

# Qualitative Study of Treatment Preferences for Rheumatoid Arthritis and Pharmacotherapy Acceptance: Indigenous Patient Perspectives

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**Objective.** To explore patient preferences that influence decision-making in the management of rheumatoid arthritis (RA) by indigenous patients living in southern Alberta, Canada.

**Methods.** We conducted a qualitative narrative-based study within a social constructivist framework. Thirteen in-depth interviews with indigenous patients with RA who had attended 1 of 3 rheumatology practices in southern Alberta (1 rural and 2 urban) were completed. Codes generated through 2 phases of analysis were condensed into main themes, triangulated, and used to produce theoretical statements.

**Results.** Patients preferred to use a combination of nonpharmacologic and pharmacologic treatments to manage their RA. Nonpharmacologic treatments included physical, mental, emotional, and spiritual strategies. Patients' preferences for taking medications varied and were influenced by factors that were clinical (i.e., trust in health providers and understanding drugs' mechanisms of action, benefits, harms, and administration burden), familial (i.e., support), and societal (i.e., access to medications and stigmatization of drug dependency).

**Conclusion.** Indigenous patients apply a holistic approach to the nonpharmacologic management of RA. Increases in preferences for RA medications could be supported through enhanced communication strategies to increase patient understanding of medication effects and health provider recognition of societal and familial influences on patient decisions. A patient–provider relationship based on trust was fundamental to reaching mutual understanding and should be fostered by models of practice that promote cultural safety, empathy, compassion, openness, acknowledgment, and respect of cultural differences.

## INTRODUCTION

Indigenous peoples in Canada include members of the First Nations, Métis, and Inuit communities. In Alberta, Canada, the First Nations population has a 3-fold higher prevalence of rheumatoid arthritis (RA) than the non-First Nations population and are less likely to receive specialist care (1). System barriers (including an unresponsive specialist system [2]) or differences in the ability to access required therapies (3) may contribute to worse RA outcomes, including lower rates of remission (4,5) and worse patient-reported outcomes (5). Other factors that contribute to worse outcomes in RA may exist, including the application of

a biomedical model at the expense of a patient-centric holistic model (6) and perpetuation of health care providers' belief that indigenous patients do not “buy-in” to mainstream health services and have a low understanding of their value (2). It is critical to challenge this belief; explaining the “unwarranted variation” (7) in indigenous peoples' treatment patterns to be a result of low appreciation for Western medicine reinforces the flawed stereotype of indigenous patients as “prone to reject” Western health care services (including medications), which is at odds with the practice of patient-centered care.

Although there is supportive evidence that differences in preferences for receiving medications are related to ethnicity (8,9),

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### SIGNIFICANCE & INNOVATIONS

- Nonpharmacologic treatments accepted and practiced by indigenous patients with rheumatoid arthritis (RA) reflect the importance of addressing the physical, mental, emotional, and spiritual aspects of living with this chronic condition.
- Preference for receiving pharmacologic treatments is positively influenced by the understanding of medication benefits and harms, a trust-based patient-provider relationship, familial support, and ease of access to medication cost coverage, whereas it is negatively influenced by societal stigma related to stereotypes of indigenous peoples, which result in fear of drug dependency.
- Rheumatology care should employ shared decision-making strategies within culturally safe environments to support RA management for indigenous patients.

knowledge about Canadian indigenous peoples' preferences for RA management is scarce. It is possible that the preferences of indigenous peoples are shaped by cultural differences in treatment beliefs and approaches and by the historical colonial forces that have created health care access barriers and shaped the current relationships between indigenous peoples and nonindigenous health care providers. It is of the utmost importance to explore and understand indigenous peoples' preferences for RA management and how such preferences can include appreciation of Western-based pharmacotherapy, since treatment with disease-modifying antirheumatic drugs (DMARDs) is the only proven therapeutic strategy to prevent joint damage in RA (10). The objective of this study was to explore the management preferences of indigenous patients with RA who attended specialized rheumatology clinics in Southern Alberta, Canada.

