

Decision Needs and Preferred Strategies for Shared Decision-Making in Rheumatoid Arthritis: Perspectives of Canadian Urban Indigenous Women

Valerie Umaefulam,  Terri-Lynn Fox, and Cheryl Barnabe 

Objective. Decision-making for treatment of rheumatoid arthritis (RA) is complex, with multiple beneficial medication options available, but with the potential for treatment-related adverse effects and significant economic considerations. Indigenous patients make treatment decisions informed by an interplay of clinical, family, and societal factors. Shared decision-making may represent an approach to support treatment decisions in a culturally congruent manner. Our objective was to identify aspects of arthritis care that Indigenous participants found relevant for shared decision-making and to explore preferences for shared decision-making strategies.

Methods. A purposive sampling from rheumatology clinics that provide services to Indigenous patients in a Canadian urban center was used to recruit participants for interviews. Seven participants were recruited to reach content saturation. Interview content was coded by 2 individuals, including an Indigenous patient with RA, and the data were analyzed via thematic analysis.

Results. Participants were all women ages 37–61 years living with RA. Participants supported the idea that shared decision-making would be beneficial, primarily to support decisions around treatment plans and medication changes. Shared decision-making approaches would need to reflect Indigenous-specific content areas, such as benefits and risks of therapy informed by data from Indigenous patient populations and inclusion of traditional modes of healing. All participants were interested in having a decision coach and preferred that decision aids be in both paper and electronic formats for accessibility.

Conclusion. This study advances knowledge in the priority areas and specific content needed in the shared decision-making process and the preferences of shared decision-making strategies relevant and appropriate for urban Indigenous women living with RA in Canada.

INTRODUCTION

Rheumatoid arthritis (RA) is an autoimmune disease that causes inflammation and damage to joint tissues. Indigenous patients in Canada, including First Nations, Métis, and Inuit Peoples, experience a significant burden of RA, both in increased prevalence and in differential treatment outcomes relative to the general population (1). Colonization events and ongoing structural and interpersonal racism have created mistrust of the health care system, impacting access to care, and influencing decision-making approaches for treatment. In a prior study, we explored with Indigenous patients how they make treatment decisions.

Their approach includes the use of nonpharmacologic methods, with pharmacologic decisions representing an interplay of clinical, family, and societal factors, including ease of access to medication options and fear of drug-dependency stigmatization (2). In other population groups facing arthritis inequities, shared decision-making is increasingly advocated as a mechanism to improve patient satisfaction and decision quality (3). Additionally, shared decision-making is highly valuable to employ when there are various medically reasonable options available, such as in current-day arthritis treatment (4,5). Shared decision-making, as used in this study, involves the health provider ensuring that patients are aware of available

Dr. Umaefulam's work was supported by Eyes High Postdoctoral Scholarship, University of Calgary. Dr. Barnabe's work was supported by a Canada Research Chair, Rheumatoid Arthritis and Autoimmune Diseases, Canadian Institutes of Health Research.

Valerie Umaefulam, PhD, Terri-Lynn Fox, PhD, Cheryl Barnabe, MD, MSc: Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada.

No potential conflicts of interest relevant to this article were reported.

Address correspondence to Cheryl Barnabe, MD, MSc, Associate Professor, Department of Medicine and Department of Community Health Sciences, Cumming School of Medicine, University of Calgary, 3330 Hospital Drive NW, Calgary, Alberta, Canada T2N 4N1. Email: ccbarnab@ucalgary.ca.

Submitted for publication November 16, 2020; accepted in revised form February 9, 2021.

SIGNIFICANCE & INNOVATIONS

- The study advances understanding of shared decision-making with urban Indigenous women living with rheumatoid arthritis in Canada.
- Shared decision-making approaches would need to reflect Indigenous-specific content areas, such as benefits and risks of therapy informed by data from Indigenous patient populations, inclusion of traditional modes of healing in available options, and medication cost coverage details.
- Urban Indigenous women with rheumatoid arthritis were interested in a shared decision-making strategy that involves having a decision coach and preferred that decision aids be in both paper and electronic formats for accessibility.

treatment options, providing detailed information about choices, discussing the patient's preferences, and making treatment decisions with patients (4).

