools and material for CKD treatment options. Titles, abstracts, and full texts were reviewed independently by 2 reviewers with disagreements resolved through a third. All aspects of this project, including searching the databases were done in consultation with an Indigenous Elder.

Results: Only one retrieved article identified a comprehensive CKD tool co-developed by researchers, health care providers, and an Indigenous community. Three themes emerged from the scoping review that may inform characteristics of co-developed tools: cultural appropriateness; appraisal of utility and effectiveness and; content informed by co-development of traditional and Western chronic disease knowledge.

Limitations: Consistent with scoping review methodology, the methodological quality of included studies was not assessed. In addition, it was difficult to synthesize the findings from the research and gray literature.

Conclusion: Little is known about the co-development of Indigenous educational tools for CKD. Further in-depth understanding is required about how to best engage with Indigenous communities, specifically to co-develop contextualized CKD tools that are acceptable to Indigenous people.

Trial registration: Not applicable as this review described secondary data.

Abrégé

Contexte: Au Canada, l'insuffisance rénale chronique (IRC) touche les populations autochtones davantage que la population générale. Qui plus est, l'accès à des soins et de l'éducation sur l'IRC s'avère plus difficile pour les autochtones vivant en régions rurales et éloignées. Une situation susceptible de retarder la prise de décision informée quant aux options de traitement et donc, de compromettre les résultats de santé et la qualité de vie. Les autochtones pourraient également être marginalisés dans les systèmes de santé occidentaux.

Objectifs: L'étude visait à répertorier des outils de sensibilisation culturellement appropriés et développés conjointement avec les autochtones qui, en définitive, viendraient appuyer l'éducation sur l'IRC et la prise de décision quant au traitement de l'insuffisance rénale terminale.

Type d'étude: Étude de cadrage



Sources: Les bases de données Embase, CINAHL, Medline (OVID) et ERIC, et l'outil Matière grise de l'Agence canadienne des médicaments et des technologies de la santé (ACMTS).

Sujets: Des patients autochtone de la communauté et leurs familles, des travailleurs du secteur de la santé et des membres de la communauté.

Méthodologie: Nous avons procédé à une revue systématique de la littérature pour vérifier la disponibilité d'outils d'éducation développés conjointement avec les autochtones et de matériel relatif aux options de traitement pour l'IRC. Les titres, abrégés et textes complets ont été révisés indépendamment par deux examinateurs; les désaccords ayant été résolus par un troisième. Un aîné autochtone a été consulté pour tous les aspects de ce projet, y compris la recherche dans les bases de données.

Résultats: Parmi les articles retenus, un seul faisait état d'un outil complet développé conjointement par des chercheurs, des fournisseurs de soins et une communauté autochtone. L'étude a dégagé trois thèmes susceptibles d'éclairer les caractéristiques d'un outil co-développé: l'adaptation culturelle, l'évaluation de l'utilité et de l'efficacité, et un contenu éclairé par le co-développement des connaissances traditionnelles et occidentales sur les maladies chroniques.

Limites: Conformément à la méthodologie d'une étude de cadrage, la qualité méthodologique des études incluses n'a pas été évaluée. De plus, il a été difficile de synthétiser les résultats provenant de la recherche et de la littérature grise.

Conclusion: On en sait peu sur le développement d'outils d'éducation sur l'IRC conjointement avec les membres des communautés autochtones. Une compréhension plus approfondie des meilleures façons de collaborer avec les communautés autochtones est nécessaire, particulièrement pour l'élaboration d'outils d'éducation sur l'IRC contextualisés et acceptables pour les autochtones.

Enregistrement de l'essai clinique: Sans objet puisque cette étude discute de données secondaires.

Keywords

indigenous, CKD (chronic kidney disease), reconciliation, co-development, teaching tool

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What was known before

- Indigenous people value relational learning approaches that involve equitable sharing of traditional and Western health care knowledge. Traditional didactic methods of providing health care education have not been effective in addressing the CKD educational needs of Indigenous people.

What this adds

- Little is known about how Indigenous teaching tools might be co-developed and thus be specifically acceptable and utilized by Indigenous patients, families, and communities. Community and relational engagement with Indigenous people is required so that “how to” strategies underpinned by Indigenous

and Western experiential knowledge for CKD treatment options can inform co-development.

Introduction

Canadian Indigenous populations, experience significantly more chronic kidney disease (CKD) than the general population.^{1,2} Indigenous people with CKD, especially those who live in rural and remote areas may struggle to access treatment and information for their conditions in a timely manner.³ Informed decision making about treatment options for kidney failure may be delayed for themselves, their families, and their health care provider.⁴ Consequently, rural and remote Indigenous people who have CKD may have advanced disease and be unwell when they need to make a treatment decision, or they may further delay

¹College of Nursing, University of Saskatchewan, Prince Albert, Canada

²College of Nursing, University of Saskatchewan, Saskatoon, Canada

³Education Library, University of Saskatchewan, Saskatoon, Canada

⁴Can-SOLVE CKD Network Patient Partner, Saskatoon, Canada

⁵College of Medicine, University of Saskatchewan, Saskatoon, Canada

Corresponding Author:

Lynn Jansen, College of Nursing, University of Saskatchewan, 208-1301, Central Ave, Prince Albert, SK, Canada S6V 4W1.

