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Lived and Care Experiences of Chronic Musculoskeletal Shoulder Pain in Australian Adults: A Qualitative Study

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Objective. Australian evidence on lived and care experiences of chronic musculoskeletal shoulder pain (CMSP), irrespective of disorder classification or disease, is limited. However, such evidence is important for person-centered care and informing local service pathways and care guidelines or standards. To address this gap, we explored the lived experiences of adults with CMSP across domains of the International Classification of Function, Disability and Health (ICF) framework, and their care experiences, preferences, and priorities for CMSP.

Methods. This was a qualitative study that applied a phenomenological approach. Purposive sampling was conducted with adults experiencing CMSP. Individual semistructured interviews, informed by ICF domains, explored lived and care experiences/preferences of the participants. Data were analyzed using an inductive approach, by objective.

Results. Twenty adults (50% female) with diverse CMSP conditions/diagnoses, clinical profiles, and age (21–78 years) participated. Five lived experience themes were identified: 1) impact on body functioning; 2) impact on sleep, energy, and drive; 3) impact on mental well-being and evolving sense of self; 4) coping with CMSP; and 5) social support and participation. Four care experience themes were included: 1) care-seeking choices; 2) interactions with health care professionals (HCPs); and 3) values and preferences for components of CMSP care.

Conclusion. Adults with CMSP experience impacts across life stages in multiple domains of functioning (ICF categories) relating to personal and social dimensions. Clinical encounters, particularly interactions with HCPs, influence an individual's confidence and engagement in their CMSP care. Discussion, education, and goal setting through shared decision-making are valued attributes of clinical encounters among people with CMSP.

Musculoskeletal shoulder pain is a common condition, with an estimated median community point prevalence of 16% (range 0.7%–55.2%) across countries.[1] Although the condition is often self-limiting, up to 50% of adults who seek care continue to experience pain and/or functional problems up to two years after symptom onset.[2] A recent Australian study identified that more than two-thirds of younger adults (aged 20–55 years) experiencing shoulder pain reported symptoms exceeding 12 months duration alongside substantial quality of life impairment, high psychological distress, and reduced work participation.[3] CMSP is defined as persistent shoulder pain experienced in musculoskeletal structures for more than three months.

CMSP contributes substantially to the health care burden of musculoskeletal pain in Australia[4] and globally.[5] In Australia, the mean annual cost of health care and domestic support for CMSP is estimated at $7,563 (Australian) per person for patients on orthopedic review waitlists, increasing to $22,378 (Australian) when lost productivity is also considered.[6] National registry data also show that shoulder joint replacement surgery for CMSP in Australia is increasing over time and is projected to exceed

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SIGNIFICANCE AND INNOVATIONS

- There is limited primary research that evaluates both the lived and care experiences and preferences of people experiencing chronic musculoskeletal shoulder pain (CMSP). Yet, such research is needed to inform person-centred care and service pathways in the local Australian context. Exploring lived experiences through their intersection with the domains of the International Classification of Function, Disability and Health (ICF) Framework enables a more comprehensive understanding of the scope and significance of functioning impacts to inform holistic care. Exploring care experiences and preferences can inform service delivery pathways.
- Diversity in CMSP experiences across gender, age, place of residence, symptom duration, and level of impairment was intentionally sought with maximum heterogeneity sampling.

45,000 procedures annually by 2035 at a cost of over $1.46 billion (Australian).[7]

Although the burden and cost of CMSP have been estimated in Australia, our understanding of the lived experiences of Australian adults with CMSP across multiple domains of functioning coupled with their experiences of, and preferences for, care remain less clear. For example, existing evidence syntheses have not included any primary studies conducted in Australia[8,9] nor have they evaluated preferences for service delivery, yet local evidence acquired through qualitative research is needed to inform local service planning. A rich understanding of both lived experiences and care preferences and priorities are essential for person-centered care and for informing local care planning and delivery at service and system levels.[10,11] This is relevant to Australia given the existing knowledge gap and the structural differences in the Australian health system compared with health systems of other countries. For example, Australia has a dual public and private funding model for health care, and governance responsibilities for hospital and primary care services vary between jurisdictional and national governments.

Existing syntheses of qualitative research highlight that individuals who experience shoulder pain report physical functioning, emotional, and social impacts; hold strong biomechanical beliefs about their shoulder pain; and express fear avoidance.[8,9] Primary studies often sample cohorts with homogenous shoulder disorders, such as rotator cuff-related shoulder pain, yet experiences of CMSP and care preferences are likely to be common across shoulder pathologies (i.e. transdiagnostic)[8,9,12] and aligned with evidence for noncancer pain more generally.[13,14] This suggests that a transdiagnostic conceptualization of CMSP is warranted for informing person-centered care and care pathways at scale. Therefore, studies designed to inform care and care pathways should adopt a sampling frame irrespective of the classification of shoulder disorders. Current evidence also provides limited insight into how lived experiences of CMSP relate to functioning (defined by the ICF) and care priorities and expectations. The ICF provides a valid framework for considering multiple domains of functioning and has been used previously for qualitative explorations of lived experience of functional impacts related to other musculoskeletal conditions, such as arthritis and low back pain.[15–17] Further, although previous quantitative evidence identifies preferences of adults with CMSP related to surgery and primary care interventions,[18,19] there are very limited data from qualitative explorations relating to their values and preferences for care components and therapeutic encounters. This is important because it is well-established that preferences for, and expectations of, care can influence treatment outcomes and care satisfaction among adults with musculoskeletal pain conditions, including CMSP.[20–24] Central to care planning for an individual, and ultimately, for the co-creation of health services, is a knowledge of people's care experiences, expectations, and priorities of care.[25,26] To address these evidence gaps, this study aimed to explore the lived and care experiences and preferences of adults with CMSP using qualitative methods.