### PATIENTS AND METHODS

This was a qualitative, narrative-based study that was conducted within a social constructivist framework, which considered social reality as constructed by people's perceptions and ideas (11). We contemplated patient narratives as socially constructed forms of acting in and making sense of the world (12). Through the use of a social constructivist framework, it was implied that patients who were involved in the study constructed events through their narratives rather than simply referring to them.

**Study population.** Recruitment occurred at 3 outpatient rheumatology clinics that were staffed by faculty associated with the University of Calgary. One clinic is at the Siksika Health and Wellness Center located in the Siksika Nation, a rural First Nations reserve. This reserve has a population of approximately 7,000 members of Blackfoot origin, who are distributed throughout a

geographic expansion of 186,000 acres (13). The wellness center hosts a monthly rheumatology outreach clinic. The second clinic is at the Elbow River Healing Lodge, an urban indigenous primary service clinic in downtown Calgary. The third clinic is at the Richmond Road Diagnostic and Treatment Center in Calgary, where service is provided to the general population, including indigenous patients. Patients with RA attending these clinics and who self-identified as indigenous were invited to participate in the study. The rheumatologists for these patients provided basic information about the study purpose, and a research assistant obtained individual informed consent. All interviews were conducted in a quiet room at the clinic or at the patient's home (if preferred). A maximum variation sampling strategy (14) was performed to include people with different disease durations (i.e.,  $\leq 1$  year, between  $>1$  year and  $\leq 10$  years, and  $>10$  years). The sampling process stopped after theme saturation (15), implying that no new narratives about personal RA experiences, management, and approaches were generated during the last interviews. Using theme saturation as the main criterion to stop recruiting patients was in line with the deductive data collection approach utilized (i.e., we determined a priori that we wanted to collect stories about treatment preferences). Despite efforts to include more men, female narratives dominated in the sample, which was in alignment with the demographics of the population who usually attend these rheumatology clinics.

**Ethics.** Research was undertaken following the principles of Ownership, Control, Access, and Possession (16), and of the Tri-Council Policy Statement 2 Chapter 9 for ethical indigenous health research (17). Memoranda of understanding with the chief executive officer of Siksika Health Services (entrusted by Band & Council) and the medical director for the Indigenous Wellness Program of Alberta Health Services were developed by the principal investigator (CB) and outlined the responsibilities of the research team to the indigenous community. Eligible patients were provided with information about the study, and written individual consent to participate was obtained. The University of Calgary's Conjoint Health Research Ethics Board approved the study (REB15-2381).

**Data acquisition.** Three researchers (AL-S, TL, and PMH) conducted in-depth, individual interviews according to a semi-structured interview guide. The guide was created to facilitate the collection of narratives about illness trajectories, explanatory models of illness causation and management, and treatment decision-making and preferences. The 3 researchers iteratively refined the interview guide as the interviews were progressing and new themes were emerging (see Supplementary Appendix A, available on the *Arthritis Care & Research* web site at <http://onlinelibrary.wiley.com/doi/10.1002/acr.23869/abstract>). The interviews were conducted between February and November of 2016. Interviews were audio recorded and then transcribed verbatim by a professional transcriptionist.

**Analysis.** Transcribed interviews were anonymized and stored in a qualitative data management online platform (Dedoose). Data processing and analysis occurred in 2 main phases that were aimed at identifying narratives as social constructions that give meaning to lived experiences. All 3 researchers who were involved in data acquisition and the first round of analysis were non-indigenous; 2 were health care providers who were not involved in the care of the patients, and one had a background in journalism. These researchers have diverse training in qualitative methodology and worked together as a team to define the narrative-based methods applied in this study.

During the first phase of analysis, each investigator independently coded the first 3 interviews and discussed their coding schemes as a group in order to create a codebook. This codebook was used to identify narratives in all transcripts. Each researcher coded different transcripts and allowed for the emergence of new codes. Main codes were used to identify main themes related to preferences for illness management through a conventional content analysis (18).

