Article

An ecosystem of living with severe, long-term pain – the role of (un)accepting systems: a qualitative study

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Cassandra Macgregor[1,2,3], David N Blane[3], Sivaramkumar Shanmugam[1] and Christopher Seenan[1,4]
[1] Department of Physiotherapy, School of Health and Life Sciences, Glasgow Caledonian University. [2] Chronic Pain Service, NHS Lanarkshire. [3] School of Health and Wellbeing, University of Glasgow. [4] Faculty of Health Sciences and Sport, University of Stirling

**Correspondence to: Cassandra.Macgregor@glasgow.ac.uk*

Abstract

Background: Coming to terms with chronic pain is a complex process. In earlier research, we found that accepting chronic pain is a fluid and continuous journey, experienced within socio-cultural-political worlds, which we conceptualised as an Ecosystem. These findings showed potentially unequal opportunities to experience a positive state of acceptance, with scope for improvements. We did not know how people living with chronic pain may relate to the findings. We therefore aimed to contextualise our (earlier) findings with people who live with chronic pain and experience marginalisation, and to generate ideas for improvement based on the concept of any individual journey with acceptance taking place within an 'Ecosystem.'

Methods: We recruited through NHS contacts. We used focus groups and diaries to collect qualitative data, which we explored using thematic analysis. The research is exploratory in nature.

Results: We recruited seven participants (two men, five women), all living with severe chronic pain and multiple long-term conditions. Most described difficulty making ends meet, none were in paid employment, nor had university degree level of formal education.

We found three themes from the qualitative data analysis, two focused on structural, systemic features: 'unaccepting, disconnected and dehumanising systems: treated like 'tick boxes,'' and 'connected, understanding and accepting systems: towards inclusion.' One theme showed the individual nature of experiences; 'individual variations in the experiences and journey of coming to terms and living with chronic pain.'

Conclusions: Our findings show new insights into phenomena associated with coming to terms (and living) with chronic pain; including how state systems, structures and societal attitudes can influence experiences. Individuals with chronic pain may accept aspects of their painful condition, however, others around them, healthcare staff and institutional structures may not accept (or account for) the nature of chronic pain, leading to distress, stigmatisation, and feeling misunderstood. We demonstrate a focus on working with individuals with chronic pain, without socioeconomic privilege, to give insights into their lives and the impact of social context including political decisions – pain is unavoidably political for those at the sharp end of these experiences.

Contribution of the Paper

- 'Acceptance of Chronic Pain' has largely been conceptualised as an individual factor/behaviour, often the target of psychological interventions.
- Our findings show that 'acceptance' can also be understood as a systemic quality: *accepting systems* facilitate living better with chronic pain, reflecting qualities of connection, understanding and inclusion; conversely *unaccepting systems* are disconnected, and can 'dehumanise' people with chronic pain, treating them like 'tick boxes.'
- Our exploratory work is based on the experiences and ideas of seven people without socioeconomic privilege, living in Scotland and shows that for them, pain is a political and economic issue. Improvements are needed across sectors, including to: social security operations; political rhetoric/language; public awareness; GP consultations; earlier access to appropriate information and support, and connections between services/sectors. Furthermore, interactions need to account for the individual nature of chronic pain.

Keywords
Chronic pain; health inequalities; acceptance; social determinants of health; pain care; social security

Introduction

'Chronic pain' is a heterogeneous and broad category of conditions and pain states where the pain has persisted for over three months.[1] Prevalence ranges from 29% in the least socioeconomically disadvantaged areas in Scotland, to 50% in the most, with a smaller number of people severely impacted.[2-4] Chronic pain is a major cause of disease burden globally, commonly experienced with other long-term (including mental health) conditions,[5, 6] associated with high socioeconomic cost that includes loss of paid work, social security claims, and healthcare costs including prescriptions.[7-9] Living with chronic pain can disrupt daily life, identity, confidence, limit engagement in work and social roles, leading to distress and suffering.[10-14] A sense of shame and stigma can occur, exacerbated by the invisible and subjective nature of chronic pain, and the consequent lack of fit with healthcare systems; typified by healthcare interactions that lack empathy or understanding.[10, 13, 15, 16] Women and other groups marginalised by historic, economic and social conditions are disproportionately affected. [17, 18]

In Scotland, (where the research reported here took place), there is a framework for NHS Health Boards that promotes provisions for management of chronic pain through both specialist, multi-disciplinary services in secondary care, and generalist, primary care.[19, 20] There are, however, significant capacity restrictions across both sectors.[21, 22] While delivery of healthcare is devolved to the Scottish Parliament, social security, workplace and industrial policies (also influential in health outcomes) are largely delivered by and dependent on UK government policy. Recently, however, an important health benefit (Adult Disability Payment) is in the process of being devolved to the Scottish Government, replacing Personal Independence Payment previously delivered by the UK-wide Department for Work and Pensions.[23, 24] Rhetoric around benefits and other political/societal discourses are recognised as an important factor in health, wellbeing, and increasingly in pain research through, for example, the mechanism of stigma.[15, 25]

'Acceptance' of chronic pain is recognised as an important feature in the pain literature and therapeutic care. [26-28] When pain does not resolve for the individual, they may begin a journey of living with chronic pain, responding to painful experiences, limitations and impacts in a number of ways, that can prove helpful or unhelpful over time.[11, 29, 30] In the healthcare context, the 'acceptance' of aspects of the experiences of living with chronic pain, including its long-term nature, is understood to move the focus of the individual towards realistic goals and implementing strategies that are most likely to be effective, and improve mood, function and quality of life.[26, 27, 29]

In our earlier meta-ethnography findings, [31] we present our findings as an 'Ecosystem' of 'Accepting life with Chronic Pain' to convey the continuous and fluid nature of individual journeys that are embedded within social worlds, thus extending the concept to a broad and overarching focus. We found evidence of unequal opportunities to experience a positive state of 'acceptance', suggesting different possible mechanisms underpinning these inequities. For instance, it is possible that those with higher socioeconomic status may be more likely to become accepting of their pain due to better access to a range of material and cultural resources (including financial buffers, and good pain information and support). Understanding how social, healthcare and welfare systems enable, or obstruct, living well with chronic pain is essential to addressing both personal and structural dimensions of suffering. The meta-ethnography findings contained implications for how broad processes of accepting, and associated phenomena, could be improved. We wished to further investigate these from the perspective of people who live with chronic pain in Lanarkshire (a region of Scotland) who may adversely experience health inequities, in order to understand and address areas for improvement in an equitable way.

Our aims were exploratory in nature; to understand how people who live with chronic pain contextualised our meta-ethnography findings within their own experiences, and what ideas for improvement they may generate. Our research questions in the study reported here are: 1) How do individuals experiencing chronic pain, shaped by health inequalities, compare or contextualise their own experiences with the meta-ethnography findings? 2) In what ways do these individuals envision improvements in the process and care journey for people (themselves and others) who live with chronic pain?

Methodology and Methods

The historic process of knowledge creation in pain research (similar to health research in general) has been criticised for perpetuating inequalities in our understanding of health phenomena and pain care due to its exclusionary nature.[18, 32, 33] For example: exclusion from studies of people with comorbidities, language and literacy difficulties; and practical and financial barriers (e.g. transport issues) to participation. In conducting

the study presented here, we therefore aimed to be inclusive, minimise barriers to participation and facilitate recruitment into the study of those who may not normally take part in research. We report our qualitative study in line with the guidelines by O'Brien et al. [34] with details in Supplementary File 1.

Theoretical positions

We conducted a qualitative study informed by critical theory (particularly intersectionality) and interpretivism, recognising that experiences of chronic pain are shaped by social, economic and political contexts.[35-38] We collected data between December 2023 and May 2024, during the final months of the UK Conservative Government, following years of austerity, the Covid-19 pandemic (and associated restrictions), and the cost of living crisis. The participants that we recruited are likely to experience the sharp end of difficulties due to these issues, with less social and economic power including finances to absorb any impacts.

