




HEALTH DISPARITIES AND HEALTH EQUITY IN THE RHEUMATIC DISEASES

Understanding the Impact and Tackling the Burden of Osteoarthritis for Aboriginal and Torres Strait Islander People

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Objective. The aim of this study was to understand and describe the lived experience of Aboriginal and Torres Strait Islander people with osteoarthritis.

Methods. Qualitative study guided by cultural security, which ensures that research is conducted in a way that will not compromise the cultural values, beliefs, and expectations of Aboriginal and Torres Strait Islander people. Participants were purposively sampled through the networks of project staff. Research yarns (a cultural form of conversation used as a data gathering tool) were conducted with 25 Aboriginal and Torres Strait Islander adults with self-reported osteoarthritis in Western Australia and Victoria, Australia. Data were analyzed using a framework approach and presented through composite storytelling (hypothetical stories representing an amalgam of participants' experiences).

Results. Two composite stories were constructed to reflect themes relating to beliefs and knowledge, impact, coping, and health care experiences. Common beliefs held by participants were that osteoarthritis is caused by previous physically active lifestyles. Many participants feared for their future, increasing disability and needing a wheelchair. Pain associated with osteoarthritis impacted daily activities, sleep, work, family, and social life and cultural activities. Multidimensional impacts were often experienced within complex health or life circumstances and associated with increased anxiety and depression. Most participants reported negative health care experiences, characterized by poor patient–provider communication.

Conclusion. Our findings highlight that osteoarthritis is a multidimensional issue for Aboriginal and Torres Strait Islander people that permeates all aspects of life and highlights the need for integrated, multidisciplinary care that is culturally informed and individualized to patient need.

INTRODUCTION

The health and social disparities experienced by Aboriginal and Torres Strait Islander people in Australia (respectfully, “Aboriginal” herein; see terminology and definitions) are well documented and include a greater burden of disease, poorer self-assessed health status, and lower life expectancy (1). Aboriginal people experience rates of osteoarthritis between 1.2 and 1.5

higher than non-Aboriginal people (2). Common symptoms include joint pain, stiffness, and swelling (2). These symptoms are associated with activity avoidance and reduced physical activity, absenteeism, social withdrawal, and poor mental health, which negatively impact quality of life (3–5). Providing patient-centered, multidisciplinary care for osteoarthritis requires an understanding of the beliefs, knowledge, values, and preferences of those who experience the condition (4). No research has yet

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SIGNIFICANCE & INNOVATIONS

- This is the first study to investigate the lived experiences of Aboriginal and Torres Strait Islander people with osteoarthritis.
- A novel qualitative approach of composite storytelling, akin to a culturally relevant storytelling approach, was used to amplify multiple voices of Aboriginal and Torres Strait Islander participants.
- Opportunities to improve access to culturally secure osteoarthritis care identified included the development of culturally adapted health information resources, improving patient-provider communication by prioritizing Aboriginal and Torres Strait Islander cultural communication preferences, and integrating care to respond to the psychosocial impacts of osteoarthritis.

investigated the experiences of Aboriginal people living with osteoarthritis or the impacts of osteoarthritis on Aboriginal people. This precludes the development of culturally adapted management strategies and health care services that meet the needs of Aboriginal people.

Qualitative approaches applying storytelling can provide an insight into the lived experience of health and how individuals make sense of their symptoms (6). Storytelling centralizes individuals as experts of their health and contextualizes personal experiences to provide a deeper understanding of the lived experience (7). Social sciences and clinical research can draw on the power of stories to resonate with people and to communicate research findings in a way that is relevant for diverse audiences, including both clinicians and consumers (8). The application of storytelling in Indigenous research has emerged as a rigorous approach that not only creates space for Aboriginal voices to be heard and where participants can share their holistic health experiences but enables researchers to learn through stories as data and translate their findings (9–12). Storytelling acknowledges Indigenous oral traditions and can function as a culturally relevant and meaningful method to prioritize and engage the voices of Aboriginal participants (9–12).

The aim of this study was to adopt a method of composite storytelling to understand and describe the lived experience of Aboriginal people with osteoarthritis. The findings seek to inform and guide the development of culturally secure osteoarthritis care.

MATERIALS AND METHODS

Study design. This study was guided by the principle of cultural security (13). Cultural security is a methodologic and ethical consideration that emphasizes that Aboriginal health research must be conducted in a manner that prioritizes Aboriginal cultural values and beliefs and ways of knowing and addresses community-identified priorities. The Aboriginal philosophy of pattern thinking informed our decision to construct composite

stories. Pattern thinking is a metaphysical tenet that embodies the idea that everything is interrelated: Country is not separate from people, land, or culture. Pattern thinking describes the interrelationship of everything, where everything is part of a system and is equal in that system (14). Further methodologic considerations included strong Aboriginal community engagement, participation, and governance in all phases of the research and utilizing this project to build capacity in the Aboriginal health and research workforce (15). An Aboriginal community reference group (CRG) was formed to provide Aboriginal input and guidance on all aspects of this study.

