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BMJ Open

Understanding the chronic pain journey and coping strategies that patients use to manage their chronic pain: a qualitative, patient-led, Canadian study

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To cite: Bruce M, Lopatina E, Hodge J, *et al*. Understanding the chronic pain journey and coping strategies that patients use to manage their chronic pain: a qualitative, patient-led, Canadian study. *BMJ Open* 2023;**13**:e072048. doi:10.1136/bmjopen-2023-072048

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2023-072048).

Received 19 January 2023
Accepted 16 July 2023

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ABSTRACT

Objective To gain an insight into coping strategies that people living with chronic pain use to self-manage their pain.

Design This qualitative Patient-oriented Research study used the Patient and Community Engagement Research approach. It was conducted by people with chronic pain lived experience, ensuring that patient perspective and needs were considered and addressed throughout the research cycle. Purposeful sampling was used for recruiting individuals living with chronic pain. A focus group and one-on-one semi-structured interviews were conducted via videoconference. The data were analysed iteratively using inductive thematic analysis and narrative story analysis.

Setting Calgary, Alberta, Canada.

Participants Eleven adult participants, between the ages of 18 and 65, who self-identified as living with chronic pain for greater than 2 years.

Results Three main themes emerged from the data: (1) the elements of chronic pain, (2) the chronic pain journey to acceptance and (3) daily coping strategies for chronic pain. Participants thought it was important to discuss these three themes because the daily coping strategies that they employed at any given time (theme 3) depended on the factors discussed in themes 1 and 2. Overlaying all of this is also a grieving process that people living with chronic pain may have to go through more than once. Participants also identified recommendations for healthcare professionals to support people living with chronic pain.

Conclusions Dealing with chronic pain affects all aspects of a person's life and involves a grieving process. When treating patients with chronic pain, it is important for healthcare professionals to understand the journey that people living with chronic pain go through, not just coping strategies. Diagnosis is critical for a patient's acceptance and in helping them find their new normal where they can employ daily coping strategies to manage their pain.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study about patient experiences was led by patient research partners throughout the entire research cycle which helped create a safe environment for participants to share their experiences with others who could relate.
- ⇒ Inviting study participants back for a second focus group to review and provide input on the initial findings provided more robust outcomes and recommendations.
- ⇒ The lack of rural participants is a limitation of this study.
- ⇒ More ethnic and cultural diversity would have enhanced the generalisability of the study.

INTRODUCTION

Chronic pain is defined as a pain that occurs in one or more places in the body and persists or recurs for longer than 3 months.[1] Estimates of the prevalence of chronic pain in the population vary from 10% to over 50%.[2–4] The condition is often invisible and can affect people throughout their lifetime.[5] Chronic pain is associated with significant emotional distress and functional disability that interferes with performing the activities of daily life.[1] Chronic pain is also associated with a substantial societal burden due to productivity losses and direct medical costs.[6 7]

Recognising the challenges that the chronic pain presents to healthcare systems and societies, national strategies from many countries including the UK,[8] the USA,[9 10] Australia[11] and Canada[5] call for the transformation of healthcare services for patients living with chronic pain. To develop healthcare services that are relevant to patients, it is critical to understand patient perspectives, their needs and how they live and cope with the disease. There have been a number of studies looking at patient coping strategies for chronic pain.[12–14] Yet, fewer studies have explored the broad experiences related to living and coping with chronic pain and the impact chronic pain has on the quality of life of patients, personal relationships, mental health and employment.[15]

Our study aimed to inform healthcare professionals about what it is like living with chronic pain from a patient's perspective, offering an insight into important considerations when developing treatment plans or recommending coping strategies to provide more wholistic care during a patient's chronic pain journey. To meaningfully capture the patient-perspective, this study was conducted with patients and led by patients with chronic pain lived experience during their Patient and Community Engagement Research (PaCER) training.[16]

METHODS

PaCER is a 12 month certification programme at the University of Calgary, Alberta, Canada, which offers patients, that is, individuals with lived experience of a health issue including informal caregivers, family and friends,[17] extensive training in conducting patient-to-patient research. The patient-oriented research (POR) qualitative study reported in this manuscript was conducted by patients (JH, KM, PP and SKhan) with chronic pain lived experience, either personal experience or as a caregiver, who were interns of the PaCER programme at the University of Calgary, Alberta, Canada.[16]

