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“We do not stop being Indigenous when we are in pain”: an integrative review of the lived experiences of chronic pain among Indigenous peoples

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Reviewers of study

Title: "We do not stop being Indigenous when we are in pain": an integrative review of the lived experiences of chronic pain among Indigenous peoples

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Title: "We do not stop being Indigenous when we are in pain": an integrative review of the lived experiences of chronic pain among Indigenous peoples

Abstract

Background: Chronic non-cancer pain is a major burden worldwide. Indigenous communities experience additional inequities in pain care and management influenced by long-standing impacts of colonization, including systemic racism, oppression, and marginalization. Traditional healing knowledges, practices and methods are valued by Indigenous people when managing their pain. However, mainstream health services often disregard this knowledge and fail to provide culturally safe management strategies. **Aim:** To understand how Indigenous peoples across the globe make sense of pain when experiencing chronic non-cancer pain. **Methodology and methods:** This integrative literature review is reported according to the PRISMA checklist and CONSIDER statement. We focused on qualitative data reported by Indigenous adults with chronic non-cancer pain in empirical and theoretical studies. Electronic searches were performed in databases from health and humanities scopes, in addition to grey literature, from 1990 to August 2023. We drew from critical theory approaches to thematically analyze data from the included studies, privileging Indigenous perspectives through a Western intellectual framework (Two-Eyed Seeing epistemology). Data extraction and thematic analysis were managed using NVivo. Primary data were mapped according to geography and theoretical framework. **Results:** After removal of duplicates, 1352 studies were screened using title and abstract, from which 99 full texts were assessed and 29 studies and 3 dissertations/theses were included. Included studies reported lived experiences of chronic pain among Indigenous peoples from Oceania, North America, and South America. Thematic analysis derived four main themes that indicated pain is entwined with nature, Indigenous identity, historical trauma, and the collective. Our findings suggest that pain is interconnected to a broader scenario of feelings, thoughts, peoples and places. **Conclusion:** Our findings highlight the layered and complex aspects of the lived experiences of chronic pain among Indigenous people. Indigenous-led alternatives focusing on culturally safe care can guide approaches to clinical pain practice and contribute to achieving health equity.

Keywords: culture; Indigenous; meta-synthesis; chronic pain; critical theory; traditional knowledges; meaning making.

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Background

Pain is defined by the International Association for the Study of Pain (IASP) as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage".(1) Chronic pain is characterized by pain that lasts longer than the expected time for tissue healing, established as three months.(2) Although chronic non-cancer pain is a significant burden worldwide,(3) Indigenous peoples are disproportionally affected by this condition.(4, 5) In Aotearoa New Zealand for example, Māori – the Indigenous peoples - are 1.4 times more likely to develop chronic pain than non-Māori.(6) The uneven burden is also evident in prevalence data from other Indigenous populations. While chronic pain prevalence is reported as varying between 11% and 40%,(7) a cross-sectional study conducted in Brazil with Indigenous peoples of five different ethnicities indicates a prevalence of chronic pain between 25% and 45%.(8) Data specific to Aboriginal, American Indian and Alaska Natives peoples in Canada also indicate the high prevalence of chronic pain compared to non-Indigenous peoples in the same region.(9, 10) The data point to a situation of cumulative health disadvantage repeatedly faced by Indigenous peoples living with pain across the globe.

Mismatch between the mainstream healthcare and Indigenous worldviews may contribute to maintaining inequities in pain prevalence among Indigenous peoples.(11) For example, Indigenous peoples are at a higher risk of having financial and spatial barriers to attend health appointments despite their geographical location.(4) Furthermore, Indigenous peoples are referred less frequently to specialized services than non-Indigenous but are more frequently prescribed interventions that rely heavily on medication for managing chronic conditions.(12, 13) Also, literature indicates that Indigenous peoples often do not receive personalized management in the presence of a co-morbid health condition, including cardiac conditions and cancer.(6, 13-15) Additionally, mainstream healthcare may overlook Indigenous knowledge and worldviews, failing to incorporate non-Western knowledge into management and treatment strategies. However, clinical strategies that are not flexible – i.e., that fail to account for Indigenous perspectives - might exacerbate invisibility and lead to under optimal engagement by Indigenous peoples.(16, 17) Studies reporting lived experiences of Indigenous peoples may offer valuable insights to transform health service delivery and advance health equity.

Current published accounts of lived experience of chronic pain are mainly from non-Indigenous populations and countries where Western discourse dominate.(18, 19) This lack of representation is explicitly pointed out by Toye et al. (2021)(19) after synthesizing 170 unique qualitative studies with the goal of understanding in-depth meaning of living with chronic non-cancer pain and the process of recovery. However, pain experience and expression are influenced by multiple factors, including opinions, attitudes, socioeconomic context, psychological status, and culture.(20, 21) In this sense, the healing journey with chronic pain suggested by Toye et al. (2021)(19) may not fully align with the experiences of culturally and linguistically diverse communities not represented in the review.(22, 23) Furthermore, the values constituting and guiding Western medicine and models of care are based on scientism, identifying science as the only valued way of knowing.(24) As a dominant discourse, this scientific medicine does not explicitly acknowledge Indigenous worldviews and experiences, which may also explain the poor access to mainstream healthcare and suboptimal management of health conditions among Indigenous peoples. Overall, exploring elements composing the lived experiences of chronic pain for Indigenous peoples can inform the development of assessment tools and uphold management strategies that are culturally sensitive and safe.(25)

Cultural safety is a concept related to quality of care and health equity that considers power relationships.(25) Therefore, it requires health practitioners to engage with an ongoing practice of self-reflection, acknowledging personal biases, opinions and prejudices, and how these impact on their healthcare interactions to provide equitable care.(25) This continuous practice is critical to address health inequities. An in-depth investigation of non-dominant discourses about chronic pain experience may shed light into novel aspects to be reflected on, in addition to possibly expanding the current knowledge of what it means to live with chronic pain.(26, 27) Thus, this integrative review had two objectives: first, we aimed to access an inter- and trans-disciplinary body of literature about lived experiences of chronic pain among Indigenous peoples across the globe; second, we aimed to highlight valued elements of care and chronic pain management reported by Indigenous peoples in relation to their understanding of the pain experience. Our results may identify opportunities for culturally safe pain care and contribute to address health inequities in chronic non-cancer pain management for Indigenous peoples.

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Terminology considerations

Our conceptualization of Indigenous peoples aligns with what was formulated by the Working Group on Indigenous Populations (United Nations)(28) and the International Labor Organization in the Indigenous and Tribal Peoples Convention, 1989 (n°169)(29, 30). In this review, we adopted a working definition of "Indigenous" as an umbrella term for the search strategy and "Indigenous peoples" as a generic term. In other words, these terms reflect a pragmatic attempt to include multiple and diverse groups and nations that have i) a profound, historical, and primary link with the land they inhabit (i.e., a country or a specific territory); ii) cultural characteristics that are distinct from the societies they are part of, including social organization and references, such as worldview, spiritual, language; and iii) a history of colonization or conquest that has often – not always – led to a non-dominant condition. This history is commonly associated with violence, injustice, and expropriation of lands and resources. Wherever possible we name the specific Indigenous nations and groups who are represented in reporting of our findings.