We utilized the process of constructing composite stories, informed by the qualitative frameworks of interpretive phenomenology (16) and interpretive description (17). A composite story uses qualitative data from several individual participant interviews to tell a single story (8,18,19) and is an emerging method in qualitative health research that has been previously applied in chronic disease (7) and Indigenous health (12). In our study, we used multiple participant accounts and experiences of living with osteoarthritis to construct 2 hypothetical patient stories representing an amalgam of all participants in this study. The purpose of constructing composite stories to share Aboriginal peoples' lived experience of osteoarthritis were 3-fold: 1) to facilitate Aboriginal participants' direct and active voices to the research; 2) to present qualitative data in a way that is culturally relevant and makes the research findings accessible to wider audiences than academics; this may facilitate an increased awareness and understanding of the patient experience by health care providers (7,8); and 3) to capture an anonymous account of the complex, multidimensional, and interconnected nature of lived experience.

Interpretive phenomenology aims to describe, understand, and interpret participants' experiences of a phenomenon, such as a health condition, from their perspective and assumes that individuals' realities are influenced by the world in which they live (16). An assumption of this research was that the experience of osteoarthritis (beliefs, knowledge, impact, and health-care seeking) was inextricably linked with the cultural, social, political, and historical context of Aboriginal peoples' lives. Interpretive description aims to move beyond theory and into practice by capturing the subjective experiences of a population with the intent to use this knowledge to inform clinical practice (20). In this study, we not only sought to describe the experience of living with osteoarthritis from the perspective of Aboriginal people but to explore how these experiences interact and impact their daily interactions, social lives, and, importantly, their experiences of seeking care. The knowledge generated by participants sharing their stories would enable us to use real-world examples to inform and improve clinical practice for Aboriginal people who experience osteoarthritis.

Terminology and definitions. Terminology regarding Aboriginal and Torres Strait Islander identity is varied and

complex. In this study, we use the term ‘Aboriginal’ when referring to Aboriginal and Torres Strait Islander people, communities, coresearchers, and participants in this study. No disrespect is intended to Torres Strait Islander people, and we acknowledge the diversity of cultures of all Aboriginal, Torres Strait Islander, and Aboriginal and Torres Strait Islander peoples in Australia. We use the term ‘Indigenous’ when referring to global Indigenous populations or when referring to international concepts, such as research methods. ‘Country’ is a term used by Aboriginal and Torres Strait Islander people to describe ones’ ancestral connection to diverse geographic locations such as mountains, rivers (waterways), desert, and seas. The term also includes all living things on country and encompasses complex ideas about cultural practice, language, spirituality, family, and identity.

Ethical considerations and participatory processes.

Ethics approvals were obtained from St Vincent’s Hospital Melbourne Human Research Ethics Committee (project ID 51564/HREC Ref 185/19; approval date: December 17, 2019) and the Western Australian Aboriginal Health Ethics Committee (project ID HREC 961; approval date February 21, 2020). All participants provided fully informed verbal consent prior to commencing in the research.

Participants and setting. This study was conducted by the Enhancing Equity, Collaboration and Culturally Secure Osteoarthritis Care for Aboriginal Australians (ECCO) collaboration, which was established to address the mismatch between the burden of osteoarthritis and access to appropriate care for Aboriginal people. In the spirit of reflexivity, the authors have provided the following positionality statement. The first author (PO) is a female, White, non-Aboriginal PhD candidate and social scientist who worked collaboratively with Aboriginal researchers throughout all phases of this research to ensure that an Aboriginal cultural lens was prioritized at all times. An additional 4 authors identify as non-Aboriginal, and 6 authors identify as Aboriginal. Aboriginal authors also identify as Worimi, Ngiyampaa, Yamitji, Bard/Yjindjarbandi, and Nyangumarta. All non-Aboriginal authors came to position themselves as settler allies, whereby all are committed to addressing racism, disparities in health care, health inequity, and decolonizing research methodologies through conducting this research. This national interprofessional team live across various geographic locations in both metropolitan and regional/remote environments and have diverse professional backgrounds including public health, physical therapy, nursing, orthopedics, Indigenous studies, health services research, and Indigenous health research.

Eligible participants were adults age >18 years residing in Regiontown (the pseudonym for a regional town in Western Australia with a population of <50,000) or the state of Victoria, had a self-reported diagnosis of osteoarthritis (in any joint), and identified as Aboriginal and/or Torres Strait Islander. We recruited

eligible participants by: 1) drawing on the networks of project staff and members of the CRG, 2) partnering with Aboriginal health services, and 3) using social media and a recruitment flyer. Recruitment strategies were augmented by snowball sampling, where enrolled participants recommended additional participants from within their social, professional, and family networks (21). Eligible participants were contacted either by phone or face to face. The research team verbally explained project information or sent additional written study information to interested individuals before offering the option of participating face to face, via phone, or teleconferencing at a time and location convenient to them. Participants received a \$50 (Australian) gift voucher as reimbursement for their time.

