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To cite this article: Tessa Parkes, Rebecca Foster, Andrew McAuley, Deborah Steven, Catriona Matheson & Alex Baldacchino (2022): Chronic pain, prescribed opioids and overdose risk: a qualitative exploration of the views of affected individuals and family members, *Drugs: Education, Prevention and Policy*, DOI: [10.1080/09687637.2021.2022100](https://doi.org/10.1080/09687637.2021.2022100)

To link to this article: <https://doi.org/10.1080/09687637.2021.2022100>



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Published online: 17 Jan 2022.



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## Chronic pain, prescribed opioids and overdose risk: a qualitative exploration of the views of affected individuals and family members

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### ABSTRACT

It has been estimated that chronic non cancer pain (CNCP) affects more than 30% of people worldwide. Correspondingly, prescriptions for individuals experiencing CNCP have increased in recent years. While opioids can minimize pain, they also pose a risk of overdose. In 2019 in Scotland, prescription analgesics contributed to, or were implicated in, approximately 19% of drug related deaths. The experiences of those prescribed opioids for CNCP and family members, particularly their perceptions of overdose risk, are under-explored in the literature. This study aimed to address this gap by exploring how individuals and family members perceive the issue of overdose in relation to opioid analgesics, and their views of overdose prevention and potential interventions. Lived experiences from 12 individuals and family members living in Scotland were shared via in-depth qualitative interviews and analysed using NVivo and Framework. Coding was iterative and deductive. Analysis generated five themes: (1) living with pain and experiencing stigma; (2) taking more medication than prescribed; (3) side effects of medication; (4) overdose risk and prevention: the role of prescribers; and (5) attitudes towards naloxone to address overdose risk. Study findings have implications for the development of interventions and broader responses to reduce overdose risk among this group.

### ARTICLE HISTORY

Received 15 September 2021  
Revised 29 November 2021  
Accepted 17 December 2021

### KEYWORDS

Chronic pain; prescription opioids; qualitative research; overdose prevention; naloxone



## Introduction

### *Chronic non-cancer pain, opioids and risks*

It has been estimated that chronic pain, which can be described as a 'common, complex and distressing problem' (Mills et al., 2019, p. 1), affects more than 30% of people worldwide (Cohen et al., 2021). Chronic non-cancer pain (CNCP) is pain that is not caused by any form of malignancy which lasts longer than three months and/or longer than would have been clinically anticipated, for example longer than the length of time usually needed for tissue to heal (Brooks et al., 2015). Common causes of CNCP globally include osteoarthritis, rheumatoid arthritis, low back pain, and fibromyalgia (Brooks et al., 2015; Mills et al., 2019). The experience of pain is a deeply personal and emotive topic for many people living with CNCP, with a high percentage experiencing both physically limiting and mentally challenging effects (Scherrer et al., 2018; Sullivan et al., 2010). Living with CNCP can have a significant emotional impact on an individual's sense of self (Ljungvall et al., 2020). Further, due to the experience of pain and the changes in lifestyle it often prompts, the family and personal relationships of those with CNCP may be altered, sometimes radically (Jamison & Virts, 1990; Payne &

Norfleet, 1986; Snelling, 1994; West et al., 2012). CNCP can also affect cognitive function and memory, and the effects of pain, including depression, anxiety, and impaired sleep, may worsen these (Baker et al., 2016). In terms of wider social impacts, some individuals experiencing CNCP describe encountering profound social stigma from their underlying pain and its associated pharmacological management (Blake et al., 2007; Brooks et al., 2015; Dassieu et al., 2021a, 2021b; Holloway et al., 2007; Vallerand & Nowak, 2009).

There are a wide range of strategies to manage CNCP including pharmacological and non-pharmacological options such as exercise, psychological therapies, and complementary therapies, as well as combinations of these approaches (Scottish Intercollegiate Guidelines Network, 2019). Pharmacological management of CNCP is guided by the World Health Organisation's analgesic ladder developed in 1986 which advises on the use of different types of analgesics, including opioids (see Scottish Intercollegiate Guidelines Network, 2019). However, the benefit of opioids and the use of the WHO's analgesic ladder have come under scrutiny due to suggested omissions and the development of new techniques and medications (Bahji et al., 2020; Ballantyne et al., 2016). It is important to highlight that people experiencing

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CNCP are not a homogenous group and, relatedly, that experiences may be intensified by individual characteristics, including gender (Arman et al., 2020), age (Moore et al., 2014), and culture.

Common side effects of opioids prescribed for CNCP (including slow-release formulations) include sedation, dizziness, nausea, vomiting, constipation, physical dependence, tolerance, and respiratory problems (Benyamin et al., 2008; Faculty of Pain Medicine, 2021; Gregorian et al., 2010). While prescription opioids may improve quality of life and overall functioning for some individuals, they may not completely remove pain (Achkar et al., 2017; De Sola et al., 2020). Challenges with accessing pain clinics, and related unmanaged or poorly controlled pain, increase the risk of overdose (Nielsen et al., 2018). Consequently, CNCP patients often have to strike a difficult balance between benefitting from the positive effects of pain relief/minimisation, and experiencing these unwanted side effects, including risk of harms including opioid overdose (Brooks et al., 2015).