Cultural belief systems influence perception of engagement in health care (6) and may result in varying interests in shared decision-making. Although several approaches are available to support shared decision-making in arthritis, there is limited exploration of the role of shared decision-making in arthritis care in the context of Indigenous peoples' health care. Further, few shared decision-making strategies have been specifically developed with and for Indigenous peoples (7,8). Thus, this study sought to identify whether Indigenous patients living in an urban center had an interest in participating in shared decision-making for RA care and which aspects of that care were relevant for shared decision-making, and we sought to

explore preferences for shared decision-making strategies that could be employed.

PATIENTS AND METHODS

This study used a qualitative descriptive approach grounded in phenomenology to explore the perceptions of urban Indigenous participants on shared decision-making for arthritis care. To ensure that participants who had experienced the phenomenon of interest were included in the study (9), Indigenous patients with RA were recruited via a purposive sampling process from urban rheumatology clinics that provide services to Indigenous patients in Calgary, Alberta, Canada. Recruitment was facilitated via written formats such as posters and bookmarks. A physician, nurse, or medical assistant informed the patient of the study, and if the patient was interested in participating, introduced them to a research team member.

The Ottawa Decision Support Framework informed this study, which shows the interplay between addressing decision needs and providing the necessary support via the appropriate strategy (10). The framework constructs, including knowledge, values, clinical counseling, decision tools, and coaching (10) were integrated in the data collection instrument. Data were collected via semistructured interviews using an interview guide (Table 1). The interview guide was developed to explore patients' perceptions about the potential role of shared decision-making in arthritis care, priorities for application of shared decision-making, and preferences for shared decision-making strategies. The authors are all female Indigenous health researchers, VU possesses experience in qualitative approaches, TLF identifies as a First Nations person with lived experience of RA, and CB is a Métis rheumatologist. Participants

Table 1. Outline of interview guide

Scope	Questions
Personal narrative	Please tell me briefly about your experience living with inflammatory arthritis. What does shared decision-making mean to you? Prompts: physicians, influence of others. Have you experienced shared decision-making in health care? If yes, can you describe when and how this happened? Prompts: past experiences, importance of certain outcomes.
Shared decision-making priorities	What decisions in arthritis treatment do you feel you need assistance with, or health care providers should spend time discussing with you? Can you give some examples of decisions that you would like to be involved in when managing arthritis? Prompts: treatment plan, choice of medication, general information. What types of decision support do you need? Prompts: clarify decisions, provide facts, monitor progress?
Shared decision-making approach	There are various approaches that can be used in shared decision-making, such as using decision tools that can be completed online or by paper, or having a decision coach work with you in making decisions. Which approach would you prefer? Probes: Why would you prefer this approach? Would you like having a decision coach? Who would you like to be your coach? Prompts: friend, nurse, physician? If the shared decision-making strategy is developed, would you use the tool/strategy? When would you like to use this shared decision-making approach? Probes: Before or during arthritis treatment.

received an information brief containing a description of shared decision-making and a summary of the purpose of the study before the interview to allow for review and reflection. VU explained the reasons for the research and conducted the interviews. Each interview was approximately 45 minutes in duration and all were held in-person at medical clinics in Calgary. Nonparticipants were not present. Audio recordings were transcribed, and the transcripts were reviewed and coded by 2 individuals (VU and TF). The data were analyzed via inductive thematic analysis using NVivo software, based on thematic analysis phases, i.e., data immersion, initial coding, theme/category creation, and reviewing and refining themes (11). The data were organized into groups of meaning that represented the lived experiences of participants (9).

RESULTS

Seven participants were recruited from 3 rheumatology clinics to reach content saturation. They were all urban Indigenous women ages 37–61 years, living with RA. In summary and as described further in detail, shared decision-making was found to be acceptable for arthritis care by urban Indigenous women. Suggested priorities of support would be for treatment decisions informed by Indigenous population data, with inclusion of traditional and cultural treatment options in care plans, and reflecting available medication cost coverage options. Preferred shared decision-making strategies were those that included decision coaching and decision aid tools in both print and electronic formats. Figure 1 outlines the shared decision-making priorities and preferred approaches.