Email: lynn.jansen@usask.ca

decision making, which can result in poor health outcomes and decreased quality of life.⁵

It is now acknowledged that the legacy of postcolonization and social determinants of health contributes to chronic disease.⁶ Although efforts toward reconciliation are in primordial stages, there is a need to attend to the respectful inclusion of traditional knowledge to inform Indigenous health care decision making.^{6,7}

The Westernized health care system is focused on professionals' didactic teaching rather than co-creating learning approaches for chronic disease management.⁸ These approaches are also contrary to Indigenous learning that is underpinned by relational learning and the co-development or equitable sharing of traditional and Western health care knowledge.^{4,7} Thus, health care providers have little understanding about how to partner with Indigenous people, families, and communities to address CKD-related health issues. Therefore, Indigenous people with CKD may disengage from health education and care decision making due to mistrust and experiences of system marginalization.⁹ To inform a Can-SOLVE CKD research project—Improving Indigenous Patient Knowledge about Treatment Options for Failing Kidneys, a scoping review was undertaken to identify the availability of co-developed Indigenous educational tools about CKD.

Method

A scoping review is considered the method of choice when little is known and/or when diverse study methods have been used to inform evidence for practice and policy.^{10,11} The research question guiding this review was: what are (or are there) co-developed Indigenous educational tools for treatment options for CKD. Educational tools were interpreted as methods to impart health knowledge decision making, or health knowledge translation as guided by the participatory principles of patient- and family-oriented research.^{12,13}

Search Strategy

The health sciences librarian (M.K.) developed the searches in June 2017, with the support of the Indigenous Elder (G.L.) and other research team members involved in Indigenous research. The research assistant (K.M.) conducted and ran the searches in June, 2017, August, 2018, May, 2019, and updated it again in December, 2019. There were no new relevant articles with the last updated search. The team assisted in setting the search parameters and interpreting the findings. The search strategy was first developed using Medline (OVID) and translated to other databases using each database platform's subject headings and appropriate fields (Supplemental Appendix A for Medline search strategy). Searches were also conducted in Embase, CINAHL, ERIC, and Web of Science. The Canadian Agency for Drugs and

Technology in Health (CADTH)¹⁴ tool was used to search for free and subscription-based gray literature databases, health technology assessment websites (Canada, Australia, and the United States), Natural Medicines, and Environmental Health websites.

The 3 major concepts of “Indigenous populations,” “education tools,” and “chronic diseases” were searched and combined with the Boolean operator AND. We used a modified version of Indigenous peoples search filters from the University of Alberta Libraries to search for Indigenous population groups. Subject headings of different chronic diseases such as Diabetes, Hepatitis C, Hypertension, and Cardiovascular Diseases were combined with the Boolean operator OR. A combination of keywords and subject headings that represent education tools such as “Health Education (Methods),” “Teaching Materials,” “educational tool” and “Decision Aid” were combined with the Boolean operator OR. Due to limited Indigenous-related literature on this topic, no study type limits were applied. Citation searches were conducted from the reference section of eligible studies. As the initial searches returned limited CKD, ESRD, and Indigenous literature related to teaching tools, a decision was made in consultation with the Indigenous Elder and research team to broaden the search to include articles on other chronic diseases deemed relevant to kidney failure (ie, hepatitis C, HIV, heart conditions, hypertension, and diabetes). It was agreed that CKD care would encompass hemodialysis, peritoneal dialysis, home hemodialysis, conservative kidney management, and renal transplant.

Inclusion and Exclusion Criteria

All types of studies and articles relating to chronic disease management for Indigenous populations globally were included. A date limit of 20 years was applied, and non-English language articles were excluded.

Selection of Studies and Gray Literature

Two members of the research team (L.J. and G.M.) independently screened 367 titles and abstracts against the inclusion and exclusion criteria to identify 50 relevant research articles. The full text of the relevant research articles was obtained and evaluated independently by the same researchers. When there was a disagreement, the research assistant (K.M.) assessed eligibility. One member of the research team (L.J.) and research assistant (K.M.) independently screened 50 gray literature educational tools. Research team members (J.K. and C.B.) also assessed these tools if there was disagreement. When this was completed, comparisons were made, and discrepancies resolved to select the final 9 research articles and 12 gray literature tools (Figure 1).