The last two decades have seen considerable increases in the prescription of opioids to help manage CNCP, predominantly in high-income countries (Degenhardt et al., 2019; Mathieson et al., 2020; Neuman et al., 2019). People prescribed opioids for CNCP often have risk factors for overdose, including taking high doses, taking opioid medications alongside other sedative medications, and experiencing co-occurring mental and physical health problems (Higgins et al., 2018; Nielsen et al., 2018). In day-to-day parlance, 'overdose' can have several meanings. In the context of those prescribed opioids for CNCP, an overdose can be entirely accidental, including situations such as an individual forgetting the timing of the last dose, or even if a dose was taken at all. An overdose can also be intentional, with an individual intending to self-harm or even to end life. It can sometimes be difficult to know if overdoses are intentional or not. Occupying a liminal space between accidental and intentional, these have been described as 'ambivalent' overdoses in literature relating to people who use illicit opioids (Conroy & Bjork, 2018). For example, individuals may take more analgesics occasionally to minimize the pain but do so with knowledge of the associated risks.

The notable increase in opioid prescriptions for CNCP globally, with attendant implications including risk of overdose, is frequently characterized as an 'epidemic' (Achkar et al., 2017) or a 'public health crisis' (Rogers et al., 2020). In September 2020, the Medications and Healthcare products Regulatory Agency (MHRA) issued a warning around opioid use, specifically recommending that the risk of unintentional overdose should be communicated to all those taking opioids for pain (Medications & Healthcare products Regulatory Agency, 2020). In Scotland, the number of individuals prescribed opioids for CNCP increased by 66% between 2006 and 2016 (Smith et al., 2018), corresponding with increases found across the UK (Jani et al., 2020). Scotland also has one of the highest rates of fatal opioid overdose in Europe (National Records of Scotland, 2021). These fatal overdoses are mainly taking place amongst individuals with a history of illicit opioid use (such as heroin), and the majority are reported to be unintentional. Prescription analgesics

contributed to, or were implicated in, approximately 19% of these deaths in 2019 (National Records of Scotland, 2021).

Clinically, people who use illicit opioids and people prescribed opioids for CNCP share similarities. Those prescribed opioids for CNCP may overuse prescribed analgesia, some may also be prescribed methadone (a synthetic opioid commonly used to treat opioid dependence), and some may buy illicit heroin and/or methadone (Keane, 2013). 'Extra-medical use' refers to taking an opioid either without a prescription or taking the opioid in a manner that is not directed by a clinician, e.g. by stockpiling medication or taking more than prescribed (Larance et al., 2011). While different individual behaviours will create risks of varying severity (Larance et al., 2011), extra-medical use of prescribed opioids in general is associated with a range of negative outcomes (Wilson et al., 2020). An Australian study found that people prescribed opioids (including for CNCP) with additional substance use problems and multiple morbidities had an increased risk of requesting higher opioid doses, early script renewals, using diverted medication (transfer of any legally prescribed substance from the individual for whom it was intended), stockpiling doses, and altering doses without clinical approval (Peacock et al., 2016). The literature shows that people prescribed opioids (including for CNCP) often have very complex demographic and clinical profiles, with varying experiences of pain, ways of coping, mental health challenges, and substance use, suggesting the necessity of individualized approaches to treatment (Campbell et al., 2015). Moreover, people who use drugs have a significantly higher prevalence of CNCP than the general population (Voon et al., 2018). Consequently, the boundaries between the medical/prescribed and illicit use of opioids cannot be clearly defined (Bailey et al., 2021; Higgins et al., 2021; Keane, 2013). In addition, there is a risk that discourses on pain management that seek to establish the right to pain relief through opioids reinforce the stigma associated with taking illicit opioids. It is important to acknowledge these overlaps, as well as the need for sensitive discussions around the experiences of all of those who use opioids to avoid (re)stigmatizing those who take them (Higgins et al., 2020).

### **Addressing opioid overdose risks – take-home naloxone**

Patient perceptions of overdose risk may shape attitudes towards overdose prevention, including use of take-home naloxone (THN). In use since the 1970s, naloxone removes opioids from the receptors and blocks re-attachment, thereby reversing respiratory depression and hypoxia. With a high safety margin, naloxone is used worldwide for rapid overdose reversal administered either by intra-muscular injection or, increasingly, intra-nasally. These applications facilitate use by members of the public as bystanders (Baker et al., 2020). Formal THN programmes exist in the USA, Canada, Australia, and a number of European countries including the UK, with Scotland's programme among the most established (McDonald et al., 2017). A review of overdose education THN programmes found that, as well as use of naloxone being cost-effective, both opioid users and other bystanders were

generally willing to be trained in naloxone administration (Mueller et al., 2015).

As part of the global response to drugs overdose rates, and expansion of naloxone programs, the role of family members has come into focus as a key bystander group. Training family members in overdose awareness and naloxone administration can be an important element of wider community distribution efforts, given their proximity to people who are at risk and their motivation to hold a kit in their home (Bagley et al., 2015). A recent study has confirmed that family members of people who use opioids are significant in responding to overdoses. In a US study that retrospectively examined survey data collected between 2008 and 2015 when naloxone kits were refilled, family members totalled 27% of program enrollees and were responsible for 20 percent of all rescue attempts. Of the 860 rescue attempts by family members, 173 were rescue attempts of other family members while the remaining 673 rescue attempts were of friends, strangers, partners and clients (Bagley et al., 2018).

Those receiving opioids for pain may not see themselves as being at risk of overdose. As a result, the need or desirability for an intervention such as a THN could be perceived to be irrelevant (Fomiatti et al., 2020). Yet, with some exceptions (Nielsen et al., 2018), there is limited qualitative literature examining risk perceptions for opioid use focused specifically on people with CNCP. Furthermore, literature that takes into account the psychological impact of pain and risk awareness of family members living with someone with CNCP is even sparser.