Role of shared decision-making for RA care. Although 2 participants indicated that they had not experienced shared decision-making before in health care, most participants noted that shared decision-making was not a new concept to their general health management. For instance, a participant indicated in regards to her family physician, “She asks me questions...like, ‘What do you think...is the best decision?’ and ‘We can do this or we can do that,’ and she asks me, if I want to do this or that” (patient 1). Another participant said, “My regular family doctor, he was very more understanding, and he showed me...and he sat down with me and we talked about my medications” (patient 7). Some participants detailed how not being involved in health decisions impacted their lives. In the words of a participant, “I trusted and blindly accepted the treatments that other doctors had given me prior to this, and then I started getting to a point where I felt like they weren’t telling me what some of the drugs were. They’d just say, ‘Here, take this,’ and then I’d walk off and have side effects” (patient 3). A participant commented that the communication disconnect with physicians does not enhance or support shared decision-making and stated, “[The doctor] doesn’t seem to have any time. I mean, he allows you maybe 15 minutes, and then he’s on to the next patient. I’d like to at least

know what’s going on. Don’t rush me out of the room. I’d like to know what I can do, what I can take” (patient 5).

Conversely, some participants indicated having some exposure to shared decision-making in their rheumatology specialty care experiences. For example, one participant said, “My doctor, she does the best she can to share with me about the different meds I’m on, some of the side effects, and she supports my decisions, and she provides her expertise in her area. That this could work, but this one seems to be working well, so she always leaves it up to me...I’m also active in that decision, and that’s what I appreciate” (patient 2).

When reflecting on whether shared decision-making would have a role in arthritis care, participants voiced valuing active engagement in their care and were open to tools and opportunities to facilitate informed arthritis care decisions with their physicians. The underlying trust, respect, and relationship between the physician and patient would impact shared decision-making, and more importantly, empowerment, self-determination, and self-efficacy. A participant said, “We’re a person, and you’re a part of our health care team, and so treating someone with respect goes a long way. We feel good, and that helps. That helps in anyone’s well-being... and the health care professionals with their gentle guidance and their respect and sharing what they do, I felt empowered” (patient 2). Overall, all participants disclosed that if a shared decision-making strategy was available for arthritis care, they would use it.

Shared decision-making priorities in RA care. Given that interest in shared decision-making was supported by the participants, they were then asked what priority areas would be for its application. Two areas emerged: the identification of specific content needed in the shared decision-making process and the type of decision support desired.

Decision support priorities. Participants indicated that shared decision-making would help to support decisions around RA treatment plans and medication changes. To illustrate, a participant was interested in knowing, “if I can come off biologics and just try methotrexate. Like, how long can I be on it [biologics] before it is like, harming me, or if I stay on it for the rest of my life, is it going to...damage me more?” (patient 1). Further, another participant stated, “Well, the treatment plan, I think that they should all discuss a survey that was done...why they feel that this treatment plan would be good for you” (patient 3).

All participants expressed the need for extensive knowledge of available treatments for arthritis and the side effects of drugs prescribed. They were all concerned about the impact of the drugs on the body, whether the drugs were hurting them, and when is the best time to change medications. A participant noted, “Someone to clarify what the medications do to the body and I feel like everybody should have a right to know what they ingest or they put in their body, especially through doctors and therapists and stuff like that” (patient 3).