The work was supervised by two academic researchers with expertise in PoR (MJS and TW) and a PaCER graduate (MB). Guidance and expertise were also provided to the team by two healthcare system leaders (TW and SKashuba) and a health services researcher (EL). PaCER approach application to this project is outlined in figure 1 and consisted of three phases: SET, COLLECT and REFLECT.[18] The three phases are described in more detail below. The COnsolidated criteria for REporting Qualitative research Checklist[19] was followed to report this research, see online supplemental table S1 for details.

Phase 1: SET

During the SET phase of the study, we familiarised ourselves with the topic by reviewing past projects and relevant literature. As we formulated our research question, we received guidance from two healthcare system leaders (TW and SKashuba) and two qualitative researchers (TM and MJS). Next, we consulted with two other people with chronic pain lived experience about our research question and objectives. This 2 hour working session served as a brainstorming activity to codevelop the final research question, the direction of the work and the recruitment strategy. Once these factors were clear, we moved into the next phase, COLLECT.

Phase 2: COLLECT

In this section, we describe the recruitment, data collection and analysis during the COLLECT phase.

Recruitment

We used a purposeful sampling approach to recruit participants via our connections within local patient support organisations. These organisations included, Genuvis Chronic Pain Centre,[20] Collaborative Mentorship Network,[21] Helping Ease Alberta's Pain[22] and Alberta Health Services Strategic Clinical Networks.[23] Inclusion criteria included individuals who were[1] living with chronic

