

Opioid deprescribing

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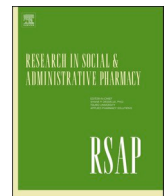
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Opioid deprescribing: Qualitative perspectives from those with chronic non-cancer pain

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ABSTRACT

Aim: Deprescribing is the systematic process of discontinuing medications when the harms outweigh the benefits. This study aimed to identify barriers and facilitators in people with chronic non-cancer pain when deprescribing opioid analgesics, and their views on resources that assist with deprescribing.

Methods: A purposive sampling strategy was used to recruit 19 adults with chronic non-cancer pain from the community who were, or had been, on long-term opioid therapy. Recruitment continued until thematic saturation was achieved. Semi-structured telephone interviews were conducted. A five-step framework and thematic analysis method identified themes for each study aim.

Results: Themes identifying barriers to opioid deprescribing raised challenges of a lack of available alternatives, managing opioid dependency and withdrawal symptoms or inability to function without opioids when in extreme pain. Facilitating themes described the value of support networks, including a trusting doctor-patient relationship and finding individual coping strategies to address deprescribing barriers. We explored a variety of resources from electronic forms such as websites and apps to paper-based or face to face. Participants expressed that whatever the form, resources need to be educational but also simple and engaging.

Conclusions: Most people suffering from chronic non-cancer pain expressed dissatisfaction with being on opioids but most were still unwilling to deprescribe due to insufficient alternatives, a lack of support from their doctors and lack of information about the deprescribing process. Deprescribing can be facilitated by improving supportive networks and strategies and providing simple and positive educational resources.

1. Introduction

Chronic non-cancer pain is a major cause of disability worldwide¹⁻³ and is associated with reduced productivity and quality of life.^{4,5} Approximately one quarter of primary care consultations involve chronic pain presentations,⁶ with patients often being dissatisfied with treatment plans, particularly those involving opioid analgesics.⁷

The increase in pharmaceutical opioid use has become a major public health concern⁸ due to evidence of the harms, such as misuse, dependence and death.^{8,9} These prescribing trends have been found mainly

across high-income countries, such as America, Canada, Western and Central Europe and Australia where access to and availability of opioids for pain treatment is greater in comparison to low- and middle-income countries.^{9,10} However, there is limited evidence to support the effectiveness of current opioid deprescribing interventions for patients with chronic non-cancer pain.¹¹

Deprescribing, the systematic process of tapering drugs with the intention to cease when the harms outweigh the benefits, can be complex. It is part of the prescribing regime, starting from opioid therapy initiation, dose titration, changing or adding drugs, and switching or

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ceasing drug therapies.^{12–14} Qualitative studies can assist with the development of effective deprescribing interventions by exploring the perspectives of people with chronic non-cancer pain on current opioid deprescribing strategies. To date, international studies^{15–17} have found barriers to deprescribing may include; lack of awareness of harms or inadequate guidance during the deprescribing process, lack of communication or empathy from clinicians and patients feeling in control of their opioid use and no need to deprescribe. Conversely, having a desire for improved health, having a supportive general practitioner (GP)¹⁷ or concerns over addiction or dependence^{18,19} may facilitate deprescribing. Although previous studies have identified resources as potential facilitators to aid deprescribing,^{20,21} research has not yet investigated the perspectives of people with chronic non-cancer pain on the types of resources they feel would assist in deprescribing. Therefore, our study aims to explore the perspectives of people with chronic non-cancer pain on opioid deprescribing and on resources that can support deprescribing in order to inform the development of improved opioid deprescribing strategies.

2. Methods

The reporting of this study follows the consolidated criteria for reporting qualitative research (COREQ) guidelines.²²

2.1. Participants

Adults (18 years and over) from the community were eligible to participate if they currently had self-reported chronic (>12 weeks)¹ non-cancer pain and were currently on long term (>6 weeks) opioid therapy or had been on long term opioid therapy but ceased within the preceding year. People were excluded from participating if they have been on opioid rotation or substitution therapy (switching from one opioid to another).²³