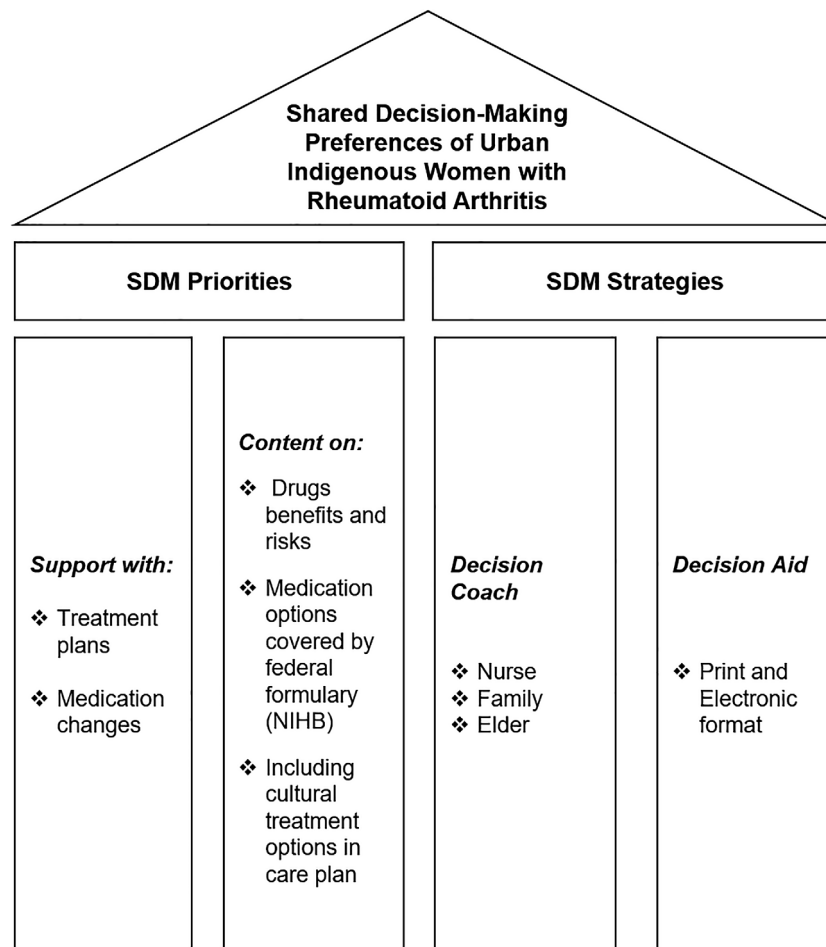


Figure 1. Priorities and preferred strategies for shared decision-making. NIHB = Non-Insured Health Benefits; SDM = shared decision-making.

Specific shared decision-making content areas for Indigenous patients. Some participants said that shared decision-making strategies should incorporate evidence from Indigenous population or patient studies, particularly regarding medications and their effects, which would assist in motivating patients in adhering to treatment plans. One participant noted, “I think there are specific data, statistics...not just general population, but maybe specific Indigenous-population data...because there’s so many of us that are affected in such a short span of time” (patient 2). Another participant emphasized drawing shared decision-making information from Indigenous communities, stating, “There’s just a lot of information here” (patient 5).

Another aspect of specific shared decision-making content was to include options related to traditional modes of healing in care plans. These modes of healing support not only physical wellness, but also spiritual, emotional, and mental wellness. Two participants mentioned the benefits of traditional practices such as prayers and sweats on health care, and suggested including traditional medicine practices and integrating Elders in care. A participant stated, “There’s an Elder here. Perhaps it could be beneficial to meet with him...that might have a holistic approach

to some kind of salve or herbs or something. You know, a lot of that wisdom and knowledge is lost today, just not been documented, and I think it would be very beneficial, instead of using all the pills or whatever the doctor wants to prescribe” (patient 5). First Nations participants with Treaty Status suggested that decision tools provide information on which medication options would be covered by the federal formulary (Non-Insured Health Benefits) and which medications would not be, as this knowledge would impact the ability to obtain medication offered in the options.

Preferred shared decision-making strategies.

Participants discussed various types of shared decision-making approaches that could be used for arthritis care. They were open to using an electronic format of shared decision-making decision aids due to its convenience and the ease of obtaining information. As one person said, “I always Google stuff if I’m unsure. Yeah, so I’m always on the computer” (patient 4). Nevertheless, patients equally acknowledged the difficulties of accessing information via devices such as computers and cell phones among individuals with limited or no accessibility. Given this fact, most participants

preferred a shared decision-making decision aid that used a combination of paper and electronic resources. One participant stated, “So, online support. And I’m saying that just for me, because I find myself...I’m privileged to be able to have a cell phone, to be able to have Internet access at home. However, there’s a majority of people on reserve that use landlines. They may not have a cell phone. They may not have access to Internet. So, paper resources” (patient 2). Another recognized the advantage of paper resources: “You can lose papers and documents, but sometimes, for some people, they keep onto that, so you know you have something to go back to, a hard copy” (patient 6).

Moreover, participants suggested that the shared decision-making strategy should incorporate Indigenous language translations, to be relevant specifically to older individuals who maintained their own language. Another suggestion was that text associated with shared decision-making decision aids should be simplified for better comprehension and include appropriate Indigenous symbols and images to demonstrate respect for Indigenous culture. According to a participant, “Translating it as best as we could, and utilizing, if it’s a visual, utilizing Indigenous symbols so that it’s meaningful to patients...so that we know you care about who we are as part of this culture, or this land area, and you’re further respecting and responding to our cultural needs as well” (patient 2).