Data collection. The primary method for data collection was semistructured research “yarning” (9). Yarning is an Indigenous cultural form of conversation. In the context of semistructured qualitative interviews, yarning is “an informal and relaxed discussion through which both the researcher and participant journey together visiting places and topics of interest relevant to the research study...[it is] a process that requires the researcher to develop and build a relationship that is accountable to Indigenous people participating in the research” (9). There are 4 main types of research yarning: social yarning, research topic yarning, collaborative yarning, and therapeutic yarning. Social yarning is an important precursor to research topic yarning, whereby the researcher and participant engage in informal social conversation to develop trust and build a relationship.

After the social yarn, the researcher may gather information relating to the research question through the process of research topic yarning. Research yarning privileges the lived experience and cultural context of Aboriginal participants and aligns with Aboriginal ways of knowing and doing, such as the use of storytelling. It ensures that interviews are informal and relaxed and requires the researcher to build a relationship that is accountable to Aboriginal people participating in the research (9). Although research yarns were informal, a semistructured research yarning topic guide was codesigned by Aboriginal and non-Aboriginal research staff with input from the CRG. Yarning guides included open-ended questions covering topics such as living with osteoarthritis (e.g., “Tell us the story of your joint pain”) and the impact of osteoarthritis on quality of life (e.g., “How does your joint pain impact your life?” and “How is your pain holding you back?”) and on management and coping strategies (e.g., “How do you cope with you joint pain?” and “Where do you go to get help?”). Research yarns in Western Australia were conducted by a physical therapist (man) and/or Aboriginal coinvestigator (woman). Research yarns in Victoria were conducted by a social scientist and/or Aboriginal physical therapist (both women). All research yarns in Regiontown were conducted face to face. Due to COVID-19 restrictions at the time of data collection, all research yarns in Victoria were conducted via teleconferencing or phone.

Average interview duration was 50 minutes. One follow-up interview was conducted with a participant in Regiontown to clarify answers and make improvements to the yarning schedule. Participants were given the opportunity to review their yarning transcript upon their request. One participant reviewed their transcript before approving it to be used in the data set. Data saturation was reached by 25 participants.

Statistical analysis. All yarns were audio recorded and transcribed verbatim either by PO or an external transcription service and uploaded into NVivo, version 12 (QSR International). Data were analyzed in 7 steps, in parallel with data collection, following a modified framework approach (22) for the construction of the composite stories. We constructed 2 separate composite stories to ensure that the voices of both men and women were represented in the most culturally appropriate way. The 7 steps are described in Table 1 and summarized in Figure 1.

RESULTS

Between May 2020 and December 2021, 25 participants (18 women, 7 men) with osteoarthritis were recruited. Of the 25 participants, 24 identified as Aboriginal, and 1 identified as Aboriginal

and Torres Strait Islander. The demographic characteristics of participants are described in Table 2. Results are presented in 2 sections. First, a narrative summary is provided for each of the 3 overarching themes of beliefs and knowledge, impact of osteoarthritis, coping and osteoarthritis management, and health care experiences. Results are then presented as 2 composite stories crafted from the perspective of hypothetical characters Marli (a woman) and Larry (a man). To contextualize the research, the stories follow Marli and Larry's experiences of living with osteoarthritis and their journey seeking care. The composite stories capture common beliefs and experiences reflected in the stories collected from the 25 participant research yarns. Alongside the composite story, the organization of codes into categories and the abstraction of overarching themes are presented in Table 3. The thematic map that details story sections shaped around the codes, categories, themes identified, and supporting quotes is presented in Supplementary Table 1, available on the *Arthritis Care & Research* website at <http://onlinelibrary.wiley.com/doi/10.1002/acr.25004>.

Theme 1 (beliefs and knowledge): “The worse thing for me is worrying if I'll end up in a wheelchair.”

Common beliefs among the participants in this study were that osteoarthritis is caused by overuse, wear and tear, a normal