Following the initial coding, an independent second analytic phase was completed through a directed content analysis (18). The aim of this phase was to identify specific narratives

about the patients' personal stories, how they experienced their health care in general, how they experienced their RA, and how they managed their RA. The codes identified were organized in a table, and the analysis team held several in-person meetings to apply constant narrative comparisons and to agree on the identified themes, representative quotes, and interpretive statements. The validity of the interpretive statements was then tested using the representative quotes, and occasionally consulting whole transcripts. In an effort to increase trustworthiness and accuracy, our results and interpretations were further confirmed by comparing the themes that were identified in each of the 2 analytic phases (i.e., methodological triangulation). The analysis was then reviewed with the remaining members of the study team, 2 of whom were members of the indigenous community in southern Alberta and have previously collaborated on qualitative research in rheumatology (LC and CB), and 2 were quantitative researchers in patient preferences in rheumatology (GH and DM).

## RESULTS

Thirteen indigenous patients with RA were recruited to the study. The average age of the group was 52 years (range 28–72

**Table 1.** Representative quotes of nonpharmacologic management approaches for rheumatoid arthritis

Theme: managing the physical aspects of illness	
Nutrition	"Food is a medicine...My kids...they just try and share the different foods or like what is naturally available that is an anti-inflammatory...they worked in ancient times and...we're just not aware, right, of these foods as medicine," (45-year-old woman)
Balneotherapy*	"I take a lot of Epsom baths too...just the Epsom Salts (magnesium and sulphates), put in the bath." (47-year-old woman)
Mobility aids	"We...get a pole put in my room...To help myself get up...And they put those lifting bars in the bathroom for me...And that bath thing you sit on. And they had to lift up my seat on the toilet in the bathroom...I'm not just on my cane, I use my walker at home and I have a wheelchair...They had to put a ramp at my house not too long ago..." (54-year-old woman)
Theme: managing the mental aspects of illness	
Self-management and self-advocacy	<i>Self education:</i> "...I educate myself, I self-educated and I've gone through a bit of schooling to have some understanding of who I am as a person and where I wanna be in life. And...it gives you a lot of insight... allows you to understand yourself." (57-year-old woman) <i>Managing appointments:</i> "...I said you know it would've been nice not to have a morning appointment...I try not to book appointments at all for early morning because...It's near impossible." (57-year-old woman)
Mindfulness	<i>Positive thinking:</i> "I refused the medication and I'm glad I did because it was something that I was able to overcome with being positive and not letting that negativity overtake me, so I believed." (57-year-old woman) <i>Meditation:</i> "I started counseling and I did more meditation and I drank more water and I did more reading about my, my illness and I tried to just be more aware and to empower myself..." (45-year-old woman) <i>Relaxation:</i> "...I relax, I get comfortable, my whole body gets comfortable, I level myself out and close my eyes and just relax and just let whatever comes through my mind..." (72-year-old woman)
Theme: managing the emotional aspects of illness	
Finding meaning from illness experience	"...it was a whole change in my emotional and mental health in making...conscious choices. This RA happened for a reason and it's teaching me something about myself and it's up to me to, to be my own medicine or to heal myself and not rely on outside factors...to heal me." (45-year-old woman)
Theme: managing the spiritual aspects of illness	
Smudging and praying	"Every morning we smudge and we pray to the Creator." (54-year-old woman) "I still smudge in the morning, I still attend ceremonies, I still paint my face at different times of the year... I pray to the old people..." (45-year-old woman)

\* Balneotherapy refers to the treatment of diseases through baths and bathing.

years). Twelve patients (92%) were female, and 9 patients (69%) lived in an urban setting. On average, patients had symptoms for 11 months (range 0–39 months) before diagnosis and had been living with the illness for 14 years (3 patients for  $\leq 1$  year, 4 patients for between  $>1$  year and  $\leq 10$  years, and 6 patients for  $>10$  years). Despite differences in age, residence location, and time living with RA, patients' narratives were consistent for the preference to use a combination of nonpharmacologic and pharmacologic treatments to manage RA. Moreover, these narratives allowed for the identification of some aspects that were associated with increasing trust between health care providers and patients, as trust was closely linked with preferences for taking pharmacologic treatment.

**Nonpharmacologic preferences.** Nonpharmacologic preferences included a variety of strategies that addressed the physical, mental, emotional, and spiritual aspects of living with RA (Table 1). Managing the physical aspects of the illness was commonly done through nutrition changes, balneotherapy, and the use of mobility aids. The mental aspects of RA were handled through self-management (such as self-education and self-advocacy) and mindfulness strategies (including positive thinking, meditation, and relaxation). Finding meaning in the illness experience was the main strategy to address the emotional impact of RA. Finally, preferences to spiritually manage the illness included the use of traditional healing practices, such as smudging and praying.