There was general interest in a shared decision-making approach that involved having a decision coach insofar as having an individual who would provide one-on-one interactions, relate with patients outside the regular clinic visits, respond to inquiries, and have knowledge of the arthritis condition and treatment options. As explained by one participant, “I would like to have somebody, talk to me and explain to me, my options about my medications. And like I said, to find out what’s good and what’s bad...what it does to my body and all this” (patient 7). Another participant stated, “I think that [decision coach] is a really good idea. I think someone who knows the industry, who knows the medication, who understands those who have been affected by extreme excruciating pain” (patient 2). There was resounding agreement for decision coaches to have sufficient time to discuss treatment options, reflecting the fact that time with the physician is often limited to enable extensive discussions. There were differing suggestions on who a decision coach might be. Some suggested nurses, as they work closely with physicians: “I feel like they [physicians] have a lot on their plate...I feel like nurses would have that extra time to sit, well, in between patients, right? To talk, to have the one-on-one” (patient 3).

One participant articulated the importance of the decision coach having lived experience of arthritis and welcomed having a family member as a decision coach. She trusted that a family member would have her interest at heart and provide appropriate guidance in making decisions and commented, “Even my grandmother... She said something to me 2 weeks ago the last time I’d seen her, ‘Well, you have to do your exercises. There’re certain

exercises you have to do. I know, because I’m speaking from experience. I don’t care what your doctor said. Listen to me.’ And of course, I’m going to listen to an 84-year-old woman. She knows” (patient 6). Several participants noted the importance of also having a decision coach who would support holistic approaches for health.

One suggestion was to have an Elder work in collaboration with the decision coach to facilitate shared decision-making; this was expressed by one participant, “It would be new. And I would say an Elder, but an Elder may not have...specific drug, pharmacy knowledge, or how it works in your body, what the side effects could do. So it could be a combination of a doctor or, you know, someone who works closely with RA specialists, as well as an Elder who would pray and maybe translate for other members, but who would support that coach or that specialist to do it in a holistic way” (patient 2).

As a check for decision alignment, participants noted the importance of introducing the strategy before and after changing a treatment plan: “Well, I feel like you especially should start the regime...there could be that nurse that I could call and talk to, saying that, you know, ‘This is where I’m at with it, and I want to know, is this where I’m supposed to be?’” (patient 3).

DISCUSSION

Our study explored whether there is a potential role for shared decision-making in arthritis care of Indigenous patients. Racial, ethnic, and cultural minority groups are more vulnerable to poor decision-making outcomes, with a majority reporting low decision satisfaction and high decision regret (6). As a framework, shared decision-making can be used to communicate with patients about health care choices and has been shown to be beneficial to patient engagement and treatment outcomes by increasing adherence to treatment plans (12). Active involvement in health care decisions promotes self-determination, especially when such decisions involve personal preferences. Urban Indigenous women with RA indicated they wanted to be involved in making decisions regarding their health and articulated the importance of health care providers working with them to ensure that they have the information they need to make complex decisions (13). This approach also supports reconciliation; the Truth and Reconciliation Commission of Canada (TRCC) provided directives to facilitate actions to be taken in Canadian society to promote healing of and reconciliation with persons directly or indirectly affected by the Indian Residential Schools system legacy (14). We propose that for a shared decision-making approach with Indigenous patients to be effective, clinicians must respond to the TRCC Calls to Action in Health (15). These include recognizing, respecting, and addressing the distinct health needs of all Indigenous peoples (Call to Action #20); ensuring that they gain training in cultural awareness and safety (Call to Action #23); understanding Indigenous health issues (Call to Action #24);

promoting and supporting Indigenous health approaches (Call to Action #22); and moving forward with reconciliatory practices in all areas and close gaps in health outcomes (Call to Action #19). Understanding Indigenous people from a historical-cultural perspective is needed, especially when striving toward health and well-being. Respecting patient perspectives and forming trustful relationships is an intentional and positive approach for shared decision-making.

Indigenous participants said that shared decision-making would be useful primarily to support decisions around treatment plans and medication changes. Patients do not always know the side effects of medications and require additional information, clear communication, and better understanding of medications. For instance, many patients suffer from medication side effects (16), rather than the actual pain and immobility of RA. Enhancing knowledge related to care may lead to medication choices better aligned with patient values and preferences in arthritis treatment (17). As patients develop a trusting relationship with their rheumatologist and educate themselves on RA and its available treatments, they gain confidence and pursue a mutual role via shared decision-making in their treatment decisions (18).