Table 1. Adapted framework analysis*

Data analysis step	Description
Step 1: Familiarization	The first author (PO; a woman, social scientist) became familiar with the transcripts by reading and rereading the transcripts.
Step 2: Open coding	Two researchers (PO and RP, an Aboriginal man and research assistant) coded the transcripts line by line using open coding, identifying broad concepts relating to the lived experience of OA.
Step 3: Developing a thematic framework	The resulting list of codes was refined into a thematic framework and grouped into 4 broad categories relating to 1) beliefs and knowledge; 2) impact of OA; 3) coping with OA; and 4) experiences of seeking care.
Step 4: Summarizing	PO applied the thematic framework (which captured both major and minor themes) to each transcript, summarizing the findings in a matrix using Excel (Microsoft). The matrix was comprised of 1 row per participant and 1 column per code. Important moments from within each transcript were extracted into each participant/code and inserted into the corresponding cell in the matrix. Narrative summaries were also written (by PO and RP) describing the experiences of each participant. Step 4 allows the research team to better understand the relationship of codes between and within each participant and note similarities and differences among participant stories.
Step 5: CRG input	A sample of participant stories were presented to the CRG for their input. Each member of the CRG was asked to identify 3–5 important moments in each story, which were discussed in a round-robin fashion until all important points were documented and incorporated into the codebook and noted for the interpretation of the results.
Step 6: Thematic mapping, story capture, and story sections	To begin constructing the composite story, a table was built to act as a thematic map (see Supplementary Table 1, available at http://onlinelibrary.wiley.com/doi/10.1002/acr.25004). Overarching themes (e.g., beliefs and knowledge, impact of OA, etc.) were placed in the first column. In the second column were placed relevant categories and codes that were identified for each theme. The third column of the thematic map was used for story capture (50). The process of story capture involves copying large sections of participant stories, which reflected each of the categories and codes directly from yarning transcripts into the thematic map. This enabled identification of a variety of relevant verbatim quotes (see Supplementary Table 1, available at http://onlinelibrary.wiley.com/doi/10.1002/acr.25004) to facilitate a direct voice from the participants to the final composite story. PO and RP then maneuvered to storyteller standpoint. Both researchers wrote sections of story which reflected the segments of raw data surrounding the verbatim quotes. To reflect the participant voice, colloquial language or Aboriginal English terms were included in bold with additional definitions provided. This process was repeated until a story section reflecting elements of all identified themes, codes, and categories was complete.
Step 7: Restructure, refinement, and review	Story sections were restructured and condensed into the 2 draft composite stories in a way that encouraged flow. Two composite stories were constructed to reflect the experiences and voices of men and women. The draft composite story was then presented to members of the CRG who provided feedback to be incorporated into the revised, final composite story.

* CRG = community reference group; OA = osteoarthritis.

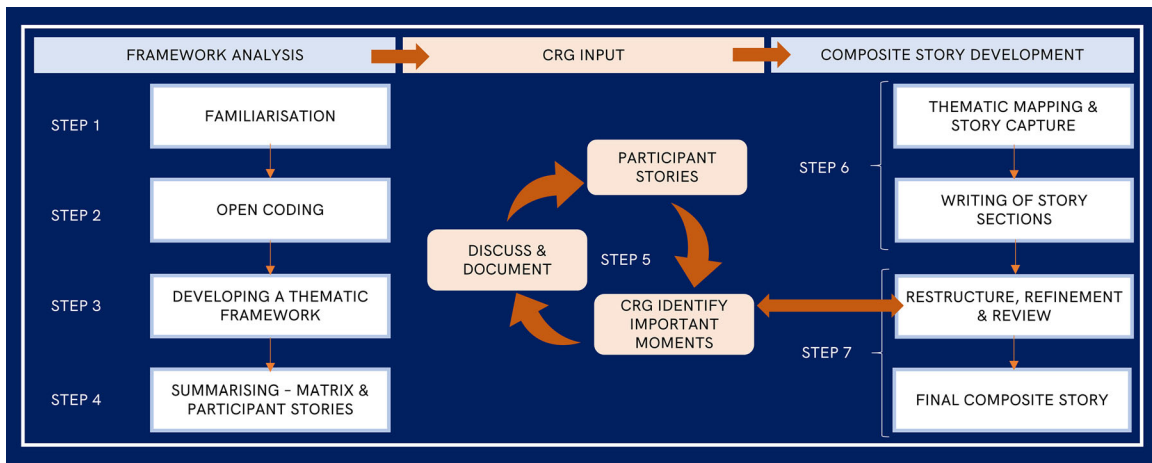


Figure 1. Data analysis process. CRG = community reference group.

part of aging, or previously active lifestyles (e.g., engaging in sports or having a physical occupation). Many participants in this study associated osteoarthritis with degeneration that they perceived would get worse over time and feared that increasing levels of disability would ultimately lead to requiring the use of a wheelchair, loss of independence, and becoming a burden on families and communities.

Theme 2 (impact of osteoarthritis): “Every bone in my body aches.” The impact of living with osteoarthritis permeated all aspects of the lives of Aboriginal people in this study. Pain and disability associated with osteoarthritis impacted daily life, including the ability to engage in daily activities (e.g., housework, gardening, and grocery shopping), adequate sleep, work/employment, family and social life, and cultural activities. Feeling exhausted