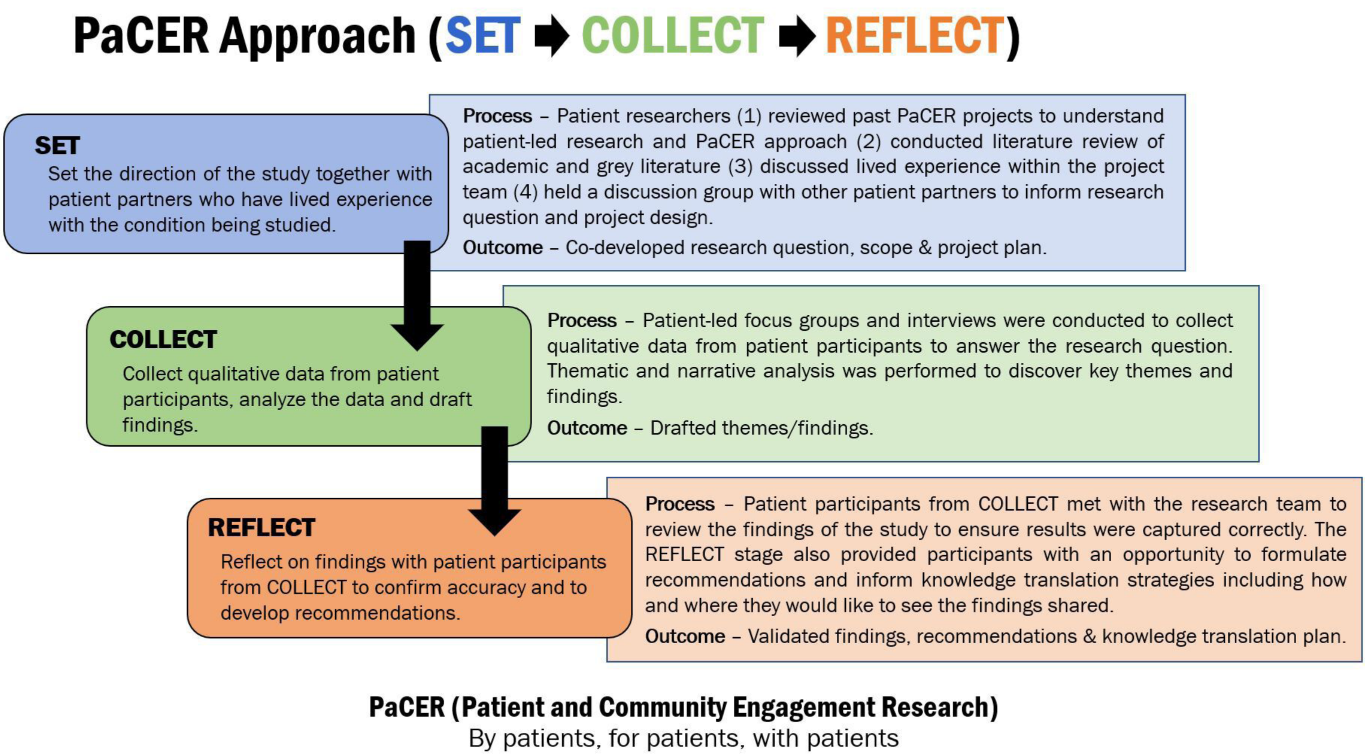

Figure 1 PaCER approach and application. PaCER, Patient and Community Engagement Research.

pain for two or more years,[2] over the age of 18 years and[3] living in Alberta, Canada.

Data collection

The COLLECT phase focused on collecting data via a focus group and one-on-one semistructured interviews.[18] Data collection took place between 25 September 2021 and 15 October 2021 over Zoom using a semistructured discussion guide (see online supplemental table S2). Following a qualitative descriptive approach,[24] the discussions focused on obtaining the lived experiences that participants had with the Alberta healthcare system, as well as any specific factors that shaped their experiences while coping with chronic pain. Although this study was conducted during the COVID-19 pandemic, it was not the focus of study and it did not affect the design of the study, as patient-oriented interviews and focus groups are often held remotely so that they are convenient for the patient participants. The question guide used in the focus group and one-on-one interviews was previously pilot tested with a patient and researcher and refined based on their feedback. Researchers took detailed notes during the sessions and captured field notes, additionally, focus groups and interviews were recorded so verbatim quotes from participants could be captured.

Focus group

Six participants were invited to participate in a focus group discussion. The consent form was reviewed by the facilitators and participants prior to starting the discussion, with signed informed consent obtained for each participant. The focus group lasted approximately 2 hours including about 75–90 min for discussion, and additional time for introductions and socialising. The focus group was audio-recorded, and notes were taken in English. Two patient researchers (SKhan and PP) facilitated the focus group notes and observations were captured by other study team members (JH, KM and MB).

Interviews

Five participants were invited to participate in 1-hour-long one-on-one semistructured interviews[25 26] using Zoom. Each interview included a participant and two members of our research team, with one member conducting the interview and one observing and taking notes.

Data analysis

The focus group data were analysed using inductive thematic analysis to find repeated patterns of meaning.[27] We reviewed the notes and listened to the recording to better understand the data collected before initial codes were developed and tested by the team. Each team member coded the data individually, using spreadsheets, and then met as a team to review the data line by line to come to a consensus on final codes. Once all the data were coded, they were sorted into emerging themes by the team. The analysis process was iterative, helping to ensure that data saturation was reached during COLLECT.

Semistructured interview data were analysed using narrative story analysis.[18] Team members systematically reviewed their interview notes to identify key themes and summarise them into a story template. Key learnings and high-level themes from the stories helped contextualise the analysis of the focus group data.

Phase 3: REFLECT

The final phase of the project involved bringing participants back for a final focus group where the themes were presented. The REFLECT participants provided feedback on and validated the themes to ensure that their experiences had been captured accurately. During this 2 hour focus group, the rapport between the participants was evident, and participants delved deeper into key themes areas, validated the findings and helped codevelop recommendations on how healthcare professionals could improve the lives of people living with chronic pain. At this final stage, participants also had an opportunity to discuss how and where they would like the findings of this study shared.

Patient and public involvement

This study was patient-led and conducted by patients with patients. The members of our core research team had lived experience with chronic pain. While designing the study, we worked with two patient partner peers to develop our research question and recruitment strategy. Results of the data collection and analysis were presented back to participants during the last phase of our research process providing participants an opportunity to confirm themes and provide additional insights prior to the results being finalised. At this time, participants were also invited to provide input into how and where they would like to see the findings shared.