### **Study aims**

The experiences of those prescribed opioids for CNCP and family members, particularly their perceptions of overdose risk, are under-explored in the literature. This study aimed to explore how individuals and family members perceive the issue of overdose in relation to opioid analgesics, and their views of overdose prevention and potential interventions. Given the public health emergency experienced in Scotland with drug related overdose, our study also specifically explored views on a proposed bespoke intra-nasal THN intervention that could be delivered by community pharmacists in a future study. This study explored views and experiences regarding overdose/risk within this group of individuals, and according to affected family members, given these should inform development of acceptable and feasible interventions to reduce risk. On the basis of this study, a new naloxone intervention was developed, is currently being piloted in a Scottish health board, and will be written up separately when that work concludes. We answer the following research question in this paper: how do individuals prescribed opioids for CNCP, and family members, perceive overdose risk and the need for overdose prevention strategies such as THN?

## **Methods**

### **Ethical review and inclusion criteria**

The University of Stirling NHS, Invasive and Clinical Research committee provided ethical approval for this study (reference

number: 18/19 No.052) which included a quality improvement component that quantified overdose risk for people prescribed strong opioids in one health board in Scotland using general practice prescribing data and has been reported elsewhere (Schofield et al., 2021). Individuals were required to have personal experience of either being prescribed strong opioids for CNCP or being a family member of someone being prescribed strong opioids for this reason. Family members were defined inclusively and included in-law and step-relationships. To be clear, family members recruited were not relations of the individuals but were separately recruited. All individuals and family members were required to be adults (over 18 years old) and could be resident anywhere in Scotland. The definition of strong opioids was guided by members of the team with clinical expertise (DS, CM, AB) and by the British National Formulary (National Institute for Health & Care Excellence, 2020). The following were included for the purposes of the study: buprenorphine, diamorphine, fentanyl, hydrocodone, hydromorphone, meperidine, morphine, oxycodone, pethidine, tapentadol and tramadol. In order to be eligible as an individual and/or family member, oral (tablet) tramadol doses needed to be at least 400 mg per day, and buprenorphine patches 20 mcg/hr. The prescription was required to be for one (or more) of these opioids and, where relevant, for the specified dose. The prescription for strong opioids could be for either current or previous use, and for any condition, illness or disease that was causing the CNCP (none were specified and no exclusion criteria for these were applied). If individuals/family members of individuals were prescribed opioids previously, the criterion was that this was no longer than five years ago to help ensure recent experiences of such prescribing.

### **Recruitment and informed consent**

Participants were purposively sampled. Recruitment for individual and family member participants was advertised via mailing lists and social media accounts of national non-governmental and research organisations and centres. Members of the team also shared information about the study amongst their own professional networks. Participants were invited to take part via email. All received the Participant Information Sheet detailing what involvement would entail. A researcher (author RF) reviewed this with all participants and answered any questions participants had before consent was obtained. No participants were known to the researcher prior to interview. All interviews were conducted by researcher RF using a short semi-structured topic guide, with very minor adaptations to suit each group (see Appendix 1). Interviews took place either face-to-face (on the university campus or in a community centre) or via telephone.

Interviews were approximately 45–60 minutes in duration. All were recorded using an audio-recorder only and no contemporaneous field-notes were made. All recordings were transcribed verbatim by a university approved transcriber. Participants received a £20 shopping voucher upon completion to thank them for their time and contribution to the study. If participants completed a face-to-face interview, they

also received refreshments (if they wished), and were reimbursed for any travel expenses incurred. All were invited to take part in a follow-up interview that was focused specifically on views towards the proposed intervention developed by the team using participant feedback. Data from these interviews are not presented here given the different aim and focus. No participants withdrew from the study. Interviews were conducted between October 2019 and February 2020. This recruitment window related to the limited timescales of the study funding period.

While participants were not invited to provide feedback on the findings (excluding the opportunity to take part in a follow-up interview detailed above), this article has been reviewed by an individual with lived experience of prescription opioid use to help ensure that we have been sensitive when representing our participants' personal experiences. This individual, alongside another with lived experience as a family member, contributed to the study and drew from these personal experiences to do so. These individuals were financially remunerated for their time and contributions, in line with best practice guidance (Hayes et al., 2012).

## Analysis

A researcher (TB) uploaded transcripts to qualitative data analysis software package NVivo (Version 12) and analysed these thematically using the Framework approach (Ritchie et al., 2013), an analytical approach commonly used in qualitative health research to systematically analysis qualitative data, typically semi-structured interview transcripts (Gale et al., 2013). TB read the transcripts in full, coded them line by line and developed a coding framework after coding an initial selection of two transcripts, chosen for the richness and variety of data in participants' responses. These codes were then applied to the remainder of the data. Coding was both iterative and deductive, with initial themes developing both from the data (in-vivo) and through the research questions. TB undertook the coding with support from RF who reviewed the codes and framework on an ongoing basis. This article presents the findings from the analysis of the 12 interviews. All interviews were analysed using the same coding framework, and findings from both individuals with lived experience and family members are presented together due to the shared themes developed from interview accounts.

## Results

### Overview of participants

In total, eight individuals and four (non-related) family members were interviewed. Six men and six women took part. There was a wide range of ages represented. Other demographic details were captured from some participants but, given that not all elected to provide them, they are not detailed here. Individuals and family members were treated as discrete groups for the purposes of the study inclusion and were assumed to have distinct experiences and views. However, much less defined demarcations emerged as the interviews were underway, echoing some of the overlaps

identified in the literature. For example, some individuals who were prescribed opioids for CNCP were also affected by another family member's prescription. Furthermore, two participants shared histories of problems with illicit drugs (including opioids), prior to being prescribed opioids for pain. Therefore, while categories are applied (including to share illustrative quotations), the varied and overlapping identities and experiences of the interviewees need to be noted.