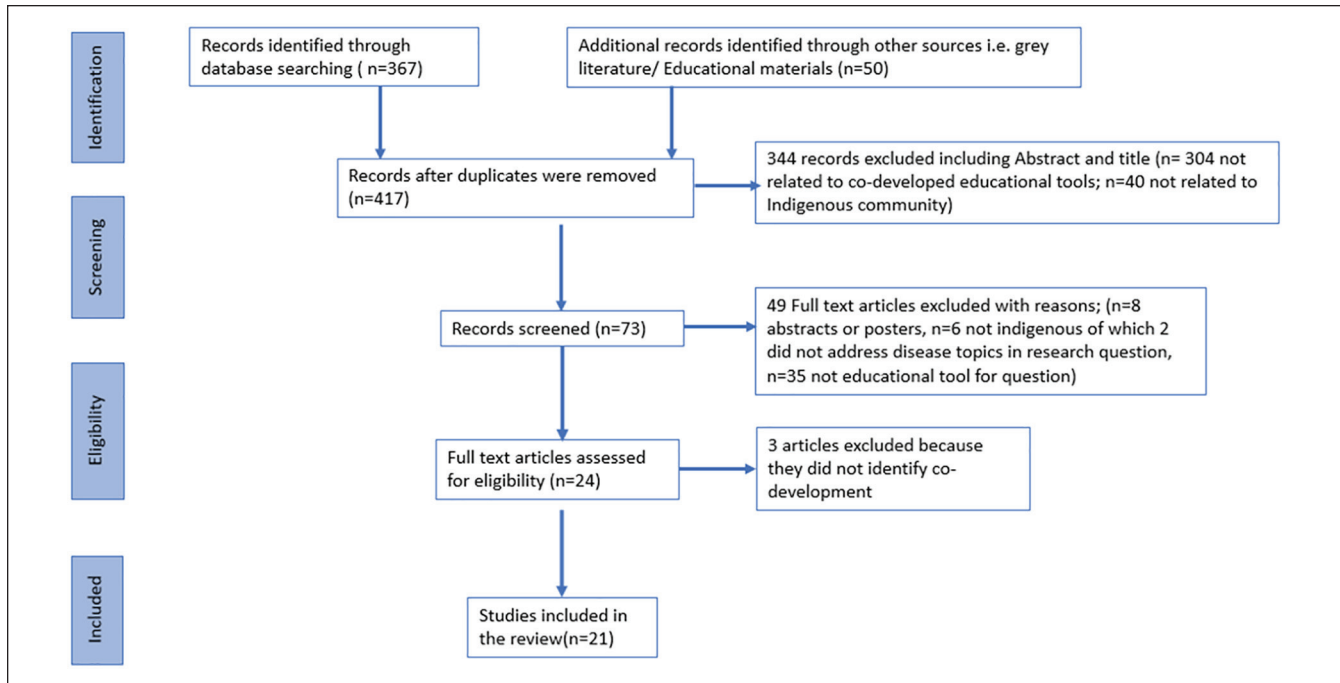


Figure 1. PRISMA for research and gray literature educational materials.

Note. PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Data Extraction

A data extraction tool (customized PINCH Table) was developed (Table 1) for research articles. Gray literature findings related to Indigenous CKD educational tools and treatment options were obtained from CADTH¹⁴ and reviewed by the research team. The 12 included tools are reported in Table 2.

Thematic Analysis

Scoping review findings were reviewed for content and themes by the research team and Indigenous Elder. Descriptive analysis was used to report results.

Results

All studies were conducted within a rural and/or remote Indigenous context. One study was reported as a randomized controlled trial; 5 were designed as community-based participatory action and the remaining were qualitative in nature. Six of the research studies were conducted in the United States, 2 in Australia and 1 in Canada. Five of these articles focused on diabetes, and the remaining 4 articles focused on heart failure, CKD, sexual reproductive health, and HIV, respectively. Gray literature sources (Canada = 3; Australia = 7; United States = 2) provided examples of CKD educational tools that may have been co-developed. An over-arching theme of cultural appropriateness emerged. The articles were then grouped according to those that *described*

culturally appropriate Indigenous education tools; those that *appraised* the utility or effectiveness of educational tools in achieving outcomes and meeting the needs of Indigenous patients; and those that *described* tool characteristics as informed by elements of co-development.

Articles Describing Culturally Appropriate Indigenous Education Tools

Roubideaux et al¹⁵ described findings derived from focus groups conducted by The Association of American Indian Physicians with tribal leaders, Indian health professionals, and American Indian community members. American Indigenous content including locally tailored print and diagrams was advised to enhance clarity and readability in traditional cookbooks, cooking classes, health videos, and pamphlets. Recommendations were also made to afford individualized patient and family teaching sessions, as well as community- and school-based workshops.

Rushing and Stephens¹⁶ described “Project Red Talon,” a sexually transmitted disease (STD/HIV) prevention project that serves the 43 federally recognized tribes in Oregon, Washington, and Idaho. Participatory research methods were used to work with Tribal leaders and members, educational organizations, parents, youth, and health experts. Risk assessments were incorporated into tools such as CD-ROMs, cell phone text messages, and computer video-games. Tools also afforded locally contextualized Indigenous teachings; age and gender appropriate content that was easily understood;

Table 1. Research Literature.