Table 2. Participant characteristics*

Location	Participant code	Gender	Age, years	Employment status	Joints affected	Years experienced
Victoria						
Regional	V1	W	†	Retired nurse	Knee	2
Metro	V2	M	47	Professional	Hips	‡
Regional	V3	M	60	Artist	Knees, hips	22
Metro	V4	W	74	Academic, nurse	Knees, hips back	10+
Regional	V5	W	#	Regional health service nurse	Hands	‡
Regional	V6	M	59	Advocate	Knees	3+
Regional	V7	M	53	Disability pension	Knees	14
Regional	V8	W	42	Public servant	Hands (also back, hips, shoulders unconfirmed)	12
Regional	V9	W	66	Retired nurse and Aboriginal Liaison Officer	Knees, hips, back, neck, hands	‡
Regional	V10	W	68	Arts program coordinator	Knees, hips back, hands, feet	30
Metro	V11	W	22	Data project officer	Hips	‡
Western Australia						
Regional	W1	W	62	Pensioner	Knees, hips, back, hands, shoulders	5+
Regional	W2	W	62	Pensioner	Knees, hips, back, shoulders	10+
Regional	W3	M	75	Pensioner	Hips, back	21
Regional	W4	W	58	Aboriginal health worker	Hips, back	2+
Regional	W5	W	48	Community engagement	Knees	6+
Regional	W6	W	64	Pensioner	Knees	14
Regional	W7	W	71	Pensioner	Knees, hips, back	22
Regional	W8	W	59	Administrator	Knees, hips, back	20+
Regional	W9	W	65	Pensioner	Hips, back	15
Regional	W10	W	†	Disability pension	Knees, hips, feet	4
Regional	W11	M	55	Unemployed	Knees, hips, back	3+
Regional	W12	M	72	Retired machine operator	Knees, hips	2+
Regional	W13	W	55	Manager	Knees	1
Regional	W14	W	68	Administrator	Ankles, knees	11+

* Totals: 25 participants; 18 women; 7 men.
 † Participant’s age was not discussed during yarn.
 ‡ Length of symptoms was not discussed in yarn.

Table 3. Themes, categories, and codes

Overarching theme and category	Codes
Beliefs and knowledge Cause believes/beliefs about osteoarthritis/joints Future worries	Sports; injury; weight; aging; degeneration/bone on bone Losing independence; wheelchair; future disability; fear of burdening others
Impact of osteoarthritis Physical/biological	Pain; night pain/sleep; exhaustion; reduce mobility; repercussions of being active; conscious movement/slowing down
Basic needs/daily life	Impact on dailies/activities of daily living; impact on work; impact on caregiving
Social/emotional/cultural	Depression and anxiety; stress/frustration; social withdrawal; feeling old/shame; impact on hobbies; impact on family; cultural knowledge
Coping with osteoarthritis Medical	Medication; total joint replacement
Methods of the mind	Push through/persevere; day by day; avoidance; resting/bed
Home remedies/ complementary medicine/ bush medicine	Hot/cold; rubbing ointment/emu oil; supplements; traditional healing;
Support strategies	Family; community; support groups
Barriers to management	Complex life; complex health; competing priorities; COVID-19; finances
Active and lifestyle strategies	Physical therapy; keeping active; exercise; diet
Health care experiences Clinician	Lack of information; trust; communication; negative/lack of solutions; racism/stereotyping; lack of support for weight loss; mismatch in patient/clinician priorities (lack of understanding of patient priorities)
Service/system	Lack of culturally secure care; private health

and “held back” from life often led to negative psychological impacts such as increased levels of anxiety, frustration, and depression. Psychosocial impacts of osteoarthritis often occurred within already stressful or complex health or life circumstances, for example, experiencing chronic health conditions, having multiple familial or caregiving responsibilities, past histories of trauma, or feeling unsafe in patients’ lived environments.

Theme 3 (coping, osteoarthritis management, and health care experiences): “That’s how angry it made me, I just walked out of the appointment.” Having to weigh competing priorities in terms of caregiving, finances, time,

and energy meant that many participants felt that they lacked adequate time to prioritize their own health or pain management. While these competing priorities meant that some people lacked adequate time to prioritize their own health, this was a source of resilience for others who had overcome challenges and were able to engage in regular and ongoing exercise, which they acknowledged as an important mechanism for pain relief.

Participants described multiple negative experiences with clinicians including physical therapists and specialists such as orthopedic surgeons. Negative health care experiences were characterized by ineffective patient–provider relationships and communication that left participants feeling like they were not listened to, that clinicians did not have time for them, and that their priorities were not understood. In some cases, this resulted in participants disengaging from health services or in clinicians offering treatment options that were discordant with the preferences of Aboriginal people seeking care (e.g., prescribing exercises that were too difficult or painful). Disengaging from services influenced participants to favor treatments that they felt they could “take into their own hands,” such as medications, resting, and alternative therapies such as supplements, heat packs, rubbing ointments, and bush medicines such as emu oil, which were common coping strategies used by participants in this study. Some participants in our study expressed particular concerns about the way clinicians approached the topic of losing weight and the negative framing of their condition (i.e., focusing on weight or activities they should avoid).

