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PLEASE DO NOT REMOVE THIS PAGE
Moving from chaos to hope: key factors influencing the narratives of people taking opioids for chronic non-cancer pain

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Zhen Zheng is a chief investigator of a NHMRC funded clinical trial investigating the role of acupuncture in reducing opioid medication consumption by patients with chronic non-cancer pain. The current qualitative study is nested in the trial. Zhen Zheng also receives financial support from the Helen MacPherson Smith Trust for the current study and from NHMRC for one other acupuncture trial for headache.

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Moving from chaos to hope: key factors influencing the narratives of people taking opioids for chronic non-cancer pain

ABSTRACT

Aims

To investigate the progression of the illness and opioid journeys of people who are taking opioids for chronic non-cancer pain.

Methods

In depth qualitative interviews were conducted with 20 people who were taking opioids for non-cancer pain. A purposive sample was drawn from patients attending two pain clinics in Melbourne, Australia. Transcripts were analysed within-case, as individual narratives, and across-case, as a thematic analysis. Conceptual explanatory variables were developed.

Results

The experience of taking opioids for chronic non-cancer pain varies greatly between individuals and these diverse narratives—chaos, restitution and quest narratives—raise questions about why and how some individuals find a way forward, whilst others remain in situations of chaotic and worsening ill health. We offer an explanation for this variability in terms of four key influences: support from individual health professionals and the health system; medical explanation or solutions; social support and social responsibilities; and the use of non-pharmaceutical interventions and self-help strategies. A unifying theme was the importance of maintaining hope.

Conclusion

The four key factors influencing the progress of people taking opioids for chronic non-cancer pain are rooted in the provisions made by society for caring for this patient group and involve relationships between patient and provider, between patients and their social world, and between different providers and their professional knowledge. In our patient sample, effective support involved the provision and maintenance of hope, and professionals who are knowledgeable about opioids and chronic pain, good communicators, and cognisant with their patients’ social support and responsibilities.

Key words:
opioids, chronic pain, qualitative research, patients’ experience, support, hope

50 words summary

This paper describes a qualitative study in which patients taking opioid medications for chronic non-cancer pain were interviewed for their experience of using these medications. We identified three patterns of experience and illustrated the importance of support, hope and access to specialist and complementary services.
INTRODUCTION

The use of opioid medications in the treatment of chronic non-cancer pain is increasing worldwide.\(^{(1)}\) For example in South Australia the number of patients on extended opioid treatment for chronic pain has increased about 10 fold over 15 years.\(^{(2)}\) The data are consistent with the results released by the International Narcotic Control Board. From 1980 to 2005, the use of morphine has increased by eight times and Oxycodone by 20 times in Australia\(^{(3)}\) and increased by 40 and 20 times in the United States in America, respectively.\(^{(4)}\) Surveys examining clinicians’ views about this treatment modality mainly focus on fears of opioid over-use or diversion\(^{(5)}\) and this approach is mirrored in clinical guidelines. For example guidelines from the Royal Australasian College of Physicians state that two of the goals are to standardise “regulatory strategies”, to reduce opioid dependence and to reduce “the diversion of pharmaceutical opioids on to the black market.”\(^{(6)}\) In depth qualitative studies of primary care providers, however, suggest a more complex range of concerns that include not only those of addiction and misuse but also patient resistance to taking opioids, potential harm from adverse effects (especially in the elderly) and inadequate training of providers.\(^{(7)}\) In-depth studies of the patients’ perspectives are rare, and mainly focus on those who experience good relief with opioid medications.\(^{(6-10)}\) Their findings suggest that patients’ concerns and experiences differ somewhat from those of health professionals. Patients focus on their experiences of balancing the perceived benefits of less severe pain and better functioning against the associated stigma, medication side effects and difficulties of maintaining access to the regime.\(^{(6-10)}\) Overall, this diverse literature suggests that taking opioids for chronic non-cancer pain is increasingly common and has the potential for substantial relief of suffering but that it is also fraught with difficulties and dangers. As such it is a fruitful topic for further research into the factors that influence the balance between benefit and harm.

We sought to build on previous qualitative studies by interviewing patients who were attending pain management clinics in Australia with chronic non-cancer pain and by including some people who had expressed interest in reducing their opioid medication. We anticipated that this sample would provide experiences from a range of users including those with a long history of opioid use, those experiencing difficulties with pain management despite specialist input, and those that were stabilising or improving with such input. We aimed to analyse their opioid and illness journeys over time and to elucidate the factors that influenced the progression of these journeys. By this means we hoped to be able to make links between the patient and provider perspectives and produce findings with clinical relevance.

METHODS

In order to gain an in depth understanding of individual patient experiences and perceptions we used qualitative individual interviews.\(^{(11)}\) Ethical approval was obtained from Alfred Health, Melbourne Health and RMIT University and data collection was carried out between July 2010 and February 2011.
Six researchers with a variety of medical and social science experience and perspectives were involved in developing the sampling frame, the interview schedule, and/or the coding categories and the final analysis was discussed with clinicians in the participating pain clinics.

**Setting and sampling strategy.**

The study ran alongside a clinical trial which was investigating the use of electroacupuncture and education to reduce opioid medication by people with chronic non-cancer pain. We drew a purposive sample of people taking opioids for chronic non-cancer pain from three groups: a) patients taking part in the trial, b) patients who had been approached but declined to take part in the trial, and c) patients who had not been approached for the trial. Twenty eight potential study participants were approached by researchers by letter and/or telephone until 20 patients with a range of age, sex and duration of condition had been interviewed. One could not be interviewed for not on opioids any more, two declined because of living too far, two being too busy, and three without providing any reasons. The 20 participants were made up of 13 from group a), one from group b) and six from group c). In this paper, Group a was coded as trial patients; whereas Groups b and c were non-trial patients.