Methodology and methods

This study adopted an integrative review design,(31) which allows inclusion of empirical and theoretical data related to the lived experiences of chronic non-cancer pain among Indigenous peoples. This design endorses an iterative interaction with the chosen philosophical or theoretical framework to guide the search strategy and data extraction and analysis.(31, 32) We followed the PRISMA checklist and the Consolidated Criteria for Strengthening Reporting of Health Research Involving Indigenous Peoples (CONSIDER) statement to report our study.(33) The CONSIDER statement emphasizes research practices and reporting attentive to the domains of governance, relationships, prioritization, methodologies, participation, capacity, analysis and findings, and dissemination.(33) Although the CONSIDER statement was developed for original health research encompassing Indigenous peoples, knowledge or land, we adapted it to the review aims and findings as a way of strengthening the rigor of working with Indigenous data (see Appendix A).

Theoretical framework

This integrative review drew upon critical theory and the Two-Eyed Seeing approach to inform the search strategy and data extraction and synthesis. Critical theory embraces various philosophical movements including, but not limited to, Marxism and

Feminism.(34) Critical theory is underpinned by social and political contexts, encouraging discussions, recognizing power relationships, social inequities, dominance, oppression and marginalization, and autonomy.(34-36) It reveals discursive elements, health practices, cultural values, interactions, and dynamics that might be unique to Indigenous peoples.

Our research group is composed of one Indigenous and four non-Indigenous researchers working in Te Tiriti o Waitangi[1] partnership in Aotearoa New Zealand. We chose the Two-Eyed Seeing epistemology to interpret our findings. The Two-Eyed Seeing approach was developed by Mudena Marshall and Albert Marshall as a means of integrating the strengths of Indigenous knowledges with the strengths of the Western knowledges.(37) This approach is echoed in the work of Eduardo Viveiros de Castro, an anthropologist, "*The meeting between Indigenous and whites can only take place in terms of a necessary alliance between equally different partners, so that together we can move the perpetual imbalance of the world a little further forward, thus postponing its end" (Castro, 2008, p. 54)(38).* Therefore, we privilege Indigenous perspectives through a Western intellectual framework in our review.

Search strategy

A recent critical commentary on appropriate search strategies for Indigenous health literature reviews highlighted the flaws of search strategies trying to comprehensively address global Indigenous peoples: emphasis on North America and Australasia axis, and absence of justification for naming some Indigenous groups over others.(39) Based on Harding, Marra & Illes(40) recommendations, we tailored our search strategy to mitigate methodological challenges by i) searching on multiple databases and grey literature; ii) contacting Indigenous organizations of interest via email, especially those from underrepresented regions (e.g., low- and middle-income countries); iii) hand-searches in specific journals focused on topics: equity, health, Indigenous, and/or community care, preferably those with a global projection and not linked to a specific geographic region; and iv) pearl growing technique,(41) i.e., using the characteristics of pre-selected gold-standard studies to search backward and forward citations, reviews, and other literature on the topic. The five "gold-standard" studies used in this review were purposefully selected by the authors for reporting in-depth qualitative data on the lived experiences of Indigenous adults with chronic pain (Appendix B).

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Electronic database searches included MEDLINE, Web of Science, PubMed, EBSCO, Scopus, Informit, LILACS, CINAHL, ProQuest, selecting specific Indigenous collections when available. The search strategy was developed in collaboration with an experienced librarian (DT) from the Ōtākou Whakaihu Waka ki Pōneke. Grey literature was searched on Google Scholar, TRIP database, and University repositories from Aotearoa New Zealand, Australia, and Brazil. Our electronic search strategy and the search results for each database are also available on Appendix B.1. After removal of duplicates using EndNote, search results were exported to ASReview(42) for title and abstract screening.

Types of included studies

We included qualitative and mixed methods studies, theses, dissertations, and reports. Mixed methods studies reporting qualitative data using numeric frameworks only (e.g., content analysis reported using word frequencies) were not included. Studies including Indigenous and non-Indigenous groups were considered only when the research reported findings that clearly originated from Indigenous participants. We hand-searched the table of contents of specific books for further literature consideration, but their content was not included because of lack of relevance (Appendix B). Also, we did not include newspaper reports, books, editorials and letters, conference abstracts, protocols, and reviews. No language restriction was applied; search period ranged from 1990 to 2023.

Eligibility criteria

To be included, studies had to report qualitative findings (i.e., lived experiences, attitudes, views, beliefs, opinions, perceptions, perspectives, experiences, expressions, among others) of Indigenous adults (> 16 years old) with chronic non-cancer pain. We also included studies reporting the perspectives or experiences of Indigenous health professionals, traditional healers, or community elders. As important members of Indigenous communities, their perspectives could add meaning and depth to understanding the lived experiences of Indigenous peoples with chronic pain. Chronic pain was defined according to the International Classification of Diseases (ICD-11),(43) which is a classification comprising common disorders related to pain and allows for an easy operationalization using pain duration. Chronic pain encompassed persistent or recurrent pain lasting longer than three months, including chronic primary pain (e.g. fibromyalgia and widespread chronic pain) and chronic secondary pain (e.g. musculoskeletal, postsurgical, headache, or visceral).(43)

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Data collection and synthesis

One author (LGF) performed the initial screening phases (title and abstract and full text), reaching consensus with a second author (HD) when uncertain of eligibility. Data extracted from the included sources were study authors, country of origin, Indigenous group(s), number and characteristics of the participants, study design or characteristics of the grey literature (i.e., thesis, dissertation or report), setting of the study/grey literature, method for data collection, study findings, and theoretical framework used in the study rationale and informing data analysis.

Study findings encompassed quotes, descriptions and interpretations, which were collected from the results and discussion sections, in addition to supplementary files and annexes, when relevant. In this sense, the epistemological and ontological assumptions of the primary study, the primary authors selection of quotations and their interpretation, were influences on how we made sense of the data from the primary studies in relation to our review purpose. In taking a contextual and expansive approach to the data contained in each included article, we also acknowledge that every article contains a selected portion of the entire data set, subjected to layers of interpretation. Acknowledging the influence of these layers to the review findings is necessary. Aware of that, readers can appreciate that our findings are one among multiple tellings of the story of the lived experiences of chronic pain among Indigenous peoples.(44, 45)

Data analysis mixed inductive and deductive approaches and was managed using NVivo software (1.7.1). We followed a reflexive thematic analysis adapted from Braun & Clarke(46, 47) but also developed codes a priori drawing from the theoretical framework informing this review (Table 2). Deductive codes were developed and discussed among the research group, and new codes were inductively created when necessary. One author (LGF) coded the entire data set, also using memos to make sense of the extracted data; and HD, CJ, and JHS coded a random subset of the data set (four studies each).

The research group met regularly to discuss the coding and interpretations. Our analysis cycle involved in-depth familiarization with data through reading the included studies, followed by rounds of coding and interpretation in relation to the theoretical framework. At each round, the theme development gained shape, i.e., preliminary prominent themes were shared among the research team for feedback and consultation in relation to theoretical fitness, before being revised.

Findings

Electronic searches in the included databases retrieved 2952 records; after removal of duplicates, 1352 studies were screened for title and abstract, of which 99 full texts were assessed, identifying 29 primary studies eligible to be included in this review (Figure 1). Grey literature, hand-searches, and additional material sent by contacted organizations and researchers resulted in three additional eligible documents(48-50). A total of 32 study reports reporting 31 unique studies were included (Figure 1).