Analysis generated five themes: (1) living with pain and experiencing stigma; (2) taking more medication than prescribed; (3) side effects of medication; (4) overdose risk and prevention: the role of prescribers; and (5) attitudes towards naloxone to address overdose risk. It should also be noted that, while the themes discussed in this paper relate most generally to individual and family member perceptions of pain medication, as well as overdose risk, we use the framing of overdose risk because we were explicitly undertaking this work to explore, and where necessary then address, overdose risks for people with CNCP via development of a new intervention.

### Living with pain and experiencing stigma

While the focus of this paper is sharing individual and family member perceptions of overdose and overdose prevention, it is important to briefly contextualize these responses. Perhaps inexorably, the experience of pain emerged as the foundation of daily life for all those prescribed strong opioids. While the opioids did not always entirely remove the pain, they eased the pain sufficiently to make it manageable. Participants feared a return to much more intense daily pain if they were not able to take their opioids, for example:

*'[...] it's very important to me that that [the medication] doesn't ever get threatened because it's my mental well-being in fact because it gives me a break from the pain.'* (Individual 1, man)

*'My husband was increasingly I guess exhausted by the pain every day [...] He didn't want to be taking opiates, strong opiates, on a daily basis, but the upshot was he was prescribed to take oxycodone [...] twice a week so that for five or six hours twice a week he would have absolutely no pain.'* (Family member 1, woman)

Participants' accounts revealed the severity of their pain and how the medication offered respite. Although the medication rarely entirely removed the pain, or removed it at all times, it made the pain more tolerable. As noted earlier, prescription opioid analgesics carry a social stigma and participants and family members recalled such experiences, for example:

*'One of the things that I know my husband, he kind of jokes about, but he's kind of sensitive about, is that he's on you know 'hillbilly heroin' and you know it's got such a bad name. But for him it's such an important part of his pain management.'* (Family member 1, woman)

*'Sometimes I get a bit anxious because I get a weekly prescription [...]. I suppose I overdosed in the past, it just kind of cuts it [the risk of overdose] down a wee [little] bit [by having access to fewer tablets at any given time], but I've noticed if I go in and say 'I've got a weekly for me', then there is people that look at me funny and kind of "why is she getting a weekly, what does that mean?"'* (Individual 6, woman)

While the switch to a weekly prescription was intended to be a safeguard against overdose, it resulted in this individual reportedly feeling stigmatized from others who attended the pharmacy because of what she felt this implied about her ability to control use of these medications. Relatedly, a woman shared feelings of shame, and feeling 'degraded' because of her opioid use:

*'I did feel shame in having to take those medications [...] my husband changes [my patch] because I have it on my back, I don't want anybody to see it [...] I do say to him, "have you any idea how degrading this is?" [...] I've only just turned forty, I am having to get my husband to put a patch on my back every three days because I can't manage it myself, and I can't manage without it [...] it does affect how you feel about yourself and your confidence.'* (Individual 5, woman)

Interviewees also described experiencing stigma when interacting with healthcare professionals. For example, one individual described how her pain did not seem to be understood or validated in her encounters with her doctor:

*'Yeah, I do find it quite difficult for doctors to believe you when you are in pain and getting any prescription, or heard, because you talk to them and they just look at you at times as if you are stupid.'* (Individual 2, woman)

This individual shared experiences of being in employment and further education where her pain was not taken seriously which she attributed in part to her attempt to lead a 'normal life' as far as possible: *'even though I look alright, people don't always understand.'* Individuals and family members highlighted the stigma that they felt was attached to opioid medications describing ways that this stigma manifested in various contexts, including when interacting with members of the public, healthcare professionals, and employers. There was also a sense that, while individuals and family members were somewhat worn down by these experiences, they preferred to endure this stigma and continue taking these medications because of the relief they brought.

### **Taking more medication than prescribed**

Due to their belief that opioids would help alleviate the pain, individuals reported occasionally resorting to taking higher doses than prescribed, such as taking a couple of extra doses, or taking the next scheduled dose earlier than advised. They were often aware of the potential negative consequences of doing this, but the desire and need to escape the pain, even momentarily, meant these consequences were ultimately discounted:

*'When I was having really bad days I was taking quite a lot of painkillers. You are supposed to have four to six hourly gaps but I was taking them quite close together. I know you shouldn't, but when you are in pain you just shove the painkillers down your throat.'* (Individual 2, woman)

*'When you've got a medication sitting beside your bed it is very, very, very tempting to take more than you are prescribed [...] you find yourself so overcome with pain that you do think, "another dose won't do me any harm, and it might just take it away just now". So that's when you are at a higher risk of overdose.'* (Individual 5, woman)

Some individuals benefitted from the watchful, caring oversight of family members who tracked their opioid usage, acting to try to prevent them from taking too much:

*'I stay with my dad and my step mum and they are really good at kind of keeping an eye on me because they know how easy it would be for me to go "Oh mum it's sore [sore], I'm just going to go and take painkillers". And sometimes my dad has said "God it wasn't that long ago you took [them]". So it kind of makes me like "Oh yeah, well actually maybe I should hold [off]."'* (Individual 6, woman)

One participant recounted their concerns regarding their family member taking multiple opioid medications at the same time:

*[...] there will be times where I don't know what to do with her, with her pain. I mean there is times where she will phone me up in tears and I can tell how much pain she is in and she doesn't know what to do. And she has taken everything [...] so there will be occasions where she will say "Maybe I should just..." and "I'll be like "Oh my God, you can't take the morphine, fentanyl and tramadol!"'* (Family member 4, woman)

One participant disclosed a previous overdose attempt which was a response to being in severe pain:

*'I did once try and overdose years ago. But yeah, there is definitely a risk of me, it would just be so easy because it's there [...] the first time I did it was just because I was in so much pain and I felt like it would just be so much easier on everyone else if I wasn't here.'* (Individual 6, woman)

As mentioned in the introduction, overdoses can be intentional, unintentional, or sometimes the intention of the person is unclear. These accounts highlight an ambivalent state, as well as the potential overlaps between these descriptions. Importantly, these accounts demonstrate that the decision (or need) to take more medication than prescribed relates to the need for adequate pain relief, rather than due to dependency, as can sometimes be portrayed.

### **Side effects of medication**

Adverse and unwanted side effects from prescribed opioids are common, with all individuals prescribed these drugs in this study mentioning at least one. The most common effects mentioned were sleeplessness and resulting tiredness:

*'Just now on the sort of highest dose that I can have, I can't drive, I can't get out of the house, my sleep is all over the place. I can't really function, I can't get on with anything.'* (Individual 1, man)

Participants who used prescription opioids spoke of their concerns that their medication frequently caused memory impairments, which could potentially lead to exceeding their dose. Several spoke of risk reduction or contingency measures, such as writing down the time they took their medication:

*'I usually have to write them down because my memory is quite bad now with the painkillers [...] I do just kind of keep a wee note or a bit of paper next to my tablets or whatever and I will just write down what time I took them.'* (Individual 6, woman)

When participants spoke about awareness of overdose risk, two dimensions emerged: firstly, awareness of their own body's reactions to a dose that exceeded their unique

physiological tolerance; and secondly, whether they felt that those in similar circumstances to themselves (those prescribed opioids for pain, or family members of those prescribed opioids for pain) were aware that opioids carried a risk. Individuals described the physical symptoms they experienced and recognized these as warning signs that they should not take any more tablets for a period:

*'It's something I've never really talked about. I have been aware that I've been close to it [overdose], not often but when I've been in quite a lot of pain [...] I'm really brain fogged and I'm really struggling and I've had to [take more tablets]. I know when I've had too many painkillers I just think "alright, enough" and I just go to bed. But it's got to the point where I just know I'm not going to die, I've got to just sleep it all off and then just work through what is happening.'* (Individual 2, woman)

*'I get a whirling feeling in my chest [...] but that may only be the symptom I get, so when I've felt like that I would move around and distract myself. If you keep yourself really busy and try and fight through it then you do eventually get through it. But I don't know if that would be the same for everybody.'* (Individual 5, woman)

### **Overdose risk and prevention: the role of prescribers**

Attitudes towards GP prescribers varied widely across the study participants. Some described their GP as a long-term ally with whom they had a good relationship, while others were frustrated because they did not feel that their GP or GP practice considered their pain to be a serious issue, as also mentioned earlier. Some participants felt that GP services should play a greater role in educating patients about the dangers of opioids, including potential dependency:

*'My best educated guess would be that the doctor or the GP that prescribed those opioid based drugs would not have sat down [to discuss] at length to, you know, the realities of how addictive they are.'* (Family member 3, man)

There was consensus among those prescribed that they were waiting for appointments for their pain management for too long. There was recognition that services were persistently understaffed, and there was frustration that they were lacking consistency in their care. For example, they were typically required to attend different pain clinics each time for appointments. One individual described being left on medication for a long period without attempts to reduce doses, or manage the situation differently:

*'I got referred years ago but there has been nothing since, so it's just kind of been like coasting. Even when I go to (the) pain clinic they are like "Oh it's fine, they seem to be working so we will just leave it". Rather than saying "Okay, what about if we try and reduce it a wee bit?"'* (Individual 6, woman)

However, there was also acknowledgement that this was complex precisely because of the need to find a solution to the pain:

*'People don't like to challenge doctors, especially if they are getting what they want, so you know if a doctor is saying to you "This is going to help you, this is going to take the pain away", people are going to take it.'* (Family member 2, man)

In summary, participants revealed different relationships with the GPs who were responsible for prescribing these

medications. Some seemed to express a sense of a 'missed opportunity' to discuss the risks of the medication at the point of prescribing. Further, while interviewees were understanding of resource issues, these manifested in experiencing unduly lengthy waits to attend the pain clinic, or the need to attend different clinics and therefore be denied consistent care. This may also constitute a missed opportunity to educate on overdose risk and support those who are able/willing to adjust their medication or explore non-pharmacological options, as one interviewee recounted. Equally, there was recognition that there could be an understandable reluctance on the behalf of patients for treatment plans to be adjusted, linking to earlier discussion on the importance of effective pain management and being in control of the pain experience.