**Pharmacologic preferences.** Patients' narratives supported various preferences for undergoing pharmacologic therapy. Some patients preferred to completely adhere to their doctors' instructions, while others preferred to alter their medication prescriptions in order to accommodate their personal needs. Moreover, some patients preferred to completely reject prescribed medications by either failing to start them or discontinuing their use. These preferences were related with different themes described below and were representative of clinical, societal, and familial factors (see Table 2).

*Clinical factors.* Relationship with health care providers. The characteristics of the relationship that patients had with their health care providers were essential for the acceptance of pharmacologic treatment. Relationships based on trust resulted in greater acceptance of medications.

Perception of medications' effects. Patients' narratives revealed that their acceptance of therapy was dependent on their experience of medications as being beneficial or harmful. Perceptions of benefits were related to experiences of improving their symptoms (i.e., pain, limited range of motion, joint swelling, fatigue, joint stiffness, and sleep problems) as well as experiences of improving their mobility and social participation. Contrastingly, perceptions of harm were related to experiences of the side effects of medications (i.e., weight

fluctuations, gastrointestinal symptoms, addiction, shakiness, and cancer risk).

Understanding of medications' mechanisms of action. Patients' narratives demonstrated the existence of different RA "explanatory models of illness" (19), which influenced their decisions to take medications. Those patients whose models were more aligned with Western biomedical beliefs were more likely to understand and accept medications' mechanisms of action, which increased active participation in their control and self-regulation (i.e., prescription modification).

Medications' administration mode. Patients' narratives suggested that mode of administration can influence their level of acceptance and their perception of the "burden" experienced by taking medications. When the frequency of taking medications interfered with their lifestyle or when the drug administration was perceived as invasive to the body, they were less likely to accept the treatment.

*Familial factors.* Feedback from family members regarding the effects and efficacy of medications influenced patients' decisions to accept the treatment or not. Family members' support for taking medications was related to their understanding of the effects of the medications and previous positive experiences taking them. In contrast, support for pharmacologic treatment was negatively affected by either personal negative experiences taking medications, or community perceptions that a specific type of medication has negative effects on health, including the risk of becoming dependent.

*Societal factors.* Fear and stigma of drug dependency. Accepting medication was negatively influenced by perceptions of losing control, becoming dependent on medications, and being considered by others as frequent users of medications or "pill poppers." The fear of becoming dependent on medications was especially present in those patients who revealed a history of addictions, either personal or familial.

Medications' affordability and availability. The cost of medications and the ease of obtaining them (e.g., getting refills) were important considerations in accepting and taking medication as prescribed. The cost of medication was particularly relevant when people did not have drug coverage and had to pay out of pocket.

Increasing patient-provider trust. Patients' narratives identified that patient-provider trust could be fostered by an environment that is safe, collaborative, and professional (Table 3). A safe environment refers to a space where patients can find empathy, a holistic approach to health issues, respect for their knowledge and experience, and acknowledgment of cultural differences. A collaborative environment requires a mutual understanding between patient and providers to be actively involved in decision-making. A professional environment requires health care providers to be perceived as knowledgeable, experienced, and reliable, exhibiting honesty, directness, effective communication, and active listening skills.