METHODS

Design. A cross-sectional design employing qualitative methods, underpinned by a phenomenological approach, was undertaken in Australia. A phenomenological approach is appropriate for exploring individuals' lived experiences and how they make sense of their experiences.[27] Data were collected between February and July of 2022. Findings are reported in alignment with recommendations from the Consolidted criteria for Reporting Qualitative research (COREQ-32) and Guidance for Reporting Involvement of Patients and the Public-version 2 (GRIPP-2) checklists (Supplementary Files 1 and 2). The design considered the exploration of lived experiences and care experiences as separate objectives. The authors' reflexivity and rigor statements are included in Supplementary File 3.

Ethical approval. This study was approved by the Human Research Ethics Committee of Curtin University, Australia (HRE2021-0396). All participants provided informed consent.

Sampling. A purposive sampling frame was used to achieve maximum heterogeneity across demographic criteria, including age, gender, occupation group, geography (metropolitan, regional, rural) and highest level of education. Neither race nor ethnicity were considered in sampling or collected as participant-level characteristics.

In this study, CMSP was defined as a persistent or recurrent pain experience perceived in the bone(s), joint(s), muscle(s), or related soft/connective tissue(s) of the shoulder complex for longer than three months that was not attributed to an autoimmune inflammatory disease or cancer, and that had necessitated a visit to a health care professional. Eligible participants needed to be aged 18 years or over; community-dwelling and a resident in Australia; currently reporting CMSP in at least one shoulder consistent with the case definition; and able to read and write in English. Participants were excluded if any nonmusculoskeletal shoulder pain condition, such as past/current history of cancer or systemic inflammatory arthritis, was identified through screening. Neck-related shoulder pain was not an exclusion criterion.

Recruitment. Participants were recruited via advertising through community health and leisure centers, arthritis and pain advocacy organizations, a state-level research engagement network, clinical practices and clinical organizations, and social media.

Data collection processes and outcome measures. Individuals who expressed an interest in participating accessed an online survey (Curtin University-licensed Qualtrics, Provo, Utah, USA) that displayed a plain language summary of the research, screened for eligibility, and captured demographic characteristics. Participants who met the inclusion criteria were sampled purposively against demographic criteria to achieve maximal heterogeneity. Participants were contacted via email (SR) and invited to participate in an interview and respond to a short online survey to capture their clinical characteristics using validated patient-reported outcome measures (Table 1).[28–30]

A semistructured interview schedule was developed by the investigators, which included a person with lived experience (BH). The schedule was informed by an earlier Community Conversation with consumers through the Western Australian Health Translation Network,[31] using the World Café method.[32] The initial community conversation identified that lived and care experiences were important to consumers and rationalized the need to explore these dimensions within a research paradigm. The interview schedule was organized into two parts to align with the study objectives: lived experiences and care experiences, expectations and preferences (Supplementary File 4), extending and refining the informal questions used in the Community Conversation. For lived experiences, questions explored the impact of CMSP aligned with key ICF domains (https://icd.who.int/browse/2024–01/icf/en), including: impairments in body structures and body functions; environmental factors; and activities and participation restrictions. For care experiences and preferences, items were informed by contemporary principles of models of care.[11] The schedule was piloted with two people with CMSP and refined before use.

Individual interviews were conducted by SR via video conference (Microsoft Teams) or phone. There were no repeat interviews. All interviews were audio-recorded, transcribed verbatim, and member-checked to allow participants to make any corrections or additional reflections. SR took notes during each interview and met with JEJ and AMB for regular debriefing and reflections.

Data from the first 10 participants were analyzed before further sampling to assess data redundancy and adequate heterogeneity in demographic characteristics. Based on review (SR, AMB, JEJ), it was agreed that further understanding of lived experience of CMSP in younger adults and older men (65+ years) was required, with another 10 interviews conducted. Criteria for ceasing sampling were (1) data redundancy in derived codes and no new information to inform categories and (2) adequate heterogeneity in demographic characteristics.

Data analysis. Sociodemographic and clinical data were analyzed using descriptive statistics (SPSS IBM Corp V29, NY). Analysis of transcripts followed an inductive approach[33] without reference to the ICF. The first 10 transcripts were read several times, with notes made to understand concepts, descriptions, and meanings of phenomena. Descriptive codes were inductively derived by two researchers independently (SR, JEJ). An initial coding framework (Excel sheet) was developed between the two analysts and refined through regular meetings and discussion of their observational and coding notes. Two other researchers

Table 1. Clinical outcome measures*

Construct	Measurement tool	Description
Shoulder pain	Pain NRS	The pain NRS measures average shoulder pain experienced in the past seven days ranging from 0 (no pain) to 10 (worst pain).
Shoulder function	Modified SPADI	The SPADI is a two-domain (pain and function) self-administered tool consisting of five and eight items, respectively, regarding the severity of an individual's pain and the degree of difficulty experienced when performing various activities of daily living requiring upper-extremity use, measured on a 10-item NRS. The means of the two subscales are averaged to produce a total score ranging from 0 (best) to 100 (worst).[28,29]
	*Q*DASH questionnaire	The *Q*DASH is an 11-item tool that measures a person's ability to perform activities of daily living. It produces a score from 0 (no disability) to 100 (greatest disability).[30]

* NRS, numeric rating scale; *Q*DASH, quick version of the Disabilities of the Arm Shoulder and Hand scale; SPADI, Shoulder Pain and Disability Index.