Our methodology was informed by different approaches and principles. We involved two advisors with lived experiences of chronic pain, low levels of formal education, and who lived in areas of relative socioeconomic disadvantage, throughout the study. We were informed by the principles of stakeholder engagement (inclusion of relevant and interested parties) to improve the relevance and impact of literature review findings.[39] Similarly, we were informed by the principles of Patient and Public Involvement and Engagement in seeking to generate further research and development ideas, based on perspectives of those who live with the conditions under study.[40]

We were guided by principles and ways of being inclusive in research as an ongoing concern.[18, 41] To minimise barriers to participation, we offered flexible consent and data-collection appointments by telephone, video call, or in participants' homes; supported literacy by using short introductory videos; covered travel costs including taxis; and provided grocery vouchers for focus-group attendance. Interpreters and taxis were available as needed.

Study Setting

The study was conducted within NHS Lanarkshire (NHSL), a relatively large health board with a population of 720, 000 people [42]. We recruited residents of Lanarkshire as advisors, participants and NHSL staff assisted with recruitment and planning. The focus groups were conducted in an NHSL community centre.

Researcher Reflexivity and Positionality

CM is employed by NHSL as a physiotherapist (part time) with the chronic pain service. She previously worked with a broader range of services, giving her experience of the difficulties that many patients encounter in both living with chronic pain and accessing care. These insights informed the research. CS and SS are physiotherapy academics. DB is a practicing GP and academic. We all consider ourselves cisgender (three men, one woman), non-disabled and middle class. In terms of ethnicity, three of us identify as White and Scottish, and one British Indian. Our broader research team included advisors with lived experience of chronic pain (detailed earlier), academics and clinical staff which gave more diversity of class and ethnic backgrounds, meaning that methodological development and interpretation benefited from a broader range of experiences - important (and we argue beneficial) when interpreting experiences within political and structural contexts. The study reported here takes place in the context of proposing 'An Ecosystem' to participants (i.e. that individual experiences take place within social worlds); we were explicitly introducing and seeking views on individual experiences within social context to the participants during the study.

Inclusion and exclusion criteria

We used purposive sampling to recruit adults with non-malignant chronic pain for over one year, with potential indicators of 'adverse experience of health inequalities', including difficulty making ends meet, accessing care, belonging to an ethnic minority group or marginalised by gender or sexuality. Further details are in Supplementary File 2.

Data Collection

Each participant completed a short demographic interview via telephone, video call, or in person at the participant's house, after taking informed consent, using a guide (Supplementary File 3) including standard tools available on paper, posted out in advance if needed.
Participants were invited to attend three focus groups (each ~90 minutes), facilitated by CM and supported by a second facilitator (DB or CS). The first explored personal resonance with prior meta-ethnography findings; the second generated improvement ideas; during the third, we sought perspectives and feedback on earlier interpretations and discussed these ideas further (Supplementary File 4). All groups were audio-recorded.

Participants were also invited to keep a brief diary to capture reflections on the research questions between focus groups, offering an alternative way of engaging.[41, 43]

Data analysis

Demographic data were collected via interview. CM assigned a participant number as a pseudonym. We summarised demographic responses and present these in the predefined categories in the first part of the findings section.

For each focus group, CM transcribed the audio recording verbatim, including vernacular, applying pseudonyms for anonymity, then added any details from the notes gathered by the second facilitator to the transcript. She removed or reduced text that was not relevant to the research questions and added diary text (as relevant to that focus group).

Following the first focus group, CM developed broad codes from the text, then reduced these further into categories where there was some shared sense of meaning, in an iterative fashion, then into a 'One Sheet Of Paper' analysis that combined the diary and focus group data.[44] She then developed a summary list of findings and met with lived experience advisor (KN) to receive feedback, and edited further, prior to giving out this sheet at the start of focus group two (Supplementary File 5).

Following focus group two, CM used the same method of transcribing, reducing the text, applying codes, developing categories, combining the diary data, then met with DB, who independently analysed a copy of the transcript, to compare initial codes and discussed areas of potential themes. CM typed up a list of summary points and formulated questions about potential themes to raise with the participants at the start of focus group three.

Following transcription of focus group three, CM arranged the data into the broad categories. To combine the qualitative analysis of all three focus groups, she laid out the distinctive categories of focus group two then added the distinctive categories of focus group one, combining these where overlap existed. CM then added focus group three data. CM reduced duplication, removed text without meaning to the research questions (for example discussion of group dynamics) and refined the categories iteratively, leading to an initial set of six categories that included both a-priori and emergent meanings. CM iteratively developed the analysis into three themes, guided by Braun and Clarke,[45] with feedback from the research team. We present findings with new meaning in this manuscript, rather than reiterate our earlier meta-ethnography findings, and we provide an extended record of analysis and removed data portions in Supplementary File 5. Techniques to enhance trustworthiness included triangulation of data sources: we collected data through diaries and focus groups across different time points. We also checked the interpretation, mainly developed by CM, with participants and within the research team as described above and in Supplementary File 5.

Ethical approval

Ethical approval was granted by Glasgow Caledonian University School of Health and Life Sciences Ethics Committee (code: HLS/PSWAHS/22/279), the Cornwall and Plymouth NHS REC, and NHS Lanarkshire Research and Development (REC no: 23/PR/1043 and R&D no: L23119). Participants could withdraw at any point, and signposting procedures were in place for emotional distress.

Findings

Seven participants gave consent (5 women, 2 men, mean age 50 years) all living with severe chronic pain and at least one additional long-term condition. Most described difficulty making ends meet, and none were in paid employment. None had university degree level of formal education. Pain intensity averaged 8.6/10, with significant functional and emotional impact (Tables 1 and 2). We stopped recruitment due to practical and time constraints.

We found three themes from the qualitative data analysis. Relating to the 'Ecosystem' concept of our earlier work which showed an individual journey related to social contexts/structures, two themes focused on structural, systemic features and one on the individual nature of experiences, and present them as follows:

- Unaccepting, disconnected and dehumanising systems: treated like 'tick boxes.'
- Connected, understanding and accepting systems: towards inclusion.
- Individual variations in the experiences and journey of coming to terms and living with chronic pain.

Quotes are attributed firstly to the individual participant, and then to the focus group number, for example, P7-3 is a quotation from participant seven at the

third focus group; D indicates a diary quote. We use vernacular in the quotations, and a translation table is in Supplementary File 6. In presenting the findings, our interpretation is given in the title theme/subtheme and the plain text, participant quotes that support/illuminate our interpretation are given in italics.

Unaccepting, disconnected and dehumanising systems: treated like 'tick boxes'

In this theme, we show how structural and ideological features impact on the lives of the participants negatively. There is society-wide lack of understanding and acceptance of the nature of chronic pain that permeates individual experiences – participants can attend for treatment, improve their own knowledge and condition management skills, but society creates barriers, leading to our framing of systems and structures as unaccepting.

P7-3 '*You're asking the people who suffer, tae accept it, but no-one else does…when you're faced with a wall of the professionals, so-called… they'll literally just, don't accept it or they'll not listen to ye*.'

P1-3 *'so people have dropped out of my life...they don't accept it, they don't understand it, or they don't want to understand it.'*

The invisible and subjective nature of chronic pain can lead to difficulties for participants; it does not align with the culturally dominant, biomedical model and associated objectivity: P2-3 '*There isnae a diagnosis for it…you cannae get an MRI done for fibromyalgia, like if ye had a stookie on or something, if ye had a plaster on every part of your body that was sore, you'd maybe get a wee bit more sympathy but you still feel shame from other people because of how they perceive it*.'