**Data collection**

KL, a researcher with a background in psychology, carried out semi-structured interviews, of 30-80 minutes duration, in people’s homes or, if they preferred, at the clinics, or in an independent research institute. KL was supervised by CP, an experienced qualitative researcher, and a constant comparative approach was used, in which data analysis went side-by-side with data collection, thus enabling later interviews to explore emerging themes. The interview began with an open question asking for some background to their current situation and then used prompts and questions to understand their experiences up to the present day. This included enquiry into their illness and disability, treatments, details of opioid use and life-world context. See Appendix for initial interview schedule. The interviews were audio-recorded and transcribed verbatim.

**Data analysis**

N-Vivo software was used to organise the data. Three researchers developed an inductive coding framework of descriptive themes, resolving differences by discussion and by attending to reflexivity and our own differing perspectives. All the data in all the interviews was then coded and during this process analytic memos were written and discussed and matrices were used to look for relationships between themes and patient characteristics. Negative cases were explored and used to deepen the analysis so that all cases were explained by it.

The accounts were also summarised as individual illness narratives within which the threads of illness and disability interwove over time with the circumstances and effects of prescribed opioid medications and with social roles and responsibilities. Each temporal narrative was depicted diagrammatically as an ‘opioid journey’ that took place alongside the individual ‘illness journey’ (see Figures 1,2,3 for examples). These temporal narratives demonstrated considerable diversity and we characterised the diversity by identifying a range of narrative categories or genres. Gergen & Gergen (1983) suggest that narratives may be classified into three fundamental or core types: stability narratives, progressive narratives and regressive narratives, whereas others use genres that are culturally available and familiar, such as tragedy, epic quest, romance and comedy. However,
we found the categories that best suited our data were those used by Frank (1995): chaos, restitution and quest. Chaos narratives are those where the individual imagines she or he will never get better. Restitution narratives are those that involve the expectation that the sufferer will become healthy again. Quest narratives are those that involve self-transformation and the offering of help to themselves and others through illness. These basic types become linked in various ways to make more complex accounts that span many years of experience.

In this study the process of categorising the narratives in these ways generated second-order constructs that were compared with the themes from the thematic analysis. As the analysis continued, we considered how these themes and constructs helped us to explain the diversity of patient narratives—what factors were important in the movement out of chaos into restitution or quest? In this paper we present a brief summary of the range of narrative genres and present in more detail the four explanatory conceptual themes. Details of the participant’s medicine taking behaviour are reported elsewhere.

FINDINGS

The twenty participants are summarised in Table 1: 10 each of men and women, an age range of 29 – 77 years (Mean ± SD: 52 ±12.5) and 19 were white Australian ethnicity and one being African origin. Ten out of 20 participants were treated for low back pain, three for fibromyalgia, two neck pain, two pain after amputation, and one each for hip pain, burn pain and facial pain. Nine of 20 participants had opioid medications for three years or less, five had between three to 10 years and six over 10 years. The types of opioids varied from transdermal patches, slow release types, such as OxyContin, to short acting ones, such as Endone.

Narrative analysis

The opioid journeys described above spanned many years of illness during which the circumstances and effects of prescribed opioid medications interwove with threads of illness and disability and social roles and responsibilities. Over these years some people had experienced periods when they had found some sense of balance, control, and quality of life, whereas others hadn’t. They were all stories in the making, being told at one point in an ongoing journey, but their diversity can be described in terms of three fundamental narrative categories: chaos, restitution and quest. Chaos narratives are those where the individual imagines she or he will never get better and all the narratives were at some point, usually near the beginning, chaos narratives i.e. they were characterised by worsening and chaotic pain and/or opioid related problems and periods of hopelessness. Whilst eight accounts remained overall as chaos throughout their time-span, others moved into a more hopeful restitution narrative – where positive expectation and action led to some stabilisation or reduction of pain and opioid use. We labelled the five accounts that moved from chaos to a more active and stable situation as restitution narratives. The remaining seven narrators indicated a further degree of progression that included a degree of adaptation and successful coping with or without continuing slow improvement in pain control. We labelled these quest narratives as they involved degrees of self-transformation and the offering of help to themselves and others through illness. Most of this group were slowly reducing their opioids or had stabilised on a lower dose and their previous severe side effects were lessened.
Figures 1, 2 and 3 provide an example of each of these genres. In this paper we report our analysis of the factors that influence, for better or worse, the experience of pain and opioid use in the chaos narratives and the complex roles these factors play in promoting the progression into a more stable and hopeful position of restitution or quest.

The analysis indicated that the most influential factors were: support from individual health professionals and the health system; medical explanation or solution; social support and social responsibilities; and the use of non-pharmaceutical interventions and self-help strategies. None of these were a single defining factor in moving forward out of chaos but together they encompass the range of influences and potential interventions that may prove helpful to people taking opioids for chronic pain. There was no evidence that age, sex, or whether or not participants were recruited from the trial had an influence on the illness trajectory. In this section we will start by describing how these narratives of opioid use for chronic pain began and then address each of the key factors that influenced how they proceeded.

Starting opioids

Starting opioids was often an insidious rather than a dramatic event and few participants foresaw the long-term nature of the journey ahead. Eleven participants had their first prescription for opioids from their general practitioner (GP). Generally this was a lower dose preparation such as Panadeine or tramadol but sometimes stronger opioids such as Kapanol, Endone or Oxycontin were prescribed on the basis of advice from a specialist. The decision to start taking low dose opioids was often perceived as routine at the time and some people had taken such medication for short periods in the past.