**Table 2.** Representative quotes of themes associated with preferences for pharmacologic management

Clinical factors	
Theme: relationship with health care providers	
Trust	<p>"I have to trust them (health providers) and well, having access to them when, it's an important thing too (to consider accepting a prescription)" (47-year-old woman)</p> <p>"...for native people there's a lot of guard up because there's hatred to both, whether who we can see can take care of us because I believe that there's a way people look at First Nation people as not as smart as they should be, so for us to have that trust,...we need to look at you in the eye and trust you..." (42-year-old woman)</p>
Theme: perception of medications' effects	
Benefits	<p>"...wanna try anything to be able to be mobile and pain free...I wanna feel normal..." (42-year-old woman)</p> <p>"I gotta take 'em (medications), make me feel better, yeah. I don't like pain even though I live with it." (67-year-old male)</p> <p>"...if I'm happy and I'm mobile then I think...that far outweighs the risks, you know what I mean, of the medication." (57-year-old woman)</p>
Harms	<p>"...when I met with Dr. the first time one of the things I told her...I will not take Methotrexate whether it's combined...of how it affected my stomach along with that sulpha stuff and the weight loss...I don't want those feelings..." (45-year-old woman)</p> <p>"...I don't think I need this (medication)...so I would...take them off...it was making me ill, sick...Oh, God, yes, big side effects." (72-year-old woman)</p> <p>"...I was experiencing so many side effects, like the nausea, I was losing my hair, I was losing weight, I was getting increased anxiety, just mood swings and just decreased appetite...so I stopped the Methotrexate for a couple of months." (45-year-old woman)</p>
Theme: understanding of medications' mechanisms of action	
Alignment with biomedical model	<p>"Yeah, I know what's happening...with my joints...My immune system is attacking my joints...these drugs that I got put on right away, I went to my drug book and I was like, what are these?...Why do I have to take methotrexate? Why do I have to take plaquenil?...And looked at the side effects, looked at if there was any interaction with any other stuff in my drug book...In two months if this doesn't work we'll try something else." (28-year-old woman)</p> <p>"My arms are balling up and they're going to whatever it is that I'm fighting at that moment, so that's taking away from my joints unable to do or function as they should. So that's my understanding of the disease...I totally felt comfortable (self-adjusting medications) because I've been on the medication before and I know that if I'm not supposed to take it (prednisone) at the end (before visiting doctor), I'll double up in the beginning and that'll give me the kick start that I need to get through this month." (57-year-old woman)</p>
Indigenous knowledge	<p>"We were raised up the Native way because my dad was a Medicine Man so you know, it was always with us with prayer and stuff like that. So...growing up (we learned) you don't really need medication. I think, yeah I think that's it...(I) wouldn't be taking the medication." (42-year-old woman)</p>
Theme: medications' administration mode	
Interfering with lifestyle	<p>"I'm not really exactly the best person for...taking pills regularly. It's really hard for me to think of...my day's dosage...I'm really bad at remembering that so...taking pills every day. That's what I don't like." (47-year-old woman, referring to preference for injection medication)</p>
Invasiveness to the body	<p>"If I had a choice between the needle and the pill I would choose liquid [laughs]. I would choose liquid form because I don't like taking pills...And liquid...it's easy and I don't like needles." (Woman)</p>
Familial factors	
Theme: support and influence from family	
	<p>"...then my cousins, they said that it helps because if I don't take it (medication) then the arthritis would get worse...So, that's why I took it, because of my older siblings and my cousins...Talking to my family helped me decide." (Woman);</p> <p>"...my folks know, know I have it (arthritis) and they know how long I've had it, and they know how painful it is, so they kind of always, in a good way, pitied me when I'd be in so much pain. And my dad would say do you need a T3, right, and I would (take it)..." (45-year-old woman)</p>
Societal factors	
Theme: fear and stigma of drug dependency	
	<p>"...I have gone with a couple of my cousins to their doctors and these doctors that they...gave them pills...with codeine...And then they got addicted to them, they stay addicted and...their younger ones seeing them on the pills, now they're on the pills and stuff like that...it effects the whole family...Well with the medication that I (got prescribed, I asked), am I going to get addicted to it?...is it going to make me feel weird? Is it going to make me high and stuff? And she said no, and if it did then I won't have to take it." (Woman)</p> <p>"I've never liked taking drugs...I'm just not a pill popper...And I don't depend on pills either to get me well." (72-year-old woman)</p> <p>"I'm very leery on what pills that I take, eh, 'cause I'm not a pill popper. I hate pills." (67-year-old male)</p>

(Continued)