Building on the difficulties that chronic pain can bring, the participants experience the social security system as ill-fitting; they feel misunderstood and discredited, with impersonal and stressful experiences permeating interactions, leading to the dehumanising descriptor, exemplified by the participants use of 'tick box' to describe how they feel that they are treated.

P2-2: '*If you go for an appeal… then you can take it through for a board… so you get classed as points, so I went to one, and I had a lawyer there, I had a gynaecologist, and I had a cardiologist… and they turned round and says to me, "do you not think that maybe your weight's a problem?"…what they done was they gave me the two points that I needed, but because I seemed alright on that day, they took two points off me so I ended up in exact same position.*'

Table 1: Participant demographics - age, socioeconomic status, gender, sexuality and ethnic background

Demographic question	response
Age in years (mean) (range)	50 (38-60)
Do you (ever) have difficulty making ends meet at the end of the month? (N)	
Always	1
Frequently	2
Sometimes	3
Rarely	1
Never	0
How do you define your class? (N)	
working	5
middle	2
What is your highest level of formal education? (N)	
High/secondary school	3
HND/HNC/College module	4
Are you in paid employment? (yes, no, part-time) (N)	
Yes	0
No	7
Are you (currently) an unpaid carer? (N)	
Yes	1 (2 children)
No	6
How do you categorise your gender? N	
Woman	5
Man	2
How do you define your sexuality? (N)	
straight	7
Are you cisgender, transgender, prefer not to say? (N)	
cisgender	7
Ethnic Background (N)	
White Scottish	6
British Indian	1

The process of engaging with the benefits system exacerbates stress and mental health difficulties, particularly given the stakes for participants of needing finances for basic essentials.

P7-2 '*See the anxiety in the lead up, going through it [benefits assessment]… and what you get isnae even enough… I'm in the house almost 24/7 and your heating, and everything, electricity, internet, like how are*

you meant to communicate? So you need to attend chronic pain… and get out to exercise and trying to get out to socialise and like the difficulty surrounding it… and then you're on the phone to someone that's doing a tick box… honestly you would go off yer nut.'

P4-2 '*you're on the phone for 2 hoors with someone you've never met, doesnae know ye, they're ticking boxes, it is… like my anxiety. I didn't sleep in the run up tae it. I felt as though I was having tae prove how much pain I was in every time I was on the phone… it's a stress…. You feel as if you're begging for money to live*.'

The following passage shows participants discussing how they may be expected to prove their incapacity for work, and be successful in claiming benefits, by degrading themselves: P1-2 '*I had to go for an assessment at Cadogan street [DWP office] in Glasgow and he [GP] said, 'even if you're feeling good on that day, don't look as if you're feeling good because they'll be watching you.*'' P4-2 '*aye, because you dae have days when you feel good, and you want to feel good on your good days, so it's like you can't win, can you*?' P7-2 '*aye, you have that as well, people saying like dress like as a tramp, and like you were on the streets, and like covered in like urine, like disgusting looking.'* P4-2 '*but that's what I mean…you feel as if you're degrading yourself to get… to live.'*

Table 2: Participant demographics - disabilities, health and pain

Demographic question	Response
Types of disabilities (chosen from standard form) (N)	
A physical disability	7
A mental health condition	4
A learning difficulty	1
A long-term illness	3
Do you identify as disabled? (N)	
yes	4
no	0
Other response	3 as follows: 'Personally, no but for practical purposes, yes.' 'I don't know because it varies.' 'Not very often, probably to a degree, probably, I suppose I do.'
Do you receive benefits related to health/disability? (N)	
yes	7
How many additional long-term conditions do you live with in addition to chronic pain? (range of the numbers of additional LTCs that participants live with)	(1-5) Most common: asthma, depression, hypertension
How long have you lived with this pain? Mean in years, (range)	13 (1.5-30)
Chronic pain core minimum dataset items	
Intensity (0-10)	8.6 (6-10)
Emotional Impact Q1 (0-3)	2.3 (1-3)
Emotional Impact Q2 (0-3)	1.6 (0-3)
Functional interference (0-10)	8.3 (5-10)

P1 and 6 could recognise their current situations now impacted them positively, for example, P6: '*I've been where all yous have been, honestly, and it's changed me, but I think now, cos I'm 60 at the end of this year, so I'm finished work, so that's maybe taken a burden off of me*.'

The focus groups took place from March to May 2024 when the UK Prime Minister made high profile announcements about benefits cut backs and suggested that some receiving benefits were undeserving recipients, as relayed to the group by P7, demonstrating the direct impact of political rhetoric and policy on the participants: '*You knew that they [government] planned it and you knew it was coming, anyway… sick lines will be over and it's just like… universally, 'people are basically at it, with their symptoms' and you know, 'it's back to work'*.'

There was evidence from the participants that they may internalise some of the stigmatising attitudes around disabled people and benefits claimants: P2-2 '*If anyone asks me what I dae for work I just say 'I'm a bum', like I mean I don't work so that's just how people will see you anyway…you just belittle yourself so that other people don't do it, because as soon as they hear you are… I'm going to put this in quotations, "disabled," they kind of lump you in, they automatically think, that you are trying to pull a fast one and just trying to get benefits for it*.'

All participants described negative experiences with health care for their chronic pain. They felt not listened to, a sense of being dismissed, frustration with the interaction, and communication that lacked empathy or clarity. A lack of relational care also surfaced – care appeared to be disconnected.

P4-1 *'they're [GPs] just no listening… and it's so frustrating… like constantly just getting telt, you've got a deficiency, a vitamin deficiency – that's how you've got pains in yer feet and you cannae walk some days, I'm like, come on.'*

P3-1 '*washed his hands of me' and it's quite disheartening'*

P1-2 '*I have an issue trying to see the same GP twice when I go – so there's that disconnect, there's no continuity to see the same GP, so you can't build up that relationship*.'

Connected, understanding and accepting systems: towards inclusion

Participants thought improvement would occur through raising awareness and understanding of chronic pain and its impact, throughout society, including healthcare staff; if others understood chronic pain then it would bring change towards inclusion of their needs, and the resulting adaptation, leading to the notion of 'accepting' systems.

P2-2 '*I think it's just understanding…. understanding chronic pain. If every part of society understood, like if GPs understood how chronic pain affected people and how to speak to people, and… refer them on to chronic pain who does understand*.'

P1-3 '*some people are more willing tae... accept, and help ye, cope with the challenges. You know, they'll make sure you're OK, and they'll make sure I've got a seat where I'm going.*'

The participants gave examples of practices that could help to make life easier. A practical solution to raise awareness and make hidden disabilities visible included the sunflower lanyard, P1-2: '*I didn't use it for ages, but then I did eventually… the sunflower badge… I found in like airports and places like that, concert venues, people saw that sunflower badge and they knew what it was- they were really helpful… so they could get you first, get you seated in a venue first*.'

P6 thought an advert to raise awareness of chronic pain would be helpful, based on an advert raising awareness of arthritis that she had seen. P6-3: *'I think people generally don't believe people for one moment that you're in the pain that you're in… I don't think anybody's going to be bothered reading into it, if it doesn't affect them, whereas something like that – a big billboard, an advertisement, or something.'*

P2 also brought in the role of the individual in accepting any external support and help, rather than struggling to do things herself. P2-3 '*I've started using things like when I'm going on holiday next month, emm, I'm using the special assistance. I actually asked for that last year and it's so much better than trying to do everything myself…. I figured that I have tae actually start using the things that are in place, when they are in place… like use it, or lose it, because people do put these things in place and you should use it*.'

Participants thought that improvements in administration of social security could occur, and that this would involve: treating people as individuals; appreciation of the severity of participants' chronic pain; listening to people with knowledge about chronic pain; adequate funding for social security and healthcare, connection

and interaction with healthcare in making assessment and examining individual circumstances.