### **Attitudes towards naloxone to address overdose risk**

Individuals and family members responded very positively to the idea of a bespoke naloxone-based intervention:

*'Better to have it and not need it than need it and not have it. So as long as it was safe to use, and it wasn't a huge risk, and the kind of dose that you were getting. My view would be it's better to have it around than not.'* (Individual 1, man)

*'From like a family member's perspective, I would find it reassuring [...] I'd quite like to have it there just in case.'* (Family member 1, woman)

However, as these quotations indicate, individuals and family members' positivity about the proposed intervention was frequently paired with a very low expectation of actually needing to use the naloxone. Most saw it as being there for reassurance, and as a 'just in case' measure: *'because it's better to be safe isn't it, than sorry, I suppose'* (Individual 8, woman). This indicates that, although they perceived themselves to be aware of the dangers of using strong opioids, many still felt that an overdose incident would be unlikely to happen to them or their family members. This seemed to be attributed to their ability to effectively manage the risk. Some interviewees expressed concerns about use of naloxone that are also important to highlight. For example, one expressed that, because naloxone reverses the effects of the opioid, it would restore the pain:

*'If this takes away the effects of the opioid that means that you are in your pain again? Is that correct? I know that the risks are, you know, it could be saving your life, are you going to be sore for the next four hours?'* (Individual 1, man)

There were also examples of participants being concerned that they would 'forget' their training on administration if the situation arose when they were required to use naloxone. This may suggest that they perceived the need to use naloxone in future as an unlikely prospect: training is only likely to be forgotten if it not utilized sufficiently frequently. Again, this may illustrate a potential lack of understanding of the risks associated with prescribed opioids. It may also reveal an anxiety concerning role adequacy regarding their ability to respond correctly if needed, or the ability of others in similar situations. For example: *'Would people be confident and*

competent to administer it to a family member?' (Family member 2, man).

## Discussion

This article has drawn attention to the under-explored day-to-day experiences of those prescribed opioids for CNCP, and affected family members, and offers unique insights into how they perceive the risk presented by opioid analgesics. Five themes were generated from the analysis: (1) living with pain and experiencing stigma; (2) taking more medication than prescribed; (3) side effects of medication; (4) overdose risk and prevention: the role of prescribers; and (5) attitudes towards naloxone to address overdose risk. These contribute to an under-explored area concerning overdose risk for people prescribed opioids for CNCP and acceptable interventions for this group.

The experience of CNCP often made everyday life difficult. Those interviewed reported experiencing or witnessing unwanted and negative side effects from their pain medication, yet this was outweighed by the benefits of pain relief, even if this relief was temporary. The stigma of pain and its associated management through opioid medication emerged strongly in the interviews, and echoes experiences reported in previous studies. The stigma experienced by these patients could be considered to be complex and layered. For example, the invisibility of the pain, and lack of a definitive cause in some cases, can cause individuals to feel as if, and be treated as though, they are imagining it (Dassieu et al., 2021a, 2021b; Holloway et al., 2007; Toye et al., 2013, 2017). Similarly, individuals can feel guilt, shame and responsibility for their pain and internalize this (Slade et al., 2009). As demonstrated in this study's accounts, and mirrored in other literature, individuals experience stigma from different sources including individuals, groups and organisations, friends and family, colleagues and healthcare professionals (Upshur et al., 2010). While this study is not unique in identifying the stigma associated with CNCP and opioid pain medications, it is important not to overlook this, particularly given the potential ramifications for receiving healthcare as well as wider informal and formal social supports. The data presented indicates that individuals would rather endure stigma than give up the analgesia.

The stigma experienced from interactions with healthcare professionals and services has both direct and indirect effects on the quality of care for patients experiencing CNCP (Buchman et al., 2016). Some medical professionals may be less likely to discuss patient concerns or risk of overdose when opioid use is seen as 'legitimate'. This may result in people experiencing CNCP having poor or inadequate understanding of their overdose risk. Indeed, patients have reported not recalling any discussion with their clinician or healthcare professional regarding overdose risk, sometimes because they note that the discussion never happened, but also because the topic was introduced at medication onset but never revisited (Mueller et al., 2017). Some clinicians fear that discussion of overdose will negatively affect the doctor-patient relationship (Binswanger et al., 2015), while patients

may fear being seen as experiencing dependency or addiction if they raise the topic in consultation (Nicolaidis, 2011). Clinicians do recognize the potential benefits of overdose education and naloxone provision, but reservations and barriers persist (Binswanger et al., 2015). Similarly, among pharmacists who are responsible for dispensing these prescriptions, barriers to initiating these conversations include a lack of training around these risks, and concern about potential negative reactions from patients (Alvin et al., 2020).

While this is a highly complex landscape, some authors such as Dassieu et al. (2021a) have argued that conversations about opioids and the risks they present must take place during clinical encounters. When developing approaches to reduce risk and prevent overdose among individuals experiencing CNCP who are prescribed opioids it is therefore essential that responses are fully cognisant of the challenge of living with pain on a daily basis. Any approach must also take account of the side effects of analgesia highlighted in our study findings, and how these shape perceptions of risk. This means allocating sufficient time for these conversations within clinical encounters. There is also a lack of clinical consensus on whether naloxone should be provided as a matter of course to patients experiencing CNCP, or if it should be targeted to those at greater risk (Binswanger et al., 2015). This study did not explore prescriber views, but there was certainly a willingness among interviewees to improve their safety. The positive relationships some had with their prescribers indicates a useful starting point for these conversations.