The characteristics of the included studies are presented in Table 1. Although mostly representing Indigenous peoples from Australasia (16 studies) and North America (10 studies) axes, five studies from South America were also identified and included, and one study included Indigenous peoples from North and South America (Mexico, Bolivia, and Brazil). All studies were published in English, except for one in Spanish(51). Twenty studies included Indigenous participants only,(8, 48-50, 52-67) six included Indigenous participants and health professionals,(51, 68-71) four included health professionals and traditional healers,(13, 21, 72, 73) and one included Indigenous participants and traditional healers.(74)

The findings were represented in four themes exploring how contextual, historical, and relational elements appear to influence how Indigenous peoples make sense of their chronic pain. The themes illustrate how pain is embodied by the Indigenous peoples participating in the included studies. As Mol and Law (2004)(75) discuss, embodiment simultaneously concerns to being, doing, and experiencing (with) our bodies, encompassing objective and subjective aspects.(76) Physical impairments and limitations imposed by chronic pain are accompanied by frustration and anguish. However, feelings of holism and identity contributed to making sense of the pain experience. For example, pain was often mentioned as interconnecting feelings, thoughts, people and places.

We selected representative quotes supporting the theme development in the text, with additional quotes presented in Table 3. Themes are described, evidenced, and discussed in the context of other relevant works, followed by a section focused on clinical implications.

Pain and nature are entwined

Indigenous participants placed emphasis on cyclic and naturistic aspects of their pain experience, as an ongoing process implying change and requiring adaptation. In this

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sense, one thing such as pain does not change without a response from the rest of the body. The cyclic aspect seems related to a holistic understanding of what causes pain, including causal understandings and pathoanatomical structures (e.g., discs, joints, bones),(50, 58) but also modulation effects of anxiety and stress.(50, 55) Further, there was often a flow to this cycle. Life changes were frequently contextualized within naturistic frameworks including the moon,(74) the seasons,(55, 74) hot and cold elements,(70) or walking into a forest/bush,(71) events that have their own rhythm and, to some extent, cannot be controlled by humans.

> "*[..] in life it's like going through the trees, the bushes and that and you stumble and you trip over these logs that have fallen and you get scratched and you break this and that and then all of a sudden you come to a clearing, but that's life, you're going through this forest and you know this happens, that happens. It's just, it's just part of life. It is, you know. And then you come to a clearing, not that that's the end of it but at least you got through that hardship. That's just it, everybody has to go through it. Like it or not, you have to go through it*." (Aboriginal participant from Canada, Thurston et al., 2024,(71))

The interconnectedness of pain and nature is, as Redford's critique of the term "ecologically noble savage" points out, potentially seen simplistically in Western discourses as a connection between indigeneity and nature conservation.(77) Its simplistic aspect not only undermines how sophisticated Indigenous knowledges are about nature resources but disregards the dynamic and evolving features of Indigenous systems,(78) in addition to reinforcing the scientific dichotomy used to delegitimate Indigenous knowledges as a "belief", unscientific and by implication not true.(24, 79)

In contrast, Barad (2006) offers an explanation for 'entanglement' that aligns with the 'entwined' idea exposed in this theme, i.e., a degree of combination in which the independent existence of the combined elements is inconceivable.(80) The inseparability between pain and nature highlights a complex process of embodying pain and the active search for ways to respond to pain demands and constraints. Moreover, the references to naturistic aspects appear to illustrate the means, not the end, to meaningfully connect with self-care and self-management strategies. Lastly, the connection with nature highlights that the fluidity of chronic pain experience encompasses both good and challenging moments of living life with pain.

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Pain and Indigenous identity are entwined

Echoing the notion of inseparability, Indigenous peoples living with chronic pain identified that Indigenous identity frames their pain experiences. This entwinement can be observed when Indigenous identity and pain experience cannot be elaborated or understood separately.(50, 55) Some reports highlight the sense of honoring ancestors by enduring pain, which is motivated by recalling the characters of Indigenous warriors relevant to their ethnicity.(55)

> "*It's strengthening to know that my family are warriors.*" She continued, referring to the Trail of Tears, "*I think it makes me stronger. Because my ancestors. How far they walked. I mean really. You mean they made you walk all the way there and all the way up and all the way down.*" (American Indian participant; Duwe et al., 2019(55))

However, this indivisibility of embodying chronic pain is experienced variably. Other reports focus on the importance of feeling strong from within, which was often reported by Māori participants from Aotearoa New Zealand, especially in relation to growing older.(54, 73) Inner strength may mean handling pain on their own although a support network might be available. Developing this strength to manage pain may be connected to the wisdom attributed to older adults or elders, in Māori (*kaumātua*)(73) and other Indigenous cultures (e.g. Kamayurá in Brazil,(8) Misak in Colombia,(70) First Nations and Métis in Canada(52)). In this sense, the pain experience appears to be understood as a way of (re)connecting with Indigenous identity, the people that came before, ancestors, and traditional knowledge, which could be empowering and contribute to favorable mechanisms to managing pain.

By contrast, the physical limitations imposed by chronic pain appear to impact identity, especially when these limitations interrupt daily activities that were once often performed or limit intergenerational knowledge to be passed on.(52, 61, 68, 73) For Māori men with osteoarthritis, for example, pain is an obstacle impacting their *mana* (essence, also translated as spiritual power) and *whakapapa* (genealogy, but broadly conceptualized as what connects everything in terrestrial and spiritual planes).(54, 65)

Diverse ways in which groups express their suffering is consistent with "idioms of distress", a concept that endorses variation in the expression of suffering, in this case chronic pain expression, based on, but not limited to, cultural understandings, traditions,

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previous experiences, familiarity with the health care, and access to care.(81) Therefore, Indigenous identities are another aspect to be added to this set. When strengthened by relationships and ancestry,(82) identity may contribute to expressing and framing chronic pain in more resilient ways.(83)

Pain and historical trauma are entwined

Identities are shaped by historical and biographical references, life events and relationships.(82). Hence, talking about lived experiences of chronic pain is to talk about Indigenous pasts. This means that elaborating on pain origins and what the pain experience means to Indigenous peoples is traced back to colonization references and memories, mainly intergenerational or historical trauma.

> "*I guess, as Aboriginal and Torres Strait Islander people, we carry different things. Every human carries different pain. We have intergenerational trauma, we have that emotional pain. And when we learn in different families, we've learned different ways to manage our pain, a different way to respond to pain.*" (Aboriginal participant from Australia and Torres Strait Islander, Bernardes et al., 2022(68))

Intergenerational or historical trauma is defined as a set of cumulative events that have a collective impact and fracture cultural flows; occurs over and impacts multiple generations.(84) Māori men with knee and hip osteoarthritis recalled their past when they were punished for speaking their native language (Te Reo Māori) when talking about chronic pain.(54) Similar experiences were observed when an Aboriginal from Canada referred to residential schools amongst their lived experiences of chronic pain.(53) Those lived experiences expose colonization practices and the influencing power of the dominant cultures. In this sense, Western neoliberal values controlling societal and economic organization influences not only the existence but the possibilities of exercising Indigenous thinking and knowledge.(85)

Colonization imposed a set of discursive norms that are also evident in the structure and organization of current Western health systems.(86) In this sense, navigating a health system that is in itself an artefact of hegemonic government policies perpetuates colonial violence. Mainstream healthcare often iterates its dominance by actively rejecting Indigenous worldviews as unscientific, referring to Indigenous knowledge and traditional medicine with distrust.(24) Therefore, chronic pain is likewise experienced in the social

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and political bodies of Indigenous peoples.