Specific content and information pertaining to Indigenous population realities were regarded as essential, particularly treatment benefits and risks unique to them, which treatment options have available medication cost coverage, and how cultural components of health could be considered in the treatment options presented. As health systems are increasingly burdened during this unprecedented time, we are reminded of the necessity of holistic health approaches, especially Elder knowledge and support, traditional herbs and medicines, and ceremonial practices and rituals that may relieve and decrease the amount of pain and discomfort felt by Indigenous patients with arthritis. Intergenerational knowledge, “blood memory” of traditional medicines and methods, is inherent in many First Nations communities, who desire to return to traditional ways. Since many Indigenous people long for traditional knowledge, particularly survivors of Indian Residential School and the Sixties Scoop, shared decision-making would be useful to support decisions around the inclusion of traditional modes of healing in care plans, especially the physiologic and spiritual aspects.

Decision support tools include decision aids that describe treatment options and their benefits and harms, and such aids may equally include a guide to decision-making (12). The tool may be web-based or printed material such as pamphlets or videos that assist patients in considering treatment options and outcomes, which proceed through the steps of deliberation and communication with the patients’ health care provider. For example, in a pilot study among RA patients, patients who used the RA Choice (a print-based resource) with their doctor reported significantly improved knowledge and low decisional conflict compared to those who did not use the tool (17). The study participants reported valuing combined electronic and print shared decision-

making aids that were user-friendly, attentive to health literacy challenges by applying plain language terms, and translated as needed in different Indigenous languages.

The need for conversation and accountability underlies the request for including a decision coach in the shared decision-making strategy. Decision coaching is a process that prepares patients to discuss options with their providers facilitated by a decision coach who may be a nurse, social worker, or other allied health professionals (19). Decision coaches may use decision support tools to guide the patient in deliberating about options with their health practitioner (19). In this study, the participants’ suggestions for a nurse, a family member, an Elder, or a community member with a lived experience with arthritis as a decision coach points to the importance of relationship, connection with tribal members, the closeness of families, role models, and the social interaction that helps mold and guide quality of life for Indigenous people. Decision coaching may improve knowledge and increase the perceived involvement in decision-making and satisfaction with the decision-making process (20).

We are aware of prior studies that have explored shared decision-making with Indigenous populations. The Ottawa Decision Support Framework was culturally adapted to produce a tool that better met the needs of Indigenous peoples (21) and enabled shared decision-making in Western health care settings. While aiming to refine the decision tool, the study also revealed that decision coaching was required to increase engagement in the decision-making process while using the adapted framework as a talking guide (21). Also, a shared decision-making strategy called “Not Deciding Alone,” developed for use by Inuit peoples in cancer care in Canada (7), included community support workers who provided peer support and facilitated the use of the tool (a booklet).

As our study was initiated in the fall of 2019, we were only able to recruit participants from the urban setting prior to the COVID-19 pandemic restrictions being enacted. Few participants were recruited, but the sample size is suitable for a phenomenologic study, which often needs 1–10 participants (9) and was sufficient to reach saturation. Participants were recruited from 3 rheumatology clinics in Calgary, and they received care from different physicians. The pandemic also limited our research population, such that individuals living in rural locations could not be included at this time. We did not include the perception of Indigenous men. Also, patients recruited to the study were actively engaged in Western health care systems and receptive to research participation; this demographic raises the possibility that the voices of Indigenous persons who have chosen to not interact with providers and researchers are not included. Future research that involves gaining insight from these groups could provide more exhaustive information on priorities and preferences for shared decision-making in RA care for Indigenous populations as we proceed to adapt and test the acceptability and effectiveness of a decision aid with this population.

Indigenous patients appreciate active engagement in decision-making for arthritis care. Our study sheds light on the importance of providing culturally safe health care practices with Indigenous patients in the health system when incorporating shared decision-making strategies. This study advances knowledge in the priority areas and specific content needed in the shared decision-making process and the preferences of shared decision-making strategies relevant and appropriate for Indigenous patients living with RA.

AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Barnabe had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Umaefulam, Barnabe.

Acquisition of data. Umaefulam, Fox, Barnabe.

Analysis and interpretation of data. Umaefulam, Fox, Barnabe.