Title	Objective/aim	Design	Main findings	Conclusion
1. Roubideaux et al ¹⁵	To describe characteristics of culturally appropriate diabetes education materials as informed by stakeholders	<ul style="list-style-type: none"> Qualitative 	<ul style="list-style-type: none"> Five focus group participants (n = 95) recommended updating of current educational materials to make their messaging simpler and clearer, specifically for diet and exercise. Requested more diabetic materials for cooking classes with traditional foods be made available to communities and schools, videos that are readily understood, workshops, all educational resources available to families Recommended culturally specific diagrams and individual teaching sessions 	<ul style="list-style-type: none"> Participants appreciate when they are consulted. Educational materials need to be tailored to cultural nuances of each tribe/aboriginal community. Hospitals and clinics, family members, community events, media, and schools are the commonest sources of information on diabetes
2. Rushing and Stephens ¹⁶	To evaluate availability and effectiveness and describe characteristics of sexual health technology-based interventions, and required resources. Participants reviewed native youth survey and a systematic review related to technology and strengths-based interventions	Community-based participatory: <ul style="list-style-type: none"> several hundred community participants and other tribal members, health advocates, teachers, and students 	Delivered with computer or CD-ROM (n = 22), and internet access (n = 12); cell phone using text messages (n = 4), video-based (n = 2), and computer-based video game (n = 3). Embedded risk, needs, or readiness assessments directly into the program (n = 18), required users to participate in multiple sessions (n = 14), involved interactions with peers or peer role models (n = 15), and virtual/in-person communication with health experts (n = 15). Most required (n = 21) interactive user participation. <ul style="list-style-type: none"> Most of the literature review interventions were deemed not to be effective 	A technology tool must demonstrate: <ul style="list-style-type: none"> Sexual risks and protective factors Frequency and repeated use Tradition and contemporary AN/AI cultural, values, and teaching Utility and readability. Consider: “(1) accurate age- and gender-appropriate; (2) early introduction and focus on abstinence; (3) holistic and real; (4) cultural relevance; (5) a focus on assets and skills; (6) dialogue while maintaining privacy; (7) interactivity; and (8) evaluation plans.”
3. Kattelmann et al ¹⁷	To determine effectiveness of Northern Plains Indians, type 2 diabetes mellitus educational intervention. Specifically, were there significant physiological changes following receipt of culturally adapted education	<ul style="list-style-type: none"> RCT 6-month period with Northern Plains Cheyenne River Sioux Tribe 	<ul style="list-style-type: none"> The education group (n = 57) randomized to receive culturally adapted educational lessons based on the Medicine Wheel Model for Nutrition had a significant weight loss and decrease in BMI. The usual care group (n = 57) who received the usual education from health providers had no change in weight. There were no between group differences due to intervention in calorie, carbohydrate, protein, fat intake, and physical activity 	<ul style="list-style-type: none"> The culturally based nutrition intervention can promote small but positive changes in weight. To achieve a desired change, time and persistence is needed for educational support to influence blood glucose and lipid parameters

Table 1. (continued)

Title	Objective/aim	Design	Main findings	Conclusion
4 Simonds et al ¹⁸	To evaluate Indian Health Services and National Institute of Diabetes, Digestive and Kidney Diseases websites, booklets, and fact sheet educational materials for: readability, vocabulary, complexity, and structure	<ul style="list-style-type: none"> Evaluation 	<ul style="list-style-type: none"> 29% of materials used for diabetes education above grade 6; 71% above grade 8 readability Levels. Reading difficulty due to language and material structure of uncommon categorical terms, unexplained medical terms, and numeric terms. Medical terms were used 28 times with only 5 terms defined. Numbers were present in all but 2 documents and used to convey amounts of food or measurement for recipes. 20 included graphs and displays, 5 required arithmetic operations, and 13 contained percentages. Two materials referenced risk 	<ul style="list-style-type: none"> Materials should be assessed and chosen to align with reading level of the intended population Educational materials should be reviewed with patients to ensure concepts are clarified and understood Use of cultural sensitivity assessment tool suggested
5 Browne et al ¹⁹	To create, distribute, and evaluate an Aboriginal diabetes educational resource* for the prevention and management of type 2 diabetes and to enhance by Aboriginal Health Workers and Aboriginal community	<ul style="list-style-type: none"> Mixed methods 	<ul style="list-style-type: none"> 276 participants trained to use Feltman resources for diabetes training. Online evaluation survey for the trainees (66 participants completed) focusing on satisfaction with the training, level, and types of resources used in the community, cultural appropriateness, and so on Participants agreed that Feltman was an ideal tool culturally appropriate for the Aboriginal people. It was also deemed highly visual, simple to use, and enabled diabetes to be discussed in a nonthreatening manner 	<ul style="list-style-type: none"> The success of the diabetes education too development was due to consultation with the Aboriginal health workers Making a visual interactive resource to support healthy literacy and different learning styles, training staff to use the tool was critical to the uptake of the resource Regular training of staff is needed due to high staff turnover
6 Carter et al ²⁰	To determine culturally appropriate content and delivery methods for a Native American diabetes education program called Strong in Body and Spirit	<ul style="list-style-type: none"> Participatory Action: Mixed Method Pilot Focus groups with community advisory group; health care and tribal health workers; patient interviews about quality of life, diet and exercise knowledge, attitudes, behaviors, and family support 	<ul style="list-style-type: none"> Baseline information obtained from patients on important diabetes information. The collaboration between Indian Health services, professionals, community members, and universities research staff ensured appropriate content and wording prior to community member feedback Document well received during pilot 	<ul style="list-style-type: none"> Need input from community, patients, tribal leaders, and the health professionals for insights into cultural presentation Integration of Western and Indigenous paradigms such as social action theory, the transtheoretical model of change, and empowerment paradigm can help realize outcomes such as healthful diet behaviors, and family and community support Traditional values and methods of knowledge dissemination are necessary such as stories, prayers, and skills-based learning for increased receptivity

(continued)

Table 1. (continued)