P1-2 '*I think there has to be some kind of interaction between the DWP and the health professionals … I don't have any issue with them [DWP] accessing my medical records. If they want me to sign something to give them a waiver then I'd do that… cos it's all there, they don't have tae employ these people to come and do it. All they're doing is they're trying to save money… they're trying not to give people money*.'

P2-2 '*understanding that no everybody fits into these tick boxes… P4 and they people understand chronic pain as well…*

P6-2 '*maybe it would be an idea if we start writing to our local [elected representatives]. My cousin wasn't getting any help financially or anything and… I did contact that [name of MSP]… he actually wrote a letter and they did eventually give her just daily living allowance*.'

Participants benefited from attending pain groups – both from being with others who understood and shared experiences, and also practically from learning helpful ways to deal with the pain and its impact. Participants also describe a temporal feature of change from scepticism on their approach to a group, to appreciating ways in which they helped now that they had worked through the group.

P2-3 '*I actually start listening to people… it's kind of like going tae slimming world but without the shame...'*

P4-2 *'Daein that chronic pain course last year, wi the way they explained everything, helped me get ma heid roon aboot stuff… it definitely explained a lot of things tae me. like the psychologist and the physios and that on that course, were brilliant and all my family, when I was daeing that, says like as if something had switched and I was different, my attitude was different, and I deal with ma flare ups different now… I used to just sit and greet all the time, I did… I was really emotional, noo, I just try and deal wi it, just try and get on*.'

Lack of ongoing support after the pain course finished was an issue and participants thought more structured follow up could be beneficial, P4-2: '*you're back tae like everybody in the hoose like for all they see you struggling every day, they don't understand like how you're feeling, like what it feels like…and just coming and talking to others that are in the same position, so if that was like, it doesn't need to be every month, it could be every three month or whatever…it's good…it's good for your brain*.'

Participants described positive interactions and a relationship with a GP where they felt listened to and supported – there were qualities of dialogue, engagement and answers that made sense. Where better understanding and acceptance of chronic pain was perceived, this was linked with better perceptions of care. Continuity and mode of care was important; participants valued seeing the same GP who knew them and their conditions and with whom they felt like they could work with on management (including making referrals).

P2-1 '*I finally got a good doctor who actually listened tae me… so I agree that having that support system from somebody who's willing to listen, who maybe… they know more about it, they understand it, they are willing to accept it*.'

P7 '*My GP that I've had for years, she's fantastic… I know that she like understands, like I came off medications, and working with her, like she referred me to pain management whereas… when she went on maternity leave and - like you were saying – the telephone calls – and I'm like, I need to speak to you face to face and give you an understanding of my conditions, and what's up with me, but when I'm phoning up there's nae point putting you on to one of these other doctors*.'

Getting information on chronic pain early in the journey is important.

P2-1 '*GP's your first call… we don't know medical stuff, we know that we hurt and we need somebody that's got that knowledge to turn round and say, "ok you hurt because of x,y,z," we then can say, "well, can you help us?"… instead of just saying here you go, there's tablets*.'

P6-3 '*I'm not sure your doctors gonna fix you, but put you in the right kind of direction of that kind of knowledge… rather than just giving you tablets, tablets, tablets… I waited four years to go to pain management… so it was a long, long road to get someone even to recognise what was going on*.'

P1 raised the issue of limited resources impacting on care including cuts to community services, highlighting the importance of adequately resources services. '*In*

Blantyre there, they used to have this place called the Haven and you could get all kind of holistic treatments like massage, and stuff like that, and they even had groups like this to chat, but the funding… dried up and so it's gone and so that's another resource that you don't have access to.' A further example is shown in limited GP appointment time impacting care. P1-D '*Lack of resources may well remove their ability to be as empathetic as they would like and definitely, they are time restricted, so I can't recall being able to spend more than 10 minutes discussing what was most pressing at that moment and maybe missing on less obvious at that time, but not unimportant issues*.'

Individual variations in the experiences and journey of coming to terms and living with chronic pain

Participants recognised while there are many commonalities in living and coming to terms with chronic pain, there are individual variations in the experience that can be related to the onset of pain, losses incurred, the nature of the condition including severity and legitimacy, and demands of condition management work including 'pain bearing' and managing limited finances.

P7-2 '*it's very individual. Depends on the condition, like some conditions might be like similar, but as in life we're individuals, and how we deal with it and everything is individual. We can relate because we have conditions.'*

P1 thought that societal acceptance was easier for him as he had Multiple Sclerosis (MS) – a condition ascribed higher levels of legitimacy in a biomedically dominant culture. P1-3 '*I think, from ma point of view… I hesitate to use the word lucky, because there's a name to my pain – MS – and I know there's people that have pain that don't have a… specific condition, so if I say I've got MS, it's accepted to an extent that there are limitations and issues wi that… if say you suffer from chronic pain, they'll be looking for, well, what causes that? … I think that it would be a long, hard fight to get people to accept that there are people that suffer from chronic pain for maybe no obvious reason*.'

Participants described differences in the onset of their pain and how this impacted on their situations. P4 and 7 experienced the onset of pain during their adult lives and experienced loss, grief and a disruption to their sense of feeling themselves, whereas P2 highlighted she had the pain since a young age, so her experience was different.

P4-1: '*I cannae dae the same things, I don't think the same way, I react to things totally different than what I did before, and it's all negative… I don't dress the same way… I don't feel like the same person, I was before this happened tae me… I used to work full time. I worked for the NHS. I always worked. I done boxing for eight year... I was really active. I'd only been married six months when this happened tae me and then my life has totally changed… I just don't feel like the same person. I feel guilt- a lot of guilt*.'

P2-1: '*I've always had problems with like pain and exhaustion since I was young, like a teenager – 15 year old and just, like, sleeping all day long. And I've never known anything different, so I don't feel as though – like you* [directed at other participant] – *you probably had to grieve a lot of things. I've always been like this*.'

Participants contemplated aspects of acceptance within their own experiences, and how these factors influenced individual responses.

P4-2: *I went to a dance show at the weekend there and it's took me days to get o'er… I knew before I went I was gonna be in agony because it's like theatre seats, and I just think when you wake up on they days, it's very hard to have the positive mind set… and say oh I totally accept what's happened to me the day, but on other days I don't feel as bad and I'm gonna make the best of what I feel…but it's hard and I don't think every day you could wake up and say I've accepted this, this is the way my life is*.'

P6-1 '*The pain management [course], she felt, was like… just accept and then whatever… whereas I felt in a different way that by learning more about it, and getting a better understanding helped me, kind of overcome things*.'

The language of acceptance was also discussed with different preferences and meanings that are applied.
P5-1 '*I think that each individual is different and they look at that word [acceptance] with a different perspective… each individual has got their own experiences… it's not easy for everybody to accept the conditions, and the struggles they go through every day*.'

P4-2 '*Stop saying 'acceptance'… coming tae terms wi it, or coping wi it, I think is better.'*

The participants in this study had severe, daily chronic pain and described the varying impact of the pain

intensity, functional and financial restrictions, emotional responses to the situations, and the demand of bearing the pain.

P5-D: '*this morning I was screaming because it was so sore and seeing I've got osteoarthritis in my left shoulder – it comes down to my elbow, the pain. I can't lie down on my left side, cos it's that bad*.'

P7-D: 'Trying to clean the flat is becoming so difficult as it triggers my pain and I have so many accidents doing so, cuts, burns, flooding my bathroom and kitchen. I try to do these tasks and cooking in small amounts however with the pain so acute and find myself having not eaten in so many hours and sick from medication.'

P4-D '*I feel anxiety more than ever in my life since my accident. I definitely relate to feeling a failure/ burden. I worry constantly about finances… other people's perception of you, weighs on your mind'*

Participants described different ways of coping and strategies they use to bear the pain, with examples as follows:
P1-D *'Eventually got up and used herbal cannabis in a vaporizer which did help to sleep until around 09:00… Spent the day crafting as I always find it easier to push the pain to the back of my mind if I stay busy.'*

P6-D 'If I am in absolute agony and not able to do anything I relax for a wee while meditate this usually helps and take my tablets.