In response to increasing concern about the opioid 'epidemic' in North America, measures have been taken to de-prescribe or reduce opioid doses (Dowell et al., 2016) which have had some unintended and unwelcome consequences, including increased barriers to accessing general practitioners (Slat et al., 2021; Lagisettey et al., 2019), and increase in the use of illicit opioids (e.g. Meadowcroft & Whitacre, 2021). In addition, these developments, coupled with intensive media coverage of this 'epidemic', have intensified the stigma of both prescribed opioids and those who take them to manage pain (Antoniou et al., 2019; Dassieu et al., 2021a, 2021b; Webster et al., 2020). Individuals may, therefore, be less willing to access support relating to overdose prevention if they feel they are going to be stigmatized in the process, whether that is in their direct interactions with prescribers/dispensers, or with others accessing a service (for example, those attending a pharmacy at the same time). This trend is also observed among those who take illicit opioids (Bennett et al., 2020; Heavey et al., 2018), and relates to the importance of patients having positive relationships with healthcare providers and specifically those prescribing (GPs) and dispensing (pharmacists). Interviewees in this study had mixed relationships with their GP prescribers and often wished to have additional support with and guidance regarding their medication, including the opportunity to discuss options such as tapering doses.

The participants in this study reported engaging in, or observing, practices and behaviours which are associated with overdose risk. For example, they described taking more



tablets than prescribed, and taking doses closer together than advised. Some of the side effects from these medications made these practices more likely, such as the effects on memory and sleep. We note the tension between these reported high risk behaviours and participant perspectives that they were not at risk of overdose. We have reported this dilemma because it was a central feature of our analysis, despite the inherent contradictions raised. Reflecting on this tension, it might be because participants had had few opportunities to reflect on their use of strong opioids, high risk behaviours and overdose risk, prior to the research interview. This connects to our points above regarding the importance of such conversations being prioritised between prescribers and those prescribed these medications. It might be because overdose and risk of death are events that individuals will naturally think are unlikely to happen to them personally, or their family members. Comprehending risks as real and present, and connected to one's daily behaviour, is something that tends to be challenging for most people, particularly given how difficult it might be to get support for genuine risk planning and related conversations with loved ones or health professionals. Overdose awareness training and related interventions can help identify risks and related behaviour change in a supportive way.

On the whole, individuals and family members demonstrated fairly high degrees of overdose awareness risk, although this did vary. Individuals were attuned to their own signs of overdose, or signs that overdose could be close, and family members were also aware of these. Interviewees were aware of overdose risk in general terms, understanding that these prescriptions posed an overdose risk to all those taking opioid medications. This was in contrast to Nielsen et al.'s Australian study (2018) which found relatively low awareness of overdose symptoms. Our study, despite having small numbers of family members (four), builds on previous work by Bagley et al. (2015, 2018) on the importance of raising awareness of overdose risk with family members, given the potential that they represent in terms of overdose reversal if trained in and supplied with naloxone.

All those interviewed in our study were positive about the proposed bespoke overdose prevention intervention and demonstrated an appetite to either receive the intervention or administer the naloxone, echoing other research which found a willingness to be trained in naloxone use (Mueller et al., 2015). Naloxone was generally perceived as a useful 'just in case' measure, and an additional safety precaution. This may suggest that there was a lack of understanding about the 'true' risks of overdose among this group, with overdose perceived to be a somewhat distant prospect, a finding which corresponds with work by Fomiatti et al. (2020) on addiction related stigma and naloxone use. There are some similarities here with work on people at risk of overdose due to use of illicit opioids. For example, within Heavey et al.'s (2018) qualitative study, while individuals using inpatient services at a substance use treatment centre demonstrated high levels of awareness of naloxone, there was a range of attitudes towards it and a tendency not to routinely carry it on one's person. While some perceived naloxone to be as important as using a clean needle, others accessed it

more opportunistically; if available, they would carry it, but not seek it out. Heavey et al. (2018) suggest that naloxone may be valued more by those who have witnessed an overdose, and this in turn may influence behaviours around carrying it. More recent qualitative research has highlighted high levels of awareness of naloxone and willingness to use it but again exposed barriers to carriage/use, including fear of legal ramifications, concern about disrupting another's euphoric experience ('high') (Lai et al., 2021), and scepticism regarding the effectiveness of naloxone when compared with traditional strategies or 'folk remedies' for overdose (Bowles & Lanckenau, 2019). This concurs with systematic review evidence which has identified persistently low carriage rates among those who inject drugs (Burton et al., 2021; McAuley et al., 2016). Despite these barriers, THN remains a highly important tool in overdose prevention (McAuley et al., 2019). Awareness of challenges relating to naloxone carriage among those prescribed illicit opioids is relevant to overdose prevention for people prescribed opioids for CNCP.

While naloxone is a life-saving measure, there was concern amongst our study participants that administering naloxone could take pain relief away, and reassurances were sought that this would not be the case. This echoes the reservations amongst those who use illicit opioids who have expressed concern that naloxone can precipitate withdrawal, or indeed have these concerns realized and have shared personal experiences of withdrawal following receipt of naloxone (Bennett et al., 2020; Heavey et al., 2018; Neale & Strang, 2015). This highlights the importance of providing comprehensive information alongside the provision of naloxone, tailored to the particular needs of patients experiencing CNCP whose experience of pain is likely to have been debilitating, and where the medication is perceived to offer some respite. Some of those interviewed expressed feelings of doubt about their ability to respond effectively should naloxone need to be administered. Concerns surrounding role adequacy have also been found in qualitative work among those taking illicit opioids (McAuley et al., 2018) demonstrating the importance of comprehensive training (including the possibility of 'refresher' training), but confidence may also be gained from becoming more experienced in administering naloxone, as McAuley et al. (2018) argue.