Ethics

This research was approved by the University of Calgary Conjoint Health Research Ethics Board (Ethics ID number REB21-1327).

RESULTS

Eleven adults living with chronic pain participated in this study, some participated in more than one phase. The gender, age, area of residence and years lived with chronic pain are shown in table 1. All participants were actively engaged throughout the data collection and validation and were eager to share their experiences.

Although the research question, which was defined during the SET phase, was limited to the daily coping strategies of people living with chronic pain, during the COLLECT phase, as participants shared their coping strategies, the conversations went beyond coping strategies to include the elements of chronic pain and the chronic pain journey to acceptance, as participants stressed the importance of understanding the whole picture, when

Table 1 Self-reported characteristics of study participants (n=11)

Characteristic	Number (percentage, %) of participants
Sex at birth	
Female	7 (64)
Male	4 (36)
Age group	
18–50 years	2 (18)
51–65 years	5 (46)
65+ years	4 (36)
Area of residence	
Urban	9 (82)
Rural	2 (18)
Years since chronic pain diagnosis	
<5 years	1 (9)
5–10 years	4 (36)
>10 years	6 (55)

determining which coping strategies should be used and when.

As shown in figure 2, the three main themes emerged from the COLLECT data included: (1) the elements of chronic pain, (2) the chronic pain journey to acceptance and (3) daily coping strategies for chronic pain. During the REFLECT focus group, when participants returned to review the preliminary analysis, they validated all three themes and said it was important to present the three themes because the daily coping strategies that they employed (theme 3) depended on understanding the other two factors reflected in themes 1 and 2. The themes that emerged, as well as the recommendations for healthcare professionals that participants believed would help transform the experiences of people who live with chronic pain, are discussed below.

The elements of chronic pain

> *I sure wish we could change bodies for about five minutes so that you could better understand exactly where I am coming from.*

To understand the coping strategies that people with chronic pain use, it was important to first understand that chronic pain impacts every aspect of a person's life. As identified during COLLECT data analysis and validated during our REFLECT focus group, individual elements of chronic pain included 'Invisible Disability', 'Complexity', 'Impacts on Future', 'Impacts on Finances', 'Impacts on Mental Health', 'Grieving Process', 'External Supports' and 'Self-advocacy'. These elements of chronic pain are defined, and the supporting quotes are presented in online supplemental table S3. The research team and participants agreed that the elements of chronic pain together form the chronic pain experience, which could be represented as branches of a tree (figure 3).

The chronic pain journey to acceptance

Once the elements of chronic pain were identified, it was important to understand how these elements weaved together to form the chronic pain journey to acceptance and how that journey centres around diagnosis. As illustrated in figure 4, diagnosis was pivotal for people