*I started off on Panadeine Forte like you know you, like normal people I guess would start on just Panadeine Forte and of course that, you know didn’t, started losing you know the - you know started not working, so they went to something stronger [Susan]*

Similarly, Max had first taken Panadeine Forte after a knee operation over ten years ago and ‘was off that in a week’ but when he was prescribed it again after an accident it made him feel sick so he returned to his GP who ‘said we’ll switch over to something else and I think he gave me 5mg ones or something like that of the Oxycontin’.

Sometimes Panadeine was prescribed immediately following an injury or sudden pain but more often it followed on a period of investigation or other medication: “he diagnosed it as fibromyalgia and it was then that he put me on the Kapanol” [Ella]; “They weren’t able to do any more apart from keeping the back moving so hence the medication” [Jack]; “none of it did any good for me and so I finally came down to using a bit of the Oxycontin stuff” [Oliver]. In these instances opioids were again experienced as a natural next step, albeit as an option of last resort in a situation fraught with persistent pain and uncertainty. However, several participants took a more active role and refused to take opioids for many months because of concerns about addiction and adverse effects. This included Rose who resisted taking oxycontin until ‘the pain made up its mind for me’; Anna, who went through two pain...
management courses before the pain clinic doctors persuaded her to take Tramadol and Eve, who was seeing her GP:

> I just didn’t want to go on them because I mean once you get on them that’s it, you’re sort of stuck on them. I didn’t want to take morphine at first because there was a girl that I went through one of the courses with and she always seemed really dopey and drugged up so it took them a long while to talk me into taking the morphine because I didn’t want to be like that [Anna]

“I refused all pain medication for about six months but then the condition got worse and in the end I just, yeah, I couldn’t go without it” [Eve]

A very strong theme throughout Eve’s account was that she had been raised to believe that she should not use medication to control pain. Rose, Anna and Eve all continued to be active in seeking alternatives to opioids and their accounts were categorised as restitution or quest narratives.

The other common scenario for starting opioids was a dramatic hospital admission for trauma or for major surgery. In these instances patients were either very ill or were undergoing major operations such as amputations and were not aware of the details of their medication.

“I was out of it, so I basically woke up two weeks later with a drip of morphine and ketamine in my arm going ‘What’s going on?’” [Lucy]

> The thoracotomy was a big operation, so I was always having - you’re having your - the nurses coming in every hour or whatever to take all your level - readings and that sort of thing and then you’ve got different people coming to see you. You’re having so many things going on that it’s all a bit of a blur and you don’t really get to understand details of the pain medication” [Tom]

Two participants described another dramatic start to taking opioids in the form of repeated pethidine or morphine injections from the accident and emergency department “because I couldn’t take the pain anymore” [William] - both of these were eventually prescribed Panadeine by their GPs.

**Four factors influencing the narratives**

1. **Support from individual health professionals and the health system**

The arena of opioid treatment for chronic pain is inevitably highly medicalised and participants’ accounts indicated that the degree and type of support they received from health professionals, especially their prescribing doctor, were of great importance. The aspects of support that were most valued were a sound knowledge base about opioid medication and pain management; good communication skills; and the maintenance of hope. Many of the accounts described an unmet desire and need for such support. Claire described two very different experiences at the pain management clinic:

> The first guy, he gave me no will. I walked out going “I might as well be dead. I’m never going to…”

> He goes “You’re going to live with this pain for the rest of your life.” And I go “I may as well just go home and kill myself. I’ve got no motivation to do it.” He gave me no positives for living, where
when I come back the next time, I got G. She was wonderful, you know. She says “All right. We may not be able to get rid of it completely. But we should be – hopefully be able to manage it for you a lot better than what it is.” And that’s all I wanted to hear.” [Claire]

Rose also described a variety of experiences with different doctors and viewed her change of GP as ‘the best thing I’ve ever done’ and as instrumental in her success in coming off opioids. She particularly valued good communication and access:

I know I could ring up my doctor and, or email him and ask him a question. So, it wasn’t as if, as if – and the pain clinic, I was happy with them as well. [Rose]

Tom valued his GP’s style of shared decision making in relation to his opioid medication:

He’s, he’s - well, I wouldn’t say he’s enthusiastic, but he’s helpful when - or he’s encouraging to - me to lower the levels when - when pain permits, so he asks me how the pain’s going and then he says do you want to drop down a level and - or I’ll suggest to him, either way, but no, he’s, my GP’s really good.[Tom]

A number of participants found that the pain clinic professionals were particularly helpful and were able to give them time to learn to accept their enduring illness and the need for medication. For these people the pain clinic counteracted previous feelings of isolation by providing a range of therapies and a sense of being ‘the same as someone else’.

Yeah because I went through two courses through here and they’re very good, they explain everything, and I mean they explain how to do meditation and all other sort of things to try and help you as well.” [Anna]

“And so just learning to live with it now sort of, and changing the way you do things and changing life and that was what the pain clinic did. I’m learning on how to bend, walk, accept the condition” [Eve]

Patients also perceived that their GPs felt supported by the clinic and that this could counteract the difficulties faced by patients when their GP’s knowledge base and experience was perceived as lacking.

RA And what about your GP? What’s his opinion of you being on the medication?