“Every bone in my body aches” (Marli’s story). Marli’s story offers understanding of living with osteoarthritis from the perspective of an Aboriginal woman. Marli is a 55-year-old Aboriginal woman who has had back and hip pain for 10 years. Marli used to think the pains were a normal part of getting older, but recently the pains have gotten worse. Rest and paracetamol used to do the trick, but they aren’t helping much anymore. Now, Marli feels like “every bone in [her] body aches.” Some nights are pretty unbearable, and the lack of sleep leaves Marli feeling exhausted.

On the better days, Marli feels motivated to do the housework or yard work, but at the end of the day, Marli suffers with painful, swollen, and stiff joints. Walking and bending during the dailies (activities of daily living, e.g., housework or grocery shopping, etc.) is hard now, so Marli breaks things down into manageable chunks with rests in between. Feeling tired and sore means Marli has given up things she loves like sports, gardening, and visiting friends in the community; now Marli is less fit and has been putting on weight.

Marli’s greatest source of support is mob (a colloquial term identifying a group of Aboriginal people, at times also associated with a particular place or country), but some of them aren’t feeling great themselves. Marli has many responsibilities as the major breadwinner and carer for family members. Being a carer for her

husband means that Marli feels like she needs to put her pains “on the backburner.” But the pains and her mobility are getting in the way of coping with her full-on life. Marli tries to prioritize herself and says to her kids and grannies (grandchildren), “I need to look after myself,” but missing important cultural and family events affects Marli’s mental health and family. Marli has struggled with mental health challenges before and feels it’s getting worse again as she feels held back from life.

More and more sick days means Marli has had to stop work. Now money is tight, and Marli isn’t able to do the things she used to do to cope with her pains, like going to the hydro-pools. She tries to rest and use a heat pack when the pains get too much.

Marli now feels like she can’t push through the pains anymore so has been to the local AMS (Aboriginal Medical Service) for a yarn (to have a talk or chat) with the GP (general practitioner). The GP says Marli has osteoarthritis, but Marli’s only seen the older Uncles and Aunties (Aboriginal Elder or older people) bent over with osteo (osteoarthritis), not younger people. The doctor said the bones were rubbing together, so Marli’s worried about not being able to walk and that one day her bones will give way. Marli has many worries and fears about the future, but the main fear is ending up in a wheelchair and burdening family and community. Marli worries and feels shame (Aboriginal English word used to describe embarrassment) about being seen to not be able to do things.

Marli asked to see the bone doctor in town to find out how to fix osteo. But the doctor’s advice was just “lose weight” and “come back when the pain’s worse.” Marli walked out of the appointment thinking that the doctor was very rude and thought to herself “to heck with you, I can’t be bothered being spoken to like that.”

“Too young for joint replacement” (Larry’s story).

Larry’s story offers an understanding of living with osteoarthritis from the perspective of an Aboriginal man. Larry is a 34-year-old Aboriginal man who’s been experiencing pains in his knees. At first, Larry’s pains were “way down the scale of what’s important,” as he’s had other health concerns to look after first. But now, Larry feels like he’s “always in agony.” Since his pains have gotten worse, Larry’s become more anxious about what’s going on, sometimes waking up in “sheer anxiety.”

Feeling worried about the pains, Larry went to yarn with his GP at the AMS. After ordering x-rays (radiographs), the GP told Larry he had “bone on bone” osteoarthritis. It made sense to Larry, because where it was “bone on bone was exactly where it hurt.” Larry thought that all that footy (Australian rules football) and injuries over the years can’t have helped his joints. The GP referred Larry to see the physiotherapy mob to help him with his knees. But Larry felt that there was not much they could do for him, as “they’re only going tell you the same thing over and over.”

In search of solutions, Larry went to see an orthopedic surgeon in town that he knew and trusted but was upset to find

“he’d gone private” (indicates that the clinician had moved from practicing in the public health system to the private health system). Larry made the long trip to another surgeon, but he felt so angry in the appointment that he walked out. The surgeon had told him he was “too young” for a joint replacement and didn’t talk to Larry about any other options for his pain. Larry felt like the surgeon didn’t listen to him and wished that he had “sat down and been a bit more approachable” – after all, the surgeons “aren’t the ones suffering the pain.” Larry’s priority is to enjoy life now while he’s got the “young spirit” in him, not wait for a better life later on.

Larry decided to take things into his own hands – he wasn’t going to “let the pain rule his life.” He started using “a lot home remedy stuff,” sometimes sleeping with a hot water bottle, using a knee brace during the day, and using emu oil (a rubbing ointment/oil made from the fat of an emu bird) to rub on his joints. Larry also began to use the natural stuff from the chemist – fish oil, glucosamine, and turmeric.

What helps Larry even more though is going to the gym. Larry goes to the gym at the local AMS twice a week to use the machines that don’t put too much pressure on his joints. He reckons when he stops going, that’s when his knees “really start playing up.” Despite the pain relief he gets from exercising, Larry believes the gym is only a short-term solution. He reckons if he got a joint replacement, he’d be able to do the things he wants to do. He’d feel “back to normal” and happy again.

