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Non-biomedical perspectives on pain and its prevention and management, volume II

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Published in
Frontiers in Pain Research

ISSN 1664-8714
ISBN 978-2-8325-8523-8
DOI 10.3389/978-2-8325-8523-8

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Non-biomedical perspectives on pain and its prevention and management, volume II

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Citation

Johnson, M. I., Thompson, K., Bonacaro, A., Georgiadis, E., eds. (2026). *Non-biomedical perspectives on pain and its prevention and management, volume II*. Lausanne: Frontiers Media SA. doi: 10.3389/978-2-8325-8523-8

Table of contents

frontiers in Pain Research

TYPE Editorial
PUBLISHED 04 August 2026
DOI 10.3389/fpain.2026.1924013

OPEN ACCESS

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RECEIVED 30 June 2026
REVISED 30 June 2026
ACCEPTED 25 July 2026
PUBLISHED 04 August 2026

CITATION
Johnson MI, Thompson K, Bonacaro A and Georgiadis E (2026) Editorial: Non-biomedical perspectives on pain and its prevention and management – volume II. Front. Pain Res. 7:1924013. doi: 10.3389/fpain.2026.1924013

Editorial: Non-biomedical perspectives on pain and its prevention and management – volume II

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KEYWORDS
care environments, lived experience, non-biomedical perspectives, pain, pain ontology, relational care, social determinants of health

Editorial on the Research Topic
Non-biomedical perspectives on pain and its prevention and management – volume II

Introduction

Pain remains a major public health challenge worldwide, contributing substantially to disability, reduced quality of life, and social and economic burden. While biomedical approaches have advanced understanding of nociception and pain-related pathology, there is increasing recognition that such perspectives alone are insufficient to account for the persistence, variability, and inequitable distribution of pain. Social, cultural, relational, and environmental factors play a central role in shaping how pain is experienced, interpreted, prevented, and managed. This Research Topic, *Non-biomedical perspectives on pain and its prevention and management – Volume II*, builds on this recognition by bringing together a diverse collection of contributions that explore pain beyond narrowly biomedical framings.

Volume I of this Research Topic demonstrated the breadth and legitimacy of non-biomedical approaches to pain, highlighting perspectives drawn from social sciences, humanities, systems thinking, and community-based practice. Volume II extends this work by further examining how such perspectives can inform prevention and management, particularly through attention to upstream conditions, relational processes, and care environments. Rather than proposing a single alternative model of pain, this Research Topic reflects the plurality of non-biomedical perspectives and their relevance to real-world pain contexts.

In methodological terms, the contributions to this Research Topic largely take an exploratory and interpretive approach, focusing on developing ideas and understanding experience rather than on testing specific interventions or outcomes. Many papers examine how pain is recognised, understood, and lived with in situations where standard biomedical measures on their own do not fully capture what matters to people. Others use analytic or evaluative approaches to place pain within wider social,

relational, and systemic settings. Although a small number of studies focus on interventions or evaluations, these are situated within a broader non-biomedical perspective that emphasises care environments, communication, and lived experience. Overall, the Research Topic reflects a field that is concerned with learning, reflection, and opening up new ways of thinking about pain, rather than with providing final answers through testing alone. Future research can build on this work by bringing together experience-focused approaches with longer term, comparative, or mixed methods designs, and by paying greater attention to how non-biomedical perspectives are taken up, supported, or limited within different services, settings, and policy contexts, helping to connect new ways of understanding pain with changes in practice.

Overview of contributions

Across the contributions, several overlapping themes can be identified. These themes do not represent discrete categories but rather points of emphasis that reflect different ways of relocating where pain is recognised, understood, and addressed.

Making pain visible: recognition, meaning, and expression

Several contributions focus on how pain is recognised, interpreted, and made visible, particularly in contexts where conventional assessment tools or biomedical indicators may be limited. These papers highlight that pain is not always self-evident and that its recognition often depends on interpretive, communicative, and cultural processes.

Pain in later life and in cognitive impairment is addressed by Kruijer et al. in *Observing and treating pain in people living with dementia in long-term care facilities*, which draws attention to the challenges of identifying and responding to pain when verbal self-report is constrained. This work highlights the importance of observational, relational, and contextual approaches to pain recognition in care settings.

The meaning attributed to pain is further explored by Wong et al. in *The meaning of manageable neuropathic pain after SCI*, which examines how individuals living with spinal cord injury understand and live with pain that is not eliminated but rendered manageable. This contribution highlights that pain outcomes cannot be reduced to intensity alone and that meaning plays a key role in how pain is experienced and integrated into daily life.

Complementing these perspectives, three papers explore expressive and interpretive modalities that extend beyond conventional clinical language. *Putting pain into words: The Psalms of Lament as an aid for the alexithymic* by Bäckryd examines the role of metaphor, narrative, and shared cultural texts in articulating pain that is otherwise difficult to express. *Exploring Pain and Suffering Through Spatial Acousmatic Music* by Stavropoulos and Johnson considers how artistic and auditory experiences can offer alternative ways of engaging with pain and suffering. *Exploring magical thinking in the context of pain*, by Heckemann et al. examines symbolic and imaginative meaning-making often dismissed or pathologised in clinical discourse. Through reflective dialogue between a nurse researcher, a writer-practitioner, and a pain scientist the authors explore magical thinking not as belief in altering physical reality, but as a personal orientation that supports sense-making, emotional regulation, and relationships with self, others, and the wider world. By situating magical thinking alongside recognised psychological and cultural practices, this contribution invites broader reflection on the role of symbolism, ritual, and imagination in living with chronic pain.

Taken together, these contributions highlight that making pain visible often requires modes of expression and interpretation that extend beyond conventional biomedical or clinical language.

Pain as relational and socially mediated

A second group of papers emphasises the relational and social dimensions of pain, aligning with the Research Topic's focus on moving beyond individualised accounts of pain experience and responsibility.

The value of collaboration is explored by Andréll et al. in *The importance of partnership in chronic pain – co-creation of tomorrow's pain care*, which highlights co-creation across research, implementation, and knowledge dissemination. This perspective situates pain care as a shared endeavour involving patients, clinicians, researchers, and communities.

Relational processes are further examined by Świdrak in *Healing synchrony? Potential benefits of interpersonal synchrony for chronic pain management*, which explores how interpersonal alignment and coordination may influence pain experience and management. This work draws attention to subtle, often overlooked social dynamics that shape pain encounters.

Together with the contribution on pain in dementia care by Kruijer et al., these papers emphasise that pain recognition, interpretation, and management are inherently relational processes. They challenge models that locate pain solely within individual bodies and instead highlight the social contexts through which pain is understood and addressed.

Pain patterned by place, population, and context

Several contributions examine how pain is patterned across populations and contexts, reflecting the Research Topic's emphasis on upstream determinants and social ecology.

Exploring Chronic Pain: Demographic and Social Determinants of Health Insights in Maine by Ou et al. provides population-level insights into how social and demographic factors shape chronic pain prevalence and experience. This work highlights the uneven distribution of pain and the importance of contextual factors such as geography, socioeconomic status, and access to resources.

Heterogeneity within diagnostic categories is addressed by Åkerblom et al. in *Identifying and characterizing clinical subgroups in individuals with endometriosis*, which demonstrates the diversity of pain experiences within a single medical

condition. Similarly, Bretonneau et al. explores intervention effects within a specific physiological and social context in *Whole-body cryostimulation exposures effectively alleviate menstrual-related pain and associated sleep disturbances in young women*.

A second contribution by Åkerblom et al. *Long-term pain and health economic outcomes in adults receiving multidisciplinary CBT for chronic pain* examines the long-term interplay between psychological processes, pain outcomes, and economic factors. Together, these contributions emphasise that pain cannot be understood independently of population-level patterning, contextual influences, and social conditions.

Care design and the shaping of pain outcomes

A further set of papers focuses on how care practices, information, and systems are designed, addressing the Research Topic's concern with prevention and management rather than treatment alone.

Information provision is examined by Stamenkovic et al. in *The information that patients, their families, and medical staff wish to know about postoperative pain and its management*, highlighting mismatches between informational needs and current practices. Educational and participatory approaches to care are explored by Ayres et al. in *The Knee-SCHOOL: A brief patient-centered multidisciplinary educational program for knee osteoarthritis*, which emphasises patient-centred learning and shared understanding.

The integration of broader sources of meaning into pain care is addressed by Perrin et al. in *Developing a best practice guide for integrating spiritual care interventions in chronic pain therapy*. This contribution highlights how attention to spiritual and existential dimensions may complement other approaches to pain management.

Collectively, these papers draw attention to care environments as active influences on pain outcomes, suggesting that prevention and management depend not only on interventions but also on how care is organised, communicated, and experienced.

Reflecting on non-biomedical perspectives

One contribution explicitly reflects on the conceptual breadth of non-biomedical approaches. *An Integral Vision of Pain and Its Persistence* by Johnson offers a whole-person, whole-system perspective that invites readers to consider how biological, psychological, social, and contextual factors interact over time. Positioned alongside the other contributions, this paper provides

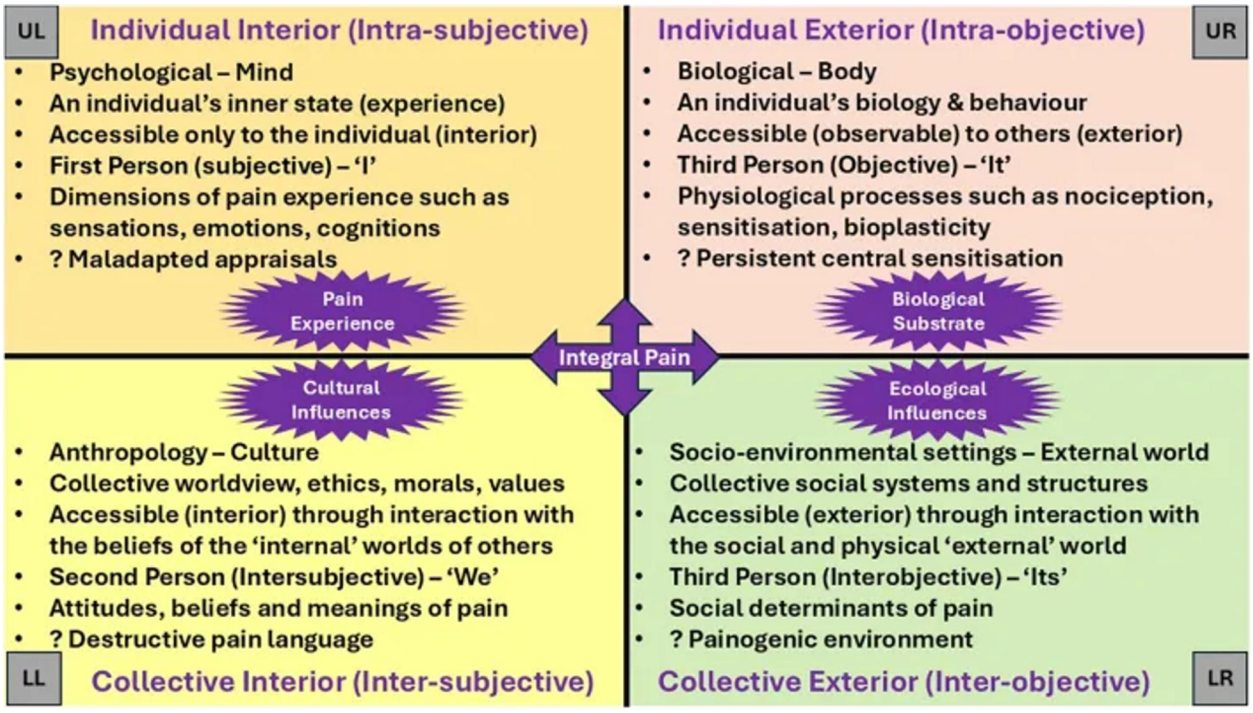

FIGURE 1
Taken from An integral vision of pain and Its persistence by Johnson. The quadrants framework offers a comprehensive lens through which to understand the multifaceted nature of pain. The Upper Right (UR) quadrant represents the objective, observable aspects of the individual, including neuroscientific and biological mechanisms that govern bodily functions and behaviours. In contrast, the Upper Left (UL) quadrant represents the subjective, psychological, and experiential aspects of the individual's inner life. The Lower Left (LL) quadrant encompasses the intersubjective perspective, highlighting the cultural, moral, and relational aspects that shape meaning within collective society. Finally, the Lower Right (LR) quadrant captures the interobjective perspective, focusing on systemic, structural, and environmental aspects of the broader socio-ecological context. Together, these quadrants provide a holistic framework for understanding pain as a complex interplay of individual and collective, internal and external factors.

a reflective lens rather than a unifying framework, encouraging dialogue across perspectives rather than seeking conceptual closure (Figure 1).

Potential impact

Together, the contributions in this Research Topic reflect the growing breadth and maturity of non-biomedical pain research. Rather than advancing a single alternative account of pain, Volume II highlights multiple ways in which attention to meaning, relationships, populations, and systems can enrich understanding of pain prevention and management. These papers collectively invite continued exploration of how pain is shaped by social, cultural, and environmental conditions, and how care practices might respond to these realities.

As the field continues to evolve, non-biomedical perspectives will remain essential for addressing the persistence and inequities of pain. This Research Topic offers an orientation toward that broader landscape, inviting readers to engage with the diverse contributions and consider their implications for future research, practice, and policy.

Author contributions

MJ: Writing – original draft, Writing – review & editing. KT: Writing – review & editing. AB: Writing – review & editing. EG: Writing – review & editing.

Conflict of interest

The author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Publisher's note

frontiers | Frontiers in Medicine

TYPE Original Research
PUBLISHED 03 January 2025
DOI 10.3389/fmed.2024.1497774

OPEN ACCESS

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RECEIVED 17 September 2024
ACCEPTED 02 December 2024
PUBLISHED 03 January 2025

CITATION
Ayres DVM, Uchiyama SST, Prates AO, Lopes RAF, Silva ABS, Tsukimoto DR, Amorim RA, Ribeiro TS, Santos ACA, Sugawara AT, Montagnini M, Battistella LR and Imamura M (2025) The Knee-SCHOOL: a brief patient-centered multidisciplinary educational program for knee osteoarthritis. *Front. Med.* 11:1497774. doi: 10.3389/fmed.2024.1497774

The Knee-SCHOOL: a brief patient-centered multidisciplinary educational program for knee osteoarthritis

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Background: Knee osteoarthritis (KOA) is the most common form of arthritis in adults and a leading cause of years lived with disability, representing a significant burden on healthcare worldwide.

Objective: Describe the structure and educational elements of the Knee-SCHOOL, a brief patient-centered multidisciplinary educational program for patients with KOA.

Design: Observational prospective study.

Setting: Academically affiliated rehabilitation outpatient center in Brazil.

Methods: The program consisted of three in-person educational sessions (4.5 hr each) for 55 community dwelling adults, aged ≥50 years, with primary KOA-related pain. Study measures included demographic data (age, sex, and educational level), pain duration (years), pain intensity (visual analogue scale), affected knee (right, left, or both knees), comorbidities (presence of hypertension, diabetes, and hypercholesterolemia), Body Mass Index (BMI), Bristol Stool Scale, Adapted Healthy Eating Index (AHEI), bioelectrical impedance, daytime sleepiness, and the impact of the KOA on pain, symptoms, activities of daily living, recreation, and quality of life. Participants attended educational sessions delivered by a multidisciplinary team (two physicians, two nurses, two physical therapists, one occupational therapist, one dietitian, one psychologist, one social worker, and one physical educator) addressing several aspects of KOA. They also participated in supervised exercise practice and a home exercise program.

Results: Fifty-five subjects completed the study. The mean age was 67.73 (± 7.73) years; most were females (70.9%), 92.7% had bilateral KOA, with mean pain duration of 12.41 (± 10.17) years. The mean BMI was 32.52 (± 5.99), 65.5% were obese, and 96.4% reported an inadequate diet. KOA had a more negative impact on sports, recreation and quality of life. Daytime sleepiness was uncommon.

The mean pain intensity, measured with visual analogue scale, score reduced from 5.52 (± 2.11) at baseline to 4.04 (± 2.38) after the program (week 2). The effect size was 0.7 (95% CI 0.32 to 1.07). All participants received the program well, with no drop-out rates or reported adverse events.

Conclusion: The Knee-SCHOOL utilized a multidisciplinary educational approach and an exercise practice addressing multiple aspects of KOA pain. While more studies are needed to assess the longitudinal impact of the program, it was promising in managing pain.

KEYWORDS

knee osteoarthritis, education, rehabilitation, pain, self-management

Introduction

Knee osteoarthritis (KOA) is the most common type of arthritis in adults and a leading cause of years lived with disability (1). It also represents a significant financial burden on healthcare systems worldwide (1). The global prevalence of KOA was approximately 600 million in 2020 and is estimated to increase by almost 75% in 2050 (1). In addition to chronic pain and physical disability, patients with KOA frequently experience sleep problems (2, 3) and psychological symptoms, including depression and anxiety (4, 5). Population studies demonstrate a higher prevalence of KOA in women, older patients, and patients with obesity (6–8). In addition, there are increased cardiovascular risk factors in patients with KOA (9–12).

The overall management of KOA includes proper analgesia and improved function and quality of life. Pharmacological interventions for KOA-related pain include topical analgesics (such as diclofenac gel and capsaicin), oral analgesics (like non-steroidal anti-inflammatory drugs (NSAIDs), acetaminophen, paracetamol, and duloxetine), and intra-articular therapy (such as steroids and hyaluronic acid) (13). Non-pharmacological agents including complementary and integrative health interventions such as acupuncture (14), meditation and yoga (15), tai chi (16), and transcutaneous electrical nerve stimulation (17) improve pain and function in patients with KOA. Self-management is considered a mainstay approach for the management of osteoarthritis (OA) (18). It involves the patient actively managing the chronic condition. Self-management can be achieved through educational interventions focused on enhancing the understanding of the disease, pain management, establishing an exercise routine and activity pacing, weight loss, sleep, and other modifiable risk factors, including joint alignment and joint preservation (19–22).

Several studies demonstrated the benefits of patient education and exercise therapy in osteoarthritis-related pain (23–25). Hansson et al. (26) demonstrated that patient education is feasible and can improve self-perceived health and function in primary care patients with KOA. In addition, recent systematic reviews documented that patient education effectively reduces pain related to knee and hip OA (23), and combination therapy of exercise and education interventions improves physical activity and pain reduction in knee and hip OA (24, 25).

KOA represents a significant health system burden in Latin America (27). In Brazil, KOA has become a significant public health concern due to the growth of the aging population. It is estimated that 9.6% of Brazilians over 39 years of age suffer from KOA (28). Despite being one of the largest public health systems in the world (29), Brazil has historically lacked public health policies addressing the management of OA in the general population (30). In 2018, the Brazilian Ministry of Health launched a health systems research initiative focusing on interventions to improve the care of individuals with disabilities. Researchers from our institution, the Instituto de Medicina Física e Reabilitação (Instituto de Medicina Física e Reabilitação do Hospital das Clínicas da, Faculdade de Medicina da Universidade de São Paulo - IMREA HCFMUSP), successfully obtained grant funding under this governmental initiative to develop a clinical trial for studying interventions for KOA-related pain. The initial phase of this clinical trial involved implementing a multidisciplinary educational program for managing pain in a sample of community-dwelling adults with chronic pain related to KOA, the Knee- SCHOOL.

The goal of this paper is to describe the structure and educational elements of the Knee-SCHOOL. We also explore the impact of this program on reducing pain in patients with KOA.

Materials and methods

This is a descriptive and observational prospective study of a multidisciplinary educational program for community-dwelling adults with KOA. The study is part of a major Randomized Clinical Trial (RCT) conducted at IMREA HCFMUSP, a teaching hospital of the University of São Paulo School of Medicine and approved by the Institution Review Board (CAAE: 0875619.8.000.0068). IMREA is accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) and fully integrated into the public health system, providing tertiary care in an academic setting.

Study participants were recruited from the institution's patient registry and the community. In addition, patients referred to IMREA for pain related to KOA were screened to participate in the study. Study investigators assessed eligibility for the study by reviewing medical records, radiologic data, and by patient interviews.

The inclusion criteria included patients older than 50 years and with moderate to severe pain related to KOA for at least 3 months duration who met the American College of Rheumatology (31) and the Kellgren-Lawrence radiographic grading criteria (32) for primary KOA.

The exclusion criteria included patients with severe psychological or psychiatric diseases, fibromyalgia, systemic inflammatory rheumatic diseases and neoplasia. Patients with other forms of KOA (e.g., post-traumatic, inflammatory and hemosiderosis arthritis) were

excluded from the study. Participation was voluntary and all patients provided informed consent before enrollment.

Study measures included demographic (age, sex, and educational level), pain duration and intensity, affected knee (right, left, or both knees), comorbidities, and Body Mass Index and other nutritional measures, daytime sleepiness, and the patient's rating of the KOA on five domains: pain, symptoms, activities of daily living, sports/recreation activities, and quality of life. Frequency of attendance was captured and recorded as patient participation.

Pain intensity was assessed using a 10-cm visual analogue scale (VAS) at the beginning and end of the program. The participants were instructed to mark their perceived pain intensity on the scale (zero: no pain, 10: the worst possible pain).

The Knee injury and osteoarthritis outcome score (KOOS) (33) was used to evaluate patient's opinion about their knee and associated problems. It is a self-administered questionnaire that evaluates five outcomes related to KOA: pain, symptoms, and activities of daily living, sports /recreational activities, and quality of life. The scoring is based on a 0 to 100 scale, where zero represents severe knee problems and 100 indicates no knee issues.

The nutritional measures included information on Body Mass Index (BMI), bowel habits based on the Bristol scale (34), Adapted Healthy Eating Index (AHEI), bioelectrical impedance, and comorbidities (diabetes, hypertension, and hyperlipidemia).

The nutritional status was classified based on the BMI cut-off points adopted by the Pan American Health Organization (PAHO) for the SABE Study: $\leq$23 kg/m^2 = underweight; >23.0 and < 28.0 kg/m^2 = normal weight; $\geq$28.0 and < 30.0 kg/m^2 = overweight; $\geq$30.0 kg/m^2 = obesity (35).

The Bristol Stool Scale is a tool used to assess the shape and consistency of stool; the scale categorizes stool into seven types based on shape and consistency (34). Stool shape and consistency is categorized as: Type 1: Separate small lumps, Type 2: Sausage-shaped with irregular surface. Type 3: Sausage-shaped with smooth surface. Type 4: Smooth sausage or cylinder. Type 5: Ball or oval-shaped. Type 6: Flaky or fragmented. Type 7: Liquid or completely unformed. Types 3 and 4 are considered normal.

The Avanturi nutritional analysis software program was used to calculate the 24-hour food record (Santana RI. Avanturi: nutritional assessment software, version 4.0. Rio de Janeiro, 2009). Eating habits were calculated using the adapted Brazilian version of the Healthy Eating Index (36). This index evaluates 12 components, including food groups such as cereals, fruits, vegetables, legumes, meats, dairy products, oils and fats, sweets and sugars, as well as nutrients (total fat, saturated fat, and cholesterol) and food variety. Diets scoring below 71 points on the AHEI are classified as poor quality, while those between 71 and 100 need improvement, and above 100 are considered good quality (36). Poor quality and need improvement categories were considered as inadequate diets.

A bioelectrical impedance test was also performed using the InBody 370S device (Ottoboni, Rio de Janeiro, Brazil). BMI, fat percentage, and skeletal muscle mass index (SMI) were calculated as body composition measures.

The Epworth Sleepiness Scale (ESS) (37) was used to evaluate the degree of daytime sleepiness. It is a self-administered questionnaire that assesses the probability of falling asleep in eight everyday situations. The scoring for each item varies from 0 (no chance of napping) to 3 (great probability of napping). The total score is based on a scale of 0 to 24. A score of $\geq$11 was defined to indicate daytime sleepiness.

Program structure

The Knee-SCHOOL consisted of three face-to-face educational sessions of 4.5 hr each over two consecutive weeks. Each session was limited to ten participants. The sessions included presentations by the members of the multidisciplinary research team, including two Physical Medicine and Rehabilitation physicians, two nursing professionals, two dietitians, two physiotherapists, one occupational therapist, one psychologist, one social worker, and one physical educator. The sessions also included supervised exercise practice; all participants received a prescription for home exercises. Table 1 describes the educational content of each session.

In addition to attending the educational sessions, participants received printed materials containing the educational content from each discipline, exercise instruction, and links to educational videos on the IMREA website.[1] The use of the content on the IMREA website was strongly emphasized for the home exercise program.

Each educational session began with an interactive discussion about the session objectives, patients' goals and expectations, feedback on their exercise routine, and general questions. The research team met weekly to review the program logistics and discuss each patient's needs. Elements of the program, such as exercise prescription and dietary plans, were individualized based on the patient's feedback, physical limitations, exercise tolerance, and comorbidities. Patients were instructed to complete their exercise prescription for at least 30 min daily, however, no log was required from the participants. The study social workers assisted in identifying local facilities for the daily exercise routine if desired by the patient. We have not monitored analgesic medication use, however, patients were instructed to maintain their prescribed or over-the-counter analgesic regimen.

Statistical analysis

The baseline characteristics were described as means and standard deviations for continuous variables and percentages for categorical variables. Pain intensity was assessed for each knee (R and L) with the VAS at baseline (Session 1) and at the completion of the program (Session 3). The mean pain level for each knee was tested for normality with the Shapiro–Wilk test. Comparisons before and after the intervention were conducted using the Student's T-test for dependent samples and the Welch approximation for different variances. For the VAS, a significance of 0.05 was established, and the Cohen's d effect size

1 https://redelucymontoro.org.br/site/area-do-paciente/materiais-educativos/acesse-aqui-os-videos-da-cartilha-cuidando-do-seu-joelho/

10.3389/fmed.2024.1497774

TABLE 1 Educational content of the Knee-SCHOOL.

Team member	Session 1	Session 2	Session 3
Physician	Participants received printed material (booklet) (https://redelucymontoro.org.br/site/area-do-paciente/materiais-educativos/acesse-aqui-os-videos-da-cartilha-cuidando-do-seu-joelho/) containing relevant information from all disciplines. Review of the program's goals and objectives. Discussion of patients' expectations. Definition of KOA and progression; modifiable and non-modifiable risk factors; symptomatology; anatomy of the knee; treatment options and benefits; pathophysiology of chronic pain; hypersensitivity of the nervous system; and the impact of pain in function. Duration: 60 min.		
Physiotherapist	Education on stretching exercises of the posterior muscle groups of the lower extremities, isometric exercises for the hip abductors and adductors, and isometric exercises for the knee extensors; three daily sets of ten repetitions. Discussion of exercise techniques based on pain's intensity and the patient's experience with physical activity. Duration: 30 min	Exercise practice (direct instruction using an elastic band for stretching and a plastic ball for isometric exercises; booklet review). Duration: 30 min	Same exercise practice as Session 2. Instruction on independent exercise practice at home and in the community using digital resources available on IMREA's website. https://redelucymontoro.org.br/site/area-do-paciente/materiais-educativos/acesse-aqui-os-videos-da-cartilha-cuidando-do-seu-joelho/ Duration: 30 min
Occupational Therapist	Discussion of the impact of KOA on pain, quality of life, healthy aging, activities of daily living, mobility, and work-related activities. Duration: 30 min	Instruction on adaptation strategies for daily activities. Education about posture and positioning during occupational performance, environmental modifications, and the use of assistive technology for maintenance and promotion of function. Duration: 60 min	
Nursing Professional	Education on health promotion and sleep hygiene. Sleep hygiene consisted of education on establishing a regular sleep routine, such as going to bed and waking up at the same time, creating an optimal sleep environment (dark, quiet room with comfortable temperature), and avoiding light stimuli, such as electronic device screens, before bedtime, regulating diet and fluid consumption, especially stimulants, and regular physical activity. Patient education and skill development on self-care. Duration: 30 min	Recognizing limitations in essential physiological functions, including bladder function and sleep quality. Establishing life goals based on constraints. Patient education on pain, sleep, and sleep hygiene practices. Duration: 30 min	

(Continued)

TABLE 1 (Continued)

Team member	Session 1	Session 2	Session 3
Dietitian	Education on a healthy diet based on typical foods available in the patient's environment and seasons. Discussion of the food pyramid using an educational tool. Education on food preparation, portions, categories, and label reading. Duration: 30 min	Review of the food education tool. Education on food portions, preparation, processed foods, and healthy food choices. Duration: 30 min	Education on establishing a healthy diet and food choices based on the presence of comorbidities (e.g., diabetes, hypertension, dyslipidemia, etc.). Patients with diabetes and dyslipidaemia were advised to choose whole grains, avoid sugars, replace them with natural sweeteners, and avoid low-fiber carbohydrates. Patients were also instructed to select adequate vegetable intake, drink water instead of sweetened beverages, low-fat dairy products, and lean meats, and divide meals throughout the day, avoiding long periods of fasting. In addition to the above guidelines, patients with hypertension were encouraged to reduce salt intake to no more than five grams/day. Avoid pre-packed seasonings and replace them with natural choices. Guidance on using healthy seasonings, recipes, and tasting of herbal salt. Education about lean meats, dairy products, and reading food labels. Duration: 60 min
Psychologist	During psychoeducational care, patients were instructed on the characteristics, personal meaning, and emotional aspects involved in the pain mechanism (anxiety, fear, irritability, and depression) and how to deal with negative emotions. Duration: 30 min	In the second session, patients were led to reflect on the beliefs that negatively influence pain treatment and their sense of control. They were also encouraged to exercise self-empowerment as a pain management and quality of life skill, and to review of the impact of their own belief system on their life experiences. Duration: 30 min	Relaxation practice to promote greater body awareness. Reflection on the experience of being part of the group. Discuss expectations, adherence, difficulties encountered, self-care, changing attitudes in the daily routine and resuming social interactions. Duration: 30 min
Physical Educator	Importance of creating a physical exercise routine that can performed safely independently. Guidance on exercise intensity based on muscle strength, and instruction on aerobic exercises. The guidelines were based on a booklet with six exercises for muscle strengthening of the lower limbs that could be adapted and individualized depending on the patient's physical capacity and as a way of progressing in intensity and complexity. Duration: 60 min	The home exercise practice included strengthening exercises 2 to 3 times a week on alternating days, with 2 to 3 sets of 8 to 15 repetitions. Patients were instructed to perform at least 30 min of aerobic exercises daily. Exercises could be distributed in periods of 10 min throughout the day. The exercise prescription was adjusted for each patient based on their functional capacity and feedback, such as changing from standing to silted or lying down, the number of repetitions, load, or technique. Duration: 30 min	
Social Worker	Education on quality of life and basic social needs, community partnerships, and social challenges resulting from pain and disability. Education about social benefits, including free transportation, and health insurance for low-income families. Referrals to Social Service Reference Centres. Guidance on community resources for physical activity, and primary care clinics. Promoting social interactions and expanding social network as a buffer mechanism for pain management. Duration: 30 min	Reflecting on the need for social interaction and avoiding social isolation. Promoting of a healthy lifestyle. The importance of leisure time in parks and public spaces as a distraction from pain. Identifying of social demands and the importance of connection to the social support network as a coping mechanism. Duration: 30 min	

was calculated for significant differences. All statistical analyses were conducted with STATA14®.

Results

We recruited 176 participants and 55 were enrolled in the study. The study was conducted from February 2022 through July 2023. All fifty-five subjects completed the Knee-SCHOOL program. Six (10.91%) patients attended one of the sessions online due to the inability to attend the class in person. No adverse events were reported.

Table 2 outlines the characteristics of the participants. The mean age was 67.73 (± 7.73) years; most were females (70.9%), and fifty-one (92.7%) had bilateral KOA. The mean BMI was 32.52 (± 5.99), 65.5% were obese (>30 kg/m^2), and 96.4% reported an inadequate diet. Most participants had normal bowel function. According to the KOOS, KOA had a more negative impact on sports and recreation and quality of life. Daytime sleepiness, measured by the EES, was uncommon among participants.

The Shapiro–Wilk test demonstrated that the pain intensity at baseline and at completion of the study was parametric ($p > 0.05$) regardless of the side, and the variances were similar along the pain measures. Therefore, the comparisons were conducted with paired Student *T*-tests without corrections. The mean pain level decreased from 5.52 (± 2.11) at baseline (Session 1) to 4.04 (± 2.38) at completion of the study (Session 3), a mean reduction of 1.48 points (± 2.37). This reduction was statistically significant ($p = 0.0001$) with Cohen's d effect sizes of 0.70 (CI95% 0.32 to 1.07) (Figure 1).

Discussion

The Knee-SCHOOL is unique because it incorporates a comprehensive face-to-face educational component customized to each patient, and it can be completed in less than 2 weeks. The program covers disease understanding, treatment options, self-management strategies, and coping mechanisms. Additionally, it provides education on physical activity, lifestyle changes, sleep hygiene, nutritional health, and the psychosocial aspects of pain. It includes an exercise plan tailored to the patient's physical abilities and tolerance. Moreover, it uses booklets and web-based resources to reinforce the educational content covered during the in-person sessions and the home exercise practice (see footnote 1).

Existing self-management programs for KOA often only cover patient education and physical exercise (19–25). The Knee-SCHOOL, however, provides a more comprehensive approach by addressing additional elements, such as nutritional health, sleep hygiene, and psychosocial factors. It is grounded on a solid multidisciplinary team, so all those elements can be adequately addressed.

Physical exercise is a core component in any self-management program for KOA. Exercise programs are safe and effective for pain and strength improvement in KOA (19–25, 38). The Knee-SCHOOL strongly emphasizes the importance of physical activity, and each patient receives an individualized prescription containing stretching and strengthening exercises based on their physical ability. Patients unable to perform exercises in a standing position are taught exercises that can be performed on a chair or lying down. A walking routine is also integrated into the program. The physical therapists and physical educator supervise each patient individually to ensure they learn their exercise routine correctly. In addition, patients are encouraged to access the exercise videos on the IMREA website for their home exercise program.

KOA significantly affects a person's daily life, causing difficulties in performing activities of daily living (ADL) (39), limited mobility, and reduced participation in work-related activities. Individuals with KOA attribute their difficulty in performing daily activities to symptoms such as pain and limitations in performing essential tasks. In our program, Occupational Therapists assess ADL performance, teach adaptation strategies, and use assistive technology to maintain and promote functionality.

The Knee-SCHOOL prioritizes nutritional health and uses various measures to assess nutritional status. Most participants were found to be overweight or obese, which is consistent with findings in other studies (40). BMI is linked to the severity of pain and should be routinely assessed in pain management educational programs (41). In addition to BMI, our program includes a more in-depth assessment of the patient's body composition. Some patients were identified as having a low skeletal mass index. We also discovered that a significant number of individuals had unhealthy eating habits, systemic hypertension, and dyslipidemia.

We provide general nutritional education and personalized dietary plans to address these findings. Poor diet is associated with an inflammatory status that can exacerbate symptoms of KOA (42, 43). Proper education on food quality, quantity, meal intervals, and eating habits is also essential to the Knee-SCHOOL (44). Compared to other studies (45, 46), the nutrition education component in our program was much more comprehensive and personalized.

Nursing professionals provided education on the basic physiological functions of the body and other aspects of health education, including an assessment of sleep and education on sleep hygiene. Despite evidence linking sleep duration, restlessness, and sleep quality to KOA (2, 3), sleep is often overlooked in exiting self-management programs for KOA (19, 21, 23–25). We found only two KOA educational programs (45, 47) addressing sleep hygiene, and none included a formal assessment of daytime sleepiness. Restful sleep improves the body's inflammatory response (48) and can reduce pain and stiffness in KOA, improving quality of life (49). Conversely, lack of sleep or poor-quality sleep can worsen pain perception and affect mood, creating a harmful cycle of insomnia and chronic pain (49). In our study, some participants reported possible or probable excessive daytime sleepiness, and one patient was later diagnosed with sleep apnea. It is essential to routinely assess sleep dysfunction in any self-management program for OA, provide proper education on sleep hygiene, and ensure that patients with more severe symptoms are appropriately evaluated for sleep disorders.

Some educational programs for OA include community resources education (50). Our team social worker provided education on community resources for exercise practice, social benefits, and the importance of having a solid network and social activities, as chronic pain usually causes social isolation and sedentarism.

Another significant component of the Knee-SCHOOL is the education on the psychological aspects of chronic pain. Strong

10.3389/fmed.2024.1497774

TABLE 2 Baseline characteristics of study participants (n = 55).

Characteristics	Values
Women, *n* (%)	39, 70.9
Age (years), mean (± SD)	67.73 (7.73)
Education level (n; %)	
Elementary School	8 (14.6)
Middle School	5 (9.1)
High School	19 (34.5)
Technical Degree	1 (1.8)
College Degree	22 (40)
BMI (kg/m^2), mean (± SD)	**32.52 (5.99)**
Underweight, *n* (%)	3 (5.5)
Normal, *n* (%)	11 (20.0)
Overweight, *n* (%)	5 (9.1)
Obesity, *n* (%)	36 (65.5)
Pain duration, mean years (± SD)	12.41 (10.17)
Comorbidities, n (%)	
Hypertension	37 (67.3)
Diabetes	20 (36.4)
Hypercholesterolemia	24 (43.6)
Unilateral KOA, *n* (%)	4 (7.3)
Bilateral KOA, *n* (%)	51 (92.7)
Right Knee K & L Classification*, *n* (%)	
0 (absent)	1 (1.8)
I (doubtful)	19 (34.6)
II (mild)	11 (20.0)
III (moderate)	15 (27.3)
IV (severe)	7 (3.6)
Left knee K&L Classification, *n* (%)	
0 (absent)	1 (1.8)
I (doubtful)	21 (38.2)
II (mild)	10 (18.2)
III (moderate)	15 (27.3)
IV (severe)	8 (14.6)
Baseline pain intensity (VAS), mean (± SD)	5.52 (2.1)
Bristol stool scale, *n* (%)	
1	6 (10.9)
2	1 (1.8)
3	35 (63.6)
4	12 (21.8)
5	0
6	1 (1.8)
Body Fat percentage, mean (± SD)	**42.17 (9.41)**
Skeletal Muscle Index, mean (± SD)	7.79 (1.58)
Low, *n* (%)	6 (10.6)
Normal, *n* (%)	49 (89.1)
Healthy Eating Index, mean (± SD)	**78.17 (15.14)**
Poor, *n* (%)	15 (27.3)
Needs improvement, *n* (%)	38 (69.1)
Adequate, *n* (%)	2 (3.6)
KOOS, mean (± SD)	
Symptoms	56.95 (19.85)
Activities of daily living	47.70 (22.31)
Pain	44.70 (20.28)
Quality of life	25.68 (19.31)
Sports and recreation	20.18 (20.97)
Epworth sleepiness scale, mean (± SD)	**8.49 (5.57)**
Unlikely, *n* (%)	32 (61.5)
Possible, *n* (%)	13 (25.0)
Probable, *n* (%)	7 (13.5)

KOA, knee osteoarthritis; n, number; SD, standard deviation; BMI, body mass index; K&L, Kellgren-Lawrence osteoarthritis classification; VAS, visual analogue scale; KOOS, Knee Injury and osteoarthritis outcome score; ADL, activities of daily living; * Two patients had total knee replacement on the right side.

emphasis was given to teaching patients to recognize and reconstruct negative thoughts and behaviors associated with chronic pain, as pain evokes brain modifications (nociplasticity) as an unconscious and involuntary learning process. Such thoughts and behaviors negatively affect patients and their family members (51). Educating and promoting experiences addressing negative ruminations can enhance social support and positive outcomes (52). During the Knee-SCHOOL, patients also received instruction on self-guided relaxation to increase body awareness and relaxation and to improve self-efficacy. Promoting social interactions in the community and within the group was another crucial element, as group-based interventions effectively manage chronic pain (53). The Psychologist promoted group discussions and interactions so participants could share their experiences with the program and reflect on the difficulties and challenges of changing attitudes and behaviors in daily life. Group members supported each other and shared their experiences on solutions to similar challenges.

The multidisciplinary team's awareness of the importance of lifestyle modifications may play a role in empowering patients to make behavioral changes. Group-based educational intervention allows individuals to develop tools for self-management, enabling them to manage their conditions more effectively (54). Information does not guarantee adherence or modification to different programs (55). What sets the Knee-SCHOOL apart is its focus on lifestyle awareness through a patient-centered multidisciplinary team that includes peer participation from individuals with KOA, facilitating the exchange of information, experiences, and practical strategies. A meta-analysis suggests that strategies aimed at motivating or changing behaviour can enhance adherence to exercise (56), whereas coping counselling and exercise recommendations through audio/video or text message encouragement alone did not significantly improve adherence (56, 57).

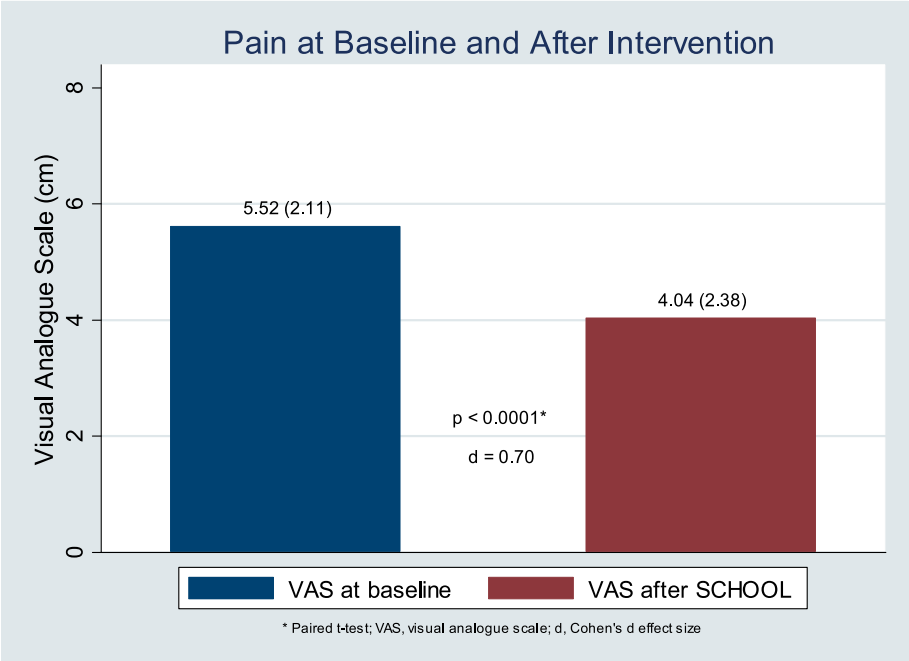

FIGURE 1
Pain reduction after the Knee-SCHOOL, per visual analogue scale.

All participants received the program well, with no drop-out rates or reported adverse events. Based on the preliminary findings on pain, the Knee-SCHOOL is being considered as the initial step in the treatment plan of patients referred to our institution for KOA-related pain. Also, we observed a reduction in pain level in the short-term, with a Cohen d effect size of 0.7, even though this result should be seen with caution, as no control group was included in this analysis.

Some of the study's limitations include a small sample size, the absence of a control group, and the lack of measurement of pain beyond the program duration. Additionally, our study does not capture changes in quality of life, functional status, nutritional health, and sleep status following the completion of the program. The Knee-SCHOOL is the initial intervention of a large clinical trial involving other therapies for KOA-related pain. Upon the trial's completion, data on the long-term effects of the Knee-SCHOOL and the different interventions on pain and additional outcomes will be reported. We have not controlled for analgesic medication use; however, patients reported no changes to the analgesic medication used during the study. Moreover, the Knee-SCHOOL also uses a robust multidisciplinary approach, which may limit its reproducibility in less resourced settings.

Conclusion

The Knee-SCHOOL employed a comprehensive and team-based educational approach to address pain's physical, functional, nutritional, and psychological aspects. The program used a patient-centered approach and emphasized collaboration among the healthcare team as a crucial element. It showed promising results in managing KOA-related pain, however future research is also needed to evaluate the long-term impact of Knee-SCHOOL on pain and other outcomes, as well as its applicability in different environments and cultures.

Data availability statement

The data presented in this article is available upon request. Please submit an inquiry to Dr. Marta Imamura on the following email address: marta.imamura@fm.usp.br.

Ethics statement

The studies involving humans were approved by Comissão de Ética para Análise de Projetos de Pesquisa do HCFMUSP. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

DA: Conceptualization, Investigation, Methodology, Visualization, Writing – original draft, Writing – review & editing. SU: Conceptualization, Investigation, Methodology, Writing – original draft, Writing – review & editing. AP: Investigation, Methodology, Writing – original draft, Writing – review & editing. RL: Investigation, Methodology, Writing – original draft, Writing – review & editing. ASi: Investigation, Writing – original draft, Writing – review &

editing. DT: Investigation, Methodology, Writing – review & editing. RA: Investigation, Writing – original draft. TR: Investigation, Writing – review & editing. ASa: Data curation, Formal analysis, Investigation, Methodology, Writing – review & editing. ASu: Conceptualization, Investigation, Methodology, Writing – original draft, Writing – review & editing. MM: Conceptualization, Methodology, Validation, Visualization, Writing – review & editing. LB: Conceptualization, Investigation, Methodology, Project administration, Supervision, Validation, Visualization, Writing – review & editing, Funding acquisition, Resources. MI: Conceptualization, Investigation, Methodology, Project administration, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

Funding

The author(s) declare that financial support was received for the research, authorship, and/or publication of this article. This study was supported by a grant from the Brazilian Ministry of Health (PRONAS; NUP: 25000.014364/2018-35).

Acknowledgments

Patients or the public were not involved in the design, conduct, reporting, or dissemination plans of our research.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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frontiers | Frontiers in Pain Research

TYPE Perspective
PUBLISHED 05 February 2025
DOI 10.3389/fpain.2025.1463321

OPEN ACCESS

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RECEIVED 11 July 2024
ACCEPTED 14 January 2025
PUBLISHED 05 February 2025

CITATION
Świdrak J (2025) Healing synchrony? potential benefits of interpersonal synchrony for chronic pain management.
Front. Pain Res. 6:1463321.
doi: 10.3389/fpain.2025.1463321

Healing synchrony? potential benefits of interpersonal synchrony for chronic pain management

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Fibromyalgia is called a pathology of misconnection at the neurophysiological, psychological, and social levels, and is characterised by widespread musculoskeletal pain, which is accompanied by a series of symptoms, such as chronic fatigue, depression, anxiety, body perception disturbances, and cognitive deficits. In this article, I argue that interventions that in various ways enhance interpersonal neural synchronisation (INS) may bring long-term benefits to people with fibromyalgia (PwF). In the first part, I briefly introduce studies on INS in the general population. In the second part, I hypothesise that interpersonal synchrony may contribute to symptom reduction for individuals with fibromyalgia, in the sense that repeated experience of being in sync with others may play a role in restoring both the brain-body and self-others connection in this population and consequently result in simultaneous lasting improvement of wellbeing. In the final part, I discuss potential future research directions.

KEYWORDS

fibromyalgia, bodily self, chronic pain management, interpersonal neural synchrony, interbrain coherence

1 Introduction

With one in ten adults diagnosed each year (1), chronic pain is one of the major health challenges in the world. It has a detrimental effect not only on the wellbeing of those who suffer from it (2), but also on their social and family environment (3, 4). These consequences are evident in fibromyalgia, the most common central sensitivity syndrome, characterised by a combination of symptoms known as FIBRO: Fatigue and Fog (cognitive dysfunction), Blues (depression, anxiety) Rigidity (stiffness), and "Ow!" (chronic pain, tenderness) (5). It is "a pathology of misconnection" at the neurophysiological, psychological, and social levels. Perrot (6) observed that due to its invisibility and lack of a specific biomarker, people with fibromyalgia (PwF) are disconnected from society. They are also disconnected internally due to the complex pathophysiology that leads to a desynchronisation of the brain and body. Consequently, the recommended treatments aim to restore good connections (6). Essential pain symptoms are related to augmented sensory processing (central sensitisation) and an inability to modulate pain effectively (7). I argue that interventions that in various ways enhance interpersonal neural synchronisation (INS) may facilitate a simultaneous body-brain and self-other reconnection and bring long-term benefits to PwF. In this paper, I will briefly introduce studies on INS in the general population and explain its

potential role in the treatment of widespread chronic musculoskeletal pain in the context of existing evidence.

2 Synchronised brains in synchronised bodies

After studying human cognition in isolated individuals (single-brain studies), in the last two decades the interest of social neuroscientists has been shifting towards second-person neuroscience thanks to advances in hyperscanning. This is a simultaneous measurement of more than one person's neural activity (dual-brain studies) (8). Hyperscanning studies led to a discovery of INS which can be defined as a phenomenon "that promotes social interactions by enabling functional integration of multiple brains" (9, 354). Despite its short history, second-person neuroscience has already provided sophisticated theoretical frameworks which attempt to explain the interplay of inter- and intrabrain networks, for example, the hypothesis of hyperbrain cell assembly (10), the plasticity of the interbrain (11), the two-body joint forward model for interpersonal action coordination (12). Another interesting approach is the embodied mutual prediction theory which states that the coherence of neural signals between two brains can arise during a social interaction between two people as their brains simultaneously control own actions and mutually predict each other's actions (13). Importantly, interbrain coherence should not be investigated in isolation from the body, but as a process simultaneously happening on behavioural, psychophysiological, and neural level. These levels need to be analysed jointly, as visual, auditory, and motor processes mediate any coordination between two brains (Figure 1) (14).

Syncing with others leads to an increased predictability of incoming signals which offers many benefits ranging from basic information processing at the individual level to the bonding of dyads and larger groups (15, 16). Furthermore, synchrony increases cooperation (17), social connection, and improves affect (18). It is associated with self-other overlap (19), which also reduces sensitivity to own bodily pain (20) and increases empathy for the pain of others (21). Interpersonal synchrony during touch can potentially reduce acute pain (22). Thus, synchrony tends to feel good and creates a sense of connection (23). I argue that looking at complex chronic pain conditions such as fibromyalgia through a lens of embodied INS offers an exciting opportunity to reinterpret existing evidence and open new research pathways. I hypothesise that interpersonal synchrony can be healing for PwF, in the sense that repeated experience of being in sync with others may play a role in restoring both the brain-body and self-others connection in this population and consequently result in simultaneous lasting improvement of several key symptoms, such as pain, depression, anxiety, and attention deficits (Figure 2).

3 Social bodily self

Similarly to the second-person social neuroscience, a recent shift from the first- to the second-person perspective of the bodily self can be observed (24, 25). The bodily self originates from the multisensory integration of bodily-related signals, with the motor systems playing a key role (26). The social self links the bodily self with that of others (27). It plays a fundamental role in the constitution of the other as another self. It seems that this connection is bidirectional, as there is evidence that social contact enhances bodily self-awareness (28, 29). At the same time, interpersonal synchrony is also known to blur self-other boundaries (30), which may lead to the weakening of affective self-regulation (23). This perspective helps to understand the relationships between a broken brain-body connection, as observed in PwF (31) and the social alienation of this population (3).

According to the sensorimotor theory of pain, changes in sensorimotor processing, especially motor deficits, sensory

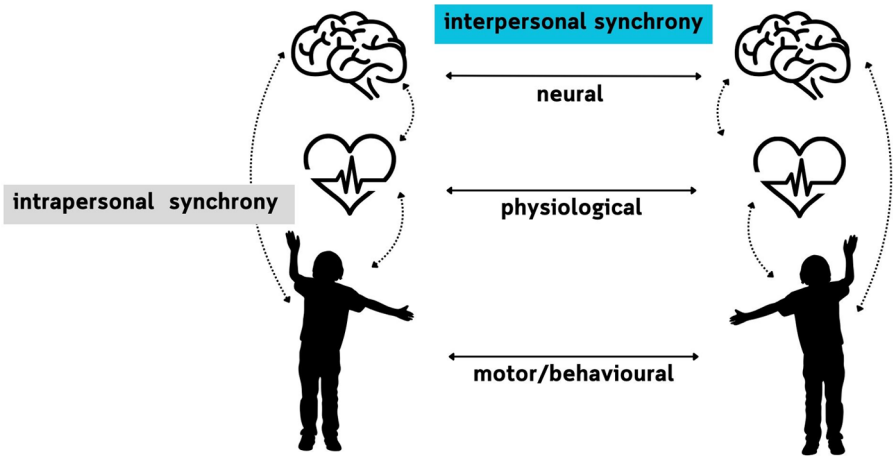

FIGURE 1
The interplay between the intra- and interpersonal synchrony.

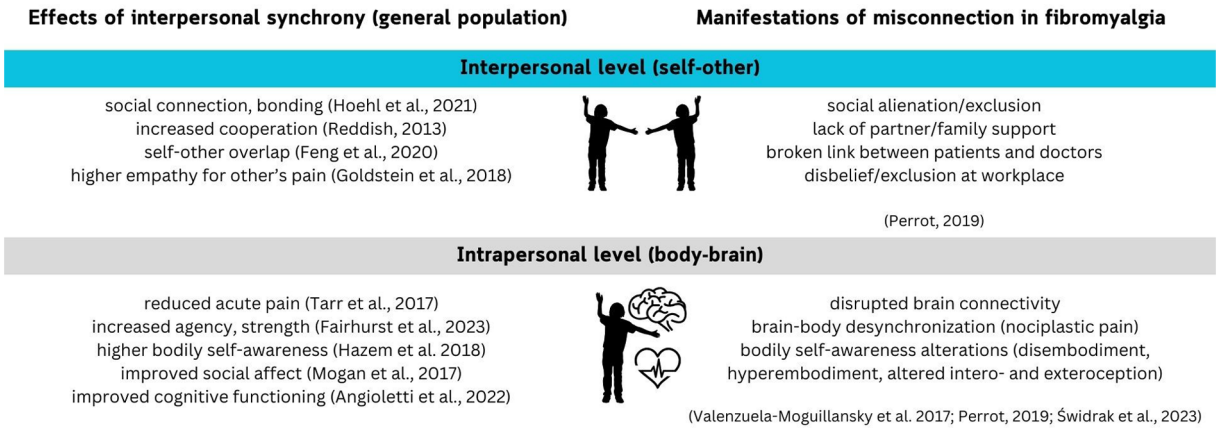

FIGURE 2
Effects of interpersonal synchrony on typical adults (left) compared to misconnection observed in fibromyalgia (right).

changes, and body representation distortions, may be a reason for persistent pain (32). Chronic pain often includes not only continuous nociceptive stimulation, but also multiple sensorimotor distortions that lead to a disrupted body experience (33), including distortions in body image (perceiving own body as a physical object with its size and shape) and body schema (representation of a body for action planning and control) (34). Pain is a fundamentally social experience, because it challenges basic human needs, such as the need for autonomy, the need to belong, and the need for justice/fairness (35). People diagnosed with fibromyalgia indeed often struggle with fulfilling these needs as they are commonly alienated, discriminated, and disbelieved by others when discussing their symptoms. This experience of a broken social bodily self manifests in perceiving their bodies as a barrier to the social world, leading to a disruption of a basic sense of being with others (36).

Simple social contact, such as direct gaze, improves bodily self-awareness (28, 29). Furthermore, focussing on its one's own physiological processes during a socially framed task that requires motor synchronisation "boosts" the hemodynamic correlates in the regions of the brain that support sustained attention, reorientation of attention, social responsiveness, and synchronisation (37), cognitive functions often disturbed in fibromyalgia (38, 39). One of the best examples of a recurring embodied social interaction aimed at improving the broken body-mind and social connections is psychotherapy. Therapeutic alliance – the bond between the therapist and the patient/client built throughout the therapeutic process – is one of the main drivers of therapy success (40). There is a growing body of evidence that this success positively correlates with movement synchrony between therapists and patients (41). Furthermore, a review by Sened, Zilcha-Mano, and Shamay-Tsoory (42) indicates that high interbrain coherence is associated with better relationships in both therapy and in daily life, while deficits in the ability to achieve interbrain synchrony are associated with a variety of psychological and developmental disorders. Affective symptoms, such as depression and anxiety, are extremely common in fibromyalgia, and psychotherapy is a central element of many interdisciplinary treatment programs (43). Indeed, evidence indicates that various psychotherapeutic treatments obtain positive effects in short-, mid-, and even long-term (44–48). Interestingly, a comparison of group therapy alone and multidisciplinary programs which contained group therapy demonstrated that the latter are only slightly more effective in reducing primary and secondary symptoms of fibromyalgia (49).

Following this pathway, we can speculate that social interactions that simultaneously promote spontaneous synchronisation with others and a concentration on own bodily signals, such as psychotherapy, yoga and other mind-body activities, may facilitate reconnecting brain-body processing, particularly in the motor and prefrontal areas (50).

4 Benefits of moving together

The broken connection between PwF and their social networks often leads to loneliness and depression, and therefore more social and family-orientated research initiatives are recommended (4). Regular physical activity is one of the pillars of the treatment of fibromyalgia, due to its multiple positive influences, including improved mood and sleep quality, raising pain thresholds, breaking the vicious cycle of pain-inactivity-pain, and reducing physical deconditioning (51, 52). Thus, the only "strong" EULAR[1] recommendation for PwF is exercise (53). Adherence to exercise programmes in chronic pain treatment is the key to their efficiency, but it varies significantly

[1]The European Alliance of Associations for Rheumatology, https://www.eular.org/

(54), and can be improved by implementing a social component in the programme (55).

One of the most beneficial types of physical activity for PwF is dance. Dance reduces musculoskeletal pain and dance therapy is recommended as an effective addition to the treatment of chronic pain (56), including fibromyalgia, with PwF who dance report lower depression, anxiety and kinesiophobia (fear of movement), and dance-based interventions effects described as large (57, 58). Zumba dance, compared to treadmill walking and control groups, also improves cognitive functioning (59). According to the Synchronicity Hypothesis of Dance, humans dance to enhance both intra- and interbrain synchrony (60). Dance engages both interoceptive and exteroceptive processes, in addition to the haptic, visual, and auditory processing, which influence group synchrony, with haptic coupling having the most general effect on synchrony during group dancing (61). Exertive and synchronised movement modulates pain and may be an effective group bonding activity (20). For example, in a nine-month group exercise programme, participants reported that the social connections created within the group helped them reduce isolation, frustration, and depression (55). These results are in line with the literature on movement synchrony, as moving in sync with others makes us happier and more connected. For example, in a study in which participants were walking together, greater coordination resulted in greater feelings of agency, strength, and happiness (15). Such synchronisation also occurs implicitly, since humans tend to sync their movements with others (15, 62).

Interpersonal synchrony occurs in many contexts, and not everyone finds group dance or yoga attractive. Paying more attention to personal factors in pain management interventions by including activities that, for example, offer enjoyable and meaningful connections within one's social networks, could lead to improvements in physical and psychological well-being (63). Thus, it may be useful to study INS in people with chronic pain also during other types of social learning, such as learning to play music together with others or playing collaborative games (64).