**Table 2.** (Cont'd)

Theme: medications' affordability and availability	
Cost	<p>"Like...it (taking medications) comes down to the medications too, right. Like I mean it comes down to cost." (57-year-old woman) "...cause there's a lot of drugs that aren't covered by NIHB...so that...influences things... some of...even...I have to pay for and they're expensive...It's kind of a pain in the butt so, but then I found this one (medication), I'm not sure if NIHB will cover it but I hear it's a cheaper drug and it's effective,...so I just wanted to try it." (47-year-old woman)</p> <p>"Price...At that time I was working and I was able to find these things or she would go buy them for me. But then it came to price...Cost, yeah...there was times I wasn't working so I couldn't afford it...Yes if it's covered or not; if it's not covered I can't take it 'cause I have no coverage and I have no money...I have coverage but there's only so much Indian Affairs will cover." (45-year-old woman)</p>
Availability	<p>"...I probably would have liked...the pill...because of the convenience...I could go see any doctor for a refill." (45-year-old woman)</p>

## DISCUSSION

Our study contributes an exploration of indigenous patients' preferences for RA management. The nonpharmacologic preferences expressed by the patients demonstrate the importance of addressing the physical, mental, emotional, and spiritual aspects of living with this chronic condition, which is in line with the holistic indigenous model of health, as has been shown in other qualitative studies on the indigenous conceptualization of pain [20]. This holistic conceptualization of well-being contrasts with the biomedical model (21) that has dominated Western medicine over several decades and is linked with colonization (22), which may lead to rejection of Western medications by some indigenous peoples (23–26). Further, it has been proposed that facilitating access to both indigenous and Western medicine should become a standard of practice for the care of all North American indigenous peoples with RA (24). This proposed standard aligns with Call to Action Number 22 in the Truth and Reconciliation Commission of Canada (Call 22), a commission formed to inform Canadian society about the effects of residential schools. Call 22 recommends that health care–system decisionmakers recognize the value of indigenous knowledge as it relates to health and make it accessible for indigenous peoples (27).

The preferences of indigenous patients with RA for pharmacologic treatment were also explored. Decisions to undergo pharmacologic treatment were influenced by clinical, familial, and societal factors. Clinical factors for acceptance of pharmacologic treatments were described by the patients in terms of the relative importance they place on the desirable (benefits) and undesirable (harms) aspects of treatment (which is not unlike findings from the general RA population), and understanding medications' mechanisms of action, perceived benefits, harms, and administration burden were important to increase patient acceptance of DMARDs (28). It is recognized that this understanding is influenced by cultural interpretations about how medications work (8,29) and stresses the importance of utilizing forms of communication that resonate better with indigenous patient understanding of pharmacologic treatment in a manner that is sensitive to a more holistic view of their health-related experiences. The role of the provider–

patient relationship is integral to this aspect as well. Building a relationship of trust between indigenous patients and health care providers through a safe, collaborative, and professional environment appeared to be fundamental for our participants to prefer the use of pharmacologic treatment. This finding resonates with those of a qualitative meta-synthesis by Kelly et al, which demonstrated that “partnering with health providers” on decision-making was a facilitator in overcoming resistance to taking RA medications (30). The importance of a good patient–provider relationship to increase acceptance of medications has also been quantitatively observed in different cultural groups of people living with chronic diseases (31,32). One approach to building trust-based relationships with indigenous patients is to involve them as partners in decision-making. Various shared decision-making strategies exist (33), but having a peer-supported discussion through a decision aid has been demonstrated as effective in the Canadian indigenous population (34). Another approach that has been described in the literature for diabetes mellitus, the Educating for Equity framework, is an interactive continuing professional development strategy for physicians to learn strategies to re-center relationships and engage with patient social realities (35).

Familial factors were also a key contributor to preferences for pharmacotherapy. The degree of support and positive feedback provided by kin regarding medication use influenced patients' decisions on whether to take pharmacologic treatment. Family influence on acceptance of RA medications has also been identified in other qualitative studies involving non-indigenous patients (30). In addition, increasing family support to take medications has been quantitatively associated with the acceptance of biologic treatment in a British cohort of people living with RA (29). Therefore, the influences of family members on decision-making in the management of RA should inform the approach taken by the rheumatologist during the clinical encounter and result in the creation of space for broader discussions and consultation with family members prior to a final decision on therapy being enacted.