The idea of trying to stay 'positive' while pain-bearing arose during the group, two participants used this to cope mentally. P5: '*you have to try to keep positive in order to try to keep your sanity and keep going… in the beginning it was very hard for me to do it as well… you have to start putting it into a routine*.' However, P4 questioned whether this approach was realistic or helpful for her: *'I think that's alright saying that but see when you are saying that and you're in absolute agony – like obviously you [P5] are tae, but it is very hard to always have that positive outlook.*'

Discussion

Summary of qualitative findings

The findings of this study expand on our earlier research findings and show context specific to life for people with severe, chronic pain in Scotland in 2024, without socioeconomic privilege. By exploring the idea of an 'Ecosystem' with people who live with chronic pain and experience marginalisation, we show new insights into phenomena associated with coming to terms (and living) with chronic pain; including how state systems, structures and societal attitudes can influence experiences. Individuals with chronic pain (such as the participants of this study) may accept aspects of their painful condition, however, others around them, HCPs and institutional structures may not accept (or account for) the nature of chronic pain, leading to distress, stigmatisation, feeling misunderstood and lack of inclusion. Participants describe difficulties associated with the invisible and subjective nature of chronic pain – an ill-fit with the objectivity often sought within society. Participants felt that they do not fit and are discredited, whereas one could interpret that it is their condition – (severe) chronic pain – that is not adequately accounted for by systemic structures. 'Acceptance' and 'accepting' should therefore be not only understood as individual factors/processes, but as systemic qualities, demonstrating why systemic and societal structures should be the targets of improvement focused work.

Participants described positive experiences when they felt chronic pain was understood and accepted, shown when they were listened to, supported, with trust and time important features of the healthcare journey. Participants valued pain groups, learning ways of coping and meeting others who shared their experiences. Participants thought it was important to get good information early in the journey with chronic pain – an important area for improvement that proves complex to deliver. Participants also highlighted the financial impact of chronic pain, and how insufficient finances were detrimental to health and wellbeing through increased worry, limited capacity to engage in socialising and exercise, and maintain a warm house. Individual experiences of accepting varied, including differences in: language preferences; personal socioeconomic situations and social networks; the nature of the painful condition including severity, legitimacy, and the onset, and ways of coping and managing condition/s and health. Drawing out the individuality of the phenomena associated with accepting adds to our earlier research.

The findings give a snapshot of life for people with severe, chronic pain in Scotland in 2024, without socioeconomic privilege. The participants have rich experiences of living with chronic pain, and engaging with healthcare and social security systems, thus provided

many helpful insights and focus towards areas for improvement.

Comparison with existing literature

The nature of chronic pain as an invisible condition, often poorly understood and accepted across society, featured throughout the findings, and the problems that this can bring for individuals are well documented.[15, 46, 47]

The data shows harm to participants' health that has occurred related to the benefits system and the wider discourses surrounding it, causing stress, anxiety, and stigmatisation. Stress and psychological factors are well known to influence pain perception, with increased distress associated with chronicity and severity of chronic pain.[48-50] The negative impact of social security interactions on health is found elsewhere in the literature. Garthwaite[51, 52] found that her participants receiving incapacity benefit in England experienced a sense of worry, mistrust, depersonalisation and stigmatisation, that impacted negatively on their health. Any negative impact on health appears to have worsened with the introduction of Universal Credit, which led to food insecurity, crimes of survival such as shoplifting, worsening mental health including suicidal thoughts, with further shame over the need to seek financial assistance from friends or family, or use food banks.[25]

Our data demonstrates the difficulties of negotiating a disabled identity and the emotional work of proving disability and ill health for the purposes of gaining social security benefits. The chronic illness literature shows that disruption to identity (and any associated reconciliation) may be connected to: access to socioeconomic resources; health expectations that may be influenced by age and/or poverty; illness trajectory and severity, and to discourses that marginalise or stigmatise individuals who cannot work, have pain, take drugs, are disabled, or receive benefits.[13, 15, 53-56] These factors may be complicated by moral judgements about self-worth,[52, 57, 58] and can lead to difficulties accepting help and financial support, perhaps one of the reasons why benefits are underclaimed in the UK.[25, 51, 52]

The language and policies promoted by the UK government and politicians in recent years has been criticised for including sick and disabled people in an active process of marginalisation.[25, 52, 59] Furthermore, in recent years, higher loss of social security payments across local authority areas is associated with earlier deaths in the areas most affected.[60]

Recent evidence shows that people with health conditions are more likely to leave workplaces that lack flexibility and control over roles and tasks.[61] Characteristics of chronic pain including unpredictability, limited mobility and poor sleep bring further challenges.[62] Characteristics of successful and sustainable return to work for people with low back pain, across high-income countries, includes adaptation of workplaces, job redesign and less strict social security criteria that offers flexibility.[63] However, unlike many other high-income countries, the UK has not taken a pro-active approach to worker health.[61]

Pain is a political and economic issue; the individual continually engages with institutions, discourses, norms and pressures.[12, 64] Our findings echo calls for caring and inclusive societal models and narratives that are accepting of individuals with chronic pain and their needs. For example, concepts of an inclusive economy where equity is deliberately fostered and different types of work accounted for [65] could prove positive for health outcomes and equity. Addressing prevention of ill health may further benefit from 'wellbeing economy' models and policies that place priority on human and ecological wellbeing.[66]

Our findings show a need to improve GPs' knowledge of chronic pain, access to relational care, continuity and sufficiently resourced care, similar to recent literature recommendations.[67-69] Provision of knowledge and information about chronic pain and referrals for input beyond medications were also thought important and should be provided earlier in the journey, similar to recent research.[69] Higher socioeconomic groups more readily access knowledge, prestige, power, and beneficial social connections which can have a positive impact on health.[70] Access to knowledge and information is proposed as influential in successful management of chronic illness.[71] Structural and systemic features of healthcare are important enablers of any uptake of information and knowledge about health, and lend weight to concepts such as 'health literate' organisations,[72] again, switching the focus of improvements to systems and structures over individuals.

Strengths and Limitations

Strengths of the study include the steps that we applied to foster inclusion. We wanted to recruit people who may not have otherwise put themselves forwards

for research involvement, hoping to counter the epistemic injustice (silencing) that can occur, and to contribute to improved participation in research. The strength of the dual role of clinician-researcher should also be recognised here in identifying the need for the study topic, providing insights into participation/inclusion and in recruitment.

Limitations of the study are mostly due to the nature of the cohort and the recruitment; a higher number of participants may have given a more diverse range of perspectives and insights. The study was not designed to achieve data saturation; rather, purposive sampling was used to recruit participants with specific, relevant lived experiences, consistent with qualitative approaches prioritising depth and contextual specificity over breadth, for example, Smith et al.[13]. We did not aim for the cohort to be representative of all with chronic pain, or who may experience marginalisation within an intersectional framing. We had limited perspectives of current caring responsibilities and those at paid work – many at work may struggle to make ends meet and have difficulty even attending for healthcare appointments.[73] All participants identified as straight and cis-gender, and we gained limited understanding of racialised marginalisation. The 'ecosystem' concept is contextual and should be expected to vary across groups of people, and the research here was exploratory in nature.

We only involved four GP colleagues in recruitment who had limited time to raise potential study participation with patients. Another factor that potentially limited recruitment was the time commitment and lack of flexibility regarding the days and location of the study. In future we could improve flexibility by conducting a one-off focus group or world café in different locations.