(AMB, INA) independently reviewed and validated the coding framework with a subset of the transcripts (25%), with further refinements made. The coding framework was then used to deductively code the remaining 10 transcripts. Where new concepts were identified, new codes were inductively developed.

Codes were then developed into categories through identifying shared concepts or relationships using an iterative process. Data redundancy was identified after 20 interviews, which was evidenced by no new codes or information to further develop categories. Summary descriptions of categories were developed to identify overarching themes that were discussed and iterated (AMB, JEJ, and SR). The thematic framework was reviewed at a workshop with all investigators and considered against the ICF domains. Participants were provided with a plain language results summary.

RESULTS

Of the 60 people who expressed interest in the study, 37 (61.7%) were screened as eligible and 20 (54%) participated in interviews.

Demographic and clinical characteristics. Demographic and clinical characteristics of the 20 participants are shown in Tables 2 and 3, respectively. There was equal representation between genders with a mean (SD) age of 50.8 (18.7) years (range: 20–78 years). Mean (SD) CMSP duration for the group was 55.5 (55.9) months (range: 4 months to 19 years). Pain duration and the Shoulder Pain and Disability Index and quick version of the Disabilities of the Arm Shoulder and Hand scale outcomes (Table 3) showed substantial variation across the sample (from very high to very low pain and disability), which was consistent with the maximum heterogeneity sampling frame. Most (85.0%) participants resided in metropolitan areas, and the median [interquartile range] decile for relative socioeconomic advantage and disadvantage was high (8 [4]) with a wide range (2–10), based on the Australian Socio-Economic Indexes for Areas (SEIFA) (Table 3).

Table 2. Demographic characteristics of the included sample, N = 20

Characteristic	N (%)
Highest level of education completed	
University post-graduate degree	10 (50)
University undergraduate degree	3 (15)
Trade school or trade college	4 (20)
Secondary/high school	3 (15)
Current work status	
Full time normal duties	6 (30)
Part time normal duties	4 (20)
Full time modified duties	1 (5)
Not working and receiving compensation	1 (5)
Not working (unrelated to shoulder problems)	8 (40)
Usual occupation	
Manager	2 (10)
Professional	7 (35)
Clerical and admin	1 (5)
Sales worker	2 (10)
Retired	7 (35)
Student	1 (5)

Qualitative data. The mean interview length was 29 minutes (range: 19–48 minutes). Figure 1 illustrates a thematic map of findings. Although each research objective was analyzed separately, our findings also signal interdependence between lived and care experiences. Specifically, lived experiences influenced care experiences, particularly care-seeking behaviors, and care experiences influenced lived experiences of CMSP, notably body functioning and coping.

Objective 1: lived experiences. Five key themes were identified, with participants highlighting the impacts of CMSP on body functioning and consequences for valued life activities and sense of self; sleep, energy, and drive; mental well-being and evolving sense of self; coping with CMSP; and social support and participation. These themes were interdependent, as illustrated in Figure 1. The themes are discussed subsequently with salient subthemes italicized. Table 4 provides a summary of themes and all subthemes, and Supplementary File 5 provides additional supporting quotes.

Theme 1.1: impact on body functioning. CMSP was associated with reduced body functioning, particularly physical functioning of the upper limb, which limited participation in valued activities. This theme was prominent among all participants irrespective of age and gender. Participants consistently identified shoulder pain and impairments in range of motion and strength as key barriers to participation. Physical functioning limitations were commonly associated with a sense of frustration and loss that individuals could not participate in activities that were important or meaningful to them. Valued activity restrictions included *independent living and instrumental activities of daily living* (iADLs), including care for children; *work and study*, where for some this required retraining for a new occupation; and *social and leisure participation*, including sport.

Body functioning impact manifested differently across ages. For example, young people (eg, 20–32 years) described “feeling left out” when unable to participate in activities with their peers or family. Older people, such as those in retirement (age 65–76 years), particularly women, were more accepting of participation restrictions: “I also had this feeling that I’m getting older all the time and perhaps it’s perfectly reasonable to expect that I don’t want to do, or can’t do, some of the things I do.” (PID01)

Body functioning impacts related to work manifested differently according to occupation type. Participants employed in less physically demanding occupations were better able to perform their duties and retain employment. Some people had to make adjustments, such as better self-care across the working day, whereas for others, CMSP did not restrict their work participation.

Table 3. Clinical characteristics of the included sample, including individual-level (PID01–PID20) and pooled data*