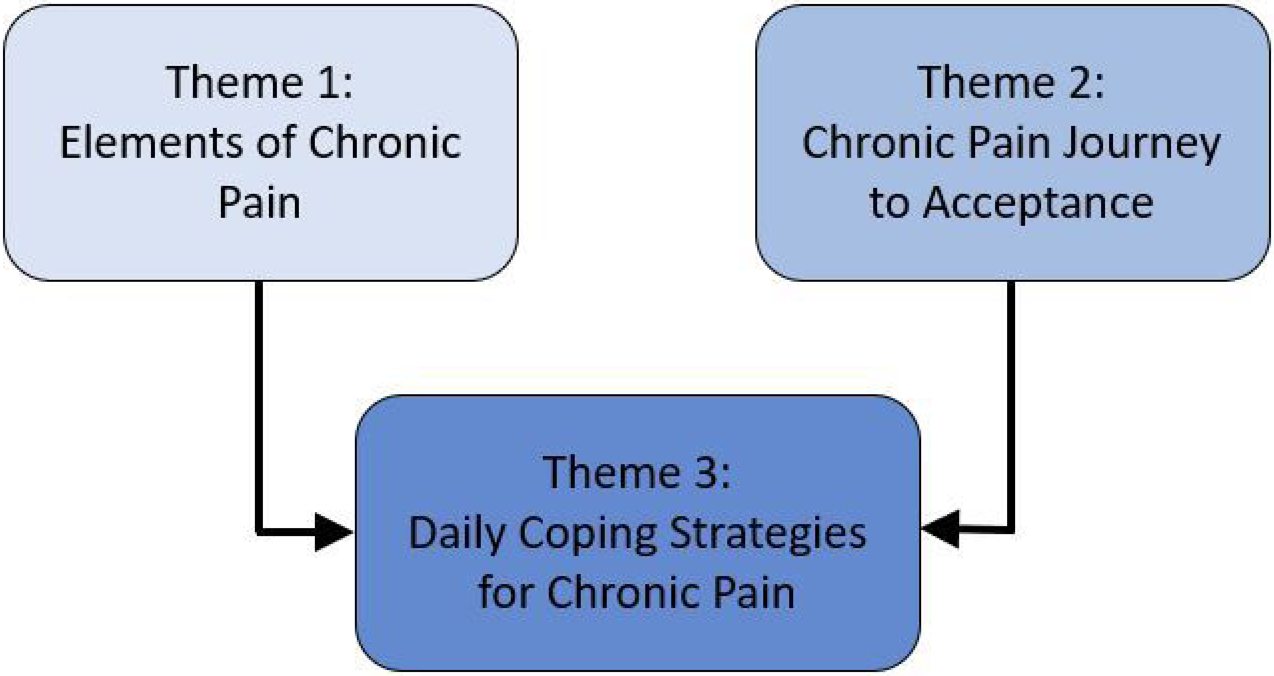

Figure 2 Main themes.