Conclusions

Our findings show new insights into phenomena associated with coming to terms (and living) with chronic pain; including how state systems, structures and societal attitudes can influence experiences. Individuals with chronic pain may accept aspects of their painful condition, however, others around them, HCPs and institutional structures may not accept (or account for) the nature of chronic pain, leading to our framing of 'accepting' or 'unaccepting' systems. We hope this prompts both wider investigation of how systemic and societal acceptance of chronic pain could be improved (where adaptive), and action to address areas for improvement including: awareness of chronic pain; the importance of time and communication in appointments for chronic pain (these should respect the individual nature of language and experiences with chronic pain), and the influence of political rhetoric and social security system operations.

Without a societal shift to prevention (including primary prevention to address the social determinants of health), chronic pain is modelled to increase in coming years, continuing to disproportionately affect socioeconomically disadvantaged groups.[74] Understanding and addressing mechanisms of inequalities should be a focus of research, care and policy programmes. In our research we demonstrate a focus on working with individuals with chronic pain, without socioeconomic privilege, to give insights into their lives and the impact of social context including political decisions – pain is unavoidably political for those at the sharp end of these experiences. While we only recruited seven people and cannot claim to represent the broad diversity of experiences of marginalisation, we hope the study offers insight into the impact of systems and directs focus towards improvements across healthcare, social security, workplaces, policy, political rhetoric and economic systems.

Conflict of interest:

DB is academic lead for the Scottish Deep End Project, a collaboration between academics and frontline primary care practitioners working in the most socioeconomically disadvantaged communities in Scotland.

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Author Contributions:

CM: Conceptualisation; Methodology; Investigation; Formal Analysis; Data Curation; Project Administration; Funding Acquisition; Writing – Original Draft; Writing – Review and Editing. CM conceived and led the study, obtained ethical approvals, led participant recruitment, facilitated all three focus groups, transcribed and led the analysis of qualitative data, and drafted the first version of the manuscript.

DB: Investigation; Methodology; Supervision; Formal Analysis; Writing – Review and Editing. DB co-facilitated focus group two and conducted independent analysis of the second focus group transcript, contributing to interpretation of findings.

SS: Supervision; Writing – Review and Editing. SS contributed to supervision of the study, and interpretation of findings.

CS: Investigation; Methodology; Supervision; Formal Analysis; Writing – Review and Editing. CS co-facilitated focus groups one and three, conducted independent analysis of the transcripts, contributed to supervision of the study, and contributed to interpretation of findings.

All authors contributed to revisions of the manuscript and approved the final version.

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Supplementary File 1: qualitative reporting criteria table as per O'Brien et al. (2014).

Qualitative reporting Criterion	**Where point is addressed in manuscript**
S1 Title	y
S2 abstract	y
Introduction	
S3 Problem formulation	1.0
S4 Purpose/research question	1.0 and 2.0
Methods	
S5 Qual approach and research paradigm	2.0 and 2.1
S6 researcher characteristics and reflexivity	2.3
S7 Context/setting	2.2
S8 sampling strategy	2.4
S9 ethical issues	2.7
S10 data collection methods	2.5
S11 data collection instruments and technologies	2.5 and 2.6
S12 units of study	2.4
S13 data processing	2.6
S14 data analysis	2.6
S15 techniques to enhance trustworthiness and credibility	2.6
Findings	
S16 synthesis and main findings	3.0
S17 links to empirical data	3.0
Discussion	
S18 integration with prior work, implications, transferability, and contribution(s) to the field	4.1 and 4.2
S19 Limitations	4.3
Other	
S20 conflicts of interest	As per journal preference
S21 funding	As per journal preference

Supplementary File 2: Inclusion and Exclusion Criteria

Inclusion criteria
1. People who lived with long-term, non-malignant, chronic pain for over 1 year. 2. Willing and able to offer views on research findings, and give informed consent to take part. 3. Self-identified as experiencing *one or more* of the following: • May experience difficulty in making ends meet. • Presence of comorbidities in addition to chronic pain, including depression or anxiety. • Disabled by chronic pain (possibly limiting work including unpaid work such as care or household management) and/or receive benefits related to chronic pain. • Belong to an ethnic minority group. • May have difficulty accessing services, this could include attending appointments, childcare restrictions, or travel difficulties. • Marginalised due to gender or sexuality (e.g. experience of domestic violence, or of discrimination).
Exclusion Criteria
• Could not give informed consent to participate in the study (the participant required capacity to give consent). • The study involved potentially talking about upsetting experiences including the topic of accepting life with chronic pain. Exclusion therefore applied to those with significant uncontrolled/ unstable psychiatric disorders, including if they were actively suicidal. • Resident of the UK of less than a year prior to recruitment (limited perspectives on care in this country). • Any of CM active patients. • Chronic pain associated with cancer or other terminal illness. • Risk of violent behaviour to others.

Supplementary File 3: Demographic Interview Guide

The interview guide contains questions about participant demographics including standard tools for the collection of ethnic background and disability data respectively, questions from the Scottish Core Minimum Dataset. Participants will choose from those forms for the relevant questions as they come up in the schedule below. Postcode will be converted to SIMD decile using www.simd.scot and SIMD is what will remain recorded after the interview. Items six to ten of the Scottish Core Minimum Dataset are also used and are given at the end of the guide. This interview schedule also includes some questions about the study logistics.

CM to explain purpose of data collection: '*Our personal characteristics may affect how we experience pain. The demands that are placed on us including work and aspects of our health may affect our experience of living with chronic pain. Different aspects of our identities may affect discrimination we face. Because of this, I would like to ask you a few details about your own identity and situation, if that is OK?...[await response] I also need to take some logistical details for planning the study. The details that you give me will be kept confidentially and securely. I will type it straight into a password protected form on my laptop. I would also like to advise you that you are free to skip questions or not answer them without repercussion*.'

The questions are as follows:

Age:

Socioeconomic details

1. What is your postcode:
2. Do you ever have difficulty making ends meet at the end of the month? never, rarely, sometimes, frequently, always:
3. How would you define your class? E.g. working, middle, upper
4. What is your highest level of education? primary, secondary, tertiary HNC, HND, modules, tertiary degree level or above:
5. Are you in paid employment? Full time, part time, no
6. Are you an unpaid carer? Number of hours:

Gender and sexuality:

7. Are you male, female, non-binary/ third gender, prefer not to say:
8. Are you cisgender (same gender as you were assigned at birth), transgender (different gender from assigned at birth), other or questioning:
9. How would you define your sexuality? straight, bisexual, lesbian, gay, prefer not to answer:

Ethnicity:

10. Please choose from the standard form (below):

Disabled status and disabilities:

11. Please choose from the standard equalities from (types of disabilities, form below):
12. Do you identify as disabled:
13. Do you receive benefits related to your health or disabled status?

Health and pain:

14. In addition to your painful condition/ chronic pain, what other long-term conditions/ illnesses do you live with e.g. asthma, high blood pressure, diabetes, rheumatoid arthritis, hypothyroidism, depression, IBS?
    Follow up, are there are any others that you think your GP may have recorded on their system for you?
15. How long in years and months have you lived with this pain?

16. Scot core min data set items 6-10 complete using form below:

Study requirements and arrangements:

GP letter details

17. Name of GP and practice:
18. Participant's date of birth:

The participant's preference for receiving information about the meta-ethnography findings, will be taken, along with preference for focus group time, location and transport requirements. The researcher will offer to show the participant short videos of the meta-ethnography findings, or they may prefer to watch these in their own time, or at another time. The researcher will also give the participant a diary and explain it's use, with an alternative option of emailing any diary entries to the researcher.