Participants 1–20	Gender	Age (years)	CMSP duration (months)	Shoulder pain diagnosis (self-reported)	QDASH (scale range 0–100)	SPADI pain subscale (scale range 0–100)	SPADI disability subscale (scale range 0–100)	SPADI total score (scale range 0–100)	Geographic area[a]	SEIFA index of relative socioeconomic advantage and disadvantage (decile) in 2021[b]
PID01	Woman	76	60	Osteoarthritis	40.9	42.0	18.8	30.4	Metropolitan (MM1)	6
PID02	Woman	32	108	Unknown	13.6	46.0	26.3	36.2	Metropolitan (MM1)	8
PID03	Man	30	228	Instability	6.8	0.0	3.8	1.9	Metropolitan (MM1)	10
PID04	Woman	71	7	Fracture	20.5	30.0	20.0	25.0	Metropolitan (MM1)	5
PID05	Man	78	60	Osteoarthritis	6.8	12.0	6.3	9.2	Metropolitan (MM1)	10
PID06	Woman	49	12	Frozen shoulder	29.5	44.0	37.5	40.8	Metropolitan (MM1)	9
PID07	Woman	48	38	Rotator cuff-related pain, subacromial bursitis	4.5	16.0	0.0	8.0	Regional (MM2)	5
PID08	Woman	56	6	Frozen shoulder	15.9	32.0	25.0	28.5	Metropolitan (MM1)	9
PID09	Woman	32	24	Unknown	15.9	48.0	48.8	48.4	Metropolitan (MM1)	10
PID10	Man	41	22	Unknown	38.6	56.0	65.0	60.5	Rural (MM3)	5
PID11	Man	53	60	Osteoarthritis	27.3	64.0	35.0	49.5	Metropolitan (MM1)	6
PID12	Man	40	6	Rotator cuff-related pain	0.0	0.0	0.0	0.0	Metropolitan (MM1)	6
PID13	Man	22	12	Subacromial impingement	4.5	28.0	5.0	16.5	Metropolitan (MM1)	3
PID14	Man	62	60	Rotator cuff tear, osteoarthritis	25.0	32.0	36.3	34.2	Regional (MM2)	3
PID15	Woman	77	80	Radiation neuropathy	72.7	56.0	87.5	71.8	Metropolitan (MM1)	2
PID16	Woman	20	120	Unknown	27.3	70.0	45.0	57.5	Metropolitan (MM1)	9
PID17	Woman	64	120	Osteoarthritis	22.7	4.0	7.5	5.8	Metropolitan (MM1)	8
PID18	Man	75	66	Osteoarthritis	13.6	36.0	23.8	29.9	Metropolitan (MM1)	9
PID19	Man	49	4	Rotator cuff-related pain	20.5	48.0	17.5	32.8	Metropolitan (MM1)	10
PID20	Man	40	16	Rotator cuff-related pain	45.5	28.0	45.0	36.5	Metropolitan (MM1)	9
Pooled mean (SD)	–	50.8 (18.7)	55.5 (55.9)	–	22.6 (17.2)	34.6 (20.5)	27.7 (22.9)	31.1 (20.2)	1 (0)[c]	8 (4)[c]
Female mean (SD)	–	52.5 (19.9)	57.5 (46.7)	–	26.4 (19.1)	38.8 (19.1)	31.6 (24.9)	35.2 (20.6)	1 (0)[c]	8 (4)[c]
Male mean (SD)	–	49.0 (18.3)	53.4 (66.3)	–	18.9 (15.2)	30.4 (21.9)	23.8 (21.3)	27.1 (20.2)	1 (0)[c]	7.5 (6)[c]

* CMSP, chronic musculoskeletal shoulder pain; IRSAD, Index of Relative Socio-Economic Advantage and Disadvantage; QDASH: quick version of the Disabilities of the Arm Shoulder and Hand scale; SEIFA, Socio-Economic Indexes for Areas; SPADI, Shoulder Pain and Disability Index.

[a] Geographic area was defined according to the Australian Modified Monash Model (MMM),[34] which defines whether a location is metropolitan, rural, remote or very remote. Areas classified MM 2 to MM 7 are considered regional, rural, or remote.

[b] SEIFA is a product developed by the Australian Bureau of Statistics that ranks areas in Australia according to relative socioeconomic advantage and disadvantage. The IRSAD summarizes information about the economic and social conditions of people and households within an area. This index includes both relative advantage and disadvantage measures. Expressed in deciles (1–10), a low score indicates relatively greater disadvantage and a lack of advantage in general, whereas a high score indicates a relative lack of disadvantage and greater advantage in general [Australian Bureau of Statistics (2021), Socio-Economic Indexes for Areas (SEIFA), Australia, ABS Website, accessed 9 September 2024].[35]

[c] Expressed as median (interquartile range).

Figure 1. Thematic map for both research objectives. Themes for lived experiences were interrelated and a dependency between lived and care experiences emerged.

For people in physically demanding occupations, some had to transition to other employment because their CMSP prevented them continuing in their role.

Theme 1.2: impact on sleep, energy, and drive. Problems with sleep and sleep quality due to CMSP impacted people across genders and age. Sleep impacts included a reduced length and *quality of sleep*, characterized as being unable to fall asleep, and multiple awakenings due to shoulder pain. These sleep impacts manifested as *impaired concentration at work or at school/study tasks*, as well as *fatigue and reduced energy, motivation, and productivity levels*. Impacts were particularly pronounced for younger and middle-aged adults who were employed or studying. They experienced concentration impairments and reduced energy, motivation, and productivity levels. Participants also described temporal changes in their mood, such as feeling "irritable," which were associated with fatigue due to poor or inadequate sleep: "I had a lot of trouble focusing in school. I would rock up to school tired until Year 11…but my mood wasn't that good either. I would be really moody." (PID03)

Theme 1.3: impact on mental well-being and evolving sense of self. Participants consistently cited a change in their self-identity attributed to their CMSP. They reported reduced confidence in their body to perform functional tasks, including sports, coupled with a *fear of reinjury or symptoms exacerbation*. Their loss of confidence and/or fear was represented through a change in their perceived sense of self-worth and general well-being, such as feeling "*damaged*." For some, their loss of confidence also manifested as an emotional toll (eg, feelings of depression and low mood) as they attempted to navigate life with CMSP. However, a few participants expressed the opposite side of the coin, describing a positive sense of well-being. Their perspective seemed to be based on their stage and/or rate of recovery and their care experiences, without negative impacts on mental well-being: "I'm improving every day, and I can't really ask for more than that, I don't think. I'm pretty happy." (PID08)