DISCUSSION

This study provides insight into the lived experience of osteoarthritis from the perspective of Aboriginal people for the first time. The findings highlight that osteoarthritis is a multidimensional issue for Aboriginal people that permeates all aspects of life. The multidimensional and interrelated impacts of osteoarthritis on Aboriginal people’s lives underscores the need for integrated, multidisciplinary care that is both culturally informed and individualized to patient need. Two composite stories were constructed to reflect beliefs and knowledge, impact, coping, and management of osteoarthritis, as well as the experience of Aboriginal people seeking care for osteoarthritis.

Common osteoarthritis-related beliefs identified in this study have been identified in previous qualitative studies involving non-Indigenous populations (4,23). For example, the belief that osteoarthritis is caused by overuse and that activity that loads the joints may further damage already weak or damaged joints. Such beliefs can lead to ongoing avoidance of activity by people with osteoarthritis (23,24) and are often exacerbated by health care professionals using terminology such as “bone on bone.” Many participants in this study reported health care professionals using terminology such as “bone on bone,” “wear and tear,” and “worn out,” which fits within an impairment discourse, i.e., language that frames pain and disability associated with osteoarthritis a

sign of joint damage (25). Best practice guidelines as well as recently published research (25) recommend that clinicians shift from using an impairment discourse to a participatory discourse when communicating about osteoarthritis. Participatory discourse focuses on concepts such as healthy aging, empowerment, and what individuals are able to do with osteoarthritis rather than what they cannot do because of osteoarthritis. In doing so, a participatory discourse may therefore encourage people with osteoarthritis to remain physically active and engage in healthy behavior change, consistent with clinical guideline recommendations (25).

Many participants feared increasing disability and the ultimate need for a wheelchair, which is consistent with a common belief identified among clinicians and the wider community that osteoarthritis is characterized by a downward trajectory (23). This belief conflicts with scientific evidence that multiple trajectories exist for people with osteoarthritis that are influenced by engaging in nonsurgical interventions (26). For example, education and exercise interventions have been shown to reduce pain, improve function, and lead to trajectories of stability and recovery (26). Our findings suggest that the development of comprehensive, evidence-based, and culturally adapted health information resources may be required to address the knowledge gaps about osteoarthritis. Clinical guidelines for osteoarthritis currently recommend providing information, education, and support for people with osteoarthritis so that they can effectively self-manage their symptoms (27,28). However, there are currently no culturally adapted health information education resources for Aboriginal people in Australia who experience osteoarthritis (29,30). Culturally adapted resources that highlight the value of engaging in exercise and the potential consequences of avoiding activity should be a future priority.

Our findings highlight that the impact of living with osteoarthritis permeates all aspects of the lives of Aboriginal people. This is consistent with the notion, “It’s not just a joint, but a whole life,” described in a qualitative study of non-Aboriginal people on the waitlist for total joint replacement (31) as well as the experiences of Māori men (32) and women in Aotearoa (New Zealand) (33). Physical and psychosocial effects of osteoarthritis identified in this study are consistent with previous studies involving non-Aboriginal populations (4). However, in our study, the psychosocial impacts of osteoarthritis often occurred within already stressful or complex health or life circumstances. Many health disparities, including barriers to care, experienced by Aboriginal people have been linked to underlying social determinants of health (1,34). Therefore, targeting the psychosocial determinants of osteoarthritis consistent with domains of well-being that are specific to the sociocultural context of Aboriginal people may optimize care outcomes (4,35,36). Such strategies may include prioritizing Aboriginal cultural values in health services, providing culturally secure psychological support, self-management support, and integrating additional social services into clinical care pathways (37).

The majority of participants in this study had sought care to better manage their osteoarthritis. This finding challenges the notion that Aboriginal people do not seek health care for osteoarthritis and suggests that the care being accessed does not meet the needs of Aboriginal people (38). Most participants described negative health care experiences that were characterized by ineffective patient–provider communication and relationships. Given that language is an important component of culture, ineffective communication in the clinical context can further contribute to the cultural chasm between Aboriginal patients and health service providers (39). Discordant patient–provider communication in clinical consultations for arthritic conditions has been identified in previous qualitative studies in which patients felt “like no one is listening to them” or that clinical assessments did not capture an understanding of how arthritis affects everyday life (40). Although this is not necessarily unique to the experience of Aboriginal people seeking care, existing barriers to health care, including experiences of discrimination, racism, and ineffective communication between health care providers and their Aboriginal clients are likely to exacerbate these issues (39,41). Some participants in our study expressed particular concerns about the way clinicians approached the topic of losing weight and the negative framing of their condition (i.e., focusing on weight or activities they should avoid), which further supports the above recommended shift towards participatory discourse. Moreover, patients’ experiences of weight stigma or perceptions of negative judgment from health professionals have been reported to result in poorer health outcomes or patients avoiding health care appointments (42).