REFERENCES

- Ng C, Kue Young T, Chatwood S. Arthritis in the Canadian aboriginal population: north-south differences in prevalence and correlates. *Prev Chronic Dis* 2011;8:A04.
- Loyola-Sanchez A, Hazlewood G, Crowshoe L, Linkert T, Hull PM, Marshall D, et al. Qualitative study of treatment preferences for rheumatoid arthritis and pharmacotherapy acceptance: indigenous patient perspectives. *Arthritis Care Res (Hoboken)* 2020;72:544–52.
- Barton JL, Trupin L, Tonner C, Imboden J, Katz P, Schillinger D, et al. English language proficiency, health literacy, and trust in physician are associated with shared decision making in rheumatoid arthritis. *J Rheumatol* 2014;41:1290–7.
- Stiggelbout AM, Pieterse AH, De Haes JC. Shared decision making: concepts, evidence, and practice. *Patient Educ Couns* 2015;98:1172–9.
- Li LC, Adam PM, Backman CL, Lineker S, Jones CA, Lacaille D, et al. Proof-of-concept study of a web-based methotrexate decision aid for patients with rheumatoid arthritis. *Arthritis Care Res (Hoboken)* 2014;66:1472–81.
- Hawley ST, Morris AM. Cultural challenges to engaging patients in shared decision making. *Patient Educ Couns* 2017;100:18–24.
- Jull J, Hizaka A, Sheppard AJ, Kewayosh A, Doering P, Macleod L, et al. An integrated knowledge translation approach to develop a shared decision-making strategy for use by Inuit in cancer care: a qualitative study. *Curr Oncol* 2019;26:1–27.
- Jull J, Giles A, Boyer Y, Lodge M, Stacey D. Shared decision making with aboriginal women facing health decisions: a qualitative study identifying needs, supports, and barriers. *Altern An Int J Indig Peoples* 2015;11:401–16.
- Starks H, Trinidad SB. Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qual Health Res* 2007;17:1372–80.
- Stacey D, Légaré F, Boland L, Lewis KB, Loiselle MC, Hoefel L, et al. 20th anniversary Ottawa decision support framework: part 3 overview of systematic reviews and updated framework. *Med Decis Mak* 2020;40:379–98.
- Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. *Int J Qual Methods* 2017;16:1–13.
- Hoffmann TC, Légaré F, Simmons MB, McNamara K, McCaffery K, Trevena LJ, et al. Shared decision making: what do clinicians need to know and why should they bother? *Med J Aust* 2014;201:35–9.
- Deber RB, Kraetschmer N, Urowitz S, Sharpe N. Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations. *Health Expect* 2007;10:248–58.
- Government of Canada. Truth and Reconciliation Commission of Canada. 2020. URL: <https://www.rcaanc-cimac.gc.ca/eng/1450124405592/1529106060525>.
- National Centre for Truth and Reconciliation. Calls to action. Winnipeg, Manitoba; 2015. URL: <https://nctr.ca/records/reports/>.
- Curtis JR, Xie F, MacKey D, Gerber N, Bharat A, Beukelman T, et al. Patient's experience with subcutaneous and oral methotrexate for the treatment of rheumatoid arthritis. *BMC Musculoskelet Disord* 2016;17:1–11.
- Barton JL, Trupin L, Schillinger D, Evans-Young G, Imboden J, Montori VM, et al. Use of low-literacy decision aid to enhance knowledge and reduce decisional conflict among a diverse population of adults with rheumatoid arthritis: results of a pilot study. *Arthritis Care Res (Hoboken)* 2016;68:889–98.
- Mathews AL, Coleska A, Burns PB, Chung KC. Evolution of patient decision-making regarding medical treatment of rheumatoid arthritis. *Arthritis Care Res (Hoboken)* 2016;68:318–24.
- Stacey D, Kryworuchko J, Bennett C, Murray MA, Mullan S, Légaré F. Decision coaching to prepare patients for making health decisions. *Med Decis Mak* 2012;32:E22–33.
- Dawn S, Légaré F. Engaging patients using an interprofessional approach to shared decision making. *Can Oncol Nurs J* 2015;25:455–69.
- Jull J, Giles A, Minwaashin Lodge, Boyer Y, Stacey D. Cultural adaptation of a shared decision making tool with aboriginal women: a qualitative study. *BMC Med Inform Decis Mak* 2015;15:1–13.