Focus group logistics:

19. Preference for time of day and location (in Lanarkshire):
20. Transport requirements, will participant be using their own means of transport or would they like a taxi booked for them:

Preference for receiving initial information about the meta-ethnography findings

21. Would you prefer to receive information about the findings by watching videos, reading our summaries of this, or both (provide with video links, or paper as requested). I can show you the videos in a moment using my laptop if this is convenient for you:

We would like participants to use a diary to record any thoughts you have about the findings and this is optional. The first diary is about how you relate the findings. Please record the date and any ideas that you have about how your own experiences relate to the 'Ecosystem of Accepting life with chronic pain.' We suggest you could make a brief note when you have a good day, or a bad day and just a one line description, and that you leave the diary in a place where they will see it most days.

22. Are there any adaptations that would be helpful like emailing entries? (may include a voice recording converted to text by phone if person unable to write)
23. Do you have any questions about the diary?

Finish the time with participant by showing study video to participants using my laptop (estimated approx. 10 minutes).

Check if further questions from participant.

NHS Scotland: Equalities Monitoring Form

Q4. What is your **ethnic group**? (Choose **ONE** section from A to E then X **ONE** box which best describes your ethnic group or background)

A. White

Scottish ☐ Other British ☐ Irish ☐

Gypsy / Traveller ☐ Polish ☐

Other white ethnic group, (please specify) _____

B. Mixed or multiple ethnic groups

Any mixed or multiple ethnic groups, (please specify)

_____

C. Asian, Asian Scottish or Asian British ☐

Pakistani, Pakistani Scottish or Pakistani British
Indian, Indian Scottish or Indian British ☐
Bangladeshi, Bangladeshi Scottish or Bangladeshi British ☐
Chinese, Chinese Scottish or Chinese British ☐
Other Asian group, (please specify) _____

D. African
African, African Scottish or African British ☐
Other African group, (please specify) _____

E. Caribbean or Black
Caribbean, Caribbean Scottish or Caribbean British ☐
Black, Black Scottish or Black British ☐
Other Caribbean or Black group, (please specify) _____

F. Other ethnic group
Arab, Arab Scottish or Arab British ☐
Other ethnic group, (please specify) _____
Prefer not to answer ☐

Q1. Do you have any of the following? (Please X **ALL** that apply)

Deafness or severe hearing impairment ☐
Blindness or severe vision impairment ☐
A physical disability ☐
A learning disability (such as Down Syndrome) ☐
A learning difficulty (such as dyslexia) ☐
A mental health condition (such as depression or schizophrenia) ☐
A long term illness (such as diabetes, cancer, HIV, heart disease or epilepsy) ☐
Other – please write

None of the above ☐
Prefer not to answer ☐

Items from Scottish Core Minimum Data set for chronic pain (Laskawska et al., 2022)

Pain Intensity

In the past three months, on average, how intense was your pain rated on a 0-10 grade scale where 0 is “no pain” and 10 is “pain as bad as it could be”.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

No Pain — Pain as bad as it could be.

Emotional Impact

Please circle the option that applies to you.

Over the past 2 weeks, how often have you been bothered by any of the following problems?	Not At All	Several Days	More Than Half the Days	Nearly Every Day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed or hopeless	0	1	2	3

Functional Impact

In the past six months, how much has this pain interfered with your daily activities rated on a 0-10 scale where 0 is “no interference” and 10 is “unable to carry on activities”

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

No interference — Unable to carry on activities

Supplementary File 4: Focus Group Guides (for all three rounds of groups)

Focus Group 1 Guide

Facilitator preparation

Two facilitators are present - CM and supervisor. CM leads the facilitation and supervisor supports the facilitation, and notes observations. There is tested, and working, audio recording equipment. The venue is accessible and there is enough space for participants to stand up or move if they wish. Housekeeping items are known including likelihood of fire alarm drills, fire procedures, location and working state of toilets. Water and refreshments are available. Projection equipment to display slides and give overview of meta-ethnography themes is available and working. Required paperwork including the ecosystem illustration is available. Travel arrangements for participants is in place such as taxi prepayment.

For working with interpreter/s the process for this has been pre-arranged.

Introduction to group and ground rules

- Welcome, thanks and housekeeping
- Purpose of the focus group is explained and outline of session given including break. CM will remind participants of the purpose of the group being the focus on engagement with the meta-ethnography findings; that the group is not a therapy group and request that participants do not go into graphic descriptions of previous traumatic events. CM will acknowledge acceptance can be upsetting and that we may discuss this during the session. If this raises issues for people, they may flag this to me and I can advise on any further care they may seek for this (as outlined in protocol).
- Reminder of audio-recording taking place.
- Ground rules including confidentiality - sharing of perspectives but not personal details
- CM will tell the participants that they do not need to answer all of the questions, participation is voluntary and they can withdraw or take time out at any point.

Icebreakers and personal introductions

- Each person is asked to say their first/ preferred name (also for purposes of audio-recorder)
- Each person is asked to share a piece of non controversial information about themselves – a theme of favourite ice cream flavour is a suggestion.

Main session: relatedness of findings to participants own experience

Cass gives brief overview of the meta-ethnography finding use the illustration of the ecosystem, using PP slide. Each person also has a paper version of this

- How do these findings relate to your own experience of living with chronic pain?
- Are there ways the findings do not relate to your own experience?

BREAK 10-15 mins

Cass prompts a reminder of each individual cluster finding with a question in turn, after each section

- Are there any things in particular about an individual aspect of the ecosystem that relates to your own experience?

Fluid and continuous journey and fluctuating states: nature of fluid and continuous journey, fluctuating states, turning point, iterative steps, mental health
Language and meaning: difficulty with underpinning fluidity, terminology of acceptance, meaning of the painful condition – important to have a diagnosis/ name for symptoms that is associated with management and validity
Caring, supportive, coherent system

The challenge to identity in a capitalist, ableist system + limits of individualism

Cass prompts a reminder that the ecosystem is a whole system

- Is there anything about the ecosystem as a whole that relates?

Feedback from diaries

Are there anything from your diaries that we haven't discussed yet that you would like to raise?

Summary

Summarise some of main points, co-facilitator will assist with this. Ask for any feedback about the running of the group.

Closing

- Thank participants
- Reminder of my contact details if required and that I will check in with them between focus groups
- Diaries collected and new diaries for next focus group given and explained – ideas for improving journey
- Next focus group arrangements

Focus group 2 guide

Facilitator preparation

Two facilitators are present - CM and supervisor. CM leads the facilitation and supervisor supports the facilitation, and notes observations. There is tested, and working, audio recording equipment. The venue is accessible and there is enough space for participants to stand up or move if they wish. Housekeeping items are known including likelihood of fire alarm drills, fire procedures, location and working state of toilets. Water and refreshments are available. Projection equipment to display slides and give overview of meta-ethnography themes is available and working. Required paperwork including the ecosystem illustration is available. Travel arrangements for participants is in place such as taxi prepayment.

For working with interpreter/s the process for this has been pre-arranged.

Introduction to group and ground rules

- Welcome, thanks and housekeeping
- Purpose of the focus group is explained and outline of session given including break. CM will remind participants of the purpose of the group being the focus on engagement with the meta-ethnography findings; that the group is not a therapy group and request that participants do not go into graphic descriptions of previous traumatic events. CM will acknowledge acceptance can be upsetting and that we may discuss this during the session. If this raises issues for people, they may flag this to me and I can advise on any further care they may seek for this (as outlined in protocol).
- Reminder of audio-recording taking place.
- Ground rules including confidentiality - sharing of perspectives but not personal details
- CM will tell the participants that they do not need to answer all of the questions, participation is voluntary and they can withdraw or take time out at any point.

Re-introductions

- Each person is asked to say their first/ preferred name (also for purposes of audio-recorder)

Presentation of findings from Focus group 1

- CM will give a summary of the main themes of the first round of focus groups about how participants related to the findings

Main session: How could the findings be used to improve the process and care journey?

- How could these findings be used to improve someone's experience on the journey? Could prompt in each individual cluster finding

BREAK 10-15 minutes

- What do you think about how we talk about 'acceptance'?
- Some of the findings are about wider societal issues and about our culture and political influences. How do you think future research or developments should factor in these aspects of the findings?