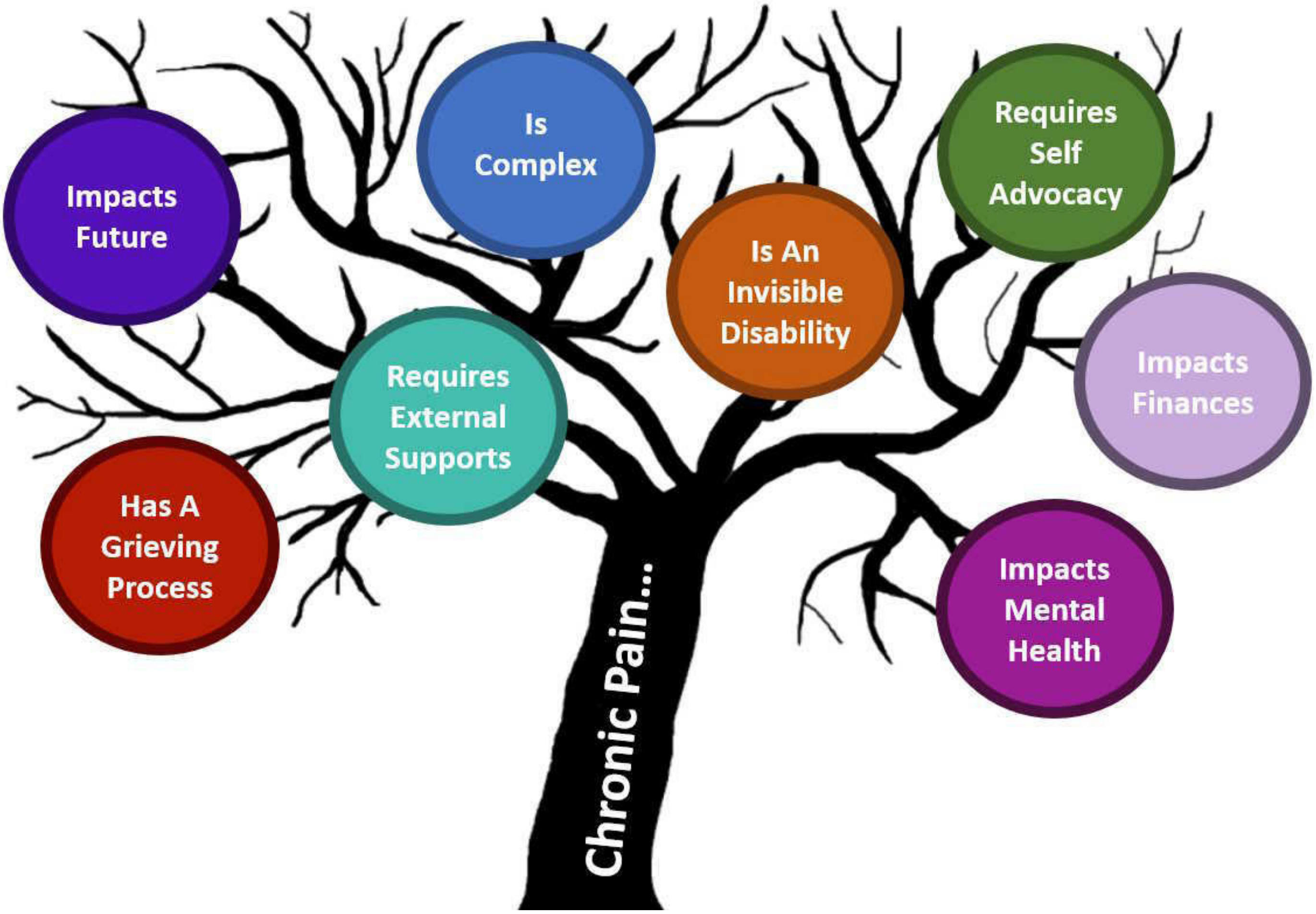

Figure 3 The elements of chronic pain.

suffering from chronic pain to be able to cope and take control.

> *The diagnosis was, was huge, it was a huge relief to finally hear, I mean like people would ask, you know, what's wrong, what's your diagnosis, nothing, I don't know, it's super frustrating to have nothing wrong with you but that's ridiculous… I know something is wrong.*

Prior to diagnosis, individuals experienced huge and unpredictable emotional swings as they struggled for answers. Participants felt that a diagnosis allows people suffering from chronic pain to start taking control of their life by making modifications to their lifestyle and to begin getting the support that they need. Although there were still swings after diagnosis, in this second

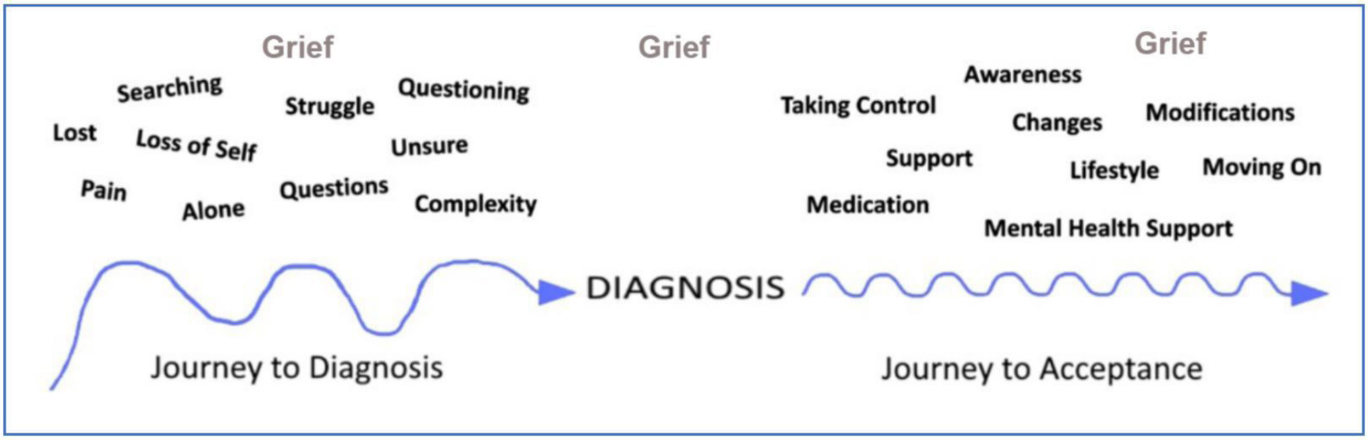

Figure 4 The chronic pain journey to acceptance.

part of the journey to acceptance, the swings became less pronounced as patients started to accept their new normal and to have a better understanding of their limitations and what strategies could help them cope with their pain on a daily basis.