Title	Objective/aim	Design	Main findings	Conclusion
7 Clark et al ²¹	To create a culturally appropriate computer-based educational resource for heart failure knowledge for Aboriginal and Torres Strait Islanders and to conduct a feasibility study regarding effectiveness of tools developed	Mixed methods two-phase study 1st phase developed pilot tool with health professionals and community stakeholders • 2nd phase pilot-tested with 5 patients	<ul style="list-style-type: none"> Stakeholder feedback ensured that the resource reflected identity and culture, comprehensiveness for local population. Interface should be user friendly, with voice over presented by Aboriginal and Torres Strait Islanders. Materials were evaluated by patients who deemed them to be acceptable, comprehensive, and impactful. They also reportedly increased heart failure knowledge with high satisfaction 	<ul style="list-style-type: none"> Active engagement of Aboriginal and Torres Strait Islander researchers and stakeholders was vital to the success of the project The touch screen technology was an appropriate alternative of presenting health information. Cultural recognition is key in developing an educational tool
8 Kaufman et al ²²	To evaluate circle of life curricula, designed for HIV prevention among AI/AN youth	• Evaluative mixed methods tested in 18 urban and rural schools in classrooms of 12 to 32 students	<ul style="list-style-type: none"> Increased vulnerability of AI/ANs to HIV/AIDS and other STIs. Although curricula well received, implementation of content related to sexual abstinence, substance use, and abuse, homosexuality, and condom use was challenging, given school budget and policy restrictions 	<ul style="list-style-type: none"> Flexibility and contextualized local enhancements needed to increase engagement and interest among youth. Effective education tools must integrate expert and community input, be based on sound theoretical underpinnings, and consider appropriate technological advances for the target population
9 Paterson et al ⁷	To explore the “causes of nonadherence” to CKD management amongst community members and to develop a “prototype” for a culturally relevant toolkit to support treatment adherence	• Community-based Participatory Action: Community Advisory Committee (n = 22) and 12 interview participants: Elder (n = 1), patients (n = 5), family caregivers (n = 3) and health care providers (n = 3)	<ul style="list-style-type: none"> A literature review and individual interviews with community stakeholders, families, and clients were conducted. The principles that guided the research project include: (1) affirming the uniqueness of each Indigenous person, (2) integrating the Indigenous voice and agency in the toolkit, (3) including content that reflects family and community relationships, (4) attending to emotional, spiritual, and physical wellness and, (5) incorporating experiences and stories of those receiving dialysis and their caregivers 	<ul style="list-style-type: none"> Attend to community advice in the research process, for example, community preferred hand-delivered invitations versus posters to advertise celebration event for toolkit. Provide interviews by trusted community members and in language of choice. Adapt tool kit for use by various indigenous groups Include many different Aboriginal foods in discussion of diet Use relevant Aboriginal stories, photographs, and pictures in the toolkit

Note. BMI = body mass index; AI/AN = American Indians and Alaska Native; CKD = chronic kidney disease; RCT = randomized control trials.

*Life size resource with movable felt organs. Includes interactive DVD

Table 2. Gray Literature Tools.

	Source	Aim of educational tool	Content	Lessons learned from educational tool
1	Northwest Regional Renal Program at Thunder Bay Regional Health Sciences Center 2016 http://tbrhsc.net/new-kidney-treatment-video-aims-to-support-aboriginal-patients-in-decision-making/	To create a decision-making support video with Indigenous renal patients for CKD treatment options	Treatment options included: conservative CKD management, kidney transplant, hemodialysis, and peritoneal dialysis. Changes in diet, residential environment, and family relationships are also discussed	Formal evaluation has not occurred, the videotaped CKD-related experiences of patients and families are anticipated to support decision making for Indigenous CKD treatment
2	Ontario Renal Network (2019) https://www.ontariorenalnetwork.ca/en/kidney-care-resources/clinical-tools/first-nations-inuit-metis	To support access amongst First Nations, Inuit, and Métis people in language of preference: English, Oji-Cree, and Inuktitut	Fact Sheets for Diabetes, Phosphorus and Kidney Disease, and Sodium and Kidney Disease	Information sheets can be accessed by health care providers and Indigenous people with CKD to support learning
3	Kidneycheck.ca http://www.cansolveckd.com/research/kidney-check/about-kidney-check/	To provide traveling-team-based assessment and intervention for kidney, diabetes, and hypertension in rural and remote Canadian communities	A comprehensive website has been developed with a suite of provider resources for teaching and reporting to patients about CKD test results and interventions for prevention and treatment. Real-time results are provided along with postscreening educational tools	Content appears to be largely health provider focused with limited evidence of Indigenous cultural responsiveness. However, Kidney Check has developed tools to initiate leadership engagement in rural and remote areas including Indigenous communities
4	Kidney Health Australia https://kidney.org.au/your-kidneys/support/indigenous-resources	The following Kidney Health Australia resources were created to provide culturally responsive CKD educational and treatment support Tools	This electronic source contains comprehensive links to Indigenous CKD educational documents within a rural and remote Australian context for health care providers, Indigenous patients, and families	Australian Indigenous content may be considered for application to a northern Canadian context and used by health care providers in Indigenous education. Appear to be culturally appropriate and co-developed; however; process thereof is not known
4 a	kidney.org.au/yourkidneys/support/indigenous-resources/kidney-stories		Indigenous produced video with narrative and song. Kidney Stories Video: Let the medicine come to you: PD—It's Easy	Includes recording of community interaction
4 b	https://kidney.org.au/cms_uploads/docs/how-do-my-kidneys-work-new.pdf		Information sheet with diagrams to describe kidney functioning and mal-function.	Clear pictorial and narrative messaging
4 c	https://kidney.org.au/your-kidneys/support/indigenous-resources/bush-tucker-healthy-eating-and-wellness-1299		Bush Tucker in Diabetes and Kidney Failure book Designed for health professionals to teach Indigenous people with diabetes and CKD about diabetic and renal diets, specifically how to manage with local Australian fruits and vegetables	Renal diet with Bush Tucker ingredients to afford local nutritional adaptations as part of managing CKD. May afford attention to how previous traditional diets may be applied to prevent and manage CKD.