2.2. Recruitment

Our sampling strategy aimed to recruit participants with varying characteristics based on patient factors we have previously found to be associated with increased opioid prescription i.e. gender, age, geographic location (i.e. city versus rural) and socioeconomic status.²⁴ We advertised for participants living in Australia through pain association newsletters (Pain Australia, Musculoskeletal Australia and the Australian Pain Society), advertisements in community pharmacies and on social media (Facebook). Ninety-eight people responded to the advertisement, however due to ineligibility or being uncontactable, nineteen participants were recruited and completed the interview, after which recruitment ceased as we reached data saturation. There were no prior relationships between the researchers and participants. Participants were informed of the reasons for conducting the research prior to providing verbal consent. Recruitment continued until thematic saturation was achieved, being when no additional data was identified during the analysis.²⁵

2.3. Data collection

We took a phenomenological frame work approach to understand the experiences of people with chronic pain to opioid deprescribing. We conducted telephone interviews (MH) between the July 15, 2019 and the December 20, 2019 using a semi-structured interview guide (Table 1) which was developed by the author team who had expertise in qualitative design, quality use of medicines, pharmacy and opioid stewardship. The interview guide was piloted with two people with chronic non-cancer pain to ensure the questions addressed the study aims. Prompt questions were asked if responses were brief or to expand on any relevant information. The interviews lasted between 30 and 60 min, were audio-recorded and transcribed verbatim using a professional

Table 1
Interview guide.

Topic	Interview question	Prompt question/s
Barriers	1 . What difficulties have you faced/do you think you will face when reducing or stopping your opioid medicine?	1 . What are/may be the effects on your pain when you reduce or stop your opioid medicines? What are/may be the effects on your general wellbeing? How did/will you manage the pain?
Facilitators	1 . What has/will motivate or encourage you to reduce or stop opioids? 2 . What has made the process of reducing or stopping opioids easier for you?	1 . What in your life could be better if you reduce or stop your opioids? What would you hope to achieve by reducing or stopping your opioids? 2 . What might support you in coming of your medicines? What could your friends or family/doctor do to help?
Patient resources	1 . What information would be helpful to help someone like you reduce or stop opioids? 2 . Have you seen or used resources, designed to help people reduce or come off their medicines? Can you tell me about them and what you liked and didn't like? 3 . If you could design a resource to help people like you reduce or come off their opioid medicines, what would it be? What would it look like?	1 . Prompt: what questions would you have about reducing or stopping opioids? 2 . Is there anything else you would like to add?

transcription service. Researchers checked all returned transcripts for accuracy. Participants did not formally provide feedback on the findings.

2.4. Analysis

An inductive thematic analysis method was used²⁶ (Table 2) to allow meanings to emerge from the interviews. The coding process first identified subthemes as abstract concepts for each category. Following

Table 2
Five-step process of the framework analysis.

Framework steps	Approach
1. Familiarisation	Two researchers (MH, SM) read and coded two transcripts independently by leaving comments for discussion on potential themes arising from the data. MH has prior experience in qualitative methods and SM has extensive experience in researching the quality use of medicines and investigating issues in the management of pain.
2. Identifying a thematic framework	Preliminary themes were identified after discussion during Step 1 and a draft coding framework was developed. Two researchers (MH, SM) independently coded four additional transcripts using the draft framework and met to discuss the coding results. Differences were resolved via consensus.
3. Indexing	The framework was refined after each step and used to code all remaining transcripts by one researcher (MH). Two additional transcripts were double-coded by a second researcher (SM).
4. Charting	The data was summarised in an Excel® spreadsheet, with the participant IDs as rows and the themes as columns. The cells of the spreadsheet contained the direct quotes from the transcripts.
5. Mapping and interpretation	Themes were summarised to bring up the main ideas and to determine any higher order themes (MH, SW). Data were reviewed to determine if saturation was achieved. Thematic analysis was used to describe any patterns and relationships between the subthemes and the themes.

discussions, these concepts were then refined to more specific overarching themes after the merging of similar subthemes into the final framework (MH, SM). Analysis was conducted concurrently with sampling and data collection, which was necessary to determine when saturation was achieved.²⁵

3. Results

3.1. Study population

Thematic saturation was achieved after nineteen participants were recruited and demographic characteristics are summarised in Table 3. Only one respondent to the advertisement was not eligible to participate. All other respondents who were screened participated in the study and there were no withdrawals.

3.2. Thematic results

The themes are outlined in Table 4 and key quotes from each theme are illustrated below. The themes are presented in relation to our research aims of understanding the barriers to deprescribing, facilitators to deprescribing and resources for deprescribing.