> "*Yeah, I think we're quiet about pain 'cause no one listens to us anyway. They haven't been listening to us people for a long time.*" (Aboriginal participant from Australia; Strong et al., 2019)

The delegitimization of Indigenous knowledges evidences a systemic lack of cultural safety.(25) The role that Indigenous traditional protocols have in making sense of and managing chronic pain is not well understood and does not have space within the mainstream Western care.

> "*...that holistic approach is something that Western medicine doesn't instinctively kind of make the connection to. [...] my orthopedic never asks me about [my mental health] and [neither] did my physio. So, like, you can really see the difference in terms of, I guess, kind of care*" (Aboriginal participant from Australia and Torres Strait Islander; O'Brien et al., 2023)

Inequities define the challenges faced by Indigenous peoples when navigating health systems that operate based on Western worldviews and values, i.e., lack of justice deliberately constructed and systemically implemented.(4, 87) Corroborating our interpretation, statistical data from Brazil,(88) Australia,(89) US,(90) Canada(91) and Aotearoa New Zealand(92) indicate disparities in various long-term health conditions, including chronic pain and reduced life expectancy, between Indigenous and non-Indigenous peoples.(4)

A nuance encompassed by this theme related to disclosing one's Indigenous identity when seeking help in the mainstream healthcare. Racial stereotypes, discrimination and stigma frequently generates situations of doubt, confusion, and more pain.(51, 55, 61) Furthermore, distrust was frequently exposed in the narratives of Indigenous peoples with chronic pain about their journeys interacting with mainstream healthcare.(50, 53, 68) When encounters with health systems and health professionals disregard Indigenous knowledge and systems, failing to accommodate or being hostile towards Indigenous worldviews, this can result in resignation and/or resistance. Resistance is explicit when participants ceased to trust their health professionals and mainstream health system as whole and became reticent for fear of being criticized or stigmatized.(49, 52, 64) Resistance can be accompanied by contestation, an active participation to defend a positioning or fight marginalization.(93) Resignation is observed in the experiences of

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racism, discrimination, blaming, and stigmatization, which altogether appear to be a contemporary set of colonial actions.(51) In those cases, for example, keeping quiet about the experience of pain seems to be a response to the systematic and continued absence of listening from health professionals.(64)

Resistance and resignation behaviors point to the structural violence faced by Indigenous peoples when seeking help in the mainstream care for pain management. Structural violence is a concept coined by Paul Farmer and colleagues (2006) when referring to the oppressive structure that shapes how disadvantaged, vulnerable, and marginalized groups access — or not — healthcare.(93) Therefore, the reports evidence the difficulty of navigating a system that fails to accommodate or is hostile to Indigenous values and knowledges (i.e., holistic approach) when considering health and illness.(54, 61, 68) Moreover, being othered in the health system may prompt feelings of not belonging, distancing, and frustration.(94) In the face of continued colonial violences perpetuated by mainstream services, Indigenous peoples may feel compelled to avoid confrontation by choosing silence or opt not to share the complexities of their lived experiences with health professionals.(64) Therefore, family, friends, peers, and the community of Indigenous peoples are also part of the chronic pain experience.

The entwining of pain and historical trauma highlights how the experience of pain cannot be separated from social and political bodies.(61) Physical pain may be inextricably linked to past and current emotional and spiritual aspects of pain. In this sense, colonization history, its memories, and the multifaceted features of pain add cumulative layers and complexity to the lives of Indigenous peoples living with chronic pain. This entwinement also indicates that pain is not a condition isolated in time nor tied to individual bodies.

Pain and the collective are entwined

The collective embodiment of pain reveals the community-centred relational aspects involved in making sense of pain. Living with chronic pain seems to prompt dilemmas linked to connecting with others and participation in life roles. Some research participants understood that prioritizing the community or the health of others is culturally driven.(49, 50, 69) This collective embodiment highlight that participation in community roles and duties appeared to contribute to a sense of belonging and purpose, and caring for others first may give life a meaning and cultural identity.(54) Although adapting and changing the ways to partake in community roles may be required due to pain, it allowed continued

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and sustained participation.(54)

> "*I think it's um definitely part of the collective nature of um Māori thinking and then um prioritizing the whānau (extended family) above your individual needs. However, if there are no whānau needs then my individual needs can take priority.*" (Māori participant; McGavock, 2011(50))

Participation appeared to facilitate embracing the ups and downs inherent to chronic pain experience. Ullrich, Demientieff and Elliot (2022) have pointed out that an interconnected system of relationships is crucial for knowledge exchange, which may contribute to resilient strategies.(45) Nevertheless, a contrasting sense of nostalgia is also evident, suggesting that pain may adversely impact the capacity for collective embodiment.(54, 61) This can be seen when other participants indicated that the limitations caused by chronic pain may hinder participation in community roles.(61) In those situations, the passing of cultural knowledge to future generations via experiential practices may also be put on hold.(61) When community participation was restricted due to pain, feelings of shame, frustration, and embarrassment were experienced.(49, 61, 69)

> "*It's one of those things where because it is invisible [pain], it's hard for people to see just how brutal it can be to a person. But for us, there's no way to really tell unless we complain about it. 'Oh, geez, there he goes again, complaining about it.*" (Native American participant; Katonak, 2017(49))

The ambiguity in how community and cultural aspects contribute to the lived experiences of chronic pain exposes the uncertainties of this condition. Ambiguity was also observed in the dilemmas arising from the interface between pain and relationships. Some studies highlighted the helpful support and understanding participants received after sharing their pain experiences with others.(21, 50, 61, 95) The support network appeared to encompass a variety of configurations including family, friends, and peers, present in-person and via online groups. However, opening up about pain experiences with others or even considering this possibility could also motivate feelings of confusion, insecurity, and discomfort.(55, 64, 69) Included reports testify that the invisible nature of pain may prompt disconnection, distancing, and judgement from others.(50) Furthermore, fear of being a burden to others was also part of relational dilemmas,(50, 55, 68) and participants could end up receiving a different support than what they thought was needed. For instance, some participants reported being “pitied in a good way” by family members,(95)

but having others taking part in doing chores on their behalf also disturbed their sense of autonomy and triggered feelings of self-doubt.(61) Altogether, chronic pain seemed to trigger a set of dilemmas that went beyond the physical limitations and impacted on the person in relation to people. These dilemmas were projected on to the relationship with others (family and friends), the community, the healthcare system and health professionals, or were connected to societal expectations.