(continued)

Table 2. (continued)

	Source	Aim of educational tool	Content	Lessons learned from educational tool
4 d	https://kidney.org.au/advocacy/guidance-and-tools/indigenous-health/resources-for-health-professionals		Balanda Life Stories: Used to foster interactive learning and dialogue through contextualized Indigenous diagrams Flipcharts address conveys meaningful stories and key messages about kidney function, transplantation, and palliative care	Provides examples of Indigenous interactive and relational learning strategies
5	3.5 Australian Screen https://kidney.org.au/cms_uploads/docs/kidney-stories-no-5-haemodialysis.pdf https://kidney.org.au/cms_uploads/docs/kidney-stories-no-6-peritoneal-dialysis.pdf		This provides further sublinks to the Indigenous resources in the areas of end-stage kidney treatment via dialysis care	Series of Indigenous-oriented stories with diagrams, information flow from diagnosis to treatment in-hospital and home dialysis
6	3.6 NFSA Australian Screen https://aso.gov.au/titles/documentaries/big-girls-dont-cry/notes/	The film is created in English and Aboriginal languages of Pitjantjatjara, Warlpiri, and Arrernte.	“Big Girls Don’t Cry,” 3 videos illustrate how 3 women experience CKD. Five sections are included: <ul style="list-style-type: none"> • “How do you feel?” • What is diabetes? • Why have I got diabetes? • What could happen to me? • If you have diabetes or think you might have diabetes.” 	For health professionals; no explanation of co-development To provide teaching that is in language of choice, clear understanding of medical terms, and meaningful interpretation Video conveys strength-based approach to treatment.
7	Indian Health Service: The Federal Health Program for American Indians and Alaska Natives https://www.ihs.gov/diabetes/clinicianresources/diabetes-education-lessonplan-outlines/	To provide diabetic teaching to foster self-management and prevention of diabetes	American Indians/Alaska Natives and Kidney Disease: what is it? Factual guides are available online regarding at risk factors, what patient should do, and how to prevent diabetes. Videos with Indigenous teaching content are also available	Content appears to be health provider focused although cultural print and diagrammatic material is included to assist with lesson plans. No evidence is provided regarding co-development of teaching material although messaging exists to support working with Indigenous people Material does reference Indigenous cultural images and content; however, it does not reference co-development
8	American Indians/Alaska Natives and Kidney Disease (The National Kidney Foundation, 2015) https://www.kidney.org/atoz/content/AmericanIndians-KD	To provide fact sheets both printable and online to support education and prevention of CKD	Fact sheets on CKD risk factors, kidney function and associated tests, and how to access care	

Note. CKD = chronic kidney disease; NFSA = National Film and Sound Archive; PD = peritoneal dialysis.

and repetitive interactive approaches to engage high-risk populations in educational initiatives and evaluation plans.

Canadian gray literature tools included a video created with 2 Indigenous patients and their families who share their experience of managing CKD interventions.²³ The Ontario Renal network²⁴ has developed educational diabetes, nutrition, CKD, and dialysis pamphlets for First Nations, Inuit, and Métis people in the language of English, Oji-Cree, and Inuktitut. The third Canadian resource, Kidney Check,¹³ can be accessed through an app and in-person interdisciplinary presentation. The Kidney Check material supports CKD education and collaboration with First Nations communities and provides real-time feedback on diagnostic tests, CKD, and treatment options.

Australian gray literature educational resources²⁵⁻³¹ are used to foster interaction, sharing of information, and CKD questions between health care educators, patients, and families. The use of contextualized tribal pictures, flipcharts, DVDs, and stories about managing diagnosis and treatment, including hospital- and home-based dialysis, are also available to support succinct and clear messaging about kidney function, transplantation, and palliative care. Similarly, American gray literature included diabetes-related pamphlets, printed literature, videos³² and printed material for kidney risk, required tests, and how to access care and treatment.³³

Articles Reporting Appraisal of the Utility or Effectiveness of Pre-Existing Educational Tools

Kattelman et al¹⁷ assessed the effectiveness of a Medicine Wheel informed diet education intervention versus usual care for type 2 diabetes in a randomized control trial with Northern Plains Cheyenne River Sioux Tribe participants. The culturally based tool fostered education based on the traditional “hunter-gatherer diet” which supported individualized meals, self-monitoring of diet and physical activity, adjusting environment for traditional food choices, and problem solving for food choices. Small but positive changes in weight were found; a change in physical parameters such as blood glucose and lipid levels may also be promoted through sustained health care provider educational support. Sustained high participation rates (90%) may have occurred due to Tribal involvement in the design and delivery of the intervention.