3.2.1. Barriers to opioid deprescribing

Most participants would prefer to deprescribe, reporting feeling desperate to try anything else which would help alleviate their pain. However, the themes describing barriers to deprescribing raised the challenges of managing genuine pain often in combination with opioid dependency and barriers such as a lack of alternatives, managing withdrawal symptoms or the inability to function when in extreme pain.

Theme 1. Perceived benefits of taking opioids outweigh the challenges of deprescribing.

When participants were asked about their views on deprescribing, many expressed fearing potential increased pain and although they considered alternatives, such as paracetamol or ibuprofen, they felt they were less effective or just as harmful as opioids. *“Unless I have alternatives or some other type of medication or assistance for pain management, I’m not prepared to just have none and have no options ...”* (PT08). Some participants acknowledged they lacked motivation to deprescribe as they were not experiencing side effects or dependency. Participants justified their ‘self-prescribing’ behaviour and only take opioids ‘as needed’, such as to help them sleep or to ‘take the edge off their pain’. *“That’s enough for me to just take them as I need them, and then just to get over the flare-up, the initial flare-ups, and then go off them”* (PT04). Participants also reported that withdrawal symptoms make deprescribing very difficult, particularly when going ‘cold turkey’ *“like the headache, nauseous, dizziness, not able to sleep very well at all, and they’re quite drastic symptoms given that it’s a very low dose”* (PT08). However, even when tapering slowly under the guidance of a GP, many participants reported feeling a range of withdrawal symptoms which varied between individual experiences.

Participants mentioned that their pain stops them from engaging in recreational and social activities or doing daily tasks, and opioids were perceived necessary to enable a ‘normal’ life: *“I can’t really even just go to the shops or – sometimes I’m bedridden, I can’t move, and then impacts my relationship, my partner”* (PT05). Some participants expressed how pain can lead to a lack of sleep and inability to work, which then creates mental health issues, such as anxiety or depression. *“I seriously thought that if I couldn’t control my pain, the best way out would be for me to commit suicide. And I mean, unless you’re living it, you can’t fully understand what effect it (pain) has on your life”* (PT09). Participants said their mental health state also influenced their ability to cope with increasing pain or the withdrawal effects during deprescribing. Participants commonly felt the psychological aspect of being in pain is more challenging than the physical aspect, and hence some participants were unwilling to

Table 3
Baseline characteristics of participants.

Participant characteristics	Number of participants (n = 19)
Gender	
Male	7
Female	12
Age category (years)	
<35	2
35 - 44	5
45 - 54	4
55+	8
Index of socio-economic disadvantage ^a	
1 (Most disadvantaged)	1
2	1
3	0
4	2
5	1
6	2
7	2
8	2
9	1
10 (Most advantaged)	7
Locality ^b	
Major City	14
Rural	0
Regional	
Inner regional	4
Outer regional	1
Remote	0
Healthcare concession card ^c	
Yes	14
No	5
Employment Status	
Paid employment	6
Student, volunteer, home duties	2
Not employed, disability pension	10
Other	1
Average pain intensity over the past week	
1 (least pain)	0
2	0
3	2
4	2
5	1
6	3
7	7
8	3
9	0
10 (worst pain)	1
Pain location/cause	
Arthritis	7
Fibromyalgia	3
Chronic back or neck problems	8
Other	1
Stage of deprescribing	
Never attempted deprescribing	1
Attempted deprescribing ^d	12
Completed deprescribing	6

^a Australian Bureau of Statistics Socio-economic Indexes for Areas (SEIFA) 2016 by postal area code <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/2033.0.55.0012016?OpenDocument>.

^b The SEIFA decile was calculated based on the location of the GPs primary clinic from The Australian Bureau of Statistics Socio-economic Indexes for Areas (SEIFA) 2016 by postal area code <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/2033.0.55.0012016?OpenDocument>.

^c The Australian Health Care Card is a card issued by the Australian Government which evidences the entitlement of the cardholder to concessions, such as the cost of some prescription medicines, medical services, and other government concessions. Eligibility for the card is determined by the eligibility (and registration) for various federal government welfare payments.

^d Includes people who reported taking opioids ‘on and off’.

deprescribe *“I got no real desire to never have a prescription again. I’ve got no desire to completely cease”* (PT05).

Theme 2. Feeling abandoned along the deprescribing journey.

Table 4

Illustrative participant quotes for each theme.