> *If you are not accepting, if you are constantly fighting against it and try to figure out what's wrong or how do we turn this off, like it's like beating your head against a brick wall as opposed to learning, finding ways to cope with it. Coping cannot start until you accept it.*

The grieving process was mentioned earlier as an element of chronic pain, but bears repeating as the journey to acceptance is considered. Participants described needing to grieve the life that they had lost as they struggled to find their new normal. The grief did not end at some point of journey, instead it came back again as new losses were experienced throughout different ages and stages of a person's life.

> *I don't go through the grieving process to get to the other end. You are kind of grieving all the time.*

Daily coping strategies for chronic pain

After the elements of chronic pain and the journey to acceptance had been understood, the next theme to consider was coping strategies. Participants identified a number of daily coping strategies that they used to manage their chronic pain, including exercise, therapy, various supports, medical professionals, self-advocacy, listening to own body, modifications and adaptations, distraction, diet and mental health resources. These categories of coping strategies are described in detail in online supplemental table S4. The coping strategy that an individual might use depended on where they were in their chronic pain journey to acceptance, what element of chronic pain they were dealing with at the time and what particular challenges they were facing. Participants described the list of coping strategies as a suite of options that they draw on depending on the day or the circumstances.

Recommendations

During the REFLECT focus group, after reviewing and validating the key themes, participants came up with the following recommendations for the healthcare professionals as key actions to improve care and support people living with chronic pain.

1. Chronic pain treatment should include multidisciplinary care to support primary care physicians in treating patients with chronic pain, for example, Family Doctors, Physiotherapists, Occupational Therapists, Psychologists, Dieticians, Naturopaths and Chiropractors.
2. Doctors should encourage people living with chronic pain to seek support, for example, a person or support group and other mental health supports.
3. Care should be focused wholistically to include preventative strategies such as peer mentoring, exercise and mental health support, instead of just reactive solutions such as medication.
4. Mental health support for people living with chronic pain should include grief support as patients experience many losses.
5. Chronic pain guidelines should be developed for both patients and physicians with information on how to understand and treat chronic pain.
6. Doctors should be provided with further training and education on chronic pain, so they are better able to understand and support patients. Ensure that people living with chronic pain are involved with this by sharing their experiences as part of that training.

DISCUSSION

To the best of our knowledge, this is the first patient-led (PaCER trainees) study to offer insights into the interplay between the chronic pain journey and coping strategies used by patients. This PoR qualitative study presents healthcare professionals with a deeper understanding of what needs to be considered to effectively treat individuals living with chronic pain, from a patient perspective. We originally set out to discover daily coping strategies of people living with chronic pain. However, our research followed an iterative approach that involved engaging peer-to-peer with patients to collect data and reflect on key findings. Through this iterative process, our research went beyond daily coping strategies to discover the journey that people who experience chronic pain go through. When treating patients with chronic pain, understanding the patient journey, and key elements of chronic pain, are important first steps when determining coping strategies.

This study contributes to the understanding of coping with chronic pain and illustrates how important it is to have context regarding how a person is experiencing chronic pain before determining which coping strategies to apply to help treat their chronic pain. The study also found that understanding the elements of chronic pain and the chronic pain journey to acceptance are important precursors to being able to use the better-known and more well-documented[12–14] daily coping strategies. Chronic pain often impacts every aspect of a person's life, and therefore treatment needs to be considered in the context of a person's life.

Patients want to be validated and believed, although invisible, their pain is very real. Diagnosis is a critical turning point for people suffering from chronic pain because it is most often an invisible disability or illness. Pietilä Holmner *et al* discussed the importance of a chronic pain diagnosis and acceptance.[28] Dow *et al* noted that the two main sources of frustration in chronic pain relate to the invisibility of pain and the limitations in diagnosis and management of the pain.[29] Our participants validated this as they described the turmoil that they experienced prior to diagnosis and how things started falling into place for them once they received a diagnosis. Overall, participants underscored the complexity of the healthcare system as an obstacle to attaining improved outcomes. This recurring theme has been documented in previous literature;[30–32] however, its persistent emergence may suggest that insufficient efforts have been made to address this issue.