Lucy: He’s okay with it as long as he can get the right support to keep the permits up which he wasn’t getting; he wasn’t getting any answers from the [Hospital name]. ........“He’s like “Well, how much do we put you on? What do we do?” He’s had to ring up people and get advice and I can’t believe it but he actually went home one night and did two hours worth of research on the internet and so I’ve got a good doctor. So he knew what he was doing dealing with my burns so he’s been sort of flying blind…. [Lucy]

In contrast to these experiences of good support, many accounts highlighted a lack of medical support in relation to pain management and opioid medication. Lack of knowledge about opioids was described in terms of their GPs ‘being out of their depth’, ‘doesn’t know which way to go’, or ‘completely unaware of pain management’.

The example below illustrates how such comments were usually qualified with appreciation of the
individual doctor’s efforts or with the constraints of the system that they were working in.

Ben: but the GP’s are completely unaware of pain management I think. Um I think that they’re, I think that they’re, I, I shouldn’t have been allowed to have gone for so many years in the state I was, you know and it wasn’t for, for, for shyness, I, they knew about it, I, I wasn’t sitting at home complaining to myself.

RA: Do you feel like there just hasn’t been enough support from your GP?

Ben: Oh it’s not just my GP, the difficulty with the GP’s these days is that it’s very difficult to see a regular GP so the, the, there’s rarely consistency in the medical profession you know, and that’s more so as it becomes more and more um overwhelmed with, with the public you know in [place name] you can wait weeks if you want to see a particular GP and and you know my one that I like I, I will wait upwards of a month to see so ah, so when you’re in pain and you need something more instantly you have a tendency to just take anyone they’ve got, so, and I don’t think there’s a crossover, I don’t think there’s a crossover of information between the various people and the ones that I was seeing certainly weren’t um supportive that way no, no.

Many people felt let down by the organisation of health services for people with chronic pain, especially in relation to waits of up to 12 months after referral to the pain clinic – periods when all else had failed and their pain and medication were poorly controlled

2. Medical explanation or solutions

Many patients perceived their doctors to lack satisfactory explanations for their own individual illness or experience – a phenomenon that often disrupted the doctor-patient relationship and frustrated patient’s attempts to ameliorate symptoms using non-opioid approaches.

“He hasn’t got a clue. He - he didn’t really have a clue how to treat me, because chronic pain is sort of something I don’t think he’s probably ever had before too, had to deal with. Yeah. So, he was pretty useless in that regard. I mean, he tried everything, you know. He sent me to, um, like, heaps of investigations, from X-rays to, you know, MRI or whatever, but, um, bottom line is, who knows what causes the problem, I suppose.” [Andrew]

The data also suggests that patients perceived that doctors were themselves sometimes hampered by the inability of their professional theories and knowledge to provide an explanation and effective treatment. Patients perceived two consequences of this. Firstly, this uncertainty was often seen to be linked with being started on opioids, as described above, and secondly, these doctors often transmitted, or added to, a profound sense of hopelessness.

She (rheumatologist) couldn’t help me any more yeah, she didn’t know what else to do. She said to me; oh go and listen to music, I can’t do anything else for you, go and listen to some music that you like and I’ll refer you to the pain management.[Ella]
“He’s, I think, pretty much at a lost end, he’s quite a young doctor and he’s bounced me to every single person I think he can think of, and he hasn’t had any answers so he just writes scripts. [Max]

All three patients who had been diagnosed as having fibromyalgia – a diagnosis they experienced as unsatisfactory as an explanation or a guide to treatment – had narratives that remained in the chaos category. In addition, several participants described how a sense of hopelessness, coupled with severe pain, led to suicidal ideas or attempts:

I can handle the pain I’m in now. It’s yes – I can handle it. Whereas before, it was just – I, I couldn’t handle it anymore. Um and if I didn’t have kids, I probably would have killed myself knowing that – you know, this is the second spinal surgery I’ve had and I’m just sick of being in really, really bad pain, and it’s depressing. I’m on anti-depressants now. I’ve been on them for about two months now because I just – sometimes I, I just can’t see the light at the end of the tunnel. It’s like I’m stuck in a rut, no one knows what’s happening, no one can tell me what’s going to happen. We just have to wait [Kath]

I have overdosed before, that was the one thing I haven’t mentioned to you before, and it hasn’t been the first time, in the past had, it’s overwhelmed me, and I think that’s something that people need to be aware of because chronic pain can, it can overwhelm you, and being on medication all the time it does overwhelm you, and it does get the better of you, and unless you have a really good psychologist that you’re seeing constantly, maybe not constantly, I mean I see her now every six weeks [Susan]

3. Social support and responsibilities

Half of the participants spoke of the importance of being well supported, emotionally and physically, by their family – support that helped them to deal with the pain, the medication, and physical disabilities associated with their condition and/or with the adverse effects of medication. Claire, who had in the past taken an intentional overdose on more than one occasion, describes her partner’s support:

And at the end, my partner says – we sat down there and he goes “Stay on them.” He goes, he goes “If you’re on them, yes they’re addictive, but he goes you’re not trying to kill yourself.” So he goes “We look at that point. He goes I don’t want you dead, and he goes “So we stay on them. When it comes to the time when we get a – the doctor or whoever, and we decide that we have to take you off them, we will all hold you and support you as you go down”. He goes “But right now, just stay. Do – you need to protect your body right now.” “Okay”, because everything I’ve done, I’ve always spoke to my partner, and if he’s been unsure – we’ve both been unsure, we’ve both gone into the doctor together to ask questions.(Claire).

Eve indicated that her family’s support helped her gain control of her pain and her opioids:
Yeah, thank god they do live here sometimes. They do a lot, they do the floors and the lawns and all that sort of thing for me. I think if you’ve got someone to help you do these jobs you also lessen your medication. [Eve]

However several participants noted the conflict between the caring role and a need to be bringing in a wage.