Themes	Example quotes
Barriers to opioid deprescribing	
1. Perceived benefits of taking opioids outweigh the challenges of deprescribing	<p>“While I’m going reasonably well in what I’m taking, there’d be no point in taking me off the Tramal or the occasional Endone to then going to cannabis which he thinks to this stage hasn’t been properly worked out and besides it’s expensive as well” (PT02).</p> <p>“And it’s (opioids) very expensive, and she (doctor) run hours late, and she only works Fridays, and all this inconvenience, but I guess it’s better than not having anything”(PT05).</p> <p>“But at this point in time, I’m just a bit scared of the pain and the suffering that I feel when I have really bad back pain that it’s kind of not worth it for me” (PT19).</p>
2. Feeling abandoned along the deprescribing journey	<p><i>“I had an uncooperative employer over the rehabilitation. They had a chance to offer me two office-based positions and wouldn’t do because doctors have said you can’t work more than 30 h. They were not interested unless I could do 38 h..... They weren’t prepared to be flexible, even though I’d actually been doing one job for four months because it was vacant” (PT14).</i></p> <p>“I had quite a lot of arguments with the doctors in the hospital because I knew I was on inadequate doses and it needed to go up. And anyway, they eventually got the pain under control and then I brought it all back down again” (PT01).</p> <p>“Well, I can tell you one thing for sure, I’ve been hospitalised in Westmead more than half dozen times and I can tell you one thing for sure that there was no follow-up, no nothing, no follow-up, no nothing”(PT03).</p>
3. Limited availability and accessibility to healthcare	<p><i>“They usually run on a point system and if you don’t match up to that amount of points, then tough luck. That’s the same as trying to get on to a disability pension. You’ve got to have 20 points. If you don’t get that 20 points, then too bad, tough luck, suffer”(PT12).</i></p> <p>“I had a referral to a back specialist and I remember ringing them in August, I think, of 2013 and they said the earliest we could get you in would be April next year. I just said I wont be around April next year if I didn’t get to see someone very soon”(PT10).</p> <p>“All that stuff is expensive, physios and all that, so they haven’t got a budget for it – unless you can run it out of the hospital but even then, it’s quite limited, I suppose. If you can’t afford your healthcare, you’re gonna be doing it harder” (PT04).</p>
Facilitators to opioid deprescribing	
4. Supportive relationships enable people to achieve more than they could do alone	<p><i>“I’ve been through domestic violence, so I’ve got like a counsellor I can talk to if I feel too stressed or the withdrawals are too much. I suppose there would be help out there in that sense, but I’m not too sure about that one. I know that family support helps me a lot in terms of picking up the slack and helping me do things or driving when I can’t, things like that but with a lot of family support, I find ways to manage” (PT19).</i></p> <p>“I know it’s funny, but he (grandson) seems to sense or knows when I’m in pain, and all he wants to do is sit beside me and comfort me. He comes home from school and goes, “Grandma, you’ve had a bad day today, haven’t you?” (PT15).</p> <p>“I guess the good thing is because I’ve been so unwell in the last four, five years and developed a good relationship with my GP, he’s very on-board with trying to help me in all the ways he can, to the point where because of me making it a suggestion, he’s actually going through the process of trying to become an approved person to do the approvals for cannabis oil through the government, which that’s not something he would have ever thought about and I’m grateful that he’s even open to those sort – because a lot of doctors aren’t” (PT08).</p>

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Table 4 (continued)