In regard to social factors, we identified that the cost and ease of obtaining RA medications greatly influenced people's preferences to take them. Many studies have shown that low consistency in taking RA medications is associated with their

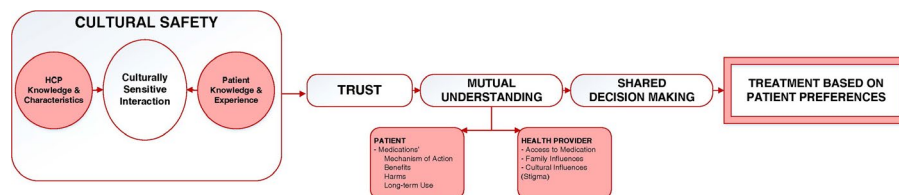
**Table 3.** Representative quotes for patient–provider environments that promote trust

Safe environment	"The reason I trust Dr...is because she knows about my background, she knows I don't like taking medication, so she's trying to...finding different ways to help me with my pain and stuff like that...instead of giving me more pills...that is so profound...because in the past...Majority of doctors with the Native people because they're getting paid for it all they do is prescribe pills and pills...And they don't realize that it's killing the majority of our people and damaging them. And it's not only them damaging the person, it's damaging the whole family. Like the kids and the next generation, that's what they don't realize." (Woman, age unknown)
Collaborative environment	"...because every time I see her (physician) she gives me alternatives...she discusses it with me and she tell me there's...like she gives out some other, what I think will help...she explains it and what's going to happen with the body...Yes (she gives me a choice)...the treatment...it's been really helping me and she's been referring to the right medication for me...The trust is there." (54-year-old woman)
Professional environment	
Providers' knowledge, experience and reliability	"...I obviously wouldn't go to, no offence, but I wouldn't go a brand new grad rheumatologist doctor...Because I feel like okay, you're just new, you don't know...I mean you've studied all the medications but...You don't have experience...Watching years and years and years on one medication or changing it or you know." (28-year-old woman) "Dr., he sat me down and he compared each and every one of his patients to someone like me to, in order to make the decision...So he knew someone who was already on certain medications and the side effects that they had and then the type of condition I had who he treated, so that helped me, you know what I mean, like helped me with all this information...he already knew, he threw everything out what he knew that, I said okay, then I can do it 'cause all this I already wanted to know, he already presented to me so." (42-year-old woman)
Providers' personal characteristics and communication skills	"...he looked after anything, my ailments, anything I needed. He looked after me, he explained it, everything was good...there was good communication, otherwise I wouldn't stay." (72-year-old woman) "Her honesty, she's not, she's not there just because...she's human...she's really there to help First Nations people...she's what doctors should be...she really cares about the people she treats." (45-year-old woman) Yeah, the way they care about you, how they take the time to listen, because some people will sit there and...don't, they just want you in and out...They have to have the patience that listen...So I think there's a way that when they present themselves and care about you when you're in an appointment is what matters to me...listening and caring and finding that trust is why I'll be loyal to them (health providers)." (42-year-old woman)

availability and cost (36–38), and low socioeconomic level has been observed as an important factor for low RA medication utilization (38). In addition, social deprivation conditions faced by indigenous peoples in New Zealand and North America have been clearly associated with lower use of pharmacologic treatment (24,39). The known historical and social structural forces that create social health inequities for indigenous peoples worldwide are also present in Canada (2), and our results underline the importance of inquiring about social resources and advocating to payers to eliminate this barrier to pharmacotherapy acceptance. Further, the social stigma of "pill popping" that is related to taking any medications in indigenous communities is also importantly associated with preferences to take RA pharmacologic therapy. This stigma is linked to a fear of drug dependency, which is closely linked to the colonial stereotype of indigenous people as highly susceptible to substance abuse, due to a "personal failing of character" (40). Recent studies have shown that substance abuse among indigenous peoples is not associated with an individual failing of character but rather the structural violence (41) produced by colonialism through "intermediate" and "distal" social determinants of health (42,43). This structural violence not only reproduces unconscious

racist practices towards indigenous peoples but also erodes their self-image. Consequently, health care providers who interact with indigenous people with RA should acknowledge the past and present harms done to the community and look beyond the immediate social determinants of health to consider those social and historic factors that continue perpetuating the disadvantageous conditions in these communities.