“I am very much housebound, I can’t get out by myself, somebody has to be with me and push me in the wheelchair. My husband, he is very, very good to me, he takes me out when he can but he has to work because we can’t survive otherwise. My daughters all work.” [Sophie]

Participants who lived alone without close family were sometimes supported by friends or workmates and several people described how they actively sought social involvement in voluntary activities or support groups.

In contrast to these instances of social support, some participants described being isolated or having caring responsibilities that added extra work and anxiety and a need for increased medication. Several people described the isolating effect of not being able to continue their paid work, or the difficulties of working when on high dose opioids.

“I mean I lost my mother, um I lost my partner, um it all happened in such a short space of a couple of years you know” [Chris]

“I get tired and that but that’s looking after mum too, it’s a twenty four hour thing, you know, looking after someone” [Anna]

“Definitely my life’s changed, but that’s because I’m not, not getting out and I’m not working and that sort of thing.” [Tom]

Dealing with caring responsibilities without support sometimes had adverse effects on opioid use. Max, a single parent with a teenage son, describes his experience:

“that was a big day me being in the city by nine o’clock, and then waiting in court until eventually he, get your named called and all that, well we didn’t get home until four o’clock that afternoon, so I’d gone through probably 80mg of Oxycontin and about 20mg of Valium and that was just to go from when I got up in the morning until I got home at four o’clock …… like your back doesn’t care if you’ve got things to do.” [Max]

A lack of social support sometimes limited attendance for pain management and treatment:

“And yes, I would like to be able to to do an eight-week course or something like that. But it’s just not viable. Not with Kinder and my kids don’t – I’ve never put them into childcare. Um if I’ve got an appointment or something, someone usually will take a day off work. But my sister’s just started working…” [Kath]
Financial worries also limited the activities of several participants, some of whom described being
were pressurised to return to work when they were not fit, or their struggles to live on benefits such as
Newstart which ‘is a pittance - I can’t afford to live on it’.

4. The use of non-pharmaceutical interventions and self-help strategies
Surgical operations were a common feature of these accounts and, as might be expected in stories of
chronic pain, generally failed to improve the situation. However, two participants described how the
pain clinic referred them for specialist surgical interventions that relieved their pain, at least for a
period of time. Susan had a deep brain stimulator implanted which relieved pain for six months until it
‘broke’ and Rose had a successful operation on her neck which dramatically reduced her pain and
allowed her to stop her opioid medication.
A more common characteristic of narratives that progressed to restitution or quests was the use of a
variety of complementary therapies and self-help strategies:

Yeah, meditation. I’m quite fond of that. I just do it myself. I had some help, sorry, when I was in
hospital; I was seeing a psychologist and he was fantastic... ...I haven’t listened to it for a while, but
it’s, it makes you think about taking your thoughts away from the pain and focusing on
something.[Ruby]

I try to you know, keep on with my activities, you know, try to lose weight, and hydro, physio, and all.
So I’m doing that at the moment. And so it’s like, um, yes, it’s kind of
the situation here.[Liam]

I try to keep myself busy during the day, I knit at night-time and I do beading, beadwork during the day
and china painting. I find things to be creative and keep me looking forward to the next day and the
next day.[Sophie]

Chris described how his Buddhist faith and meditation had led to a more positive mindset and regular
exercise sessions at the gym. This had a positive effect on his pain management:
I just went to my temple one day and started to get more interested in my, my beliefs and I no longer
take pain killers, no longer take um sleeping pills so, but my pain is greatly reduced definitely.[Chris]

There were, however, a number of barriers to accessing complementary therapies. Tom had used
chiropractic in the past but explained how he was now frightened of making his unexplained back pain
worse:
Tom: but the thing is I just don’t know when it’s going to flare up again. It could flare up tomorrow
or it might not flare up for, you know – so.
RA That must be worrying, though, not knowing where you’re going to be the next day.
Tom: Yeah, well, it is, because I don’t know what I can or can’t do and I haven’t seen the MRI results so I don’t know what sort of damage there is and what risks I’m taking if I do do, you know, certain activities. I could really hurt myself, I don’t know.

Susan had found a chiropractor who helped her reduce her opioids but later explained that she was unable to continue regular treatment because of financial constraints.

Susan: So I stopped the acupuncture and the physio and ended up going to a chiropractor and I was always scared of a chiropractor because I thought nerves and I knew I couldn’t take any more pain from what I had already and this chiropractor was referred from someone that had broken his back and had nerve pain as well so I thought I’d give this new guy... and he does newborns. So I thought I’ll give him a go and I dropped my Oxycontin by half by going to the chiropractor. [Susan]

DISCUSSION

Our interviewees had a wide variety of experiences of taking opioids for non-cancer pain and these diverse accounts – chaos, restitution and quest narratives- raise questions about why and how some people taking opioids for chronic pain find a way forward, whilst others appear to remain in states of uncontrolled pain and escalating or chaotic opioid use and side effects. Our analysis has identified four concepts that are key influences on this variability in illness trajectory: support from individual health professionals and the health system; medical explanation or solutions; social support and social responsibilities; and the use of non-pharmaceutical interventions and self-help strategies. These four influences were rooted in the provisions made by society for caring for this patient group and involved relationships between patient and provider, between patients and their social world, and between different providers and their professional knowledge. The roles played by these four factors in making life on opioids and chronic pain more bearable and in moving experiences forward from uncontrolled pain and chaos towards hopefulness, stability or transformation were complex with no one concept acting as a single defining factor. Together, however, they construct a deeper understanding and encompass a range of potential interventions.