Themes	Example quotes
5. Being educated on opioid harms is empowering	<p>“So there was just a lot of talk about it, so that’s why I’m so aware of it because there was a lot of in-depth information on opioids” (PT06).</p> <p>“I’m not a medical person, but like journals or research papers where they’ve done studies about certain things. And one, I find it interesting; two, I kind of like to see the parallels between how are others responding to different treatments and think that because I know that the response of certain treatments for myself hasn’t been great and thought of just trying to pick up things of – well, what can I change to make things more workable for me” (PT08).</p> <p>“I guess I also have a bit of an advantage because I used to work for a city health for many, many years, so I was working at the hospital for a number of years, so I’ve got to see a lot of the stuff from the inside and that’s one reason I know I never wanted be really seriously sick and having to go to hospital because I know what happens in there. It’s not a place you want to be” (PT013).</p>
6. Personal reasons influence people’s motivation to deprescribe	<p>“Well, it was initiated by me because I was sick of literally popping Panadeine Forte like it was lollies and they weren’t actually doing anything for the pain” (PT13).</p> <p>“Besides the clear headedness, I wanted to be able to get in my car and drive whenever I wanted to, instead of having to assess how I was in the brain before I would get behind the wheel of a car, cause there was a lot of times where I just felt that zonked it was just like, you know what, not gonna bother. But now I feel that – if my girlfriend rings and says, “Oh, do you wanna come for a coffee?” I can say, “Yep, I’m on my way” (PT16).</p> <p>“My whole reason for saying that is because if you saw the difference in my complexion, and not just the weight but the complexion, the energy and everything I felt much better, but one thing that not feel better is I was smiling to a lot of pain, significant pain, and I don’t know what to do with that” (PT03).</p>
7. Coping strategies are critical to getting through deprescribing	<p>“Yeah. It’s not so – I probably have a little bit of baseline pain most of the time, but it really fluctuates with activity. So, when I’m standing or even if I’m just sitting, sometimes, it’s really hard. Laying down is the best thing for me, but obviously, I can’t do that throughout the day, so I have to try manage it” (PT05).</p> <p>“I exercise five times a week, if I keep doing that I actually – my pain is virtually zero. So, it’s very well managed. I get a twinge and that, but I can certainly function” (PT07).</p> <p>“Yeah. Like if you go to a shop or something like that and you’re standing and waiting in line or something like that, I actually find that I’m moving and I rock and things like that just to try and stop the pain” (PT12).</p>
Resources to assist with opioid deprescribing 8. The use of electronic versus paper-based resources depend upon individual preferences and circumstances	<p>“I’ve got an app and I’ve just started doing it. And it’s where I put in the – so, the influences, so could be like lack of sleep, a bad sleep, stressful day at work this and that and then I tick how I feel in the morning, and then tick how I feel at night. I haven’t been too consistent ‘cause I was just on holiday, but I did it today. So, maybe I can try track patterns” (PT05).</p> <p>“I guess I’m just always – whenever I get prescribed a medication or I’m thinking of a certain medication, I actually go and read a lot about it on some websites. I looked at Wikipedia because Wikipedia often has lots of interesting information and then I also look at maybe Healthline and other online websites” (PT06).</p> <p>“I think something online would be pretty good, but then you’ve got a lot of people as well that don’t have access to that, so maybe a booklet or a pamphlet or something telling them that maybe they can go to the library to find out more information. Something like that would probably be really good” (PT12).</p>

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Table 4 (continued)

Themes	Example quotes
9. Finding the right support groups can foster resilience in people with chronic pain trying to deprescribe	<p><i>"I think if you get really frustrated and stuff like that, it's good to be able to get on there and say what you wanna say. Nobody else can read it because it's a private group. So, none of your friends or your family or anything are gonna see it and you can just say what you want. Yeah. It just sort of helps you vent a little bit You've got it off your chest sort of without saying it out loud. You're putting it down in words" (PT12).</i></p> <p><i>"I did – when I was on Work Cover got sent to a support group in Adelaide for people that have had work accidents and are on medication and things. And after a few weeks, I just stopped going. I told them that the reason is I don't wanna be a victim. Some people have been going to this five, six, up to ten years. In this support group, they're victims. They stay a victim. They don't wanna move on" (PT14).</i></p> <p><i>"Yeah. They did originally get me to do the ADAPT pain management program via the Royal North Shore Hospital. And I did get a lot out of that for the mindfulness side and they did get me off all my medications, but that lasted six weeks. Once I got back home – it only lasted six weeks and then I was back on the opioids" (PT16).</i></p>

Participants expressed that they feel GPs have limited time to provide sufficient support while deprescribing, so they feel their care is compromised. Some participants expressed feeling a lack of rapport and empathy as some felt judgment from doctors for being on opioids. *"If you're not gonna offer support and you're not gonna offer services or places to go or people to see or whatever else...don't take away and rip out the rug and then go "You're on your own" (PT08).*

Participants also expressed that they were not fully informed of the potential harms when they initiated opioids, and felt they needed greater support and education from doctors as *"I probably would've taken it but I would have had more of an understanding not to go through it as fast as what I was ..." (PT15).* Participants felt that they can receive conflicting opinions and prescribing practices between GPs can differ, such as some doctors refuse to prescribe, but do not offer alternatives, whilst others freely prescribe opioids. *"I've had to go from a doctor who wouldn't try anything else to someone else who basically wanted me to go cold turkey off the opioids. So, it's been an up-and-down roller coaster ride" (PT13).*

Some participants also expressed a lack of support from family and friends, feeling that other people often lack the patience to deal with their increased pain or withdrawal symptoms from deprescribing. *"Its multifaceted too how chronic pain affects everyone – family, relationships, your work, your functionality, yourself as a contributor in a household, in a job, in a relationship, as a parent" (PT08).*

Theme 3. Limited availability and accessibility to healthcare.