5 Discussion

To the best knowledge of the author, there have been no studies on INS in people with widespread chronic pain. Therefore, this paper aims to spark interest in the pain research community in the role of interpersonal synchrony in chronic pain treatment. Importantly, the field of INS research is still relatively young and thus, faces the challenges of defining INS and forming a uniform theoretical framework which would explain the effects described in the literature (9). Therefore, one may only speculate on the precise role of INS in the alleviation of fibromyalgia symptoms and the restoration of the social bodily self. There are various types of interpersonal synchrony, and thus, the mechanisms underlying its health benefits in each case may vary. Nonetheless, one may suspect that recurringly switching attention from internal, painful to external, social stimuli could play a role in reducing the attentional bias towards painful stimuli, typical for PwF (65). Additionally, the health benefits may come from improved interoception, as social contact improves bodily self-awareness (29, 37). At last, may INS-enhancing activities feel good and make people bond (20, 23), which may improve psychological symptoms in PwF, who often suffer from social alienation and loneliness (66).

Among multiple ways forward, two main research pathways are emerging, related to (1) describing the mechanisms of INS in people diagnosed with fibromyalgia (and chronic pain in general), and (2) its potential role of modulating symptoms.

The first pathway to validate the proposed hypothesis would be to investigate whether such synchrony occurs similarly to the general population, and if not, what are the differences. For example, do higher pain levels impede INS, as one becomes too overwhelmed with their own bodily signals to direct their attention toward others? What types of activity evoke INS in PwF?

The second pathway is related to the modulating effect of interpersonal synchrony. In what circumstances can being with others distract someone from their own pain and other symptoms? Could such INS-inducing interventions help modulate fibromyalgia symptoms and which symptoms should be targeted? What frequency and duration are needed to observe the alleged benefits? These are just a few of multiple questions that need to be answered to establish what role INS can play in fibromyalgia treatment and, more broadly, chronic pain management.

There are also several important challenges that need to be addressed. First, although significant progress has been made in the last decade (51), the underlying mechanisms of fibromyalgia itself are very complex and not fully understood, leading to a large heterogeneity of the population due to diagnostical difficulties (67). Other challenges are related to the character of symptoms, which hinder adherence to treatments, as the burden of commuting to regularly participate in treatment sessions is very high (68), which could potentially be reduced by designing interventions using virtual or extended reality (69, 70).

5.1 Conclusions

This article briefly introduced the concept of interpersonal neural synchrony and linked it for the first time to studies on fibromyalgia and its treatment. Various types of interventions that can involve interpersonal synchrony, such as group dance or exercise, have been shown to be effective in lasting symptoms reduction in people diagnosed with fibromyalgia. Future research is necessary to describe the INS mechanisms in fibromyalgia and reveal their potential health benefits, to verify whether they can eventually contribute to the reconnection on both intra- and interpersonal levels for people living with this severe condition.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Author contributions

JŚ: Conceptualization, Visualization, Writing – original draft, Writing – review & editing.

Funding

The author declares financial support was received for the research, authorship, and/or publication of this article. My work is supported by (1) XR-PAIN (GA No 101070533), funded by the European Media and Immersion Lab project financial support to third parties, which is funded by the European Union, (2) META-TOO (GA No 101160266) funded by the European Union, and (3) Departament de Recerca i Universitats de la Generalitat de Catalunya (AGAUR 2021-SGR-01165 - NEUROVIRTUAL).

Acknowledgments

I want to thank Prof. Maria Sanchez-Vives and Prof. Antonia Hamilton for their invaluable comments on the manuscript.

Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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frontiers | Frontiers in Pain Research

TYPE Original Research
PUBLISHED 28 April 2025
DOI 10.3389/fpain.2025.1547540

OPEN ACCESS

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RECEIVED 18 December 2024
ACCEPTED 25 March 2025
PUBLISHED 28 April 2025

CITATION
Åkerblom S, McCracken LM, Rivano Fischer M and Perrin S (2025) Long-term pain and health economic outcomes in adults receiving multidisciplinary CBT for chronic pain: the role of psychological inflexibility.
Front. Pain Res. 6:1547540.
doi: 10.3389/fpain.2025.1547540

Long-term pain and health economic outcomes in adults receiving multidisciplinary CBT for chronic pain: the role of psychological inflexibility

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Background: Little is known about whether the recommended, non-pharmacological treatments for chronic pain yield reductions in healthcare utilization, social costs and increased productivity in actual practice.
Methods: The primary aim of this study ($n = 232$) was to conduct secondary analyses of health economic outcomes using data from national registries combined with clinical outcome data from a large pain center in Sweden conducting multidisciplinary treatment based on a cognitive behavioral approach. Specifically, pain-related and health economic outcomes at post-treatment and one, two and three years after discharge were examined. In an exploratory fashion, we also investigated whether sociodemographic characteristics, pain-related variables, and psychological *in*flexibility predicted these long-term pain-related and health economic outcomes. We also examined psychological *in*flexibility as a potential mediator of these outcomes.
Results: Small and moderate sized improvements in pain, pain interference, and depression observed at post-treatment were mostly maintained at both the 1- and 3-year follow-up. A very similar pattern was observed for health economic outcomes, with 1-year follow-up gains being maintained at long-term follow-up. Baseline psychological *in*flexibility predicted long-term pain-related outcomes, but not health economic outcomes. Changes in psychological *in*flexibility during treatment and follow-up mediated long-term pain-related outcomes and the total number of health care visits.
Conclusions: The present findings add to a small body of literature indicating that the improvements in pain and related difficulties following multidisciplinary, pain-focused, CBT programs persist at least three years following treatment, and these are accompanied by modest improvements in health economic outcomes over the same interval. Psychological *in*flexibility seems to be predominately associated with long-term clinical outcomes in pain management, and it also appears relevant to the number of health care visits.

KEYWORDS

chronic pain, long-term outcomes, health economic outcomes, psychological inflexibility, mediator, predictor

Introduction

Approximately twenty percent of adults in Europe, including Sweden, suffer from chronic pain of moderate to severe intensity with significant economic impacts for the individual and society (1). A pan-European study found 61% of respondents with persistent pain were unable or less able to work, 32% had changed or lost their jobs, and 60% had visited their doctor 2–9 times during the last six months because of pain (1). A national registry study of 840,000 patients in Sweden estimated the yearly cost of chronic pain at €32 billion (2). Similarly high estimates have been found in other European countries (1). Less is known about whether chronic pain treatments lead to reduced healthcare utilization and social costs and increased productivity (3, 4).

The first-line recommended treatment for chronic pain in Sweden (5) and elsewhere (6) is multidisciplinary treatment including pain-focused cognitive behavioral therapy (CBT). This treatment yields small to moderate effects for pain severity, pain interference, health-related quality of life, disability, distress, and mood when compared with treatment as usual/waiting list (3, 4). However, outcomes are typically assessed at post-treatment with relatively short-term follow-ups of 12 months or less. Also, there are complementary outcomes that only rarely appear in the literature, such as health care utilization, work ability, return to work, and medication use (3, 7).

Systematic reviews of the economic benefits of non-pharmacological treatments for chronic pain identify a relatively small number of studies, heterogeneous in nature, and often reliant upon patient self-reports to estimate health economic outcomes (8, 9). For individuals with chronic pain in Sweden, two exceptions are registry studies of patients undergoing interdisciplinary pain rehabilitation—each of these find reductions in social insurance compensation, one and two years after discharge (10, 11).

Psychological flexibility is defined as the capacity to act with openness, awareness, and in line with one's chosen values while experiencing unwanted thoughts, emotions, or bodily symptoms (12). The psychological flexibility model is both a model of behavior of people suffering from chronic pain or other difficulties, and also a broadly applicable model of human behavior and wellbeing in general. The model includes emotional, cognitive, attentional, self-related, motivational, overt behavioral flexibility processes that together entail effective performance as well as a parallel set of inflexibility processes that entail ineffective performance and poor health (12). In previous studies, we have shown that processes from the psychological flexibility model as applied to chronic pain (12, 13), particularly psychological *in*flexibility, act as a predictor and mediator of pain-related outcomes for multidisciplinary pain-focused CBT delivered in a specialist pain clinic in Sweden (14, 15). We have not previously examined health economic outcomes from this same treatment center nor the role played by psychological *in*flexibility in these outcomes.

The purpose of this study was to conduct secondary analyses of data from a large multidisciplinary pain center in Sweden, combined with data from national registries, to focus on pain-related and health economic outcomes at post-treatment and one, two and three years after discharge. In an exploratory fashion, we investigated whether sociodemographic characteristics, pain-related variables, and psychological *in*flexibility, predicted these long-term pain-related and health economic outcomes. We also examined psychological *in*flexibility as a potential mediator of these outcomes.

Methods

Participants and procedure

Participants in this study ($n = 232$) were consecutive referrals undergoing treatment at the Pain Rehabilitation Unit at Skåne University Hospital, in southern Sweden, between February 2014 and December 2015. This is tertiary, government supported, regional, center for chronic pain and related disability. The sociodemographic variables reported as a part of this study (age, gender, country of birth, level of education) were assessed at baseline (pre-treatment). The clinical variables were assessed at pre-treatment, post-treatment, and 1 and 3 years after discharge. The 3-year-follow up was specifically undertaken for this study. Participants were mailed questionnaires 1 year and 3 years after discharge from the day treatment program (the follow-up assessments). Health economic variables were obtained from national registries for all participants before treatment participation (pre-treatment) and at 1, 2, and 3 years after treatment at the clinic. All participants provided written informed consent. The study was approved by the Regional Ethical Review Board in Lund, Sweden (2013/381). It is in line with the Strengthening the Reporting of Observational studies in Epidemiology guidelines (STROBE) and includes the necessary items to properly report an observational study according to the STROBE checklist (von Elm et al., 2007).

Treatment program

The treatment was multidisciplinary, outpatient, and based on a cognitive behavioral approach, delivered by teams with training in CBT and extensive knowledge of pain rehabilitation. An individual rehabilitation plan was formulated during individual appointments and then followed for each patient. The treatment was biopsychosocial in orientation and primarily group-based with the focus to help patients to develop more adaptive ways of thinking and behaving in relation to pain. The emphasis was on improving practical skills, knowledge, and awareness with methods including physical exercises and relaxation (physiotherapist); pain and medication (physician); education in work-related and national insurance issues (social worker); ergonomics, time-use adaptations, problem-solving strategies, and everyday occupational performance (occupational therapist); and thoughts, emotions, behaviors, communication, and goal-setting methods (clinical psychologist). The treatment was based within a broad CBT framework and not specifically on the psychological flexibility model of chronic pain. The program was delivered over

five weeks (18 active treatment days 5–7 h per day) followed by a two-month "homework" phase, where patients work on personalized goals with support from the multidisciplinary team.

Measures

Depression

Depression was measured using the seven depression items from the 14-item Hospital Anxiety and Depression Scale (HADS) (16). Items are rated on a 0–3 severity scale, yielding total scores for anxiety and depression; higher scores correspond to higher levels of depression/anxiety over the past week. The cut-off score for the depression subscale is: 0–7 for non-cases; 8–10 for doubtful cases; and 11–21 for clinical cases (16). Consistent with the original, the Swedish version used in the current study has satisfactory internal reliability for the total ($\alpha = .90$) and depression scales ($\alpha = .82$) (16, 17).

Psychological inflexibility

Psychological *in*flexibility was assessed with the 12-item Psychological Inflexibility in Pain Scale (PIPS) (18); 8 items assess pain avoidance and 4 items assess cognitive fusion. Items are rated on a 7-point scale (*1 = never true; 7 = always true)* with higher scores corresponding to greater psychological *in*flexibility. The Swedish original (used in this study) has acceptable validity and reliability [$\alpha = .89$ (avoidance), .66 (fusion) and .87 (total scale)] (18).

Pain intensity

Pain intensity was captured with the single-item Numerical Rating Scale (NRS) where the respondent rates their pain intensity during the past week on an 11-point scale (0 = *no pain*; 10 = *worst possible pain*). The NRS is widely considered to be a valid measure of pain intensity and sensitive to the effect of pain-focused treatment (19, 20).

Pain interference

Pain interference was assessed with the 11-item pain interference subscale from the Multidimensional Pain Inventory, Version 2 (MPI-2) (21). Respondents use a 7-point scale (0 = *never*; 6 = *very often)* to rate how pain interferes in family and marital functioning, work and work-related activities, and social and leisure activities. Higher scores indicate greater functional impairment from pain. The original and Swedish version used in this study have acceptable psychometric properties ($\alpha = .72$-$.90$) and is sensitive to the effects of pain-focused treatments (14, 22).

Health economic variables

Four health economic variables were obtained from Swedish national registries for the 232 participants: (1) number of all health care visits over the past year; (2) cost of all health care visits over the past year; (3) number of compensated sick days over the past year; and (4) cost of compensated sick days over the past year. The cost variables reflect the total cost over the past year in Swedish Kronor (SEK). At the time the cost variables were obtained from the health care registries, between 10 and 11.2 SEK purchased one Euro. Regarding compensated sick days, this includes gross days and costs of sickness cash benefits, work injury sickness cash benefits, rehabilitation cash benefits, and preventive sickness cash benefits. Again, health economic variables were obtained from national registries for all participants before treatment participation (pre-treatment), and at 1, 2, and 3 years after treatment at the clinic. The values at each assessment represents the mean for the preceding year.

Statistical analyses

Descriptive statistics for the outcome measures were produced. Effect sizes (pre-to-post-treatment and pre-to-follow-up) were calculated for the mediator and outcome variables and interpreted (*Cohen's d*) as small (≥.2), medium (≥.5), and large (≥.8) (23).

Multiple predictor analyses

We conducted separate multiple linear regressions for each outcome. In the regressions, we explored whether pre-treatment values for sex, age, education-level (12 years education or less vs. more than 12 years education), pain duration, and total score on the measure of psychological *in*flexibility in relation to pain predicted treatment outcomes as indexed separately by total scores on the depression, pain interference, pain intensity measures and the number of heath care visits, costs of health care visits, number of compensated sick days, and costs of compensated sick days– all at the 3-year follow-up. The baseline value on the outcome measure under investigation was included together with the other independent variables to control for pre-treatment variation in the outcome variables.

Mediator analysis

In the mediator analysis we strictly focused on psychological *in*flexibility as a potential mediator. Mediation is the effect of the independent variable (X) on the dependent variable (Y) through another clinical variable (M). The cross-product *a*b* provides an inference as to whether and to what degree M is functioning as a mediator of the effect of X on Y, with *a* representing the relation of X to M, and b representing the relation of M to Y adjusted for X (24). Mediation studies without reference to controls and using data from repeated measurements of the same individuals are relatively common (25). In such cases, change scores on the mediators (M) and outcome variables (Y) are assumed to be influenced by the treatment program and X represents the effect of time (pre-treatment to 3-year follow-up). Even if the empirical evidence from this method is not as conclusive as mediation analyses using control groups, and random assignment, it can contribute with increased insight of change processes during treatment (26). In the current study, we assessed whether changes from pre-treatment to 3-year follow-up on the measures of pain intensity, pain interference, and depression, number of heath care visits, cost of health care visits, number of compensated sick days, and cost of compensated sick days, all used as a proxy for treatment effects, were mediated by changes in in psychological *in*flexibility from pre-treatment to 3-year follow-up. Investigation of changes during the entire study period

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(pre-treatment to 3-year follow-up) allows us to determine whether change in psychological *in*flexibility might contribute to change in outcomes during this time. The bootstrapping method with bias-corrected confidence estimates was used to test the significance of the indirect effect (27). The significance of the indirect or mediating effect is directly measured by the cross-product *a*b*. Confidence intervals are derived from an obtained distribution of *a*b* scores and if lower and upper bounds do not contain zero, the indirect effect is significant at the level specified in the analysis. All analyses were done using SPSS (Version 29) and the mediation analyses were conducted with 5,000 bootstrapped samples, with the algorithms and syntax for SPSS accessible online (25).

Incomplete data was handled using recommended procedures (28, 29). Little's MCAR test (Little, 1988) suggested that the data were missing completely at random, Hence, missing values were imputed at the item level using the Expectation-Maximization method (EM), while all available data were used if data were missing at the variable level (30, 31).

Results

Descriptive analyses

Table 1 presents the means, standard deviations, and effect sizes (Cohen's *d*), for the clinical variables at each assessment for the 232 study participants. Not reported in Table 1; the most frequently reported pain diagnoses were fibromyalgia (40.5%); neck-related pain (19.4%); and low back pain (4.7%); and approximately half (49.5%) of the participants had a pain duration of more than five years. A minority of the sample was male (14.2%) and the mean age was 41.6 (SD: 9.9). More than half of the participants had 12 years of education or less (63.2%).

Table 2 presents the means and standard deviations for the health economic outcome variables at all time points, and effect sizes (Cohen's *d*), using all available data for the 232 participants in the study. Again, the values at each assessment represents the mean for the preceding year.

Computed effect sizes for the clinical outcomes and mediator (psychological *in*flexibility) ranged from small to large, with nine out of twelve values falling in the medium range or larger. As shown in Table 1, the smallest effects were for pain intensity and the largest for psychological *in*flexibility. The effect sizes for the health economic outcomes in Table 2 ranged from small to medium, although the sick days data, for both number of days and costs, at one year showed a reverse of the expected effects in that the number of days and costs increased. Total health care visits and total health care costs both showed consistent medium effects at each follow-up. While the sick days data, again both number of days and costs, improved at the two-year and three-years marks, the effects were small.

Multiple predictor analyses

Two significant findings emerged in the regressions. Participants who reported higher psychological *in*flexibility at

TABLE 1 Means and standard deviations for the clinical and mediator variables at each assessment and effect sizes for each variable.

Variable	Pre-treatment M (SD)	Post-treatment M (SD)	1-year follow-up M (SD)	3-year follow-up M (SD)	Pre-treatment to post-treatment Cohen's *d* (*n* = 217–210)	Pre-treatment to 1-year follow-up Cohen's *d* (*n* = 164–156)	Pre-treatment to 3-year follow-up Cohen's *d* (*n* = 145-141)
Pain intensity	7.27 (1.40)	6.58 (1.80)	6.47 (1.62)	6.50 (1.90)	.39	.46	.33
Pain interference	4.69 (.80)	4.17 (.99)	4.07 (1.21)	3.89 (1.26)	.59	.59	.60
Depression	9.88 (4.26)	7.11 (4.14)	7.88 (4.66)	7.84 (4.50)	.63	.46	.39
Psychological *in*flexibility	60.32 (11.93)	50.77 (12.51)	48.97 (14.13)	49.60 (16.44)	.87	.88	.59

Pain intensity was assessed with the Numerical Rating Scale, pain interference with the Multidimensional Pain Inventory, depression with the Hospital Anxiety and Depression Scale, psychological *in*flexibility with the Psychological Inflexibility in Pain Scale.

TABLE 2 Means and standard deviations for the health economic variables at each assessment and effect sizes for each variable.

Variable	Pre-treatment M (SD)	1-year follow-up M (SD)	2-year follow-up M (SD)	3-year follow-up M (SD)	Pre-treatment to 1-year follow-up Cohen's *d* (*n* = 188-168)	Pre-treatment to 2-year follow-up Cohen's *d* (*n* = 188-168	Pre-treatment to 3-year follow-up Cohen's *d* (*n* = 188-157)
Total number of health care visits	44.95 (27.97)	31.84 (22.13)	28.58 (22.77)	30.03 (24.29)	.55	.59	.51
Total cost of health care visits (SEK)	57,015.78 (51,723.89)	29,653.84 (41,045.12)	31,383.99 (52,309.49)	23,202.35 (43,195.29)	.65	.50	.70
Total number of compensated sick days	222.02 (148.04)	247.70 (143.10)	181.27 (158.15)	141.39 (158.14)	-.15	.20	.37
Total cost of compensated sick days (SEK)	96,219.30 (75,344.77)	105,511.48 (75,384.48)	76,662.02 (77,071.71)	58,687.30 (74,167.15)	-.12	.20	.36

SEK, Swedish Kronor (10-11.2 SEK = 1 Euro, approximately); Values for the health economic variables are the means for the previous year.

baseline reported significantly worse depression at the 3-year follow-up ($\beta = 0.195$, $t = 2.166$, $p = .032$). Participants with 12 years education or less reported a higher number of compensated sick days at 3-year follow-up ($\beta = .165$, $t = 2.032$, $p = .044$).

Mediator analysis

Table 3 presents the mediation results. Psychological *in*flexibility mediated changes for all pain-related outcomes (depression, pain intensity, pain interference) and mediated the total number of health care visits. No other mediation effects were identified.

Discussion

Chronic pain can be a highly disabling and costly problem for the affected individuals and society. While moderately effective treatments in the form of pain-focused CBT programs are available, little is known about their impact on broader health economic outcomes in actual practice, or the processes through which they yield clinical and health economic improvements. This study aimed to address this literature gap by conducting secondary analyses of data from a large multidisciplinary pain center in Sweden, combined with data from national registries, to focus on pain-related and health economic outcomes at post-treatment and one, two and three years after discharge. In addition, we investigated whether sociodemographic characteristics, pain-related variables, and psychological *in*flexibility, predicted these long-term pain-related and health economic outcomes. We also examined psychological *in*flexibility as a potential mediator of these outcomes. To our knowledge, this is the first study to evaluate whether psychological *in*flexibility, a variable that has been shown to predict and mediate one-year pain outcomes in multidisciplinary, pain-focused CBT programs, predicts or mediates both changes in clinical and health economic outcomes and whether it does so over the longer term.

Our findings add to a limited literature on the durability of pain-related outcomes more than 12 months after completion of a multidisciplinary, pain-focused treatment program. In the present study, the small and moderate sized improvements in pain, pain interference, and depression observed at post-treatment were mostly maintained at both the 1- and 3-year follow-up.

A very similar pattern was observed for the health economic outcomes, with gains attained by 1-year follow-up being maintained at long-term follow-up. The largest improvements were found for the total number and costs of healthcare visits, with moderate effect sizes at the 1-year follow-up and remaining stable at both the 2- and 3-year follow-ups. The costs of healthcare visits declined by 48% during the first year after treatment and at the time of the 3-year follow-up by 59% relative to the year up to commencement of treatment. The gains in respect of days with and costs of sick pay were much more modest. There was a slight worsening in this variable at the 1-year follow-up, with small gains not observed until the 2- and 3-year follow-ups. While the decline in the number of sick days and associated costs was in the small range, this nonetheless represented a 39% reduction in the cost attributable to compensated sick days by the time of the 3-year follow-up. While further studies are needed, small reductions in sick day costs following pain-focused treatment are potentially important given the high prevalence of chronic pain in the general population.

The mean number of health care visits, even after the treatment period, was high for this treatment sample. We note that this tertiary care population in Sweden can be considered to have a high health care utilization (32). However, this study was not able to determine whether all these contacts were due to pain and whether a small subgroup with a very high health care utilization pattern was driving these results or if the utilization was more evenly divided throughout the sample. Future studies need to investigate trajectories of healthcare utilization in different subgroups with chronic pain.

In an exploratory fashion, we sought to examine potential predictors of these pain-related and health economic outcomes. In respect of predictors, individuals with 12 years of education or less reported a higher number of compensated sick days at the 3-year follow-up. This finding warrants further investigation. Scores on a measure of psychological *in*flexibility at baseline did not predict the health economic outcomes. However, psychological *in*flexibility did predict greater depression at the 3-year follow-up. The latter is consistent with previous findings from our research group which identified psychological

TABLE 3 Results of mediation analysis.

Dependent Variable	*N*	Mediator	Results for indirect effects (*a*b*)	
			Point-Estimate (SE)	95% CI LL, UL
Pain intensity	141	Psychological *in*flexibility	.212 (.114)	.006, .461
Depression	144	Psychological *in*flexibility	1.051 (.302)	.516, 1.689
Pain interference	145	Psychological *in*flexibility	.301 (.073)	.172, .457
Total number of health care visits	142	Psychological *in*flexibility	3.963 (1.842)	.842, 8.091
Total cost of health care visits (SEK)	116	Psychological *in*flexibility	452.707 (3,854.575)	−6,786.016, 8,654.477
Total number of compensated sick days	124	Psychological *in*flexibility	16.598 (12.009)	−6.546, 41.309
Total cost of compensated sick days (SEK)	124	Psychological *in*flexibility	8,199.991 (5,855.827)	−2,810.776, 20,627.030

LL, lower limit; UL, upper limit.
The indirect effect is statistically significant if the confidence interval (CI) does not include zero.

*in*flexibility as a predictor of higher scores for depression and pain interference at 12-months follow-up on patients from this clinic (15). These findings suggest that individuals with high levels of psychological *in*flexibility at baseline experienced worse treatment outcomes. This is understandable as psychological *in*flexibility can be regarded as a lack of basic skills for seizing opportunities and making the best of it. Participants high in psychological *in*flexibility might benefit from more intensive targeting of this process during treatment. One way to improve the individualization, and efficacy, of group-based CBT programs for chronic pain could be the administration of a self-report measure of psychological *in*flexibility during the assessment phase. Patients scoring high on this measure could be offered one-to-one or small group interventions specifically aimed to increase their levels of psychological flexibility in addition to the standard group treatment. Another way to address this problem could be individual and personalized process-based therapy (PBT), where evidence-based processes of change, such as psychological *in*flexibility, are addressed based on idiographic assessment, to target the needs and reach the goals of each individual (33).

As noted in the introduction, we have previously found that changes during treatment in different facets of the psychological flexibility model as applied to pain, including psychological *in*flexibility, mediated pain intensity, pain interference and depression; all primary targets of pain-focused treatments (14, 15). These findings were partly replicated in this long-term follow-up study as changes in psychological *in*flexibility between pre-treatment and the 3-year follow-up mediated changes in pain interference, depression, and pain intensity over the same interval. In addition, changes in psychological *in*flexibility over this 3-year interval mediated the total number of health care visits between pre-treatment and the long-term follow-up. These findings warrant further investigation in larger samples allowing more complex modelling strategies. It is possible that changes in psychological *in*flexibility, pain, and associated emotional difficulties, interact with other patient characteristics, symptoms, or circumstances (e.g., age, multimorbidity, and relationship status/support) to impact healthcare usage and thus costs. Overall, the present findings suggests that reductions in psychological *in*flexibility partly underpins the longer-term gains observed following treatment in a multidisciplinary CBT program for chronic pain, including small reductions in the number of health care visits. Again, one way to potentially improve outcomes for adults seeking treatment for chronic pain further could be more detailed and precise assessment and targeting of psychological *in*flexibility. Psychological flexibility has been pointed out as a counterweight to many forms of psychopathology, an essential part of psychological functioning, and a fundamental aspect of health (34–36), and its broad relevance to the investigated outcomes lends support to such notions.

The present findings must be viewed within the context of certain limitations. While the sample size was relatively large ($n = 232$), there was no un-treated or non-pain comparison group, and the data were obtained from a single, regional pain clinic. The last follow-up in this study occurred 36 months after treatment completion, which compares favourably to the 3- to 12-month follow-ups usually reported for pain-related outcomes in the literature. However, given the chronicity of pain in this sample, and as a condition more broadly, even longer-term follow-ups are needed, and again with appropriate comparisons groups. The health economic data reported in this study were not based on self-report, as in most studies, and instead obtained from Swedish government registries. Nevertheless, these findings may not generalize across pain clinics in Sweden or to pain services outside the country. The generalizability to other clinical settings might also be limited by the fact that the sample included a large proportion of women and participants diagnosed with fibromyalgia. This study included a large number of predictor variables and comparisons, which may increase the risk of type I errors. Also, this study did not control for additional treatment received during the years following completion of the pain program. Finally, future studies need to evaluate a broader range of health economic outcomes, including both direct and indirect costs, when considering the impact of pain-focused CBT.

In conclusion, the present findings add to a small body of literature indicating that the improvements in pain and related difficulties following multidisciplinary, pain-focused CBT programs appear to persist at least three years following treatment. Small to moderate improvements in health economic outcomes also occur during this same period. The present results add to previous research demonstrating that a patient's level of psychological *in*flexibility is associated with clinical outcomes in pain management. The findings expand on the literature by suggesting that changes in psychological *in*flexibility during multidisciplinary, pain-focused CBT appear important for achieving improved clinical outcomes over the longer term, and relevant to long-term health economic outcomes, at least with respect to the number of health care visits.

Data availability statement

The datasets presented in this article are not readily available due to ethical restrictions. Requests to access the datasets should be directed to sophia.akerblom@med.lu.se.

Ethics statement

The studies involving humans were approved by Regional Ethical Review Board in Lund, Sweden. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

SÅ: Conceptualization, Data curation, Investigation, Methodology, Project administration, Writing – original draft. LM: Conceptualization, Writing – review & editing. MR: Conceptualization, Supervision, Writing – review & editing. SP:

Conceptualization, Methodology, Supervision, Writing – review & editing.

Funding

The author(s) declare that no financial support was received for the research and/or publication of this article.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declare that no Generative AI was used in the creation of this manuscript.

Publisher's note

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frontiers | Frontiers in Pain Research

TYPE Original Research
PUBLISHED 11 June 2025
DOI 10.3389/fpain.2025.1540395

OPEN ACCESS

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RECEIVED 05 December 2024
ACCEPTED 28 May 2025
PUBLISHED 11 June 2025

CITATION
Wong ML, Anderson KD, Roach KE, Robayo L, Cherup NP, Vastano R, Fernandez G and Widerström-Noga E (2025) The meaning of manageable neuropathic pain after SCI. Front. Pain Res. 6:1540395. doi: 10.3389/fpain.2025.1540395

The meaning of manageable neuropathic pain after SCI

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Introduction: Chronic neuropathic pain (NP) is a prevalent and debilitating condition among individuals with spinal cord injury (SCI). Complete pain relief is often unattainable, making the concept of "manageable pain" a critical focus for improving quality of life. This study aims to elucidate the meaning of manageable pain for individuals with chronic NP post-SCI.
Methods: A mixed-methods approach was employed, involving qualitative interviews and quantitative assessments with 36 participants experiencing moderate to severe NP.
Results: The qualitative data revealed three major themes: Manageable Pain, Unmanageable Pain, and Ways to Control Pain. Manageable pain was characterized by its moderate intensity, predictability, and minimal interference with daily activities. In contrast, unmanageable pain was associated with significant emotional distress, activity hindrance, and inability to control the pain. Participants used a variety of techniques to control pain, including cognitive/emotional coping strategies, medication, and physical activity. Most participants used a multimodal approach that was severity and situation dependent.
Discussion: These findings underscore the multifaceted nature of pain management and the importance of individualized approaches that consider both pain acceptance and coping strategies. This study provides valuable insights into the personal experiences of NP in people with SCI and their perspectives on the meaning of manageable pain. These findings highlight the need for comprehensive pain management strategies that enhance daily functioning and overall well-being.

KEYWORDS

neuropathic pain, spinal cord injury, manageable pain, qualitative research, mixed-methods research

Introduction

Most people with spinal cord injury (SCI) suffer from chronic neuropathic pain (NP), and complete pain relief is often an unrealistic goal (1, 2). A more realistic goal is to reduce pain's impact on quality of life and to make pain "manageable". Manageable or tolerable pain is a construct that is not specific to NP after SCI, and research in other populations suggests that manageable pain is pain that allows the performance of daily activities or "getting something done" (3). Manageable pain may also be associated with lower levels of affective distress and less pain interference with social activities.

The concept of manageable pain has been studied using a quantitative approach in heterogeneous pain populations, including people with chronic knee osteoarthritis,

rheumatoid arthritis, limb amputation, cancer, and low back pain (4–6). For instance, manageable pain was established via cut points on the numeric pain rating scale (NPRS) that correlate with moderate functional impairment (4–6). Specifically, scores between 4 and 6 (from 0 to 10) correlates with moderate functional impairment, which individuals typically deem as intolerable pain. Although this approach provides valuable information that can be used in analyses for quantitative studies, there is often a non-linear relationship between pain severity and interference with function (5, 7–9). This is because many other factors may influence pain interference (e.g., personal coping skills, psychological strength, qualitative nature of pain, and presence of evoked pain). Additionally, other studies suggest that traditional pain scales, like the NPRS, may not be interpreted consistently across patients. Instead, using simpler binary questions about pain acceptability may offer clearer insights, though a multidimensional approach to pain assessment remains ideal for understanding what constitutes acceptable pain (3, 10, 11). Although interesting, the overall findings from these studies do not provide insight into the *meaning* of manageable pain for individuals within these populations.

We have only identified one qualitative study that directly investigated the meaning of manageable pain. Zelman et al. (3) conducted focus groups of people with pain associated with metastatic cancer, osteoarthritis, and low back pain to identify the daily goals of people who use analgesic medications for controlling persistent pain. Interestingly, the participants objected to the term "acceptable day of pain" and preferred the terms "manageable" or "tolerable". Zelman identified five key themes: in order of importance, participants stated that on a desirable day, (1) their medication takes the edge off the pain, (2) increased function is possible, (3) social engagement is desired, (4) there is sufficient nighttime rest, and (5) they have reduced negative affect. These themes provide important insight into the meaning of manageable pain, suggesting that the impact of manageable pain is not merely the result of controlling the intensity or unpleasantness of symptoms, but rather the controlling of pain to the point of approximating an unhindered life. To date, little is known about what manageable pain means, specifically to people with chronic NP after SCI.

Given the unique characteristics of people with NP after SCI, caution should be used when extrapolating Zelman et al.'s findings to this population. For example, it is known that many people with NP after SCI are doing relatively well despite having severe pain (12). Moreover, Zelman et al.'s findings were specific to "a day of manageable pain" *with medication use*. However, it is known that people with chronic NP after SCI do not always use medication for pain management and that they often engage in a variety of pain management strategies (12, 13). In fact, a previous study found that those with moderate NP after SCI used multiple approaches to manage their pain, and they used less medication than those with severe pain due to concerns about side effects and addiction (12). Thus, the purpose of this study was to examine what the term "manageable pain" means specifically to people with chronic NP after SCI. Further, we explored the differences in pain-related and psychosocial impact between those who experience manageable pain every day and those who do not have manageable pain every day.

Methods

This study was part of a larger mixed methods study regarding participants' perspectives on a novel multimodal pain intervention program. For the purposes of the present article, qualitative interview data concerning the concept of manageable pain and pain evaluations were analyzed at the first interview in 36 participants with moderate to severe NP associated with SCI. The study adhered to the principles of the Declaration of Helsinki and was approved by the Institutional Review Board of the University of Miami Miller School of Medicine.

Participants

Participants ($n = 36$) were recruited via flyers posted at the University of Miami clinics and at the Miami Project to Cure Paralysis. We also recruited participants from the Miami Project SCI volunteer research database. Men and women aged 18–70, with traumatic incomplete or complete SCI (incomplete injuries retain some level of function, whereas complete injuries result in total loss of function below the injury site) with moderate NP intensity or above (*N*PRS >3/10), were invited to participate. Potential participants were excluded if they reported a history of systemic illness (e.g., cardiovascular disease, multiple sclerosis, rheumatoid arthritis, cancer), severe depression (BDI-II >29), body mass index (BMI) >35, or scored above the threshold for unhealthy alcohol (AUDIT >10) or drug (DAST-10 >6) use within the past year.

Measures

Screening

Beck depression inventory, 2nd edition (BDI-II)

The BDI-II is a 21-item questionnaire for the assessment of depressive symptoms consistent with the DSM-IV. Common depressive symptoms over the past two weeks are rated on a 4-point scale from 0 to 3, with the overall score ranging from 0 to 63. Range of depression: 0–13 minimal, 14–19 mild, 20–28 moderate, and 29–63 severe. The internal consistency and reliability of the BDI-II among those with chronic pain conditions has been previously established.

Alcohol use disorder identification test (AUDIT)

The AUDIT consists of 10 items about alcohol use, alcohol dependence symptoms, and alcohol-related problems over the past year.

Drug abuse screening test (DAST-10)

The DAST-10 is designed to detect drug-related problems over the past year. The DAST includes 10 items rated on a yes/no binary. The DAST-10 is psychometrically consistent and reliable among various populations.

Qualitative data

Semi-structured interviews were conducted after receiving 1 month of educational sessions on pain science and management strategies, again after receiving an additional 6-weeks of guided exercise and visual illusion training, and a third time 1 month after completion of all intervention activities. Each interview was conducted by one investigator (MW) via Zoom. For the purposes of this manuscript, we only focus on the responses to the first question posed during the first interview: "What is manageable pain to you?" For participants who had difficulty responding to the question, we followed up with the opposite, "What is unmanageable pain to you?"

Interviews were audio recorded and transcribed verbatim by an independent transcribing service. A qualitative content analysis was performed by two independent researchers (EW and KA) who reviewed and described the information using NVIVO (software headquartered in Lumivero, Denver, CO). The study staff also completed quality control procedures to ensure data accuracy. First, major themes were independently coded by two investigators (EW and KA). A third investigator (MW) was added to the analysis process to interrogate the transcripts for sub-ordinate themes. The primary intent was to describe rather than to generate new theories, and the qualitative approach was designed to allow the researchers to adapt their methods to fit the specific needs of their study as the project unfolded, rather than adhering to a specific qualitative tradition. Thus, a generic qualitative research design (14), from an interpretivist paradigm, was employed for this project. Based on our prior studies, we anticipated achieving saturation within 35 participants, and no new themes emerged after 30 SCI participants. Therefore, we completed our interviews with 36 individuals with SCI-associated NP. The identified themes were then discussed in study team meetings and revised if needed.

Investigators EW and KA were both senior investigators with extensive experience in qualitative and quantitative research focused on pain in the SCI population. Investigator KA also has a SCI, providing her with a unique perspective in this work. MW is a physical therapist with extensive clinical experience in pain management and some previous experience with SCI research. These investigators had minimal contact with the study participants outside of the interviews, and they did not have prior relationships with any of the participants.

Quantitative data

To further evaluate participants' pain, psychosocial factors, and medication use, the following assessments were administered:

Days with manageable pain

This item specifies the total number of days with manageable pain during the last 7 days, including today, and the response categories range from 0 = none to 7 = seven days. This item is part of the International SCI Extended dataset (15). Because the perception of days with manageable pain is likely to change during the course of a study, we used assessment and interview data collected at the first interview for all analyses.

The international spinal cord injury pain basic data set

This tool was primarily developed to provide clinically relevant information concerning SCI-related pain that could be collected by healthcare professionals, and it has served as a basic pain measure in clinical research and clinical registers (16–18). Four items were extracted from this tool for this study: (1) "Number of days with manageable/tolerable pain in the last 7 days including today."; (2) "In general, how much has pain interfered with your day-to-day activities in the last week?" (interference with activities); (3) "In general, how much has pain interfered with your overall mood in the last week?" (interference with mood); (4) "In general, how much has pain interfered with your ability to get a good night's sleep in the last week?" (interference with sleep); and (5) "Overall, how hard is it for you to deal with your pain?" (hard to deal with pain). For days with manageable pain, possible scores ranged from 0 to 7, and for all other items possible scores ranged from 0 = "No interference" or "not hard at all" to a maximum of 10 = "Extreme interference" or "extremely hard".

Multidimensional pain inventory: SCI version (MPI)

The West Haven-Yale MPI (19) is a comprehensive instrument designed to assess a range of self-reported behavioral and psychosocial factors associated with chronic pain syndromes. The total scale consists of 50 items, but only the following subscales were used, Pain Severity (MPI-PS, 3-items), Life Interference (MPI-LI, 8-items), Life control (MPI-LC, 3-items), and Affective distress (MPI-AD, 3-items). All items are scored on a 7-point Likert scale (0–6), and the subscale score is reported as the mean of component items.

Neuropathic pain symptom inventory (NPSI)

The NPSI is one of the most widely used tools for characterizing NP symptom severity (20, 21), and it is comprised of 10 items scored on 0–10 Numerical rating scales, and that assess dimensions of NP (burning spontaneous pain, pressing spontaneous pain, paroxysmal pain, evoked pain, and paresthesia/dysesthesia). NPSI total score ranges from 0 to 100, with higher scores indicating worse NP severity. The NPSI demonstrated good psychometric properties in a cohort of people with NP after SCI (22).

Quantitative data analyses

Descriptive statistics (i.e., means, medians, frequencies, percentages, and standard deviations) were used for all variables, when appropriate. Spearman's rank correlation analysis was used to explore the associations between the number of days per week with manageable pain (M-pain days) and the MPI-SCI subscales and interference scores. All statistical analyses were conducted using Statistical Package for the Social Sciences (SPSS) v28 (IBM Corp., Armonk, NY), and figures were rendered using GraphPad Prism v9.3.1 (GraphPad Software, La Jolla, CA). Results were considered significant if values met the *a priori* threshold set at $p \leq 0.05$.

Results

Demographic and injury-related characteristics

The demographic characteristics of the sample are described in Table 1. The mean age (standard deviation) of the sample was 42.3 (14.0) years, with ages ranging from 19 to 74. Most participants identified as male (75%) and single (69.4%). There was a wide range of education levels, with over 58% having at least some college experience or holding an associate degree. Additionally, a little more than half of the participants had tetraplegia (55.6%), there was representation across all levels of the American Spinal Injury Association Impairment Scale [(AIS), levels A–D], and the average time since injury was 10 years for the entire group.

Qualitative data

Some participants had clear interpretations of manageable pain, while others found the concept nebulous and had difficulty describing manageable pain. Those who had difficulty describing manageable pain often chose to define what made pain unmanageable or described how they controlled their pain. Thus, three major themes emerged: (1) Manageable Pain, (2) Unmanageable Pain, and (3) Ways to Control Pain (Table 2). Within each of these major themes, key subthemes were also identified, and the themes and subthemes collectively provide a detailed understanding of how these individuals conceptualize the manageability of their pain. For many participants several of the subthemes were expressed, thus demonstrating the multifactorial nature of how they defined manageable pain.

TABLE 1 Demographic and pain characteristics.

Characteristic		Total $N = 36$
Age (mean, SD)		42.3 (14.0)
Sex (*n*, %)	Male	27 (75)
	Female	9 (25)
Ethnicity (*n*, %)	White non-Hispanic	8 (22)
	Hispanic	13 (36)
	African American	8 (22)
	Asian	1 (3)
	Other	6 (17)
Education (*n*, %)	Less than high school	4 (11)
	High school	9 (25)
	AA or some college	14 (39)
	Bachelor	4 (11)
	Advanced degree	3 (8)
	Other	1 (3)
Multidimensional pain inventory (MPI) subscales (mean, SD)	Pain severity (PS)	4.0 (1.7)
	Life interference (LI)	2.9 (1.8)
	Life control (LC)	3.9 (1.4)
	Affective distress (AD)	2.4 (1.5)
Neuropathic pain symptom inventory (NPSI) (mean, SD)		42.1 (22.5)
The international spinal cord injury pain basic data set (mean, SD)	Interference with activities	4.4 (3.7)
	Interference with mood	4.1 (3.2)
	Interference with sleep	4.9 (3.5)
	Difficulty dealing with pain	4.8 (3.1)

The theme Manageable Pain included four subthemes: (1) Manageable pain characteristics, (2) Pain that can be controlled, (3) Pain that can be ignored or tolerated, and (4) Pain that does is not interfere with daily life activities.

Manageable pain characteristics

The characteristics of the pain (i.e., the intensity and temporal pattern) were a defining feature of manageable pain for some. Several participants defined manageable pain as being below a 4 or 5 on an 11-point NPRS. "*Ideally, it would be zero pain, but that's pretty hard. That's pretty hard to get. Once in a while, I do get that. I think it's mostly when I'm being distracted, but manageable pain. Let's see. I think probably if you're using that scale, I think a four or five would be manageable.*" (Participant 12). Manageable pain was also described in terms of the temporal pattern: "*It would be more consistent pain rather than the spikes.*" (Participant 24).

Pain that can be controlled

Many participants ($n = 19$) described how being able to do something to reduce the intensity of the pain or take the edge off, was an important feature in making it manageable. As one participant said, "*It's pain that I could somewhat control. A pain that I could possibly take some type of medication or do some type of non-medicated therapy that could actually help alleviate or control the pain to some degree…*" (Participant 25). Another participant described it as "*Pain that you can … what's the word I'm looking for … relieved by either medication or exercise or meditation or any type of form where you can manage it where it's not overwhelming or controlling your life in a negative way.*" (Participant 8). This also highlights the importance of having knowledge of a variety of pain management strategies, and the availability of pain management tools, for many people to achieve manageable pain after SCI.

- "*It's just finding a way to manage pain. Sometimes finding ways like toughening out or, I guess, researching with your pain management to see what can help out or anything like that.*" (Participant 21)
- "*it means being able to manage it, to control it, to take care of your pain when you … Manageable pain to be able to manage it.*" (Participant 17)

Pain that can be ignored or tolerated

Many participants described the ability to ignore or tolerate the pain as a defining feature of manageable vs. unmanageable pain. For some, this was described as a struggle:

TABLE 2 Major themes and subthemes.

Major themes:	Manageable pain	Unmanageable pain	Ways to control pain
Sub-themes:	• Pain characteristics • Pain that can be controlled, managed, and dealt with • Pain that can be ignored or tolerated • Pain that does not interfere with daily life activities	• Affects mood • Hinders activity • Cannot be controlled	• Ignoring pain, using distraction • Prescription and non-prescription medication use • Using multiple approaches • Severity and situation dependent • Staying active, exercise

- "*It's something that I could force myself to deal with for a little period of time.*" (Participant 12)
- "*The ability to forget about it. So it could still be there, but you just aren't consciously thinking about it.*" (Participant 19)

For others, it was described as a process of acceptance:

- "*Just dealing with (it) I got to deal with to get through it.*" (Participant 27)
- "*If it doesn't go away, I have to learn how to live with it.*" (Participant 22)

Pain that does not interfere with daily life activities

The impact of pain on movement and activities of daily living was another defining feature of manageable for many participants. This is captured in the following quotes:

- "*It means that I can go out for a little bit throughout the day and that the pain isn't stopping me from living my daily life. I always have pain, but the manageable pain is that I can go to the store for an hour or go sit in the car, or go out and do something like that, then go back home.*" (Participant 10)
- "*Basically that something that you can go through the day without having to say, well cut back anything you have to do.*" (Participant 29)
- "*Pain that isn't bothersome so I can continue living my life. That like it's there, but it's not going to affect my day-to-day…*" (Participant 19)
- "*I could still get up and still do my daily tasks without … Well, I will complain but I'm still doing it. That's manageable.*" (Participant 26)

Unmanageable pain

Many of the participants experienced some days of unmanageable pain. The theme Unmanageable Pain included three subthemes: (1) affects mood, (2) hinders activity, and (3) cannot be controlled or tolerated.

Affects mood

Some participants described high levels of emotional distress associated with unmanageable pain:

- "*I'll tell you, sometimes I want to give up. I have my days where I don't want to be bothered. I have plenty of days where I just sit there and cry. Why do I cry? I don't know. But I just be boo-hoo crying.*" (Participant 04)
- "*Oh, man. I don't want to go through this. I would probably rather be dead than deal with something like this. It's killing you. Softly. Maybe not saying anything, but it's killing you. Even if nobody does not see it; who can see it? You're the only one that knows because you don't want to feel it.*" (Participant 16)

Hinders activity

Unmanageable pain also evoked vivid descriptions of suffering and inability to move due to the pain:

- "*Yes, especially when I'm going to a dinner or I'm going to a meeting. When I'm going to an expo, when I'm going out with my family, business, one of the main things business is, how's my pain going to be while I'm sitting there in a seven-hour conference?*" (Participant 1)
- "*where I really can't be doing most things, having a hard time getting along with people and not wanting to go out. Just being basically, I guess you could say, incapacitated, disabled from the pain.*" (Participant 35)

Cannot be controlled or tolerated

Unmanageable pain was associated with a sense of helplessness and no relief. The sense of lack of control is portrayed in the following quotes:

- "*Pain that really cannot control. For example, if I am in my bedroom, if there is no any other visual or physical activities to do, I'm just by myself, very quiet. In a very quiet environment, I would feel the pain sitting there or in my bed doing nothing. So that's where, unfortunately, I can experience the pain and nothing to do about it.*" (Participant 18)
- "*unmanageable is not being able to control it and it just having a mind of its own like it does…*" (Participant 36)

Ways to control pain

The final major theme, Ways to Control Pain, included the subthemes (1) ignoring pain, using distraction, (2) using medication, (3) using multiple approaches, (4) severity and situation dependent, and (5) staying active or exercising.

Ignoring pain, using distraction

Many of the participants described the process of mentally "blocking out" the pain as a coping mechanism. For most, distraction was the primary method of blocking out the pain:

- "*But I always try to find a positive way of try to distract it from taking advantage of my life and pretty much controlling my life throughout. I know that it's there, but I try to black it out, pretty much.*" (Participant 6)
- "*I put it in the mentality of, "Okay, is this pain hurting or is it bothering me?" Most of the times, it's just bothering me. It's not something that I cannot, how do I say it? It's not something that I cannot take all the time. Sometimes it gets really bad, but the moment I stop thinking about it or I get busy doing something else, it diminishes, it slows down.*" (Participant 37)
- "*So I just pay attention to how I'm feeling, and just let it pass with activity sometimes…*" (Participant 11)

Using medication

Participants used a variety of medications, including anticonvulsants, antidepressants, opioids (i.e., oxycodone), nonsteroidal anti-inflammatory drugs (i.e., diclofenac, acetaminophen, and ibuprofen), and anesthetic patches and ointments. Although the failure of medication to sufficiently alleviate symptoms and the negative effects of pain medications were reported by some participants, others described the use of prescribed medication as an important strategy for their pain management:

- "*But that's a big difference when you don't take a medication than when you do take your medication. And then once you take your medication… It's there. It never goes away, with the medication or whatever. With the medication, it's just a way to cope with it.*" (Participant 6)
- "*taking meds. That's the only way right now that I'm able to control it and go out and do whatever I need to get done. You know, like maybe doctor's appointments, or maybe even going to the rehab center. I have to take a gabapentin and a clonazepam.*" (Participant 28)

Several participants also described self-medicating with cannabis:

- "*I'm accustomed to it, so I just deal with it. I ain't going to lie, I smoke my little weed. Weed helps ease the pain too. It helps a whole hell of a lot.*" (Participant 4)
- "*but I honestly just smoke weed for my pain if it gets to that point. I'm not a person that takes pills or anything of the nature.*" (Participant 11)

Using multiple approaches

Most participants described using a multimodal approach to control their pain prior to their participation in the study, with varying forms and combinations of cognitive strategies, drugs, physical agents (i.e., thermal modalities and TENS), and physical activity.

- "*For example, this Saturday was my granddaughter's one year old, but I woke up with tremendous pain, one of the worst, and I had to take some marijuana cream and then I had to take Motrin to see if I could manage my pain. Where I do manage my pain more than when I just told you about it is that I redirect my pain in my thoughts. I just don't think about it. I try to just focus on the event and everything else. I blank out on the pain.*" (Participant 1)
- "*Tools being medication, stretches, exercise, rests, the list could go on, and those tools help when I get in extra pain.*" (Participant 24)
- "*I do a lot of stuff. I do a lot of reading, I do a lot of stretching, I do a lot of exercise. I do a lot of massage, I massage myself. I do a lot of stretching. I do some breathing techniques, meditation.*" (Participant 32)

Severity and situation dependent

Participants also modified their pain management approach based on the severity of the pain, with a preference for nonpharmacological approaches when the pain is mild and use of medications when the pain is severe.

- "*If it's really intense pain, then I may have to use a medication or analgesic cream on it. If it's not that bad, it's just a matter of a mind over matter.*" (Participant 8)
- "*Once it starts climbing on the uncomfortable level, I have tried to rub different things, like on my arms, or for example, when it's on my butt, which is usually where I get the other pain, I usually just get off of it from sitting down. I just just get on my bed, lay on my side, just if I can stand or I can do something else, just relieve that pressure essentially*" (Participant 35)
- "*Sometimes exercise. Sometimes medication. Sometimes deep breathing techniques. There are options. Depends on what I'm going through like that, but those are the main things actually.*" (Participant 27)

Staying active, exercise

Strategies involving physical movement were the most widely endorsed pain management strategies. Exercise and engaging in physical activity (e.g., sports) were often used as a distraction and coping mechanism even in cases when activity did not provide direct pain relief.

- "*Medication in a workout. I do stay active. Movement for my body, whatever my injuries are and whatever the signals are sent, the more I'm active, more warmed up I am, I can use my walker and push myself… stretching and exercise works better than any other therapy for me.*" (Participant 03)
- "*At the beginning, I have to tolerate the pain that I was having at that moment, still have. But it seems that playing the sport, it really mentally and physically minimize the pain. I've been playing a lot of sports.*" (Participant 18)
- "*when you got the exercise, when you have the exercise, your pain is not the same when you don't have the exercise. Now, when you manage your pain, when you manage for exercise, your pain's coming better now.*" (Participant 20)

Quantitative data

The mean (standard deviation) for the NPSI score was 42.1 (22.5), indicating that NP symptoms were moderate on average. Participants used a variety of medications to manage pain

symptoms, and the most frequently used were anticonvulsants (i.e., gabapentin and pregabalin), which were used by 56% ($n = 20$) of the participants. This is not surprising given that these medications are considered first-line treatments for NP after SCI (23). Other medications reported were antidepressants (11%, $n = 4$), muscle relaxants (25%, $n = 9$), nonsteroidal anti-inflammatory drugs (17%, $n = 6$), and opioids (22%, $n = 8$). Interestingly, Cannabis was used in over 22% ($n = 8$) of cases, suggesting an emerging preference for alternative therapies.

The mean/median (standard deviation) of reported days per week with manageable pain (M-pain days) was 4.3/5.5 (2.9) (Figure 1). Additionally, M-pain days demonstrated moderate and significant correlations with MPI subscale scores for MPI-PS ($r = -0.439$, $p = 0.007$), MPI-LI ($r = -0.484$, $p = 0.003$), and MPI-LC ($r = -0.638$, $p = 0.001$) (Figure 2). Additionally, M-pain days correlated with pain interference with activities ($r = -0.5$, $p = 0.002$) and difficulty dealing with pain ($r = -0.439$, $p = 0.007$). However, M-pain days was not correlated with the MPI-AD ($r = -0.225$, $p = 0.187$), mood interference ($r = -0.287$, $p = 0.089$), or sleep interference ($r = -0.240$, $p = 0.159$).

Discussion

In this study, we explored the meaning of manageable pain in 36 people with chronic NP after SCI and associated measures of pain and psychosocial impact. As pain itself is known to be a very individual experience, so too were the factors that contributed to the perceived manageability of pain in this group. The qualitative analyses showed that "*manageable pain*" was often perceived as pain that is moderate and predictable, pain that can be controlled and dealt with, pain that can be ignored or tolerated, and pain that does not interfere with life.

In contrast, "*unmanageable pain*" was in some ways described as the opposite of manageable pain (i.e., pain that cannot be controlled and that hinders activity); it was also described as causing severe emotional distress. To control their pain, participants engaged in a wide variety of strategies, including medications, exercise, and physical activity, as well as cognitive/emotional coping strategies (including distraction). Importantly, most participants used a multimodal approach to control their pain, with varying combinations of the strategies listed above, which they developed through trial and error over time.

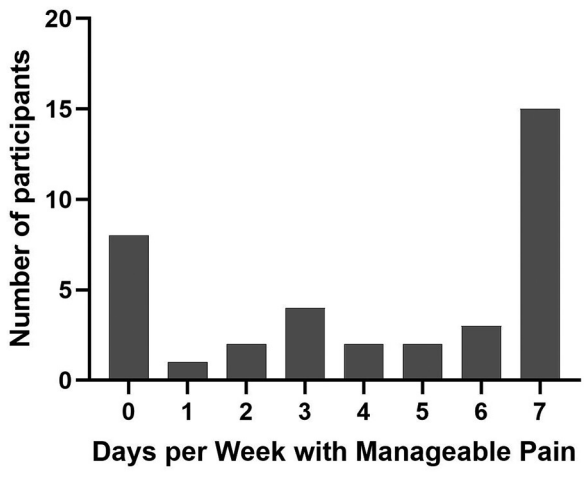

FIGURE 1
Frequency distribution of Participants by Days with Manageable Pain.

It is widely accepted that chronic pain is associated with numerous and different behavioral coping responses that may be adaptive or maladaptive, and that are dependent on individual resources (24–26). Specifically in those with SCI, adaptation and psychosocial impact have also been shown to be dependent on specific pain characteristics, including pain intensity, pain aggravation, electric quality, constancy, and distribution of pain (27). Further, repeated unsuccessful and frustrating attempts to control pain are known to actually exacerbate disability (28). It is important to note that all participants had NP with moderate to severe pain intensity (NPRS >3/10).

The present study also showed that the construct of "days with manageable pain" was supported by quantitative findings using validated questionnaires. Those who had more days with manageable pain also had lower pain severity, less pain interference with life and activities, greater life control, and reported lower levels of difficulty in dealing with their pain. It is possible that the number of days with manageable pain is influenced by the degree of pain acceptance. In another study of individuals with SCI and chronic pain, greater pain acceptance was related to better mood, social participation, and less pain interference, above and beyond the effects of same-day levels of pain intensity (29). Therefore, future studies should investigate the relationship between manageable pain and pain acceptance. However, it is also important to note that manageable pain may be influenced by a combination of personal factors such as coping skills, affective distress, resilience, nature, and the impact of pain on daily life (12, 30–35).