The need for detailed yet accessible information may be particularly necessary for those prescribed opioids for chronic pain, where lower levels of health literacy (the ability to access, comprehend and respond to health information) are associated with problems with opioid compliance (Rogers et al., 2020). Moreover, the challenges of living with CNCP are likely to have been amplified in myriad ways by the global COVID-19 pandemic, including having reduced access to pain clinics, through the exacerbation of social isolation and loneliness, and due to existing health inequalities (Karas et al., 2020). These factors may increase overdose risk. Nonetheless, following Nielsen et al.'s cautionary approach, it is important that a balance is struck when improving the safety of people who are prescribed for to ensure that they feel empowered rather than inappropriately concerned about their medication (Nielsen et al., 2018). Our study has highlighted the complex and sometimes conflicting feelings that

individuals and, albeit to a lesser extent, their family members, have towards their opioid medications. People experiencing CNCP have distinct needs which require tailored responses that take account of such complex and conflicting emotions.

This paper addresses a significant gap in the literature by presenting the perspectives of people prescribed opioids for CNCP and affected families on overdose risk. We present rich detail of their concerns, alongside their views on targeted overdose prevention strategies including THN. The study has some limitations. Firstly, our sample size was small. Timescales were strict as this was one small component of a larger study that was seeking to quantify overdose risk in this group (see linked paper Schofield et al., 2021) and develop a bespoke naloxone intervention to be piloted in a next stage study. The work was funded using a research development bursary from an NHS health board designed to support staff to undertake quality improvement projects. The resource did not allow a larger sample. In addition, we believe that the stigma associated with prescription opioids meant affected individuals and family members were difficult to recruit and remained quite hidden, despite our efforts. The interviewees were also self-selecting: it is possible that the individuals and family members involved may have higher levels of overdose awareness than others and, as such, may have been drawn to participate in the research. It may also have been the case that participants minimised concerns regarding dependency, given the formality of the interview setting. In addition, there would have been value in including healthcare provider views in this study. The original intention was to include a sample of community pharmacists to explore their views on overdose risk amongst people prescribed opioids for CNCP, in addition to individuals with CNCP and affected family members. Unfortunately, considerable difficulties were experienced in recruiting community pharmacists to the study and, due to limited study funding and time, professional views were not able to be included in this paper.

## Conclusion

This article has shed light on the day-to-day experiences of those prescribed opioids for CNCP, as well as family members of those prescribed opioids for CNCP. It offers a unique contribution to literature in sharing how individuals and family members conceptualize experiences of being prescribed opioid medications and the risk of overdose. Analysis generated five themes: (1) living with pain and experiencing stigma; (2) taking more medication than prescribed; (3) side effects of medication; (4) overdose risk and prevention: the role of prescribers; and (5) attitudes towards naloxone to address overdose risk. Study findings have implications for the development of interventions and broader responses to reduce overdose risk among this group. It is essential that lived experiences, such as those illustrated in this study, are fully considered when developing responses to the prevention of opioid overdose and mortality. More broadly, it is essential that these are considered to address the pressing,

global public health issue presented by the high rates of prescription of opioids for those living with chronic pain.

## Acknowledgements

We would like to thank all participants for taking part in the study, and for sharing their views and experiences so openly. We would like to acknowledge Tania Browne for her work on the coding of interviews and initial write up of these data, and for preparing some literature for the background section of this paper. We would also like to thank Wez Steele who inputted into the study throughout, drawing on his own experience of pain medication, and provided a helpful review of this paper, and Dr Catriona Connell who also helped to improve this manuscript. Finally, we would like to acknowledge the anonymous reviewers who helped to improve this manuscript via peer review.

## Disclosure statement

Professor Catriona Matheson has received personal fees and non-financial support from Indivior, and personal fees from Camurus, outside of this submitted work

## Data availability

The data set that informed this paper is not available for wider sharing because participants did not provide their approval for this.

## Geolocation

This study took place in Scotland, UK.

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## Appendix 1

### *Individuals and family members' topic guide*

Introduction/key terms for clarity and consistency

Definition of strong opioid for the purposes of the qualitative aspect of the study/inclusion criteria

Buprenorphine, diamorphine, fentanyl, hydrocodone, hydromorphone, meperidine, morphine, oxycodone, pethidine, tapentadol and tramadol. Oral (tablet) tramadol doses need to be at least 400 mg per day, and buprenorphine patches must be 20 mcg/hr – they are considered to be weak opioids below this strength.

Note on potential differences in practice/American usage: hydromorphone and meperidine used in US. Intervention package:

1. A protocol for pharmacists for who and when to provide the intervention package.
2. Take Home Intra-nasal naloxone product (Nyxoid).
3. Participant information sheet on the risk factors for opioid overdose such as co-use of other drugs.
4. Participant information sheet on the signs of opioid overdose and response actions.
5. Pharmacy training pack with all the information participants will require including answers to frequently asked questions.
6. Checklist to assist the pharmacy staff in ensuring correct information has been provided to patients receiving the pack and also ensuring consistency of delivery of pack.

Package to be informed by findings from these interviews, as well as the national Take Home Naloxone programme (existing good practice with this kind of intervention). Aim = reduce harm and improve patient safety.

### **Guide – adapted to suit individuals/family members**

- Start – a bit about your experiences of being prescribed opioids for pain (as much as feel comfortable sharing), or being a family member of someone prescribed opioids for pain. Prompts: how long for, type of painkiller(s), condition, general experiences and views towards medication.
- Does issue overdose resonate with you? Why/why not? In what way?
- What do you see as being the issues to consider here/things to think about?
- What would you like to see done about overdose, if anything?
- Initial thoughts on intervention (after setting out key features)
- Intervention – identifying aims, hopes, barriers, challenges
- Suggestions for intervention?
- Anything that we have missed and that we should be thinking about when it comes to responding to overdose with people prescribed opioids for pain?