The nature of mental well-being impacts varied according to how participants experienced participation restrictions, their pain severity, and social context. Participants' expression of their mental health impact varied from those who experienced high distress to others who reflected an acceptance of participation restrictions without distress yet continued to feel some level of *loss*, *sadness*, *and/or frustration*. For example, one young woman described

Table 4. Lived experience theme and subtheme descriptions, including alignment with ICF categories*

Subthemes	Description of subthemes
Theme 1.1: impact on body functioning (ICF categories: body structures; body functions)	
Impact on independent living and iADLs	Daily independent living tasks were more difficult or could not be performed because of CMSP. Functioning limitations were related to pain and impairments in range of movement and strength. Functioning limitations extended to self-care activities, such as washing and dressing, as well as care for children.
Impact on work and study	Work and study tasks, as well as productivity with work or study, were prevented or compromised by range of movement impairments and/or pain.
Social and leisure participation	Lifestyle and leisure activities were restricted or had to be discontinued because of CMSP, often leading to feelings of (or actual) social isolation.
Impact on driving	The ability to drive was restricted, especially related to pain and impairments in range of shoulder movement and strength. Participants described an inability to hold static shoulder postures required for safe driving.
Theme 1.2: impact on sleep, energy and drive (ICF category: body functions)	
Quality of sleep	The quality and length of sleep was negatively impacted because of pain and difficulty in finding comfortable positions. This led to negative impacts on a person's general sense of well-being and increased sensitivity (reduced tolerance) to pain.
Impaired concentration at work (or at school/study)	Reduced sleep duration and quality impaired concentration levels necessary to undertake study or work tasks.
Fatigue and reduced energy, motivation and productivity levels	Ongoing impacts from poor sleep resulted in fatigue that reduced productivity and motivation.
Theme 1.3: impact on mental well-being and evolving sense of self (ICF category: body functions)	
Reduced confidence in body functioning and fear of reinjury and/or symptom exacerbation	Participants cited a decreased confidence in the capacity of their body to perform physical tasks, including sports and leisure activities. Reduced confidence could result in discontinuing tasks or activities due to fear of reinjury or symptoms exacerbation, and manifested as a reduced sense of self-worth, well-being, and for some, an emotional toll.
Fear of disclosure	Participants expressed a fear of disclosing their CMSP in work or social contexts because of how they may be perceived or judged, including a concern about experiencing stigma.
Experiencing social isolation, loss, sadness and/or frustration	When individuals considered there to be no options to adapt activities to accommodate their CMSP and body functioning limitations, they withdrew from relationships and social participation, resulting in low mood, isolation, and loneliness.
Theme 1.4: coping with CMSP (ICF category: activities and participation)	
Learned behavioral responses to CMSP: experiential learning and fear of pain	People with CMSP learned to change their behaviors in response to pain, or the anticipation of pain. For some, they applied experiential learning to perform tasks at home or at work as a strategy to maintain functioning, such as using their unaffected limb for some tasks, performing tasks differently, or supporting their affected limb to function using assistive products. For others, their behaviors changed because of fear of pain, resulting in not using their affected limb at all. This avoidance behavioral strategy was reinforced by experiences of pain exacerbations associated unconscious or unplanned movement. The avoidance behaviors consistently manifested as using their unaffected limb.

(Continued)

Table 4. (*Cont'd*)

Subthemes	Description of subthemes
Acceptance of functioning limitations	Over time, participants reached an acceptance of their functioning limitations, recognizing and accepting that ways of doing tasks and aspects of everyday life were now different.
Social reference comparison and motivation to actively manage their CMSP	Participants compared their functioning limitations and symptoms to others in their social network, recognizing their own situation, in many cases, was less severe. This downward social comparison was used as a coping strategy and motivation to actively manage their condition to maintain quality of life and well-being.
Theme 1.5: social support and participation (ICF category: environmental factors)	
Accessing social support to maintain functioning and overall well-being	Accessing social support, either paid or voluntary, including family and work colleagues, was used differently across participants. Although some participants wished to remain independent, for others who experienced more severe impacts, social support was needed to maintain their functioning. Social networks also provided reassurance that supports were available, if needed.
Impact on social relationships	CMSP impacts could extend beyond personal (intrinsic) factors to also impact external (extrinsic) factors, such as relationships with family. Typically, participants perceived their families carried a burden from their CMSP.
Reengaging in social participation	Participants, particularly those who had become socially isolated, identified the value of social re-engagement to their overall well-being.

* CMSP, chronic musculoskeletal shoulder pain; iADLs, instrumental activities of daily living; ICF, International Classification of Function, Disability and Health.

feelings of mental distress and "hopelessness": "It definitely makes me feel kind of hopeless, more useless. I feel a lot of shame and guilty. I can feel very depressed and a lot of self-anger, because I feel like why can everyone else just go about and do things and function normally, but I can't?" (PID16)

For some, participation restriction in a valued life activity (eg, sports) was associated with a significant mental health impact and shifted their self-identity, for example from being active and socially engaged, to an identify of *social isolation*: "I was sad. I was sad that a lot of my friends were sporty, and I couldn't play basketball with them…I wanted to play with my friends, but I was always left out, standing on the sidelines." (PID03)

For some participants, concerns also extended to a *fear of disclosure* of their CMSP within work or social contexts. Specifically, they feared being judged or experiencing stigma, which also extended to a fear of disclosure in seeking new employment.