Finally, previous qualitative studies on NP in people with SCI have aimed to broadly describe the experiences of people in this population (13, 36–38), or to explore specific questions related to management strategies (39–41). This study was unique in that our aim was narrowly focused on describing specifically what makes pain manageable for people with NP after SCI and the associated pain and psychosocial impact characteristics. Another unique feature of this study was that it was conducted in South Florida, United States, which has a diverse population including Hispanic/Latino, Black, and White people and thus may provide a very different cultural setting from the locations in which prior qualitative studies were conducted. Specifically, other studies have been conducted in Canada (13), New Zealand (40), South Africa (38), and several countries across Europe [Netherlands (41), Sweden (42), United Kingdom (37), and Italy (36)]. Despite the geographical and cultural differences in participant cohorts across these studies, there are several important overlapping findings between these studies and ours. Collectively, these studies describe how participants with NP after SCI utilize trial and error to employ a wide range of coping strategies to manage

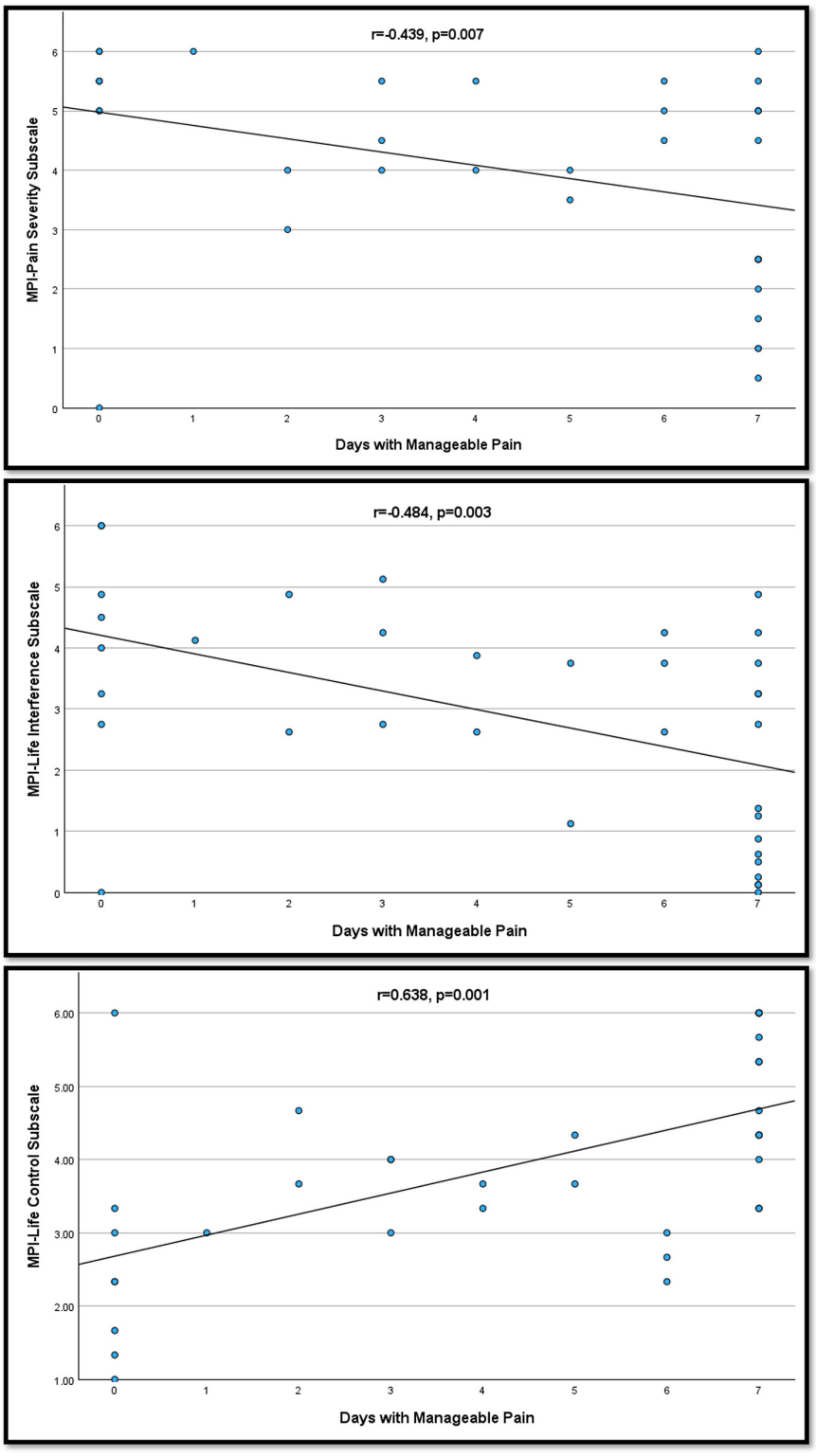

FIGURE 2
Correlation of Days with Manageable Pain with MPI Subscale Scores. MPI, multidimensional pain inventory; SCI, version.

their pain (13, 36, 38, 42). Additionally, distraction and learning to live with pain appear to be important coping strategies that cross racial, ethnic, and cultural boundaries in people with NP after SCI.

There are several limitations of this study worth discussing. All data collection was conducted in a top-ranked SCI research center embedded in a rehabilitation hospital, in an urban setting (Miami-Dade area). Thus, our sample may not be representative of all

people with SCI. Additionally, all participants were enrolled in a multimodal pain management study when these interviews were conducted. Participants had also taken part in a series of educational sessions which may have impacted their perceptions of manageable pain. Therefore, the access and resources afforded to the participants in this study may not reflect the reality for many people with SCI, and this may have influenced our results. It is also likely that other factors not assessed in this study, including access to care and prior knowledge about pain, influence the ability to achieve days with manageable pain. Despite these limitations, this study achieved its goal and provides the field with the first qualitative description of the meaning of manageable pain in people with chronic NP after SCI.

Because NP is rarely completely ameliorated, a better understanding of what manageable pain means on an individual level and the factors that contribute to manageable pain is critical to improved quality of life after SCI. The findings of this study provide important data on an individual level. Our data also suggest that evaluating days with manageable pain may be meaningful in a clinical setting. Future studies should incorporate standardized measures of pain acceptance, coping strategies, and pain catastrophizing to improve understanding of the relationships between individual level factors and group level factors that contribute to manageable pain.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by University of Miami Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MW: Data curation, Formal analysis, Investigation, Visualization, Writing – original draft, Writing – review & editing. KA: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing. KR: Data curation, Formal analysis, Investigation, Validation, Writing – original draft, Writing – review & editing. LR: Data curation, Formal analysis, Investigation, Project administration, Supervision, Visualization, Writing – original draft, Writing – review & editing. NC: Data curation, Formal analysis, Investigation, Project administration, Supervision, Validation, Writing – original draft, Writing – review & editing. RV: Formal analysis, Investigation, Project administration, Supervision, Validation, Writing – original draft, Writing – review & editing. GF: Investigation, Project administration, Validation, Writing – original draft, Writing – review & editing. EW-N: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Writing – original draft, Writing – review & editing.

Funding

The author(s) declare that financial support was received for the research and/or publication of this article. This study was funded by the U.S. Department of Defense (CDMRP #SC200152), and the funder did not play a role in the study design and collection, analysis, or interpretation of the results.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declare that no Generative AI was used in the creation of this manuscript.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpain.2025.1540395/full#supplementary-material

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frontiers | Frontiers in Pain Research

TYPE Original Research
PUBLISHED 24 July 2025
DOI 10.3389/fpain.2025.1614153

OPEN ACCESS

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RECEIVED 18 April 2025
ACCEPTED 30 June 2025
PUBLISHED 24 July 2025

CITATION
Bretonneau Q, Arc-Chagnaud C, Dugué B, Dupuy O, Delpech N, Enea C and Bosquet L (2025) Whole-body cryostimulation exposures effectively alleviates menstrual-related pain and associated sleep disturbances in young women: a randomized controlled trial. Front. Pain Res. 6:1614153. doi: 10.3389/fpain.2025.1614153

Whole-body cryostimulation exposures effectively alleviates menstrual-related pain and associated sleep disturbances in young women: a randomized controlled trial

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Introduction: Menstrual-related pain and sleep disturbances are widespread in women experiencing premenstrual syndrome and primary dysmenorrhea. Such disturbances could be alleviated through repeated whole-body cryostimulation (WBC) sessions. Therefore, this study aimed to assess the effect of menstrual-related pain on sleep parameters, and the impact of WBC exposures on pain and sleep.

Materials and methods: Pain and sleep were evaluated for two 5-day periods under different conditions (control vs. WBC), randomly assigned across two consecutive menstrual cycles. Measurements began when the first pain/symptom indicating the onset of the menstrual phase was experienced. Pain was rated using a scale, while sleep was assessed using accelerometers and questionnaires. Throughout the 5-day WBC exposure, women underwent 3-min exposure to intense ventilated cold air each evening. After data collection, participants were categorized into high (HP) or low/no pain (LP) groups based on control pain scores.

Results: Twenty-nine naturally menstruating women were assessed. Perceived sleep quality was lower in the HP group compared to the LP group during the control condition (Spiegel score: 20.1 ± 2.3 vs. 22.3 ± 1.9, respectively; Cohen's $d = 1.1$). Across both groups, perceived sleep quality improved with the number of WBC exposures (night1: 19.5 ± 3.2 vs. night5: 23.5 ± 3.8; Hedge's $g = 1.10$). In the HP group, pain was reduced in the WBC condition compared to the control condition. Changes in pain and perceived sleep quality following WBC were correlated ($r = -0.86$).

Discussion: Women experiencing higher menstrual-related pain reported poorer perceived sleep quality. Their pain was reduced by WBC exposures. This improvement was highly associated with the enhancement in sleep quality.

KEYWORDS

menstrual cycle, pain, sleep quality, whole-body cryostimulation, well-being

1 Introduction

Premenstrual syndrome (PMS) and primary dysmenorrhea (PD) are two common menstrual cycle-related complaints among women of reproductive age (1–6). Specifically, PMS is characterized by emotional, behavioural, and physical symptoms that predominantly occur during the late-luteal phase and subside with the onset of menstruation. PD is described as painful uterine cramps not associated with organic diseases, typically starting just before or concurrent with menstrual flow (4, 6, 7). In women suffering from these gynaecological disorders, pain seems to be one of the most commonly experienced symptoms, particularly in the lower back and/or abdominal regions (1, 5).

In addition to pain, women suffering from PMS and PD also experience sleep disruption (7). In the study by Baker et al. (8), women with dysmenorrhea exhibited significant differences compared to those without menstrual pain in terms of sleep architecture, nocturnal body temperature, and circulating hormones. However, the impacts of PMS and PD on sleep are still not fully understood. In women with PMS, several studies have highlighted an alteration in perceived sleep quality without observing any concomitant objective deterioration through polysomnography (9–12).

Furthermore, previous studies have reported elevated levels of inflammation in women with PMS and PD (13–15). Additionally, inflammation has been shown to be associated both with pain (15) and sleep disturbances (16, 17). Therefore, in women experiencing PMS and PD, the pain and sleep disturbances could potentially be influenced by inflammation.

The most prevalent approach to alleviate discomfort associated with the menstrual cycle is medication, often used without prior consultation with healthcare professionals (1, 18). Additionally, strategies such as the use of contraceptive pills or dietary supplements, as well as the application of heat to the painful area, are also commonly employed (4, 6, 18, 19). Two recent studies have indicated that applying cold to the painful area may also be a promising approach for reducing this type of pain (20, 21).

Body cryostimulation is a technique involving exposure of the entire or nearly entire subject's body to very cold air (−60 °C to −180 °C) for a brief period (3–5 min) (22). It is recognized for its manifold positive effects on parasympathetic activity (23), tissue oxygenation (24), feelings of well-being, and sport performances (25). Additionally, body cryostimulation is renowned for its beneficial effects on inflammatory processes and pain (26). Recent studies have also demonstrated its beneficial effects on sleep (27–29), as well as on the cardiovascular, immune and nervous system (22, 30).

Therefore, body cryostimulation could be particularly beneficial for women experiencing menstrual pain and sleep disturbances before and during their periods. Hence, this study aimed to assess (1) the effect of menstrual-related pain on objective and self-reported sleep parameters, (2) the impact of repeated whole-body cryostimulation (WBC) exposures on pain and sleep, and the association between WBC-induced changes in pain and sleep. We hypothesized that women experiencing menstrual pain before and/or during their periods would exhibit lower sleep quantity and quality compared to those experiencing minimal or no pain. Additionally, it was postulated that WBC would lead to pain reduction and improved sleep, especially in women experiencing pain, and that changes in pain and sleep induced by WBC would be closely related.

2 Materials and methods

2.1 Experimental design

This study employed a counterbalanced crossover randomized controlled design. Each participant underwent two 5-day assessment periods under two different conditions (control vs. WBC), with the order of conditions randomly assigned across two consecutive menstrual cycles (Figure 1).

2.2 Study population

2.2.1 Sample size

Assuming an effect size of 0.5, considered reasonable based on the findings of Silva et al. (21), an *a priori* power analysis indicated that a sample size of 27 participants would be required to detect a beneficial effect of WBC on menstrual-related pain ($\alpha = 0.05$; power = 0.80). To account for potential dropouts, the recruitment target was set at 30 participants (+10%).

2.2.2 Recruitment

Participants were recruited through volunteer sampling following a public advertisement of the study, which outlined the main inclusion and non-inclusion criteria. Individuals who expressed interest were invited to attend an initial visit at the MOVE laboratory of the University of Poitiers, during which all inclusion and non-inclusion criteria were assessed by the experimenters.

2.2.3 Inclusion and non-inclusion criteria

The inclusion criteria for this study were naturally menstruating women aged 18–35 years with regular menstrual cycles, defined as cycles lasting between 21 and 35 days over the past three months (31). Participants were required to have no legal guardianship or curatorship and no subordination. They had to be beneficiaries of a Social Security system, either personally or through a third party. Informed consent was obtained from each participant after a thorough and transparent explanation of the study.

The non-inclusion criteria included irregular menstrual cycles, any diagnosed gynaecological disorders (e.g., endometriosis, polycystic ovary syndrome), current use of analgesic or anti-inflammatory medications, pregnancy or breastfeeding, and specific contraindications for cryostimulation (30). Contraindications included hypertension, arteritis, recent myocardial infarction (within the past six months), stroke, and pulmonary embolism. Participants with respiratory conditions such as asthma or chronic bronchitis, circulatory insufficiency (e.g., Raynaud's syndrome), angina pectoris,

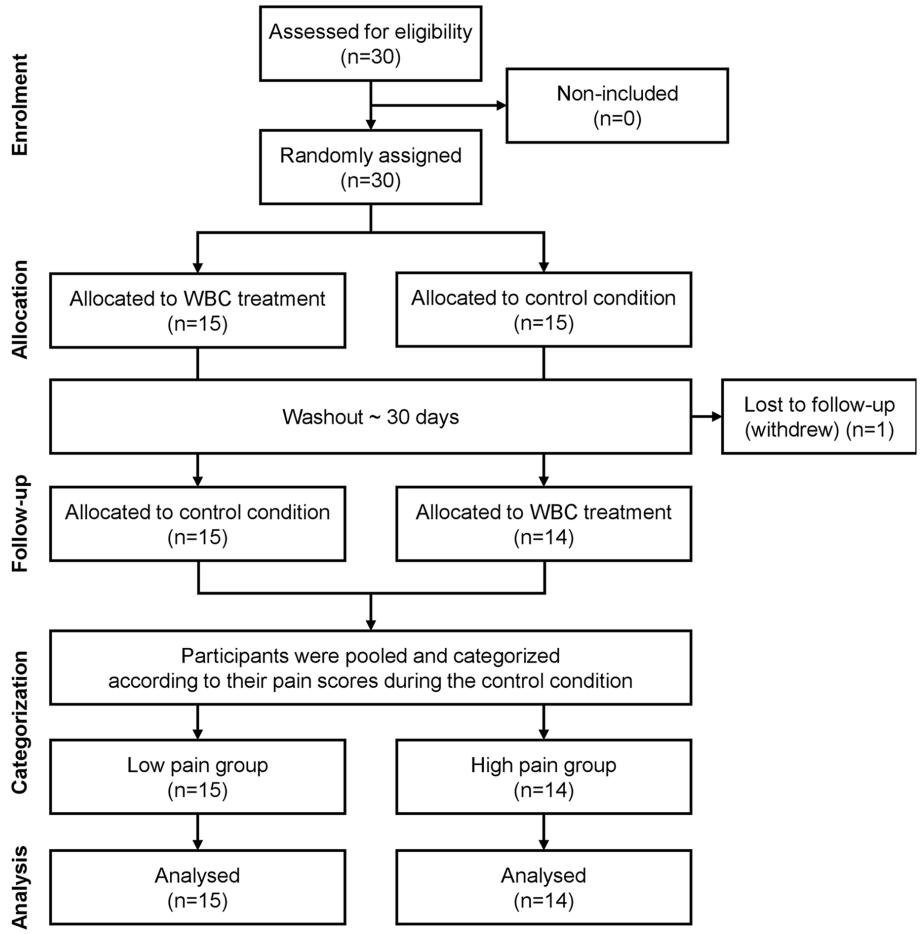

FIGURE 1
CONSORT flow diagram of the study (randomized controlled trial of non-pharmacological treatment).

or those with pacemakers or subcutaneous medical devices were also non-included in the study.

2.2.4 Randomization

Randomization was conducted by the experimenters using an online tool that generated a sequence of fifteen "1" and fifteen "2", assigned randomly (e.g., 2, 1, 1, 2, 1, 2…). Based on the order of inclusion, each participant was assigned the corresponding value in the sequence (i.e., the *n*th participant received the *n*th value), which determined the condition order for their participation: a value of "1" indicated that the participant would complete the control condition first, followed by the experimental condition. In contrast, a value of "2" indicated the reverse order.

2.2.5 Pain categorization

To determine whether the effect of WBC on menstrual-related pain was influenced by the initial level of pain intensity, participants were classified *post hoc* into two groups according to their level of pain reported during the control condition: a low/no pain (LP) group and a high pain (HP) group (Figure 1).

2.3 Measurements

Menstrual pain, menstrual flow and sleep were assessed upon the first report of pain or symptoms signalling the onset of the menstrual phase (Figure 2).

2.3.1 Menstrual pain and flow

The overall intensity of pain experienced over the day (i.e., the primary outcome) was assessed using a 0–5 verbal rating scale (VRS), where 0 signified "No pain" and 5 indicated "Unbearable pain" (32). This variable was used both as a dependent variable (for monitoring daily pain) and as an independent variable for categorizing participants (LP group: mean VRS score <2.5; HP group: mean VRS score >2.5.).

Additionally, menstrual blood flow was assessed daily using the Pictorial Blood Loss Assessment Chart developed by Higham et al. (33). This questionnaire queries the amount of blood on sanitary pads and/or tampons, the number of hygienic protections used throughout the day, and the presence of clots along with their size.

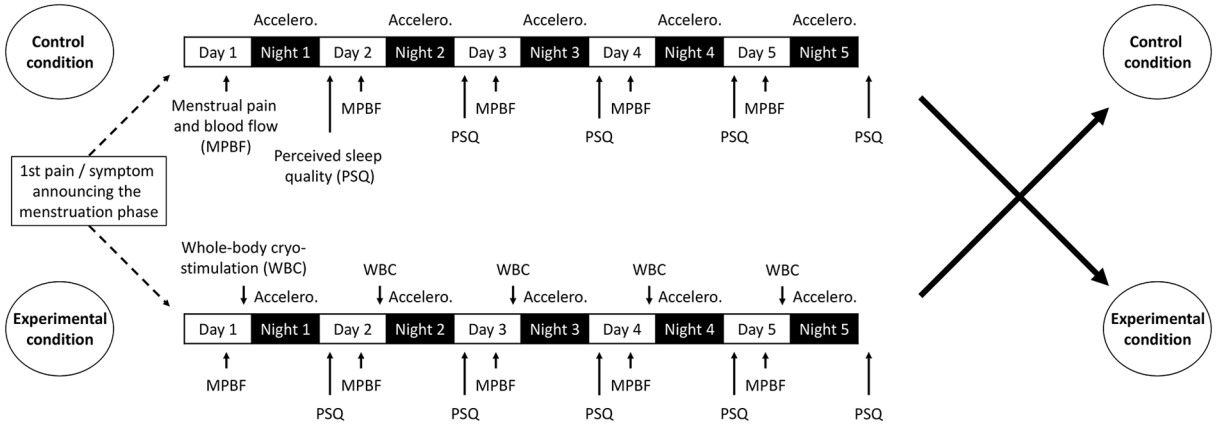

FIGURE 2
Experimental design. With Accelero., accelerometer.

2.3.2 Sleep quantity and quality

2.3.2.1 Self-reported sleep parameters

Perceived sleep quality was assessed every morning using the 6-item Spiegel questionnaire [0–30 score range; Spiegel (34)]. A score below 18 indicated sleep disturbances, and a score below 15 suggested severe alertness. A few minutes after getting up, the participants had to complete the questionnaire, which was integrated into their sleep diary. They also had to specify the bedtime (i.e., when they went to bed, not necessarily to sleep), the lights-out time (i.e., when they turned off lights or their smartphone intending to sleep) and the wake-up time

2.3.2.2 Objective sleep parameters

Every night during the analysis periods, participants were required to wear an accelerometer on the non-dominant wrist to quantify their movements (ActiGraph wGT3X-BT, ActiGraph LLC, Pensacola, USA). Counts were recorded on the three-dimensional axis. Parameters including sleep efficiency, latency, number and duration of awakenings, total sleep time and sleep fragmentation index were also assessed (35).

2.4 Whole-body cryostimulation

In the WBC condition, the first cold exposure took place on the same evening as the initial report of pain or symptoms indicating the onset of the menstrual phase. Subsequently, participants underwent cold exposure every evening for the following four consecutive days (Figure 2). Each WBC session consisted of a 30-s exposure in a first ventilated cold chamber at −25 °C (perceived temperature: −50 °C) and a 3-min exposure in a second ventilated cold chamber at −70 °C (perceived temperature: −110 °C) (Aurore Concept, Noisiel, France). Participants entered the cryo-chamber wearing gloves, slippers, underwear, a cap and a surgical mask. Throughout the exposure period, participants were closely supervised by the researcher team. They were asked about the occurrence of any adverse effects (e.g., headache, dizziness, burning sensations, numbness, erythema, skin irritation, frostbite, or persistent and/or recurrent shivering during the evening following the exposure) immediately after each session and again the following day, prior to the next exposure. Additionally, they were instructed to avoid physical activity after the WBC session to avoid disrupting the effect of cold exposure.

2.5 Ethical considerations

The protocol adhered to the Helsinki Declaration and received approval from an ethics committee (IRB00012476-2023-31-01-223). All volunteers provided written consent before beginning the protocol.

2.6 Statistics

Standard statistical methods were used to calculate means and standard deviations. Gaussian distribution was verified using the Shapiro–Wilk test. A Student's *t*-test was performed to test the null hypothesis that sleep parameters and menstrual blood flow were not different between groups (low pain group vs. high pain group) in control condition. A two-way factorial analysis of variance (group × condition) with repeated measures on the condition factor (control vs. WBC) was performed to test the null hypothesis that measures were not different between groups and conditions. A three-way factorial analysis of variance (group × condition × time) with repeated measures on both condition and time factors (Day 1 to Day 5, or Night 1 to Night 5) was performed to test the null hypothesis that measures were not different between groups, conditions and times. Compound symmetry, or sphericity, was assessed using the Mauchly's test. When sphericity assumption was violated, F-ratios were adjusted using the Greenhouse–Geisser procedure if the epsilon correction factor was <0.75, or the Huynh–Feldt procedure if the epsilon correction factor was >0.75, to control for type I errors. Multiple comparisons were performed using the Tukey *post hoc* test. Effect sizes were evaluated using Hedges' g (g) and Cohen's d (d), categorized as small ($0.2 < d$ or $g < 0.5$), moderate ($0.5 < d$ or $g < 0.8$), or large (d or $g > 0.8$). Pearson's product-moment correlation was used to test the null hypothesis of an absence of association between variables or their variations. The Cook's distance

was used once to identify and remove an outlier. Correlations over 0.90 were considered very high, between 0.70 and 0.89 were considered high, and between 0.50 and 0.69 were considered moderate (36). For data retention, participants who attended fewer than 80% of the WBC sessions were non-included in the data analysis. The significance level for all analyses was set at $p < .05$. All the calculations were conducted using Statistica (StatSoft, Tulsa, USA) and Excel (Microsoft, Redmond, USA).

3 Results

3.1 Participants

Thirty women with regular menstrual cycles were enrolled in the study. One participant withdrew, resulting in a final sample of twenty-nine women who completed the entire protocol (age: 22 ± 4 years; height: 1.60 ± 0.10 m; body mass: 60.3 ± 9.9 kg; body mass index: 26.7 ± 7.2 kg·m^{-2}; body fat percentage: 22.5 ± 3.6%). The first participant was recruited in January 2023, and the last participant was recruited in March 2023. Data were collected from January 2023 to April 2023. Fourteen participants completed the protocol starting with the control condition, followed by the experimental condition, while fifteen participants completed the protocol in the reverse order. Among the participants, 48.3% were not using any form of contraception, 37.9% used oral contraceptives, 10.3% used a copper intrauterine device, and 3.5% used a contraceptive ring.

At the end of the study, the sample was divided into two groups based on the pain level measured during the control condition, resulting in a low pain (LP) group comprising 15 participants and a high pain (HP) group comprising 14 participants. The characteristics of the HP and LP groups are presented in Table 1. Anthropometric parameters did not differ significantly between the groups.

TABLE 1 Characteristics of low pain and high pain groups.

Characteristics	Low pain group *n* = 15	High pain group *n* = 14
Anthropometry		
Age (years old)	22.9 ± 3.5	23.5 ± 3.8
Body height (m)	1.66 ± 0.05	1.62 ± 0.06
Body mass (kg)	62.2 ± 10.0	58.2 ± 9.8
Body mass index (kg m^{-2})	26.7 ± 7.7	26.6 ± 6.8
Body fat (%)	22.6 ± 3.6	22.4 ± 3.7
Contraception		
No contraception (%)	47	50
Hormonal contraception		
Oral contraceptive (%)	53	21
Contraceptive ring (%)	—	7
Non-hormonal contraception		
Copper intrauterine device (%)	—	21

Anthropometric characteristics did not differ significantly between groups, $p > 0.05$.

3.2 Context

During the control and WBC conditions, menstruation appeared 2.5 ± 1.1 and 2.4 ± 1.2 days after the first pain/symptom announcing the onset of the menstrual phase, respectively ($p > 0.05$). In both conditions, approximately 25% of participants experienced menstruation on the first day of pain/symptom, 40% two days after, 80% three days after and 100% four and five days after. In 75% of cases, the time elapsed between the onset of pain/symptoms and the onset of menstruation was identical in both conditions. This percentage increased to 93% when a difference of ±1 day was tolerated. Cold exposures were conducted at 19:41 ± 1:17 with no significant difference between the 5 exposures. Additionally, cold exposures were conducted at 19:50 ± 1:25 for participants assigned to the WBC condition before the control condition, and at 19:32 ± 1:09 for those assigned to the WBC condition after the control condition ($p > 0.05$).

3.3 Pain

As shown in Figure 3, pain experienced during both the control and WBC conditions was higher in the HP group compared to the LP group ($p < 0.05$; Cohen's $d = 2.3$). Furthermore, in the HP group, pain was lower in the WBC condition than in the control condition ($p < 0.05$; Hedges' $g = 0.8$).

3.4 Menstrual flow

During the control condition, the Higham score was higher in the HP group than in the LP group (30 ± 25 vs. 10 ± 7, $p < 0.05$; Cohen's $d = 1.1$). Across both groups, this score tended to decrease with WBC exposures (from 20 ± 29 in the control condition to 15 ± 27 in the WBC condition, $p = 0.07$).

3.5 Sleep

No significant differences were observed between groups, conditions and times for sleep parameters assessed by accelerometry. In contrast, the Spiegel score was significantly lower in the HP group than in the LP group in control condition (20.1 ± 2.3 vs. 22.3 ± 1.9 respectively; Cohen's $d = 1.1$). Across both groups, the Spiegel score was higher during the last two nights of the WBC condition than during the first night ($p < 0.05$; Hedge's $g = 1.10$; Figure 4).

3.6 Pain and sleep relationship

In the HP group, changes in pain and perceived sleep quality from the control condition to the WBC condition were associated (Figure 5).

4 Discussion

The primary purpose of this study was to assess the effect of menstrual-related pain on sleep. In this context, objective and self-reported sleep parameters were assessed in two groups of women experiencing high and low/no pain. The results indicated that women with higher levels of pain reported poorer perceived

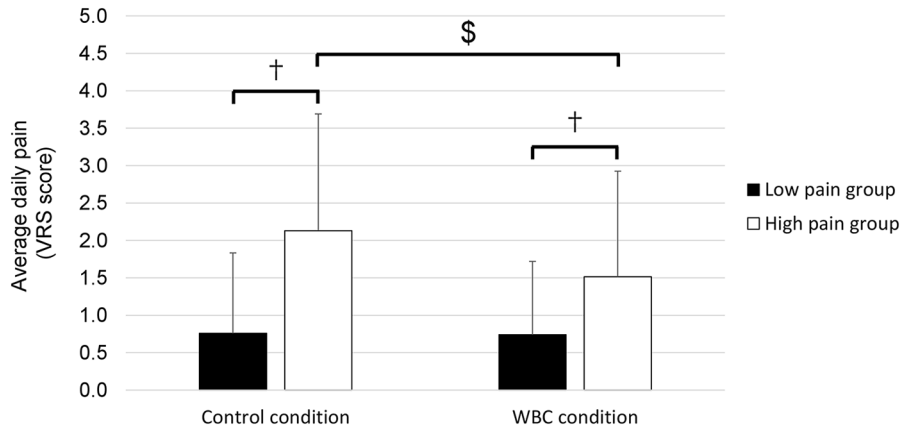

FIGURE 3
Average daily pain in low pain and high pain groups in control and whole-body cryostimulation (WBC) conditions. †, difference between groups ($p < 0.01$). $, difference between conditions ($p < 0.01$).

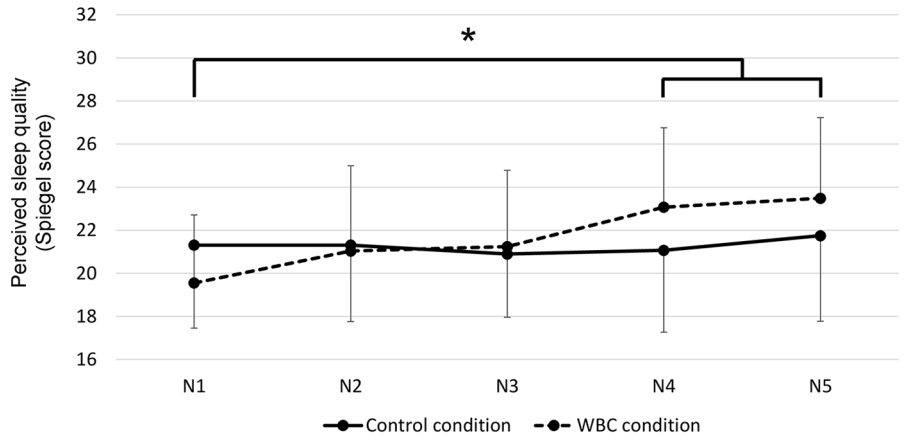

FIGURE 4
Night-to-night perceived sleep quality in control and whole-body cryostimulation (WBC) conditions. *$p < 0.001$ vs. the first night for the WBC condition.

sleep quality. The second purpose of this study was to assess the effect of repeated WBC exposures on pain and sleep. As the WBC exposures progressed, there was a corresponding improvement in perceived sleep quality. Furthermore, we observed that menstrual-related pain was reduced during the WBC exposures among women who typically experience high levels of pain. For this group, we also observed an association between the reduction in pain and the improvement in perceived sleep quality induced by WBC.

4.1 Menstrual-related pain and sleep

As shown by Baker et al. (8), sleep may be particularly disturbed in women experiencing severe PMS- or PD-related pain. These authors found that women with painful menstruation exhibited poorer perceived sleep quality, lower sleep efficiency, and shorter rapid-eye movement (REM) sleep compared to women without PD. Additionally, during the menstrual phase, where the pain was at its highest level, women with PD reported poorer perceived sleep quality and lower sleep efficiency compared to their own no-painful luteal and follicular phases, thereby underlying the potential role of menstrual-related pain in sleep disturbances. In this population, Çaltekin et al. (11) recently reported a correlation between pain and sleep disorders. In the current study, we observed that women who typically experience pain also exhibit poorer sleep quality than their counterparts who experience low/no pain, aligning with previous findings. However, this effect of pain on sleep was observed in subjective parameters, but not in those objectively assessed using accelerometery. This discrepancy has already been reported in previous studies (7, 9–12, 37), and can be explained by the fact that subjective and objective measures may assess different aspects of sleep (38).

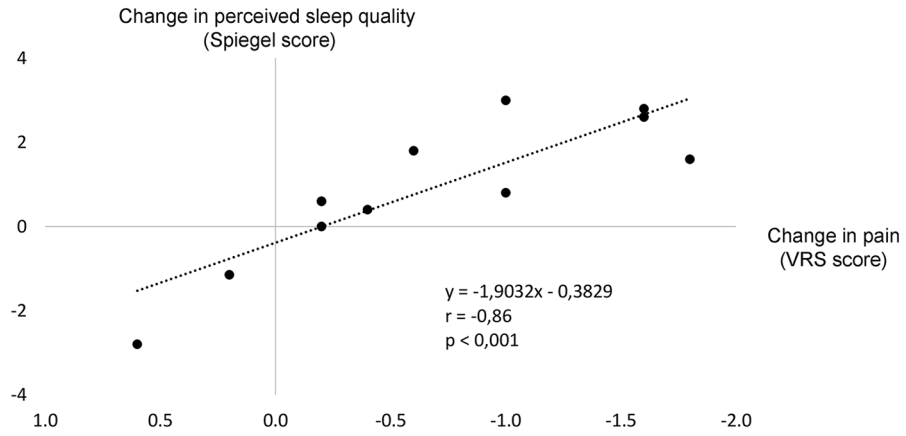

FIGURE 5
Level of association between the changes (Δ) in pain and perceived sleep quality from the control condition to the whole-body cryostimulation (WBC) condition (Δ, value in the WBC condition—value in the control condition).

The relationship between menstrual-related pain and sleep may be mediated by inflammation, which can be particularly elevated in women with PMS and PD (13, 18). In their study, Gold et al. (15) demonstrated the inflammation-pain relationship by showing that an elevated C-reactive protein (CRP) blood concentration (>3 mg/L) was significantly associated with a 40% increased odds of reporting menstrual-related abdominal cramps/back pain. On their side, Ditmer et al. (39) emphasized the inflammation-sleep relationship by demonstrating that inflammation—especially high levels of interleukin-1 beta and tumor necrosis factor alpha—may disrupt sleep architecture by promoting non-REM sleep at the expense of REM sleep. These findings are consistent with those presented in the meta-analysis by Irwin et al. (16), which demonstrated a strong association between levels of inflammation (CRP and interleukin-6) and sleep disturbances.

4.2 Effect of whole-body cryostimulation exposures on menstrual-related pain, sleep and their relationship

The secondary purpose of this study was to assess the effect of WBC exposures on menstrual-related pain, sleep and their relationship. According to our results, this innovative non-pharmacological approach, involving exposure of the body to stimulating cold thermal stress, effectively reduces pain in healthy young women who typically experience it before or during menstruation. This finding aligns with those observed in recent studies by de Araújo et al. (20) and Silva et al. (21), where menstrual-related pain was alleviated by applying an ice-pack during three consecutive days on the painful area (back or abdominal region). In addition, we observed a nearly significant decrease in the Higham score during the WBC period compared to the control period, suggesting a beneficial effect of intense cold exposure on menstrual flow and its management. This benefit could be explained by a reduction in uterine contractions responsible for a significant flow at the beginning of menstruation. This hypothesis is supported by the decrease in prostaglandin E2 concentration reported by Banfi et al. (40) in response to cryostimulation.

Furthermore, our study demonstrated that a daily WBC exposure near bedtime for five days effectively enhances perceived sleep quality before or during menstrual periods, irrespective of pain severity during this time. In previous studies conducted in active subjects or in athletes, subjective sleep parameters improved after one exposure (27, 28), or after daily exposure during several days (41). Thus, our results are consistent with the scientific literature. However, Douzi et al. (27, 28) also showed a benefit of body cryostimulation on objective sleep parameters assessed by accelerometry, a result we did not observed in the current study. It must be noted that only males were investigated in these previously cited works, and male and female participants may react differently to WBC.

Additionally, we observed a strong correlation between the reduction in pain and the improvement in sleep quality induced by WBC. In a previous study by Iacovides et al. (42), improvements in subjective and objective sleep parameters were observed after a reduction in pain induced by the administration of non-steroidal anti-inflammatory drugs in women with PD, but the authors did not described the relationship between these changes.

4.3 Mechanisms underlying the benefits of cryostimulation on pain, sleep and their relationship

The reduction in menstrual-related pain observed during WBC exposures may be attributed to a deceleration of pain signals to the brain. Indeed, a reduction in the conduction velocity of tibial nerve fibers was observed by Algafly and George (43) following cold application to the ankle. These authors also noted an associated increase in pain threshold and pain tolerance, which may provide an additional explanation for the benefits of WBC observed in our study. Additionally, cryostimulation may reduce pain

perception through the production of analgesic beta-endorphin and noradrenaline (44, 45).

Moreover, the benefits of WBC on sleep could imply thermoregulatory processes. Indeed, following cryostimulation exposure, core body temperature decreases (46, 47). In this context, the natural night-time decline in core body temperature could be accelerated and/or intensified after WBC, especially when the exposure is scheduled in the evening as in the current study. This could then improve sleep onset and quality (48, 49). However, additional studies are needed to clarify the links between WBC-induced changes in core body temperature and sleep quality.

Lastly, the primary mechanism that can explain the association between pain reduction and improved sleep quality induced by WBC likely involves the inflammatory processes. Indeed, as previously described, pain and sleep could be mediated by inflammation and repeated body cryostimulation exposures have been shown to effectively reduce the activity of pro-inflammatory cytokines and to increase the activity of anti-inflammatory cytokines (50). Therefore, analyzing blood inflammatory markers would be an interesting perspective to validate the hypothesis that WBC-induced improvements in pain and sleep are mediated by changes in inflammatory level.

4.4 Methodological aspects of the study

Between the control and experimental conditions, we observed an interesting intra-individual consistency regarding the delay between the onset of menstrual-related symptoms and the onset of menstruation. This result suggests that the difference we observed in perceived sleep quality along with the WBC exposures was probably not related to earlier or later menses from the onset of symptoms. This hypothesis is reinforced by the fact that Baker and Driver (51) did not find significant difference in perceived sleep quality between the premenstrual and menstrual phases in healthy young women.

Furthermore, precautions were taken to ensure consistent daily exposure to cryostimulation and between randomized trials (women exposed to cryostimulation before vs. after the control condition). Moreover, we did not observe significant difference regarding the timing of cryostimulation exposure. Thus, the difference we observed in perceived sleep quality along with the WBC exposures was probably not related to a variation in the timing of WBC session throughout the treatment period.

4.5 Limits of the study and possible improvements

One of the main limitations of this study is that it examined the effects of WBC on menstrual-related pain and sleep only during the WBC treatment period, and not in the post-treatment phase. As a result, it is difficult to determine, based on the current data, whether these benefits are maintained over time. Future studies should consider evaluating the residual effects of WBC on these parameters.

4.6 Conclusion and perspectives

Whole-body cryostimulation appears particularly effective in reducing menstrual-related pain and improving sleep quality. For women experiencing these issues, this innovative and non-pharmacological approach could significantly enhance well-being and quality of life before, during, and after menses. Consequently, such an approach could present socio-educational and socio-economic benefits by reducing, for instance, absenteeism in schools and workplaces, a genuine consequence of menstrual pain (52). Among athletes, where 50% of women suffer from PMS (2), cryostimulation exposures could also reduce training absenteeism, which is critical for achieving high-level performance.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors upon request, within a clearly defined framework provided by the requester, as long as they are not used for personal, professional, or commercial purposes.

Ethics statement

The studies involving humans were approved by IRB00012476-2023-31-01-223 Comité d'éthique pour la Recherche en Sciences et Techniques des Activités Physiques et Sportives (Ethics Committee for Research in Sport and Physical Activity Sciences). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

QB: Software, Data curation, Methodology, Writing – review & editing, Validation, Conceptualization, Investigation, Visualization, Writing – original draft, Formal analysis. CA-C: Data curation, Writing – original draft, Methodology, Formal analysis, Visualization, Validation, Investigation, Writing – review & editing, Conceptualization. BD: Methodology, Writing – review & editing, Validation, Supervision, Writing – original draft. OD: Writing – original draft, Methodology, Validation, Supervision, Writing – review & editing. ND: Validation, Methodology, Supervision, Writing – original draft, Writing – review & editing. CE: Methodology, Writing – original draft, Validation, Writing – review & editing, Supervision. LB: Methodology, Validation, Project administration, Supervision, Conceptualization, Writing – review & editing, Writing – original draft.

Funding

The author(s) declare that no financial support was received for the research and/or publication of this article.

Acknowledgments

The authors wish to express their sincere gratitude to all study participants for their dedication and exemplary compliance.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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frontiers | Frontiers in Pain Research

TYPE Perspective
PUBLISHED 14 August 2025
DOI 10.3389/fpain.2025.1641571

OPEN ACCESS

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RECEIVED 05 June 2025
ACCEPTED 23 July 2025
PUBLISHED 14 August 2025

CITATION
Johnson MI (2025) An integral vision of pain and its persistence: a whole-person, whole-system, salutogenic perspective.
Front. Pain Res. 6:1641571.
doi: 10.3389/fpain.2025.1641571

An integral vision of pain and its persistence: a whole-person, whole-system, salutogenic perspective

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Persistent pain remains a significant global health challenge, with prevailing biomedical and biopsychosocial models often falling short in capturing its full complexity. These models frequently lack conceptual and contextual coherence, overlooking the deeply subjective, cultural, and systemic dimensions of pain. As a result, care can become fragmented and suboptimal. This perspective article introduces an integral vision of pain, grounded in the All Quadrants, All Levels (AQAL) framework, which offers a multidimensional approach that integrates subjective experience, objective mechanisms, cultural meaning, spiritual perspectives, and systemic structures. The article outlines how a simplified AQAL framework can serve as a heuristic tool to synthesise individual and collective dynamics—including psychological development and socio-environmental conditions—thereby informing a more comprehensive understanding of pain and its persistence. This includes recognising the role of painogenic environments and the impact of evolutionary mismatch in shaping pain experiences. This integral perspective reframes persistent pain within a salutogenic social model of health, adopting a whole-person, whole-system approach that supports the co-creation of compassionate, community-driven, and context-sensitive care. Ultimately, it reconceptualises persistent pain not merely as a disease state or clinical symptom, but as a dynamic, relational, and meaning-laden experience embedded within the evolving journey of life. This integral vision challenges reductionist paradigms, advancing a more coherent, salutogenic, and humanistic model for understanding and addressing persistent pain.

KEYWORDS

pain, integral theory, All Quadrants All Levels (AQAL) framework, salutogenic, community, painogenic environment, evolutionary-mismatch, integrative

Introduction

Persistent (chronic) pain is a significant burden to individual well-being, societal health, and the sustainability of healthcare systems (1–3). Despite advances in and widespread availability of biomedical and psychological interventions, persistent pain continues to affect nearly one-third of the global population—a treatment-prevalence paradox (4–6). Pain is a complex and deeply human phenomenon that encompasses hidden subjective inner states, observable physiological and behavioural correlates, and interconnectedness to shared cultural and socio-ecological systems. Pain science is the systematic study of the biological, psychological, and social mechanisms underlying pain experience associated with actual or potential damaged and/or dysfunctional tissue (7).

Historically, the focus of pain science on damaged and/or dysfunctional tissue led to biomedical dominance and reduced emphasis on subjective, cultural, and existential dimensions (8–10). The biopsychosocial model of pain redresses the imbalance created by the dominance of the biomedical model.

The term biopsychosocial denotes an interdisciplinary approach to health, illness, and care delivery, grounded in the interplay between biological processes (e.g., genetics, physiology), psychological dimensions (e.g., emotions, cognition, behaviour), and social contexts (e.g., culture, relationships, socioeconomic status). While representing a significant advancement over reductionist biomedical paradigms—which reduce complex human experiences to their simplest biological components—the biopsychosocial model has faced critique for its limited sensitivity to the subjective experience of pain and for the conceptual fragmentation of its biological, psychological, and social domains (11–20). These domains often become disjointed in both theoretical discourse and clinical practice, resulting in fragmented care and a lack of explanatory coherence that is disconnected from the lived reality of *being* human.

This conceptual disjunction is further compounded by the cultural and epistemological underpinnings of the model itself, which originated within a Western, Educated, Industrialized, Rich, and Democratic (WEIRD) cultural worldview (21). The WEIRD worldview tends to privilege individualism, analytical reasoning, mechanistic interpretations, and impersonal prosociality, which emphasizes cooperation among strangers based on abstract norms, institutions, and rule-based fairness rather than close interpersonal ties (22–26). Such orientations may have driven the reductionist biomedical paradigm and marginalization of relational, spiritual, and existential dimensions of pain that are often foregrounded in non-WEIRD cultural contexts (27, 28). In many indigenous and collectivist traditions, pain is not merely a pathological disruption but a meaningful aspect of life's natural rhythm—interwoven with communal, emotional, and spiritual realities (29–32).

The continued influence of biomedical paradigms has contributed to the recognition of persistent (chronic) primary pain as a distinct (pathological) disease entity in the latest revision of the World Health Organization's (WHO) International Classification of Diseases (ICD-11) (33–35). While this framing offers many advantages, it also legitimizes biomedical interventions that have, at least in part, contributed to systemic harms—such as the global opioid crisis (1, 36). Moreover, the empirical foundation of many clinical interventions remains tenuous, with numerous treatments demonstrating limited efficacy in practice—often attributed to a broader crisis in research quality (37–39). Conceptual ambiguities within pain science, including the conflation of nociception with pain and the reliance on speculative constructs further undermine theoretical clarity (40–42).

A growing body of scholarship contends that pain is too idiosyncratic, context-dependent, and meaning-laden to be adequately captured by mechanistic or reductionist models (43–47). Meta-ethnographic perspectives have likened pain to an ecosystem—dynamic, adaptive, and shaped by intersecting biological, psychological, social, and environmental forces (48, 49). The sobriquet of "sticky pain"—a term coined by Borsook et al. (50) to describe persistent, treatment-resistant pain—reflects the failure of certain pain episodes to resolve. As a colloquial term "stickiness" can be used to draw attention to the ecology of pain and factors in contemporary life that may hinder pain resolution (i.e., socio-ecological risk factors).

While the biopsychosocial model nominally incorporates multiple domains, it does not explicitly engage with existential or phenomenological frameworks—those that foreground temporality, meaning, and the lived experience of suffering (11–17). There is increasing recognition that such perspectives are essential for understanding pain not merely as a clinical symptom but as a socially grounded, deeply human condition (45, 46, 51). However, the prevailing structure of professional knowledge production continues to favour specialization over integration, thereby impeding the development of comprehensive models that reflect the full scope of pain as a lived and relational experience.

In response to these limitations, this article proposes a contextual "integral" view of pain and its persistence that includes all dimensions in a unified way. An integral approach weaves together inter- and transdisciplinary knowledge, lived experience, and reflective inquiry to synthesise subjective experiences of pain with its objective mechanisms, all within the broader cultural, systemic, and environmental contexts of contemporary life. It seeks to avoid reductionism, embrace complexity, and honour both the inner life of the person in pain and the scientific understanding of pain processes. An integral approach emphasises the interconnectedness of the individual within their social and environmental context—supporting a whole-person, whole-system, whole-health perspective (52–56).

The aim of this article is to present an integral vision of pain that seeks to unify diverse disciplinary insights, fostering a whole-person, whole-system, and salutogenic perspective on understanding and addressing the persistence—or stickiness—of pain. Building on previous work, this article extends the author's earlier mapping of pain onto a simplified version of Ken Wilber's All Quadrants All Levels (AQAL) framework (57). Rooted in a contemporary, non-religious understanding of spirituality—as meaning, purpose, and connection to self, others, and nature—the integral, AQAL framework enhances the traditional biopsychosocial approach by incorporating subjective experience, objective mechanisms, cultural meaning, and systemic influences. In doing so, it offers a more holistic, context-sensitive, and experientially anchored understanding of pain and its persistence, framed through an evolutionary mismatch, salutogenic, and socially embedded model of health.

This integral perspective is shaped by the author's own positionality as a white, male academic based at a post-1992 UK university, with over four decades of experience in pain research. Drawing on critical realism, positivist science, and reflexive inquiry, this work blends methodological rigour with integral thinking that combines multiple perspectives—including individual and collective, interior and exterior, science and spirituality. It is informed by Integral Theory, biopsychosocial and salutogenic paradigms, and evolutionary psychology. The author remains critically aware of how his social and disciplinary

positioning informs his interpretations of the persistence of pain and its cultural significance, acknowledging the influence of both personal and epistemological standpoints in shaping this multidimensional approach.

Theoretical foundations and integral framework

The understanding of pain has evolved from spiritual and humoral interpretations to Descartes' mechanistic model and the dominance of biomedicine, before being reframed by Melzack and Wall's 1965 Gate Control Theory, which introduced the nervous system's modulatory role (58). This set the stage for Engel's introduction of the biopsychosocial model in 1977 arguing that complex health conditions require considering not only biological factors but also psychological and social influences (59). Following the adoption of the biopsychosocial model (60), its translation into clinical practice has remained partial, with the social dimension frequently marginalised or insufficiently addressed. Advances in neuroscience reframed pain as a complex brain-generated output shaped by context, emotion, and cognition, prompting the emergence of psychologically informed physiotherapy and interdisciplinary pain management. More recently, scholars have advocated for post-biopsychosocial approaches—such as enactive and 5E frameworks—that emphasise the embodied, embedded, enacted, emotive, and extended nature of pain (11, 13). These developments reflect a growing recognition of pain as a dynamic, lived experience shaped by both internal processes and external environments, reinforcing the need for holistic, patient-centred care.

Ken Wilber, a populist American psychologist/philosopher, developed the concept of the *integral mind* as a means of unifying the physical, emotional, mental, and spiritual dimensions of human experience (61, 62). His work is characterized by an effort to bridge longstanding divides between Eastern and Western philosophies, science and spirituality, and individual and collective perspectives. At its core, integral thinking seeks to cultivate a holistic understanding of reality in which diverse perspectives are not merely acknowledged but actively harmonized (61, 63). In practice, the integral mind reflects an individual's capacity to synthesize multiple dimensions of experience into a coherent worldview. This integral orientation aligns particularly well with existential models of pain, which offer a deeply humanistic perspective—one that recognizes both inner subjective experience and objective bodily processes as inseparable from the shared cultural, environmental, and spiritual dimensions of contemporary life.

Wilber developed the AQAL framework to create a comprehensive model for understanding complex human experiences (61, 64). All Quadrants (AQ) refers to four different perspectives on experience:

- individual-interior [upper-left (UL)]: intrasubjective, personal, inner experience
- individual-exterior [upper-right (UR)]: intraobjective, biology, behavior
- collective-interior [lower-left (LL)]: intersubjective, societal culture and meanings
- collective-exterior [lower-right (LR)]: interobjective, societal systems and structures.

All Levels (AL) refers to stages of development (complexity) that shape how individuals and collectives interpret and respond to an experience over time—represented by levels (stages) of psychological development in the left side "interior" quadrants.

The AQAL framework is underpinned by several core principles that render it particularly suitable for advancing an integral perspective of pain:

- Non-Exclusion: All perspectives—psychological, biological, social, environmental, and spiritual—are considered valid and necessary for a comprehensive understanding.
- Enfoldment: Recognizes that experiences and interpretations evolve across nested levels of personal and cultural development.
- Enactment: Emphasizes that reality is co-constructed through interaction; pain is not merely a passive experience but is shaped by relationships, environments, and meaning-making processes.

These principles resonate strongly with phenomenological and socio-ecological understandings, which emphasize the meaning-laden nature of embodied, embedded and enacted pain experience of people interconnected with the shared culture of others and environmental settings [e.g., (11, 65)]. The AQAL framework's emphasis on the "inner-world" (interiority) and developmental levels of psychological complexity supports the integration of such insights into both clinical and theoretical models (61, 64).

While the biopsychosocial model acknowledges multiple domains, it lacks the structural coherence and contextual depth. In contrast, AQAL integrates:

- Subjective experience and existential meaning of the individual (UL)
- Objective bodily correlates of the individual (UR)
- Cultural narratives and meanings of the collective (LL)
- Systemic and institutional influences of the collective (LR)
- The evolving nature of psychological understandings (levels of development)

Furthermore, the AQAL framework supports a transdisciplinary synthesis by bridging insights from philosophy, psychology, medicine, sociology, ecology, and spirituality. This consolidative capacity makes it an ideal foundation for a comprehensive, whole-person, whole-system, whole-health model of pain and its persistence that is both scientific and existentially meaningful. In this context, the act of modelling becomes inseparable from the phenomenon being modelled. Any framework used to conceptualise pain not only reflects but also shapes how pain is understood, treated, and even experienced. In this sense, models of pain do not merely describe reality—they actively participate in constructing it.

This dynamic is evident in the evolution of pain models themselves. The biomedical ["pain pathway"(*sic*)] model, with its emphasis on tissue damage and pathology, historically shaped clinical practice around physical (biomechanistic) interventions.

Nowadays, the biopsychosocial model, incorporating psychological and social dimensions, shapes multidimensional understandings and multidisciplinary clinical practices adopting *patient*-centred approaches. Building on this progression, an integral model—framed through an AQAL, evolutionary-mismatch and salutogenesis (origins of health) lens—seeks to hold multiple perspectives simultaneously to construct *person*-centred, context-sensitive, meaning-making approaches to empower people to actively reshape their living experiences of pain in the modern world. Thus, the vision for an integral framework is not only to represent the persistence of pain more comprehensively, but to actively reshape how it is lived and addressed—expanding the possibilities for healing.

Mapping pain to the AQAL framework

Previously, the author mapped features of pain onto a simplified version of the AQAL framework highlighting certain limitations of the biopsychosocial model while preserving its foundational insights, thereby enabling an extension of the biopsychosocial model's conceptual scope (57). As a heurist tool the simplified AQAL framework is capable of accommodating both personal experience and systemic context in an organizing structure that visualises the location of multidimension aspects of pain, as represented by the four quadrants in Figure 1.

All quadrants

While the biopsychosocial model emphasizes the interplay of biological, psychological, and social factors at the level of the individual, the simplified AQAL framework broadens this scope by integrating individual, collective, interior and exterior perspectives offering insights that enables a more nuanced and layered understanding within the context of structures and systems of contemporary living. The quadrant structure aligns closely with the multidimensional nature of pain, contextualizing pain within a biopsychosocial-existential paradigm. Pain emerges from an individual's biological processes (UR) to be experienced by the individual subjectively (UL), shaped by collective cultural and existential narratives (LL), and interaction with collective systems and structures of social and physical environments (LR).

Visually and conceptually distinguishing aspects of pain and its persistence between quadrants enhances the clarity of pain theory in ways that the biopsychosocial model alone does not achieve. By locating pain within the subjective (UL) quadrant, AQ mapping helps to expose conceptual errors, such as the reification of pain (the fallacy of misplaced concreteness)—treating pain as a fixed, object-like "thing"—as well as conflating pain with nociception, a miscommunication that continues to obscure theoretical and clinical clarity (40, 41). Quadrant analysis informed by transdisciplinary knowledge provides opportunities to analyse, evaluate and integrate contemporary pain theories such as the

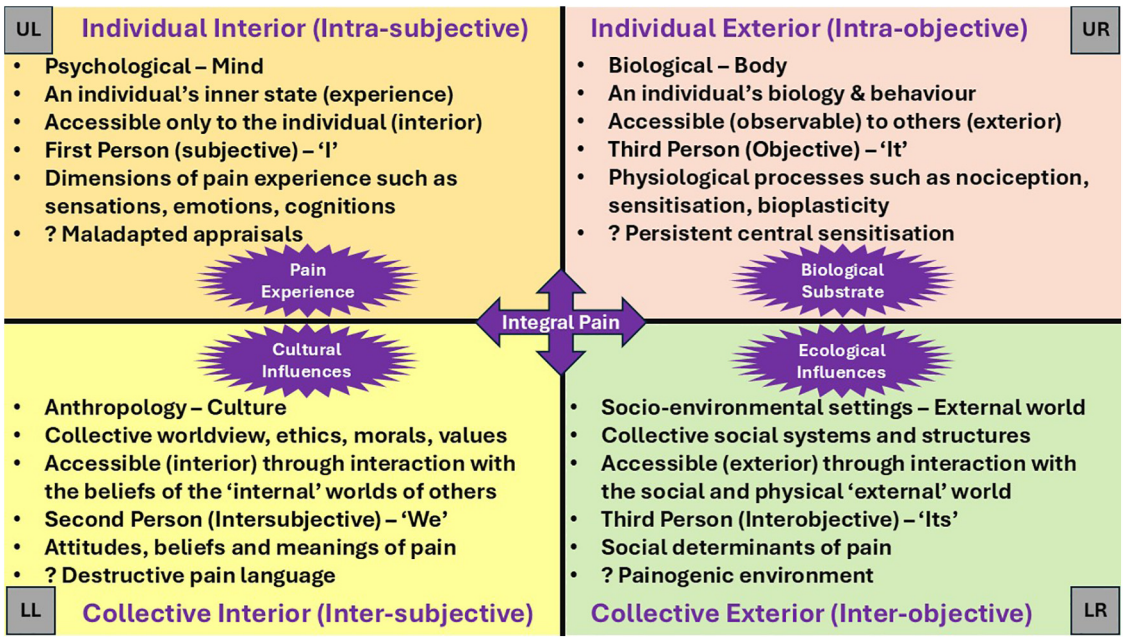

FIGURE 1
The quadrants framework offers a comprehensive lens through which to understand the multidimensional nature of pain. The Upper Right (UR) quadrant represents the objective, observable aspects of the individual, including neuroscientific and biological mechanisms that govern bodily functions and behaviours. In contrast, the Upper Left (UL) quadrant addresses the subjective, psychological, and experiential dimensions of the individual's inner life. The Lower Left (LL) quadrant encompasses the intersubjective domain, highlighting the cultural, moral, and relational influences that shape meaning within collective society. Finally, the Lower Right (LR) quadrant captures the interobjective dimension, focusing on systemic, structural, and environmental factors that influence the broader socio-ecological context. Together, these quadrants provide a holistic framework for understanding pain as a complex interplay of individual and collective, internal and external factors. Based on (57).

Embodied Predictive Processing Theory of pain experience (66), the 5E Enactive Theory of Pain (11), and the Healthy Settings Model of Pain (67), within the contextual reality of contemporary life.

For example, by embedding Bayesian and Active Inference models within a broader integral framework, we gain a more nuanced understanding of how pain is continually remodelled through both internal cognitive processes and external sociocultural structures. Active Inference and Bayesian approaches to cognition offer insights into how pain experience arises from neural tissue. Grounded in the predictive processing paradigm, these models propose that the brain is not a passive recipient of sensory input but an active constructor of experience—constantly generating predictions about the world and updating them in response to sensory evidence in order to minimise prediction error.

In the context of pain, this suggests that the experience of pain is not a direct reflection of tissue damage, but a probabilistic inference shaped by prior beliefs, contextual cues, and learned expectations. Persistent pain may reflect a state in which entrenched priors, encoded within cortical and subcortical networks, infer non-noxious stimuli as threatening or harmful—even in the absence of nociceptive input—thereby sustaining maladaptive predictions that resist revision. Active Inference extends this view by highlighting the role of action in reducing prediction error: neuroplasticity updates entrenched priors encoded in neural networks by acting on the world—or the body—to align sensory input with expectations. This dynamic interplay between perception, cognition, and action underscores how pain is not merely passively experienced but actively constructed and sustained.

A four-quadrant framework provides a structured lens through which this process can be understood. For example, the intrasubjective quadrant (UL) captures the influence of prior beliefs and expectations on a person's inner living experience; the intraobjective quadrant (UR) addresses the physiological and neurological mechanisms underpinning predictive processing; the intersubjective quadrant (LL) reflects the role of cultural narratives and shared meanings in shaping understandings of pain; and the interobjective quadrant (LR) encompasses the systemic and institutional structures that embed and reinforce these predictive models. This integrative perspective not only deepens theoretical insight but also opens new pathways for therapeutic intervention—targeting maladaptive predictions, enhancing agency, and reshaping the experiential reality of pain. Beyond informing intervention, the quadrant framework can also serve as an analytical tool to analyse and evaluate dimensions of existing treatments and practices.