In terms of study limitations, the connection between this study and a trial looking at helping people reduce their opioids will inevitably have affected both the study sample and the focus of our enquiry. We sought to minimise this by a sampling strategy that included patients who had and hadn’t agreed to participate in an opioid reduction trial or who had not been approached for the trial and by working reflexively as a group of researchers from different backgrounds. Other limitations include the lack of young participants (the youngest was 29); a predominantly white Australian sample; and a lack of resources to interview providers as well as patients. The lack of accounts of misuse or diversion of opioids does not mean that these phenomena do not happen – a different methodology would be needed to reach this group. However what we have accessed are the struggles of patients using opioids legitimately for the relief of severe chronic pain and we believe that the implications in terms of their health care needs may be transferable within Australia and to other countries.
In terms of the first of the four key influences, medical support, participants valued a sound knowledge base about opioid medication and pain management; good communication skills; and the maintenance of hope. They appreciated non-judgemental relationships within which explanations, information and guidance about opioids could be discussed and decision making could be shared - a finding that is consistent with a qualitative study on patients’ view of pain management at the primary care level. Many of the accounts described an unmet desire and need for knowledgeable support, although participants qualified these criticisms with appreciation that primary care providers themselves required more support from specialist clinics. This finding parallels the perspectives from focus groups of providers whose concerns about prescribing opioids included inadequate training of providers and potential harm from adverse effects, and suggests that the professional focus on concerns about overuse and diversion may be interfering with good doctor-patient communication in this area. It is difficult for doctors to avoid hopelessness if they themselves are unsupported. The provision of more accessible pain management clinics and good communication between them and general practitioners and hospital doctors has also been emphasised elsewhere.

The second key influence, a lack of convincing medical explanation or solutions, engendered uncertainty and hopelessness in participants, and possibly their doctors, and often disrupted the doctor-patient relationship. The uncertainty and fear of doing harm also frustrated patient’s attempts to ameliorate symptoms using non-pharmaceutical approaches. These patients found considerable solace in attending the pain clinic where they felt less alone and had access to a multidisciplinary team. The third influence we identified – the use of non-pharmaceutical interventions, both conventional and non-conventional - was key to some patients finding a way forward in terms of pain control and opioid reduction. Sometimes these interventions – surgery, meditation, physiotherapy - were accessed through the pain clinic. More often participants sought such help independently and were then at risk of frustration and disappointment when they couldn’t afford to continue treatment regularly. Self-help strategies were common and wide-ranging and appeared to play an important role in stories of adaptation, coping and transformation.

Many of these narratives spanned a decade or more of people’s lives and our fourth key influence - emotional and physical support from family and friends - helped participants deal with the pain, the medication, and physical disabilities associated with their condition and/or with the adverse effects of medication. A lack of such support, social isolation, and/or a heavy burden of caring for dependents were all perceived as important influences on pain and opioid use but it appears that they were often not shared with their doctors thereby missing opportunities for potential interventions such as additional input from social work and community resources, or links to local or on-line support groups for people in chronic pain. Our interviews show that effective support, even when coming years after the pain journey has started, could still be of great benefit.
All four of the concepts we identified linked to the importance of maintaining and building hope. In terms of recovery from illness, hope has been identified as an important coping mechanism and as providing the motivation to undertake actions to facilitate recovery. Struggles between hope and despair were central to narratives of people with chronic low back pain wherein hope was expressed in terms of adjustment of priorities and finding alternative meanings in life – issues very central to the restitution and quest narratives in our study. Other studies note the desirability of healthcare professionals attending to patients' needs for hope and the importance of discussing the meaning of hope with individuals. Although we did not explore this directly in our interviews, our findings suggest that it would be a fruitful focus for future research in this patient group.

CONCLUSIONS
The four key factors influencing the progress of people taking opioids for chronic non-cancer pain are rooted in the provisions made by society for caring for this patient group and involve relationships between patient and provider, between patients and their social world, and between different providers and their professional knowledge. In our patient sample, effective support involved the provision and maintenance of hope, and professionals who are knowledgeable about opioids and chronic pain, good communicators, and cognisant with their patients' social support and responsibilities.

Table 1 Characteristics of participants

Figure 1 Journey of William (an example of chaos)
Note: William is now 49yrs old. Eleven years ago he fractured three vertebrae in a fall at work and during a 9 month period in hospital was told he would never walk again. Two years after his surgery he did resume walking but he remained in severe pain which over the years was associated with two suicide attempts. His GP prescribed increasing amounts of opiates (and also sedatives and anti-depressants at times) which were associated with drowsiness, poor concentration and led to accidents in his part-time job. He described himself as angry and frustrated because all of his life and relationships are affected. He did not find the pain management clinic helpful but does reduce his dose of opiates temporarily at times.

Figure 2 Journey of Liam (an example of restitution)
Note: When Liam was 19 he fell and injured his back and two years later had surgery with a good result. He took opioids for a month or two around the time of the operation. However, six years later his severe back and leg pain recurred and this time surgery was less successful so that he continued to get severe recurrences of his pain despite being on opioids. With the help of the pain management clinic and his GP he reduced and stopped his strong opioids on two occasions but each time the unexplained recurrence of symptoms led to hospital admissions, problems walking and a return to opioids. Opioids made him tired, forgetful and constipated and he was unable to work. He is now 29 years old and has begun to feel more in charge of his opioid reduction and is continuing his hydrotherapy, improving his diet and doing training course on-line.