Theme 1.4: coping with CMSP. People living with CMSP adopted varied coping strategies or behaviors to continue their usual functioning, either at work or home. This included *learned behavioral responses*, with which individuals tried to improve their functioning, such as pacing, performing a task differently, or using assistive products to support functioning:

"But you learn by trial and error, as well. In the shower, I can't use a proper towel, they're too heavy. I use a camping towel…So that's what I use to dry myself after a shower." (PID15)

However, for others, habits developed as a learned behavioral strategy to avoid exacerbating symptoms. Another coping strategy described was participants arriving at a cognitive and emotional stage of *acceptance of their functioning limitations*, recognizing and accepting that ways of doing tasks and aspects of everyday life had to be different. Some participants were more accepting of their new reality, possibly hopeful of change, whereas others were resigned to their new "normal."

Creating a social reference comparison also served as a coping strategy for some, with individuals comparing their condition to peers whom they perceived to be worse off or experiencing more significant health challenges than themselves (ie, downward social comparison). This served to minimize the perceived negative impacts of their own condition on their sense of well-being. It also served as *motivation to actively manage their CMSP* to improve their quality of life and well-being.

Theme 1.5: social support and participation. Participants identified the importance of *accessing social support to maintain functioning and overall well-being*. Social supports, such as family or colleagues, were identified as important depending on the extent of functioning limitations experienced by the participant and their age. Social supports provided reassurance that assistance was available to maintain their functional ability. However, some older participants expressed a reluctance to seek support for iADLs from their social networks, aiming to remain independent: "Actually, I do not like to call on other people at all, even my friends. I don't like to. I can still vacuum and dust and do the general household things, and I don't want to ever get to the stage where I have to call on people." (PID04)

Table 5. Care experience theme and subtheme descriptions*

Subthemes	Description of subthemes
Key theme 2.1: care-seeking behaviors	
GP as the entry point to care	The GP was the most common first contact HCP for most participants experiencing CMSP, influenced by tradition, prior experience and trust. Some older participants always consulted their GP, while middle-aged participants tended to consult either GP or other HCP based on their previous experience of musculoskeletal pain (shoulder or other area) or recommendations from trusted individuals. Younger participants (20–30- year-olds) often consulted HCPs that their family typically visited. Care pathways from the GP typically followed pharmacological care and onward referral for imaging and nonsurgical interventions, before consideration for specialist referral.
Seeking care from other primary care providers	Where participants were unsatisfied with their care, they sought primary care providers (other than a GP) who were recommended by trusted family and friends.
Key theme 2.2: interactions with HCPs (positive)	
HCPs took time to listen and validate the person's story	Participants described the importance of HCPs acknowledging their concerns and validating the impact of CMSP on their lives. Participants appreciated HCPs being familiar with their case/clinical history and understanding the components of their care journey.
HCPs providing education about their CMSP	Participants valued interactions with HCPs that involved education about their CMSP and their care options, in particular when care options were staged and linked to improving functioning and recovery, and achieving personal goals. Taking an active role in care planning, through shared decision-making, led to a sense of empowerment and motivation to participate in self-care.
Interprofessional communication and coordination of care between HCPs	Participants were complimentary and appreciative of transparent, clear, consistent, and honest communication by their HCPs. They appreciated care delivered by different professions, when this was needed, as well as communication about that care between providers. Participants reflected that this communication enabled HCPs to be aware of the components of care and to better coordinate care.
Amount of time participants are able to spend with HCPs.	Participants relished time with HCPs to better understand their CMSP and receive care, in particular, learning what to do and how, to reduce pain and return to usual function.
Key theme 2.2: interactions with HCPs (negative)	
Lack of engagement and validation	Participants described negative interactions with HCPs as characterized by a lack of engagement and validation, leaving participants feeling confused and uncertain about their care.
Lack of education and goal setting	Participants described a negative interaction with HCPs as one characterized by a one-way or didactic communication style in which care for CMSP was "prescribed" without an opportunity for discussion, education, or shared decision-making to ensure interventions were aligned with goals. Participants perceived that these interactions resulted in care that was not tailored, leading to a delay in recovery and re-engagement in valued life activities.
Lack of interprofessional communication and care coordination between HCPs	Many participants described receiving mixed, contradictory information from HCPs regarding their CSMP, care, and prognosis. This promoted confusion and disillusionment with care and health care system, and for some, a prolonged recovery period.
Inadequate time with HCP	Many participants described time-poor HCPs working within a health care system in which consultation times were short, providing inadequate opportunities for discussion and limiting their understanding about their condition. Short consultation times diminished confidence in their HCP and their ability to make informed care decisions.

(Continued)

Table 5. (*Cont'd*)

Subthemes	Description of subthemes
Key theme 2.3: values and preferences for components of shoulder care	
Preference to avoid pharmacologic interventions if another nonpharmacologic treatment option was likely to provide benefit	Participants' previous experience with, and expectations of, pharmacologic care (eg, side effects of medicines) influenced their treatment preferences. Here, many participants expressed a preference to avoid pharmacologic care if a viable nonpharmacologic option, such as exercise, was available. Exercise was perceived to be safer and was associated with increased confidence in their upper limb and conferring benefits to pain, function, and well-being.
Timely care and face-to-face consultations	Participants' experiences with the COVID-19 restrictions on accessing health care influenced and informed their preferences for care. From these experiences, particularly for residents of Victoria,[a] preferences for timely access to HCPs and for consultations in a face-to-face mode were expressed.