Quadrant mapping reveals the individualistic, downstream bias of current thinking dominated by biomedical and psychological treatment, such as surgery, pharmacotherapy, and psychologically orientated interventions that focus on upper quadrant domains of the individual. Quadrant mapping fronts the collective cultural and socio-ecological dimensions, highlighting their interplay with the evolutionary mismatch between the UR and LR quadrants—namely, the tension between our Paleolithic physiology (UR) and a contemporary physical and social environment (LR) with painogenic influences that prime development and hinder resolution of pain i.e., make pain "sticky" (68, 69). Embedded within the lower quadrants are large-scale social, cultural, economic, and political forces that subtly, and often invisibly, shape individual and communal experiences in harmful or oppressive ways. Some of these influences are insidious such as medicalization of suffering, neoliberal ideologies, capitalist productivity culture, technocratic governance, colonial legacies, structural racism, patriarchy, ableism and, importantly, damage-laden and militaristic medical language (70–74). Some insidious macro-level forces go unrecognized within the conventional biopsychosocial model of pain, including damage-loaded warmongering pain language (70).

All levels

The AQAL framework also incorporates levels of psychological development across multiple lines of intelligence—cognitive, emotional, moral, and spiritual (61, 64). Levels of development reflect how individuals and societies evolve in their understanding and response to complex phenomena such as pain. They illuminate how beliefs, attitudes, and values toward pain shift over time— for instance, from premodern undifferentiated blends of philosophical, religious, and medical thought; to modernist biomechanistic models, and more recently, to postmodern biopsychosocial perspectives. Psychological developmental sensitivity offers a nuanced understanding of how pain is conceptualized and managed across diverse personal and cultural contexts. Viewing pain through a developmental lens can help explain variations in lived experiences and treatment responses, depending on whether individuals, practitioners, or healthcare systems interpret pain through biomedical, biopsychosocial, holistic, or spiritual frameworks. See reference (57) for further detail on developmental levels in the context of pain, including examples of how understandings of pain evolve across different stages of psychological development—in patients, practitioners, and healthcare systems.

In summary, the AQAL framework offers a more dynamic and personalized understanding of the persistence of pain, including the role of upstream influences—such as cultural narratives, environmental stressors, and systemic inequities—that contribute to painogenic conditions. Hence, an integral worldview would not only consider biopsychosocial domains focussing on the individual but extends this to cultural narratives, social structures and systems, and existential meaning, aiming for a whole-person, whole-system, whole-health understanding.

Main perspectives

An integral vision of pain and its persistence

The goal of applying the AQAL framework to pain begins with an integral vision: a guiding worldview that seeks to advance how pain and its persistence (stickiness) is understood and engaged with—moving beyond a fragmented, decontextualised and

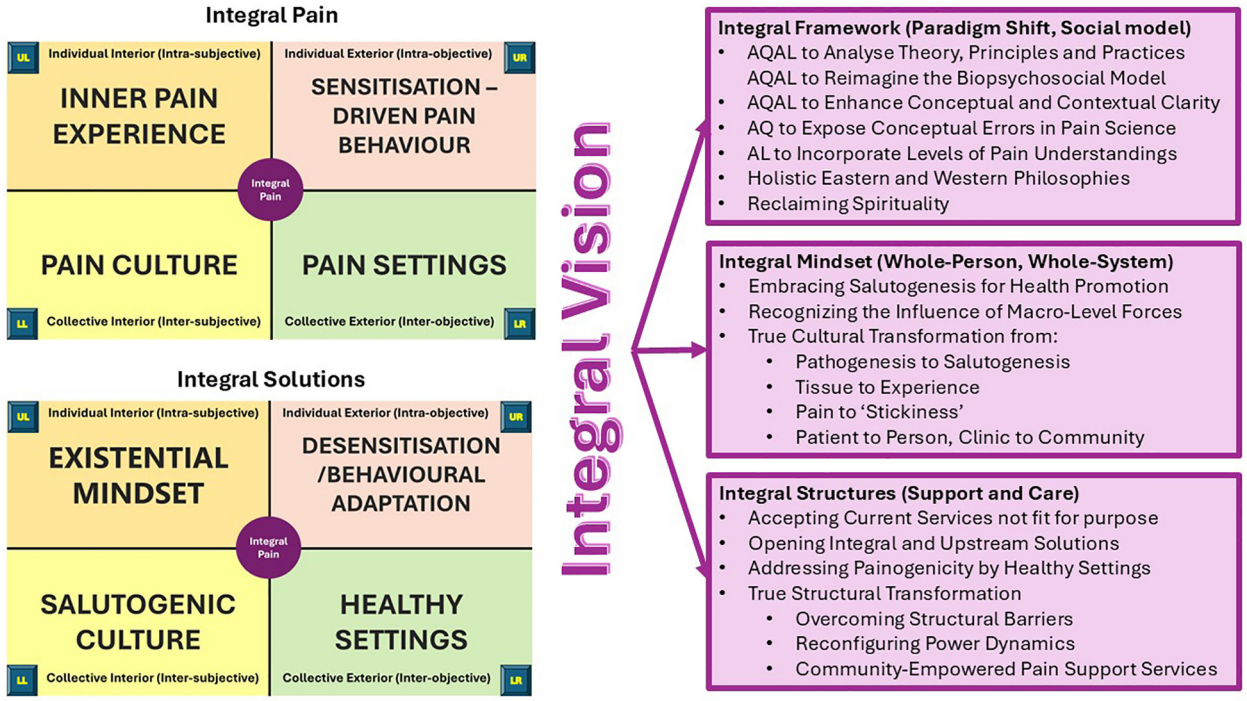

FIGURE 2
Mapping pain through All Quadrants to inform an integral vision for pain and its persistence. This figure synthesizes the outcome of applying the All Quadrants framework to the experience of pain, revealing a comprehensive, multi-dimensional perspective that transcends reductionist models. By situating pain within all four quadrants—biological, psychological, cultural, and systemic—the mapping exposes conceptual limitations in conventional pain science and extends the biopsychosocial model toward a more integrative, coherent, and holistic paradigm. AQAL framework mapping supports enhanced conceptual clarity, traces the evolution of pain theories, and aligns with holistic philosophies that reclaim spirituality and promote salutogenesis. It highlights the influence of macro-level forces, structural barriers, and power dynamics, while advocating for upstream, community-empowered, and whole-person approaches. This integral mindset reframes pain from a purely clinical issue to a lived, contextual experience—shifting the focus from tissue to experience, from pain to "stickiness," and from pathogenesis to salutogenesis. Ultimately, it lays the foundation for transformative, culturally responsive, and systemically informed pain support services. Based on (57).

symptom-focused biopsychosocial interpretation toward a more compassionate, whole-person, and context-sensitive integral perspective (Figure 2).

An integral vision of pain reconceptualizes pain as a dynamic, relational phenomenon shaped by subjective experience and meaning-making, biological processes, and interconnectedness with cultural narratives, systems and structures. In doing so, it moves beyond the traditional biopsychosocial model by expanding both its conceptual and contextual scope. Conceptually, it incorporates four irreducible dimensions of human experience: the individual-interior (subjective experience), individual-exterior (biological processes and behaviours), collective-interior (cultural meanings), and collective-exterior (social and environmental settings). It also integrates developmental levels, acknowledging that individuals and systems evolve over time. Contextually, it situates pain within broader ecological, relational, and historical frameworks, highlighting the importance of meaning-making processes that may be overlooked in conventional biopsychosocial approaches [see (57)].

An integral vision of pain reclaims spirituality as a vital dimension of psychological growth and a deepened sense of interconnectedness with broader existential realities, recognising its role in identity, resilience and healing. In a contemporary context, spirituality is understood in non-religious terms—as meaning, purpose, and connection to self, others, and nature (75). Spirituality remains central to end-of-life and palliative care yet is largely absent from guidelines about managing persistent pain (76). This omission reflects a broader tendency to overlook the existential and cultural dimensions of pain in chronic care contexts.

Systematically mapping the multifaceted nature of pain onto a simplified AQAL framework helps illuminate these neglected domains—particularly the collective cultural and socio-ecological factors implicated in an evolutionary mismatch. Evolutionarily conserved physiological systems, shaped by ancestral Paleolithic environments, may be poorly adapted to contemporary "painogenic" conditions—such as sedentary lifestyles, social disconnection, and fragmented healthcare (68). This mismatch may be particularly relevant to the development and persistence of chronic primary pain (69, 77).

An integral vision builds on insights from evolutionary-mismatch (68), salutogenic theory (78, 79), trauma-informed care (80, 81), and a socio-ecological "settings" model (67) to deepen understanding of the persistence—or "stickiness"—of pain. It provides a foundation for restoring coherence across the AQAL quadrants through narrative integration, socially responsive care,

and meaning-making practices that support healing as part of an evolving life journey. This approach addresses the evolutionary, environmental, and developmental factors that may contribute to the entrenchment of suffering, aiming not only to account for the persistence of pain but also to inform how it might be more effectively understood, lived with, and addressed. By drawing together diverse perspectives, the integral model offers a framework that supports personal narratives, reduces stigma, and encourages more empathetic, person-centred clinical dialogue.

The integration of salutogenesis—anchored in the principles of comprehensibility, manageability, and meaningfulness—transforms pain from a chaotic disruption into a coherent and meaningful aspect of one's evolving identity. This process, supported by the intrasubjective (UL) and intersubjective (LL) quadrants of the integral model, fosters a growth-oriented, life-affirming approach to pain and associated suffering. By promoting a more coherent and resilient orientation toward healing, salutogenesis also facilitates shared decision-making, affirms lived experience, and strengthens both therapeutic relationships and broader public engagement.

While building on the foundations of the biopsychosocial model, this integral approach seeks to extend its reach by more fully engaging with the lived experience of pain. Through fostering personal agency, narrative coherence, and socially responsive care, it offers a more holistic and potentially empowering path to healing—one that considers not only symptoms, but the broader context of the person's life. In this light, an integral vision invites a gradual cultural shift in how pain and its persistence are conceptualised and addressed, with an emphasis on complexity, compassion, and collective wellbeing.

An integral approach to healthcare

An integral vision advances the biopsychosocial model by reframing it as a dynamic, context-sensitive framework capable of more fully engaging with the complexity of lived experience, cultural meaning, and structural context in the understanding and treatment of persistent pain. It offers a conceptual architecture for reconfiguring the limits of healthcare, enabling a more inclusive, multidimensional approach that aligns healthcare with the full spectrum of human experience and systemic complexity—supported by communities committed to whole-person, whole-system care.

Applying the integral perspective: a case illustration

The case of a 45-year-old office worker with chronic low back pain illustrates how the integral framework can enrich understanding: in the intrasubjective quadrant (UL), they contend with fear of movement, emotional distress, and limiting beliefs such as "I'm broken," which shape their inner world and influence their pain experience. The intraobjective quadrant (UR) quadrant captures observable physical symptoms including muscle tension, altered posture, and reduced mobility, alongside diagnostic findings from laboratory tests, imaging, or clinical assessments. In the intersubjective quadrant (LL), cultural norms—such as a damage-loaded pain narrative, ideals of masculinity, expectations of productivity, and beliefs about aging—inform how the individual interprets and communicates their pain, while the presence or absence of social support from family, colleagues, or healthcare providers significantly affects their coping capacity. The interobjective (LR) quadrant reflects broader systemic and environmental influences, including living conditions, income, employment status, workplace ergonomics, access to healthcare, and policy frameworks that shape the trajectory of recovery. Together, these dimensions create a whole-person, whole system understanding of the person's situation.

The four-quadrant framework informs a comprehensive care strategy to address the full spectrum of the individual's experience. For example, psychological support such as Cognitive Behavioural Therapy (CBT) or Acceptance and Commitment Therapy (ACT) targets maladaptive beliefs, emotional distress, and fear-avoidance behaviours, fostering greater self-efficacy and meaning-making (UL). Physical rehabilitation, including physiotherapy, graded activity, and movement-based interventions targets observable impairments such as muscle tension, reduced mobility, and postural dysfunction, alongside ongoing review of diagnostic findings (UR). Culturally sensitive pain education and therapeutic dialogue help reframe internalised narratives around pain, masculinity, and productivity, while peer support and family involvement strengthen social cohesion and emotional resilience (LL). Systemic and environmental interventions may include workplace adjustments, improved ergonomics, coordinated multidisciplinary care, and navigation of healthcare access pathways (LR).

Together, these quadrant-aligned strategies advance the biopsychosocial model into a more integral, whole-person, whole-system paradigm—one that supports healing through coherence, connection, and contextual responsiveness across all domains of human experience. Framing this support within a salutogenic perspective, further enhances care by fostering comprehensibility, manageability, and meaningfulness—three foundational elements that help individuals make sense of their pain, feel equipped to navigate it, and find purpose in their recovery journey.

Reimagining pain within a salutogenic social model of health

An integral vision supports a reconfiguration of persistent pain within a social model of health with equal partnerships between pain livers, the voluntary, community and social enterprise (VCSE) sector, and healthcare providers. It opens opportunities to frame persistent pain not merely as a clinical symptom but as a socially embedded, meaning-laden phenomenon. It has potential to facilitate a shift from a fragmented, pathogenic model of care to a coherent, salutogenic, and humanistic paradigm. An integral vision supports the co-production of culturally relevant services, tailored to local needs and grounded in shared values. It emphasizes relationality, empowerment, and systemic awareness.

First-person research suggests that individuals living with persistent (chronic) pain benefit from approaches that validate their pain through meaningful explanations so that they feel their personal stories are heard and acknowledged (49, 82). A healing journey with chronic pain involves being reconnected with a sense of identity and purpose to restore self-worth and reintegration into social life—especially within safe and supportive environments that foster a sense of belonging and community (49). Healthcare services often fail to address these experiential and existential needs, focusing instead on downstream interventions. An integral model of care shifts the focus upstream, reimagining support services aligned with health promotion, community-based settings and salutogenic principles.

Antonovsky's concept of *salutogenesis*, introduced in 1979, shifts the focus from the origins of disease to the origins of health (78, 83). Within this framework, the experience of persistent pain is understood not solely as a pathological condition but as an opportunity for individuals to derive meaning and coherence from suffering. Central to this approach is the *sense of coherence*, which enables individuals—either independently or collectively—to interpret pain in a way that supports psychological resilience and positive adaptation. Salutogenesis acknowledges the influence of socio-economic, environmental, and contextual factors on health outcomes, recognising that individuals can maintain or regain health despite ongoing pain.

The salutogenic model of health promotion (78, 84, 85), which emphasizes the origins of health and well-being, aligns closely with the integral approach by highlighting three key salutogenic dimensions:

- Comprehensibility – making sense of pain and its persistence
- Manageability – having the resources to cope with and transform through painful experiences
- Meaningfulness – finding purpose in experiences of pain and its persistence

Salutogenic strategies promote positive health behaviours through education and literacy, social support, and community engagement that validates pain through compassionate listening, self-kindness, and safe social reconnection—principles that are often absent in conventional pain care.

Cultural transformation: from integrative to integral

The greatest challenge to integral transformation lies in dismantling entrenched structural hierarchies. Despite widespread acknowledgment of the importance of environmental determinants of health—such as housing, transport, and living conditions—public health and health promotion in countries like the UK, US, and Australia continues to prioritise individual behaviour change. This disconnect is attributed to "lifestyle drift," where policies initially aimed at addressing upstream social determinants shift focus to downstream lifestyle interventions. Lifestyle drift is partly due to the relative ease of designing and evaluating individual-level interventions compared to structural ones.

In pain management, this trend is particularly evident, with care guidelines remaining individual-centred. Green et al. (65) argue that while health promotion should target structural factors, it is often reduced to personal responsibility, and then medicalised—e.g., lifestyle medicine, prescriptive exercise. Nonetheless, there is growing recognition that health is shaped largely by factors beyond individual control, prompting international calls—such as the Shanghai Declaration (86)—to prioritise supportive environments that make healthy choices more accessible.

Despite long-standing policy commitments to community-empowered care, power, funding, and decision-making remain disproportionately concentrated in healthcare-led institutions, marginalising the very social, relational, and community assets essential for whole-system change. Contemporary healthcare systems promote integrated or integrative pain care, often through multidisciplinary teams that combine biopsychosocial approaches. The International Association for the Study of Pain (IASP) defines integrative care as a coordinated, evidence-based model that blends conventional and complementary treatments (87–89). Integrative services frequently remain extensions of existing systems, relying on mechanism-guided, single-treatment interventions that privilege UR quadrant domains. This narrow focus not only overlooks the socio-ecological complexity inherent in the experience of pain, but also externalises the financial, logistical, and administrative burdens of coordinating multiple services—consequences that often manifest as systemic inefficiencies, increased clinician burnout, and the perpetuation of fragmented care pathways (90–92). A persistent "silo effect" and misalignment between clinicians and patients further hinder collaboration and shared understanding.

Gaudet (56) argues that incremental improvements in existing services are no longer sufficient, calling for systemic "true" transformation across healthcare, culture, and community.

> "We are starting from the wrong place. To change the outcomes of the system, we need to change the conversation. We need to start with discovering what gives each of us a sense of meaning and purpose. What matters most deeply in our lives?" (56) p.2

An integral vision is for "true cultural transformation" through reinterpretation of the persistence of pain within a social model of health aligned with whole-person perspectives (93, 94), person-centred health care (51), and unitary care science (95). An integral vision would be to reconfigure pain from always being a pathologic problem to be eliminated, to a meaning-making, growth-orientated experience that warrants interpretation within an evolving life-journey. Such a shift necessitates aligning what is important to patients with reimagined care systems, professional roles, and cultural narratives.

Rethinking Pain: community-based support for chronic pain

Overcoming structural and cultural barriers is a major challenge to integral transformation. UK health policy has long

advocated for community-empowered care yet implementation has been limited (96, 97). Funding and authority in the UK and elsewhere remain concentrated in healthcare-led services, often sidelining social care, patients and community organizations (98–100). An integral vision of pain challenges this imbalance, advocating for the redistribution of power and the collaborative design of services that reflect the lived realities of those they aim to support. This is exemplified by initiatives such as the UK's Rethinking Pain programme (101, 102) commissioned by a National Health Service (NHS) Integrated Care Board (ICB) and led by a VCSE-sector organisation [Keighley Healthy Living (103)].

Rethinking Pain is a co-produced, community-based pain support service that values relationality, community empowerment, and systemic awareness, developed under NHS clinical governance to address chronic pain and health inequalities through culturally adapted, holistic care. Informed by guidelines for assessing and managing persistent pain published by the National Institute for Health and Care Excellence (NICE) (104) and the Scottish Intercollegiate Guidelines Network (SIGN) (105), the Rethinking Pain service integrates physical, mental, social, environmental, and spiritual dimensions of health. With input from service users, VCSE partners, clinicians, health promoters, and academics, Rethinking Pain offers a three-tier care pathway to support people living with persistent pain through a holistic, culturally responsive approach. The service includes workshops that cover a wide range of topics such as beliefs, faith and spirituality, "your story", creative therapies, emotional wellbeing, keeping active, diet therapy, sleep therapy, and pain education. These workshops are delivered in various languages to ensure they are accessible and culturally relevant. Service users also engage in personalised care planning, working alongside trained health coaches to co-develop strategies tailored to their individual physical, emotional, social and spiritual needs (102). Grounded in salutogenic principles and community ownership—with health coaches as the cornerstone of delivery—Rethinking Pain enhances engagement, treatment adherence, and equity by aligning care with diverse cultural values and lived experiences. While not explicitly structured around the AQAL framework, the Rethinking Pain service reflects many of its core principles, particularly its commitment to whole-person, whole-system, whole-health care for individuals with persistent pain not linked to serious underlying medical conditions.

Challenges and priorities

Looking ahead, the AQAL framework offers a powerful tool for enhancing service design and delivery by ensuring that all fundamental dimensions of the pain experience—individual and collective, internal and external—are systematically addressed. Its integrative architecture promotes conceptual and contextual coherence, helping services avoid reductionist tendencies and instead embrace the full complexity of human experience. By accommodating different levels of psychological development and cultural worldviews, AQAL can guide the tailoring of interventions and narratives to meet the evolving needs of diverse individuals and communities. This makes it especially valuable for designing dynamic, community-based, person-centred care models that are both inclusive and adaptive—advancing the biopsychosocial model into a truly integral paradigm.

Despite its conceptual strengths, the AQAL framework has had limited exposure in peer-review academic literature and lacks empirical validation. While theoretically rich, levels of psychological development as formulated by Wilber (61, 62, 64, 106) are conceptually fluid and may be prone to overinterpretation, e.g., transpersonal levels of development lack mainstream psychological acceptance (107, 108).

A common critique of Wilber's integral framework is its perceived complexity, which not only encompasses quadrants and levels but also includes lines of development, states of consciousness, and types—making it challenging to apply in practical or clinical contexts without significant interpretive effort (63, 107, 108). A challenge in applying the integral model to clinical practice lies in the overwhelming complexity that emerges when attempting to account for every possible variable. This level of detail introduces a substantial computational burden, making real-world implementation difficult without deliberate simplification. To address this, model reduction becomes essential—a process of selectively narrowing the scope to focus on the most relevant and influential variables. Achieving model reduction within an integral vision of pain, while preserving its theoretical depth and multidimensional scope, requires balancing conceptual richness with clinical usability. This can be accomplished by adopting the four quadrants as the primary heuristic framework and selectively incorporating developmental levels to align narratives with an individual's worldview, thereby simplifying the model into a more accessible and clinically useful tool (57).

Rather than aiming for exhaustive quadrant coverage, clinicians can use the quadrants as a reflective guide to identify patterns and gaps in care. Translating the model into practical tools for practitioners and livers—such as structured checklists or narrative-based guides—would further enhance applicability. Distributing quadrant responsibilities across interdisciplinary teams fosters shared ownership and would reduce cognitive burden, enabling the AQAL framework to function as a flexible, coherent, unifying lens. When integrated with established models such as the biopsychosocial framework or Bayesian and Active Inference theories, AQAL supports enhanced clinical reasoning without overwhelming practitioners.

To enhance the applicability and scholarly credibility of the AQAL framework within pain science, several research priorities warrant attention. Cultural and contextual analyses are needed to examine how sociocultural and environmental factors contribute to the persistence of pain and influence treatment outcomes. At the macro level, it is important to investigate the impact of broader social forces—such as public policy, socioeconomic inequality, and media representations—on the lived experience of pain. Evaluative studies of AQAL-informed policies and community-based programs can help assess their effectiveness in improving health outcomes and promoting health equity. Integrating diverse research

paradigms may also facilitate a more holistic understanding of pain, shifting the focus beyond symptom alleviation to encompass broader outcomes such as wellbeing and quality of life. Interdisciplinary collaboration across all quadrants—biological, psychological, cultural, and socio-ecological—is essential to ensure comprehensive analysis. Engaging a wide range of stakeholders, particularly individuals with lived experience of persistent pain, is vital for validating research findings and ensuring their relevance. Finally, the design of interventions should remain adaptive, incorporating ongoing stakeholder feedback and responding to evolving cultural narratives.

Conclusion

This article proposes that an integral perspective—drawing on the AQAL framework, evolutionary mismatch theory, and salutogenic principles—offers a novel way to reconceptualize the nature and treatment of persistent or "sticky" pain. From this foundation emerges an integral model, a practical tool that maps the biological, psychological, social, cultural, and existential dimensions of pain across individual and collective contexts, offering a more coherent and holistic approach that acknowledges pain as a deeply embedded, meaning-rich experience.

By conceptualising pain as both a physiological event and a meaning-laden experience, this approach interprets its persistence as a reflection of broader cultural and environmental conditions in contemporary life. It challenges the limitations of reductionist paradigms and fragmented understandings by reframing the biopsychosocial model to account for the dislocated domains of pain—where biological, psychological and social influences are often treated in isolation rather than as interconnected elements. This reconceptualization positions pain as a dynamic, relational, and context-sensitive phenomenon, capable of more fully engaging with the complexity of lived experience, cultural meaning, and modern habitats.

By enhancing conceptual clarity, the AQAL framework invites the general public into a more nuanced and relatable understanding of pain by building on established pain education concepts—such as an "overprotective brain *(sic)*" and reductive explanations focussing solely on a hyperexcitable nervous system. Through narrative and storytelling, mapping lived experiences across four interrelated domains can be brought vividly to life. For instance, a woman living with fibromyalgia may describe how her body flares up under stress (UR), how she feels emotionally dismissed and misunderstood (UL), how her daily environment lacks appropriate adaptations to support her condition (LR), and how her family struggles to believe that her pain is as severe as she reports (LL). These stories help individuals explain their pain within a broader, integrative framework—one that validates their experience, challenges fragmented models of care, and opens new pathways for healing that are both compassionate and contextually grounded through salutogenesis to catalyse a sense of coherence. Such conceptual clarity lays the foundations to develop an integral vision that empowers communities and the VCSE sector services to co-create health-promoting solutions. With the support of healthcare providers, this model exemplifies a shift toward relational, whole-person, whole-system care.

Ultimately, an integral vision calls for a cultural transformation in how persistent pain is conceptualized, communicated, and addressed—emphasizing the importance of meaning-making and ensuring access to resources that support coping and psychological growth through health promotion. An integral vision of pain places individual empowerment at its core—recognizing each person's capacity to transform painful experiences into transformative purpose (109). Realizing this integral vision requires a shift from institutional control to fostering personal agency within empowered communities rooted in the cultural and environmental realities of contemporary life.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Author contributions

MJ: Conceptualization, Writing – original draft, Writing – review & editing.

Funding

The author declares that no financial support was received for the research and/or publication of this article.

Conflict of interest

The author is a member of a research team that serves as an academic partner to the Rethinking Pain service. Since 2000, the author's employer has received income for expert consultancy services from the Committee of Advertising Practice, Medi-Direct International, Philips Research Europe, GlaxoSmithKline, TENSCare, and LifeCare Ltd., all of which are unrelated to the submitted work. The author also declares receipt of book royalties from Oxford University Press.

Generative AI statement

The author declares that Generative AI was used in the creation of this manuscript. During the preparation of this manuscript, the author occasionally used Microsoft Copilot powered by GPT-4 (GPT-4-turbo variant), for the purposes of refining grammar, syntax, and overall readability, ensuring the content is clear and

accessible to a broader audience. The author has reviewed and edited the output and takes full responsibility for the content of this publication.

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Publisher's note

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frontiers | Frontiers in Pain Research

TYPE Perspective
PUBLISHED 26 September 2025
DOI 10.3389/fpain.2025.1672412

OPEN ACCESS

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RECEIVED 29 July 2025
ACCEPTED 08 September 2025
PUBLISHED 26 September 2025

CITATION
Stavropoulos N and Johnson MI (2025) Exploring pain and suffering through spatial acousmatic music: innovative perspectives beyond conventional music therapy. Front. Pain Res. 6:1672412. doi: 10.3389/fpain.2025.1672412

Exploring pain and suffering through spatial acousmatic music: innovative perspectives beyond conventional music therapy

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In this perspective article we contend that acousmatic music, which departs from the traditional "instrumental music paradigm" by obscuring or removing the origin of sounds, may deepen a person's understanding and expression of pain and suffering, offering therapeutic potential. We propose that intentional engagement with acousmatic music can reshape listening habits, articulate and reframe the meaning of bodily and emotional experiences, and alleviate distressing sensations, feelings and thoughts. We propose that acousmatic music evokes memories of previous psychological traumas, such as painful events, and by doing so can prompt listeners to curiously explore the meaning and purpose of distressing symptoms. We argue that creative engagement with acousmatic music may allow individuals to express their somatic, emotional, and cognitive experiences, potentially leading to a deeper understanding of their living experiences. We discuss future directions for research and practice. We offer readers a stereo reduction excerpt of acousmatic music to facilitate an appreciation of the unusual nature of acousmatic music composition (https://soundcloud.com/nikos-stavropoulos/topophilia).

KEYWORDS

pain, acousmatic music, music therapy, sound, suffering, emotional memory

Introduction

There is growing use of engagement with art, including music, to alleviate suffering and facilitate "healing" of various health conditions reflected in a proliferation of systematic reviews and meta-analyses evaluating the impact of music for therapy, for example in the management of pain [e.g., the following since 2022 (1–17)]. Research on the use of music in healthcare settings focuses on the "instrumental music paradigm," based on the concept of musical notes; an arrangement of sound(s) that creates expressive content through combinations of form, harmony, melody, and rhythm of determinate pitched sounds of a certain stability and duration (18)—what the general public may recognise as familiar, conventional music.

The instrumental music paradigm is an oversimplification of the nature of music and treats music as a homogeneous "intervention", overlooking the inherent complexity and diversity within and between musical genres and neglecting influence of the characteristics within and between specific pieces of music (19, 20). Martin-Saavedra and Saade-Lemus (21) advocate for a more objective analysis of music, employing

theoretical terms such as mode and tempo, rather than relying solely on genre or artist. This broader analytical framework may reveal new avenues for exploring music's therapeutic potential. For instance, a preclinical experimental study in mice by Zhou et al. (22) demonstrated that the signal-to-noise ratio—the volume of sound relative to ambient noise—is critical in raising nociceptive thresholds, indicating that the delivery and environmental context of sound significantly influence nociceptive responses. Their findings revealed that even simple sounds, such as white noise, can modulate the flow of nociceptive information through corticothalamic circuits. This challenges the assumption that only structured or traditionally "musical" sounds possess therapeutic potential and highlights the role of contextual factors in music-induced analgesia. It also opens the door to broader, more accessible sound-based interventions in healthcare.

The aim of this article is to present a perspective on the potential of acousmatic music to express and deepen an individual's understanding of their lived experiences of pain and suffering through spatial sound, moving beyond the scope of conventional music therapy.

Perspective

We contend that acousmatic music—by obscuring or removing the source of sound and departing from the traditional instrumental music paradigm—may deepen a person's understanding and expression of pain and suffering, offering therapeutic potential.

Our perspective has been shaped in part by informal conversations with audiences comprising individuals both with and without lived experience of pain, following short acousmatic music performances. Many audience members were surprised by how acousmatic music sparked emotional curiosity—particularly around experiences of pain—in ways that differed from more familiar, conventional music. This led us to consider whether acousmatic music might support deeper reflection on health and illness. We suggest that it can foster emotional insight, openness, and empathy by encouraging listeners to explore their own feelings, engage with a wide range of emotions, and consider the experiences of others. This process may offer new ways of understanding and easing suffering, while supporting a more holistic and personally meaningful approach to healing.

Our discussion is grounded in our interdisciplinary perspectives as an artist (NS, Professor of Music Composition) and a pain scientist (MIJ, Professor of Pain and Analgesia), drawing on our combined expertise to explore how acousmatic sound may open new avenues for engaging with health, illness, and healing. Acousmatic music is a genre characterized by the deliberate obscuring of sound sources, thereby encouraging listeners to focus exclusively on auditory qualities. Explaining the nature of acousmatic music in words undersells the listening experience so we offer some examples here and encourage readers to listen before proceeding (https://soundcloud.com/nikos-stavropoulos/topophilia).

Discussion

Theoretical foundations

Acousmatic music diverges from the traditional instrumental music paradigm by deliberately obscuring the origin of sounds, thereby encouraging a focus on the auditory experience itself. The term "acousmatic" originates from the teachings of Pythagoras, who delivered lectures from behind a screen to ensure that his students concentrated solely on his voice (23). In contemporary practice, acousmatic music is a genre of electronic music that emphasizes the separation of sound materials from their original context, offering a unique listening experience that is both immersive and abstract.

Acousmatic music is distinguished by source ambiguity, which intentionally obscures or removes the origin of sounds, thereby fostering a purely auditory engagement (24).

> "…electroacoustic (is) more concerned with spectral qualities than actual notes, more concerned with varieties of motion and flexible fluctuations in time rather than metrical time, more concerned to account for sounds whose sources and causes are relatively mysterious or ambiguous rather than blatantly obvious." (24) p. 109.

Acousmatic music often exploits the dual nature of sound as both an aural phenomenon and a sign or referent, recontextualizing real-world sounds within new musical frameworks (25).

The absence of visual stimuli develops and strengthens cognitive and sensory aspects of listening. This allows listeners to engage with and interpret abstract soundscapes, constructing meaning, mental images, and narratives on auditory stimuli alone. Acousmatic music often confronts listeners with unfamiliar aural experiences—both in the content of the sound itself but also in obscuring the sound sources—inviting them to question perceptual habits and engage with new ways of interpreting sound phenomena (26).

Beard (26) describes how acousmatic listening can be used to disrupt habitual listening patterns "*…as an intentional practice, one that will enable critical reflection on listening*" (26) p. 129. This intentional practice fosters reflection and contemplation with potential to interrupt listening-habits, opening a different listening experience.

> "When we stop trying to decide whether we recognize a sound, or whether we can imagine the source of a sound, and instead immerse ourselves in the experience of the sound, we listen differently." (26) p. 131

Proposed mechanisms

Acousmatic music encourages engagement with multiple listening modes including (27):

- **Reduced Listening:** Focusing on the intrinsic features of sound, independent of its source.
- **Causal Listening:** Speculating about the potential sources of sounds.
- **Semantic Listening:** Interpreting symbolic meanings or personal associations with sounds.
- **Rhetorical Listening:** Analysing how sounds relate to each other within the composition's narrative or emotional arc.

Acousmatic listening involves focussing on the sound itself and making elements of the listening experience explicit, rather than trying to recognise the sound or querying its origin. This requires an "acousmatic attitude" (28) p. 5 that shifts a listening activity from being reflexive to reflective by,

> "…strip[ping] away expectations and schema that interfere with the listening process" (26) p. 131.

Kane's ontology of the acousmatic experience (29), highlights the significance of the empty space between the source, cause, and effect of acousmatic sound,

> " …the being of acousmatic sound is to be a gap… " (29) p149.

Soddell (30) identifies the potential of this gap to facilitate free connections between sounds, real-world events, lived experiences and more abstract concepts and exploit the acousmatic experience to "understand states of anxiety and distress, and the inner world of the psyche", using what Soddell terms as *Experiential Listening* as a method for shaping and understanding ideas through sound (30).

Spatialization and sound movement are integral aspects of acousmatic music, enhancing sensory experiences and deepening emotional engagement (31). The immersive nature of acousmatic music facilitates a heightened sense of presence, encouraging greater cognitive focus and emotional responses to auditory stimuli. Furthermore, acousmatic music has the potential to facilitate communication and social interaction by reappraising sensory input and developing cognitive control strategies (32). Techniques employed in acousmatic music can evoke powerful emotional responses, drawing upon and expanding real-life experiences (33, 34).

Therapeutic potential

The therapeutic potential of acousmatic music remains largely unexplored, and a search of PubMed on 08 April 2024 using the search term "pain" combined with "acousmatic" or "music" or "sound" or "audio" failed to identify any records pertaining to acousmatic music (Supplementary Material). To our knowledge there has been no attempt to explore the potential of acousmatic sound for health and wellbeing.

Based on our experiences delivering short, 15-min performances of acousmatic music to academic colleagues, and to a group of cancer sufferers and survivors—both with and without pain—in our periphonic (full 3D) Ambisonics studio (Figure 1), we have found that audiences are often surprised by the nature of acousmatic music. It is something they have never encountered before. Performances comprise two immersive acousmatic works by Stavropoulos, Topophilia and Khemenu that explore the notion of aural intimacy through novel recording techniques, using bespoke microphone hardware, and new ways of using ambisonics technology in the composition of acousmatic works (https://soundcloud.com/nikos-stavropoulos/topophilia) (33). Both compositions display strong spatiality, increased perceived materiality of sound materials and are acknowledged internationally in various composition competitions.

Acousmatic music seems to trigger emotional responses, especially related to previous trauma and adversity such as painfully distressing medical procedures and events. Emotional memories seem to be both "negative", (e.g., threat, anxiety, goosebumps, increased somatosensory awareness of aches and pains) and "positive" (e.g., sense of calm, comfort, happiness, and bodily warmth). We are interested in how elements within the music trigger emotional memories and whether acousmatic

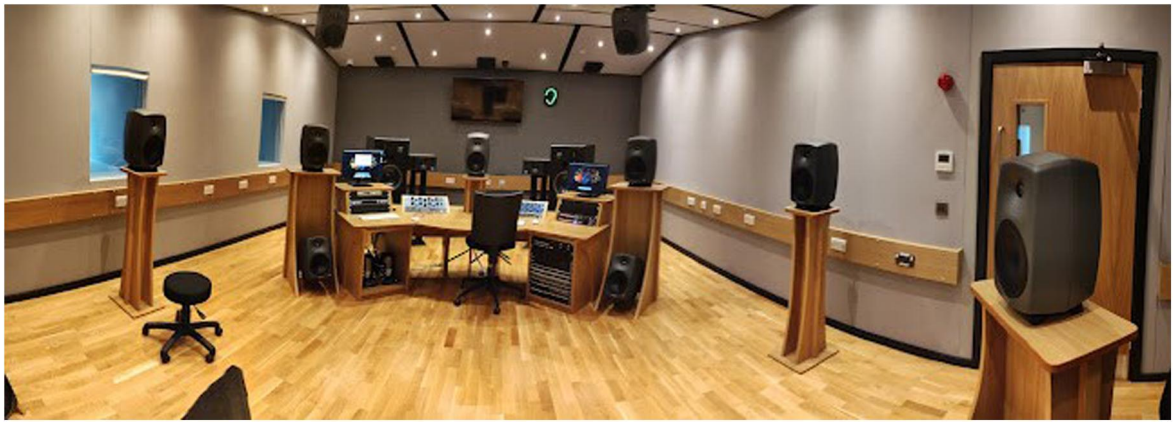

FIGURE 1
The periphonic (full 3D) ambisonics studio at Leeds Beckett University.

music practice could be used to spark conversations and curious exploration of illness, health and well-being.

By engaging several listening modes simultaneously, acousmatic music connects the cognitive aspects of musical experience to the physiological response(s) to auditory stimuli. This connection is enhanced by the construction and articulation of acoustic space, which is often an integral part of acousmatic music practice. Immersive sound experiences contribute to a person's sense of presence and engagement, which enhances cognitive focus and emotional responses to [the acousmatic] stimuli. Moreover, acousmatic approaches engage spatial auditory perception either by recreating real auditory spaces, enhancing the real experience of those for the listener by augmenting or subverting those, as well as creating hyperreal or imaginary acoustic spaces.

Acousmatic music and pain: toward a therapeutic framework

To further investigate the therapeutic potential of acousmatic music, we propose four lines of inquiry:

1. Reshaping the listening experience

From our perspective, acousmatic music may foster the development of new listening skills, enabling individuals to "filter in" soothing sounds while "filtering out" distressing sounds associated with experiences such as pain. Audience members report that "unnatural" or "threatening" sounds—such as metal-on-metal, scream-like tones, or overbearing noise—often triggered unpleasant memories and emotions. In contrast, "natural" or "safety" sounds—such as nature-like textures, welcoming tones, and soothing rhythms—evoked comforting and pleasant associations. This suggests a potential for acousmatic music to support the re-association of sounds linked to painful experiences with more positive emotional responses. As a distinct and intentional listening experience, acousmatic music opens new listening channels and cultivates the ability to engage with sound in a more exploratory and therapeutic way.

2. Exploring sounds from the past

From our perspective, acousmatic music has the potential to trigger latent emotional memories, facilitating a journey of discovery and recovery. This form of listening may be particularly valuable in contexts where trauma—whether major ("big T") or minor ("little t"), including adverse medical procedures or childhood experiences—has contributed to the persistence of pain and suffering. Acousmatic music offers a means of bringing non-conscious emotional memories into awareness to prompt reflection, discussion, and curious exploration of past, present, and future experiences of living with pain. When guided appropriately by healthcare professionals or mind-health coaches, this process may support reconceptualization of pain-related experiences and emotional healing.

3. Expressing painful experiences

There is strong evidence that people often struggle to express their pain to others, and even when they do, they may feel unheard (35). From our perspective, acousmatic music production offers a creative and empowering avenue for individuals living with pain to articulate their experiences. Using simple recording devices—such as smartphones—and basic, easily learned music engineering techniques, individuals can capture sound bites and compose musical representations of their pain. With support from a music technician if needed, these compositions can serve as powerful tools for expressing distressing sensory, emotional, or cognitive experiences. Sharing such works with healthcare professionals during clinical consultations may enhance communication, foster empathy, and support more person-centred care. This process not only validates the lived experience of pain but also opens new possibilities for therapeutic engagement through sound.

4. Reshaping the meaning of pain

From our perspective, acousmatic music may support individuals in reconceptualizing the meaning of distressing sensory, emotional, and cognitive experiences, moving beyond simplistic narratives—such as the belief that pain necessarily indicates bodily damage. Many people struggle to make sense of their pain when biomedical treatments fail, often finding it difficult to attribute any positive or meaningful interpretation to their suffering (36). Engagement with the arts can help individuals reframe the meaning of pain by fostering a more holistic understanding of the embodied self, situated within a broader social and emotional context (37). Acousmatic music, in particular, offers a unique tool for exploring, expressing, and reshaping the meaning of lived experiences, including pain. By matching sound characteristics—such as texture, rhythm, timing, timbre, and pitch—to sensations, emotions, and thoughts, individuals can create sonic representations of their experiences. This process might include mapping pain-event timelines, expressing the rhythm of a pain journey, or exploring themes such as grief, growth, and transformation. Through this creative engagement, acousmatic music may open new pathways for understanding and healing.

Risks, challenges, and ethical considerations

The abstract, non-representational soundscapes of acousmatic music present risks, challenges, and ethical considerations that must be navigated to ensure safe and inclusive practice.

Individual variability in perception and response

The degree of individual variability in how people living with pain perceive and emotionally respond to acousmatic music is unknown. Responses to acousmatic music are likely shaped by personal auditory associations, neurological sensitivity, cultural background, and cognitive readiness. Hence, acousmatic music may liberate imaginative engagement and facilitate cognitive distraction from pain in some individuals, but the lack of familiar musical cues may also provoke confusion, discomfort, or emotional disengagement in others.

Ethical practice necessitates a highly individualized approach that involves obtaining informed consent that clearly explains the nature of acousmatic music and its potential effects. Collaborative music selection should be encouraged, allowing participants to choose or reject sound materials based on their comfort and preferences. Cultural sensitivity is also essential, as abstract sounds may carry unintended symbolic or emotional weight depending on the listener's background.

Emotional distress and trauma sensitivity

Acousmatic music has potential to evoke deep emotional responses. Certain sonic textures—such as dissonant frequencies, distorted voices, or abrupt dynamic shifts—may inadvertently trigger traumatic memories or psychological distress, particularly in individuals with a history of post-traumatic stress, anxiety, or depression. This risk is pertinent in people with persistent pain where co-occurring mental health conditions are common.

Ethical practice necessitates screening for trauma history and emotional sensitivity prior to introducing acousmatic sound. Sessions should be structured to avoid coercion or pressure to engage with soundscapes that provoke discomfort and emotional responses closely monitored with provision for immediate support and opt-out mechanisms if distress occurs. Facilitators must be trained to recognize signs of emotional flooding and respond with appropriate interventions, including grounding techniques and referral to psychological support when necessary.

Sensory overload and cognitive fatigue

The complex, layered, and unpredictable nature of acousmatic music poses a risk of sensory overstimulation, particularly for individuals with heightened sensory sensitivity—a common feature for people living with pain. The cognitive effort required to interpret and make sense of abstract soundscapes may lead to mental fatigue, exacerbating symptoms such as "brain fog" or reduced cognitive capacity due to pain or medication.

To mitigate these risks, facilitators should carefully curate the listening experience, selecting sound materials that are appropriate to the sensory profile and cognitive state of participants. Session pacing should be adjusted to avoid overstimulation, and breaks should be incorporated to allow for cognitive recovery. Ethical practice involves educating participants about the potential for sensory overload and encouraging open communication about their experiences during and after sessions.

Therapeutic accessibility and engagement

Acousmatic music is unfamiliar to most people and individuals may find the genre alienating or difficult to engage with meaningfully and facilitators should introduce and scaffold the listening experience in a way that fosters openness and emotional resonance by demystifying the genre through clear explanations and examples that emphasizes therapeutic potential rather than artistic complexity. Participants should be empowered to actively engage in the listening process, including the option to reject or modify sound materials that do not resonate with them. Therapeutic opportunities should not be limited by technical knowledge or cultural familiarity but focus on creating inclusive, person-centred experiences that respect individual preferences and needs.

Specialized expertise and safe facilitation

The safe and effective use of acousmatic music in therapeutic contexts requires facilitators—whether artists or therapists—to possess foundational digital audio skills and a working knowledge of sound design. These competencies are essential not only for adapting the listening experience to meet individual needs, but also for guiding participants through abstract emotional landscapes in a way that facilitates reflective dialogue and allows for close monitoring of emotional distress.

When participants are encouraged to compose or manipulate sound, the process must be ethically structured through supportive guidance that establishes clear boundaries around emotional content and sound choices. To ensure emotional safety and therapeutic coherence, debriefing sessions should be incorporated to help participants process both their creative output and any emotional reactions that may arise. Ethical practice demands that the therapeutic process remain coherent, responsive, and attuned to the participant's emotional state throughout.

Misconceptions around technical requirements

A common misconception is that acousmatic music therapy demands advanced compositional expertise and professional studio facilities. While high-fidelity listening environments can enhance the experience, basic tools such as stereo speakers, headphones, and mobile phones are sufficient for therapeutic engagement. Accessible software platforms allow for sound manipulation without requiring extensive technical training.

Ethically, facilitators should emphasize the simplicity and accessibility of the process, empowering patients to participate in sound creation using everyday technology. This democratization of sound creation not only reduces barriers to participation but also enhances the therapeutic value by fostering agency, creativity, and emotional expression. Facilitators should avoid perpetuating the notion that acousmatic therapy is reserved for those with specialized skills or resources, and instead promote inclusive practices that prioritize participant empowerment.

Integration with broader care plans

In healthcare settings, acousmatic music therapy should not be viewed as a standalone intervention but rather as a complementary

component within a broader pain management strategy. Pain specialists must avoid over-reliance on music therapy as a singular solution and instead position it within a multidisciplinary framework that includes pharmacological, psychological, and physical interventions.

Ethical integration involves ongoing dialogue with patients about their goals, preferences, and progress, fostering a collaborative and transparent therapeutic relationship. Ethical practice involves coordination with multidisciplinary pain teams, including psychological professionals to ensure compatibility and continuity of care. Documentation and evaluation of therapeutic outcomes through records of patient responses, session content, and any adverse reactions, are essential to ensure efficacy and safety and to refine therapeutic approaches.

Future research

While we did not collect qualitative data from audiences following the performances—a limitation we fully acknowledge—this perspective paper aims to share our initial observations and signal the need for further empirical investigation. An obvious and essential first step is to capture the phenomenology of engaging with acousmatic music among people living with pain. To this end, we have already designed an interdisciplinary study exploring how acousmatic music can facilitate connections between memories, events, thoughts, and emotions. Using a participatory approach, the study will engage participants in listening, co-creation, and active dialogue through a series of structured activities. An embedded qualitative component will be used to better understand the impact of the intervention. The research team will bring together expertise in acousmatic music and health sciences from Leeds Beckett University, in collaboration with Balbir Singh Dance Company—an Arts Council National Portfolio Organisation known for its innovative community engagement—and community-based networks such as the Mid Yorkshire Breast Cancer Support Group. This phenomenological approach would help ground future experimental and clinical research in the realities of those who may benefit most.

The lack of experimental research on acousmatic music presents significant opportunities to investigate its effects on psychophysiological responses, particularly in relation to pain and health. This includes exploring how compositional structures, sound intensity levels, and spatial auditory perceptions influence physiological and emotional states. As a foundational step, we propose a scoping review to map the current state of knowledge and practice concerning acousmatic music and health. Experimental approaches could then examine responses in diverse populations, such as individuals living with persistent pain or healthy participants exposed to noxious stimuli. Variables of interest might include compositional structures (e.g., texture-carried, gesture-carried, or hybrid forms), stable vs. unstable sound spectra, event rate, musical form, and intensity dynamics. Further dimensions include the use of relaxation- vs. stress-inducing materials (e.g., expectation, release, resolution, stasis), spatial disposition and trajectory, sensory deprivation to heighten cognitive focus, recognition of sound source and cause, spectromorphological and spatiomorphological change, and auditory immersion formats (e.g., binaural, discrete channels, Higher Order Ambisonics). These parameters offer a rich terrain for investigating how acousmatic music may modulate perception, emotion, and bodily experience.

Conclusion

We contend that the intentional practice of acousmatic music, whether through listening or production, presents promising opportunities for enhancing health and wellbeing, particularly in contexts where people experience long-standing symptoms causing distress and suffering, e.g., persistent pain. Acousmatic music, by embedding listeners in unfamiliar auditory environments, offers unique opportunities for engaging with sensory, emotional, and cognitive reactions that may lead to new understandings and therapeutic strategies, including opening up conversations with others. We intend to direct future research on elucidating the potential of acousmatic music to reshape listening, articulate living experiences and evoke memories, thereby facilitating a deeper exploration of suffering. Art-led practices, including engagement with music, are increasingly recognized as effective modalities for supporting individuals living with pain and other long-term conditions e.g., the Unmasking Pain project (37, 38). Future collaborations with arts organizations could facilitate the development and evaluation of how acousmatic music may be utilized to express and explore the narratives of living with pain.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Author contributions

NS: Conceptualization, Writing – original draft, Writing – review & editing. MIJ: Conceptualization, Writing – original draft, Writing – review & editing.

Funding

The author(s) declare that no financial support was received for the research and/or publication of this article.

Acknowledgments

We express thanks to Balbir Singh, Devika Rao and audiences for attending acousmatic music performances.

Conflict of interest

MIJ wishes to declare that in the previous 5 years, his employer has received income for expert consultancy activities from GlaxoSmithKline, TENSCare, and LifeCare Ltd. that lie outside of the submitted work. MIJ declares book royalties from Oxford University Press and re-imbursement of expenses for speaking at conferences.

The remaining author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declare that Generative AI was used in the creation of this manuscript. Microsoft Copilot, based on the GPT-4 architecture was employed to refine grammar, syntax, and overall readability of parts of the manuscript, ensuring the content is clear and accessible to a broader audience. The authors have reviewed and verified the accuracy of the AI-generated suggestions.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpain.2025.1672412/full#supplementary-material

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frontiers | Frontiers in Pain Research

TYPE Original Research
PUBLISHED 14 November 2025
DOI 10.3389/fpain.2025.1682702

OPEN ACCESS

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RECEIVED 09 August 2025
ACCEPTED 29 October 2025
PUBLISHED 14 November 2025

CITATION
Perrin J, Hasenfratz K, Peng-Keller S, Rufer M and Naef R (2025) Developing a best practice guide for integrating spiritual care interventions in chronic pain therapy: a qualitative Delphi study.
Front. Pain Res. 6:1682702.
doi: 10.3389/fpain.2025.1682702

Developing a best practice guide for integrating spiritual care interventions in chronic pain therapy: a qualitative Delphi study

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Chronic pain patients (CPPs) often face complex, multifactorial challenges, with many reporting that their pain management lacks comprehensiveness. Spiritual care has emerged as a potential resource in addressing the diverse needs of CPPs, but remains underutilized due to healthcare professionals' (HCPs) uncertainty about how to integrate it into clinical practice. This study aimed to develop a best practice guide for integrating spiritual care into chronic pain therapy using a qualitative Delphi study. Three rounds of data collection, involving a panel of CPPs and HCPs with expertise in chronic pain from various disciplines, were conducted. Participants shared their experiences and suggestions for addressing spiritual aspects in pain therapy. The process led to the formulation of a consensus-based best practice guide, outlining practical strategies for HCPs to engage with spiritual care in a way that is respectful and sensitive to individual patient needs. Results indicated that incorporating spiritual care in chronic pain therapy can enhance therapeutic relationships, foster more meaningful patient interactions, and provide additional coping mechanisms. The guide was rated as clinically applicable, and offers a structured yet flexible framework for integrating spiritual care into multimodal pain treatment and is expected to improve patient outcomes by addressing existential aspects of chronic pain.

KEYWORDS

chronic pain, best practice guide, health professionals, Delphi study, spiritual care, chronic pain patients

Introduction

About 20% of the European population lives with chronic pain (1), which is a multifactorial, complex condition that affects all dimensions of being (2, 3). Up to two thirds of the chronic pain patients (CPPs) consider their pain management to be insufficient (4, 5); many of them do not feel understood by their health care professionals (HCPs) (6). The high symptom burden, which leads to restrictions in everyday life and limitations in meaningful social interaction, coupled with a lack of

effective treatment, may raise existential questions of meaning (7). A comprehensive, holistic and person-centered approach to health care, as recommended by the WHO (8), requires HCP to address the spiritual dimension of health (9–13).

Studies have shown that spiritual care is associated with a range of positive health outcomes (14–17), including overall well-being and a constructive interpretation of illness experience (18–20), which are of importance for CPP. In previous studies about CPPs' and HCPs' spiritual needs and concerns it was shown that up to 60% of participating CPPs would like spiritual aspects of health to be included in the treatment process, regardless of their religious believes or denomination (21).

Despite potential benefits, the spiritual dimension of health is seldomly addressed in multi-modal pain treatment (22): Both groups, HCPs and CPPs, seem to perceive spiritual aspects as a very private matter or even a taboo (23). They report to be unaware that the spiritual dimension is an integral part of health care (23). Although HCPs are generally open to integrating the spiritual dimension of health into care, they hesitate due to a lack of best practice guidance, time constraints, and inexperience (23, 24).

To address the lack of guidance in clinical practice, a best practice guide for the integration of spiritual care interventions in chronic pain therapy was developed. The aim of this study was to develop an interprofessional expert consensus on integrating spiritual care interventions in chronic pain therapy.

Materials and methods

Design

We used a three-round Delphi study (25, 26) with patient and health professional experts on chronic pain, which was carried out between December 2020 and July 2022. The Delphi method was chosen as it is regarded as a suitable method for research questions that require gathering subjective information from experts (27) in a given area of uncertainty or lack of empirical evidence (25, 26), and where no consensus has been reached before (28). Following Delphi standards (29, 30), the first round used open and broad questions, followed by more specific, in-depth ones in subsequent rounds. The data from each round was analyzed qualitatively and descriptively and was incorporated into the questions for the second and third round (25, 31).

Setting and participants

Participants ($n = 47$) included CPPs and HCPs (physicians, nurses, social workers, physiotherapists, occupational therapists, psychologists) working with chronic pain patients in the German-speaking part of Switzerland.

Abbreviations
CPP, chronic pain patient; HCP, health care professional.

Inclusion criteria for HCPs were regular clinical activity with CPPs for at least one year in acute, rehabilitation, community or primary care setting, an age of at least 18 years and no research activity in the area of spiritual care in order to exclude specific in-depth expert knowledge in this area as far as possible. Students were excluded.

Inclusion criteria for CPPs was a diagnosis of chronic pain [pain for ≥6 months with a pain intensity of ≥5 on the 11-point Numeric Rating Scale (NRS; 0 = no SZ, 10 = worst pain)] due to non-terminal illness.

Data collection processes

Experts were selected by the research group following the above criteria. Recommendations by selected experts were used to recruit further experts (snowball sampling), still according to the defined selection criteria. The same recruitment process was used for round two in order to compensate partially for declining response rates. Since round three was mainly used to evaluate a synthesis of the knowledge generated in rounds one and two, experts who missed round one and round two were excluded from round three.

Each expert was assigned an individual and group-specific code for pseudonymization. Communication with the experts was effectuated via email for the entire study to minimize group pressure for conformity (32), dominant voices taking over the discussion (31), or the influence of seemingly deemed superior expert individuals over others (33).

The first Delphi round was conducted in December 2020, the second in September 2021, the third in June 2022. For each round, the experts had a response time of two months, with an additional month after one reminder, sent out per e-mail. The data collection form with questions for each of the three rounds was accompanied by a cover letter and further documents including the most recent version of the best practice guide in German, all of which can be found in Supplementary Material. The final version of the best practice guide and other resources are available for download at https://www.spiritualcare-leitfaden.ch.

First Delphi round—drafting the best practice guide

The goal of the first round was to map and explore which spiritual care aspects were seen as most important by the experts to integrate into multimodal pain management. The questions (Table 1) were deliberately open and based on findings from former studies performed by the research team (21, 23, 24, 34). A definition of *spirituality* that is established in the health care context was introduced at the beginning to ensure a common departure point (35). A multidimensional understanding of *spiritual distress* (36) and *spiritual well-being* (37) served as the theoretical basis for this study. We intentionally chose a broad and inclusive definition of *spirituality* as a dynamic dimension (38) or a *travelling concept* (39), persons with no religious affiliations are not excluded (40) and different backgrounds are acknowledged (41).

Second Delphi round—refining the best practice guide

The questionnaire used in the second round (Table 1) included a mix of six open and close-ended questions that were formulated based on the findings from the first Delphi round. In addition, the experts were asked to evaluate a first digital version of the best practice guide, which the research team had drafted based on the results of the first Delphi round. In particular, the experts were asked whether they considered the first version of the best practice guide appropriate and helpful in a clinical setting. The experts' feedback on suitability of the best practice guide was elicited narratively and with a numerical rating scale (NRS).

TABLE 1 Questions used in the three Delphi rounds.

Questions used in the three Delphi rounds	
Question No.	First Delphi round—introductory questions
1	From your experience, what could be suitable starting points for addressing spiritual aspects (both resources and burdens)? How can these be recognized?
2	Are there questions, phrases, images, or metaphors that have worked well in conversations with patients about spiritual resources and stresses?
3	What do you see as key factors that make it difficult to address the spiritual dimension in treatment?
4	Suppose your patients were to fill out the assessment instrument we developed (see appendix) as part of their treatment. How would you address the answers in the treatment? What would you focus on and how?
Question No.	Second Delphi round—follow-up questions
1	Does the guide in this form reflect your suggestions from the first round? Do you have any additions or suggestions for adaptation?
2	How do you rate the appropriatness of the guide for clinical work with persons with chronic pain (comments on content are also very welcome)? Please give an assessment using NRS 1 (=absolutely unusable)—10 (=perfectly suitable) and a brief written explanation.
3	Metaphors that are experienced as helpful for the conversation have been mentioned repeatedly: (a) Do you have good experiences with certain metaphors? With which ones? (b) Would picture cards/photos help? If so, in what form/which pictures?
4	What further support/additional materials could be helpful for such clinician-patient interactions?
5	How important do you think it is to document the explored r/s resources and burdens in the patient dossier or similar and what should be paid attention to?
6	What further assistance would you need or recommend for the implementation of the guide? What collaboration would you recommend?
Question No.	Third Delphi round—follow-up questions
1	What experiences have you had with the guide? Do you have any input on adjustments to the content or design?
2	With (approximately) how many patients (nominally and/or as a percentage) have you used the guide or individual questions from it in recent weeks?
3	How suitable is the guideline in clinical practice? Please give an assessment using NRS 1 (=absolutely useless)—10 (=perfectly suitable).
4	Does the guide in this form reflect your suggestions from the second round?

Third Delphi round—implementing the best practice guide

Before the third and final round, the best practice guide was further refined, graphically redesigned and adapted according to the findings of the second round. The most significant adaptation was the separation of the best practice guide into a pocket card and an accompanying booklet, according to the experts input (see *Results*). The final version of the best practice guide, along with five follow-up questions, was distributed to the experts for review (Table 1). This time, the experts were asked to use the best practice guide in practice and then report on their experiences by evaluating the clinical applicability, again both in narrative form and by using a numerical rating scale (NRS).

Data analysis

After each Delphi round, expert answers were collected, pseudonymised, and analyzed using qualitative content analysis according to Mayring (42, 43), which was supported by using HyperResearch®, a computer-aided qualitative data analysis software for semantic coding. The content analysis method aims to maintain a source's complexity while systematically condensing its content and sort it into categories. It does so by capturing the content of the source text using *in vivo* codes before grouping them, therefore increasing confirmability and traceability of the results (44).