Participants in this study expressed a desire for clinicians to use more positive framing of their condition so that they could feel “in the right mindset to help themselves.” There are fundamental differences between Aboriginal and biomedical worldviews, and this contributes, in part, to the failure of current approaches to health messages (43). Previous literature has described Aboriginal people’s preferences for health messaging that focuses on creating positive emotions, building trust, and that is targeted to family and community rather than individuals (43). Positive health communication that supports patients to feel empowered to manage their own condition should be a key objective of clinicians in the clinical encounter (44). Those participants who indicated that they were “in the right mindset to help themselves” were empowered to engage in evidence-based management strategies and also reported having positive ongoing relationships with health professionals who provided holistic care. Being “understood as a person and not merely as a disease” is an important component of patient–provider relationships for people living with arthritis (44,45). This may be particularly relevant in the context of cross-cultural health care encounters, whereby respectful partnerships between Aboriginal people and health care providers rely on establishing a communication pathway that includes self-awareness, respect, adaptability, active listening, recognition of differences, and collaborative strategies to health care planning

(45,46). Respectful partnerships and communication that address the historical legacy of racism and disempowerment are essential elements of delivering equitable health care that is culturally secure for Aboriginal people (13). Patient-centered frameworks of communication that promote mutual understanding and prioritize Aboriginal cultural communication preferences, such as clinical yarning, should be implemented to improve patient-provider communication (47).

This study is an important first step in the development of culturally secure osteoarthritis care for Aboriginal people. Using a composite story approach provided a way to present qualitative research findings efficiently and concisely while retaining rich detail and protecting the anonymity of participants. This method of presenting data, and the resultant composite story, may be a useful tool in both patient and provider health education materials and for use in clinical settings, for example, in creating patient vignettes. Approaches that support the provision of health information resources within clinical consultations have been shown to have positive effects by reinforcing verbal teaching and helping to facilitate meaningful patient communication in the wider population (48). Patient vignettes that reflect the life experiences and social and cultural context of Aboriginal people may be used by clinicians as a framework for discussing common perceptions and experiences of people seeking care for osteoarthritis, therefore prompting clinicians to explore care seekers' beliefs about osteoarthritis, what causes them, expectations for the future, and treatment beliefs. This framework for communication may support clinicians in identifying opportunities to address knowledge gaps and misconceptions and in supporting individual patient needs (49).

We acknowledge that by merging stories from different individuals and presenting them as one that the final composite story may become overly simplistic or be perceived as a stereotype account of events. There is also considerable weight on the researchers to construct a story that accurately reflects the underlying data (7,18). To address this challenge and mitigate these risks, we demonstrated transparency and trustworthiness of our research processes by: 1) conducting rigorous framework analysis to inform the development of the composite story, 2) providing a detailed and transparent description of the way the composite stories were constructed, for example, by including a thematic map and associated story sections as an appendix (18), and 3) by embedding mechanisms for maintaining an Aboriginal cultural lens, for example, by including CRG input in all steps of the research. Moreover, the vast majority of participants in this study identified as Aboriginal, while 1 participant identified as Aboriginal and Torres Strait Islander. As is inherent to qualitative research methods, the findings of this study are not intended to be generalizable to reflect the experience of all Aboriginal and Torres Strait Islander people. This highlights an opportunity for future research that may further examine the lived experience of osteoarthritis from the perspective of different cultural and geographic groups, especially Torres Strait Islander people.

A further limitation of this work was the gender balance of participants. More women than men participated in this study, and although women experience a greater burden of osteoarthritis, it is possible that experiences of living with osteoarthritis that are gendered and specific to men may not have been captured. We attempted to mitigate gender imbalance by presenting a composite story from both the female and male voice. We captured some differences in the experiences of men and women in this study, for example, women more often explained the impact of osteoarthritis in the context of family and caregiving responsibilities, and men were more likely to be engaged in ongoing exercise. Although exploring gendered differences in the experience of living with osteoarthritis was not the main priority of this study, we believe this may be an opportunity for future research with Aboriginal people who experience osteoarthritis. We also relied on self-reported diagnoses of osteoarthritis for participants to be included in this study, which may be considered a limitation due to the potential of this to be less reliable than other sources of diagnosis such as medical records. Last, all participants in this study were seeking health care, and therefore this finding of the study may not reflect the experience of people who do not seek care for osteoarthritis.

In conclusion, osteoarthritis is a multidimensional issue for Aboriginal people that permeates all aspects of life. The multidimensional and interrelated impacts of osteoarthritis on Aboriginal people's lives underscore the need for integrated, multidisciplinary care that is both culturally informed and individualized to patient need. This research highlights the current lack of culturally secure health care services, characterized by ineffective communication and negative attitudes by health care providers. These issues need to be addressed to improve access to culturally secure osteoarthritis care for Aboriginal people.

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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. Ms O'Brien 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.

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