* CMSP, chronic musculoskeletal shoulder pain; HCP, health care professional; GP, general practitioner.

[a] Victoria is a state in Australia where the longest number of days in lockdown were recorded for the COVID-19 pandemic.

Participants also identified that the impacts of living with CMSP extended beyond personal (intrinsic) factors and also affected *social relationships*. Some reflected that their families were burdened by their condition, having to "do the heavy lifting" around the home: "…it's just more stress in the household that you're putting on your partner, when there's enough happening at home. So yeah, again, just conscious that it's putting more stress on her." (PID20)

Objective 2: care experiences. Participants' reflections about their care experiences related to: care-seeking behaviors; positive and negative interactions with health care professionals (HCPs); and values and preferences for components of CMSP care. These themes explored subsequently with salient subthemes italicized and discussed in further detail. Table 5 provides a summary of themes and all subthemes, and Supplementary File 6 provides additional supporting quotes.

Theme 2.1: care-seeking behaviors. Participants described variation in entry points to care. Participants of all ages described trust in and loyalty to their general practitioner (GP), and for most, the *GP was the entry point to care*. Younger and middle-aged participants tended to consult either GPs or other HCPs for their CMSP based on their previous experience(s) of musculoskeletal pain (shoulder or other bodily area) or used recommendations from trusted individuals. Older participants (aged 60–77 years) described more consistently consulting their GP and were influenced by a lack of understanding about what other HCPs could (potentially) offer them: "I think a lot of people my age might say the same thing, that you thought the doctors were gods anyway and whatever they said, you did…We also, rightly or wrongly—and it's wrongly—thought that allied health, like physios and OTs, 'What do they do?' That was a bit of a mystery to us." (PID15)

Among participants who consulted GPs, pharmacologic care and referral for exercise therapy and imaging were typically first-line management. However, for some participants, onward referral for surgical review was initiated following GP consultations and review of imaging.

When participants were less confident or less satisfied with the care they received, they proactively *sought care from other primary care providers* to address their pain and functioning loss. Usually, alternate care pathways were informed by experiences or recommendations from family or friends.

Theme 2.2: interactions with HCPs (positive and negative). Participants expressed both positive and negative care interactions with their HCPs, which included GPs, allied health professionals, and medical specialists. These experiences were centered around HCPs' communication skills, their commitment to education, and shared decision-making that supported care aligned with individuals' goals, time afforded by HCPs, and interprofessional communication and coordination.

Positive experiences were characterized by HCPs with excellent communication skills (verbal and written) and when *HCPs took time to listen to and validate the person's story*, understand their problems, and include them (through shared decision-making) in the care planning and delivery. Participants identified that these characteristics positively influenced their adherence with treatment and optimized their care experiences and outcomes: "I keep going back…I always feel like they're treating me with respect and they're treating me as an intelligent participant in the treatment process, rather than simply a person to be fed information to…." (PID01)

On the other hand, a lack of engagement and validation by HCPs was perceived as a negative interaction in which participants were often left feeling confused and uncertain about their care. Similarly, when participants experienced limited opportunities for discussion and shared decision-making with their HCP, there was potential for misalignment between their recovery expectations and those of their HCP.

Participants valued interactions with HCPs in which they were provided with education about their CMSP. This empowered individuals to actively engage in their care decisions and self-manage. This also promoted confidence in their role in recovery and return to valued activities. Conversely, experiences characterized by a one-way interaction were viewed negatively, resulting in a "*prescription of care*" without the opportunity for discussion, education, and shared decision-making.

Care experiences were often colored by the *amount of time participants were able to spend with their HCPs*. Positive experiences were ones in which participants felt they had adequate time with their HCP to discuss their concerns and understand their condition and care options. When consultation times were inadequate, participants felt less confident and satisfied with their clinical encounter and ill-equipped to make informed care decisions.

Theme 2.3: values and preferences for components of shoulder care. Participants' preferences for components of CMSP care were strongly influenced by their clinical encounters and where they had previously experienced benefit. Many participants, irrespective of age, expressed a preference to *avoid pharmacologic interventions if another nonpharmacologic treatment option was likely to provide benefit*. This preference was largely informed by previous experience with medicines in which little benefit was experienced and side effects outweighed benefits: "Panadol and Nurofen barely touch the edges. I get more side effects from them than I do relief, so I don't bother…" (PID07)

Participants expressed greater confidence in and a preference for exercise therapy. Irrespective of age, exercise was identified as instilling a sense of confidence in using their limb and more sustained benefits for pain, functioning, and a sense of well-being.

DISCUSSION

Adults living with CMSP experience wide-ranging impacts that manifest across four ICF domains (body structures, body functions, activities and participation, and environmental factors), consistent with other musculoskeletal pain research that has interpreted findings in relation to the ICF.[15–17] These impacts resonate with a contemporary understanding of the multidimensional experiences of living with chronic pain,[14,36] as well as condition-specific experiences such as low back pain (LBP) or osteoarthritis.[37,38] Body functioning impacts were strongly identified and interrelated for physical functions (activities of daily living, work/study, leisure, and driving), sleep and vitality, and psychosocial health, highlighting the importance of holistic care for CMSP that considers health and well-being beyond impairments to body structures. The range of coping strategies described (many of which were informed by experiential learning and avoidance behaviors) also point to a need to coach people with CMSP in helpful self-care strategies to optimize their functioning and return to valued life activities. Care experiences were characterized by variability in accessing care and navigating care pathways. Many participants relied on their past experiences, recommendations from social networks, and their GP as their starting points for care.