In each round, the codes and categories were generated abductively (45, 46), which means that they were formed both deductively, top-down starting from the research question, and inductively, driven bottom-up by the data and the codes. During this process, each code and category were described and defined in a standardised format to maintain intersubjective neutrality. Codes were justified by a comment if it could not unambiguously be assigned to a text passage. Text passages could fall under different codes, if they fulfilled the respective code criteria. An example of the coding procedure is given in Table 2.

TABLE 2 Example for the coding procedure.

Category	Conversation_content
Subcategory	Steer conversation toward spirituality via inquiry about potential stresses
Code	Addressing stress enables transition to spiritual aspects
Code description	Expert uses the stress discussed as a transition to spiritual aspects. In contrast to "Addressing the intrapersonal coping strategy of the CPP enables transition to spiritual aspects", the focus is on a subjectively perceived burden for the patient, less on a possibly counterproductive coping strategy.
Examples	1_107_02: […] "When you think about the back pain is there anything that is bothering you as a whole person or that is good for you as a whole person?" 1_504_04: […] In the case of conspicuous spiritual burdens, I would bring this up and ask whether the person concerned has already talked about it with someone else […].

The first Delphi round resulted in a set of 45 different codes that were grouped into 13 categories, some of them including subcategories. The second round resulted in 34 codes grouped into 7 categories, and the third round yielded 11 codes in 3 categories. Numerical rating data were expressed as median and range.

Rigour

Following the standards of qualitative-explorative research, the trustworthiness (47) of the analytic results after each round was fostered through critical discussions between the first and second author, both with experience in qualitative-explorative research, the Delphi method and the data analysis used. Before each round, the result of the analysis as well as the set of expert questions were presented and agreed upon by all the members of the research group.

Results

Participants

A total of 44 HCPs and 3 CPPs participated. The majority of HCPs worked in acute medical and outpatient settings with a few working in rehabilitative institutions. While the response rate of the experts contacted across the three rounds declined, the diversity of the responding expert group remained relatively constant, with CCPs having the highest response rate throughout (Table 3).

Overview of results across the three Delphi rounds

Analysis of the first Delphi round showed that HCP-CPP communication around spirituality can be structured into three overlapping phases with specific themes (Table 4), namely:

Phase *a) Creating context for interaction* before and while initiating the conversation; further differentiable into *a_1) Acknowledging challenges* and *a_2) Setting the stage for meaningful conversations.*

Phase *b) Starting intentionally* the phase of topic progression and exploration; further differentiable into *b_1) Initiating the talk* and *b_2) Exploring topics for intervention.*

Phase *c) Concluding the interaction purposefully*; further differentiable into *c_1) Explicating as an intervention* and *c_2) Considering additional interventions.*

TABLE 3 Overview of participants and response rates.

Profession (Code)	First round: contacted/ responding	Second round: contacted/ responding	Third round: contacted/ responding
Physicians (1xx)	19/8	20/8	10/3
Nurses (2xx)	4/2	4/2	3/0
Social workers (3xx)	2/2	2/0	2/0
Physiotherapists (4xx)	7/4	7/3	3/0
Occupational Therapists (5xx)	4/4	4/2	4/1
Psychologists (7xx)	2/1	2/1	3/1
CPPs (6xx)	3/3	3/3	3/2
Total	41/24 (56%)	42/19 (45%)	28/7 (25%)

TABLE 4 Results—overview.

Phase	Themes	Conversations about the spiritual dimension of health in a therapeutic setting …
a) Creating context for interaction	a_1) Acknowledging challenges	… are considered challenging by HCPs for a wide variety of individual, societal, and institutional reasons.
	a_2) Setting the stage for meaningful conversations	… are more likely to occur given sufficient time availability, a private setting, and openness of the HCP to the topic.
b) Starting intentionally	b_1) Initiating the talk	… can be initiated by HCPs both directly and indirectly. Metaphors can support the transition to and conduction of conversations on spiritual aspects.
	b_2) Exploring topics for intervention	… can best be initiated by HCPs through: • Exploration of resources • Understanding CPP's metaphors or by using metaphors oneself as a HCP • Addressing concepts of illness
c) Concluding the interaction purposefully	c_1) Explicating as an intervention	… can be seen as an intervention in itself, in the form of an investment in the therapeutic relationship. The conversation should be documented to improve current and future treatment.
	c_2) Considering additional interventions	… can give way to specific interventions such as: • Exploring and strengthening spiritual resources or integrating them into individual treatment goals • Searching for new resources • Developing a joint concept of illness • Consolidating or resolving metaphors together with the CPP

These phases provide insight into how clinicians can better address spiritual care during interactions with chronic pain patients, and were used to structure the best practice guide.

The findings from the second round were used to adapt and refine the results of the first round by further specifying the key topics of the best practice guide, namely Phases b) and c): These two phases are strongly related to the HCP-CPP communication itself and can easily be influenced by individual HCPs, whereas Phase a) refers to the context in which the communication takes place and requires organizational measures.

After drafting and refining the guide in the first two rounds, the third round of the Delphi study focused on evaluating its clinical applicability. This final evaluation provided key insights into how the guide could be practically implemented in various clinical settings, and further informed the findings structure, resulting in six key themes informing the guide (Table 4):

First Delphi round—drafting the best practice guide

Phase a) Creating context for interaction

Conversations about spiritual concerns often come with uncertainty and unique challenges, requiring a supportive setup. Openness, trust, and understanding were reported to be important prerequisites for making room for spiritual issues to be addressed. Anchor examples supporting the results can be found in Table 5.

Theme a_1) acknowledging challenges

HCPs described conversations about spiritual aspects with CPPs as particularly challenging. On the one hand, general reasons were mentioned, such as an overwhelming pain symptomatology, different socio-cultural backgrounds, or language barriers, all three of which make conversations between HCP and CPP complex and often difficult. HCPs also mentioned their own and society's approach to and significance of spirituality as a difficulty for a successful start to the conversation. For HCPs, addressing the spiritual dimension, which was often a taboo topic in the clinical setting, was sometimes associated with a feeling of transgressing boundaries. A majority of the experts expressed uncertainty: They stated that they lack training and personal familiarity with spiritual care as well as a conversational repertoire including vocabulary, suitable questions, expressions, images or metaphors for a conversation about spiritual aspects in chronic pain. HCPs experienced the role of spiritual care in chronic pain therapy to be intertwined with potentially divergent and interplaying expectations of patients, the health system, and society at large. Lastly, a large number of experts also described a lack of time resources as an obstacle.

Theme a_2) setting the stage for meaningful conversations

Spiritual aspects were often understood by the experts as a very private topic. It was important for them to set the stage in a way that fosters meaningful conversations—whether the conversation is planned or arises spontaneously. Almost all experts stated that a conversation about spiritual aspects requires an authentic and interested attitude toward the topic. HCP's own examination of and reflection on spirituality helps to be open and curious about the CPP's perceptions, even if it may differ from their own stance. It was acknowledged that spiritual aspects are not equally important for all patients, but there was consensus that all those who have a need to talk about them are more likely to do so if the other person signals openness and availability. The experts repetitively pointed out that especially in the often very busy inpatient setting, it is important to create privacy for conversations about spiritual aspects in order to open up a space in which personal views and experiences could be shared. If a conversation on spiritual topics is planned, it is worth reserving sufficient time for it, alike it is already practice for conversations on other topics considered intimate.

Phase b) starting intentionally

HCPs mentioned various topics that can serve as an introduction to a conversation about spiritual aspects with CPPs by either addressing them directly or indirectly. Prominently and frequently mentioned topics are the exploration of spiritual resources, the recognition or use of metaphors or symbolic language as well as the discussion of illness understandings and burden of illness. Anchor examples supporting the results can be found in Table 5.

Theme b_1) initiating the conversation

Examples in the data showed that the initiative for conversations about spiritual aspects was taken more often by the HCPs than by the CPPs. This is why HCPs stressed the need for an openness and familiarity with spirituality as an essential part of therapeutic interactions in health care. The experts felt that conversation about spiritual aspects with CPPs could be initiated in direct and indirect ways, with them having no general preferences. They argued for an indirect entry, e.g., by addressing patients' resources in a general way if it is unclear what significance spiritual aspects have for the CPP. Indirect approaches therefore may not lead to a spiritual topic, but to other areas that are important for the therapy of CPP. Depending on the context and the care process, spiritual aspects may be approached again later. According to the experts, specific spiritual resources or distress can also be asked about directly if the context, relationship, and previous discussions allow for it.

Theme b_2) exploring topics for intervention

A clear majority of the experts reported that an exploration of resources, which is reflective of an indirect approach, can be a useful starting point to address spiritual aspects. Examples include questions about what helps or helped the CPP to bear the pain in the sense of intrapersonal coping strategies; addressing concrete situations that made the pain bearable or addressing a search for meaning caused by the chronic pain. Another way to start addressing spiritual aspects is by using symbolic language or by asking for CPP's metaphors for chronic

TABLE 5 First Delphi round—anchor examples.

First Delphi round—anchor examples		
Theme	Code	Anchor example
Phase a) Creating context for interaction		
a1) Acknowledging challenges	Expectations make it difficult to address the spiritual dimension	404_03: I am a physiotherapist. Expectation and order from patients, employer, health insurance that I mainly take care of the knee, shoulder, etc.
	Aspect of boundary violation makes it difficult to address the spiritual dimension	105_03: it is much easier to ask the patient about his sexuality than about his spirituality. This topic is at least to a certain extent occupied by shame, viewed on a meta-level, of course, completely unjustifiably.
	Lack of thematic reflexion makes it difficult to address the spiritual dimension	601_01: Personally, I think that in the case of a spiritual question or problem, I could also provide too little assistance and therefore would not bring it up on my own.
	HCP has no specific approaches in conversations on spiritual aspects	202_02: Experience and literature show that professionals often lack words.
	Lack of time makes it difficult to address the spiritual dimension	601_05d: Due to limited time and also lack of training, I did not address the importance of daily yoga practice.
	Somatic issues make it difficult to grasp the spiritual dimension	101_03: Pronounced pain symptoms that dominate the patient's entire experience, leaving no room for the topic of "spirituality".
a_2) Setting the stage for meaningful conversations	Conversation on spiritual aspects requires openness	105_01: There are also always patients who talk about their spirituality between the lines or quite openly.Then "the thread" can be picked up well. 501_02: In my experience, patients do not bring spiritual thoughts into therapy on their own and this happens even less the more technical the wording and instructions are. For example, when someone is told to sit up, "Try to straighten your chest". sounds different than "Lift your heart against the ceiling".
	Conversation on spiritual aspects requires understanding	106_03: [Spirituality eventually] is also too personal, they don't want to give away too much of their inner self, knowing that the other person's understanding is not necessarily given.
	Conversation on spiritual aspects requires trust	502_03: The prerequisite is always a trusting relationship with the patient. 601_03: I think that it is unfamiliar for both the practitioners and the patients to talk about spiritual concerns, because it is a very personal topic that is associated with a lot of shyness. So there is probably a lot of uncertainty on both sides.
Phase b) Starting intentionally		
b_1) Initiating the conversation	Patient expresses a desire to talk about spiritual aspects	105_01: There are also always patients who talk about their spirituality between the lines or quite openly.
	Patient directly expresses wanting to talk about spiritual aspects	105_01: There are also always patients who talk about their spirituality between the lines or quite openly.
	Spiritual aspects are asked indirectly	402_01: I am rather reluctant to address them directly. Most of my patients were born abroad. Thus, in most cases, their spiritual roots can hardly be assessed. During the exploration of resources and positive/healthy behavioral strategies, spiritual aspects are often addressed. Mostly these are assessed as resources recognized.
	Spiritual aspects are asked directly	104_02: "Are there powerful, helpful and strength-giving transcendent inner images that help them in crisis situations?"
b_2) Exploring topics for intervention	Addressing resources enables transition to spiritual aspects	401_01: In the conversation, look at the various resources and from these resources come into the conversation about possible spiritual support. 603_04: And in general I would come about resources and what gives energy, longings, dreams etc. on deficiently perceived aspects instead of directly about burdens.
	Addressing situations that make the pain more bearable allow transition to spiritual aspects	107_01: "Are there moments, places, or encounters that you feel make the pain more bearable?"
	Addressing CPPs intrapersonal coping strategy enables transition to spiritual aspects	101_04: Would I address basic life attitudes and clarify what "rails" he wants to lay or has already laid for his life. 107_02: "When you think about the back pain is there anything that is bothering you as a whole person or that is good for you as a whole person?"
	Addressing meaningfulness allows for transition to spiritual aspects	104_01: Question about inner images experienced as meaningful and comforting, previous access to religiosity or lived spirituality. 102_02: "What gives meaning to your life? what still keeps you alive?, what gives you strength?"
	Addressing thoughts that make the pain more bearable allows transition to spiritual aspects	503_02: Very different: Sometimes we use the image of the car that also needs gasoline to drive.Thus the question: Where do you refuel? Or what is the gasoline for them? 301_02: Positive formulations and images from the pain-free phase with the focus of the coping strategy through the inclusion of spiritual aspects are extracted.
	Addressing concepts and explanatory models enables transition to spiritual aspects	104_06a: CPP with migrant background from Serbia experiences her severe work accident and the subsequent psychosocial consequences as divine punishment. 107_01: Letting the pain tell: for example, "Are there moments, places, or encounters that you feel make the pain more bearable? What do you think makes the pain more bearable?"
	Addressing stresses enables transition to spritual aspects	403_02: Always having to fight and experiencing setbacks—trying to run up a sand dune and not getting off the ground. Frustration of the situation—the grass does not grow faster when you pull on it. Hopelessness and aimlessness—standing at the railroad track but no train comes.

(*Continued*)

TABLE 5 Continued

First Delphi round—anchor examples		
Theme	Code	Anchor example
Phase c) Concluding the interaction purposefully		
c_1) Explicating as an intervention	Intervention already happens by listening	301_06b: Relief can come with just thematizing, as these are very deep-seated and often shame-ridden feelings. 107_06b: Patients often already feel understood when they notice that the medical professional is interested in the individual explanation pattern in the sense of transcultural sensitivity.
	Intervention happens through interdisciplinary collaboration	402_06b: In the case of spiritual stresses, I offer space for the patient's narrative. In doing so, I make sure that what is said is manageable for me. If the patient brings up deep-seated spiritual injury, I try to mark the boundaries of physiotherapy. In the best case, I succeed in pointing out to the patient that the content is a good topic for psychotherapy.
	Spiritual aspects are addressed repeatedly	201_01: It seems important to me that the spiritual aspects are not asked once, but are taken up and addressed again and again in the course. 202_06c: Take your time, also say that you have time. Express that you can understand [the patient]. Bring it up in several conversations … in stages.
c_2) Considering additional interventions	Intervention by addressing the spiritual dimension as part of the therapy goals	108_05b: Nature as a "place of power" was used to achieve a concrete treatment goal (to be able to go to the place of power again). For the patient, spirituality was the motivator, so to speak. 106_05d: Physical therapy alone would not have motivated the patient, but the prospect of being able to go back into the forest would have.
	Intervention through direct promotion of circumstances that make the pain more bearable.	102_07b: With the patient, try to find the really important things in life, to live in the here and now. What is really important.
	Intervention through exploration of alternative resources	402_05c: I try to find out why the place of power (e.g., forest, home, or mountains) is important and what the place triggers in the person. The focus is on the physical reactions. Then we try to explore whether this positive feeling can be reproduced in other places or other activities.
	Intervention by promoting access to existing resources	107_05b: To talk primarily about the forest, the vacations or the Jasskränzchen [social Swiss card game] and in this way, without making direct recommendations, to stimulate thoughts.
	Intervention by dissolving negative concepts	106_06b: Correct an idea that is burdensome for the patient, where the disease comes from 102_06b: Clarify the question of guilt, Often people feel guilty where they are not guilty but did not fulfill the expectations of others.
	Intervention by reversing a negative connotation	107_05a: I often had similar experiences: It seems important to me that the negative connotation is transformed into a positive one: Instead of "I can't do all that anymore" better "if I could, it would certainly do me good". This can be about places like in the example "forest", about points in time like "on vacation" or also about human encounters "in the Jasskränzchen".

pain. The experts repeatedly stated that metaphors, proverbs, and idioms expressed by the CPP may be indicative of their beliefs. Use of metaphors was considered particularly helpful as some CPPs are better at communicating in images than abstract words. According to the experts, these images can be taken up or developed together with the CPP.

Phase c) concluding the interaction purposefully

Most experts viewed conversations on spiritual aspects as an accessible, generalist intervention in itself. In addition, various starting points for further specific spiritual care interventions emerged from the experts' responses. Anchor examples supporting the results can be found in Table 5.

Theme c_1) explicating as intervention

Even the low-threshold inclusion of spiritual aspects into interactions with CCPs was understood as an investment in the therapeutic relationship and reflective of spiritual care, which may mean that additional, specialized interventions may not always be necessary. So, according to the experts, an open conversation that does not exclude spiritual aspects can be understood as a spiritual intervention because it can trigger CPP's reflection on spirituality and its potential for their health and well-being. Moreover, many experts emphasized the importance of interdisciplinary collaboration, which is necessary for conversations, especially about spiritual aspects.

Theme c_2) considering additional interventions

Sometimes specific interventions relating to spiritual aspects were also considered useful by the experts. Possible interventions mentioned by the experts were, for example, exploring and strengthening spiritual resources or integrating them into individual treatment goals, opening up new resources, or addressing negative concepts of illness that lead to spiritual distress.

So, according to the experts, the spiritual dimension can be taken into account in jointly formulated therapy goals. This can be done in the sense of promoting access to spiritual resources or integrating them into therapeutic actions, e.g., through targeted occupational or physical therapy, pain therapy or everyday life planning. If, for example, a CPP had experienced long walks in the woods as spiritually healing before becoming unable to walk longer distances, physiotherapy could enable the CPP to do so again.

Similarly, the patient can be encouraged to search for alternative and new resources. Chronic pain or illness and the associated limitations potentially make it difficult or impossible to access existing spiritual resources. According to the experts,

the point here is not to make suggestions to the patient or even to impose something on the CPP. What is meant is the accompaniment of a search for new supportive values, experiences or practices. Initially, this sometimes involves simply acknowledging the losses experienced.

The explanation of the origin of pain and the joint development of an individual illness understanding is an important basis in pain therapy. If, according to the experts, it becomes clear that spiritual distress (such as feeling punished by God) are related to the illness, addressing them can be important for the patient. CPPs often find it helpful and relieving to be able to talk about and understand this spiritual distress. An ongoing accompaniment and support in developing a less stressful perspective can be important for the therapy. For a low-threshold access to all specific interventions, a search for and unfolding of helpful metaphors is again seen appropriate. This is often implicitly recognized by the experts when they repeatedly speak figuratively of opening up "places of power".

Second Delphi round—refining the best practice guide

Phase b) starting intentionally

In the second Delphi round, expert feedback pertained mainly to *b) Starting intentionally* and *c) Concluding the interaction purposefully*. The focus was especially on how to structure conversations around spiritual aspects by using specific techniques, such as images and language. Anchor examples supporting the results can be found in Table 6.

b_2) Exploring topics for intervention

The experts saw value in the use of metaphors to initiate and then focus on spiritual aspects during interactions. Around half of the experts explicitly stated that they had already used them consciously or unconsciously. As in the first round, the experts emphasized the benefits of both physical images and language images in case of cultural or linguistic communication barriers. The experts also repeatedly stressed the importance of taking the physical images of metaphors of CPPs as a starting point to explore them jointly.

HCPs saw value in the use of hardcopy images or objects (such as pictures or puppets), although only a few had experience using them. There were reservations about their use for hygienic reasons.

Phase c) concluding the interaction purposefully

In this second round, two topics were relevant, namely how to document spiritual care interventions in *c_1) Explicating as intervention* and the types of images used for spiritual care intervention in *c_2) Considering additional interventions.*

c_1) Explicating as intervention

In the second round, almost all experts explicitly stated that it is important to document the content of discussions on spiritual aspects with CPP, e.g., in the patient dossier. Two main reasons were given by the experts: On the one hand, recording spiritual aspects including spiritual resources and distress allows HCP and CPP to jointly set and review goals in multimodal pain therapy. On the other hand, information about the conversations can reach all current and future treatment providers, which is relevant for interdisciplinary collaboration in multimodal pain management. Furthermore, according to the experts, the recording of spiritual aspects in a patient dossier or elsewhere gives them greater weight and visibility. Some experts argued in favor of sketchy documentation only, since extensive documentation could be perceived as intrusive by the CPP. What seemed most important was to maintain prudence in documentation, as should be the case for all potentially sensitive topics in trusting therapeutic relationships.

c_2) Considering additional interventions

Asked about their experiences with suitable examples of metaphors, the experts stated the usage of images with positive connotations significantly more frequently. This applies both to images for moving a conversation towards spiritual dimensions or continuing to work with an image in a therapeutic way. The most frequently mentioned images were those of nature: A tree as a symbol of growth, weathering a storm, home and shelter for birds, a river as a symbol of serenity, continuity or transience. Images of nature often overlap with images of movement and dance, which were also often mentioned: A mountain to be climbed or a garden where one can dance. A third group, repeatedly mentioned, included images from mechanics: A car that needs to be refueled, or a train station at which one waits. Religious symbols, such as a cross or a prayer chain, were hardly used by the experts.

Rating of the best practice guide by the expert group

With regard to the suitability of the best practice guide to integrate spiritual care into their clinical work with CPP, the experts gave the refined draft as used in the second round a median NRS score of 8 out of 10 ($n = 13$, min = 7, max = 10). The majority of experts reported narratively that the current version integrated their own inputs from the first round well. The practically oriented structure with examples was appraised to be a clear, helpful and beginner-friendly guide to enable discussion about the spiritual dimension of chronic pain and its management with CPP.

Nonetheless, minor modifications were considered necessary for the guide to be usable in everyday clinical practice for each group of therapeutic professionals, as it would otherwise be too generalizing. Also, some experts wished for an introduction or training in the use of the best practice guide.

There was somewhat conflicting feedback on the desired length and level of detail: Some experts wanted the best practice guide to be more detailed, with more examples and a theoretical background. Other experts noted that it is precisely the brevity and clarity of the current version that make the guide usable in everyday clinical practice—and would even prefer a slimmer, more reduced version.

TABLE 6 Second delphi round—anchor examples.

Second Delphi round—anchor examples		
Theme	Code	Anchor example
Phase b) Starting intentionally		
b_2) Exploring topics for intervention	Expert works with metaphors	401_03a: Images of nature such as trees, rivers, landscapes contribute a lot to stability; more often I have also experienced images of movement as power images, such as sailing, mountain climbing, etc.
	Expert expresses positive opinion about metaphors	111_03a: Yes, vivid comparisons help to convey content, often helpful when related to the patient's world of experience. 503_03a: Yes! However, rarely in an initial interview. Images are more likely to emerge in the work with clients. Perhaps also to change beliefs, to develop new power images.
	Expert expresses positive opinion about physical images	105_04: Personally, I always like to work with drawings, mind maps, etc., but these are developed together with the patient on a sheet of paper or on a flip chart. 110_03b: Could be supportive via the additional visual input.Would also be an option with people from immigrant backgrounds. 601_03b: For people who may find it more difficult to have an abstract conversation or who may not understand everything due to a language barrier, picture cards might be helpful. The picture of the sand dune and the garden are very helpful for me.
	Expert expresses herself ambivalently to negatively about picture cards/ photos	201_03b: Rather impractical or costly due to hygiene regulations.
	Expert suggests physical objects with image meaning	101_04: Instead of cards, one could use objects with analog content, or have the patient bring them: Object that relieves pain, strengthens the patient. 701_04: Possibly natural materials (e.g., stones, flowers, roots,…) or symbolic objects (e.g., wooden figures, candles).
Phase c) Concluding the interaction purposefully		
c_1) Explicating as an intervention	Documentation is important	102_05:Be sure to write down resources or techniques that help deal with acute pain. So that one can remind the patients in the given case again. 112_05: Importance of religion/spirituality should be given the same weight as family or work. 203_05:Possibly brief documentation, possibly create patient documentation in Kisim [common clinical information system in Switzerland] on request, whether desired and permitted by the patient. Explain that in principle it is also important for the entire treatment team to know what resources are available or whether beliefs are present. But actually only in terms of "what is important for the treatment team" document from my point of view.
	Freedom from judgment and respect are important in documentation	101_05: This seems very important to me, because this is relevant information for all those treating. However, it is important to document r/s aspects respectfully and not in a judgmental way. Documenting also lifts spirituality out of the taboo sphere, especially if the patient notices or is told about it. 110_05: Documentation is important, also with regard to possible changes of therapists, to check agreed goals, etc; but also in the sense of multimodal pain therapy. In the latter context, coordinated collaboration of the various disciplines under the same concept with the same goal is crucial. Care must be taken to ensure that documentation is free of judgement
	Documentation should be discreet	105_05: I could imagine that the topic of religion and spirituality is even more shameful than questions about sexuality. For this reason I would recommend to make only very superficial documentations concerning this. Such as: has spiritual needs or is open about spirituality. Nothing more.
	Spirituality is a taboo subject	603_05: Important but only in consultation with the patient.
c_2) Considering additional interventions	Example for negative images	101_03a: I find pictures very helpful, especially when they come from the patient. Painting therapy is a valuable approach here. I have often continued to work with images from painting therapy. The fire that burns, the hammer that crushes. Also r/s symbols can appear here spontaneously: Light, darkness, the cross, the hand of God.
	Example for positive images	602_03a: Pictures from nature (tree, meadow, river) 501_03a:—sth. is "in flow", it is "running" vs. blocked, stagnant—walk, path, steps, vs. seeing a mountain, abyss, obstacle—view, looking back on a way vs. "turning in the wheel", lack of perspective—creating islands as a symbol for breaks/relief/relaxation

Third Delphi round—implementing the best practice guide

The last round focused on rating the clinical applicability of the finalized best practice guide, which was rated with a median NRS score 8.75 out of 10 ($n = 7$, min = 8, max = 10).

Those experts participating in the third round felt that their feedback and expertise that they had provided were well represented in the final version of the best practice guide. The experts praised the inclusion and openness of the guide's examples regarding different forms of spiritual aspects and described it as helpful support for less experienced HCP. Some experts even reported using the best practice guide with success with non-chronic pain patients. As expressed earlier, HCPs saw a need to increase awareness and to offer education and training on how to integrate spiritual care into chronic pain management, based on the best practice guide.

Discussion

The aim of this study was to develop a comprehensive best practice guide for the integration of spiritual care interventions into chronic pain therapy. To accomplish this, we used a three-round Delphi method involving an expert panel consisting of health professionals and patients with chronic pain. Through iterative rounds and using qualitative methods, we gathered insights on essential components of spiritual care and identified specific challenges in incorporating spiritual conversations in the clinical setting. Each Delphi round allowed for refinement of the guide, aligning expert input with the practical needs of chronic pain management. The guide was finalized based on consensus feedback on its clinical applicability, which was rated as high. It provides a structured framework that facilitates respectful and meaningful integration of spiritual care.

The findings underscore the need for spiritual care as a critical component in multimodal pain management. Experts reported that the guide's structured approach supports HCPs in addressing spiritual aspects with CPPs, enhancing therapeutic rapport, and reducing the taboo surrounding spirituality in healthcare. The resulting guide offers accessible tools, such as metaphors and specific conversation strategies, to foster open discussions about spiritual resources and distress. Overall, the integration of spiritual care in chronic pain therapy, as advocated in the guide, promises improved patient outcomes through more holistic, patient-centered care.

As far as the applicability is concerned, the best practice guide has been found valuable by the experts to provide HCPs with an accessible and usable tool to initiate conversations with CPPs on spiritual resources and distress relevant to their chronic pain management. In daily practice, this can contribute to (a) reducing the taboo surrounding spiritual aspects, (b) addressing them, (c) integrating them into clinical treatment, and (d) documenting them systematically.

a) **Reducing the taboo surrounding spiritual aspects:** As long as spirituality is considered something private or a taboo topic even by experts on chronic pain, the hurdle of addressing it in clinical setting is enormous for less experienced HCPs (48–50). This uncertainty in regard to the inclusion of spiritual care may lead HCPs to be less open regarding spiritual aspects due to the fear of making mistakes or to transgress a patient's sense of privacy. Qualitative findings, which synthesize expert consensus, demonstrate that there are several practicable and feasible ways to address spiritual aspects in conversation with CPPs, especially in light of an inclusive definition of spirituality that is not limited by religious beliefs or faith traditions.
b) **Addressing spiritual aspects:** The experts particularly emphasize the relevance of using metaphors to facilitate provision of spiritual care across interactions and conversations with CPPs (*creating context for interaction, starting intentionally, concluding the interaction purposefully*). Images can be incorporated or picked up at a low threshold in the conversation and facilitate communication across language or cultural boundaries that may exist between provider and patient. In the best practice guide, we included multiple examples for metaphors or questions, as recommended by the experts, together with additional background information in the accompanying booklet.
c) **Integrating spiritual aspects in clinical treatment:** As shown in our previous studies (23, 24), HCPs find it challenging to integrate the spiritual dimension into chronic pain management, which was confirmed in the present study. There is a fear of imposing oneself and intruding into a very personal realm. We were able to show that HCP's apprehension may be mitigated by proopsing different ways to approach spiritual care, for example by addressing them in indirect ways through engaging in a conversation on general resources and capacities. Moreover, we found that it was important for HCP to understand that an invitation to express spiritual resources or distress constitutes a spiritual care intervention. The best practice guide that details concrete and different approaches to spiritual care is is meant to assist HCPs to work with CPPs in a supportive way and to enable them to draw forth meaningful and helpful practices, values and experiences.
d) **Documenting spiritual aspects:** Qualitative findings also demonstrated the need to document spiritual care in the patient record first, to make the importance of spiritual aspects in chronic pain patients visible, ensuring that patient needs for spiritual care are addressed, and second, to enable collaborative, interprofessional spiritual care.

Strengths and limitations

This study contributes to the growing efforts to promote the integration of spiritual aspects in healthcare. The broad range of experts on chronic pain from different professional backgrounds allowed to incorporate a variety of viewpoints, which is key in Delphi studies. In line with good practices related to Delphi research, the coding system was generated in several deductive and inductive processes. Qualitative content analysis with documentation principles enabled a critical examination of results to be rooted in the original data. Frequent discussions with the entire research group supported the trustworthiness of the results.

Limitations of the study include the rather small sample size with a moderate and declining response rate. The overrepresentation of the expert group of physicians also leads to a bias in favor of their beliefs and experiences, while the voices of the CPPs were relatively underrepresented by the small expert group in comparison to the sum of the different HCP subgroups as a whole.

These aspects underline the necessity of a validation of the best practice guide on a larger scale in follow-up projects. Furthermore, the sampling procedure might have resulted in a selection bias with an overrepresentation of participants who take a keen

interest in spiritual care or who have open attitudes towards spirituality. These limitations need to be taken to account when transferring the results of this study to other contexts.

Conclusions and future directions

Using the Delphi method, we generated an interprofessional expert consensus on spiritual care provision in chronic pain patients, primarily based on HCP perspectives. The consensus informed the development of a best practice guide that was also appraised for its utility in clinical practice. This represents the first step, as no comparable guideline has been developed and tested in this area to date. In a next step, utility and applicability of the guide needs to be evaluated in larger group of HCPs and especially CPPs.

The best practice guide attempts to address many areas of discussing spiritual aspects that experts consider difficult in interactions between HCPs and CPPs. Nevertheless, such a guidance will not be able to replace, but complement spiritual care training in health care staff. In this regard, further interventions are needed to raise awareness and provide continuing education.

Another aspect repeatedly mentioned by the experts that prevents the integration of spiritual aspects is the time factor—and thus, indirectly, the costs. Therefore, cost-benefit analyses of spiritual care need to be conducted, focusing on whether the training for HCPs and the resulting intervention outweighs its cost in terms of efficiency and effectivity.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Ethics statement

Ethical approval was not required for the study involving humans in accordance with the local legislation and institutional requirements. Written informed consent to participate in this study was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and the institutional requirements.

Author contributions

JP: Writing – review & editing, Writing – original draft, Investigation, Project administration, Formal analysis, Conceptualization, Data curation, Methodology, Visualization. KH: Data curation, Conceptualization, Supervision, Writing – review & editing, Project administration. SP-K: Funding acquisition, Writing – review & editing. MR: Conceptualization, Writing – review & editing. RN: Methodology, Supervision, Conceptualization, Writing – review & editing.

Funding

The author(s) declare that financial support was received for the research and/or publication of this article. This work was financially supported by Swiss National Science Foundation, Grant No. 407440_167507/1.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpain.2025.1682702/full#supplementary-material

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frontiers | Frontiers in Pain Research

TYPE Perspective
PUBLISHED 08 December 2025
DOI 10.3389/fpain.2025.1659170

OPEN ACCESS

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RECEIVED 03 July 2025
REVISED 12 November 2025
ACCEPTED 21 November 2025
PUBLISHED 08 December 2025

CITATION
Bäckryd E (2025) Putting pain into words: the psalms of lament as an aid for the alexithymic. Front. Pain Res. 6:1659170. doi: 10.3389/fpain.2025.1659170

Putting pain into words: the psalms of lament as an aid for the alexithymic

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This paper explores how existentially and religiously laden texts such as the psalms of lament can help alexithymic persons living with chronic pain to articulate their emotions. It is proposed that verbalizing emotions through psalms of lament can promote coping, and this hypothesis is exemplified by a reading of Psalm 13. The first part of Psalm 13 helps the alexithymic reader turn existential anguish into questions, expressing feelings of being forgotten, ignored, worried, and antagonized. In the second part, there is a shift towards expressing expectations using the imperative mood, highlighting assertiveness. Assertiveness, though not part of alexithymia, relates to emotional expressiveness, and learning to express requests and expectations is health-promoting. In the third part, hope is introduced. This is linked to the psalmist's ability to say "I." Self-assertion is crucial for overcoming externally-oriented thinking, empowering persons to see themselves as active agents. Trust and hope are active stances, essential for living well despite chronic pain. Hence, texts viewed as sacred by alexithymic readers can help them get a language with which to express their discomfort.

KEYWORDS

alexithymia, existential, lament, pain, suffering

Introduction

It has been claimed that about a tenth of the population is alexithymic (1). Simply put, the construct of alexithymia designates problems with putting emotions into words. The Toronto Alexithymia Scale (TAS-20), a questionnaire that is often used to assess alexithymia (2, 3), consists of three subscales, illustrating three important facets of the construct: *difficulty identifying feelings*; *difficulty describing feelings*; and *externally-oriented thinking*, i.e., the tendency of individuals to focus their attention externally and not on the inner emotional experience (4). Using the international threshold criterion for alexithymia (TAS-20 sum score ≥61), it has been estimated that the prevalence in the general population is 10 percent (5). There seems to be an association between this construct and male gender, increasing age, low educational level, poor perceived health, and depression (1).

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" (6). Pain is hence by definition both a sensory and an emotional experience. In the present paper, the emotional component of pain is in the foreground. Needless to say, this focus does not in any way invalidate the very real effect that pain has on the lived experience of patients. Neither does it reduce pain to an irrational feeling without reference to the real world.

Chronic pain is real, and because it is real, it has an emotional component. In this context, it is interesting to reflect on the relationship between pain as an emotion and difficulties in putting this emotion into words. Alexithymia, literally meaning no words for emotions (*a* = lack, *lexis* = word, *thymos* = emotions), has been described as a prominent feature in chronic pain conditions (7, 8). Hence, the alexithymia construct is not only theoretically or interpersonally relevant; it also seems important from a health perspective in general, and perhaps for chronic pain in particular.

About 20% of the adult population suffers from chronic pain (9). Chronic pain can often be viewed as a disease in its own right rather than just a symptom of another underlying disease or injury. Given the present status of medical science, such chronic pain is very difficult to treat pharmacologically (10). Research is ongoing concerning the pathophysiology of different chronic pain conditions (11), the long-term vision being that it might become possible in the future to prescribe effective analgesics for chronic pain using valid and reliable biomarkers (12). Meanwhile, patient education, psychotherapy, and judicious physical activity are central to evidence-based chronic pain rehabilitation. Simply put, if it is not possible to take away the pain, it is still possible to help patients live meaningful lives despite pain. In such circumstances, not being able to identify and put your emotions into words is probably a drawback. In a broader context, Pennebaker's work on expressive writing (13) has put the benefits of emotional expression on the agenda of medical research, e.g., concerning the psychological well-being of cancer patients (14).

Believers have for centuries used the Book of Psalms in prayer and devotion. Between one third to one half of the 150 psalms are laments (15), and Psalm 13 has been characterized as being a typical psalm of lament (16). Generally speaking, in lament, "Everything in on the table: doubt, anger, despair, guilt, resentment. There is no requirement of politeness. There is no need of gentility" (15). Typical for lament is also "a distinctive movement from plea to praise" which is "an act of boldness" in the sense that lament thereby entails the possibility of change and transformation (15). In that sense, lament is dynamic, it is a movement, an active involvement not only with God but with the world and the circumstances that the believer faces. It has been suggested that biblical psalms of lament can have an important function as means of coping with trauma (17), or resolving anger towards God (18). Even the imprecatory psalms, which are psalms that describe feelings of hate and animosity, have been said to be useful in the sense that they "provide a valuable mechanism for the cathartic release of negative emotion" (19). All in all, it has been proposed that the psalms, many of which were shaped thousands of years ago by traumatic circumstances such as war and deportation, can serve as religious coping means that believers may draw upon in the present when facing trauma and adversity (17).

The aim of this paper at the interface of reader-response studies and medicine is to show how a psalm of lament such as Psalm 13 might help alexithymic believers, who suffer from for instance chronic pain, to put their existential emotions into words. In doing so, I will assume that such verbalization is helpful and promotes coping. I will also assume a formative use of biblical texts, i.e., I will assume that a putative believer uses such texts in devotions and spiritual practices aiming at character formation (c.f., the tradition of *lectio divina*). Importantly, this paper is hypothesis-generating and theoretical rather than empirical, i.e., the hypothesis that is here described needs to be tested in empirical and confirmatory studies with an appropriate methodology, the elaboration of which is outside the scope of the present paper.

Methods

This is not an exegetical paper. The original text, its Hebraic wording and meaning is not the focus of this study. Rather, this work is akin to a reader-response approach to biblical texts (20), focusing on the way putative alexithymic readers might be helped by reading Psalm 13. Hence, I will simply use the translation of New International Version (NIV):

> [1]How long, LORD? Will you forget me forever?
>
> How long will you hide your face from me?
>
> [2]How long must I wrestle with my thoughts
>
> and day after day have sorrow in my heart?
>
> How long will my enemy triumph over me?
>
> [3]Look on me and answer, LORD my God.
>
> Give light to my eyes, or I will sleep in death,
>
> [4]and my enemy will say, "I have overcome him,"
>
> and my foes will rejoice when I fall.
>
> [5]But I trust in your unfailing love;
>
> my heart rejoices in your salvation.
>
> [6]I will sing the LORD's praise,
>
> for he has been good to me.

A superficial analysis of this short psalm reveals a threefold division consisting of two verses each. It will be argued that each part can be hypothesized to be beneficial for alexythemic believers who try to put their existential anguish into words, for instance in a chronic pain setting.

Turning existential anguish into questions

Verses 1-2 express four strong human emotions: being forgotten; being ignored; being worried; being antagonized. Of course, the well-known parallelistic tendency of biblical poetry must be taken into account. Hence, the twin ideas in verse 1 of being forgotten and being ignored are in many ways synonymous (i.e., synonymous parallelism). Being forgotten conveys a feeling of geographical distance, God being portraited as a relative or friend on a journey far away who never sends any news. On the other hand, the feeling of being ignored, i.e., that God's face is hidden, assumes proximity in space—it is as if the psalmist views him- or herself in the same room as God but without being able to see the Face. The God who is present is nonetheless invisible, and the psalmist feels ignored. "I know you are there, so why do you hide?" Feeling ignored is a powerful emotion, and there is neuroscientific evidence suggesting that social exclusion activates a network of brain neurons that are also involved in the experience of pain (21). If God is in any sense "real" to the believer, it seems reasonable to hypothesize that the ability to somehow overcome this sense of isolation and "reconnect" to God might be helpful. Being able to put one's existential questions into words can be seen as a first step, and psalms of lament can be used to that effect by believers—and perhaps particularly by alexithymic believers. In many ways, verse 1 is about the actualization in real life of what philosophers of religion call "the hiddenness of God" (22). This "problem" is reminiscent of, but partly different from, the problem of evil in the philosophy of religion.

In verse 2, worry is expressed—worry in general, but also in particular worry about "enemies". Applied to a pain medicine context, it is well-known that psychological distress is common in chronic pain patients, and a subset of them also express what could be characterized as social distress—e.g., reporting low levels of social support and high levels of punishing responses from significant others (23). Metaphorically and congruent with a reader-response use of the Bible, this verse could hence help alexithymic believers to put both pain-related psychological and pain-related social distress into words.

All in all, verses 1-2 can help believers turn their anguish into tough existential questions addressed to the God they believe in. Indeed, biblical spirituality, as expressed paradigmatically by the attitude of the suffering Job, does not shy away from asking tough existential questions in prayers and devotions—as illustrated by these four questions that all begin by "How long?" The implication is that suffering has been taken place for too long, a situation that chronic pain patients by definition can identify themselves with (24). The alexithymic believer can here find words in which his or her emotion can be clothed. There seems to be some empirical support for the notion that chronic pain patients more often than others feel abandoned by God (25).

Expressing existential expectations by using the imperative mood

In NIV, verses 1-2 are questions, whereas verses 3-4 express expectations by using the imperative mood. Spirituality is not only about asking questions, it can also be about using the imperative mood in prayer and devotion. Hence, the psalmist is here very assertive. Interestingly, alexithymia and assertiveness have been described as "two indirect measures of the difficulties in emotional expressiveness" (26). Hence, although assertiveness is not strictly speaking part of the concept of alexithymia, it is nonetheless a related concept. As expressed by Duckworth and Mercer (27):

> Assertive behavior usually centers on making requests of others and refusing requests made by others that have been judged to be unreasonable. Assertive behavior also captures the communication of strong opinions and feelings. Assertive communication of personal opinions, needs and boundaries has been defined as communication that diminishes none of the individuals involved in the interaction, with emphasis placed on communication accuracy and respect for all persons engaged in the exchange.

A low capacity for assertiveness is problematic (28, 29). For instance, there is some evidence to support the notion that assertiveness might protect against burnout (30). All in all, learning to express requests and expectations might be viewed as health-promoting, and verses 3-4 can help believers do just that when they turn the words of the psalmist into their own. Hence, Psalm 13 can help the suffering believer to state his or her wishes frankly—directly into God's "face", but also, as a consequence, to humans who act like "enemies" (verse 4).

Hope and being able to say "I"

Now to verses 5-6. Here, in the final third part of the text, hope emerges, and this hope is associated with the psalmist's capacity to say "I". Commenting on verse 6, Old Testament exegete Helmer Ringgren says that the "I" is here emphasized, i.e., it could therefore be translated "I, for one" (16). Of course, there seems to be a link between the capacity to say "I" and being able to be assertive (c.f. verses 3-4). Another side of assertiveness is being able to say "I", i.e., asserting yourself and your point of view in a balanced way can be viewed as "the behavioral middle ground, lying between ineffective passive and aggressive responses" (27). Moreover, learning to say "I" can also be part of overcoming one of the three facets of the concept of alexithymia, namely externally-oriented thinking. Learning to say "I" shifts the focus from only a description of circumstances to a vision of the self as an agent capable of having a say-so on life. Hence, there is something empowering in the ability to say "I" and, in the case of the psalmist, this is parallelled by the rise of hope. Trusting in God is not to be equated with passivity. Trust and hope are active stances grounded in healthy self-awareness. Applied to the chronic pain setting, one is reminded of the importance of a rehabilitative stance, whereby the patient is not a mere passive recipient of biomedical interventions but instead is an active agent whose "work" (not least psychologically) is essential for the ability to live a good life despite the pain that present medical science is not able to alleviate.

Conclusion

I have argued that Psalm 13, if used in devotions and spiritual practices in the *lectio divina* tradition, can help the alexithymic believer who suffers from chronic pain (a) to put deeply human emotions into words by asking questions (verse 1-2), (b) to assert oneself by using the imperative mood (verses 3-4), and (c) to put hope and trust into words by use of the personal pronoun "I" (verses 5-6). Of course, Psalm 13 is merely one example of the rich tradition of psalms of lament. Also, the example of chronic pain has been chosen due to the profession of the author; if the basic contention of the paper is right, there is nothing that hinders a wider application of the principles described in it. All in all, viewed from the perspective of a formative reading of the Bible, the psalms of lament can be viewed as effective forms of emotional expression that can help the alexithymic believer get a language with which to express his or her discomfort.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Author contributions

EB: Conceptualization, Formal analysis, Methodology, Writing – original draft, Writing – review & editing.

Funding

The author(s) declare that no financial support was received for the research and/or publication of this article.

Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

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frontiers | Frontiers in Pain Research

TYPE Original Research
PUBLISHED 12 December 2025
DOI 10.3389/fpain.2025.1610109

OPEN ACCESS

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RECEIVED 11 April 2025
REVISED 22 October 2025
ACCEPTED 17 November 2025
PUBLISHED 12 December 2025

CITATION
Åkerblom S, Peppler Jönsson I, Ringqvist Å, Nordengren J and Zhao X (2025) Identifying and characterizing clinical subgroups in individuals with endometriosis.
Front. Pain Res. 6:1610109.
doi: 10.3389/fpain.2025.1610109

Identifying and characterizing clinical subgroups in individuals with endometriosis

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Background: Classification attempts and treatment strategies for endometriosis have been predominantly biomedical. Symptom profiles observed in individuals with endometriosis are multidimensional and may be more effectively captured by a biopsychosocial model.
Methods: The aim of this study was to identify distinct subgroups of individuals with endometriosis based on their biopsychosocial profiles, using Latent Class Analysis. In a subsequent phase, the identified subgroups were compared in terms of sociodemographic characteristics and various indices of functioning.
Results: Two distinct subgroups were identified: Class 2, representing a high biopsychosocial burden (BPS) group characterized by both significant psychological strain and severe pain characteristics, and Class 1, representing a low BPS group with low scores on these indicators. The high BPS group reported worse control/powerlessness and greater deficits in social support.
Conclusion: Moving forward, clinical assessment of patients with endometriosis may benefit from integrating core principles from the biopsychosocial model. This approach can help identify individuals facing significant psychosocial challenges who may require multidisciplinary interventions alongside evidence-based biological treatments.

KEYWORDS

endometriosis, biopsychosocial model, pain intensity, pain extent, pain catastrophizing, depression, anxiety

Introduction

Endometriosis is an inflammatory disease in which endometrial-like tissue grows outside the uterus. It is a common gynaecological disorder with a prevalence of approximately 10% in women of reproductive age (1, 2). Pain is a predominant feature, and both its intensity and other associated symptoms often fluctuate cyclically. Research shows that a substantial subgroup of individuals with endometriosis experience chronic pain, defined as pain lasting more than three months (3, 4). In recent decades, the scientific understanding of pain in endometriosis has shifted, since studies have demonstrated a weak correlation between lesion characteristics and pain severity. As pain becomes chronic for some patients, central nervous system mechanisms, such as central sensitization, are thought to become more influential. However, many clinicians and patients still believe that endometriosis-associated pain

is solely due to the lesions, and most research and reviews continue to focus on lesion characteristics, rather than the pain (3, 5).

Beyond the physical symptoms, individuals with endometriosis often experience reduced quality of life and negative impacts on important life areas, such as relationships, sexuality, fertility, work, and leisure activities (6, 7). Individuals with endometriosis have also been shown to suffer from psychiatric comorbidities, such as anxiety and depressive disorders (8, 9), and often experience heightened pain catastrophizing (10). These clinical factors likely have a significant effect on disability and quality of life (10–12). Still, classification attempts and treatment strategies for endometriosis have primarily been biomedical, including hormone therapy, surgical methods, analgesics and in some instances opioids. The latter with negative side effects for a subgroup of patients (13–17).

The variable effectiveness of current treatment interventions suggests a need for greater optimization and personalization to improve outcomes for individuals with endometriosis (18–20). In line with this, a growing body of literature highlights the multidimensional nature of symptom profiles among individuals with endometriosis (8, 9, 21). These profiles may be better understood through a biopsychosocial model, which considers biological (e.g., pain intensity, disease severity), psychological (e.g., anxiety, depression), and social factors (e.g., financial hardship) and their interactions. The biopsychosocial burden of a specific individual is a multidimensional experience, encompassing the cumulative impact of these factors (22).

Subgrouping patients can be useful to capture the core aspects of symptoms experienced by individuals with endometriosis, enable more effective and personalized interventions, and support the healthcare system in optimizing costs and resources (23). Notably, Bendifallah et al. (24) proposed a model that focuses on clinical and symptomatic indicators to predict endometriosis using machine learning techniques. However, self-perceived psychological factors, such as pain catastrophizing, were not included in the model (24). This exploratory study aims to identify distinct subgroups of individuals with endometriosis, receiving care at a tertiary clinic, based on their biopsychosocial profiles, using Latent Class Analysis (LCA). Clinical factors, including biological characteristics (pain intensity and extent) and psychological variables (depression, anxiety, and pain catastrophizing), will serve as indicator variables (12). In a subsequent phase, the identified subgroups will be compared in terms of sociodemographic characteristics and various indices of functioning.

Methods

Participants

This cross-sectional study included patients referred for evaluation at the Endometriosis Clinic, Skåne University Hospital, Malmö, between April 2019 and May 2024. To be eligible, participants were required to meet the following inclusion criteria: (1) Referral to the clinic during the study period; (2) A confirmed diagnosis of endometriosis, verified either by: laparoscopic surgery, or ultrasound. The clinic is a government-supported, regional tertiary care center providing services for adults with endometriosis. All participants gave informed consent, and the study was approved by the Swedish Ethical Review Authority (2019-00023).

Measures

All measures were based on self-report.

Indicator variables

Biological factors

Pain Extent, or the number of pain locations was measured using 36 predefined anatomical areas (18 on the right side and 18 on the left side of the body) where the patients recorded areas with pain: (1) head/face, (2) neck, (3) shoulder, (4) upper arm, (5) elbow, (6) forearm, (7) hand, (8) anterior aspect of chest, (9) lateral aspect of chest, (10) belly, (11) sexual organs, (12) upper back, (13) lower back, (14) hip/gluteal area, (15) thigh, (16) knee, (17) shank, and (18) foot. The number of pain locations reported by the respondent (range: 0–36) was summed.

The Numerical Rating Scale (NRS) was used to assess self-reported pain intensity. Respondents were asked to rate their pain during the past week on an 11-point scale, where 0 = no pain and 10 = worst possible pain. The NRS is widely used in pain research and is an acceptable measure of pain intensity with demonstrated sensitivity to subjective changes in pain across various contexts (25, 26). Regarding pain intensity, the following cut-off points were used: 0–3 for mild pain, 4–6 for moderate pain, 7 and above for severe pain (27).

Psychological factors

The Hospital Anxiety and Depression Scale (HADS) was used to measure the degree of depression and anxiety symptoms over the past week (28). It is a 14-item scale, where seven items assess depression and seven items assess anxiety. The items are rated on a scale from 0 to 3, with higher scores indicating greater symptom severity. The cut-off points for the subscales are as follows: 0–7 for non-cases, 8–10 for doubtful cases, and 11–21 for clinical cases (28). The validity and reliability of both the English original and the Swedish version used in this study are well established (28, 29).

The Pain Catastrophizing Scale (PCS) measured pain-related catastrophizing within three subscales: helplessness, magnification, and rumination (30). The 13 items are scored on a 5-point scale (0 = not at all; 4 = all the time) and summed to produce a total score. Should read: Higher scores denote greater levels of catastrophizing, and a total score of 30 or above represents a clinically significant level of pain catastrophizing. The psychometric properties of the PCS are considered satisfactory (30).

Predictor variables

The sociodemographic variables included age and education level.

The Endometriosis Health Profile-30 (EHP-30) was used to assess control and powerlessness, social support, and self-image. EHP-30 is an endometriosis-specific self-report measure used to assess health-related quality of life in individuals with endometriosis (31). It includes 30 core items divided into five core subscales measuring pain, control and powerlessness, self-image, emotional wellbeing, and social support. Additionally, there are six supplementary modules comprising 23 items divided into work, relationship with children, sexual relationship, feelings about the medical profession, feelings about treatment, and feelings about infertility. Each item is rated on a five-point scale: (0 = never; 4 = always). The scores in each domain are converted to scale of 0–100, where 0 indicates the best health status and 100 the worst. The psychometric properties of both the original and the Swedish version of the EHP-30 have been found to be satisfactory (31, 32).

Analysis

LCA was used to identify subgroups among the participants. Based on a previous Swedish study of patients with chronic pain (12), five indicators were used in a finite mixture model: anxiety, depression, pain extent, pain intensity, and pain catastrophizing. To detect the optimal latent class solution, 2- to 6-class solutions were modelled. Enumeration indices for selecting the optimal solution included the adjusted Lo-Mendell-Rubin Likelihood Ratio Test (LMR-LRT) (33), Akaike information criteria (AIC), Bayesian information criteria (BIC), and sample-size-adjusted BIC (34). Specifically, we ran five models and collected the fit statistics listed above. The optimal model should show lower values on AIC, BIC, and sample size adjusted BIC, as well as higher entropy. The adjusted LMR-LRT produces a significant result ($p < 0.05$) if moving from k–1 to k latent classes leads to a statistically better model fit. Other than these fit statistics, we also considered a subgroup size smaller than 5% as problematic (34).

Following the identification of latent classes, five covariates (i.e., control and powerlessness, social support, self-image, age, and education level) were included as predictors of latent class membership. To extend the unconditional mixture model, a three-step approach (35) was employed using auxiliary variables, enabling the investigation of how latent class indicators exert their influence. Data were managed in R 4.4.0, and all major analyses were performed in Mplus 8.10 (36, 37).

Results

Participant characteristics

The study involved 113 female participants, with a mean age of 36.9 years ($SD = 8.0$; range = 21–61). The majority of participants (70.8%) were born in Sweden or another Nordic country. In terms of education, 62.5% had completed tertiary education, while 27.7% had completed secondary education. The mean pain extent among participants was 9.7 locations (SD = 6.7). Additionally, two participants (1.8%) reported only one pain location, while 96 participants (85.0%) had four or more pain locations. For pain intensity, 23.9% of participants reported mild pain (scores: 0–3), 28.4% reported moderate pain (scores: 4–6), and 47.7% reported severe pain (scores greater than 6). Notably, 54.9% had a clinically significant level of pain catastrophizing. Regarding mental health, results from the depression subscale showed that 47.8% were non-cases, 23.0% were doubtful cases, and 29.2% were clinical cases. The anxiety subscale revealed that 28.3% were non-cases, 25.7% were doubtful cases, and 46.0% were clinical cases. For more information, see Table 1.

Identifying latent classes

To identify relevant clinical subgroups among the participants, LCA was used. As shown in Table 2, although key information criterion values (i.e., AIC, sample-size-adjusted BIC) decreased as the number of classes increased, their entropy metrics remained similar at approximately 0.80. Moreover, the 5- and 6-class solutions produced very small subgroups (i.e., classes with only four members), indicating these solutions were problematic. Judging from the adjusted LMR-LRT values, only the 2-class solution showed a statistical improvement from 1-class to 2-class, and further increases of class number did not enhance this fit. Thus, the 2-class solution was deemed optimal. Figure 1 presents the estimated means of these two latent classes (subgroups). Class 2 members clearly showed elevated levels across all indicators, suggesting they experienced greater psychological distress and more severe pain characteristics than Class 1 members.

Covariates of latent class membership

Logistic regression using the three-step approach identified two covariates with statistical significance (Table 3). Compared

TABLE 1 Participant characteristics ($N = 113$).

Variable	*n* (%) or M (SD)
Age (years)	36.9 (8.0)
Birthplace	
Sweden or Nordic Country	80 (70.8%)
Other country	33 (29.2%)
Education level	
Elementary school	8 (7.1%)
Upper secondary school	31 (27.7%)
University	70 (62.5%)
Other	3 (2.7%)
Pain extent (0–36)	9.7 (6.7)
Pain intensity	5.6 (2.7)
Pain catastrophizing	31.9 (12.3)
Depression	7.9 (4.4)
Anxiety	10.3 (4.7)

TABLE 2 Summary of fit statistics of 2-to 6-class solutions.

Solution	AIC	BIC	SSABIC	Entropy	LMR-LRT (*p*)	Smallest subgroup size (%)
c2	3,383.55	3,427.19	3,376.62	0.81	131.69 (0.000)	53 (46.9%)
c3	3,369.59	3,429.59	3,360.06	0.82	25.08 (0.254)	27 (23.9%)
c4	3,360.21	3,436.58	3,348.08	0.82	20.65 (0.397)	19 (16.8%)
c5	3,348.86	3,441.59	3,334.14	0.83	19.43 (0.621)	4 (3.5%)
c6	3,341.69	3,450.79	3,324.37	0.83	16.68 (0.770)	4 (3.5%)

Note: AIC, Akaike information criteria; BIC, Bayesian information criteria; SSABIC, sample-size- adjusted Bayesian information criteria; LMR-LRT, adjusted Lo-Mendell-Rubin Likelihood Ratio Test. *p*: *p*-value.

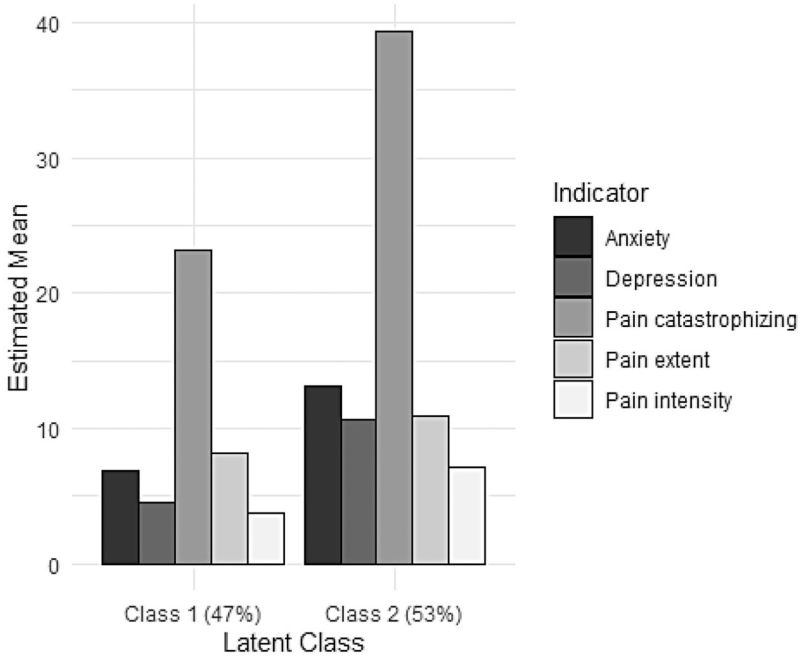

FIGURE 1
Estimated means of indicators in two latent classes. Class 1 means: Anxiety = 6.9; Depression = 4.6; Pain catastrophizing = 23.2; Pain extent = 8.2; Pain intensity = 3.8. Class 2 means: Anxiety = 13.2; Depression = 10.7; Pain catastrophizing = 39.3; Pain extent = 11.0; Pain intensity = 7.1.

with Class 1, Class 2 members reported worse control and powerlessness ($b = 0.29$, $p = .013$, $OR = 1.34$) and greater deficits in perceived social support ($b = 0.36$, $p = .001$, $OR = 1.44$).