Clinical implications

Our review findings can be incorporated by stakeholders and inform public policies in the field of chronic pain. Considering the interconnected ways of embodying pain may be a first step towards disrupting the Western and scientific dominance to promote diversity in the discourses and understandings of chronic pain. Understanding that disruption must happen in multiple levels to be sustainable, diversity will influence what is legitimized in clinical care, service design and delivery, and the policies that direct actions. This consideration would allow deeper engagement with Indigenous knowledge and systems.(96)

Achieving equitable health outcomes for Indigenous peoples with chronic pain is possible with health initiatives that are embedded in cultural safety.(25, 97) Furthermore, actions may be guided by existing successful initiatives and recommendations. For example, among the pragmatic strategies to equity-oriented care elaborated by Browne et al. (2016)(97), (re)centering care programs to Indigenous knowledge systems and address interrelated forms of violence resonate strongly with our findings.(96) These strategies drew from the findings of a preliminary ethnographic study conducted within two Aboriginal heath centers in Canada,(53) which also informed this review findings. Importantly, although these strategies must be adapted to local Indigenous knowledge and contexts and should not be used as a mere checklist, they endorse action at multiple levels.(97) Simultaneously addressing intrapersonal (individual with chronic pain), interpersonal (individual, health professionals, family networks) and contextual (health systems, community) levels is also endorsed by Palmer et al. (2019)(98) to achieve equitable outcomes for Māori and is the foundation of specific Indigenous health systems implemented in Brazil, Ecuador and Chile in early 2000s.(99) Furthermore, Barnabe (2021)(100) emphasizes the community and development of relationships as pillars for empowering Indigenous health and achieving self-determined health systems. The theme "structural and relational dilemmas of embodying pain" places emphasis in those same

aspects. Therefore, fostering health equity for Indigenous peoples warrants acknowledging that the Western medicine with its scientist discourses is one ethnomedicine among many. Consequently, changes must occur beyond the operational dynamics of mainstream health care.(97, 98) In this sense, our review findings may add to this scenario and stimulate critical reflections by health professionals working with pain management.

Also, culturally safe care for Indigenous peoples may vary by cultural context and there is no singular method of culturally safe ways to approach the topic of pain. This is exemplified in the use of talking circles, artwork and arts narratives by Latimer et al. (2018) in their work with First Nations youth and children with chronic pain.(101) The authors reported that the arts-based approach created a safe space for the emotional aspect of pain to be expressed.(101) Moreover, using arts-based approaches foster aspects that were identified in our findings as valuable for chronic pain care and management, including (re)connection with Indigenous identity, expression of Indigenous worldviews, and development of relationships with the community.(102) Our findings also indicated that pain is often not confined to the physical and its inextricable links with emotional and spiritual aspects endorses the combination of strategies for management. In this regard, Poitras et al. (2022)(103) analyzed 19 studies encompassing initiatives developed for and with Indigenous peoples from Oceania and North America to understand what culturally safe initiatives in primary care for chronic diseases looked like. Initiatives were mostly structured upon a combination of trustful relationships (family networks, support groups) that were delivered in accessible language (including the use of interpreters, if needed), also using cultural elements (storytelling, language, outdoors activities) and respecting Indigenous knowledge and worldviews (including Indigenous workforce), in addition to upholding participation (using technology, home visits, or referral systems).(103) Other successful examples of culturally safe initiatives strongly underpinned by community participation were reported for mental health,(104) dementia,(105), and maternity care(106).

Further initiatives that contribute to culturally safe care in the specific field of chronic pain can be informed by existing strategies, the deeper understanding of what means to live with chronic pain for Indigenous peoples provided by this review, and community-based and participatory narrative approaches. In research, beyond investigating the implementation of initiatives with any specific set of methods, Linda Tuhiwai-Smith

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(2012)(107) underlines choosing Indigenous frameworks as the methodological approach. This way, research questions and their operationalization will necessarily be framed, discussed, and shaped to encompass Indigenous perspectives, respecting Indigenous knowledge and systems.(107)

Strengths and limitations

The search developed for this review did not find any study from locations such as Europe, Africa and Asia, therefore the perspectives of Indigenous peoples for those geographies are not represented. We purposively selected umbrella and specific terms aiming to address gaps identified by previous research,(39) mostly derived from a broad definition of Indigenous peoples agreed among the research team. However, conceptualizing indigeneity is widely debated among scholars, governments, organizations and Indigenous institutions,(108) and using a formal definition of Indigenous peoples is rejected by the United Nations and other institutional bodies. Seeking for a single and universal definition of Indigenous peoples risks reproducing oppressive approaches experienced throughout history.(28, 40) Second, we deliberately differentiated Indigenous peoples from other minority groups. Consequently, we might have missed studies about the lived experiences of chronic pain that included Indigenous peoples living outside their ancestral geographic land, who were thus referred to as ‘refugees’ or ‘minorities’. This problem is raised by Corntassel (2003) when discussing approaches to Indigenous identity.(108) According to the author, failing to acknowledge the Indigenous identity when the proximity to the ancestral land is absent or changes in the cultural traditions occur can be seen as “penalizing freedom of movement”.(108) In many contexts, Indigenous peoples were forced to migrate to urban areas as consequences of colonization practices and settlement policies.(84, 108)

Language is another component that influenced the process of making sense of our review findings and should be examined. First, Ullrich, Demientieff and Elliot (2022) highlight the role language plays in the interconnected system of relationships.(45) According to the authors, relationships are central to life and living, and language is the connecting thread that allows Indigenous knowledge to be passed onto generations via stories and teachings.(45, 109) However, the oral nature of many Indigenous languages challenges their preservation,(110) in addition to colonial practices that adopted strategies to purposefully exterminate them, including residential schools.(109) Losing Indigenous languages may mean losing identity, space, knowledge, governance systems, and

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more.(109) Second, language is also the filament to interpretation, and our interpretation was through and in the language of publication. Of note, most studies included in this review were published in English, the predominant language for communicating science, but also a colonial language imposed on Indigenous peoples in North America and Oceania.(109, 111) Although English was the first language to some participants in the included studies, few studies also stated the need of translator/translation, and others reported specific words/phrases in Indigenous languages and dialects spoken by the participants. Therefore, nuanced or particular meanings related to the lived experiences of chronic pain among Indigenous peoples from the primary studies may be lost in translation or failed to be fully integrated to our findings. Nevertheless, interpretation is constitutive of qualitative research and by drawing from critical theory we aimed to expose and challenge existing social structures related to the lived experiences of chronic pain among Indigenous peoples.(112)

Lastly, we emphasize that this review does not attempt to find rules or patterns that can be applicable across all Indigenous peoples worldwide. Instead, we endorse curiosity to understand the particularities of each context, community and person with chronic pain, recognizing the complexities of every situation.(45) More in-depth investigations on the lived experiences of chronic pain among Indigenous groups are needed. Because non-Western perspectives are powerful and transformative to redefine, rethink and redesign pain care to all peoples, particular relevance should be placed on research led by Indigenous scholars and adopting Indigenous methodologies and frameworks.

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Conclusion

This integrative review aimed to investigate and summarize the literature about the lived experiences of chronic non-cancer pain among Indigenous peoples. Our findings highlighted aspects related to pain meaning making that might be directly or indirectly overlooked by mainstream Western pain care. Cognisant of the cultural differences among Indigenous peoples across the globe, our findings emphasize a set of umbrella aspects in chronic pain experience. Spiritual, emotional, physical, ancestral, collective, historical, biographical, and ecological elements appear to be implicit to meaning making, and form interconnected layers that influence how pain is understood and experienced. Therefore, pain management approaches that are attentive to the elements encompassed by this review and draw from successful examples of culturally safe care might contribute to

achieving health equity for Indigenous peoples with chronic pain. Moreover, our findings can guide self-reflective practices for health professionals working on the mainstream healthcare, which may strengthen the Indigenous allyship network, also contributing to culturally safe practices. Having mainstream health care that is inclusive and representative of diverse worldviews and knowledge is an aspiration to keep acting towards.