Figure 3 Journey of Ruby (an example of quest)
Note: Ruby has had diabetes since she was six and is now 40 years old. Four years ago her recurrent diabetic ulcers worsened and a 14 month spell in hospital resulted in bilateral lower leg amputations. In hospital she was started on high dose opioids which gave rise to severe hallucinations and when she was discharged to live with her supportive mother she continued to suffer from ‘clouded’ thinking, drowsiness and headaches. She said ‘my identity was, like, in a cupboard and I was this person that was looked after by everybody’. She values her relationship with the doctors at the pain management clinic and has slowly reduced her medication, despite severe phantom pains and pains in her stumps. She is now less drowsy and more confident and aims to stop opiates completely if possible.
<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Trial participation</th>
<th>Age</th>
<th>Health problem</th>
<th>OM and dosage (daily) at interview</th>
<th>Years in pain and OM (initial OM)</th>
<th>Who initiated opioids</th>
<th>Narrative category</th>
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<tbody>
<tr>
<td>Ella</td>
<td>Female</td>
<td>Trial</td>
<td>58</td>
<td>Fibromyalgia</td>
<td>Kapanol 100 mg + tramadol</td>
<td>8 / 8 (OxyContin)</td>
<td>GP</td>
<td>chaos</td>
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<td>Jack</td>
<td>Male</td>
<td>Trial</td>
<td>64</td>
<td>Low back pain, lumbar disc problems</td>
<td>Norspan 20 + Norspan 5 (patch) + Panadeine</td>
<td>15 / 14 (OxyContin)</td>
<td>GP</td>
<td>chaos</td>
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<td>Sophie</td>
<td>Female</td>
<td>Trial</td>
<td>69</td>
<td>Systemic vasculitis, hip pain</td>
<td>OxyContin 210 mg + Endone</td>
<td>over 3 / 3 (OxyContin + Endone)</td>
<td>rheumatologist</td>
<td>restitution</td>
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<td>49</td>
<td>Low back pain due to 3 fractured lumbar vertebra due to a fall</td>
<td>OxyContin 80 mg + Panadeine</td>
<td>12 / 12 (Panadine)</td>
<td>acute hospital</td>
<td>chaos</td>
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<td>Oliver</td>
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<td>Trial</td>
<td>66</td>
<td>Severe back pain</td>
<td>OxyContin 20 mg + Endone (rarely)</td>
<td>3 / 2 (OxyContin)</td>
<td>GP</td>
<td>restitution</td>
</tr>
<tr>
<td>Anna</td>
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<td>Trial</td>
<td>64</td>
<td>Knee and back pain</td>
<td>Norspan 10 (Patch) + Kapanol 50 mg</td>
<td>16 / 14 (tramadol)</td>
<td>pain clinic</td>
<td>restitution</td>
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<td>Lucy</td>
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<td>39</td>
<td>Severe burns</td>
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<td>3 / 3 (IV morphine)</td>
<td>acute hospital</td>
<td>quest</td>
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<tr>
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<td>Amputation, osteomyelitis,</td>
<td>Kapanol 90 mg</td>
<td>13 / 13 (morphine)</td>
<td>acute hospital</td>
<td>quest</td>
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<td>Non-trial</td>
<td>44</td>
<td>Amputations, diabetic ulcers</td>
<td>OxyContin 5 mg + Endone 5 mg (rarely)</td>
<td>4 / 4 (OxyContin + Endone)</td>
<td>acute hospital</td>
<td>quest</td>
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<td>Liam</td>
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<td>Trial</td>
<td>29</td>
<td>Low back pain, lumbar disc problems</td>
<td>Norspan 5 (patch) + Endone 5 mg</td>
<td>3 / 3 (Norspan + Endone)</td>
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<td>restitution</td>
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<td>Low back pain following accident</td>
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<td>4 / 4 (OxyContin + Panadeine Fort)</td>
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<td>chaos</td>
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<td>Thomas</td>
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<td>53</td>
<td>Spinal pain, pneumothorax</td>
<td>OxyContin 20 mg + Endone</td>
<td>5 / 5 (OxyContin)</td>
<td>acute hospital</td>
<td>quest</td>
</tr>
<tr>
<td>Eve</td>
<td>Female</td>
<td>Non-trial</td>
<td>44</td>
<td>Neck pain, cervical disc problems</td>
<td>OxyContin 40 mg + Endone</td>
<td>4 / 3 (tramadol)</td>
<td>GP</td>
<td>quest</td>
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<tr>
<td>Andrew</td>
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<td>Trial</td>
<td>55</td>
<td>Fibromyalgia</td>
<td>Oxycontin 30 + Endone</td>
<td></td>
<td>GP</td>
<td>chaos</td>
</tr>
<tr>
<td>Ben</td>
<td>Male</td>
<td>Non-trial</td>
<td>46</td>
<td>Low back pain, lumbar disc problem, shoulder pain</td>
<td>tramadol 150 mg</td>
<td>4 / 4 (tramadol)</td>
<td>GP</td>
<td>quest</td>
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<tr>
<td>Rose</td>
<td>Female</td>
<td>Non-trial</td>
<td>50</td>
<td>Neck pain, cervical spine problems</td>
<td>Mersyndol + Panadeine</td>
<td>34 / 6 (Mersyndol + Panadeine)</td>
<td>GP</td>
<td>quest</td>
</tr>
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<td>Chris</td>
<td>Male</td>
<td>Trial</td>
<td>77</td>
<td>Spinal fractures, osteoporosis</td>
<td>Norspan 20 (patch)</td>
<td>over 3 / over 3 (Pethidine Injection)</td>
<td>acute hospital</td>
<td>quest</td>
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<td>Claire</td>
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<td>Trial</td>
<td>50</td>
<td>Fibromyalgia</td>
<td>Patch 20 microgram</td>
<td>16 / 13 (Panadine)</td>
<td>GP</td>
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<td>Susan</td>
<td>Female</td>
<td>Non-trial</td>
<td>47</td>
<td>Facial pain, neuralgia from root canal filling</td>
<td>Kapanol 60 mg + Ordine (pm)</td>
<td>16 / 19 (Panadine)</td>
<td>GP</td>
<td>restitution</td>
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<td>Kath</td>
<td>Female</td>
<td>Non-trial</td>
<td>35</td>
<td>Low back pain, lumbar disc problems</td>
<td>Norspan 20 + Norspan 10 (patch) + Endone</td>
<td>6 / 6 (Tramadol)</td>
<td>GP</td>
<td>chaos</td>
</tr>
</tbody>
</table>
Journey of William (an example of chaos)