Participants with chronic pain felt that it was difficult for them to get healthcare professionals to hear their story. What they longed for was to be respected and heard, they needed healthcare professionals to listen to their individual concerns and the challenges that they encounter while living in pain. Although doctors are important, our study participants felt that having, the right team, or a multidisciplinary medical team made up of doctors, pharmacists, nurses and other specialists focused on alternative care, for example, physiotherapy and massage therapy was important.

There are many aspects to consider when treating a person with chronic pain. Recommendations to healthcare professionals developed during this study outline some of those important considerations. Healthcare professionals who treat individuals with chronic pain should discuss the following with their patients: Where are they on their chronic pain journey? What supports do they have in place? Do they have a diagnosis? Do they have required mental health supports? Have they accepted their new normal? What coping strategies have they tried and are those strategies working? Do they have financial burdens that are impacting their ability to cope? Chronic pain cannot be treated with pharmaceuticals alone, it needs be looked at and treated wholistically. These recommendations correspond with finding from other studies and established clinical guidelines, emphasising the importance of individualised, patient-centred, biopsychosocial and multidisciplinary approaches to managing chronic pain.[28 33–36] The recommendations also underscore the diversity of interventions that appeal to patients, encompassing both conventional and less traditional methods. Previous research on patient perspective about chronic pain management also highlights patient interest in alternative and less traditional methods,[37] as those are commonly viewed as relatively benign options that can help achieve pain relief. It is essential for healthcare providers to recognise and acknowledge patient preferences and perspectives regarding their condition and treatment options. This understanding both fosters a stronger rapport with patients, and also offers opportunity for patient education about clinical effectiveness of different interventions and facilitates shared decision-making in the selection of suitable treatment strategies tailored to individual needs.[30 38 39]

Strengths of our study included the diversity of ages and sex of our participants, our participants ranged from 18 years of age to over 65 years of age and a good mix of males and females. Also, being patients with lived experience ourselves, a significant amount of time was spent building rapport with participants, by explaining how we codeveloped our research with patient partners. We believe that the rapport we built enhanced our data collection as participants were comfortable and eager to share their experiences with us as it was evident that the facilitators who had lived experience themselves understood the struggles that the participants faced.

A limitation of our research was lack of cultural and ethnic diversity. Our research team wonders how different cultural beliefs, customs or language barriers might introduce more elements of chronic pain or impact someone's journey to acceptance. Additionally, our sample did not include many rural individuals. Living in rural or remote locations can add complexity and other stressors that may have enriched the data and recommendations presented.

Our study team was very intrigued by the role that grief plays in the lives of people living with chronic pain. As patients with chronic pain lived experience, health services researchers and health system leaders, this concept resonated with all of us and we believe that future research focused on grief and tools to cope with the grief experience while living with chronic pain is important.

CONCLUSION

Chronic pain is a complex, often invisible disability. Chronic pain affects all aspects of a person's life and involves a grieving process. When treating patients with chronic pain, it is important for healthcare professionals to understand the journey that a person living with chronic pain goes through. Diagnosis is critical for a patient's acceptance and in helping them find their new normal where they can work with their healthcare team to employ daily coping strategies to help treat and manage their pain.

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Acknowledgements The authors would like to thank the patient partners who helped design our study, the patient participants for sharing their stories and recommendations, the Strategic Clinical Networks of Alberta Health Services for their support and contributions to help make this study possible and our instructor Dr Tamara McCarron.

Contributors JH, KM, SKhan, PP and MB substantially contributed to the conception and design of the work as well as the acquisition, analysis and interpretation of data for the work. M-JS, TW and SKashuba substantially contributed to the conception of the work and interpretation of data for the work. EL substantially contributed to the interpretation of data for the work. All authors participated in drafting the work and revising it critically for important intellectual content; provided final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The first lead MB and senior author M-JS are guarantors and affirm that this manuscript is honest, accurate, and transparent.

Funding This work was funded by the Strategic Clinical Networks™ of Alberta Health Services.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by This research was approved by the University of Calgary Conjoint Health Research Ethics Board (Ethics ID number REB21-1327). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available. No additional data are available from the authors since transcripts were not produced for this study. The research team relied on detailed notes and listening to the recordings to capture verbatim quotes.

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