Positionality statement/Author's information

Our research team is diverse and interdisciplinary, composed of Indigenous and non-Indigenous researchers. XXXX is a doctoral student with previous experience in qualitative methodology and qualitative data synthesis. XXXX is a senior lecturer, researcher and a pain management physiotherapist. XXXX has wide-ranging methodological expertise, including qualitative and mixed methods research. XXXX is an experienced Māori community researcher, partner, and manager of XXXX. XXXX is a medical anthropologist with extensive research experience using critical approaches.

Terms and explanations

[1] Te Tiriti o Waitangi (Treaty of Waitangi) is the founding document of Aotearoa New Zealand as a British colony, signed by the British Crown and Māori rangatira (chiefs) in 1840. It represents the responsibility of the Crown in protecting and guaranteeing Māori rights (the Indigenous peoples of Aotearoa, tangata whenua). Te Tiriti o Waitangi is structured in articles that uphold Māori governance (kāwanatanga), self-determination (rangatiratanga) and equity (ōritetanga).

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Table 1. Characteristics of the included studies

Author(s), year	Country	Indigenous group (s)	Characteristics of the participants / chronic pain condition	Study design and methodology	Theoretical orientation	Data collection and analytic process	Topics encompassed by the study/report		
							Pain experience and expression	**Pain management**	**Pain and health system/services**
O'Brien et al., 2023	Australia	Aboriginal and Torres Strait Islander	Osteoarthritis	Qualitative Interpretive phenomenology	-	Interviews and development of composite stories	v	v	v
Dixon et al., 2021	New Zealand	Māori	Osteoarthritis	Qualitative Kaupapa Māori and Māori health frameworks	Kaupapa Māori	Interviews and thematic analysis	v	-	v
Lin et al., 2012	Australia	Aboriginal	Chronic low back pain	Qualitative Clinical ethnography	-	Interviews (clinical yearning)	v	-	-
Alarcon et al., 2013	Chile	Mapuche	individuals with musculoskeletal conditions and traditional healers (Machi)	Qualitative Ethnography	-	Interviews and thematic analysis	v	v	-
Carod-Artal et al., 2007	Mexico, Bolivia and Brazil	Kamayurá, Uru-Chipaya and Tzeltal Maya	Shamans, healers and medicine-men's perspectives on headache and migraine	Qualitative Ethnography	-	Interviews		v	
Barnabe et al., 2019	Canada	First Nations and Métis	Inflammatory arthritis	Qualitative Patient and Community Engagement	Grounded Theory	Interviews and thematic analysis	v	v	v

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				Research (PaCER)					
Loyola-Sanchez et al., 2020 (1)	Canada	Siksika Blackfoot	Rheumatoid arthritis	Qualitative Social constructivism	Social constructivism	Interviews, thematic analysis, and development of narratives			v
Loyola-Sanchez et al., 2020 (2)	Canada	Siksika Blackfoot	Rheumatoid arthritis	Qualitative Social constructivism	Social constructivism	Interviews, thematic analysis, and development of narratives		v	v
McGruer et al., 2019	New Zealand	Māori	Osteoarthritis	Qualitative Kaupapa Māori	Kaupapa Māori	Interviews and thematic analysis	v	v	-
Browne et al., 2011	Canada	Aboriginal	Unassigned	Qualitative Ethnography	Postcolonial theories	Interview and participant observation, thematic analysis			v
Bernardes et al., 2022	Australia	Aboriginal and Torres Strait Islander	Individuals with persistent pain (back, limb, multi-site) and Aboriginal and Torres Strait Islander Hospital Liaison Officers	Qualitative Phenomenology	Phenomenology	Focus groups and interviews, thematic analysis		v	v
Caroselli S.,	Chile	Aymara	Unassigned	Ethnography	-	-	v		
De Moraes et al., 2021*	Brazil	Ashaninka, Huni Kuin, Kanamary,	Unassigned	Mix-methods	-	Interviews and survey,	v	v	

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		Marubo, and Matis				descriptive analysis			
Devan et al.,	New Zealand	Māori	Kaiāwhina (Māori community health workers) with and without musculoskeletal conditions	Qualitative Kaupapa Māori	Kaupapa Māori	Interviews and thematic analysis	v		v
Haozonous et al., 2016	USA	American Indians and Alaska Natives	Persistent pain > 12 weeks	Qualitative	-	Focus groups, content analysis and thematic description	v	v	v
Lin et al., 2014	Australia	Aboriginal	Chronic low back pain	Qualitative Clinical ethnography	-	Interviews, thematic analysis			v
Lin et al., 2013	Australia	Aboriginal	Chronic low back pain	Qualitative Clinical ethnography	-	Interviews, thematic analysis	v		
Mittinty et al., 2022	Australia	Aboriginal and Torres Strait Islander	Unassigned	Mix-methods	-	Interviews, thematic analysis	v		
Morunga et al., 2023	New Zealand	Māori	Kaumātua**	Qualitative -	-	Interviews, thematic analysis	v	v	
Ospina-Caicedo et al., 2022	Colombia	Misak	Traditional healers, health professionals and individuals with rheumatoid arthritis	Qualitative Ethnography	-	Field notes, interviews, and thematic analysis	v	v	

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Quintana et al., 2020	Argentina	Qom	Rheumatoid arthritis	Qualitative Ethnography	-	Interviews, non-participant observation, and thematic analysis	v		v
Strickland CJ, 2001	USA	American Indian	Arthritis and orthopedic injuries	Qualitative Grounded Theory	-	Interviews and focus groups, grounded theory methods (theoretical sampling, coding, theory generation)	v	v	v
Te Karu et al., 2013	New Zealand	Māori	Gout	Qualitative Kaupapa Māori	Kaupapa Māori	Interviews, thematic analysis	v	v	v
Thurston et al., 2014	Canada	First Nations, Inuit and Métis	Arthritis	Qualitative Grounded Theory	Social constructionism	Interviews, grounded theory methods (theoretical sampling, coding, theory generation)	v		v
Umaefulam et al., 2022	Canada	First Nations, Inuit and Métis	Rheumatoid arthritis	Qualitative Phenomenology	-	Interviews, thematic analysis			v
Duwe et al., 2019	USA	American Indians	Chronic pain	Qualitative Interpretative phenomenology analysis	Interpretative phenomenology analysis	Interviews, thematic analysis	v		
Strong et al., 2015	Australia	Aboriginal	Unassigned	Qualitative	-	Focus groups, thematic analysis			v
Magnusson & Fennel, 2011	New Zealand	Māori	Kaumātua and Māori Health professionals	Mix-methods	-	Interviews and questionnaires	v		
Katonak R., 2017[#]	USA	American Indians	Chronic pain	Qualitative Qualitative descriptive	Symptom management theory	Interviews, content analysis	v	v	v

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Baker N., 2018[#]	New Zealand	Māori	Musculoskeletal conditions	Qualitative Kaupapa Māori	Interpretive phenomenology, embodiment, and ecosocial theory	Interviews, Rourou method***	v	v	
McGavock Z., 2011[#]	New Zealand	Māori	Chronic pain	Qualitative Kaupapa Māori	Interpretive phenomenology	Interviews, interpretive phenomenological analysis and narrative	v	v	v

[#]Dissertation/thesis

*Data from de Moraes et al., 2021 was complemented with study information disseminated via a scientific communication media (https://agencia.fapesp.br/indigenas-da-amazonia-tem-dores-frequentes-mas-nao-reclamam/28342) and its respective master's degree dissertation.