Our findings on the lived experiences of CMSP support and extend the extant evidence for shoulder pain conditions. Specifically, our findings add to the body of evidence about the multidimensional impacts of shoulder pain disorders, framed through a transdiagnostic perspective, highlighting that experiences and impacts are relevant across diagnoses and classifications. For example, recent qualitative evidence syntheses have identified interrelated physical, psychological, and social impacts of living with various shoulder disorders and nontraumatic shoulder pain.[8,9] However, these reported impacts were not classified using the breadth of ICF domains. Our data also suggest that impact domains are interrelated and, for many impacts, are cascading. For example, body structure impairments limit body functioning and lead to reduced participation and activities; for many, this manifests as mental health impairment, social withdrawal, and isolation. These impacts further compound body functioning impairments, such as sleep disturbance. For some, these impacts were nontrivial, limiting their ability to work and study. These impacts have implications for financial security and the future livelihoods of younger people, including fear of disclosure to employers, consistent with previous investigations.[13,15,39] For many participants, the impact of loss of physical functioning over time influenced their evolving sense of self, such as their self-worth, social connection, and (lack of) confidence in their bodies, including a belief of being "damaged." This belief about structural damage or fragility aligns with previous shoulder pain research[8] and also transcends musculoskeletal pain conditions, commonly expressed by people living with LBP or osteoarthritis.[40–45]

Participants' care experiences reflected attributes of helpful and unhelpful therapeutic encounters that shaped their values and preferences for care. Our findings are consistent with recent evidence,[12] extending it to also feature the importance of validation, consultation time, and interprofessional communication and coordination. Participants strongly preferred consultations that featured validation of their pain experience, a space to share their CMSP-related impacts and goals, opportunities to receive education and support to engage in goal-directed self-care, interprofessional cooperation and collaboration, and adequate consultation time. These therapeutic encounter attributes also align with the values and preferences of people experiencing other musculoskeletal pain conditions that extend over the course of their life[13,46,47] and those that have been identified as independent predictors of satisfaction with GP encounters.[48] Relevant to our findings, a recent evidence synthesis by Klem et al[13] suggested that "helpful" therapeutic encounters could buffer allostatic load associated with sequelae of chronic musculoskeletal pain, whereas "unhelpful" encounters could increase the allostatic load. Similar findings were identified in a review by Eriksen et al[49] who identified that health care experiences perceived as negative impacted both the physical and mental well-being of patients.

Our findings have important implications for practice and improving service delivery for people living with CMSP. Holistic, person-centered care requires recognition of the dependency between lived experience and care preferences and needs,[11] as illustrated in Figure 1. Our findings also signal that experiences may vary by age, suggesting that stage of life may be an important contextual factor in care planning and delivery. Clinical assessment that is limited to body structure impairment alone is unlikely to elucidate functioning and participation limitations that are meaningful to an individual, resulting in a care pathway that does not align with their expectations or goals. Clinicians should recognize that CMSP is typically associated with multidimensional and interrelated impacts and could actively explore these areas with patient-reported outcome measures (PROMs) as part of clinical consultations. PROMs may be helpful in practice to make sense of a person's impact "loop" or impact "cascade" by evaluating, for example, sleep, mental well-being, coping mechanisms, and social support. Making sense of shoulder pain in a personalized, meaningful, and understandable manner, grounded in an approach that targets emotions, cognitions, and behaviors, is important to improve functioning and self-efficacy, as identified in LBP care.[50] This is important, considering the evidence that patients with shoulder pain are dissatisfied when their expectations and understanding of their experience are misaligned with explanations provided by their health care providers.[8]

Our data also suggest that interprofessional collaboration and consistent communication are valued. Therefore, building transprofessional competencies in chronic pain care will be important to improving care experiences.[51,52] This context, taken together with clear preferences for how care could be optimally delivered, points to an opportunity and targets for optimizing person-centered care for CMSP, such as through the creation of a Clinical Care Standard to drive improvements in health outcomes and care experiences and reduce unwarranted care variation. For example, Australian Clinical Care Standards have been developed for high burden musculoskeletal conditions such as LBP and osteoarthritis.[53,54] Considering wide-ranging impacts and clear preferences for, and variation in, service delivery experiences, our data suggest it may be timely and warranted to consider a Clinical Care Standard for CMSP.

To our knowledge, this is the first primary study conducted in Australia examining both lived and care experiences as well as the care preferences of adults with CMSP. Strengths of this study include its co-creation from inception with people with lived experience, exploration of lived experiences informed by, and interpreted in relation to, ICF domains, and examination of care preferences where current evidence is limited. The purposive sampling frame to achieve balance between genders, wide age distribution, and diversity in clinical profiles enabled more confidence in the transferability of our findings and will likely strengthen the confidence of findings in future evidence syntheses.[9] Nonetheless, our sampling was limited to people largely residing in high socioeconomic areas and underrepresents some groups, such as indigenous Australians, potentially limiting transferability of findings to those communities. Care experiences described by the participants may also be influenced by unique structural characteristics of Australia's health system and Australia's public health response to the COVID-19 pandemic, with extended lockdown periods in the state of Victoria.

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AUTHOR CONTRIBUTIONS

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