Note: William is now 49yrs old. Eleven years ago he fractured three vertebrae in a fall at work and during a 9 month period in hospital was told he would never walk again. Two years after his surgery he did resume walking but he remained in severe pain which over the years was associated with two suicide attempts. His GP prescribed increasing amounts of opiates (and also sedatives and anti-depressants at times) which were associated with drowsiness, poor concentration and led to accidents in his part-time job. He described himself as angry and frustrated because all of his life and relationships are affected. He did not find the pain management clinic helpful but does reduce his dose of opiates temporarily at times.

314x173mm (96 x 96 DPI)
Journey of Liam (an example of restitution)

Note: When Liam was 19 he fell and injured his back and two years later had surgery with a good result. He took opioids for a month or two around the time of the operation. However, six years later his severe back and leg pain recurred and this time surgery was less successful so that he continued to get severe recurrences of his pain despite being on opioids. With the help of the pain management clinic and his GP he reduced and stopped his strong opioids on two occasions but each time the unexplained recurrence of symptoms led to hospital admissions, problems walking and a return to opioids. Opioids made him tired, forgetful and constipated and he was unable to work. He is now 29 years old and has begun to feel more in charge of his opioid reduction and is continuing his hydrotherapy, improving his diet and doing training course on-line.

308x159mm (96 x 96 DPI)
Journey of Ruby (an example of quest)

Note: Ruby has had diabetes since she was six and is now 40 years old. Four years ago her recurrent diabetic ulcers worsened and a 14 month spell in hospital resulted in bilateral lower leg amputations. In hospital she was started on high dose opioids which gave rise to severe hallucinations and when she was discharged to live with her supportive mother she continued to suffer from ‘clouded’ thinking, drowsiness and headaches. She said ‘my identity was, like, in a cupboard and I was this person that was looked after by everybody’. She values her relationship with the doctors at the pain management clinic and has slowly reduced her medication, despite severe phantom pains and pains in her stumps. She is now less drowsy and more confident and aims to stop opiates completely if possible.

308x175mm (96 x 96 DPI)
Appendix Interview Questions

Interview Schedules

The interviews are semi-structured. Questions are divided into four categories: knowledge of OM, opinions about OM, experience of reducing OM and family history. The interviews will be conducted using standard open questions (in bold below) but then the flow of the conversation will run its own course to ensure that the interviewees viewpoints, ideas and priorities are fully explored, within the confines of the research questions. The more detailed questions will be reserved as prompts, and used at appropriate points in the interview to ensure all areas are covered by the end.

Interview patients who taking OM:

1. We are interested in your views and experiences of taking painkillers, especially the stronger ones that are called opioid medications. Could you start with telling me a bit about your pain? Then tell me about your own experiences of taking these? (if necessary, this can be clarified by identifying the actual ones that the interviewee is currently taking)

Knowledge of OM

• How many opioid medications (OM) are you taking or using and what are they? (identify the important type of OM. In the following, XX refers to the OM concerned.)
• When did you start to take XX? And Why?
• Who prescribed XX?
• Were the reasons explained to you when the doctor prescribed XX?
• When XX was initially prescribed, did you know for how long you would be on XX? Did you know the potential side effects? Did you know how to cope with the side effects?
• How often do you have XX prescribed and by whom?
• Every time when XX was prescribed, did the doctor explain to you any side effects? Or did the doctor ask you about your use of XX?
• Have you tried different opioid medications before?
• Where do you get information about XX and other opioid medications from?

Opinions and experience about OM

• What were your initial thoughts when XX was prescribed for you?
• Have your thoughts or understanding about OM changed since?
• What is your experience of taking XX and other opioid medications? Say is XX effective for your pain? Do you have any problems with it?
• Do you have any side effects and how do you cope with them?
• Are you happy to continue using XX?
• Do you tell your friends or family about your use of XX?
• If you do, what is their reaction?
• Do you see any other health professionals apart from doctors?
• Do you tell them you are taking XX?
• What is their reaction to XX? Does that affect you?
• Do you know anyone else who is in pain and taking opioid medications? Do you communicate with each other?
• What is the commonest theme of your communication related to your pain and opioid medications?
  • What is your GP and pain specialists’ opinion about the OM?

About family history
• Do you have any family member who have taken or are taking opioid medications? Why?
• Do you have any family member who suffers from chronic pain? How do they cope?

Opinions and experience about OM dosage
• Do you think the dosage is adequate?
  • Do you want to increase or reduce XX? Why?
• Have you tried to increase or reduce XX or other opioid medications before? How did you do it? Was it successful? What is the biggest difficulty when you tried to reduce these medications?

Knowledge about referral.
• How did you come to the pain clinic?
• Why have you been referred?

Open end question
• Do you have anything you would like to add?

End of questions
Check that they are still happy about it having been recorded
Thank you very much for your time and for sharing with me your thoughts!