Participants expressed difficulties accessing services, such as psychological support or pain specialists due to long waiting lists, not meeting eligibility criteria or an overall lack of services in remote areas. Many participants said that if they could afford alternatives, such as physiotherapy or massage on an ongoing basis, *"That would help. If I could have physio once every couple of weeks...I'm sure I could live without them (opioids)" (PT07).* However, participants said the out-of-pocket costs were a major barrier to deprescribing as many participants reported being on disability pensions, making it difficult to afford alternatives or specialist appointments which are not covered by government subsidies. *"They usually run on a point system and if you don't match up to that amount of points, then tough luck. That's the way it goes" (PT012).*

3.2.2. Facilitators to opioid deprescribing

Participants stated a variety of facilitators to deprescribing, such as having support networks, being educated on the harms of opioids, personal reasons and finding individual coping strategies to manage pain while deprescribing.

Theme 4. Supportive relationships enable people to achieve more than they could do alone.

Participants felt having emotional support from a variety of sources was essential to coping not only physically, but also to manage the mental health challenges associated with deprescribing. Having rapport and a trusting relationship with their doctor enabled open discussions to the deprescribing process and also reassured people they would not be abandoned when trying to manage their pain and withdrawal symptoms. *"I had a very good GP who was very compassionate to me and who got me to the pain clinic and looked after my healthcare and stuff like that ..." (PT04).*

Participants also expressed gratitude in having supportive family, friends and work colleagues while deprescribing, as suffering from increased pain or other withdrawal effects would often compromise people's ability to socialise. Participants also valued having access to counsellors or psychologists to provide additional emotional support.

Theme 5. Being educated on opioid harms is empowering.

Most of the participants considered themselves to be health conscious and were generally aware of what they are putting into their bodies. Some participants commented on trying to educate themselves on their medications by *"any drug I go onto I have always researched when I started so I know that if I get any kind of side effects or making sure that they're not interacting in a bad way" (PT07).* Being informed by their doctors of opioid harms made people feel more empowered to manage their health condition and then become motivated to deprescribe when they experienced side effects, such as drowsiness which interferes with their life (e.g. not being able to drive a car). Several participants had a background in healthcare, such as nursing, which they felt made a big difference to their ability to deprescribe as they already had good health literacy and knew about the harms of opioids.

Theme 6. Personal reasons influence people's motivation to deprescribe.

Participants reported wanting to cease opioids for various reasons; the stigma associated with being on opioids and the judgement received from some doctors negatively impacts their mental health. *"I mean, I've wanted to get off them as well because I was so sick of the stigma attached to them and like I said and he [the GP] was so painful about it, it made me feel like I was committing a crime every time I went back to get scripts"* (PT07). Some participants said it was just a hassle to continue to see their doctors for repeat prescriptions whilst others mentioned having goals such as to work, socialise more or family reasons (e.g. become pregnant) helped motivate them to deprescribe. Fear of dependence was another main reason for people wanting to deprescribe, with some having already experienced a history of addiction *"I'm obviously quite aware and didn't obviously wanna fall into addiction through an injury which is one of the very common things in people's relapse"*(PT18).

Theme 7. Coping strategies are critical to getting through deprescribing.

Many participants expressed that they would prefer to take a more holistic approach to deprescribing, mentioning a variety of non-pharmacological therapies, such as physiotherapy, massage and hydrotherapy. Some participants find distractions the best way to control their pain, for example playing games, socialising, working or *"manage by trying to modify my behavior and my activity and also with Panadol"* (PT01). Participants also reported using mindfulness techniques, such as positive thinking or repeating affirmations to help manage their pain when avoiding opioids. *"I'd actually say it's probably not my medication, it's actually my psychological side of things, just accepting the pain is there"* (PT18). Participants mentioned other medications such as paracetamol, diazepam, pregabalin and a few mentioned trying medicinal cannabis as they considered these medications as effective as opioids but safer. *"So, the Endone didn't really work that extremely well. The Valium actually, that works much better"* (PT06).