TABLE 3 Logistic regression predicting latent class membership.

Variable	Estimate	S.E.	*P*-value	Odds ratio
Control and powerlessness	0.29	0.12	0.013	1.34
Social support	0.36	0.11	0.001	1.44
Self image	0.01	0.13	0.948	1.01
Age	0.04	0.06	0.506	1.04
Education	1.21	0.83	0.145	3.36

Note: Class 1 was used as the reference group. Control and powerlessness, social support, and self image were measured with the Endometriosis Health Profile-30.

Discussion

This study aimed to use clinical factors from the biopsychosocial model (including pain intensity, pain extent, depression, anxiety, and pain catastrophizing) to identify distinct subgroups of individuals with endometriosis, receiving care at a tertiary clinic. Two distinct subgroups were discerned: Class 2, characterized by a high biopsychosocial (BPS) burden with elevated psychological distress and severe pain, and Class 1, defined by a lower BPS burden with comparatively mild symptoms across domains.

These subgroups were also compared in terms of sociodemographic characteristics and different indices of functioning. Notably, the high-BPS burden group reported worse control/powerlessness and greater deficits in perceived social support. To our knowledge, this is the first study to

cluster clinically verified endometriosis patients based on the biopsychosocial model, which considers the dynamic interaction between biological, psychological, and social factors (19, 22). Overall, the findings extend the chronic pain literature into the field of gynaecological care, highlighting the potential benefits of interdisciplinary integration for improving clinical understanding and treatment.

The high-BPS burden group represented 53% of the sample, indicating that a substantial proportion of patients at a tertiary care center experience complex, multifaceted difficulties. This underscores the need for comprehensive assessments incorporating core components of the biopsychosocial model when evaluating individuals with endometriosis (22). The findings also emphasize the need to move toward individualized, stratified, phenotype-based treatment approaches in endometriosis care, tailoring interventions based on biopsychosocial burden rather than relying on one-size-fits-all strategies.

Overall, psychological strain was high across the entire sample, with 54.9% reporting a clinically significant level of pain catastrophizing, 46.0% meeting criteria as clinical cases of anxiety, and 29.2% as clinical cases of depression. These findings are consistent with existing research highlighting elevated rates of psychiatric comorbidities and pain catastrophizing among individuals with endometriosis (8, 9, 11, 38). Pain catastrophizing, in particular, has been shown to moderate the relationship between pain severity and symptoms of depression in individuals with endometriosis, and to have strong associations with quality of life (39, 40). Depression, anxiety, and catastrophizing are also considered key factors in pain-related functioning (41, 42). In line with this, Class 2 participants exceeded clinical thresholds for all three indicators and exhibited more severe pain profiles. The group also reported feeling worse powerlessness, an experience conceptually linked to helplessness, further emphasizing the role of catastrophizing in shaping clinical presentation.

The elevated levels of depression and anxiety reaching clinical significance in the high-BPS burden group align with a growing body of evidence in chronic pain and pain phenotype research, which identifies subgroups characterized by heightened pain severity and pronounced emotional symptoms (23, 43). A positive correlation between pain intensity and anxiety symptoms has been demonstrated in patients with endometriosis (44). Moreover, anxiety, which may be triggered by specific gynecological procedures, is known to amplify the perception of pain (45). The observed overlap between pain and emotional symptoms in Class 2 suggests a bidirectional relationship, emphasizing the central role of mental health in the clinical manifestation of pain (43, 46). These findings further underscore the contribution of anxiety and depression to more severe clinical presentations in individuals with endometriosis. The additive effect of emotional symptoms in the high-BPS burden group potentially requires targeted interventions addressing these symptoms specifically. Hence, psychological therapies such as Cognitive Behavioral Therapy (CBT), with a sound evidence base in chronic pain, may be of particular importance in this subgroup of individuals with endometriosis. This aligns with chronic pain management guidelines where such interventions are the front-line treatment, but are not yet routine in endometriosis care (47).

Regarding pain characteristics, the average number of pain locations was 9.7 (on a scale from 0 to 36), suggesting that most participants experienced regional pain, as pain is typically described as localized, regional, or widespread (48). Only 1.8% reported having only one pain location. A total of 85.0% reported having four or more pain locations, potentially indicating pain spreading. For pain intensity 28.4% reported moderate pain, and 47.7% reported severe pain.

In the high-BPS burden group, severe pain intensity ($M = 7.1$) was observed, compared to moderate pain ($M = 3.8$) in the low-BPS burden group, along with more pronounced spreading of pain (11.0 locations compared to 8.2 in the low-BPS burden group). Prior studies have identified pain extent as a clinically meaningful marker (12). More widespread pain has also been associated with a longer pain duration and a more severe clinical picture with strong associations to health and pain aspects (pain intensity and pain interference) (49, 50). In addition to indicating severity, pain spreading can also, to some extent, predict poorer outcomes of pain rehabilitation programs (50). Pain spreading is also linked to central sensitization and nociplastic pain mechanisms, making the slightly higher number of pain locations in the high-BPS group clinically noteworthy (51). However, it should be noted that 8 or 11 locations indicate mild to moderate pain spreading (50). Nonetheless, even this relatively subtle difference in pain spreading between the high- and low-BPS burden groups may have clinical implications and should be considered in clinical evaluations.

Pain intensity, by contrast, differed more distinctly with moderate pain ratings in the low-BPS burden group and severe pain ratings in high-BPS burden group. This indicates that high pain intensity is coupled to a more severe clinical picture, which is not surprising. The result aligns with previous studies showing that endometriosis and high pain intensity are correlated with lower quality of life (39, 52). The findings are also in line with previous research demonstrating that individuals with higher pain intensity report elevated pain-related disability and emotional distress (52, 53).

Clinical assessment of patients with endometriosis may benefit from integrating core principles from the biopsychosocial model. Treatment strategies for endometriosis have traditionally been biomedical, yet they often yield suboptimal outcomes for a substantial subgroup of patients. The characteristics of Class 2 reveal significant, complex difficulties in several areas of the biopsychosocial model, potentially pointing to a need for intensive, multidisciplinary interventions grounded in the biopsychosocial model at a tertiary level of care. The low-BPS burden group (i.e., Class 1) may benefit from less resource-intensive, monodisciplinary interventions. Implementing subgroup-based treatment strategies could significantly improve quality of life for individuals with endometriosis. Stratifying patients based on their biopsychosocial profile may also enhance allocation of healthcare resources, providing multimodal care to

those with higher psychosocial burden, and primarily unimodal care to those with lower burden. Further longitudinal studies are needed to validate these findings and guide the development of tailored treatment approaches.

Our study had several limitations. This exploratory study utilized real-life clinical data from eligible patients referred to the Endometriosis Clinic, Skåne University Hospital during the study period. As a result, a formal sample size calculation was not performed prior to data collection. While this approach reflects routine clinical practice and enhances the study's ecological validity, it may limit the statistical power and generalizability of the findings. Future research with predefined sample size estimations is needed to confirm and expand upon these results. The cross-sectional nature of this study also hindered us from analyzing causality. Future studies should investigate how biopsychosocial profiles evolve over time and how they respond to targeted interventions. Diagnostic confirmation through laparoscopy or ultrasound enhances the study by ensuring diagnostic accuracy and clinical consistency across the cohort. However, this approach may limit generalizability, as it excludes important subgroups of individuals with endometriosis, such as those who are asymptomatic or remain undiagnosed. Additionally, this study relied on self-report for other data which may introduce bias. The sample was relatively small and taken from a single-center tertiary clinic based within the Swedish national health services, serving as a regional, specialist center providing healthcare services for individuals with endometriosis, where a small subgroup had planned surgical interventions. Hence, the high proportion of approximately 50% with a higher degree of biopsychosocial symptoms might not generalize to other levels of care, as the sample most likely represents patients with a higher disease burden. Future research should aim to replicate these findings in both primary and secondary care settings, as well as in more diverse populations, including asymptomatic individuals and those identified through community-based screening. Broadening the research scope in this way will help improve generalizability and better reflect the full spectrum of individuals affected by endometriosis. Additionally, while this study focused on biological and psychological indicators, social dimensions were underrepresented. Future research should incorporate explicit social variables—such as employment status, financial strain, or relationship functioning—to more fully capture biopsychosocial dynamics. Integration of biopsychosocial phenotypes with biological markers or disease stage could also help develop a more comprehensive classification system.

In conclusion, this study identified two distinct biopsychosocial subgroups among individuals with endometriosis, highlighting the relevance of psychological and pain-related factors in clinical presentation. The high-BPS burden group showed significant emotional distress and severe pain characteristics, suggesting the need for multidisciplinary care. Integrating biopsychosocial assessment into routine practice may support more personalized and effective treatment strategies, improving outcomes and resource allocation in endometriosis care.

Data availability statement

The datasets presented in this article are not readily available due to reasons of sensitivity. Requests to access the datasets should be directed to sophia.akerblom@med.lu.se.

Ethics statement

This study involving humans was approved by the Swedish Ethical Review Authority. The study was conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

SÅ: Conceptualization, Investigation, Project administration, Formal analysis, Data curation, Methodology, Writing – original draft. IP: Data curation, Writing – review & editing, Investigation, Project administration. ÅR: Conceptualization, Writing – review & editing. JN: Conceptualization, Writing – review & editing. XZ: Writing – review & editing, Software, Investigation, Conceptualization, Methodology, Formal analysis.

Funding

The author(s) declare financial support was received for the research and/or publication of this article. This research was funded by the Skåne University Hospital Psychology Research and Development Grant.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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frontiers in Pain Research

TYPE Original Research
PUBLISHED 02 March 2026
DOI 10.3389/fpain.2026.1728929

OPEN ACCESS

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RECEIVED 20 October 2025
REVISED 21 January 2026
ACCEPTED 30 January 2026
PUBLISHED 02 March 2026

CITATION
Stamenkovic D, Petrović M, Unic Stojanovic D, Novovic M, Radovanovic D, Ladjevic N, Jukic A, Dubljanin Raspopovic E, Rancic N, Miljkovic M, Bulatovic S, Bulatovic B, Meissner W and Zaslansky R (2026) The information that patients, their families, and medical staff wish to know about postoperative pain and its management. Results of the survey after mixed surgical procedures.
Front. Pain Res. 7:1728929.
doi: 10.3389/fpain.2026.1728929

The information that patients, their families, and medical staff wish to know about postoperative pain and its management. Results of the survey after mixed surgical procedures

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Background: Informing patients and families about perioperative pain management is a fundamental element of care. However, patients and their families are often not involved developing such resources. Thus, their viewpoints on content, timing, and methods of presentation remain unknown. Our survey aimed to assess perioperative pain information content, timing, and presentation methods most valued by patients, their families, and medical staff.

Methods: The survey took place as part of a multi-center, quality improvement study in 6 hospitals. On the first postoperative day, patients, family members or friends, and medical staff were asked to complete a questionnaire addressing content about pain, side effects of analgesics, the timing of providing the information, and the preferred method of receiving the information. A composite score was created for questions regarding information content.

Results: A significant difference in total composite score of information items about pain characteristics and management ($p < 0.05$) was observed between the groups. No significant difference was observed between groups for questions evaluating side effects of analgesics ($p = 0.099$). A significant difference was observed between patients and family members for questions concerning information post-discharge ($p = 0.037$).

Conclusion: We found that healthcare providers and patients differ in the some aspects of postoperative pain management they consider important. Patients and families were interested in post-discharge pain management, while medical staff rated pain characteristics and management in immediate period the highest. For all groups, the preferred time for providing information about perioperative pain was before surgery at the pre-operative clinic by an anesthesiologist or surgeon.

KEYWORDS

acute pain, pain education, pain management, patient communication, patient perspective

1 Introduction

Providing patients and families with information about postoperative pain management is a fundamental element of care (1). The American Pain Society recommends that the clinicians provide patients and their family, individually tailored, education that includes information on options for managing postoperative pain and document the plan and goals of care. This is a strong recommendation, yet, the quality of the evidence is low (2, 3). Schug and colleagues state in the Acute Pain Management: Scientific Evidence that patients and their caretakers will have greater control over the quality of their pain relief if they are informed regarding treatment efficacy and any adverse effects (4). The positive effects of preoperative educational interventions on pain have been found to reduce opioid use (5, 6) and improve psychological outcomes, particularly with regard to anxiety and personalization of medical care (7, 8).

During our literature review, we found that patient resources (9, 10) have generally been compiled by healthcare providers, with little or no input from patients (3). This was remarkable as it is, in fact, contrary to current standards whereby patient and public involvement is a core principle for developing high-quality evidence-based clinical practice guidelines (11). The principle standard of patient involvement is based on the premise that resources which involve patients and the public will improve the relevance of the outcomes and quality of the decisions that are made (11, 12). Patient and public involvement aims to shift providers from doing something to or for patients, where the health care provider's perspective is dominant, to doing something with them in partnership (11, 13–16).

In a study of patients undergoing outpatient surgery, patients gave the highest priority to information addressing how to care for the pain and side effects once they were home (17). On the other hand, addressing addiction was given the lowest priority (17). In a follow up study interviewing patients whose primary language was not English, findings were similar and surgical subtype, health status, and age did not affect the results (18). Patients after spine surgery expressed interest in establishing realistic expectations about the surgery as a part of the pre-operative process and preparing a comprehensive pain management plan, which included family and social support, after surgery (19). These studies did not explore optimal timing or preferred delivery modality.

The aims of our survey were to: (1) investigate the information that patients, their families and medical staff wish to know about pain and its treatment options in terms of (i) content (ii) presentation and (iii) timing perioperatively; (2) evaluate whether there is a commonality in the information sought after by patients and by family members; (3) evaluate differences about information preferences between patients and medical staff responsible for their care.

We hypothesized that in terms of content, patients in our sample will be similar to those interviewed by Kastanias et al., in that they would like to receive information on how to address their pain and side effects once discharged (17). The information preference on pain management at home is expected to be particularly valued by family members who might be acting as patient advocates. We hypothesized that medical staff will opt for information about pain management delivered on the ward, consistent with routine clinical practice.

2 Methods

2.1 Survey design and setting

This survey was part of a larger multi-center, multi-national quality improvement (QI) study (Ethical Committee MMA No. 8/2020 date 04.08.2020) (20). Research teams from 6 hospitals in one country (Republic of Serbia) participated in this survey during 3 months.

2.2 Participants

The sample included patients who underwent mixed surgical procedures, requiring overnight hospital stay. Inclusion criteria were: (i) providing consent for participation; (ii) age ≥18 years old; (iii) on the first day after surgery (POD1) and on the ward for at least 6 h, and (iv) ability to read in the native language. For family and/or friends present at the time patients were approached, consent was given orally. The medical staff sample consisted of consultant anesthesiologists and surgeons, anesthesiology and surgery residents, and nurses on the ward, who gave oral consent. Since this was an internal anonymous audit performed on a voluntarily basis, no consent was needed

from medical staff and family members in line with local regulations at the time of survey performance.

2.3 Components of the questionnaire

The original tool "The Information Needs Questionnaire—Pain and Pain Management" (INQPP) was developed based on clinical guidelines, and analyzed and edited by the multidisciplinary committee [Pain Management Education Team (PMET)] dedicated to pain management education (17). PMET consisted of 22 physicians and nurses' experts in the pain field and "allied health professionals" from pharmacy and physiotherapy (17). The tool was tested by postsurgical patients during their hospitalization "for comprehensiveness of content areas and usability" [Kastanias (17), p. 24]. The initial version of the tool was corrected to increase sensitivity by changing the response format from a 5-point to 10-point Likert scale (17).

The original INQPP consisted of 19 questions grouped into 3 sections: (A) pain characteristics and management; (B) side effects of pain medications, and (C) management of pain and side effects once discharged from the hospital (17). We adapted the INQPP, with permission, for use in our patient population and modified the question ratings to an 11-point Likert scale from 0-not important to 10-extremly important. The adapted questionnaire underwent forward translation and back-translation from English to Serbian. Questions were added to assess preferences regarding timing (section D) and methods of presentation (section E) using dichotomous yes/no answers. The adapted questionnaire was then piloted on the national population in 9 patients-family member dyads in postoperative period (Supplementary file). No formal validation of the original or the adapted version of questionnaire was performed.

2.4 Data collection

An investigator, who was not involved in the patient's clinical care, approached participants on the first postoperative day (POD1) to provide background regarding the survey and oral guidance on how to complete the questionnaire. The patients were provided with a printed version of questionnaire and left to complete the questionnaire independently without the investigators involvement. In each center, we aimed for a convenience sample, ≥20 patients, matched to a family member or friend. Medical staff consisted of anesthesiologists, surgeons, residents and medical nurses directly engaged in medical care of patients treated on the surgical wards and were invited to complete the survey. However, the medical staff on the ward did not participate as investigators in the survey to overcome potential researcher bias. No target number for staff members and percentage of kinds of professionals that participated was made.

2.5 Data analysis

Results are presented as count (%) or mean ± standard deviation, and 25th to 75th percentile range, depending on the data type and distribution. The evaluations reported by the groups were compared using one-way ANOVA, chi-squared, and independent samples t-test, depending on the type of data and analysis. All p-values less than 0.05 were considered significant. Data were analyzed using SPSS 29.0 (IBM Corp. Released 2022. IBM SPSS Statistics for Windows, Version 29.0. Armonk, NY: IBM Corp., USA).

2.5.1 Ranking

Items 1 through 19 in the questionnaire were summed to obtain a composite score which was subsequently compared between the groups. Separate composite sub-scores were calculated for the 3 sections addressing pain (items 1–9), side effects of pain medications (items 10–16), and post-discharge (items 17–19). The scores were averaged by question for all groups (i.e., patients, family member, staff), and later ranked from lowest to highest, where higher scores indicate a greater level of importance to the individual completing the questionnaire. We color coded the rankings using conditional formatting in Excel, where a green background indicates the most important, while a red background indicates the least important information, with the midpoint, marked in yellow, being the 50th percentile.

3 Results

3.1 Participants

Of the subjects enrolled between August 2019 and March 2020, data from 143 patients, 130 family members or friends of the patient and 168 members of staff from 12 wards and 6 hospitals, were analyzed (Figure 1). The demographic characteristics of the study sample are presented in Table 1. Participants completed the survey in 10–15 min.

3.2 Content of information

3.2.1 Pain (pain duration, treatment, whom to speak to)

The one-way ANOVA revealed that there was a statistically significant difference for content of information for the total composite score (ANOVA, $F = 5.661$, $P = 0.001$) and for the composite score of items 1–9 (ANOVA, $F = 10.835$, $P < 0.001$). Following these significant one-way ANOVA a *post-hoc* Tukey Honest significant difference (HSD) test was performed to identify which group means differed significantly. The test revealed that patients had significantly lower total sum scores

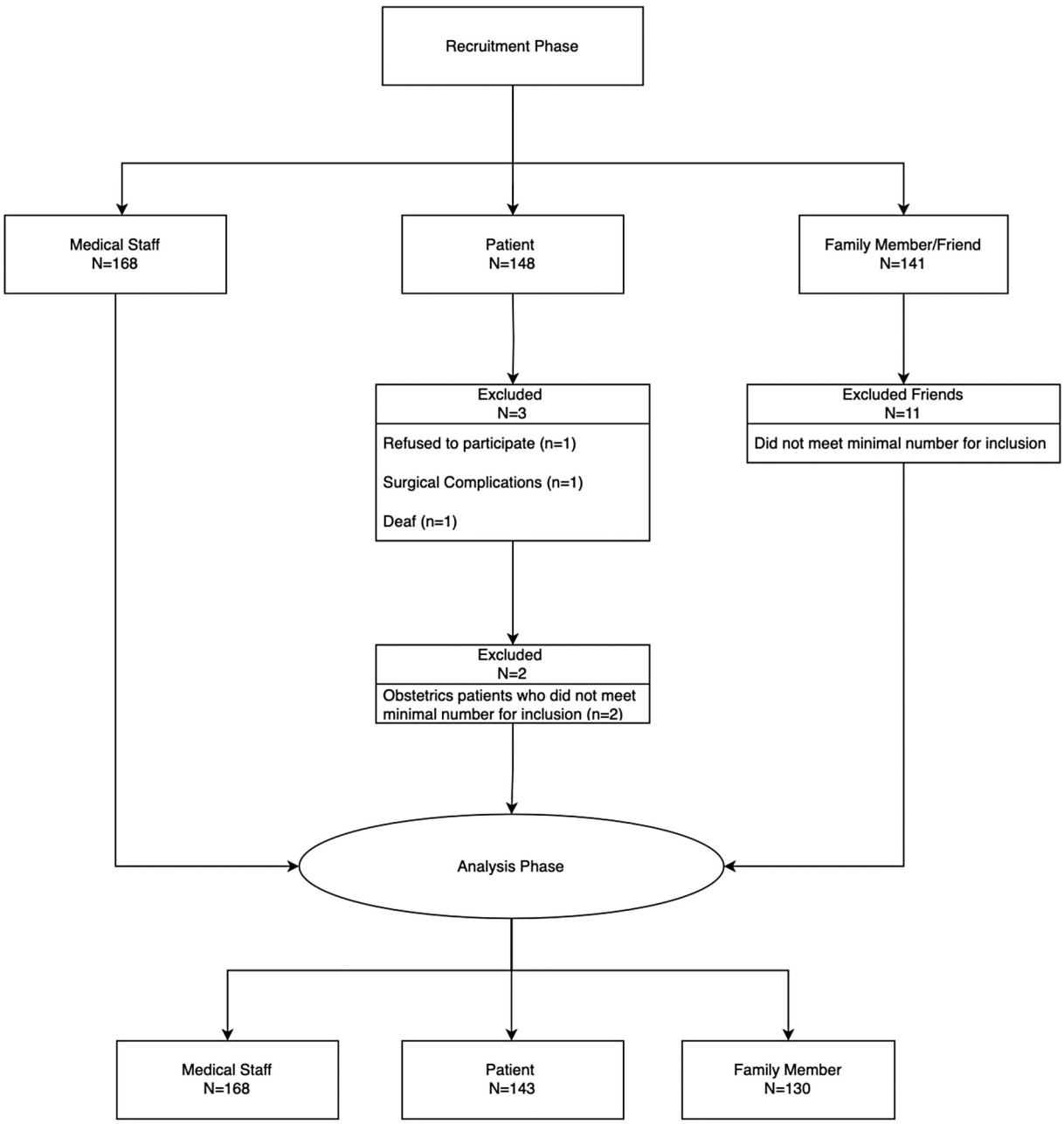

FIGURE 1
Participant flowchart.

compared to family members [mean difference = −16.223, 95%CI (−28.46, −3.99), $p = 0.004$], and staff [mean difference = −16.208, 95%CI (−27.7, −4.72), $p = 0.002$]. These results suggest patients rated postoperative pain information lower than family members and staff.

Information about pain intensity (item 1) and duration of postoperative pain (item 2) were ranked significantly lower among patients compared to medical staff and family members (rank 10 vs. 1 vs. 7, respectively) (Table 2). Items 6 and 7 regarding addiction to pain medication, common concerns about pain (item 8) and pain medicine and financial resources for analgesics (item 9) were among the lowest ranked between the three groups (Table 2). Similar findings were observed in the rankings by family and medical staff. For family members, the least important question was regarding financial resources (item 19), and for medical staff the least important was regarding common concerns about pain (item 8).

3.2.2 Side effects of pain medications (duration, treatment, whom to speak to)

With regard to questions 10–16, evaluating side effects of pain medication, we did not observe a statistically significant difference between groups ($F = 2.103$, $P = 0.099$). However, when comparing

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TABLE 1 General characteristics of the study population.

Demographics	Patient	Family Member	Medical Staff
Sex (Male)	69 (48.3%)	51 (39.2%)	47 (28.0%)
Age	59.2 ± 15.6	49.9 ± 13.1	38.2 ± 10.4
Highest Level of Education			
Elementary	17 (13.5%)	9 (6.9%)	0 (0%)
High School	81 (64.3%)	66 (50.8%)	99 (58.9%)
College/University	45 (35.7%)	55 (42.3%)	69 (41.1%)
Marital Status			
Single	10 (7.0%)	12 (9.2%)	64 (38.1%)
Married	110 (76.9%)	110 (84.6%)	91 (54.2%)
Divorced	8 (5.6%)	5 (3.8%)	12 (7.1%)
Widowed	15 (10.5%)	3 (2.3%)	1 (0.6%)
Employment Status			
Full time	50 (35.0%)	81 (62.3%)	166 (98.8%)
Part time	4 (2.8%)	3 (2.3%)	2 (1.2%)
Self Employed	5 (3.5%)	7 (5.4%)	0 (0.0%)
Retired	61 (42.7%)	21 (16.2%)	0 (0.0%)
Unemployed	22 (15.4%)	11 (8.5%)	0 (0.0%)
Student	1 (0.7%)	7 (5.4%)	0 (0.0%)
Type of Surgery			
General	50 (35.0%)	N/A	N/A
Orthopedic	20 (14.0%)	N/A	N/A
Obstetrics	10 (7.0%)	N/A	N/A
Urology	20 (14.0%)	N/A	N/A
Cardiovascular	43 (30.1%)	N/A	N/A
Self-reported health status			
Poor	7 (4.9%)	5 (4.5%)	2 (1.2%)
Fair	49 (34.5%)	21 (18.9%)	37 (22.0%)
Good	71 (50.0%)	51 (45.9%)	63 (37.5%)
Excellent	15 (10.6%)	34 (30.6%)	66 (39.3%)
Persistent Pain (yes)	28 (24.8%)	5 (5.2%)	15 (9.9%)

All values are presented as mean ± SD or *n* (%).

only patients and family members, there was a statistically significant difference observed ($F = 2.103$, $P = 0.026$). Furthermore, we found that patients and medical staff were more interested about who to refer to in the presence of side effects (item 13, rank 7 and 8, respectively), while family members, on the other hand, were more interested about the type of side effects (rank 6).

3.2.3 Information important after leaving the hospital

Items in this section (questions 17–19) were of greatest importance for patients especially knowledge about the plan for analgesia type and timing (item 17) (Table 2). When further comparing patients to family members, we observed a statistically significant difference with regard to the questions concerning information after leaving the hospital, questions 17–19 ($t = 2.096$, $P = 0.037$). The patients prioritized the plan about pain management (item 17), while family member ranked information about person responsible for information if pain is "not well controlled" (item 18) as number 1 (Table 2).

3.3 Timing of providing the information

With regard to timing of providing information about perioperative pain (item 20), overall, the preferred time for providing information about perioperative pain was before

TABLE 2 Descriptive statistics for each question (Q1–19) in sections A, B and C (information content) of the questionnaire. Results are presented as means and 95% CI [Rank] for mean and *p*-values when comparing means between the three groups. We ranked the questions from 1 (most important) through 19 (least important) based on the mean scores for each question. The coloring was done using conditional formatting in Excel, where a green background indicates the most important, while a red background indicates the least important information, with the midpoint, marked in yellow, being the 50th percentile. Composite scores are presented as mean ± standard deviation.

Questions	Patient	Family	Medical Staff
A) Info about pain			
1. How much pain to expect?	7.3 (6.7–7.9) [10]	8.4 (8.0–8.9) [7]	9.2 (9.0–9.5) [1]
2. How long I can expect to experience pain after surgery?	7.7 (7.2–8.3) [5]	8.6 (8.2–9.0) [5]	9.1 (8.8–9.4) [2]
3. Whom to speak to if I experience pain?	8.0 (7.5–8.5) [4]	8.7 (8.3–9.1) [4]	8.6 (8.3–9.0) [5]
4. The best words to use to explain my pain	5.9 (5.3–6.5) [14]	7.0 (6.5–7.5) [13]	7.5 (7.07–8) [13]
5. How my pain would be treated?	7.6 (7.1–8.2) [6]	8.3 (7.8–8.7) [8]	8.5 (8.1–8.9) [7]
6. If I can get addicted to medications used to treat pain?	5.5 (4.8–6.1) [17]	6.7 (6.1–7.3) [16]	7.1 (6.6–7.6) [15]
7. Other ways of dealing with my pain in addition to medicines	5.4 (4.8–6.1) [18]	6.9 (6.3–7.5) [14]	7.2 (6.7–7.7) [14]
8. Common concerns many patients have about pain and pain medicines	5.2 (4.6–5.9) [19]	6.7 (6.1–7.3) [17]	6.3 (5.8–6.8) [19]
9. If I can get help to pay for pain medicines once I am discharged	5.5 (4.8–6.2) [16]	6.3 (5.7–7.03) [19]	6.8 (6.2–7.3) [17]
Composite Score (Items 1–9)[a]	58.14 ± 23.48	67.62 ± 18.06	70.27 ± 16.85
B)Information about the side effects of pain medications			
10. Which side effects I am most likely to experience?	7.5 (6.9–8.1) [9]	8.51 (8.01–9.01) [6]	7.79 (7.3–8.2) [10]
11. Which are possible side effects, even the rare ones?	5.7 (5.1–6.4) [15]	6.8 (6.2–7.3) [15]	6.7 (6.2–7.1) [18]
12. How likely I was to get the side effects?	6.2 (5.6–6.8) [13]	6.6 (6.1–7.2) [18]	6.9 (6.4–7.4) [16]
13. Who should I speak to if I had side effects?	7.6 (7.1–8.2) [7]	8.1 (7.6–8.6) [9]	8.2 (7.9–8.6) [8]
14. What side effects I should report to staff caring for me?	7.2 (6.6–7.7) [11]	8.1 (7.6–8.6) [10]	7.9 (7.5–8.4) [9]
15. How long might side effects last?	7.1 (6.6–7.7) [12]	7.9 (7.4–8.4) [12]	7.7 (7.2–8.1) [12]
16. How might side effects be treated?	7.5 (6.9–8.1) [8]	8.0 (7.5–8.5) [11]	7.7 (7.3–8.2) [11]
Composite Score (Items 10–16)	48.80 ± 20.99[b]	54.04 ± 17.65[b]	52.89 ± 17.60
C)Information after leaving the hospital			
17. The plan for which medications to take and when	8.7 (8.3–9.2) [1]	9.2 (8.8–9.5) [3]	8.8 (8.4–9.2) [3]
18. Who to call if my pain is not well controlled?	8.7 (8.3–9.1) [2]	9.3 (9.0–9.5) [1]	8.6 (8.3–8.9) [6]
19. What can do if I still have pain or side effects?	8.7 (8.3–9.1) [3]	9.2 (8.9–9.5) [2]	8.7 (8.4–9.1) [4]
Composite Score (Items 17–19)	26.06 ± 7.01[b]	27.57 ± 4.74[b]	26.04 ± 5.94
Total Composite Score (Items 1–19)[a]	133.00 ± 45.93	149.22 ± 35.33	149.21 ± 36.17

A p-value < 0.05 was considered statistically significant.
[a]Statistically significant difference identified by one-way ANOVA.
[b]Statistically significant difference identified by an independent-samples t-test.

surgery at the pre-operative clinic (Table 3). The second choice was different among the groups. Patients and medical staff opted for getting information after surgery, on the first day, while family members tended to prefer "before surgery, as a leaflet sent to my home" (Table 3). There was a significantly higher number of patients compared to family members and medical staff who expressed that they do not wish to have information about pain (Chi-squared, $p = 0.001$).

3.4 Preferred method of receiving information about pain

The preferred methods for receiving information (item 21) is shown in Table 4. All three groups, gave the highest preference to receiving the information orally by the anesthesiologists, followed by the surgeon and then nurse. The second most preferred option for patients and family members was a leaflet left on the ward, while for medical staff the second most preferred option was oral information presented by a nurse.

4 Discussion

This survey identified differences between patients, their families, and medical staff regarding information needs on postoperative pain and its treatment. Patients and families prioritized information about pain management after discharge, while medical staff emphasized information about pain intensity and duration. Most participants preferred receiving information

TABLE 3 Section D (item 20) on timing of providing information about perioperative pain with using dichotomous yes/no answers. We present the number of patients who answered yes (*n*) and the percentage. The percentage exceeds 100, as more than one answer was allowed. All values are presented as *n* (%).

Question 20 and answers	Patient	Family Member	Medical Staff
20.When would you have liked to receive the information? (yes)			
Before surgery at the pre-operative clinic	99 (62.3%)	112 (87.5%)	163 (96.4%)
Before surgery, as a leaflet sent to my home	54 (37.8%)	61 (47.3%)	66 (39.3%)
After surgery, on the first day	58 (40.6%)	59 (45.7%)	92 (54.8%)
Any time after surgery	55 (38.5%)	55 (44.0%)	73 (43.4%)
I do not wish to have this sort of information	31 (21.7%)	23 (17.8%)	14 (8.3%)

TABLE 4 Section E (item 21) address the preferred method of receiving information using dichotomous yes/no answers. We present the number of patients who answered yes (*n*) and the percentage. All values are presented as *n* (%). Multiple responses were allowed for this question.

Question 21 and answers	Patient	Family Member	Medical Staff
21. How would you like to receive the information? (yes)			
Orally by an Anesthesiologist	99 (69.2%)	103 (79.2%)	161 (95.8%)
Orally by a Surgeon	93 (65.0%)	97 (74.6%)	120 (71.4%)
Orally by a Nurse	79 (55.2%)	71 (54.6%)	109 (64.9%)
As a booklet which I can find on the ward	82 (57.3%)	73 (56.2%)	62 (36.9%)
As a poster in the ward	67 (46.9%)	55 (42.3%)	45 (26.8%)
As a leaflet sent to my phone	50 (35.0%)	46 (35.4%)	41 (24.4%)
As a video sent to my phone	38 (26.6%)	39 (30.0%)	31 (18.5%)
As a video in closed circuit TV on the ward	58 (40.5%)	56 (43.4%)	40 (23.8%)

during the preoperative clinic visit. However, preferences for the second-best timing varied: patients and staff preferred the first postoperative day, while families favored "before surgery, as a leaflet sent to home." Across all groups, the preferred format was verbal information delivered by an anesthesiologist or surgeon.

4.1 Content of information

The content of the information provided is of the utmost importance. Irrelevant content information in concurrence with the vulnerable state of patients, particularly in conjunction with nonfamiliarity of the hospital environment may lead to increased patient stress and anxiety (21, 22). Although we as medical staff have constant communication with patients that does not necessarily mean that we are giving them the information of their interest (3). All groups were interested in knowing the person to whom they should speak with if they experience pain, which suggests that patients rely on communication with medical staff as this offers patients the possibility of taking an active role in their pain management (3, 23).

Patients rated information about postoperative pain duration and treatment during hospitalization lower than family members and staff, highlighting a potential area for further investigation in patient support mechanisms (3). Most patients and their family members ranked the questions regarding information after leaving the hospital as the most important. Similar findings were reported in previous studies (17, 18). Medical staff should be encouraged to provide patients and their families with realistic expectations for the recovery process which includes pain management (19); however, the lack of education for this type of conversation is noticeable in practice (3, 16).

Of note is that addiction to analgesics was of low interest for all participants in our survey similar to Kastanias (17), Kastanias (18). However, patients expressed concerns regarding medication side effects after discharge from hospital which was similar to studies that explored opioid analgesic use during that period (24). The difference regarding perception of opioid addiction during the immediate postoperative period and post-discharge period might be the result of treatment duration i.e., short opioid application for postoperative pain management while patient is in the hospital. The literature has also discussed the possibility that information on pain treatment could raise patients' expectations for pain reduction, potentially leading to a higher demand for postoperative opioids (25, 26). The question remains whether our results indicated a greater confidence in receiving appropriate medical care and the belief that pain will be treated with adequate medications when necessary, thus, sparing opioid use (20) or if our results simply reflect lack of awareness toward the addiction in the population we studied. A recently published review concluded that limited data are available about adult patients "perceptions and experiences" with

opioid use during surgery and the immediate postoperative period (27). Therefore, additional investigations are recommended as patient perceptions and experience have an influence on opioid prescription (27). Apart from opioids, the awareness about side effects related to non-opioid analgesics and adjuvants if used for longer periods of time, must be addressed to patients.

4.2 Timing of providing the information

Providing information at the pre-operative clinic gives patients the opportunity to think and prepare, and it is therefore unsurprising that all groups preferred for this timing. In our survey, patients and medical staff preferred receiving information on the first day after surgery as a second option, while family members tended to receive information before surgery, as a leaflet sent to their home. Education and providing information to patients should be considered as a continuous process, and not just be limited to the preoperative period.

Surprisingly, a sizable portion of patients (21.7%) and family members (17.8%) in our survey opted that they do not wish to receive information. This might be a consequence of patients not identifying their role and its function in pain management, as was noticed in qualitative interpretive phenomenological research in patients from single cardiac rehabilitation center by Walton at al (28). However, the patients presented this role through different terms including the discussion of the subjective nature of pain and the importance of using a pain assessment tool (28), which may similarly reflect the desire for perioperative pain-related information, found in our study. Additionally, ignoring deeper knowledge about pain might be culturally related to the belief that surgery is supposed to be painful and that they will deal with the pain. This phenomenon has been previously described as the "positive social appraisal of ability to cope with pain" [Eshete (29), p.10), which may stem from patients being unaware of their situation and thus disregarding the information they receive, either because they do not fully understand it or due to fear of being perceived as "weak" by society for acknowledging their pain. The concept of patients' medical ignorance or their "right not to know" (Davies, 2020, p.300) was recently discussed, suggesting that in stressful situations, such as awaiting surgery or a diagnosis, information might be distressingly overwhelming for patients (30). However, this data necessitates further exploration so that medical professionals can be properly guided.

4.3 Preferred method of receiving information about pain

While our surveyed groups preferred orally delivered information, other cohorts opted for a combination of oral and written forms (23, 31). The difference in our patients' opinion and results from other studies might be due to cultural differences. Both forms of information presentation have their benefits and shortcomings. Providing information orally facilitates interactive communication between patients and the medical staff ("face to face") and can be more effective in improving postoperative pain outcomes compared to video presentations (7). However, receiving information orally might be overwhelming and difficult to memorize in potentially stressful circumstances such as when waiting for surgery, while the written form offers a format that can be referred to repeatedly (23). Additionally, if the information is delivered in the preoperative clinic, patients have time to absorb and process the information, offering the opportunity to ask additional questions. Similarly, to other studies, our participants found physicians i.e., anesthesiologist as a valuable source of information (3, 23).

4.4 Survey limitations

Our study has several limitations. The first limitation is that study took place in single country, and therefore cultural differences in how pain is perceived and managed, as well as healthcare practices, could limit the generalizability of the findings to other settings or countries. However, our study offers valuable information regarding patients' and family members' needs in middle income countries, particularly that patients from middle- and low-income countries are less frequently presented in pain outcome standardization initiatives (11). Secondly, the survey relied on reports by patients and their families without including information from patient's medical records and we were, therefore, unable to evaluate associations with factors such as reasons for surgery (e.g., cancer-related vs. not or acute vs. chronic condition) which might influence the nature of information that patients request.

The third limitation is the lack of medical staff breakdown in types or years of experience in our survey might impact the survey results, therefore we advocate for future studies to explore this topic. The fourth limitation worth noting is the exclusion of pharmacists from the survey. While the role of pharmacists varies between countries, many of the questions relate to side effects and pain management after discharge—areas where pharmacists could play an important role.

The participants were asked about their information needs and preferences after the surgery on POD1, and patients' experiences may change over time. It is worth noting that participating patients were fully alert and willing to take part in the survey, they also filled the questionnaire without assistance. Additionally, we relied on a convenience sample which may not fully represent the broader population of postoperative patients, leading to potential biases in the findings. For example, patients who volunteered to participate might have different experiences of pain (i.e., less pain) or attitudes than those who did not. To the best of our knowledge there is no formally validated questionnaire for exploration of patients' needs regarding information on postoperative pain management. For our survey we adapted the original INQPP tool, which had only been used in surgical contexts in previous studies (17, 18). With development of core outcome sets for acute pain which includes

pain (intensity and duration), pain influence on physical functioning, quality of recovery and analgesics use (11) there is a need to develop a validated tool for assessing patients' needs regarding information on postoperative pain management, that will enable the comparison over healthcare settings and populations.

4.5 Future directions

We suggest that future studies should include additional parameters in the evaluation such as presence of comorbidities, preoperative diagnosis, and history of previous surgeries. Furthermore, it is important to take into consideration the country's economic level and type of healthcare system model (i.e., national health insurance vs. private) as there could be a difference in findings.

The findings of this study could contribute to development of educational programs for healthcare providers on effective communication with patients and their families regarding pain and its management. Future directions should focus on improving methods for information transfer by actively involving patients as partners in the co-creation of educational materials that are understandable to both patients and their family members (32). At this point during the patient information development phase, priority should be given to continuous perioperative information about pain with information given predominantly in the preoperative clinic preferably by an anesthesiologist or surgeon. None of the previous studies evaluated the time needed to provide patients and family information about postoperative pain. This is noteworthy as information presentation, which is of the highest importance to patients, proper timing, and methods might streamline delivery. Future studies should assess the generic topics of interests in patients to aid in the further development of a more applicable education materials.

5 Conclusion

Our findings support that in relation to information needs following a surgical experience, patients are most interested in pain management after hospital discharge. While the majority of respondents expressed a strong desire for perioperative pain-related information, a subset of patients reported a limited interest in receiving such information, highlighting the need for further investigation into factors influencing informational preferences. Across all study groups, the preferred timing for the initial presentation of information was the preoperative clinic, most commonly delivered by an anesthesiologist or surgeon. Although patients and their family members generally favored in-person communication, our findings support that written materials should also be made available.

Our survey demonstrates that the focal point of medical staff differs from patients', therefore, we still need to learn more about this topic. Availability of such knowledge will enable development of a conversation model dedicated to postoperative pain information and interaction between the patient, their family, and medical staff as a tool for improving clinical practice.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Military Medical Academy, University of Defense. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

DS: Conceptualization, Data curation, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. MP: Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. DU: Data curation, Investigation, Writing – original draft, Writing – review & editing. MN: Data curation, Investigation, Writing – original draft, Writing – review & editing. DR: Data curation, Investigation, Writing – original draft, Writing – review & editing. NL: Data curation, Investigation, Writing – original draft, Writing – review & editing. AJ: Data curation, Investigation, Writing – original draft, Writing – review & editing. EDR: Data curation, Investigation, Writing – original draft, Writing – review & editing. NR: Data curation, Investigation, Writing – original draft, Writing – review & editing. MM: Data curation, Investigation, Writing – original draft, Writing – review & editing. SB: Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. BB: Data curation, Formal analysis, Investigation, Writing – original draft, Writing – review & editing. WM: Conceptualization, Data curation, Investigation, Methodology, Resources, Supervision, Writing – original draft, Writing – review & editing. RZ: Data curation, Investigation, Methodology, Resources, Supervision, Writing – original draft, Writing – review & editing.

Funding

The author(s) declared that financial support was received for this work and/or its publication. Funding was received from the Institute for Cardiovascular Diseases "Dedinje" for the publication of this article.

Acknowledgments

Portions of this work were presented in oral form at the European Pain Federation Congress, Budapest, Hungary, September 19–22, 2023.

Conflict of interest

The author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declared that generative AI was not used in the creation of this manuscript.

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Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpain.2026.1728929/full#supplementary-material

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frontiers in Pain Research

TYPE Perspective
PUBLISHED 09 March 2026
DOI 10.3389/fpain.2026.1765233

OPEN ACCESS

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RECEIVED 10 December 2025
REVISED 06 February 2026
ACCEPTED 12 February 2026
PUBLISHED 09 March 2026

CITATION
Andréll P, Heckemann B, Grimby-Ekman A, Göran G, Olsson M-L, Johansson R, Forslund P and Wolf A (2026) The importance of partnership in chronic pain – co-creation of tomorrow's pain care by working together in research, implementation, and knowledge dissemination. Front. Pain Res. 7:1765233. doi: 10.3389/fpain.2026.1765233

The importance of partnership in chronic pain – co-creation of tomorrow's pain care by working together in research, implementation, and knowledge dissemination

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Chronic pain is a long-term condition that affects the daily lives, identities, and well-being of millions of people worldwide. Effective pain care remains limited. Moreover, lack of knowledge and awareness among healthcare professionals and patients, combined with the invisibility of pain, often leads to disbelief, delayed diagnosis, prolonged suffering, and significant societal costs. Novel approaches are necessary to improve pain care, as most countries' healthcare systems are struggling to provide adequate support for persons living with chronic pain. This article highlights the importance of partnership in chronic pain management. We present examples from Sweden that demonstrate the benefits of stakeholder collaboration to improve pain care. Partnership between patients and healthcare professionals is a core element of person-centered care (PCC). We present PCC as a necessary strategy that combines ethical commitment with demonstrable clinical and economic benefits. We highlight the unique value of patient and public involvement (PPI) in pain research and innovation, where patients with lived experience can help researchers identify deficiencies in pain care and service provision, formulate relevant research questions, and develop projects that address real needs and priorities. Finally, we provide concrete examples of successful cooperation between patients, healthcare professionals, patient associations, and researchers in raising awareness of chronic pain and translating research findings into clinical practice. Collaboration among healthcare professionals, patient associations, and researchers is essential to make the best use of knowledge and lived experience to co-create and implement effective pain care, advance research, and raise awareness of chronic pain in healthcare and society.

KEYWORDS
chronic pain, partnership, patient and public involvement, person-centered care, societal impact of pain

1 Introduction

Almost 20% of the European population live with moderate-to-severe chronic pain (1). Prevalence of chronic pain increases with age (2), affecting many people in midlife and often interfering with work (3). Despite affecting millions of people, poor management of chronic pain is a massive burden on society, with low back pain being the leading cause of years lived with disability worldwide (4). Contributing factors include inaccessible pain care, lack of adequate pain diagnosis and treatment, as well as insufficient knowledge among healthcare professionals and patients (5). Although vast evidence demonstrates the benefits of pain rehabilitation in enhancing clinical outcomes for persons living with chronic pain, its implementation in clinical practice remains limited. There is a need for new approaches to address these issues and improve pain care, as today's healthcare system is insufficient to support people living with chronic pain. In this perspective article, we highlight the importance of stakeholder partnerships in chronic pain management and present examples from Sweden that demonstrate the benefits of collaboration across multiple sectors to innovate and improve pain care.

2 Partnership in person-centered care - clinical evidence and implications

Chronic pain and other chronic conditions remain complex challenges in modern healthcare. Biomedical approaches alone are insufficient to address their multidimensional impact, which extends beyond symptoms and affects daily functioning, identity, relationships, and social participation. Person-centered care (PCC) has therefore gained recognition as a necessary strategy that combines ethical commitment with demonstrable clinical and economic benefits. The partnership between patients and healthcare professionals is a core element of PCC.

The University of Gothenburg Centre for Person-Centred Care (GPCC) has developed a systematic framework integrating ethics with clinical practice (6), it is among the most used frameworks in controlled trials of PCC. The framework's philosophical foundation is rooted in personalism, particularly the work of Ricoeur and Mounier (7), which emphasizes dignity, agency, vulnerability, and relationality. Thus, it can be considered a structured method for enacting ethical principles in everyday care, rather than an abstract ideal.

The GPCC framework is based on three interconnected processes: (1) eliciting the patient's narrative, (2) establishing a partnership based on a shared health plan, and (3) documenting the plan to ensure transparency and continuity (8).

Quantitative and qualitative evidence support the effectiveness of PCC, including shorter hospital stays, improved self-efficacy, enhanced symptom control, better health-related quality of life, improved physical function, and cost savings. For instance, in the PCC-HF (heart failure) trial, systematic follow-up of a person-centered health plan during hospitalization reduced mean length of stay by 30% and improved activities of daily living among patients with chronic heart failure (6). Systematic reviews have identified similar benefits in cancer, mental health, inflammatory bowel disease, and chronic pain in a variety of settings, suggesting broad applicability across clinical contexts (6, 9). Qualitative studies emphasize the importance of partnership in practicing the ethics of PCC – adherence to the GPCC framework is not achieved through rigid routine adherence, but rather through the consistent application of its ethical principles (6). The relevance of partnership is particularly pronounced in chronic pain care. Patients with persistent pain often report that their experiences are overlooked by clinicians. Eliciting the patient's narrative enables clinicians to align interventions with personal goals, such as maintaining employment, engaging in family life, or managing anxiety. The co-created health plan promotes self-management and autonomy, while documentation strengthens continuity of care across settings. In digiphysical contexts, where digital and face-to-face encounters are combined, these principles have been shown to improve patient engagement and communication. Evidence from five consecutive GPCC studies conducted in inpatient, outpatient, primary care, and home-based settings affirms the effectiveness of the GPCC framework in physical as well as digital environments (10). These studies showed consistent improvements in patient-reported outcomes, functional ability, and quality of life, which were accompanied by reductions in healthcare utilization in several cases. These results demonstrate that the GPCC framework is robust across diverse levels and modes of healthcare delivery. Health economic assessments further strengthen the case for PCC. A recent systematic review of economic evaluations showed that PCC is often either cost-saving or cost-effective compared to standard care (11). In many evaluations, PCC "dominated" standard care by delivering better outcomes at lower or equivalent cost. Where costs were higher, the incremental cost per quality-adjusted life year (QALY) remained within accepted thresholds. These findings suggest that investment in PCC infrastructure, such as staff training, documentation systems, and digital tools, is justified by improved outcomes and system-level sustainability.

The implications of PCC for chronic pain care are multi-level. For patients, partnership translates into improved self-efficacy, reduced uncertainty, and a better quality of life. For clinicians, PCC fosters more accurate assessments, stronger therapeutic relationships, and enhanced job satisfaction (12). For organizations, structured PCC can support coordination across services, reduce duplication, and shorten hospital stays. At a societal level, partnership-based PCC contributes to more sustainable and equitable healthcare, as functional improvements and enhanced quality of life reduce both direct costs and broader socio-economic burdens.

However, challenges remain. Existing trials have relied on outcome measures defined by researchers rather than patients, which risks misalignment with the ethical foundation of PCC (6). Future research should adopt goal-attainment scaling and incorporate person-centered outcomes. Organizational structures and governance also require strengthening, including adequate training, supportive documentation systems, and leadership commitment. To create a system that addresses the unmet needs of persons living with chronic pain, we need to move beyond co-creation and strive for co-integration with all relevant stakeholders in the healthcare ecosystem. Thus, we need to transition from working in a linear and transactional fashion to a person-centered

ecosystem approach that builds on continuity, trust, and relationships. Without these conditions, the partnership among stakeholders risks being episodic rather than systematic.

In the next section, we describe the importance and benefits of involving patients in pain research and innovation efforts.

3 Partnership in research and innovation – the importance of patient and public involvement

Patient engagement is the "active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision making is guided by patients' contributions as partners, recognizing their specific experiences, values, and expertise" (13).

Patient and public involvement (PPI) in research and innovation promises unique value: people with lived experience of health conditions, direct use of care services, or a user's view of the healthcare system are key to identifying deficiencies in care and health service provision. In the context of chronic pain, PPI can provide a deeper understanding of the lived experience of persons living with chronic pain and their carers, as well as inequalities in pain care. PPI can hence enable researchers to formulate relevant research questions and develop projects that address real needs and priorities, strengthening both the quality and the relevance of pain research and innovation projects (14).

Over the past two decades, the importance of PPI for improving the quality and effectiveness of healthcare processes has been recognized internationally. In a 2023 framework for meaningful engagement, the World Health Organization stressed: "The right to participate is an essential feature of the right to the highest attainable standard of health. People have the right and duty to participate individually and collectively in the planning and implementation of their health and wellbeing" (15). This was further emphasized in the 2024 update of the Declaration of Helsinki: "*Researchers should enable potential and enrolled participants and their communities to share their priorities and values; to participate in research design, implementation, and other relevant activities; and to engage in understanding and disseminating results*" (16). In addition, involving patients in research planning and implementation is stated as a key objective of the European Pain Federation's (EFIC) Pain Research Strategy 2025 (17).

In practice, PPI is gradually becoming a key feature of healthcare systems as patients and the public are increasingly involved in shaping healthcare at the micro, meso, and macro levels, in policy and practice (18). In many countries, including the United States, Canada, Australia, the UK, and the Netherlands, PPI is part of public policy. In Sweden, PPI even has a legal foundation, namely the Swedish Patient Act (19), a legal framework that promotes patient integrity, self-determination, and participation in care decisions. Moreover, a major healthcare system transition focusing on "person-centered integrated care" is underway. "Person-Centered integrated care" is an agreement between the Swedish Association of Local Authorities and Regions and the Swedish government. It centers on organizing and delivering healthcare based on patients' needs and health conditions and prioritizes coordinated, person-centered, and importantly, co-created care (20). The transition entails a paradigm shift towards person-centered integrated care, where patients and healthcare professionals become equal partners in health research and clinical innovation and implementation (21, 22).

Funders and policymakers are increasingly mandating or prescribing equality and participation of patients and the public in decision-making. The National Institute for Health and Care Research (NIHR), UK Research and Innovation (UKRI), the Wellcome Trust, and the European Commission (especially for public procurement initiatives) have all made PPI a mandatory criterion in grant application evaluations. Hence, PPI has also become a cornerstone of health research and innovation (23), marking a radical change in how research and innovation projects are designed and conducted. Traditionally, researchers and healthcare professionals determined research and innovation agendas, and patients were seen primarily as study "subjects" whose role was restricted to providing data (24). Today, recognition has grown of the need to make research and innovation more democratic. Through PPI, patients and their carers can provide unique expertise that is rooted in their lived experience and shape how research questions are framed, interventions are designed, results are interpreted, and solutions to care problems are developed (24–26).

A key justification for PPI is that it strengthens democracy (27), by including the experience and expertise of citizens who use and pay for healthcare services or publicly funded research (28). Democratic processes that foster the inclusion of multiple perspectives and experiences can also lead to better decision-making (27). PPI inclusion is possible in every phase of the research cycle, from formulating research questions through to the implementation and dissemination of findings (29). Involving patients, family carers and/or the public can improve the relevance of research and provide different and valuable perspectives (30–32). However, effective PPI requires consideration and clarity about the purpose, methods, and expected level of participation. A recurring concern in the discourse about PPI is tokenism. People are invited in for consultation, but their influence remains limited, and the real decision-making power remains with the researchers. Thus, PPI can become a symbolic gesture of inclusion and mimic participation while leaving traditional hierarchies intact (33). Such practices risk eroding trust and diminishing the value of lived experience. Researchers need to carefully consider when PPI is needed, and what level of meaningful and democratic participation is appropriate at each phase. The representativeness of PPI is another crucial concern. Research teams need to strive for a balanced perspective within the project team and assess whether to engage individuals with personal lived experience, or patient associations that represent diverse views of a broader segment (34).

In summary, involving patients and the public as equal partners in research and innovation has the potential to strengthen democracy in healthcare. Yet, researchers and clinicians must be prepared to invest the time and effort to grow fruitful collaborative relationships.

In the next section, we discuss how healthcare professionals, researchers, and patients can work together to change pain policies on a societal level.

4 Partnership in societal impact of pain - working together to raise awareness of pain

Societal Impact of Pain (SIP) Sweden is one of twelve national platforms in SIP Europe, a multi-stakeholder partnership led by the European Pain Federation (EFIC) and Pain Alliance Europe (PAE), where patients, researchers, and healthcare professionals work together to raise awareness and knowledge about pain, improve pain care, and change pain policies (35, 36). SIP Europe has four main long-term priorities:

1. Integrated pain management
2. Pain in employment and economic considerations
3. Promoting pain research and education
4. Recognition for pain as a chronic condition

Chronic pain has a major impact on peoples' lives affecting work ability (3, 37). Absence from work (sick leaves and early retirement) constitutes the largest component of the societal costs related to chronic pain (38). Musculoskeletal pain is also the most common reason for visits to general practitioners by frequent attenders in primary care in Sweden (39). Few are aware that chronic pain is a disease, and even fewer know what they can do to prevent pain from becoming chronic or recurring, or to manage the comorbidities associated with chronic pain. There is a lack of recommendations regarding self-care for persons living with chronic pain, and there is no established health coach support or specialist nurses for patients with chronic pain in Sweden. Furthermore, patients report challenges beyond healthcare in contacts with employers, social security, and employment services, and not being justly treated in society in many different situations, for example, in conversations with unsympathetic employers, colleagues, relatives, and friends (5, 40, 41). In contrast, people seeking care for hypertension or diabetes rarely describe that their physician lacks adequate knowledge to treat their disease, nor that their family members and employers are unaware that hypertension or diabetes is a disease. The inequalities evident in healthcare mainly stem from a lack of knowledge about chronic pain and the lack of recognition that chronic pain is a disease in its own right.

In Sweden, patient associations, healthcare professionals, and researchers have addressed the lack of pain care and insufficient knowledge of chronic pain by developing "The Swedish healthcare pathway for adults with chronic pain - a person-centered and coherent care (P3C) pathway" (5). The P3C pathway emphasizes the need for coherent, evidence-based and personalized delivery of healthcare, including early pain analysis, a biopsychosocial approach to assessment and treatment, an early rehabilitation plan, dialogue and joint plans between levels of care, patient participation, and education on pain and its consequences. The aim of the P3C pathway is to provide equal, accessible and evidence-based pain care across Sweden, where the initial biopsychosocial pain analysis, screening for risk factors for development of chronic pain and treatment (including rehabilitation) of pain should be performed in primary care.

The development of the P3C pathway included mapping of the current situation from both the healthcare and the patient perspectives. During this process, patient representatives described experiencing a lack of empathy during healthcare contacts and mistrust in the healthcare system, stressing that knowledge about chronic pain and its management is limited among both healthcare professionals and patients. They also called attention to the lack of a holistic approach and insufficient support for returning to a life with good management of both pain and its consequences. These barriers often lead patients to seek solutions outside the healthcare system, as they perceive a lack of knowledge among healthcare professionals. However, such solutions are frequently not evidence-based and, in the worst cases, may create additional health problems. To address these issues, the PC3 pathway promotes patient empowerment and equality in care, dialogue between patients and practitioners, self-management of pain instead of prolonged medical intervention, and increased knowledge about chronic pain, based on existing evidence and experiences. Cooperation brings together different perspectives, experiences, and the necessary knowledge to implement evidence-based pain care and increase awareness of chronic pain in the healthcare system.

SIP Sweden has identified three main priorities for the upcoming years to improve pain care nationally:

4.1 Promoting implementation of the P3C pathway and ICD-11

One of SIP Sweden's aims is to promote the implementation of the P3C pathway and the International Classification of Diseases (ICD-11) by arranging workshops and educational events for both healthcare professionals and patient associations. These efforts seek to ensure that chronic primary pain is recognized and that all affected persons can get a timely diagnosis and the right support from the healthcare system.

4.2 Facilitating research collaboration

Patient associations and researchers have identified a need to facilitate connection routes to enhance collaboration in pain research. Thus, SIP Sweden aims to create a "research hub" facilitating contact between patient associations and researchers. Working together from the start of a project ensures that the research is relevant from both the medical and patient perspectives and that the study design is feasible and adapted to participants with chronic pain and associated comorbidities. In these efforts, patient associations are also crucial for the dissemination and implementation of research findings.