Simonds et al¹⁸ evaluated the literacy requirements of printed diabetes resources used on a northern American Crow Reservation. Analysis frameworks for readability, vocabulary, and numeracy demand for 36 teaching materials. Diabetes educational materials were assessed as neither culturally relevant nor aligned with the reading skills of the Crow population. Indigenous diabetic patients may have experienced limited understanding of these materials, and health care providers may have encountered barriers to the provision of diabetic education. Inclusion of charts and graphs, definitions of health-related terms, and attention to

how Indigenous story-telling and health provider social interaction was recommended to inform understanding of diabetes print education. The use of the Cultural Sensitivity Assessment Test³⁴ although not Indigenous in nature was suggested as a method to assess cultural alignment of printed material.

Articles That Identified Tool Characteristics Underpinned by Co-Development

Five articles described culturally appropriate educational resources and tools that appeared to be informed by co-development: (1) extensive consultation with Indigenous stakeholders; (2) infusion of cultural elements into the tool; (3) integration of Western with traditional Indigenous knowledge, and (4) evaluation to measure tool effectiveness.^{7,19-22}

Browne et al¹⁹ described an engagement process of producing, disseminating, and evaluating an Indigenous-specific diabetes resource to prevent and manage type 2 diabetes in Australia. The process began with consultation and partnership with Victorian (Australia) Aboriginal Health Workers, Aboriginal Controlled Community Health Center Workers, and Diabetes Australia to develop a diagrammatic felt body. This life-size body, named the “Feltman” features movable felt organs that are used interactively by educators, diabetic patients, and families to support understanding about diabetic-related physiological changes, particularly related to digestion and food metabolism. The Feltman package also includes an interactive educational DVD, a manual and a series of cards to be used by health workers in patient and community educational settings. Findings from a survey completed by health workers who participated in the study revealed the “Feltman” was culturally appropriate and increased the health workers’ confidence in providing diabetes education.

Carter et al²⁰ designed culturally relevant diabetes materials for a Native American educational program in Rio Grande, Mexico entitled “Strong in Body and Spirit.” This collaborative pilot project between Indian Health Service Professionals, community members, and university research staff was based on Social Action Theory and the Transtheoretical Model of Stages of Change. A strength-based perspective was applied to the project by incorporating Indigenous prayer, stories, and interactive skill-based learning. Curriculum content and design was informed by focus group discussions with a community advisory group; feedback from health care and tribal health workers; and baseline interviews with diabetic patients about quality of life, diet and exercise knowledge, attitudes, behaviors, and family support. Traditional Indigenous-led educational approaches were also integrated in the program through stories, brochures, and videotaped educational sessions. Results of this project revealed that culturally appropriate brochures could supplement curriculum content and decrease the length of the education program.

Clark et al²¹ redesigned a heart failure resource with health care providers, heart failure patients, researchers, and clinicians to support culturally appropriate education for Indigenous and Torres and Strait Islander people in Australia. Indigenous peoples' voices conveying active presence were used to record the narratives. Text was written in plain language and converted to first-person tense to support cultural alignment. The resources were then empirically tested for feasibility. Patient satisfaction was measured using a pretest and posttest design with a validated questionnaire. Findings supported patient satisfaction and feasibility, specifically for increased knowledge and self-care.

Kaufman et al²² described an HIV curriculum development process with American Indian and Alaskan youth. The development of 2 curricula, one for kindergarten to grade 6, and one for middle year to high school students, was based on integration of the medicine wheel philosophy, behavioral change theories such as social-cognitive³⁵ and research-based curricula models.³⁶ Feedback obtained from Indigenous communities, educators, and students during pilot implementation suggested that HIV knowledge was enhanced, and sexual behavior was delayed. Additional recommendations were made to promote flexible curricular implementation, specifically by attending to local Indigenous contexts and innovative budget management. A digitized model was ultimately developed through collaboration with a sexual health program to mitigate implementation costs and promote adaptability to diverse educational settings.

Paterson et al⁷ conducted a participatory research study with the Elsipogtog First Nation communities in New Brunswick, Canada to explore why community members with CKD may refuse treatment. The project also intended to create strategies to support treatment decision making. A community advisory committee that comprised elders, family members, health care providers, and clients receiving dialysis provided guidance for the study. Indigenous theoretical perspectives of holistic connections, relationships, and historical oppression were embedded in the research approach. The study was also guided by holistic health perspectives from the Aboriginal Life Promotion Framework in Research³⁷ and an iterative process of "Thinking, Planning, Knowing, Action and Evaluation."³⁷

The project culminated in a co-developed culturally appropriate toolkit "Ripples in the Water" that addressed strategies for CKD treatment decision making. The toolkit, which comprised DVDs, a manual, and a calendar diary, can be adapted and introduced to the patient and family when they feel it is appropriate to participate in educational sessions. It can also be used to encourage collaborative discussions amongst patient groups, patients and families; support the grieving process, access and advocacy for preferred health services; and importantly, promote working relationships among patients, family members, and health care practitioners.