3.2.3. Opioid deprescribing resources for patients

Participants discussed the usefulness of resources to assist them with deprescribing, and emphasised that since each individual has their own way of coping with chronic pain, no single resource would be effective for everyone. We explored a variety of resources from electronic forms such as websites and apps to paper-based or face to face. However, participants expressed that whatever the form, resources need to be educational but also simple and engaging.

Theme 8. The use of electronic versus paper-based resources depend upon individual preferences and circumstances.

Most participants said they find information about their medications by 'googling', however, they expressed difficulty in knowing where to find reputable information. Some participants used 'apps' to help manage their pain which keeps track of their pain patterns and provides advice on alternatives to opioids. Telehealth was also mentioned as a valuable resource for people in remote locations to access advice from their doctors. *"I've looked at some forums, I've looked at medical websites for contraindication of drugs, and things like that 'cause I'd like to be as well-informed as I can ..."* (PT08).

Whilst most participants preferred to use electronic resources and would not refer to a hand-out or pamphlet, some participants said they cannot always access the internet, in which case paper-based resources were beneficial. *"So, he did give me like a medical printout. I don't know where it came from, but it was just an outline of what [Oxycodone] is... I found that really informative"* (PT19).

Participants stated that resources need to be easy to access with content that is simple, positive and provides practical advice on various non-opioid options to manage their pain. In contrast, participants found that some resources can be dismissive of people's pain or provide unrealistic advice, such as certain exercises which are inaccessible for

people in severe pain. *"When you are in a lot of pain and people say, 'Let's just try a bit of yoga, try some acupuncture,' you just wanna punch them in the face because the thing is if you haven't experienced chronic severe pain, you have no idea how it feels. You have absolutely no idea. So you have to be careful of that as well"* (PT06). Generally, most participants preferred seeking advice from their doctor and said they feel the need for more educational resources to be provided and explained by doctors and pharmacists to help them know what to expect during deprescribing. *"And they're very long, very detailed...and, obviously, something like that would put most people off because they wouldn't bother to read it. But it's something very to the point and simple, pointing out the dangers, the side effects ..."* (PT01).

Theme 9. Finding the right support groups can foster resilience in people with chronic pain trying to deprescribe.

Participants expressed that chronic pain can be an isolating condition so felt a need to be connected with others, particularly if they lacked support from their family, friends or doctors. However, most participants said that support groups such as social media platforms can be opinionated, negative and do not offer solutions. Conversely, aspects of support groups that some participants found useful included the opportunity to go out and socialise and *"... and often talking about it with somebody else...learning from other people that also have the experience ..."* (PT18).

Several participants reported that attending pain management courses through pain clinics taught them various ways to manage their pain, such as mindfulness. *"So, there is, a course that the hospital is running on pain management, trying to help you to cope in different ways, trying to get you exercise more with tai chi, walking ..."* (PT012). However, whilst most found these courses were helpful, some said they still felt at risk of relapse when the program ended.

4. Discussion

Our results identified several barriers, facilitators and resources associated with opioid deprescribing by people with chronic non-cancer pain. The perception that challenges of deprescribing outweigh the benefits of being on opioids, a lack of support and limited access to treatment alternatives present barriers to cease opioids. Being supported, personal motivations, being educated on opioid harms and having coping strategies for pain were identified as facilitators to deprescribing. Additionally, our study uncovered perspectives on resources to assist with deprescribing; people prefer electronic resources over paper-based and need resources to be simple and incorporate a patient-centered approach.