** Kaumātua are the holders of traditional knowledge for Māori, the Indigenous peoples of Aotearoa New Zealand

*** The Rourou method was described by Glenis Mark (2012) and consists of a collaborative research method that aims to build up and construct knowledge together with participants. Data from interviews are discussed in groups, favoring expansion of topics rather than fragmentation into codes or units of interpretation.

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Table 2. A priori codes developed from the theoretical framework

Theoretical framework	Major codes	Specific codes
Critical theory	Power relations Ideology Oppression and marginalization Discourses Autonomy Social structure and aspects	Power relations – with health professionals/in the health encounter Power relations - with family and friends Power relations – the healthcare system Power relations – the Western biomedical approach Discourses – from health professionals Discourses – from participants Discourses – voices that are absent Discourses - exclusion
		Management – self-management Management – seeking help Management - individual responsibilisation (i.e., when a word like autonomy is a 'disguise' for blaming individuals or groups for not doing something that other's think is 'good' for them or that they 'should' do, or are expected to take responsibility for (even if they do not have the power or resources or capacity or opportunity to do be autonomous)
		Access to health services Health outcomes Structural violence Accumulated challenges to access/navigation
Two-Eyed Seeing approach	Combining the strengths of Indigenous and Western knowledges and ways of knowing	Specific methods of data collection and analysis (e.g., yarning, story circle, ethnographic interviews, others – identify) Ways of partnering with Indigenous groups Specific terminologies and definitions, words in other languages and dialects Research team profile – positionality statement

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Table 3. Supporting quotes from the included studies illustrating the review findings

Themes	Supporting quotes
Pain and nature are entwined	"*These are the lessons my grandmothers teach. Roll with change, because everything's always changing. And learn what you can out of it. For the better. And that's I think really native culture. They were always going through changes cause they were nomadic. Can't control the weather. Can't control the universe. Got to adapt."* (American Indian participant; Duwe et al., 2019)
	"*The pains are connected to the moon; the people have less pain when the moon is waning and more pain when it is waxing, and all this is related to the cycles of the earth, the climate, and the lunar cycles/moon phases."* (Mapuche participant; Alarcon et al., 2013)
	"*You know and Kokum used to tell us this story. Indians said in life it's like going through the trees, the bushes and that and you stumble and you trip over these logs that have fallen and you get scratched and you break this and that and then all of a sudden you come to a clearing, but that's life, you're going through this forest and you know this happens, that happens. It's just, it's just part of life. It is, you know. And then you come to a clearing, not that that's the end of it but at least you got through that hardship. That's just it, everybody has to go through it. Like it or not, you have to go through it. (32IP)"* (Aboriginal participant from Canada; Thurston et al., 2014)
Pain and Indigenous identity are entwined	*"Hoani, L438: Yes, being Māori has influenced my experience of pain, and handled my threshold of pain."* (Māori participant; McGavock, 2011)
	"It's strengthening to know that my family are warriors." She continued, referring to the Trail of Tears,

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	"I think it makes me stronger. Because my ancestors. How far they walked. I mean really. You mean they made you walk all the way there and all the way up and all the way down." (American Indian participant; Duwe et al., 2019) *"It's made me a strong person. I really do think that all this stuff has made me a very strong person. And no matter how much opposition and adversity, I can shove right through it. I can get focused. I'm like a warrior."* (American Indian participant; Duwe et al., 2019) *"Because I'm handling it. Uh, they'll all come running if I talk like that eh, and that is not helping me to see them running like that. My son lives [nearby], he'll prop me up if he needs to, I know that. But, I have this thing about trying to be strong within myself as I'm getting older, because to me that it's so important that I stay as strong as I can be right now."* (Māori participant; Morunga et al., 2022) "*I really miss my hunting … that's what I miss the most. Getting my boys and the dogs, then just spending a day or two out in the bush with them. It's priceless those moments … They're memories I will cherish forever; it's the time I spent with my boys bringing them up and teaching them the life skills that were passed down to me. It's whakapapa really my boy*." (Māori participant; Dixon et al., 2021)
Pain and historical trauma are entwined	"*I was beaten when I was younger for speaking Māori even though it's my native tongue*." (Māori participant; Dixon et al., 2021) "*You know, you're always told to shut up and we didn't have any opinion about anything*." (Aboriginal participant from Canada; Browne et al., 2011) *"This young woman is going to come and stay with us because she needs awhi [support] for her, not just*

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this foot, but her depression, her mental well-being, the grief of her mother dying and not being able to go home - All in this foot." (Māori participant; Morunga et al., 2022)

"But I guess as Aboriginal and Torres Strait Islander people, we carry different things. Every human carries different pain. We have intergenerational trauma, we have that emotional pain. And when we learn in different families, we've learned different ways to manage our pain, a different way to respond to pain." (Aboriginal participant from Australia and Torres Strait Islander, Bernardes et al., 2022)

"*We are safe with our medicines, we are used to taking our medicines like people here and it happens to us. We can always heal, but they distrust that we can heal them"* (Aymara participant; Caroselli, 2013)

"*I've got a lovely lovely doctor but she doesn't, she's not open to alternative medicine, anything even the name Arnica [homeopathic remedy for muscle aches and bruises] she'll probably just sort of raise an eyebrow you know, which kind of goes, you know, clashes with me a bit*" (Māori participant; McGavock, 2011)

"*The hospital itself doesn't understand our culture. Whereas, you know, like I get put in a room, you know, with three women. That can't happen […]*" (Male Aboriginal participant from Australia; Bernardes et al., 2022)

"One of the things that made me acutely aware of the pain was when a GP said to me "oh you're Indigenous therefore you need to go on – cholesterol tablets, Lipitor". He put me on them as a preventer because I was Aboriginal. Well, what a stupid thing for the GP [to do], it's the GPs that need

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educating…Because he actually stereotyped me" (Aboriginal participant from Australia and Torres Strait Islander; O'Brien et al., 2023)

"We won't give you something because we don't want you to become addicted to it" [participant's interpretation of the health professional's attitude] (First Nations and Métis participant; Barnabe et al., 2019)

"I have a good doctor, but sometimes I have to go to other doctors or something, I don't tell them everything, the whole truth because I feel like I'm going to get labeled." (Native American participant; Katonak, 2017)

"See my disability makes them think I am faking it; that is stressful because one always feels like they are defending themselves." (American Indian participant; Duwe et al., 2019)

"Yeah, I think we're quiet about pain 'cause no one listens to us anyway. They haven't been listening to us people for a long time." (Aboriginal participant from Australia; Strong et al., 2019)