Taking into consideration the identified clinical, familial, and societal factors that are linked to acceptance of pharmacologic treatment of RA, we constructed a model to aid in the understanding of how patient preference–based decisions of indigenous peoples could be supported in the clinical setting (Figure 1). Integral to this model is shared decision-making during an encounter of multiple cultures, which requires mutual understanding between patients and health care providers. This understanding could be fostered through strategies that recognize knowledge of indigenous medicine and of Western medicine as having equal value, such as the "two-eyed seeing" approach (44), or through methods that respect cultural boundaries while promoting intercultural collaboration, such as the "patient-centered boundaries" methodology (described in a

**Figure 1.** Heuristic model describing how health providers could increase medication acceptance in the clinical setting.

study by Hitziger et al [45]). The proposed model implies that achievement of mutual understanding between health care providers and indigenous patients requires the patients to comprehend medications' mechanisms of action, which in turn allows them to recognize medication benefits and harms, and provides them with the rationale to proceed with the associated treatment for a long time. Moreover, mutual understanding requires health care provider recognition of the contextual factors that influence patients' decisions to take medications (i.e., access, stigma about "pill-popping," and family input). Attaining trust to foster mutual understanding requires a culturally sensitive interaction between health care providers who need to be perceived by patients as knowledgeable, experienced, reliable, honest, direct, and good communicators/listeners, and indigenous patients, who need to feel that their knowledge and experience are acknowledged, valued, and respected by health providers.

The multicultural nature of the health care provider-indigenous patient interaction entails "cultural safety" as a prerequisite to build trust. Cultural safety is a concept that extends beyond cultural competence (which focuses on cultural understanding and knowledge of the health care provider) toward achieving a power equilibrium that produces a sense of security from harm in the patient (46). In cultural safety, culture is conceived as a complex network of meanings entrenched within historical, social, economic, and political processes, and contains the concepts of cultural knowledge, awareness, sensitivity, and humility (46). Consequently, our model infers that a culturally safe clinical practice is important for indigenous patients with RA to appraise their preferences about whether and how to undergo pharmacologic treatment.

Our study has certain limitations. The patient characteristics limit the representability of our findings to a population of indigenous female patients with RA who attend rheumatology clinics. In addition, in spite of most of our results being consistent with narratives of non-indigenous patients that have been published in the literature, our relatively small sample limits our confidence that all relevant themes and understanding of RA management in the indigenous population of Southern Alberta have been exhausted. Moreover, we did not conduct any member-checking strategy to confirm our interpretations, which could have had an impact on the trustworthiness of our results. Nevertheless, all interpretations and themes were confirmed through methodological triangulation, which certainly increases the confidence in their validity. These limitations urge further exploration of this topic with a broader population. Given our specific focus to challenge current health care providers' beliefs that indigenous peoples with RA are prone to reject Western treatments, we focused our interviews on patient pharmacologic preferences, and the nonpharmacologic preferences were not explored in great detail. Therefore, the generalizability of these results is limited, and it will be important to confirm and further explore the nature and rationale for use of the nonpharmacologic treatments reported in this study.

In conclusion, indigenous patient preferences to manage RA included a range of nonpharmacologic and pharmacologic treatments and demonstrated a desired holistic approach for illness control and achievement of wellness. Consequently, it is important to integrate holistic indigenous frameworks of health within the rheumatology care of indigenous peoples. Our findings challenge the belief that indigenous peoples are prone to reject pharmacologic treatment and shows that their preferences for accepting this treatment is dependent upon the type of relationship they have with their health care providers in the context of clinical, familial, and societal factors. Shared decision-making is an approach to support RA management and requires a culturally safe environment that allows for mutual (i.e., patients and health care providers) understanding about medications' characteristics and indigenous realities, resulting in genuine trust-based relationships. Further research is needed to understand how to build cultural safety in rheumatology practice and its effects on pharmacologic treatment preferences.

## 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. Loyola-Sanchez 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.** Hazlewood, Crowshoe, Marshall, Barnabe. **Acquisition of data.** Loyola-Sanchez, Linkert, Hull.

**Analysis and interpretation of data.** Loyola-Sanchez, Hazlewood, Crowshoe, Linkert, Hull, Marshall, Barnabe.

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