Our findings suggest that opioid deprescribing is a unique experience to every individual. Some participants from our study were unwilling to deprescribe when they were functioning well while taking opioids and feared their pain would increase and interfere with their daily life. Similarly, a US study²⁷ reported that opioids enable people improved function and quality of life, without signs of misuse. However, the same view is not shared by all, as other participants from our study said that opioids interfered with their ability to function more than the pain. These contrasting responses highlights that deprescribing needs to be personalised to address the perceived benefit versus harm ratio in individuals. Similar to our study, another US study²⁸ found that concern of the side effects of opioids motivated patients to deprescribe. These personal motivating factors can be incorporated with other strategies such as ensuring regular appointments for ongoing support, goal setting and informing patients that people with chronic non-cancer pain often experience improvements in pain levels and function after deprescribing.¹³

Chronic non-cancer pain and dependence on opioid analgesics often coexist, making it difficult to treat the underlying cause of common symptoms, such as inability to function, anxiety or depression.^{27,29,30} For example, some participants from our study voluntarily shared a history of mental health issues, trauma or substance use disorder which

originated from having chronic pain, but then contributed to opioid dependence or addiction. Therefore, clinicians should consider assisting their patients who are deprescribing in accessing psychological support and addiction specialists as recommended by opioid guidelines.³¹ In contrast, some participants from our study, and those from US and UK, identified a reason to deprescribe was the fear of potential addiction.^{27,29,32,33} This finding highlights the importance of clinicians in providing alternative pain relief while also knowing how to recognize and manage the differences between dependence, tolerance and addiction through the use of individualized tapering regimes with the patient and their family.

Many participants from our study, as well as others conducted in different Australian^{18,21,34} and Canadian²⁷ populations perceived they had been insufficiently informed, supported or not involved in shared decision making with their doctors. Additionally, some participants felt stigmatised and judged by their doctors, family or friends. The issue of stigma surrounding opioid use has also been raised in US and UK studies,^{27,35,36} however, although some people reported that stigma negatively influences their mental health, confidence and social life, some expressed that stigma was a motivating factor for them to deprescribe. In contrast, participants from our study who expressed having a trusting relationship with their doctors articulated improvements in pain management when they felt supported and empowered during the deprescribing process. Therefore, the impact of providing support and education on people's self-efficacy should not be undervalued and are valuable considerations for clinicians when initiating conversations on deprescribing.

Most participants could not recall being offered resources, such as pamphlets or brochures and perceived they lacked support to deprescribe from opioids. Similar to another Australian study,³⁴ we found participants preferred resources to be simple and informative while providing guidance on deprescribing. Our study supported previous findings³⁷ that consumer education, information and support such as decision aids for people with chronic non-cancer pain can lead to improvements in knowledge about chronic pain and how people manage pain. However, previous research has found deprescribing resources often do not meet the health literacy levels of the average patient and therefore fail to inform people of the benefits and harms of deprescribing.²⁰ Therefore, more accessible resources need to be developed to inform people of what is involved in deprescribing and allow shared decision making. Further studies should explore the effects of such educational resources in reducing opioid use in this population.

4.1. Strengths and limitations

A key strength of this study is our robust qualitative design and thematic analysis method which allows a greater in-depth exploration of the perspectives of people with chronic non-cancer pain. Whilst existing research^{19,20} has already captured the perspectives of people who have not yet attempted to deprescribe or while they are deprescribing, our study has added further knowledge by exploring the perspectives of people who have attempted and/or successfully deprescribed from their opioid medications. Our sample of participants included more females than males from higher socioeconomic (SES) areas and major cities. As we were unable to recruit people from vulnerable populations such as Aboriginal and Torres Strait Islanders, or from lower SES or remote locations, we may have missed perspectives of people from specific populations where, in Australia have higher dispensing rates of opioids.²⁴ While concerns with dependence and addiction were raised in our study, we did not focus on how different patterns of opioid use may influence the deprescribing process as this was outside of the scope of our studies aims. We are also aware that the experience of deprescribing may vary greatly depending on the duration of opioid therapy and the pain condition it was treating. Therefore future research which explores more specific patterns of opioid use, including duration may provide additional and valuable information.

5. Conclusion

Most people suffering from chronic non-cancer pain were dissatisfied with being on opioids but struggled to deprescribe due to barriers including; pain reducing their quality of life, not being offered an adequate alternative and a lack of support or information from their doctors in the deprescribing process. Facilitators identified included patient empowerment by improving knowledge of the harms of opioids, improving ongoing support and access to a wide variety of healthcare services and utilizing people's personal motivators could all assist with overcoming the barriers. Perspectives to resources to assist deprescribing highlighted the need for simple, positive and provide practical advice on various non-opioid options to manage pain.

Ethics approval

The Human research ethics committee of the University of Sydney approved the ethical aspects of this study (Project No. 2019/161).

Declaration of competing interest

All authors have no conflicts of interest to declare.

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