"*The doctor tells us that there is nothing wrong with us, that nothing is wrong, they take the blood pressure, the lung tests, but they say that it doesn't hurt, but the person says that it hurts*" (Aymara participant; Caroselli, 2013)

"Never really been a big fan of doctors boy. Everything to do with the pākehā way of life is just different to our life. Not to say one is better than the other, just different" (Participant 1)." (Māori participant; Dixon et al., 2021)

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	"*…that holistic approach is something that Western medicine doesn't instinctively kind of make the connection to. […] my orthopedic never asks me about [my mental health] and [neither] did my physio. So, like, you can really see the difference in terms of, I guess, kind of care"* (Aboriginal participant from Australia and Torres Strait Islander; O'Brien et al., 2023)
Pain and the collective are entwined	*"I think it's um definitely part of the collective nature of um Māori thinking and then um prioritizing the whānau (extended family) above your individual needs. However, if there are no whānau needs then my individual needs can take priority."* (Māori participant; McGavock, 2011) "*When I go and help with the marae and that, it [pain] doesn't really affect me. Although, I've got to sit down a bit … I still partake in that sort of thing, it hasn't stopped me doing that*" (Māori participant; Dixon et al., 2021) "*It has an effect on how much of your cultural knowledge you pass on because if you're not interacting with the next generation and mentoring, if you have restrictions in that way, then you can't effectively do what we normally could do if we didn't have it*" (Aboriginal participant from Australia and Torres Strait Islander; O'Brien et al., 2023) "*Dealing with just pain in your back and in your knees, you really feel older and you can't interact properly with your grandchildren. You can't even get down on the floor, you feel embarrassed so there's a lot of social, emotional stuff."* (Aboriginal participant from Australia and Torres Strait Islander; O'Brien et al., 2023)

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	"*I need my whänau when I'm in pain.*" (Māori participant; Magnusson & Fennel, 2011) "*…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*." (Siksika Blackfoot participant from Canada; Loyola-Sanchez et al., 2020) "*My family knows that I'm not great physically, if I'm going to lift something, "oh mum, you better not lift that, I'll do that for you" people just know that me and my back is a problem*" (Aboriginal participant from Australia and Torres Strait Islander; O'Brien et al., 2023) "*It's one of those things where because it is invisible [pain], it's hard for people to see just how brutal it can be to a person. But for us, there's no way to really tell unless we complain about it. 'Oh, geez, there he goes again, complaining about it*." (Native American participant; Katonak, 2017)

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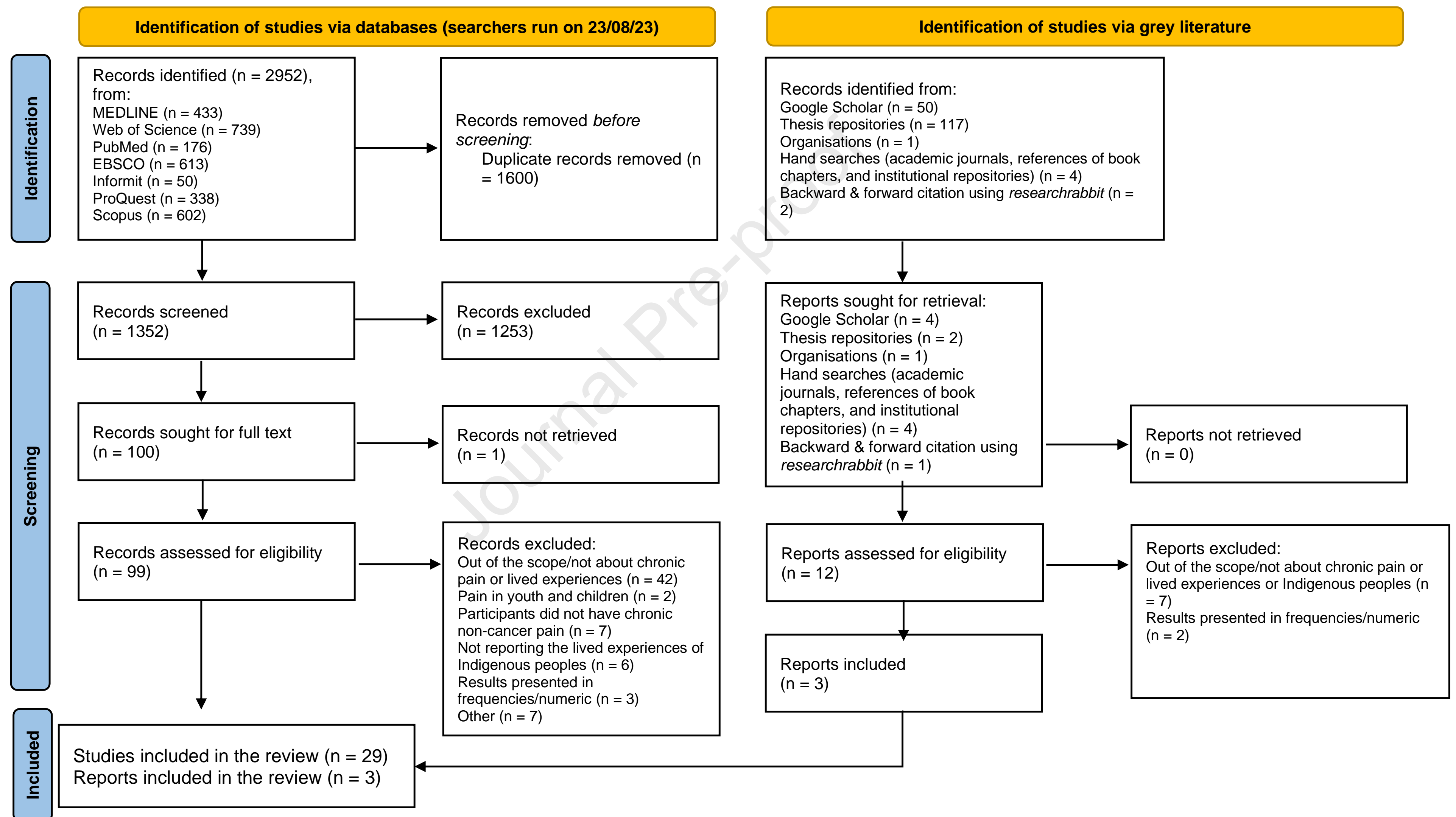
Figure 1. PRISMA flowchart for the integrative review



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

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Highlights

- Chronic pain experiences appeared to be interconnected to a broader scenario;
- Naturistic frameworks may contextualize life changes in response to chronic pain;
- Talking about the lived experiences of chronic pain is to talk about history;
- Prioritizing the health, care, and wellbeing of the community is culturally driven;
- Activities fostering community participation can contribute to pain management.

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Statement ethics approval was not required

N/A for institution and ethics committee. This integrative review did not collect data directly from participants. All data was extracted from previously published, publicly available studies, with each having their own ethics approval. Lastly, Integrative review study design is exempted of institution and ethics committee according to the guidelines of the Ōtākou Whakaihu Waka | University of Otago (https://www.otago.ac.nz/council/committees/committees/humanethicscommittees#does-your-research-require-university-of-otago-human-ethics-committee--health--approval-) and the international ethical guidelines for health-related research involving humans (p. 90, https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf).

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