4.3 Increase knowledge about pain among healthcare professionals and in society

SIP Sweden's most important aim is to promote knowledge exchange and education about pain for healthcare professionals, patients, and the general public. SIP Sweden launched the

"European Day on Pain Awareness" in Sweden by hosting a webinar on "Chronic pain and mental health – the associations you need to know about" for all associations in SIP Sweden.

Developing and delivering pain education remains an important task for universities in Sweden and across Europe. As standardized education is a prerequisite for delivering equal pain care, SIP Sweden will also support teaching staff to improve nursing and medical undergraduate and graduate education across Swedish universities.

5 Discussion

Until recently, patient associations, researchers, and healthcare professionals have advocated separately for improved pain care. To raise visibility of chronic pain and to improve knowledge of chronic pain and its consequences for both healthcare professionals and in society, we see an urgent need for increased cooperation and collaboration between stakeholders. The development of the Swedish P3C pathway is a successful example that highlights the importance of ongoing collaboration to advance research, implement evidence-based care, and disseminate new knowledge to persons living with chronic pain (5). By working together to improve pain care by early assessment and management in primary care, chronification of pain and its consequences might be prevented. Furthermore, improved collaboration between stakeholders to support persons with chronic pain re-entering the workplace after sick leave is warranted (40, 42).

The GPCC framework provides a robust, evidence-based model for operationalizing partnership in person-centered care. The growing body of evidence, including clinical outcomes, qualitative findings, and health economic analyses, demonstrates that partnership is an ethical imperative, as well as a clinically effective and economically sustainable strategy. In the management of chronic pain and other chronic conditions, partnership must be recognized as a standard of care that is central to the future of health systems.

Involving patients and the public as equal partners in research and innovation has the potential to strengthen democracy in healthcare and is increasingly mandatory, reflected in EFIC's research strategy 2025 and the updated declaration of Helsinki 2024 (16, 17). PPI aims to improve the relevance and quality of publicly funded research and innovation efforts by taking into account the lived experience of patients and the public and addressing their specific needs.

To increase knowledge and awareness of pain, a joint effort is required. Together, we must strive for evidence-based pain care that places partnership at its core, provides interventions that strengthen patients' self-efficacy, and empowers patients to self-manage pain in addition to fundamental medical pain care, rehabilitation, manual therapies (43), and support.

6 Conclusion

Partnership is a prerequisite and a way forward for advancing chronic pain care. Healthcare professionals, researchers, and patient associations must work in collaboration to co-create, implement, and integrate effective pain care, conduct relevant and innovative research, and raise awareness of pain in healthcare and society.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Author contributions

PA: Conceptualization, Writing – review & editing, Writing – original draft. BH: Writing – original draft, Writing – review & editing, Conceptualization. AG-E: Writing – original draft, Writing – review & editing. GG: Writing – original draft, Writing – review & editing. M-LO: Writing – original draft, Writing – review & editing. RJ: Writing – review & editing, Writing – original draft. PF: Writing – review & editing, Writing – original draft. AW: Writing – review & editing, Writing – original draft, Conceptualization.

Funding

The author(s) declared that financial support was not received for this work and/or its publication.

Conflict of interest

PA is president of the Swedish Pain Society and a member of the steering committee for Societal Impact of Pain Sweden. AE is a member of the steering committee for Societal Impact of Pain Sweden. GG is a member of the steering committee for Societal Impact of Pain Sweden. M-LO is a member of the steering committee for Societal Impact of Pain Sweden.

The remaining author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The author(s) declared that generative AI was used in the creation of this manuscript. During the preparation of this manuscript, the authors used ChatGPT 5 for language editing for the purposes of refining grammar and overall readability. The authors have reviewed and edited the output and take full responsibility for the content of this publication.

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frontiers in Pain Research

TYPE Original Research
PUBLISHED 13 April 2026
DOI 10.3389/fpain.2026.1763519

OPEN ACCESS

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RECEIVED 08 December 2025
REVISED 11 March 2026
ACCEPTED 16 March 2026
PUBLISHED 13 April 2026

CITATION
Ou P, Bean EN and Cao L (2026) Exploring chronic pain: demographic and social determinants of health insights in Maine.
Front. Pain Res. 7:1763519.
doi: 10.3389/fpain.2026.1763519

Exploring chronic pain: demographic and social determinants of health insights in Maine

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Introduction: Chronic pain is a serious public health problem in Maine. We initiated a pain registry for the adult population across Maine to characterize the population with persistent or recurrent pain, with a special focus on the relationships between social determinants of health (SDOH) and chronic pain outcomes (pain level and co-morbidities) and management, therefore, to identify targeted public health interventions to improve pain care in Maine.
Methods: The registry uses the REDCap data collection platform to administer an anonymous survey, which includes questions regarding pain characteristics, pain management, and demographic and SDOH factors. The survey was distributed through both hard- and electronic copies of a flyer.
Results: The current study reports the initial cross-sectional descriptive analysis of the first 109 respondents with the focus on the relationships between selected socio-demographic factors and pain outcome measures. Compared to Maine's census data, the current participant pool is overrepresented in biological females, individuals 65 and older, minority racial/ethnic groups, and education attainment, but underrepresented in veterans. The majority of participants experienced pain for more than a year and described their pain as moderate to severe. Low back was the most frequently reported pain location, and trauma/injury was the most frequently identified cause. Fatigue, pain interference, reduced physical function, and sleep disturbance were major co-morbidities. Higher SDOH risk was significantly associated with worse pain-related outcomes. Being younger and having lower education levels were associated with increased anxiety and depression but reduced cognitive function. Lower education level was also associated with greater fatigue and pain score. The White-only race was associated with lower levels of anxiety, depression and sleep disturbance. Within the current participant pool, biological sex, veteran status and rural living did not significantly affect any pain outcomes.
Discussion: In summary, additional recruitment efforts to reach all socio-demographic groups are warranted and further data analysis could inform research in pain and pain treatment as well as public health strategies for pain prevention in Maine.

KEYWORDS
chronic pain, disparities, pain registry, PROPr, REDCap, social determinants of health

1 Introduction

Chronic pain is a significant and costly public health concern in the United States (US). The annual cost of pain in the US ranges from $560 to $635 billion and is attributed to both health care costs and costs due to loss of productivity, with the amount exceeding the annual costs of heart disease, cancer, and diabetes, respectively (1). According to the Centers for Disease Control and Prevention (CDC), approximately 24% of US adults are affected (2). Those living with chronic pain can have reduced quality of life, frequent healthcare utilization, and comorbidities such as depression and anxiety (3). The experience of chronic pain is complex and influenced by multiple factors including but not limited to demographics, lifestyle behaviors, physical activity, and mental health (4). Collectively, these components are encompassed within the framework of social determinants of health (SDOH), which are increasingly recognized as critical influences on the development and management of chronic pain (5–7).

National surveillance data, such as those reported by the CDC in 2024, indicate that the prevalence of chronic pain is disproportionately higher among certain subpopulations, including older adults, females, and those living in nonmetropolitan areas (2). Geographic variation plays a role in the burden of chronic pain, with some states experiencing higher prevalence rates than others. For example, a study by Malon et al. (2018) examined chronic pain in Maine using insurance claims data (2006–2011) and identified 29.5% of Mainers have chronic pain (8), which is similar to a national-wide web-based survey study (30.7%) conducted in 2008–2009 for US adults but greater than the national average published by the CDC (20.4%) obtained through the 2016 US adult National Health Interview Survey (NHIS) data (9, 10). The prevalence of chronic pain in Maine increased with age specifically for those over 65 and it was found that the burden of chronic pain is significantly higher in females, patterns which are consistent with epidemiology studies conducted over the past decades (2, 9–11).

Maine presents a particularly unique landscape for chronic pain research. According to the 2024 U.S. Census data, Maine has the highest proportion of residents aged 65 years and older, a demographic that has a high prevalence of chronic pain. Despite this, literature within the state remains limited. Current knowledge of chronic pain prevalence in Maine is limited to the sole study from Malon et al. (2018) (8), which used the Maine all payers insurance claims database from more than a decade ago. While understanding the distribution of who experiences chronic pain in the state is useful, this dataset does not provide insight into how SDOH such as race, veteran status, rurality, and mental health intersect to influence chronic pain and its associated burden.

The absence of studies with robust information on the impact of SDOH on chronic pain and its management and the lack of qualitative data regarding chronic pain in Maine warrants a SDOH-focused data collection and analysis. Such research can inform more equitable and effective public health strategies, healthcare policies, and clinical interventions tailored to at-risk populations. The objectives of our research team are to identify a broader range of SDOH factors that may affect chronic pain in Maine and describe how specific factors can influence individuals' pain experiences. In this study, we took advantage of our newly established SDOH-focused pain registry in Maine and conducted the analysis with the "first-look" of the data collected from the registry. It is our hope that our findings can contribute to a better understanding of chronic pain within the state and hopefully offer insights applicable to similarly structured rural and aging populations.

2 Materials and methods

2.1 Overview

Through a pilot grant from the Northern New England Clinical & Translational Research Network (NNE-CTR), in collaboration with MaineHealth, we initiated a longitudinal SDOH-focused pain registry (PainRegistryforME) designed to investigate the relationships between chronic pain and SDOH among adults residing in Maine. The registry was launched in the summer of 2023 and continues to collect data with the goal of generating a robust dataset that captures both the clinical and contextual aspects of chronic pain across communities in the state. This PainRegistryforME study was reviewed and approved by the MaineHealth Institutional Review Board (IRB) (IRBnet ID:1970910).

2.2 Participants and recruitment

Individuals living in the state of Maine who are ≥ 18 years old with any type of persistent or recurrent pain are eligible to participate. Persistent or recurrent pain is defined as pain experienced most days or every day. To ensure accessibility and confidentiality, the study utilized an anonymous, self-administered online survey hosted on REDCap (Research Electronic Data Capture), a secure, HIPAA-compliant survey instrument. Study data were collected and managed using REDCap electronic data capture tools hosted at University of New England (12, 13). REDCap is a secure, web-based software platform designed to support data capture for research studies by providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources.

The survey link and Quick Response (QR) code was distributed virtually and physically through institutional networks, collaborating clinics, and chain grocery stores via the study flyer. To target areas with high prevalence of patients with chronic pain, clinical collaborators including specialists in pain management and opioid use disorder assisted with outreach. To reach potential participants throughout the state, clinical collaborators within the University of New England clinical training partners and Northern Light Eastern Maine Medical Center assisted in flyer distribution. Specifically, Northern Light Eastern Maine Medical Center has connections with Maine rural residents. Additional dissemination occurred through seminars, email listservs, social media postings, and professional association events. This recruitment strategy was designed to

capture a wider geographic and socioeconomic diversity among respondents. In this study, we used the results from the "First Look" interim analysis of the data that included data collected up to February 2024. A total of 109 out of 112 participants had entered responses and their data were eligible for analysis in this study. The remaining 3 participants had empty entries for the entire survey and therefore could not be used.

2.3 Survey design and measures

The PainRegistryforME survey has a total of 75 questions organized into four major sections: (1) Demographics, (2) Pain Characteristics, (3) Pain Management, and (4) Social Determinants of Health (SDOH). SDOH factors were assessed using the Upstream Risks Screening Tool by HealthBegins, one of the first developed comprehensive SDOH screening tools (14, 15). Due to the relatively small participant pool, selected key demographic variables related to SDOH were used in this initial data analysis. These variables included age, biological sex, gender, veteran status, race, and county of residence. Education level was assessed based on the highest degree earned and higher level of schooling completed. Other SDOH variables related to housing, employment, and healthcare access are also collected in the full registry and will be explored in future analyses.

Pain characteristics and related health outcomes were assessed using the NIH Patient-Reported Outcomes Measurement Information System (PROMIS®) 29 + 2 Profile v2.1 (PROPr), a validated instrument widely used to evaluate health-related quality of life in individuals with chronic conditions and available through RedCap (16). This tool includes 31 questions divided into eight health domains: anxiety, depression, fatigue, pain interference, physical function, sleep disturbance, ability to participate in social roles and activities, and cognitive function. Participants respond to each item on a 5-point Likert scale and scores are then summed per domain to obtain domain scores. Additionally, a single-item numeric rating scale was used to assess pain intensity in the past 7 days, with values ranging from 0, indicating no pain, to 10, indicating the worst possible pain. Furthermore, the calculated single preference-based PROPr score obtained using the scores for 7 PROMIS domains (depression, fatigue, pain interference, physical function, sleep disturbance, ability to participate in social roles and activities, and cognitive function) for each participant could be used to represent the individual health state related to chronic pain with 1 indicating the optimal health and 0 indicating the worst outcome such as death (17).

2.4 Data analysis

Descriptive statistics were performed using Microsoft® Excel to characterize the sample and provide a profile of demographic and SDOH distributions. For further statistical analysis, individual one-way ANOVA (ANOVA) was conducted via IBM SPSS Statistics (Version 29, Armonk, NY) to assess the associations between categorical variables (demographics and SDOH factors) and pain outcome variables measured across 8 individual PROMIS domains. For each ANONA test, pre-tests were conducted to confirm the statistical assumptions for running each one-way ANOVA test. Given this is the first look of the data collected in the registry, we have no clear evidence regarding how individual factors we examined were interacting with each other or any of them were confounders. Therefore, there is no solid evidence for adjusting p values when conducting each one-way ANOVA individually. $p < 0.05$ was considered to be statistically significant. Data were graphed using SigmaPlot 14.5 (Systat Software Inc., San Jose, CA). When comparisons to Maine's census data were made, the 2024 Maine Census data were used unless specified otherwise.

3 Results

Out of the 112 respondents, data from 3 respondents were excluded from the data analysis due to missing data in all fields, leaving 109 subjects eligible for analysis. Therefore, all percentages were calculated based on the total sample size as 109. For any analysis, if a participant provided no response (blank) to a particular question, the participant was not included in the sub-category analysis involving this question.

3.1 Socio-demographic profile of participants

Demographic and selected SDOH characteristics are summarized in Table 1.

In this initial cohort, we had participants in every age group with the age groups 25–29 years of age and 55–59 years of age having the greatest numbers of participants. Each of these groups had 12 participants (12/109, 11.0%). The participant pool was overrepresented by individuals 65 and above (35/109, 32.1%) compared to the Maine's census data (22.5%).

Both questions regarding biological sex and gender were asked in the survey. Our respondents predominantly reported as female sex (76/109, 69.7%) and female gender (73/10, 67.0%). Therefore, our participant pool is overrepresented by females compared to the Maine state census data (50.7%).

Our respondent pool was more diverse than Maine's general population reported in the census data. Among the 109 participants, 92 respondents reported to be White only (84.4% vs. 93.9% in Maine's census), 6 to be Black/African American only (5.5% vs. 2.0% in Maine's census), and 9 participants had Hispanic origin (8.3% vs. 2.0% in Maine's census).

Our results showed 5.5% (6/109) of respondents being veterans, which is underrepresented per the Maine census data that reported about 7.2% of the population being veterans.

In regards to county of residence, 77.1% (84/109) of respondents lived in urban counties in Maine which includes York, Cumberland, Androscoggin, Sagadahoc and Penobscot counties (18). The majority lived in Cumberland and York counties (75/109, 68.8%), reflecting the fact that these are the two most populated counties in Maine (32.1% and 15.7% of the Maine's population, respectively).

Two different sets of questions in the registry pertained to education level. The first asked respondents what their highest educational degree earned is and the other question asked the

10.3389/fpain.2026.1763519

TABLE 1 Demographic and SDOH characteristics of respondents (total $N = 109$).

REDCap Survey Questions		N	Frequency (%)
What is your age?	18–24 years	7	6.4
	25–29 years	12	11.0
	30–34 years	7	6.4
	35–39 years	9	8.3
	40–45 years	7	6.4
	45–49 years	6	5.5
	50–54 years	4	3.7
	55–59 years	12	11.0
	60–64 years	10	9.2
	65–69 years	8	7.3
	70–74 years	11	10.1
	75–79 years	8	7.3
	80 years and above	8	7.3
What is your biological sex?	Female	76	69.7
	Male	30	27.5
	Prefer not to answer	1	0.9
	No response [blank]	2	1.8
What is your gender (what you identify yourself as)?	Female	73	67.0
	Male	29	26.6
	Transgender	3	2.8
	Non-binary	1	0.9
	Prefer not to answer	1	0.9
	No response [blank]	2	1.8
Are you Hispanic or Latino?	Yes	9	8.3
	No	94	86.2
	No response [blank]	6	5.5
Which race(s) are you?	American Indian/ Alaskan Native only	2	1.8
	Asian only	3	2.8
	Black/African American only	6	5.5
	Native Hawaiian only	0	0.0
	Pacific Islander only	1	0.9
	White only	92	84.4
	Mixed	5	4.6
Which county in Maine do you reside in?	Androscoggin	6	5.5
	Aroostock	3	2.8
	Cumberland	40	36.7
	Franklin	3	2.8
	Hancock	5	4.6
	Kennebec	4	3.7
	Knox	1	0.9
	Lincoln	3	2.8
	Oxford	2	1.8
	Penobscot	3	2.8
	Piscataquis	1	0.9
	Sagadahoc	0	0.0
	Somerset	1	0.9
	Waldo	2	1.8
	Washington	0	0.0
	York	35	32.1
Are you a US military veteran?	Yes	6	5.5
	No	100	91.7
	No response [blank]	3	2.8
What is the highest level of school you have completed?	Elementary	0	0.0
	High	15	13.8
	College	53	48.6
	Graduate/Professional	40	36.7
	Prefer not to answer	1	0.9
What is the highest degree you earned?	High School	13	11.9
	GED	0	0.0
	Vocational (Post high school or GED)	3	2.8
	Associate's degree	9	8.3
	Bachelor's degree	49	45.0
	Master's degree	23	21.1
	Doctorate	11	10.1
	Prefer not to answer	1	0.9

highest level of school completed. Our respondents were overrepresented by a highly educated population compared to Maine's general population, with 3 in 4 participants possess a Bachelor's degree or higher (83/109, 76.1%, vs. 37.1% in Maine's census data), and 4 in 5 participants completed some college or graduate/professional school [93/109, 85.3% vs. 66.6% in the MaineSpark-2023 report (19)].

3.2 Pain characteristics of participants

Most respondents experienced moderate to severe pain according to the 0–10 numeric pain score (survey question: *In the past 7 days: How would you rate your pain on average? Note that: 0 = No pain and 10 = The worst possible pain*) (5.25 ± 2.01) (Figure 1A). All respondents met the chronic pain diagnosis as all subjects reported having pain for at least 3 months (20) when responding to the question "*How long have you been experiencing your pain?*". Most respondents had pain for 1 year or longer and approximately 1 in 5 participants had pain for 20 years or longer (Figure 1B), with the longest stated as 52 years.

Other pain characteristics are summarized in Table 2. Nearly half experienced pain in the low back area (52/109, 47.7%) followed by pain experienced in shoulder(s) (31/109, 28.4%) and

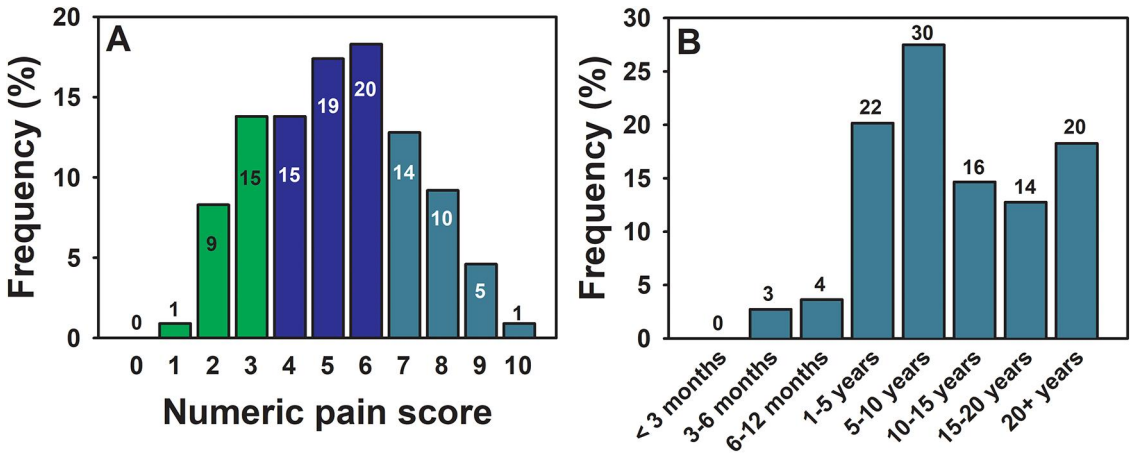

FIGURE 1
The numeric pain score and the reported pain-experiencing times of the current participant pool. Data are shown for the 109 participants. In **(A)**, the frequency of each numeric score (0-10) is presented and numbers of participants with each score are shown within each colored bar. Score 0 = no pain, 1-3 = minor pain, 4-6 = moderate pain, and 7-10 = severe pain. In **(B)**, the frequency of each pain-experiencing duration reported by participants are shown. The numbers of participants with each duration are listed on top of each bar.

neck area (30/109, 27.5%) (Table 2). Other reported locations that were not in the provided list mostly included extremities (7/109, 6.4%) and abdomen (3/109, 2.8%). More than half of the participants (including 7 individuals who selected "whole body") selected more than one location in their responses (61/109, 56.0%).

As for precipitating events, more than a third of the participants reported the pain was due to trauma or injury (39/109, 35.8%), which is followed by chronic non-cancer illness (30/109, 27.5%) (Table 2). Other causes written in by participants mainly included excessive usage, genetic, emotional status, and combination of multiple factors.

Another important set of pain characteristic outcome measures were obtained from the PROPr instrument assessing pain-related comorbidities. The sum score for each of the 8 domains anxiety, depression, fatigue, pain interference, physical function, sleep disturbance, ability to participate in social roles and activities, and cognitive function, as well as the calculated preference-based PROPr scores are summarized in Table 3.

3.3 Socio-demographic impact on pain-related outcomes

To assess the relationship between SDOH and pain outcomes, we first calculated the total SDOH scores (higher score = higher risk) for each participant from the Upstream Risks Screening Tool by HealthBegins according to its guidelines, and examined its association with the calculated overall preference-based PROPr score. Although we were able to obtain the PROPr scores for all participants except one individual, the total SDOH score could only be generated for participants who completed all fields of the SDOH portion (near 30 questions) of the survey (total of 86) while excluding those who marked the "prefer not to answer" option for any question or left any field blank. Therefore, 85 out of 109 individuals were included in the association test between the total SDOH score and the PROPr score. Note that there did not appear to be any common characteristics within the group that did not have a total SDOH score. Therefore, we do not believe this has resulted in any systemic error. With the available scores from 85 participants, it was found that SDOH score was significantly negatively correlated with the PROPr score (Figure 2, Pearson correlation, correlation coefficient = -0.553, $p = 4.11 \times 10^{-8}$).

Next, we examined the relationships between selected socio-demographic factors and each of the 8 pain outcome domains used by the PROPr instrument: anxiety, depression, fatigue, pain interference, physical function, sleep disturbance, ability to participate in social roles and activities, and cognitive function, plus the numeric pain score. Note that the two questions asked in cognitive function domain had to do with the subject's ability to concentrate and remember common tasks.

Age was collected in 5-year interval in the survey but due to the limited sample size within each 5-year interval, age was collapsed into 10-year ranges for analysis. Although the prevalence of chronic pain increases with age, in our current participant pool, being younger was associated with worse pain-related outcomes including anxiety (Figure 3A, one-way ANOVA, $p = 0.013$), depression (Figure 3B, one-way ANOVA, $p = 0.007$), and cognitive function (Figure 3C, one-way ANOVA, $p = 0.008$).

Regarding race and ethnicity, due to the small sample sizes for non-White or Hispanic populations in our current participants, comparisons were made between White only and all others combined. Significant differences between White only and all others were identified in the following 3 PROPr outcome domains: anxiety (Figure 4A, one-way ANOVA, $p = 0.048$), depression (Figure 4B, one-way ANOVA, $p = 0.019$), and sleep disturbance (Figure 4C, one-way ANOVA, $p = 0.007$), with those who identified as White only having better outcomes in all three domains.

Regarding the education level and pain outcomes, both education level measurements (the highest level of school

TABLE 2 Selected pain characteristics of respondents (total $N = 109$).

REDCap Survey Questions		N	Frequency (%)
Where is your pain located? (Check what best describes your pain; check all that apply)	Whole body	19	17.4
	Most of the upper body	5	4.6
	Most of the lower body	9	8.3
	Most of the left side (upper and lower body)	7	6.4
	Most of the right side (upper and lower body)	2	1.8
	Head	12	11.0
	Oral facial	10	9.2
	Neck	30	27.5
	Upper Back	19	17.4
	Lower Back	52	47.7
	Shoulders	31	28.44
	Primarily joint(s) (large and small, except shoulders)	23	21.1
	Primarily limb(s) (upper or lower)	20	18.4
	Other	12	11.0
What do you think was the original cause of your pain (Please choose one only)?	Trauma/Injury	39	35. 8
	Surgery procedure(s)	9	8.3
	Chronic non-cancer illness (such as arthritis	30	27.5
	Cancer	1	0.9
	Other	26	23.9
	Prefer not to answer	4	3.7
	No response [blank]	5	4.6

TABLE 3 Summary of pain comorbidities measured by the PROPr instrument[a].

Domain name	Mean ± SD
Increased morbidity with higher scores	
Anxiety (up to 20)	8.9 ± 3.9
Depression (up to 20)	8.4 ± 4.2
Pain interference (up to 20)	11.4 ± 4.1
Fatigue (up to 20)	12.1 ± 4.2
Sleep disturbance (up to 20)	11.2 ± 1.9
Increased morbidity with lower scores	
Physical function (up to 20)	8.7 ± 3.6
Ability to participate in social roles and activities (up to 20)	11.3 ± 3.7
Cognitive function (up to 10)	7.8 ± 1.9
PROPr score (range 0–1, with 0 = worst outcome and 1 = optimal health)	0.29 ± 0.17

[a]There were no missing responses for the PROPr instrument, however, one subject's responses did not yield an overall PROPr score via the online calculation portal.

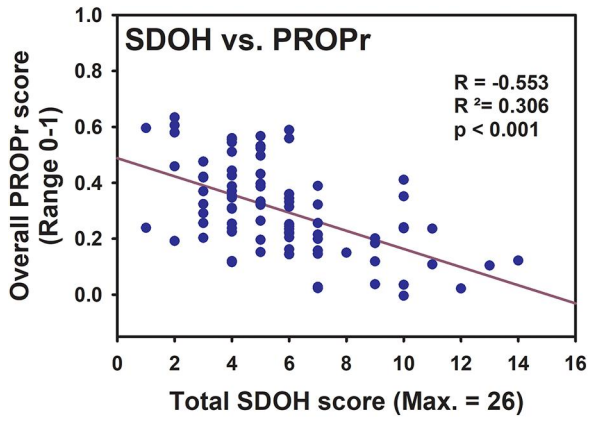

FIGURE 2
Relationship between the total SDOH score and the overall PROPr score. Data from 85 participants were available for both scores and presented here. The regression line, R, R^2, and p value from the Pearson Correlation are shown.

completed and the highest degree earned) showed significant correlations with PROPr pain outcome domains: anxiety, depression, fatigue, and cognitive function, i.e., higher education levels were associated with better outcomes in all 4 of these measures. Relations between "the highest level of school completed" vs. respective domains are shown in Figure 5 (one-way ANOVA for all; 5A, Anxiety, $p = 0.010$; 5B, Depression, $p = 0.006$; 5C, Fatigue, $p = 0.013$; and Cognitive function, $p = 0.007$). In addition, the highest degree earned was negatively associated with the numeric pain score (Figure 5E, one-way ANOVA, $p = 0.021$) and notably, groups that earned Bachelor's degree and higher showed significantly lower pain scores (Figure 5E, follow up post-hoc test, $p < 0.001$ and $p < 0.05$ between each of the groups with education level below the Bachelor's degree vs. any groups with education level at or above the Bachelor's degree).

In addition, we also examined the relationships between other socio-demographic factors: sex, gender, veteran status, and county of residence (rural vs. urban counties) vs. pain outcome domains. No significant correlations between these factors and any of the PROPr domains for pain outcomes were detected with this initial participant pool.

4 Discussion

The long-term goal of our study is to characterize and identify a broader range of SDOH factors that may affect those living with pain in Maine. The state's higher portion of older individuals and its rural geography creates a unique opportunity to study chronic pain considering the higher pain prevalence in individuals with advanced age and geographical barriers to access of health

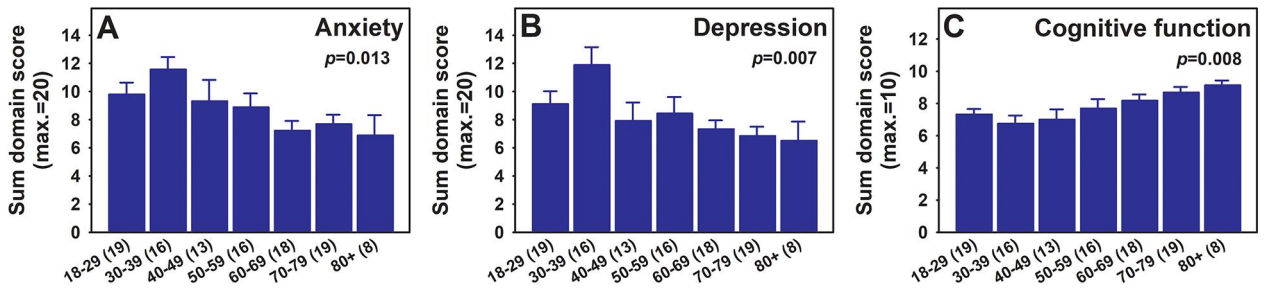

FIGURE 3
PROPr anxiety **(A)**, depression **(B)**, and cognitive function **(C)** scores across age groups. The mean sum scores for each indicated outcome domain are presented across all age groups (mean ± SEM). One-way ANOVA *p* values are shown in respective graphs. Numbers of participants within each group are listed with respective group names in parenthesis on the X-axis. Note that higher scores for anxiety and depression correlate to worse outcomes, while higher score for cognitive function correlates to better outcomes.

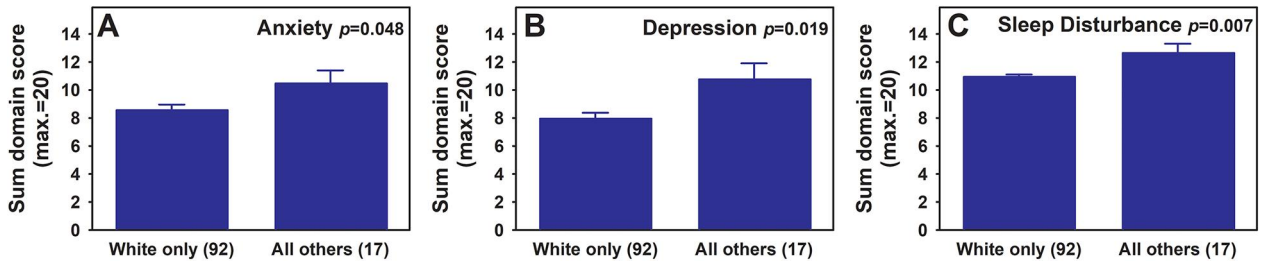

FIGURE 4
PROPr anxiety **(A)**, depression **(B)**, and sleep disturbances **(C)** scores for white only race vs. all others combined. The mean sum scores for each indicated outcome domain are presented for both race groups (mean ± SEM). One-way ANOVA *p* values are shown in respective graphs. Numbers of participants within each group are listed with respective group names in parenthesis on the X-axis. Note that for all three domains, higher scores correlate to worse outcomes.

services to manage pain. Furthermore, few studies have explored pain in social context beyond age, sex/gender and race/ethnicity (21). Our analysis aims to not only explore these characteristics but also additional social dimensions as they relate to pain-related outcomes. To achieve this, we established the first pain registry in Maine, PainRegistryforME (now PainRegistryforME2). This report reflects our analysis of the "first-look" of the data. This initial cohort was predominantly white, female, highly educated, and residents of urban counties. Although it has a greater racial diversity than the Maine's general population, it underrepresents the veteran population. All participants met the diagnosis criteria for chronic pain and most participants experienced moderate to severe chronic pain. Our participant pool is overrepresented by individuals at and above 65 and females compared to the census data. This is consistent with many previous reports that chronic pain is more prevalent in older individuals and females (2, 8–11). Regarding pain co-morbidities, besides pain interference and physical functions, fatigue and sleep disturbance are more notable adverse outcomes than depression and anxiety in our participants. This may be related to our community-based data collection approach that analyzed a different respondent population compared to clinic-based settings (22). Further, among our participants, nearly half of them reported low back pain, which is much greater than what was reported for the US adults (28.1%) (23) and the veteran population (10.3%) (24). This may be associated with the type of our participants' daily activities at home and at work or other demographic characteristics, and requires future investigation. More than a third of individuals believed that their pain originated from previous trauma/injury. This speaks to the importance of injury prevention. This is particularly critical in populations who exhibit risk factors associated with post-traumatic chronic pain, such as those prone to spinal cord injury or disc-vertebra trauma, with history of mental health issues and/or alcohol use disorder, and being female (25). Additionally, our results demonstrated an overall negative impact SDOH risk factors on pain outcomes (Figure 2) in our cohort, which is consistent with previous report (7). Detailed discussion with regard to selected individual SDOH factors are below.

Similar to past research on the impact of pain on different age groups, our analysis showed that older participants with chronic pain demonstrated better mental health outcomes including less anxiety and depression (26). Older adults tend to use a wide variety of coping strategies compared to younger adults including utilizing social support, positive thinking, and pacing themselves such as by taking breaks and moving more slowly in response to their pain (27). A notable finding from our analysis is that older adults with chronic pain demonstrated better cognitive function which conflicts other studies showing an association with a decline in cognitive function specifically related to memory and attention (28). A possible explanation for this could be attributed to the large percentage of individuals with Bachelor's degrees and higher in our current cohort.

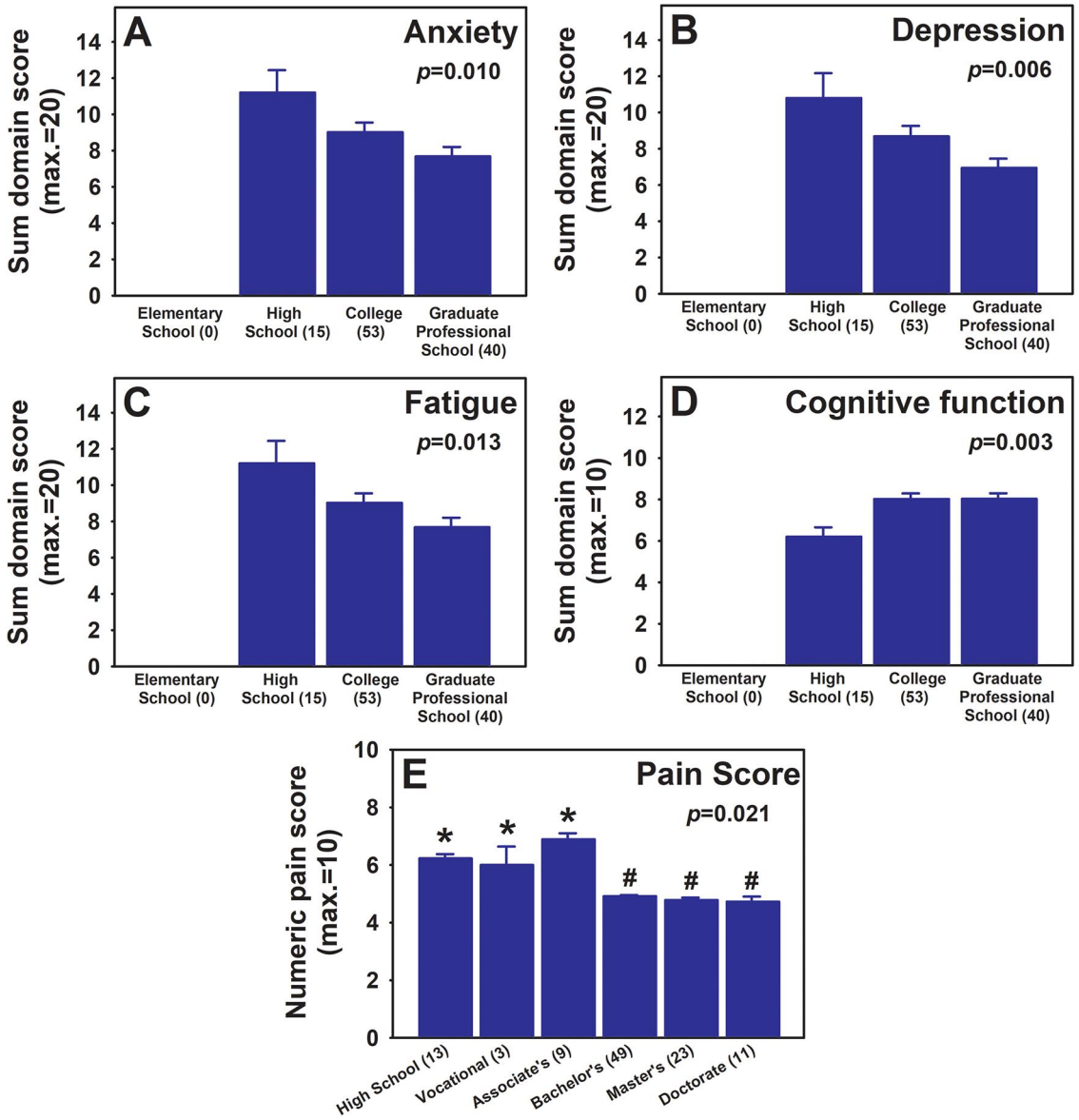

FIGURE 5
Relationships between education levels and selected PROPr pain outcome measures. PROPr anxiety **(A)**, depression **(B)**, fatigue **(C)**, and cognitive function **(D)** scores across education levels dictated by highest level of school completed are shown. Higher mean scores for anxiety, depression, and fatigue correlate to worse outcomes. The mean sum scores for each indicated outcome domain are presented for each education level (mean ± SEM). The mean numeric pain scores across education levels represented by the highest degree earned are presented in **(E)** (mean ± SEM). For **(A–E)**, one-way ANOVA p values are shown in each graph. In **(E)**, $p < 0.05$ between any of the groups indicated by * vs. any groups indicated by #. Numbers of participants within each group are listed with respective group names in parenthesis. Note that higher scores for anxiety, depression, and fatigue correlate to worse outcomes, while higher score for cognitive function correlates to better outcomes. Higher score for numeric pain score correlates to worse pain experienced.

Several studies have found racial disparities in the experience and management of chronic pain with Black individuals reporting significantly more disability along with symptoms of depression compared to White individuals (29). There is also evidence that minorities often receive lower quality pain care than non-Hispanic white people (29). Consistent with these reports, our analysis showed that White race was associated with better outcomes in anxiety, depression, and sleep disturbance. A recent study of 600 participants diagnosed with Fibromyalgia syndrome who were predominantly female and 85% White displayed similar racial and sex makeups to our Maine samples. Our observation aligns with the results from this study that found that racial and ethnic minorities experienced greater mood disturbance, depression, and sleep disturbance (30).

Education attainment remains an important component of socioeconomic status (SES). People with lower SES often face barriers to accessing quality medical care as well as adequate social and financial resources, and could not benefit from the schooling process (i.e., time spent before achieving a degree, involving quality of education, interactions with peers and mentors, institutional resources, etc.) to health, thus putting them at risk for poorer health outcomes, and potentially negatively affecting the health of the subsequent generations due to the lack of resources to pursue higher education (31).

Although past research has suggested that higher levels of education are correlated with lower pain prevalence (32), few studies have explored beyond prevalence to examine the pain disparities associated with education levels (33). Consistent with the previous study (33), our study also identified lower reported pain scores in individuals with greater levels of educational attainment, with a particular cut-off being with or without a Bachelor's degree. In addition, our analysis found that higher education was associated with better outcomes in depression, anxiety, fatigue, and cognitive function, aligning with a previous study of patients with fibromyalgia (34). Factors that may explain our specific findings include that higher education level allows for richer resources and better medical care of their pain which potentially translates into lower fatigue levels and improved mental health. Furthermore, having access to social and economic resources could result in fewer concerns about pain and depressive symptoms, both of which have been linked to the lower pain levels in patients with fibromyalgia (34). Better cognitive function in those with higher education in our sample may reflect the direct benefits of education as well as the indirect effects of improved overall health (31).

Although no significant correlations were found between the following factors and any of the eight pain-related outcome domains, it is important to acknowledge why these characteristics were chosen to explore based on existing studies on chronic pain. Multiple studies have suggested that women are more likely to experience a variety of chronic pain syndromes at higher intensities than men (35). Our results showed that most participants identified as female which is consistent with CDC national data on chronic pain (2) and our previous report on Maine's population (8). Sex refers to the biological attributes including genetics and hormones while gender refers to more of a social role. Hormones such as estrogen play a role in signaling pathways and anatomical differences may account for differences in pain perception. With gender, it is suggested that because of societal norms, women are more inclined to report pain and have more maladaptive coping mechanisms (36). Veteran status was a demographic factor that was of interest because military veterans are more likely to have chronic pain compared to the general population (37) and Maine has a significant veteran population (7.2% according to the census data). Chronic pain in this population becomes complicated by mental health conditions and substance use disorders which are common comorbidities (38). However, our results only included 6 (5.5%) veterans, which is an underrepresentation based on Maine's census and provides insufficient power for robust analysis. Pain prevalence is higher in rural areas compared to urban areas (39). Rural areas often face limited economic opportunities, which can restrict access to healthcare services and health-enhancing activities (40). Although Maine is largely rural, making this demographic relevant, most of our participants resided in urban counties that reduced the statistical power of our analysis significantly.

Our findings should be interpreted with several limitations. The pain registry was created at the University of New England and widely distributed on our two campuses in Biddeford and Portland and surrounding mostly urban areas, accounting for the most densely populated region of the state. This may account for skewed data comparing to Maine's general population particularly pertaining to more participants with younger age, urban residence, non-white ethnicity, and higher education levels, with fewer participants being veterans and living in rural counties. Despite using a multi-modal recruitment strategy, enrollment was dependent on voluntary response and how active dissemination channels were in promoting the study. Efforts were made to distribute the flyers to collaborating sites but it is uncertain whether those on the receiving end distributed the flyers and whether the recruitment efforts were sustained over time. Current participant profiles call for further recruitment of Mainers living with greater SDOH risk factors, particularly those living in rural counties. Additional outreach and recruitment plans are being designed to capture individuals with these characteristics. With the continued effort, we believe that our participant pool will evolve and reflect the general population in Maine over time. The study utilizes data collected through an online survey which is subjected to self-selection and self-reporting biases. Participant burden related to the length of the survey and its online platform may have influenced who chose to participate. Overall, the survey usually took the participants 10–30 min to complete. As we provided an option "Prefer not to answer" for each question, the survey completion rate for each participant is relatively high. Another challenge with an online survey is the risk of responses from automated sources which led to temporary interruptions in data collection for this registry while measures were taken to ensure data integrity. Although the registry is designed to be longitudinal, this current report performed a cross-sectional data analysis and does not allow for further causal inference. Interpretation of these results should be undertaken with caution as this analysis is done on preliminary "first look" data in an ongoing and active registry. Demographic and SDOH factors were selected based on previously known literature and research on chronic pain. With continued data collection and larger sample sizes, the patterns observed within this registry cohort are subject to change and may evolve or strengthen. Therefore, comparisons with our dataset to state and national estimates are presented to contextualize the current findings. Further, other factors collected in the registry, such as those related to pain management and other SDOH factors (such as health insurance, housing conditions, food intake, etc.) may help to identify additional impact of SDOH on chronic pain and mediators between selected SDOH factors and chronic pain.

In summary, although the initial cohort from the pain registry identified several relevant SDOH factors in pain, continued data collection from PainRegistryforME is necessary to understand the pain population in Maine and how specific demographic and SDOH characteristics could influence individuals' chronic pain experiences. The higher prevalence of pain and related comorbidities reported by certain social groups can inform clinicians when assessing patient's risks for developing chronic pain and identifying appropriate preventative and treatment options. Further results can guide public health strategies and interventions for pain prevention and management in Maine.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Maine Health Institutional Review Board (IRB) (IRBnet ID:1970910). The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements.

Author contributions

PO: Data curation, Formal analysis, Investigation, Validation, Visualization, Writing – original draft, Writing – review & editing. EB: Data curation, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Validation, Writing – review & editing. LC: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – review & editing.

Funding

The author(s) declared that financial support was received for this work and/or its publication. The Northern New England Clinical & Translation Research Network (NNE-CTR) pilot program [NIH/NIGMS 5U54GM115516-07 (PI: Rosen), with the subaward: CTR-Pilot-Yr7-UNE-Cao (PI: Cao)] founded the initiation of the PainRegistryforME and the initial data collection, management, and analysis. PO was awarded with the University of New England College of Osteopathic Medicine (UNE COM) Peter Morgane Student Research Fellowship during the academic year 2024–2025 to participate in the pain registry related study.

Acknowledgments

We would like to thank the help and support from a group of NNE-CTR funded Research Navigators from MaineHealth in facilitating the progress of this study. Specifically, Melissa Graham for her help with advice in study design and IRB application, Emmaline Ashe for her expertise in managing data within RedCap, and Wendy Craig for her help and advice in study design and data analysis.

Conflict of interest

The author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

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frontiers in Pain Research

TYPE Original Research
PUBLISHED 08 May 2026
DOI 10.3389/fpain.2026.1812648

OPEN ACCESS

EDITED BY
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RECEIVED 17 February 2026
REVISED 24 March 2026
ACCEPTED 15 April 2026
PUBLISHED 08 May 2026

CITATION
Kruijer SD, Achterberg WP, van Dalen-Kok A and Caljouw MAA (2026) Observing and treating pain in people living with dementia in long-term care facilities.
Front. Pain Res. 7:1812648.
doi: 10.3389/fpain.2026.1812648

Observing and treating pain in people living with dementia in long-term care facilities

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Objectives: Neuropathological changes in dementia compromise communicative abilities, causing pain to present atypically and making assessment challenging. Although pain is highly prevalent in people with dementia and can be managed pharmacologically and non-pharmacologically, comprehensive studies on pain assessment and management in this population remain scarce. This study aimed to explore how pain is observed, assessed, and managed in people living with dementia in long-term care facilities.
Design: Mixed-methods sequential explanatory design.
Setting and participants: Medical staff, healthcare professionals, nursing staff, and managers employed in long-term care facilities, as well as informal caregivers of residents with dementia in these facilities, in the Netherlands.
Methods: Between April 9 and July 1, 2024, participants completed a nationwide survey ($N = 387$) containing questions about pain observations and the use of non-pharmacological and pharmacological interventions. The number of questions varied from 4 (for the managers) to 15 (for informal caregivers), and additional in-depth interviews were conducted ($N = 20$). Quantitative data were analyzed descriptively using SPSS to calculate frequencies and distributions. The interview summaries were analyzed for recurring themes and illustrative quotes used to support survey findings.
Results: Pain was most considered when medical and nursing staff observed non-verbal indicators such as behavioral changes, supported by physical examination and, in some cases, pain observation scales. Approximately half of respondents reported using observational pain scales in routine practice. Pain management relied predominantly on pharmacological treatment, primarily paracetamol, with less frequent and unsystematic use of non-pharmacological interventions such as distraction, exercise, and music therapy.
Conclusion: Pain assessment and management for people with dementia in long-term care facilities remain predominantly pharmacological. The limited and inconsistent use of validated observational tools and non-pharmacological interventions highlights the need for systematic implementation in clinical practice and future research.

KEYWORDS
dementia, long-term care, non-pharmacological interventions, pain, pain assessment, pain management, pharmacological interventions

1 Introduction

Half of the people living with dementia in long-term care facilities experience pain regularly (1). Despite this high prevalence, pain in people with dementia is often not recognized and therefore undermanaged (2). One of the main reasons for this is the loss of communicative abilities, as people with dementia are frequently unable to verbally express their pain effectively (3). As a result, pain may manifest indirectly through challenging behaviors such as agitation, aggression, and depression, as well as changes in physical functioning (4). The range of pain-related behaviours can also include observable indicators such as body gestures, facial expressions, and vocalizations, which are commonly used in observational pain assessment in dementia (5). Together, these behavioural and physical changes may signal the presence of pain (6–10).

Given these communication difficulties, observational tools are essential for assessing pain in people with dementia who cannot communicate verbally (11). These tools focus on pain-related behaviors such as facial expressions, movement, and vocalization (12). Although research shows that systematic use of observational tools can improve pain management, their implementation in daily practice remains inconsistent (2). Previous research shows that changes in behavior or physical functioning may indicate the presence of pain in people with dementia (13). Informal caregivers, who know the person with dementia well, are particularly able to recognize subtle changes in behavior or functioning, thereby contributing to more accurate pain identification.

In terms of treatment, medication remains the primary approach to pain management in people with dementia (2). Nevertheless, several guidelines recommend non-pharmacological interventions before initiating pharmacological treatment, including the guideline followed by elderly care physicians working in Dutch nursing homes (Verenso) and best-practice guidance for health professionals in the United Kingdom (14).

These recommendations reflect the limitations of pharmacological interventions in older persons (15). Analgesics can cause adverse effects in people with dementia, such as drowsiness and an increased risk of falling. For this reason, non-pharmacological interventions are often preferred as a first step for treating mild pain, while pharmacological treatment may be added for moderate to severe pain to achieve a synergistic effect (15).

In this context, non-pharmacological interventions—defined as "therapies that do not involve taking medicine or any other active substance" (16)—have gained increasing attention. Evidence from older adults without dementia supports interventions such as acupuncture, mindfulness, meditation, massage, and cognitive behavioral therapy (17). More recently, systematic reviews and meta-analyses in people with dementia indicate moderate efficacy for sensory-based interventions, such as reflexology and ear acupressure, and more consistent effects for interactive interventions, including music, singing, art-based activities, play, and robotic care (4, 18–20). However, effectiveness varies by intervention type, frequency, and care setting. A summary of these findings is provided in Table 1.

Although pain in dementia is complex and increasingly prevalent due to demographic ageing, research describing the daily practices of observing and managing pain remains scarce. In particular, the use of systematic observational pain assessment tools and how different caregiver groups—such as medical staff, nursing staff, management, and informal caregivers—are involved in pain management (2, 21, 22).

The Dutch long-term care setting provides a relevant context to study these issues, as care for people with advanced dementia is highly organized, multidisciplinary, and guided by national recommendations for pain management (23). At the same time, variability in implementation across facilities may limit optimal pain care. Understanding usual care in this context is therefore relevant not only nationally, but also internationally, as many countries face similar challenges in translating evidence-based pain management strategies into routine long-term dementia care (24). Therefore, this study aims to provide an overview of how pain is recognized, assessed, and managed in long-term care facilities, with specific attention to the roles and perspectives of different caregiver groups. Also, given their growing role in dementia care in the Netherlands, this study aimed to explore whether informal caregivers are currently involved in assessing pain in people with dementia and applying non-pharmacological interventions.

2 Methods

2.1 Study design

A mixed-methods sequential explanatory design was used, consisting of an online survey and in-depth interviews. The study was exempt from review by the Medical Ethics Review Committee, as the non-WMO Review Committee determined that the Dutch Medical Research Involving Human Subjects Act (WMO) did not apply (protocol nr. N 24-3008).

2.2 Recruitment

Participants were recruited via academic care networks ("University Network for the Care sector South- Holland" (UNC-ZH) (25), "Collaborating Academic Networks for the Elderly Care" (Samenwerkende Academische Netwerken Ouderenzorg or SANO). Through SANO regional academic research networks were approached like the Academic Networks of Elderly Care in the North (UNO-UMCG) and the University Network for Elderly Care in North-Holland (UNO Amsterdam) to distribute the survey in several long-term care facilities in the northern part of the Netherlands. Recruitment was also done through social media and by the UNC-ZH website. Informal caregivers were approached through Minters (36), which distributed flyers during educational meetings and Alzheimer Nederland (a network for people with dementia and their loved ones).

2.3 Sample size

A total of 220 respondents were expected to be representative of the population: 150 medical staff, healthcare professionals, and nursing staff; 20 nursing home managers; and 50 informal caregivers (26). No formal power calculation was conducted.

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TABLE 1 Summary of a literature review on the effectiveness of non-pharmacological interventions in pain in dementia (in nursing homes).

Author, year	Study design	Setting	Diagnosis	Interventions	Results
Bao & Landers (18)	Mixed methods systematic review 8 studies	Residential care settings, memory clinics, patients' homes.	People with dementia Diagnosed with pain using SVS, PAINAD, M-PADE, DOLOPLUS	**Interactive interventions:**	
				Singing & painting:	Duration of pain decreased significantly from baseline compared to week 16 ($p = 0.01$). Intensity of pain was significantly reduced from baseline to week 16 ($p = 0.009$). Overall pain levels decreased but did not reach a significant level. Both interventions are equally effective at reducing pain.
				Play activities:	Reduction of pain intensity ($d = 2.47$).
				Therapeutic: robot	Patients calmed down resulting in reduction of pain.
				Non-interactive interventions:	
				Massage:	one study showed no statistical significance ($p = 0.93$) in the reduction of pain. Another study showed statistical significance pain reduction ($p < 0.001$)
				Listening to music:	No significant reduction of pain ($p = 0.0582$) but it can distract from the pain.
				Ear acupressure:	Was significant in effectively managing pain ($p < 0.001$)
Pu et al. (20)	Systematic review of randomized controlled trials 9 articles on 8 studies RCT design (parallel, cross-over, cluster, multi-arm, cluster-study with multi-arm)	Long-term care facility, the community, and a memory clinic	Dementia or MCI Pain measured with self-report (NRS, SVS, VDS) or pain observation scales (PACSLAC, CNPI, PAINAD, BPI, DOLOPLUS 2, DS-DAT, WOMAC)	Sensory stimulation: *(reflexology, massage, ear acupressure, music, showering)*	Statistically significant reduction of observed pain (SMD = −0.58, 95% CI [−0.99, −0.17)
				Physical activity intervention: *(Tai Chi, Passive movement therapy)*	No statistical significance in reduction of pain (SMD = −0.24, 95% CI [−1.06,0.59)
				Individual intervention:	Significant result in reduction of pain (SMD = −0.55, 95% CI [−1.01, −0.09)
				Group interventions:	No significant reduction in pain (SMD= −0.27, 95% CI [−1.06, 0.53)
				Medication use:	No significant effect was found, but a decrease in daily acetaminophen dosage was found for the Tai Chi group, compared to an increase in the control group.
Liao et al. (19)	Systematic review 11 articles Quantitative research	Community-dwelling individuals, hospital settings, long-term care facilities	Dementia and no dementia (separate results for people with dementia and people without dementia) Dementia diagnoses Pain: persons experiencing pain, chronic pain, or people taking pain medication for at least one month	Massage:	One of the studies reported no significant change in self- reported pain in the intervention group ($p = 0.21$). Another study reported a decrease in pain (lower back pain and limb pain) post-intervention. Pain increased slightly after two months. The control group showed an increase in pain after regular care and an increase in pain after follow-up.

(*Continued*)

TABLE 1 Continued

Author, year	Study design	Setting	Diagnosis	Interventions	Results
			Pain assessment: PAINAD, M-PADE, DOLOPLUS 2, BPI, Algoplus Tool, CNPI, GMPI, Abbey pain scale, NRS and SVS	Ear acupressure:	Significant reduction in pain measured after two months ($p = 0.001$)
				Music therapy:	Significant reduction in pain when listening to preferred music for more than 30 min ($p < 0.05$).
				Painting and singing:	Pain scored with SVS and BPI; significant reduction in pain after the intervention ($p = 0.01$, $p = 0.009$, respectively). When measured with the NRS, no significance reduction in pain ($p = 0.057$).
				Exercise:	No significant decrease in pain.
				Social activities:	No significant decrease in pain.
				Cognitive- Behavioral therapy:	Significant reduction in pain scores ($p < 0.001$).
				Personal assistive robot (PARO):	Significant pain reductions when measured with the PAINAD ($p = 0.004$), no significant reduction when measured with the NRS. Medication use was significantly lower in the intervention group ($p = 0.025$).
				Reflexology:	Significantly reduction in pain scores after intervention.
				Tailored pain intervention:	No significant reduction in pain scores.
				Play activity:	Significant reduction in chronic pain ($p = 0.019$) and significant difference in pain reduction between the intervention group and control group ($p = 0.002$.
				Patient- centered environmental program:	Significant reduction in pain severity after intervention ($p = 0.002$).
Saragih et al. (4)	Meta-analysis and a systematic review RCT, quasi-experimental study or experimental study	Nursing home, elder care facility, memory care facility, community setting	People with dementia and mild to moderate MCI Pain measured with PAINAD, C-PAINAD, PACSLAC-D, CNPI, VAS, AQoL-8D, NRS, and VDS	Massage, exercise, meditation, painting instruction and robotic care	**Overall effects assessed immediately after the intervention** No significant reduction in pain between the intervention and the control group. **Subgroup analyses** Intervention delivery frequency: Significant reduction in pain in the two intervention groups (interventions given once or twice a week and interventions given three times or more a week) ($p = .86$, $p = .85$, respectively). Post-intervention evaluations: Significant pain reduction 4–8 weeks after the intervention, compared with the control group. Results were greater after 4–8 weeks then diminished after more than 8 weeks.

DSM-V, Diagnostic and Statistical Manual of Mental Disorders fifth edition; NINCDS, National Institute of Neurological and Communicative Disorders and Stroke; ADRDA, Alzheimer's Disease and Related Disorders Association; SVS, Simple Visual Scale; PAINAD, Pain Assessment in Advanced Dementia; M-PADE, Modified Pain Assessment in the Dementia Elderly; MCI, Mild Cognitive Impairment; RCT, Randomized Controlled Trial; NRS, Numeric Rating Scale; VDS, Verbal Descriptor Scale; PACSLAC, Pain Assessment Checklist for Seniors with Severe Dementia; CNPI, Checklist of Nonverbal Pain Indicators; BPI, Brief Pain Inventory; DS-DAT, Discomfort Scale of Dementia of the Alzheimer's Type; WOMAC, Western Ontario and McMaster Universities Osteoarthritis Index; FAST, Functional Assessment Staging Scale; MMSE, Mini-Mental State Examination; GMPI, Geriatric Multidimensional Pain and Illness Inventory; VAS, Visual Analogue Scale; AQoL-8D, Assessment Quality of Life-8D.

The obtained sample size is considered to provide a reasonable representation of the different professional groups.

2.4 Survey

An online survey was developed by (SK and MC) based on clinical experience and recent literature. The purpose of this survey was to gather information from different caregiver groups about the assessment and observation of pain, its treatment, and the roles these groups have within the overall process of pain management. They survey was validated with the LUMC Validation Castor Checklist, where the first and second part of the checklist was filled out by the researchers and the third part was filled out by an independent party. Non-pharmacological interventions included in the survey were derived from a search for articles on systematic reviews and meta-analyses conducted in 2023, using the following search criteria: "Pain" AND "Dementia" AND "Non-pharmacological interventions", and published after 2020, to obtain most recent researched interventions (4, 18–20). Interventions shown to reduce pain in people with dementia were included (Table 1).