Discussion

This review revealed that there are few co-developed Indigenous CKD educational tools, which are both comprehensive and holistic. Although gray literature tools are anticipated to foster collaborative learning and patient- and family-decision making for renal treatment options, little evaluative evidence exists to support effectiveness or how to go about co-development to meet Indigenous peoples' educational needs. The foci of the articles that were included in the review varied from elements of cultural appropriateness, appraisal of the utility, and effectiveness of the tools to characteristics informed by co-development. Findings also provided insights into the importance of the *process* of educational tool development—a process that engages and incorporates Indigenous culture, traditional and Western health knowledge, and relational learning through working relationships and community engagement. Lessons learned from this process can be applied in the co-development of Indigenous CKD educational tools and more broadly with other chronic conditions. Cultural appropriateness is an important element in provision of care to Indigenous populations.³⁸ Health care providers and practitioners need to find ways to strike a reciprocal partnership with Indigenous communities when developing such tools.

Consistent with the limitations of scoping review methods, the methodological quality of the included studies was not assessed. It was also difficult to synthesize findings from the research and gray literature, create distinct categories due to conceptual and method variability and in this instance, few retrieved Indigenous tools.³⁹ Thus, narrative tool description is used as a method of reporting and summarizing findings. Platforms where gray literature is found are very fluid and materials are constantly changing. Hence it may not be possible to unearth information relevant for such a review. In addition, this scoping review provided insights into the co-development of Indigenous educational tools.

Optimizing cultural appropriateness of educational tools requires appropriate utilization of the language and culture to inform the development of the resource. In addition, appraising the effectiveness of an existing educational tool can lead to the improvement of the educational tool or a determination of its usefulness in meeting its intended purpose. A primary consideration for assessment of educational tools is evaluation of literacy alignment with local Indigenous community languages and cultures. Development of Indigenous educational resources should utilize cultural assessment frameworks¹⁸ and include culturally relevant language with a well-defined content.^{20,23,24,40} Visuals such as graphs and charts^{15,26,28-31} and other interactive modalities and participatory strategies have been found to be effective.^{19,25,27} Infusion of Indigenous cultural elements such as Indigenous prayer^{7,20}; traditional stories¹⁸; and inclusion of an Indigenous voice in videotaped material^{7,20,21,23} can enhance ownership of the educational product.

Extensive consultation of Indigenous stakeholders including Indigenous health professionals and those who work in these communities, community leaders and patients, is a vital safeguard for the co-development of culturally appropriate materials.^{7,16,19-22} Such an approach is likely to foster a sense of community ownership in the outcome, improve working relationships with the community and enhance tool uptake by both Indigenous people with chronic disease and health care providers. Participatory action approaches provide insights and practical strategies to support culturally responsive approaches to educational tool development. Ultimately, these approaches can inform co-decision making for CKD treatment options, including health care providers' understanding of co-developed processes to enhance Indigenous equitable treatment as defined within the "Calls to Action" of the Truth and Reconciliation Commission.⁶

Incorporation of Indigenous philosophical perspectives and ways of knowing and identity in the education tools not only honors Indigenous knowledge but also ensures that the Indigenous people are actively engaged from the conceptualization of the project to its conclusion. Diverse forms of Indigenous philosophies that were incorporated in the articles reviewed include those that use the medicine wheel,^{17,22} and strength-based approaches such as "Strong in Body and Spirit."²⁰ These studies underline the importance of representation and identity within stories, Indigenous images and voice in educational resources. Studies have shown that Indigenous health promotion tools are more effective if they are couched in terms that are in harmony with Indigenous worldviews.⁴¹ Such projects must be based within a complex social environment that respect Indigenous knowledge, culture, and social systems⁴² and be adaptable to local community contexts.

Researchers and Indigenous partners integrated frameworks such as the Aboriginal Life Promotion in Research³⁷ and Western-informed social action and change theories^{20,22} to guide the co-development of the educational tools. This approach is consistent with Indigenous Cultural Responsiveness Theory⁴³ and the concept of "2-eyed Seeing," theoretical frameworks that embrace Indigenous and Western ways of knowing and apply these 2 perspectives to solve questions about the health of the Indigenous people and communities.⁴⁴

As we proceed with the project Can-SOLVE CKD to develop Indigenous CKD educational tools, this review can inform the development of these tools for Saskatchewan, British Columbia, and Ontario Communities. The co-opting of a northern Indigenous knowledge keeper with extensive knowledge of community where the tool will be applied has proved to be of tremendous benefit to the review. The framework for co-development of Indigenous-specific educational tools for CKD can be also utilized for the co-development of other health educational tools in Indigenous communities considering the findings of this review related to tool characteristics, utility, and effectiveness and implications for co-development in meeting the needs of Indigenous people.

Conclusion

The findings of this scoping review suggest the importance of essential connections and working relationships amongst researchers, health care providers, family, Indigenous community members, and Indigenous patients with CKD. A co-developed approach to support educational processes versus a didactic focus on educational tool content and tasks is needed. Application of strength-based perspectives and "how to" strategies underpinned by Indigenous and Western experiential knowledge is important to inform culturally responsive educational approaches to CKD education and treatment options. The key finding from the review is that for Indigenous education tools to be specifically acceptable and utilized by patients, families, and communities, they must be co-developed and applied.

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Ethics Approval and Consent to Participate

Ethics approval and consent were not obtained as secondary data were used for this scoping review.

Consent for Publication

All co-authors reviewed this final manuscript and consented to its publication.

Availability of Data and Materials

The data and materials that support the findings of this scoping review are available from the corresponding author L.J. upon reasonable request.

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ORCID iD

Lynn Jansen  <https://orcid.org/0000-0002-7390-9990>

Supplemental Material

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