After providing informed consent, eligible participants answered demographic questions and were directed to a role-specific survey based on their relationship with a person with dementia living in a long-term care facility (medical staff, healthcare/nursing staff, management, or informal caregivers). Surveys differed by role to reflect variations in responsibility and involvement in pain recognition, assessment, and management. Most questions were multiple choice, with occasional free-text options. Participants received a notification when a question was not answered to ensure that all questions were answered and no data was missing. Participants who did not meet the inclusion criteria were unable to access the survey. The full survey is shown in Table 2. At the end of the survey, participants could indicate interest in an in-depth interview.

2.5 Participants and eligibility

Participants included medical staff (*elderly care physician, physician in training)*, healthcare professionals *(physical therapist, music therapist, psychologist, massage therapist etc.*), nursing staff (*nurses and nursing aids*), management from Dutch long-term care facilities, and informal caregivers of residents with dementia. All participants were older than 18 years old, proficient in the Dutch language, and involved in caring for people with dementia who experience communication difficulties. Professionals were required to have at least 12 months' experience in long-term dementia care. Informal caregivers had to be family members of residents living in a long-term care facility for at least six months and be responsible for medical decision-making.

2.6 Procedure and quantitative analysis

The survey was conducted in CASTOR and open from April 9 to July 1, 2024, and was accessible via a link shared on the collaborating networks' websites and in newsletters. Information about the study, how data was collected and how the results of the study would be used was also provided (27).

Surveys containing only demographic data were excluded from analysis (Figure 1). Results were analyzed using SPSS version 29. Quantitative analyses were primarily descriptive (Table 3). Frequencies, percentages, means, and standard deviations will be reported. Where appropriate, ranges are also provided.

2.7 Interviews

Participants who were interested in attending in-depth interviews provided contact details at the end of the survey. Interviewees were purposively selected to ensure multidisciplinary representation and diversity based on gender, level of education and relationship to residents of the long-term care facilities. To obtain a divers representation of the participants, at least 15 interviews will suffice to support the results of the survey for more clarification.

2.8 Procedure and qualitative analysis

Participants were contacted via email first with additional information about the interview and the study. Then one of the researchers (SK or JL) contacted them by phone to schedule an interview appointment. The informed consent form was emailed and asked to sign the form before the interview started.

Interviews were semi-structured, conducted by (SK, Psychologist and PhD candidate or JL, Master student Psychology) via Microsoft Teams or at the participant's workplace, and focused on pain recognition, assessment, and management (Appendix 1). Interviews were recorded, transcribed verbatim, and thematically summarized. Each interview was transcribed by one researcher and subsequently checked for accuracy by the second researcher. Two researchers independently analyzed the data, and illustrative quotes were selected to complement or contrast survey findings.

The answers on the survey were analyzed and reported. Subsequently, two researchers independently reviewed the interview transcripts to identify quotes and information that either supported or contradicted the survey findings. These quotes and the information were then discussed collaboratively, and consensus was reached regarding the selection of the most representative and relevant quotes or information.

No formal codebook was developed. The primary analysis focused on the survey data. The transcribed interviews were subsequently reviewed to identify quotes that could support or contextualize the survey findings. The interviews were therefore used to complement and further illustrate the quantitative results rather than to conduct a separate qualitative analysis.

3 Results

3.1 Survey

A total of 1,272 potential participants clicked on the survey link (Figure 1). Of these, 766 opened the survey but did not

TABLE 2 Questions in the survey and results perrelationship.

Questions	Medical staff (*N* = 98)		Healthcare professionals (*N* = 131)		Nursing staff (*N* = 81)		Informal caregivers (*N* = 53)		Managers (*N* = 24)	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Assessing pain										
1. When is pain considered?[a] *(y)*										
• Change in behavior	98	100	125	95.4	80	100.0				
• Lab results	16	16.3	44	33.6	24	30.0				
• Completing pain observation checklists every so often	23	23.5	97	74.0	58	72.5				
• Observations from nursing staff	96	98.0	–	–	–	–				
• Observations from family members	95	96.9	108	82.4	53	66.3				
• No involvement in pain assessment	–	–	8	6.1	0	0				
• Other (non-verbal expressions, after trauma, decreased functionality, mood swings, self-reports of pain, change in sleep patterns)	15	15.3	17	13.0	4	5.0				
Missing (NA, NASK)					1					
2. Are you informed whether your family member is in pain?[b] *(y)*							44	83.0		
2.1. Are you informed about whether the cause is being investigated?(y)							32	60.4		
Missing (NA, NASK)							10			
3. How is pain diagnosed?[a] *(y)*										
• Physical examination	89	90.8	2	1.7	0					
• Pain observation checklists	81	82.7	1	0.9	0					
• Observations by the physician	94	95.9	2	1.7	0					
• Starting trial medication	74	75.5	–	–	0					
• Other (consultation with informal caregivers, observations during ADL, observations of changes in posture)	4	4.1	0		0					
Missing (NA, NASK)	1		15		13					
4. Have you ever been asked to observe pain?[b] *(y)*			94	72.3	72	88.9	12	22.6		
Missing (NA, NASK)							1			
4.1. Do you use a pain observation checklist for this?(y)	115	54.2			59	62.8	56	78.9		
	47				37		10			

(*Continued*)

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TABLE 2 Continued

Questions	Medical staff (*N* = 98)		Healthcare professionals (*N* = 131)		Nursing staff (*N* = 81)		Informal caregivers (*N* = 53)		Managers (*N* = 24)	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Missing (NA, NASK)										
5. Have you ever reported that your family member is in pain? (y)							43	81.1		
Missing (NA, NASK)							1			
6. What follow-up actions are taken?[a] (y)										
• Start pain medication	82	83.7								
• Gather more information	97	99								
• Consult with care staff and other disciplines	86	87.8								
• Consult with family	68									
• Other (SI investigation, involving other disciplines, consultation with the patient, using non-pharmacological interventions)	7	7.1								
Missing (NA, NASK)	1									
7. Is family ever asked to observe pain? (y)	40	40.8								
Missing (NA, NASK)	1									
Management of pain										
8. Is pain always treated? (y)	77	78.6								
Missing (NA, NASK)	1									
9. Are you involved in creating a treatment plan?[b] (y)			89	69.0	54	68.4	2	3.8	4	16.7
Missing (NA, NASK)			2		2		43			
9.1. Involvement by: (y)										
• Managing the team									4	16.7
• Setting goals									1	4.2
• Brainstorming treatment options									3	12.5
• Considering possible interventions									2	8.3
• Evaluating whether a resident is suitably placed in the specific long-term care facility									3	12.5
• Other ways									–	–
Missing (NA, NASK)									20	

(*Continued*)

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TABLE 2 Continued

Questions	Medical staff (*N* = 98)		Healthcare professionals (*N* = 131)		Nursing staff (*N* = 81)		Informal caregivers (*N* = 53)		Managers (*N* = 24)	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
10. Are guidelines followed? (y)									23	95.8
Missing (NA, NASK)									1	
10.1. Are you informed of deviations from the guidelines? (y)									11	45.8
Missing (NA, NASK)									2	
11. What is the basis for the treatment plan?[a] *(y)*										
• General guidelines	66	67.3								
• Own guidelines	16	16.3								
• Own knowledge	55	56.1								
• Other (palliative care, self-care products used)	2	2.0								
Missing (NA, NASK)	23									
12. Do you have any non-pharmacological interventions at your disposal?(y)	87	88.8								
Missing (NA, NASK)	3									
13. Are you familiar with non-pharmacological interventions?[b] *(y)*							30	56.6		
Missing (NA. NASK)							1			
13.1. Which of the following non-pharmacological interventions do you know?[a] *(y)*										
• Music therapy			101	79.5	59	73.8	18	34.0		
• Massage			96	75.6	51	63.7	16	30.2		
• Activities matching interests			109	85.8	57	71.3	18	34.0		
• Exercise			114	89.8	67	83.8	21	39.6		
• Painting			67	52.8	29	36.3	6	11.3		
• Acupressure			22	17.3	12	15.0	9	17.0		
• Singing			83	65.4	52	65.0	12	22.6		
• No interventions used			1	0.8	3	3.8	—	—		
• Other (proper footwear, Qwiek.up, snoezelen, adjusting environment and posture, distraction, aromatherapy)			47	37.0	19	23.8	6	11.3		
Missing (NA, NASK)			4				23			
13.2. Are these interventions ever used? (y)			111	88.8	65	82.3				

(*Continued*)

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TABLE 2 Continued

Questions	Medical staff (*N* = 98)		Healthcare professionals (*N* = 131)		Nursing staff (*N* = 81)		Informal caregivers (*N* = 53)		Managers (*N* = 24)	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Missing (NA, NASK)			6							
13.3. Have you ever been asked to perform an intervention for pain treatment? (y)			68	54.4	32	41.0				
Missing (NA, NASK)			6							
13.4. Were positive effects observed? (y)	70	71.4	87	41.0			8	15.1		
Missing (NA, NASK)	24		113				39			
14. Are any non-pharmacological interventions included in the treatment plan?[b] *(y)*	74	75.5	79	90.8	41	78.8				
Missing (NA, NASK)	13		44							
14.1. Non-pharmacological interventions are not included because: [a] *(y)*										
• Insufficient staff	4	4.1	3	6.8	1	3.1				
• Lack of time	4	4.1	2	4.5	2	6.3				
• Lack of knowledge	8	8.2	6	13.6	10	31.3				
• Not the right staff for the interventions	–	–	0	0	2	6.3				
• Not considered	8	8.2	4	9.1	10	31.3				
• No clarity about execution and effect	6	6.1	2	4.5	2	6.3				
• Other (Verenso guidelines, role of family)	2	2.0	1	2.3	0	0				
Missing (NA, NASK)	87		87		49					
14.2. Which interventions are included in the treatment plan/ have you been asked to perform?[a] *(y)*										
• Music therapy	49	50.0	15	21.7	12	38.7				
• Massage	28	28.6	21	30.4	13	41.9				
• Activities matching interests	63	64.3	26	37.7	17	54.8				
• Exercise	65	66.3	39	56.5	18	58.1				
• Painting	20	20.4	2	2.9	3	9.7				
• Acupressure	1	1.0	2	2.9	1	3.2				
• Singing	27	27.6	10	14.5	7	22.6				
• No interventions used	1	1.0	0	0	0					
• Other (complementary care, aromatherapy, referrals to occupational therapist or physiotherapist, PDL, SI, heat and cold, spiritual care)	27	27.6	26	37.7	7	22.6				

(*Continued*)

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TABLE 2 Continued

Questions	Medical staff (*N* = 98)		Healthcare professionals (*N* = 131)		Nursing staff (*N* = 81)		Informal caregivers (*N* = 53)		Managers (*N* = 24)	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Missing (NA, NASK)	24		62							
14.3. Did the treatment reduce pain?			62	91.2	25	80.6				
Missing (NA, NASK)			63		50					
14.4. Which intervention showed positive effects?[a] *(y)*										
• Music therapy	39	39.8								
• Massage	22	22.4								
• Activities matching interests	45	45.9								
• Exercise	56	57.1								
• Painting	8	8.2								
• Acupressure	1	1.0								
• Singing	23	23.5								
• No interventions showed positive effects	1	1.0								
• Other (complementary care, aromatherapy, referrals to occupational therapist or physiotherapist, PDL, SI, heat and cold, spiritual care)	22	22.4								
Missing (NA, NASK)	24									
14.5. How are the effects observed?[a] *(y)*										
• Physical examination	16	16.3								
• Observation lists	30	30.6								
• Observations by doctors and care staff	66	67.3								
• Observations by family member	47	48.0								
• Observations after stopping intervention	20	20.4								
Missing (NA, NASK)	25									
15. Do you ever mention that non-pharmacological interventions are available? (y)			2	28.6	11	100				
Missing (NA, NASK)			124		70					
16. Have non-pharmacological interventions ever been used with your family member? (y)							14	26.4		
Missing (NA, NASK)							23			
17. Would you want pain medication to be started for your family member? (y)							50	94.3		

(*Continued*)

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TABLE 2 Continued

Questions	Medical staff (*N* = 98)		Healthcare professionals (*N* = 131)		Nursing staff (*N* = 81)		Informal caregivers (*N* = 53)		Managers (*N* = 24)	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Missing (NA, NASK)							1			
18. Would you want non-pharmacological interventions to be used for pain? (y)							41	77.4		
Missing (NA, NASK)							1			
19. What interventions did your family member use at home to reduce pain?[a] *(y)*										
• Pain medication							41	77.4		
• Walking							14	26.4		
• Sports							8	15.1		
• Massage							8	15.1		
• Meditation							–	–		
• Other (acceptance, acupuncture, distraction, conversation, going to a doctor)							8	15.1		
Missing (NA, NASK)							2			
19.1. Would you want this to still be used now? (y)							42	79.2		
Missing (NA, NASK)							2			
19.2. Has the staff ever asked about these interventions? (y)							13	24.5		
Missing (NA, NASK)							2			
19.3. Do you ever undertake activities to reduce pain for your family member? (y)										
Missing (NA, NASK)							25	47.2		
20. How long would you use non-pharmacological interventions? (y)										
• 1–5 days	16	16.3								
• 1–2 weeks	26	26.5								
• 3 weeks–1 month	27	27.6								
• What is indicated in literature or guidelines	10	10.2								
Missing (NA, NASK)	19									
21. Which do you choose? (y)										
• First medication	18	18.4								
• First non-pharmacological	6	6.1								

(*Continued*)

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TABLE 2 Continued

Questions	Medical staff (*N* = 98)		Healthcare professionals (*N* = 131)		Nursing staff (*N* = 81)		Informal caregivers (*N* = 53)		Managers (*N* = 24)	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
• Combination	59	60.2								
• Missing (NA, NASK)	15									
22. Are you ultimately responsible? (y)	68	69.4								
Missing (NA, NASK)	9									

ADL, General Daily Activities (Algemene Dagelijkse Levensverichtingen); SI, Sensory Information processing; PDL, Passivities of Daily Living; NA, Not Answered; NASK, Not Asked.
[a]Multiple answers possible.
[b]Question answered with "yes" directed to the follow-up question.
(y) the results are the percentage of "yes" answers to the question.

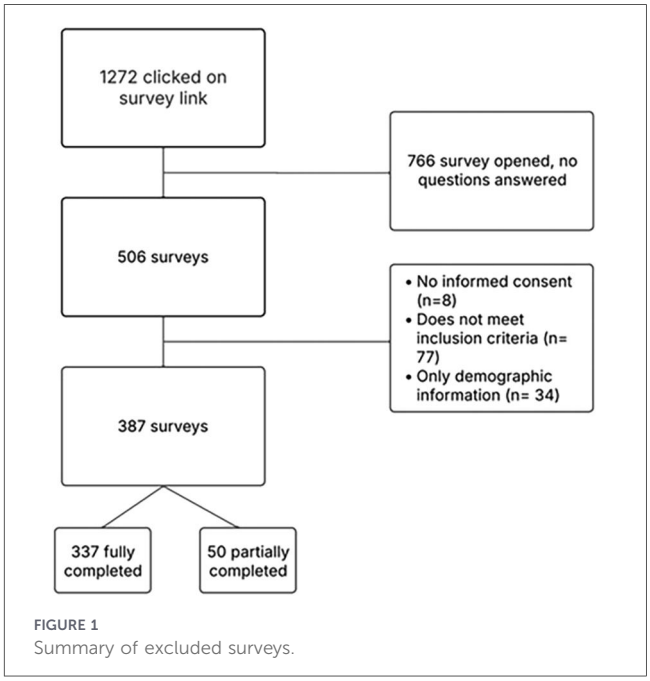

FIGURE 1
Summary of excluded surveys.

answer any questions. 50 participants completed the survey partially, and 337 completed the entire survey. In total, 387 respondents who completed at least one substantive survey item, in addition to the demographic questions, were included in the quantitative analyses.

3.2 Interviews

At the end of the survey, 77 respondents indicated their willingness to participate in an in-depth interview. After being approached, 20 participants, participated in the interviews: four with medical staff and twelve with healthcare professionals and nursing staff. Only two informal caregivers and two managers were willing to participate in an interview. Given the study's primary focus on professional decision-making in pain assessment and management, informal caregivers were included to complement, rather than dominate, the qualitative findings.

3.3 Demographics

Survey participants had a mean age of 48.5 years (SD = 14.3; range 19–67), and 78.8% ($n = 305$) were female. More than half of the respondents ($n = 205$; 52.9%) had completed higher professional education or a university degree. Additional demographic characteristics of the survey sample are presented in Table 3.

Table 4 presents the professional distribution within the survey sample of healthcare professionals, which was subdivided into (1) nursing staff (registered nurses and nursing aids) and (2) healthcare professionals (e.g., physical therapists, psychologists, music therapists, and massage therapists).

One elderly care physician completed the survey intended for healthcare professionals. The data from this participant was retained for overall descriptive statistics where the professional role was not a determining factor.

10.3389/fpain.2026.1812648

TABLE 3 Demographic characteristics of the participants ($N = 387$).

Characteristics *n* (%)	
Age, *Mean* (SD)	48.5 (14.3)
Gender, *n* (%)	
Male	79 (20.4)
Female	305 (78.8)
Other	2 (0.5)
Missing (NA)	1 (0.3)
Highest level of education, *n* (%)	
Pre-vocational education (*VMBO*) or intermediate general secondary education (*MAVO*)	26 (6.7)
School of higher general secondary education (*HAVO*) or pre-university education (*VWO*)	63 (16.3)
Higher national education (*HBO-kort, HTI or HTS*) or Bachelor's degree	91 (23.5)
University Master's degree or PhD	205 (53.0)
Missing (NA)	2 (0.5)
Country of birth, *n* (%)	
Netherlands	364 (94.1)
Other (*Argentina, Belgium, Curacao, Ecuador, France, Germany, Hungary, Indonesia, Cameroon, Mauritius, Russia, Saint Maarten, Suriname, Syria, USA, South- Africa*)	23 (5.1)
Relationship with residents, *n* (%)	
Medical staff (elderly care physician, physician in training)	98 (25.3)
Healthcare professionals (physical therapist, music therapist, psychologist, massage therapist)[a] and nursing staff (nurses and nursing aids)	212 (54.8)
Managers of a LTCF	24 (6.2)
Informal caregivers	53 (13.7)

Not Answered (NA), Long Term Care Facility (LTCF).
[a]One elderly care physician filled out the survey intended for healthcare professionals and nursing staff.

TABLE 4 Professional groups within healthcare professionals and nursing staff and daily tasks[b].

Professions	*N* (%)
Nursing staff	
Care assistant (*assist in personal care and help in daily activities*)	5 (6.2)
Nursing aids (*personal care, support in daily activities*)	28 (34.6)
Nurses (*direct care and medical procedures, like giving medication and wound care and guidance in daily life*)	48 (59.3)
Healthcare professional	
Psychologists (*diagnosing and treating psychiatric diseases*)	34 (8.8)
Physical therapists (*treatment, exercise therapy and prevention of falls*)	20 (5.2)
Occupational therapists (Music therapist, psychomotor therapist, creative therapist) (*treating and advising psychosocial and behavioural problems in residents with dementia*)	10 (2.6)
Occupational therapists (*assess what someone can still do independently and advising and training on the use of assistive devices*)	15 (3.9)
Social workers (*supporting residents with loss or coping and supporting family with feelings of guilt and acceptance*)	3 (0.8)
Employee activities and well-being (*organizing activities and giving individual attention*)	1 (0.3)
PA/nursing specialist (*diagnosing and treating geriatric diseases*)	21 (5.4)
Others (Social workers, Employee activities and well-being, Social pedagogy, Livingroom assistants, Practical nurse/practical researcher, Professional mentor, Exercise therapist, Dementia case manager, Complementary care practitioner, Behavioral consultant, Spiritual Counselor, Quality practitioner, Speech therapist)	27 (7.1)
Elderly care physician[a] (*diagnosing and treating geriatric diseases*)	1 (0.3)

PA, Physician Assistant.
[a]One elderly care physician filled out the survey meant for health care professionals and nursing staff.
[b]Small differences in daily tasks can be seen in different long-term care organizations.

3.4 Recognizing and assessing pain

Among survey respondents, all medical staff (100%), health care professionals (95.4%) and nursing staff (100%) indicated that they consider pain when challenging behavior is observed. Observational pain scales were mentioned to assist in identifying pain by 23.5% of medical staff, 74.0% of healthcare professionals and 72.5% of nursing staff When asked to observe pain, 62.8% of the health care professionals and 78.9% of the nursing staff uses observational pain scales.

However, more discrepancy on this was illuminated by interview data. Medical staff as well as healthcare professionals and nursing staff described observational scales as useful for identifying pain and evaluating treatment effects, particularly when pain signals are unclear. At the same time, they emphasized that high workload and time pressure often lead nursing staff to draw rapid conclusions without extensive analysis of underlying causes.

In the survey medical staff reported that pain assessments were frequently informed by family members (96.9%). However, only 40.8% indicated that informal caregivers were actively asked to observe or formally assess pain using an observation scale. Informal caregivers confirmed that they often observe and report pain-related behaviors (81.1%), yet only 22.6% reported being explicitly asked to do so.

Interview participants across professional groups described nonverbal cues—such as grimacing, resistance during care, pushing staff away, agitation, or aggression—as key indicators of pain. One psychologist stated: "*Pain is often signaled through behavioral changes like agitation, aggression, or repetitive behavior.*" Additional survey results on pain recognition and assessment are presented in Table 2.

3.5 Management of pain

Following pain assessment, medical staff reported several initial management steps: administering medication (83.0%), collecting additional information (99.0%), and consulting other disciplines (87.8%). Most medical staff (88.0%) indicated that

non-pharmacological interventions were available to them and could be included in management plans. Nevertheless, a combination of medication and non-pharmacological interventions was included in only 60.2% of reported management plans.

Informal caregivers expressed a preference for combined approaches, indicating that they would initiate medication (94.3%) as well as non-pharmacological strategies (77.4%) when pain was suspected. Nearly half (47.2%) reported engaging in activities with their loved one to reduce pain.

3.6 Non-pharmacological interventions

Survey data showed that commonly recommended non-pharmacological interventions included exercise or movement, activities tailored to personal interests, and music therapy. These were reported by medical staff (66.3%, 64.3% and 50.0% respectively), healthcare professionals (56.5%, 37.7% and 21.7% respectively) and nursing staff (58.1%, 54.8% and 38.7% respectively). Other interventions mentioned less frequently included massage, yoga, and structured daytime activities.

Barriers to the use of non-pharmacological interventions were reported mainly by nursing staff and healthcare professionals and included insufficient knowledge about available interventions (respectively 31.3% and 13.6%) and failure to consider non-pharmacological interventions during the formulation of management plans (respectively 31.3% and 9.1%%).

Interview data added important nuance to these findings. Medical staff acknowledged that medications—particularly opioids—are often used first, despite growing awareness of their adverse effects. One elderly care physician noted: "*non-pharmacological interventions are used less frequently than medication and are often not used systematically.*" Limited staffing, time constraints, and lack of resources were repeatedly mentioned as barriers to implementing non-pharmacological interventions.

Several interviewees also offered suggestions to overcome these barriers, including better staff training, clearer protocols for non-pharmacological interventions, improved interdisciplinary collaboration, and greater involvement of informal caregivers. Informal caregivers emphasized that non-pharmacological interventions could be valuable complements to medication if they were structurally embedded in care routines.

No inferential comparisons between professional groups were conducted, as the study was exploratory in nature and group sizes were unequal.

3.7 Responsibility and decision-making

Medical staff were reported to hold primary responsibility for pain management plans (69.4%), typically guided by clinical guidelines. Managers became involved when deviations from these guidelines were considered. Despite the acknowledged role of informal caregivers in recognizing pain, interviews revealed that they were rarely involved in composing management plans.

4 Discussion

The purpose of this study was to provide an overview of how pain is observed, assessed, and managed in people with dementia living in long-term care facilities in the Netherlands. Overall, medical staff, healthcare professionals, and nursing staff reported considering pain when people with dementia exhibit behavioral changes. Although observational scales can be useful for assessing pain, only half of the respondents used them, often due to time constraints and high workloads. Medication is predominantly used in pain management (2) but our study found that non-pharmacological interventions were used more often than expected. This is in line with the mostly used guideline in Dutch long-term care facilities, the guideline of the Dutch Association of Elderly Care Physicians—Verenso—on pain in people with dementia (28). Informal caregivers were reportedly rarely involved in observing and managing pain in their loved ones.

Although observational pain scales are recommended in national and international guidelines [Verenso (14, 28)], it is not used systematically in practice. This limited use is consistent with international literature and highlights a persistent gap between guideline recommendations and daily clinical practice. While time constraints and high workloads were frequently cited as barriers in this study, these factors alone do not fully explain the underuse of observational tools. Additional systemic barriers may include limited training in pain assessment, lack of routine integration of pain scales into care workflows, insufficient organizational support, and the perception that observational tools are time-consuming or add limited value (21, 24, 29, 30). Addressing these barriers likely requires organizational-level interventions, such as embedding pain assessment tools into electronic care records, aligning assessments with routine care moments, and reinforcing their importance through leadership and education (31).

Pain was most often recognized through behavioral changes, a finding consistent with the study by Tagliafico et al. (32), which described clusters of pain-related behaviors including facial expressions and psychomotor and psychosocial changes (32). However, reliance on behavioral cues alone may increase the risk of misinterpretation, as such behaviors may also be attributed to dementia-related symptoms rather than pain (33, 34). This further underscore the importance of structured and validated observational tools to support clinical decision-making.

Informal caregivers were rarely involved in pain observation and management, despite their familiarity with the person with dementia. Bullock et al. (13) emphasized that knowing a person's usual behavior is crucial for optimizing pain assessment (13). Greater involvement of informal caregivers aligns with international principles of person-centered care and may improve the accuracy and quality of pain assessment.

Pain management remained predominantly pharmacological, consistent with earlier findings (2). Although non-pharmacological interventions were reported more frequently than expected, they were not consistently included in pain management plans. While interventions such as exercise, massage, distraction, and music therapy were mentioned, the frequency and duration of use and effectiveness were not

mentioned. Chen et al. (35) demonstrated that interventions such as music therapy can reduce pain and depression and are low-cost, noninvasive, and relatively easy to implement (35). However, even such interventions require time, staff engagement, and organizational support to be used consistently in long-term care facilities (21, 31).

Standardized pain management guidelines and stepwise protocols for pain assessment and management in long-term care facilities may contribute to reducing the underdiagnosis and undertreatment of pain in individuals with dementia. Structured approaches, such as the *Sta-op!* method support systematic observation and identification of pain-related behaviors. Using this method in combination with the guidelines on pain in people with dementia, such as the Verenso Guideline, may promote increased use of non-pharmacological interventions for pain management (28). To our knowledge, this is the first study to provide an overview of how pain is observed, assessed, and managed in Dutch long-term care facilities. Strengths of this study include mixed-methods sequential explanatory design and the use of in-depth interviews to contextualize survey findings. The nationwide distribution of the survey contributes to the generalizability of the findings. Also, findings like the emphasis on behavioral changes as key indicators of pain in individuals with impaired communication are likely relevant beyond the Dutch context and reflect issues faced in long-term care facilities internationally. However, several limitations should be acknowledged. Participants were not asked to specify their long-term care facility, limiting insight into organizational diversity. Therefore, there could be a bias where facilities with solidly embedded pain management programs participated in the study, while facilities with less embedded programs did not. Also, participant were not asked which specific observational pain scales were used in practice. This information could have provided insight into the usability of different instruments. The small number of managers and informal caregivers restricts generalizability for these groups. Another limitation is that different subgroups have different roles in the interprofessional team that provides the pain observations and management, but the subgroups were too small to analyze separately. Both survey and interview data may be subject to socially desirable responses, and the study title may have led to overreporting of non-pharmacological intervention use. Self-reported measures of pain are widely considered the gold standard, including in populations with dementia. However, in the present study, specific inquiries regarding the utilization of self-report instruments for pain assessment were not conducted. Consequently, it remains unclear whether self-reports are employed in individuals with dementia, the frequency of their use, or whether individuals are first asked about their pain experience prior to implementing observational assessment tools. Additionally, most participants were female and highly educated, which may limit representativeness.

5 Implications for future research and practice

Future research should focus on the development and validation of standardized and feasible observational pain assessment protocols for long-term care facilities, and implementation studies examining non-pharmacological interventions, including their frequency, duration, effectiveness, and resource requirements. Such studies should apply implementation frameworks that address staff training, workflow integration, interdisciplinary collaboration, and structured involvement of informal caregivers.

6 Conclusion

Despite the high awareness of the relationship between pain and challenging behavior, pain assessment practices remain inconsistent. There is limited use of validated observational tools and input from informal caregivers is underutilized. Pain management is predominantly pharmacological, even though the value of non-pharmacological interventions is increasingly recognized. However, these interventions are underused due to a lack of knowledge, time, and resources. Informal caregivers have expressed a willingness to support pain assessment and management, yet they are rarely involved in decision-making processes. These findings underline the need for a more systematic, interdisciplinary approach to pain management in dementia care. This approach should include better integration of non-pharmacological interventions, and greater involvement of formal and informal caregivers in developing pain management plans.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

SK: Project administration, Writing – review & editing, Resources, Writing – original draft, Formal analysis, Data curation, Methodology, Visualization, Software, Conceptualization, Investigation, Validation. WA: Methodology, Supervision, Conceptualization, Visualization, Validation, Writing – review & editing. AD-K: Writing – review & editing, Supervision, Conceptualization, Visualization, Validation. MC: Project administration, Methodology, Formal analysis, Validation, Supervision, Visualization, Software, Writing – review & editing, Conceptualization, Investigation, Resources.

Funding

The author(s) declared that financial support was not received for this work and/or its publication.

Acknowledgments

We thank Janine Legemaat (JL), psychology master's student, for her hard work during this study, especially her efforts in collecting and analyzing survey data and conducting interviews.

Conflict of interest

The author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The Reviewer SL declared a past co-authorship with the author WA to the handling editor.

Generative AI statement

The author(s) declared that generative AI was used in the creation of this manuscript. Chat GPT: to find specific references.

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Publisher's note

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10.3389/fpain.2026.1812648

Appendix 1

Topic list
Assessment of Pain

- Use of measurement scales: Are these used, and if so, why; if not, why not?
- Changes in behavior due to pain: Are changes observed in the behavior of the residents, and how is this managed? Is pain considered as a cause?
- Overlap between behavior and pain: When there are changes in behavior, what is the primary focus (cause or treatment)?

Pain management

- Medication: Is it commonly used for pain, and is it given on trial or based on scientifically validated surveys?
- Non-pharmacological interventions: Are they used, and if so, why; if not, why not? Are they used first, or is medication used initially?
- Duration of non-pharmacological treatment (these treatments often take longer to show effects than medication).
- Opinion on non-pharmacological treatment: Do you think it is important to try this first and then use medication, or to use a combination? What do you think about the use of non-pharmacological interventions for people who might not have much longer to live?

Communication

- Treatment plan: Is there communication about it? Do you have a say in it? Are non-pharmacological interventions included in the plan?
- Duration and outcome of treatment: How long would you use the intervention? How are the outcomes tracked? Are they evaluated?
- Tapering off medication: If medication is used alongside non-pharmacological interventions, is the medication tapered off? Is anything used when tapering off medication?

frontiers in Pain Research

TYPE Perspective
PUBLISHED 23 July 2026
DOI 10.3389/fpain.2026.1753496

OPEN ACCESS

EDITED BY
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RECEIVED 24 November 2025
REVISED 06 May 2026
ACCEPTED 26 June 2026
PUBLISHED 23 July 2026

CITATION
Heckemann B, Snell L and Johnson MI (2026) Exploring magical thinking in the context of pain.
Front. Pain Res. 7:1753496.
doi: 10.3389/fpain.2026.1753496

Exploring magical thinking in the context of pain

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This perspectives article explores magical thinking (which is often dismissed as irrational or pathologized) as a potentially valuable personal orientation and resource for people living with chronic pain: as a way to make more sense of their complex and challenging life experience, psychologically as well as socially. *Magical thinking* entails a broader acceptance of connectivity between phenomena generally considered to be independent, and it includes symbolic *meaning-making acts* such as rituals. The authors explicitly exclude in their discussion *magical superstitions* which involve the conviction that magical acts can directly impact physical reality (such as enabling levitation or turning people into frogs). Drawing on a reflective, interpretive, and conversational methodology, a pain scientist, a nurse researcher, and a writer-practitioner of magical thinking explored how magical thinking functions as a personal orientation and resource that enables symbolic meaning-making and supports emotional regulation and relation with self, others and the wider world. As such, it may be potentially valuable for people living with chronic pain. The article shows that traces of magical thinking can be found within psychology and medicine and invites a broader conversation about how the symbolic and imaginative modes of magical thinking might be valuable in pain care.

KEYWORDS
chronic pain, coping strategies, illness narrative, magical thinking, meaning-making, mind body connection, patient experience, subjective experience of pain

1 Introduction

This article explores and discusses magical thinking in the context of chronic pain. While few publications address this topic, a recent article highlights the relevance of magical thinking (which is often dismissed or pathologized) to evidence-based practice medical care (1). Magical thinking, like religion and spirituality (2) or artistic expression (3), may help people make sense of the complex and often challenging experience of living with chronic pain. While religion and art have received some scholarly attention in pain research (2, 3), magical thinking[1] remains largely marginalized and excluded from the scholarly pain discourse.

[1]At this junction, it is important, however, to distinguish between *magical thinking* and *magical beliefs (superstition)* Magical thinking entails the conviction that symbolic associations, rituals, or intentions can influence real-life outcomes, independent of empirical causality. Magical beliefs (superstition) is an extension of magical thinking that entails the conviction that magical entities, forces can directly impact or transform physical realities without any causal link (such as turning lead into gold) (4). This article is exclusively concerned with *magical thinking* and seeks to contribute to the scientific discourse by integrating insights from authorial dialogue and interdisciplinary literature, including anthropology, psychology, and religious studies to challenge prevailing assumptions.

2 Aim

This article offers an exploration, discussion and an invitation to consider magical thinking as a potentially supportive orientation for people living with chronic pain.

3 Approach: interpretive conversational inquiry

We adopted a reflective, interpretive, and conversational approach grounded in life- and practice-based experience to co-construct conceptual insight rather than generating empirical generalisations.

We conducted a series of online conversations via Microsoft Teams, organised in dyads and triads (see Table 1).

Conversation 3 between BH and LS which explored LS's viewpoints on magical thinking[2] was recorded and auto-transcribed. BH and MIJ identified key insights from the conversation. All authors discussed the key insights based on a purposeful (rather than systematic) search of databases (PubMed and Google Scholar). They selected scholarly sources for their conceptual relevance.

Author position statements are provided in the Supplementary Material.

TABLE 1 Conversations, topics and participants.

Online conversation #	Topic	Participants	Date
1	An initial conversation focusing on the integration of magical thinking into everyday life and its relevance for pain.	BH, MIJ	2025 04 08
2	Exploration of shared interests, decision and verbal agreement to co-author a manuscript based on a conversation between BH and LS.	BH, MIJ, LS	2025 04 11
3	In-depth exploration of the topic through a conversation.	BH, LS	2025 05 08
4-6	Discussions of key insights.	MIJ, BH	2025 06 10 2025 07 17 2025 10 04

4 Exploring magical thinking through conversation and scholarship

This section presents the key insights from Conversation 3 and discusses them in relation to relevant scholarly literature.

4.1 Conversation starter 1: what does magical thinking mean to you personally?

4.1.1 Key insight: magical thinking offers a sense of agency and empowerment in responding to life's challenges

LS shared stories from a higher-level perspective, drawing on his lived experience and long-standing engagement with magical practice. He explained how people use symbolic action[3] to try and make things happen or achieve a goal in situations where learned knowledge does not help. LS illustrates this by recounting a story about young men who think that attracting a female partner is a problem that can be solved by knowledge acquisition. They study psychology, read self-help books, and try to understand "what women want" (LS). Yet they are not successfully attracting women. Frustrated, they turn to buying clothes, such as a T-shirt with a logo from a fashionable brand, convinced by adverts that wearing this brand will make them more attractive. And indeed, LS continued, wearing the T-shirt makes the students feel more confident, they act differently, and suddenly they are more able to connect with women. For LS, this T-shirt acts as a symbolic object, a modern talisman[4]. While the T-shirt itself has no power, it enables a transformation from failure to success through symbolic action. For LS, this example captures how symbolic action can restore a sense of agency when reason and knowledge fall short. He suggests that magic often begins at the point where people seek power through symbolic means when rational strategies and reason fail.

4.2 Conversation starter 2: how would you define magical thinking?

4.2.1 Key insight: magical thinking invites understanding rather than definition

LS explained that he prefers not to define magical thinking but rather understands it as a way of engaging with the world, an orientation. LS considers magical thinking as a discrete

[2]Authors BH and MIJ developed conversation starters that guided conversation 3:

1. What does magical thinking mean to you personally?
2. How would you define magical thinking?
3. How do you use magical thinking to support your wellbeing or manage pain?
4. Why do you turn to magical thinking to support wellbeing or manage pain?

[3]Symbolic action is the use of symbols, gestures, rituals, or language to convey a meaning or value that extends beyond the literal or practical utility of the act itself. It may be compared with artistic expression.

[4]A talisman is an object that is thought to have magic powers and to bring good luck. Reference: https://languages.oup.com/google-dictionary-en/

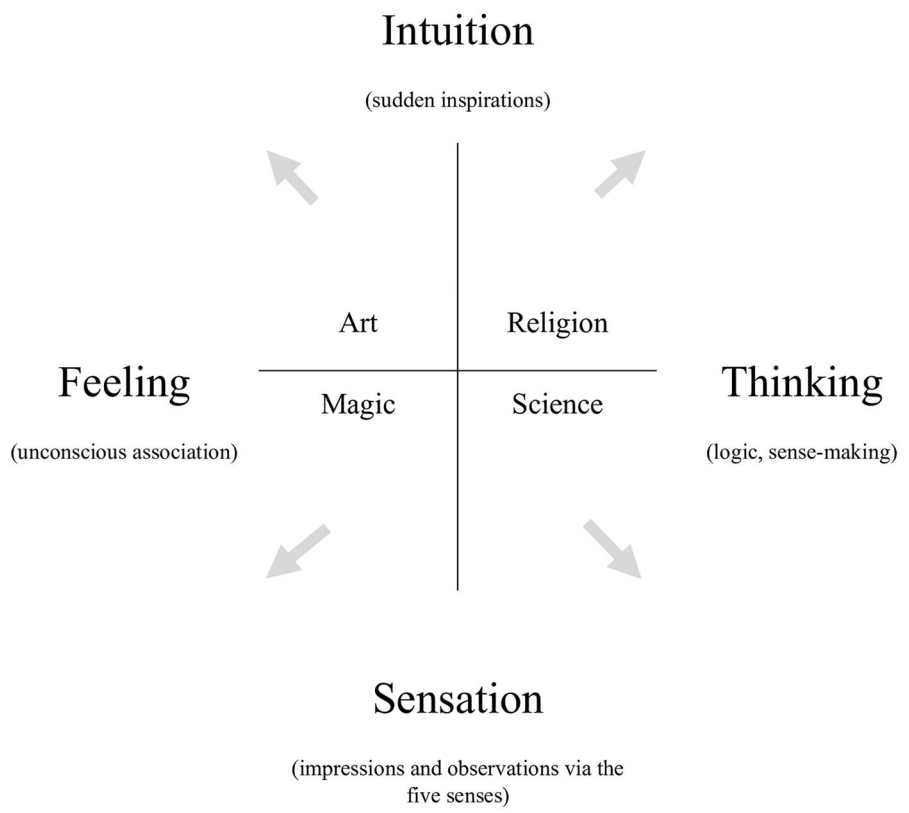

FIGURE 1
Mapping the intersection between art, science, religion, and magic across psychological Jungian functions. Reproduced and adapted with permission from the original creator and co-author L.S. [Snell (26), p. 125].

category but an approach to life that is about searching and discovering. LS mapped the relationship between the four disciplines art, science, religion and magic in relation to the Jungian psychological functions thinking and feeling, intuition and sensation in his published work (5, 26) (Figure 1). However, a map is never the territory, and Figure 1 illustrates that the disciplines are orientations rather than defined categories, and overlaps may occur between the fields.[5]

To illustrate this, he returns to the example of the young university students who would dismiss a magical thinking approach to attracting women as nonsense. Yet they slip into magical thinking. Wearing the "latest trendy things," LS observed, can change how a person feels and how others respond, producing effects that are psychologically real even if not empirically causal or residing in the object. For LS, magical thinking is therefore not opposed to science or psychology, but reflected in both disciplines, through symbolic action and meaning making. Thus, magical thinking is not a fixed or discrete belief system, but a context-dependent engagement mode that people move in and out of, often without explicit acknowledgement. This understanding of magical thinking aligns with broader anthropological and psychological perspectives that regard magical thinking as an ordinary, situational and everyday human behaviour rather than a practice or a belief limited to specific groups or individuals.[6]

4.3 Conversation starter 3: how do you use magical thinking to support your wellbeing or manage pain?

4.3.1 Key insight: magical thinking as a natural human capacity that creates meaning

In our conversation, LS described magical thinking as a natural human trait. He explained how magical thinking is present throughout life, from infancy to adulthood. He described how babies first discover the physical world through repetition, for example dropping a spoon, watching it fall, and thus learning that some things (the spoon always falls down) are

[5]Psychology as a science, for example, may work with anchors such as visualization, suggestion or images which are techniques that can also be found in magic, art and religion.

[6]It is necessary to distinguish LS's descriptions from the scholarly definition of magical thinking: the belief that "thoughts, actions or symbols possess the power to cause, change, or prevent real-world events" and that "thoughts can exert physical influence" (6, p. 132). While we acknowledge the conceptual and cultural breadth of this definition, our focus remains on the practical application of magical thinking—specifically, how individuals mobilize it to manage pain when conventional biomedical reasoning feels insufficient. Our position does not endorse supernatural causality; rather, we aim to understand how symbolic and imaginative practices provide meaning, coherence, and agency.

predictable. This early experimentation, which he called a form of "protoscience," marks the beginning of causal understanding. Yet when the mother's reactions vary, sometimes picking up the spoon, sometimes not, the child begins to notice that not everything follows fixed rules. The mother's behaviour introduces unpredictability, prompting the child to infer the existence of other minds, and the wish to communicate with these minds. From this insight grows the capacity to perceive agency beyond the self, not only in people but also in animals, plants, the weather, or even objects. For LS, this transition from materialist certainty (the spoon always falls) to relational curiosity (how can I make mama pick up the spoon?) represents "the beginning of magical thinking," the recognition that "minds could exist outside your own head."

LS's reflections exemplify how magical thinking can mature into a reflective and relational worldview. He describes moving from a youthful, instrumental approach "making things happen" to dialogue and participation. Everyday objects become personalised rather than being inanimate tools: he speaks to his car keys and thus remembers where he put them. He also explains how behavioural change can happen through personalising objects. Regarding one's running shoes as partners to establish a fitness routine supports building new habits and continuity. This approach can be likened to the currently popular "life hacking"[7], but he highlighted that the relationship between the object and the person goes deeper, that indeed an ongoing social interaction, like a partnership, with an object might occur. He explained that when using magical thinking "[…] you're part of this bigger universe", a world is animated, meaningful, and responsive.

4.4 Conversation starter 4: why do you turn to magical thinking to support wellbeing or manage pain?

4.4.1 Key insight: magical thinking embraces ritual and wonder and creates resilience

In our conversation, LS described how the health-related value of magical thinking lies less in measurable outcomes than in orientation. It fosters a stance of resilience and curiosity that transforms misfortune into engagement rather than despair. As he explained:

> "A lot of people I know are much more vulnerable to moods, depressions… I'm more resilient. I think it's [magical thinking] contributed to that. When I have a run of bad luck […] I'm as much curious as to what's happening as I'm miserable about the round of bad luck." (LS)

LS describes a shift from emotional reactivity toward a curious, reflective stance. From this perspective, personal or cultural events are interpreted as part of larger patterns or cycles, rather than as isolated threats to the individual. This perspective supports resilience and coping by creating psychological distance and meaning. A similar stance can be observed in religious contexts, for example when hardship is framed as "God is testing my faith" (LS). LS also described magical thinking as enriching life through seasonal and celebratory rituals, less instrumental than expressive, as a way of attuning to nature. For him, it simply "makes life more interesting." (LS), by opening a space where mystery and imagination coexist with everyday reality. The world becomes populated with subtle energies, spirits, and presences "things that cannot be seen with the eye" (LS) yet shape what happens around us. If flowers bloom unusually well, one might attribute it to "flower spirits" (LS) rather than analyse soil or weather conditions. LS' openness cultivates a world that is alive, relational and dynamic and never entirely understood.

4.5 Conversation starter 5: when do you use magical thinking to support your wellbeing or manage pain?

4.5.1 Key insight: magical thinking as communion between mind and body

LS described using magical thinking to relate to recurring pain or distress rather than eliminate it. Drawing on his book *The Little Book of Demons* (7), he likens pain to an unwelcome but familiar visitor "a boring neighbour who keeps coming round" (LS). Rather than "killing the messenger," he might talk to the pain and asks about its message:

> "Pain, why are you here? Why are you in my arm? What do you want?" "Are you asking me to stop gym workouts? For ever? Or how long?" Maybe the pain suggests that you stop barbell curls for a while to allow your arm to heal. Every few days you might check: "Do you still want me to stop doing exercise? Is it working? Are you healing?" And the pain says "Yes" (LS).

He explains that these answers are not expected to arrive as spoken language. Instead, while focusing on the sensation of pain, the individual might rehearse various alternatives in imagination—such as changing their diet, massaging the area, increasing exercise intensity, or bypassing certain movements—to sense which scenario invokes a feeling of relief. This approach, he suggests, transforms pain from an enemy into an advisor, part of an ongoing relationship with the body. In this reframing, pain is personified—not as a hostile force to be fought, but as a familiar presence to be acknowledged, negotiated with, and even befriended. Magical thinking thus becomes a form of embodied dialogue that restores agency, curiosity, and acceptance in the face of discomfort.

LS suggests that both religious and magical thinking offer frameworks of meaning and orientation toward forces perceived as larger than the individual, which can transform the pain experience. Whereas religious believers may frame suffering as "God is testing me", LS personally adopts a more animistic stance, treating the body itself as a wise, ancient entity shaped by millions of years of evolution and capable of considerable self-healing. By asking his [personified] pain "to explain what it

[7]A strategy or technique adopted to manage one's time and daily activities in a more efficient way.

is doing," (LS) he engages his body as a partner rather than an object to be managed, LS describes his approach to managing health and pain as guided by instinct, moderation, and trust in natural processes. He identifies as a naturopath by inclination, preferring to minimise medication and observe the body's response before escalating treatment after surgery:

> "If they [healthcare professionals] say, if you don't take it [pain medication] today, tomorrow you'll be in agony, OK, I'll take [one] because I trust them—but I won't take three just to see what happens." (LS)

5 Discussion

In this section, we discuss these key insights in relation to scholarly literature before relating magical thinking and chronic pain.

5.1 Agency and empowerment

LS' view of magical thinking as fostering agency and empowerment echoes anthropological accounts that see it as a pragmatic response to uncertainty. Malinowski (1979) argued that magical thinking is not an irrational practice but an adaptive strategy that enables action and motivation when rational strategies fail (8). This description resembles how Indigenous peoples engage with the world, as described in anthropological literature on animism and relational ontology (9, 10), a worldview grounded in reciprocal coexistence with land, animals, and even inanimate objects (9). From this non-human-centric vantage point, magical thinking becomes a collaborative, non-dominant way of relating to the world.

5.2 Understanding

In contrast to LS' description, scholarly literature often *defines* magical thinking as "the belief that thoughts, actions, or symbols possess the power to cause, change, or prevent real-world events" (1: Iserson 2023, p. 132). Magical thinking ususally makes no sense within the current paradigm of science as it relies on subjective experiences and the assumption that imperceptible forces cause real-world effects" (6). Although LS rejects this definition[8], both views agree that magical thinking is not irrational but an alternative orientation that creates meaning, detects patterns, or offers practical ways to handle existential and other challenges, serving social, cognitive, emotional, or adaptive functions (6).

5.3 A natural human capacity

LS's account of how magical thinking develops aligns with Piaget (11) who regarded magical thinking as a stage of childhood cognition that adults outgrow, and more recent literature which suggests that magical thinking persists and transforms across the lifespan (4). As children mature, scientific reasoning strengthens, but symbolic and imaginative sense-making remains and may be expressed through artistic or everyday rituals in later life.

According to LS, magical thinking makes the world a more exciting place. Likewise, Subbotsky (2010) argues that, for adults as well as children, magical thinking brings colour and excitement to everyday life, counteracts monotony, and rekindles a sense of wonder. The desire for magic explains the enduring appeal of magical narratives such as *The Lord of the Rings* or *Harry Potter* (4).

5.4 Ritual, wonder and resilience

LS considers himself more resilient than many other people when experiencing a streak of bad luck. As a magically thinking person, he considers himself part of a bigger universe and can simultaneously feel miserable and curious about his situation. This capacity has been described as self-distancing (12), which has been shown to be effective to facilitate emotion regulation in challenging situations (13).

Seasonal, social or private rituals help structure experience, mark transitions and create coherence amid uncertainty (14). They foster a sense of belonging and wonder. This sense of mystery and connection parallels the experience of awe and wonder that literature links to wellbeing and flourishing (14, 15). Rituals, however, need not involve magical thinking; secular or therapeutic practices such as mindfulness can retain symbolic functions without any magical connotations (16).

5.5 Communion between body and mind

LS describes a strong attunement between mind and body, seeing them as communicating rather than separate. By "talking" to the painful parts, he can selectively follow medical advice in ways that maintain coherence and preserve his sense of agency despite the pain. The literature shows that magical thinking can give a sense of control over illness. This "illusion of control" may reduce anxiety, support a more adaptive mindset, and shape stress and meaning-making processes that influence how pain is experienced (17).

5.6 Magical thinking and chronic pain

Even within broadly dualistic Western traditions, pain is increasingly understood as a complex and relational experience that exceeds the Biopsychosocial (BPS) model, which is necessary but not sufficient to capture how pain is lived and managed over time

[8]LS argues that "magical thinking" is not merely a belief, but a form of personal experimentation based on trial and error. He distinguishes between three frameworks: science (objective testing), magic (subjective experience), and religion (communal identity). While science and magic both grow through open observation, LS defines religion as a community held together by shared beliefs and the rejection of dissent.

He illustrates this by critiquing the secular "sceptics" movement of the early 21st century. Although these groups claimed to defend science by campaigning (for example) to ban homeopathy, LS suggests their behaviour was actually religious. By forming a community based on institutional prohibition and the denial of alternative views—rather than on open experimental debate—they adopted the dogmatic structures they intended to oppose.

(18). In addition to biological, psychological, and social factors, pain is shaped by ecological processes: the material, institutional, and environmental conditions within which people act, including healthcare systems, work and domestic arrangements, cultural practices, and technologies of care. These ecologies structure concrete actions and practices, such as: navigating fragmented services, self-monitoring symptoms, experimenting with treatments, avoiding or ritualising daily activities, and developing personalised routines to manage uncertainty. Within such contexts, practices sometimes described as "magical thinking" can be understood not as irrational belief, but as situated attempts to establish causal coherence, restore a sense of agency, or stabilise meaning when reliable explanations or effective interventions are lacking. While the BPS model guides chronic pain treatment, it is often applied in practice as a checklist, privileging biomedical factors while under-addressing these broader contextual dynamics (19). Several contemporary models of chronic pain (particularly enactive, embodied, and contextual approaches) foreground relational and meaning-making dimensions that align with the concerns outlined here.

Karos et al. (2018) conceptualized pain as a complex social experience that "shifts control away for the person with pain to others, […] excludes, and […] is often associated with (perceived) injustice", p. 1692 (20). As a consequence, chronic pain threatens a person's needs for autonomy, belonging, justice and fairness (20). An orientation towards magical thinking may support a person feeling more empowered and as a part of "a bigger universe" (LS), and, as a result, more resilient and less helpless.

Another recent perspective, the integral model of pain, extends the BPS model by positioning pain as a relational, context-sensitive, and embedded experience in a whole person, health and wider system (21). Consistent with salutogenic thinking, this perspective shifts attention from dysfunction towards the cultivation of health, meaning, and coherence. A sense of coherence rests on three interrelated components: comprehensibility (structured and predictable life challenges), manageability (belief in coping resources), and meaningfulness (life's demands are worth engaging with) (22). While key insights *agency and empowerment* align with the manageability component, the magical thinking orientation (with its non-rational assumptions) stands in tension with comprehensibility and meaningfulness: with a magical-thinking orientation, a person can easier cope with challenging situations. LS illustrates this with his description of a streak of bad luck, where one feels miserable but curious at the same time. This ability to be distressed while also being a curious observer has been shown to decrease the intensity of acute pain sensations (23).

The concept of painogenic environments highlights how cultural, organisational, and socio-ecological conditions, contribute to sustaining pain and undermining resilience by shaping how people experience, interpret, and respond to pain over time (24). Painogenicity encompasses both indirect conditions that increase the likelihood that pain will persist once present and, in some cases, upstream exposures that directly cause diseases in which pain is an intrinsic feature. What unifies these influences is not their mechanism of action but their ecological role: they shape the background conditions within which pain emerges, persists, and becomes difficult to resolve. Some painogenic factors act indirectly by undermining recovery, increasing regulatory strain, or restricting adaptive responses, while others exert more direct biological effects through tissue damage or disease processes. Painogenicity therefore functions as an ecological lens rather than a claim about causation per se, highlighting how diverse influences, direct and indirect, interact to sustain enduring patterns of pain.

From this perspective, pain is not only physiological but relational, and managing it may require reconnecting with social contexts, everyday environments, and opportunities for meaningful participation (25). Taken together, the integral, salutogenic, and painogenic perspectives echo Indigenous ontologies that emphasise relationality between individuals, communities, and environments (9, 10), and resonates with what LS describes as a "magical thinking" orientation, in which the self is understood as part of a "bigger universe", a metaphor for embeddedness within wider relational and ecological worlds.

6 Limitations

This perspectives article is not based on rigorous empirical research but aims to open a space for discussion. We sought to corroborate our key insights with relevant literature. Although confirmation bias cannot be ruled out, we addressed this by engaging with diverse sources and considering counter-positions where possible.

7 Conclusion

This perspectives article, grounded in an interpretive dialogical inquiry, invites consideration of magical thinking as a potentially supportive orientation for people living with chronic pain. Although imagination and symbolic meaning-making are central to human experience, they are often marginalised within dominant Western ontologies. Recognising their role may offer new insights into patients' lived experiences, not by treating magical thinking as a testable belief or therapeutic intervention, but as a situated mode of meaning-making that shapes how pain is understood, endured, and managed.

From a research perspective, magical thinking can be explored using established qualitative and interpretive approaches including: narrative and phenomenological studies of pain experience, ethnographic observation of everyday coping practices and rituals, participatory and co-design methods, and comparative analyses of pain models that foreground relational and symbolic dimensions. Such approaches do not seek to validate or promote specific beliefs, but to understand how symbolic and imaginative forms of meaning-making operate within broader ecologies of care.

The clinical relevance of this article lies in its balanced analysis of magical thinking, framing it as a significant and deeply human trait that carries both potential and risk. Despite its prevalence, magical thinking is currently stigmatised and dismissed within Western biomedical approaches to pain and illness treatment. Stigmatising these beliefs encourages patient non-disclosure, which obscures the identification of potential risks associated with magical thinking and prevents the integration of adaptive magical-thinking coping strategies into treatment. When

symbolic or culturally embedded forms of meaning-making are marginalised in healthcare encounters, patients may disengage from care, selectively follow medical advice, or turn away from Western models altogether. Conversely, unexamined magical thinking may contribute to selective adherence or the substitution of symbolic practices for essential treatments. These tensions highlight the need for an interpretive and dialogical approach that engages with patients' meaning-making while maintaining a commitment to safety, evidence, and shared decision-making.

In this way, alternative ontologies, including forms of magical thinking, may complement biopsychosocial models by illuminating how people make sense of pain as a multifaceted, relational phenomenon, without requiring the rejection of biomedical care. However, as the practical integration of these divergent worldviews remains underexamined, further research is needed to explore how clinicians might engage with symbolic meaning-making while upholding safety and evidence-based standards. Qualitative methodologies offer valuable frameworks to explore and illuminate how magical thinking can safely coexist with, and potentially even enhance, current medical approaches to pain treatment.

Data availability statement

The raw material can be made available upon reasonable request.

Author contributions

BH: Validation, Data curation, Methodology, Visualization, Conceptualization, Project administration, Writing – original draft, Writing – review & editing, Formal analysis, Software, Investigation. LS: Formal analysis, Writing – original draft, Data curation, Writing – review & editing, Investigation, Validation. MJ: Formal analysis, Writing – original draft, Methodology, Data curation, Validation, Investigation, Conceptualization, Software, Writing – review & editing.

Funding

The author(s) declared that financial support was not received for this work and/or its publication.

Conflict of interest

MJ wishes to declare the following interests that are outside of the scope of this study. In the previous 5 years, MJ's employer has received income for expert consultancy activities from GlaxoSmithKline, TENSCare, and LifeCare Ltd. that lie outside of the submitted work. MJ declares book royalties from Oxford University Press.

The remaining author(s) declared that this work was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

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The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpain.2026.1753496/full#supplementary-material

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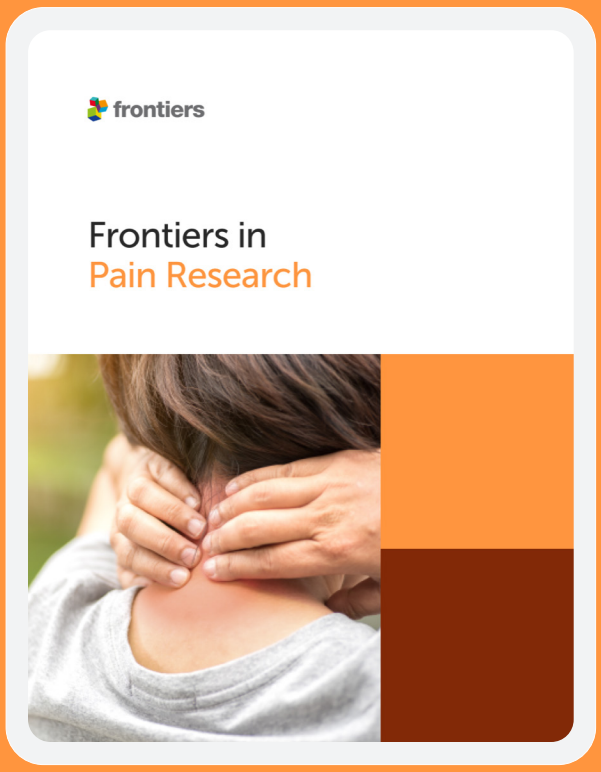

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