Feedback from diaries

Are there anything from your diaries that we haven't discussed yet that you would like to raise?

Summary

Summarise some of main points, co-facilitator will assist with this. Ask for any feedback about the running of the group.

Closing

- Thank participants
- Reminder of my contact details if required and that I will check in with them between focus groups
- Next focus group arrangements

Focus group 3: incorporating nominal group technique 14th May 2024

Facilitator preparation

Two facilitators are present - CM and supervisor - CS. CM leads the facilitation and supervisor supports the facilitation, and notes observations. There is tested, and working, audio recording equipment. The venue is accessible and there is enough space for participants to stand up or move if they wish. Housekeeping items are known including likelihood of fire alarm drills, fire procedures, location and working state of toilets. Water and refreshments are available. Flipchart paper is available. Required paperwork including the ecosystem illustration is available. Travel arrangements for participants is in place such as taxi prepayment.

Require: blank flipchart paper, travel money, refreshments, printed out summary sheet of FG1, 2 and specific questions, print out of PAS info, pain concern info, sheets for voting, pens/ pencils.

Introduction to group and ground rules

- Welcome, thanks and housekeeping
- Purpose of the focus group is explained and outline of session given including break. Show ground rules sheet as previous.
- Reminder of audio-recording
- Ground rules including confidentiality - sharing of perspectives but not personal details.
- I will remind the participants that they do not need to answer all of the questions, participation is voluntary and they can withdraw or take time out at any point.

Main session:

Summary of findings from focus group 2 – give summary sheet and explain this, also give summary sheet of focus group 1 as a reminder.

[Begin audio recording]

Ask for any feedback or thoughts on FG 2 summary.
Ask specific questions based on queries I have about the data/ findings/ perspectives so far
Specific questions for start of Focus group 3:

1. Understanding has been raised as an important issue – what are the key things that you want people who don't have chronic pain to understand?
2. In focus group 1, GP's knowledge of chronic pain was raised as an issue – do you think this is connected to the issue of 'understanding' in some way?
3. I am wondering if wanting others to understand is also about other people and systems ***accepting*** the nature of chronic pain – what do you think about acceptance applied to the systems and people around you?
4. If you ran an awareness raising campaign, what would you want people to know?
5. Ongoing group support has been suggested as an idea for improvement. Are you aware of the monthly Pain Association groups that run in Lanarkshire? [give out PAS sheet https://painassociation.co.uk] Is this the type of thing you mean, or do you mean something different?
6. Understanding and, sharing with others who have similar experiences were things that were important to many of you – is this like a sense of 'solidarity' that you get? Is it something else?
7. You were all talking, in some way, about the way that the benefits system and societal judgements/ expectations can make you feel. For the analysis, I have to make sense of this. I am wondering if you think there is a sense of shame that comes from having chronic pain and it's impact? If so, how do you relate to that?

BREAK

Nominal group technique

The question is: for people coming to terms with chronic pain, how can the process and experience (or the ecosystem – show picture) be improved?
Check if any questions about the question/ task.
Silent generation of ideas based on the question.
Add ideas to flipchart paper. CM goes around the group one at a time, adding ideas to the flipchart paper. This is done one idea at a time and participants take turns until all ideas are added.
Clarification of ideas – the ideas are discussed and clarified, and if appropriate can be grouped together. CM summarises (with CS help) final sheet and this is added to the wall with numbered ideas.
Voting on ideas – participants will be asked to pick their 5 top ideas and rank these in order of preference. The most important idea will be ranked one and allocated 5 points, with this decreasing in value to the fifth idea allocated 1 point. This will allow for a summed prioritisation of ideas. [CS – tally votes]
Future dissemination of ideas – group ideas for how findings should be disseminated:
Do you have any ideas for how we can share or communicate this work with others?
Who should it be shared with?
What is the best way to get the ideas across?

Closing

- Summarise some of main points, co-facilitator will also be handy here.
- What happens next with our research work – CM analysis – will post out an update of the study/ summary of findings. May seek further feedback, but don't have anything further in ethics protocol.
- Thank participants

Supplementary File 5

Supplementary file 5 has four sections: 1) a record of the fuller data analysis process; 2) summary points of focus group 1; 3) summary points of focus group 2; 4) removed portions of data text.

Extended record of the data analysis process

For each focus group, CM transcribed the audio recording on to Microsoft Word, verbatim including vernacular, applying pseudonyms instead of participant names. CM then checked and edited the transcription while listening to the recording and added any details from the notes gathered by the second facilitator. On the Microsoft word file of the transcript, CM labelled each section of data with both the focus group and participant number. For each transcript CM removed or reduced text that was not relevant to the research questions, for example social interactions amongst group members. CM typed up the diary analysis after each of the first two focus groups. She kept 'field notes' throughout the whole focus group and data analysis process, of when she conducted what tasks, phone calls and arrangements, decisions made about coding, meetings with other team members/advisors, and her own perspectives on focus groups.

In approaching initial coding for each focus group, we expected that there would be both a-priori and emergent codes, due to the nature of the research. Following the first focus group, CM developed broad codes on the Microsoft Word file, and then reduced these further into categories where there was some shared sense of meaning (Pope et al., 2020). CM combined the diary analysis, extending the coding categories as necessary, reduced and summarised the points into a One Sheet Of Paper (OSOP) analysis that combined the diary and focus group data (Pope et al., 2020). CM met CS to compare codes, who had independently coded a copy of the transcript. He used framework analysis based on the meta-ethnography (therefore all codes that he had were based on that and could not use this to compare any of CM's new codes). CM revised her codes slightly based on the discussion. CM then developed a list of bullet point summary findings and met with lived experience advisor (KN) to go through the summary points and check how she understood these, and edited these further, prior to giving out this sheet at the start of focus group two (see below).

Following focus group two, CM used the same method of transcribing, reducing the text, applying codes, and then developing categories, combining the diary data. CM then met with DB, who independently analysed a copy of the transcript, to compare initial codes and noted where there were similarities and differences and we discussed areas of potential themes at that point. CM typed up a list of summary points (see below) and formulated questions about potential themes to raise with the participants at the start of focus group three (see supplementary file 4).

Following transcription of focus group three, CM arranged the data into the broad categories that occurred which were largely based on the interview questions. To combine the qualitative analysis of all three focus groups, CM laid out the distinctive categories of focus group two, and then added the distinctive categories of focus group one, and combined some categories where there was overlap. The categories that she combined across the data for focus groups one and two, were mainly around ideas for improvement, and also the individual variations in experiences of acceptance. CM then added the sections of the focus group three data to this combined transcript, reduced down duplication and removed text without meaning to the research questions. CM then read and re-read the combined transcript, to get a sense of where there was shared meaning thus categories could be combined into a coherent sense of meaning.

CM found an initial set of six categories that included both a-priori and emergent meanings. She wrote summary lines for each category, and at this point, kept all of the data portions that contained any distinct aspect of meaning relevant to my research questions, and removed sections that did not. CM then passed the combined analysis to ET (an advisor) for feedback and we met in August 2024 to discuss aspects of key meaning from the data, and possible ways of reducing the high volume of data (and therefore bringing out key points).

In extending the analysis, CM set aside small portions of the combined analysis data that replicated the meta-ethnography findings and did not give new meaning/ insight to those findings, or address the research questions. The portions that set aside included sections called 'relating to the rosebush', and a section where the participants discussed their participation in the research process (mainly enjoyment of sharing, and expressed care for each other). CM added the removed data sections to the appendix for transparency (see below). CM re-read the analysis text and extended her analysis into three themes. CM reallocated some of the data portions between themes, and reduced down the data to distil and display the data to best represent her interpretation. CM sought further feedback on the themes of the analysis from SS and then slightly revised and clarified the meaning of the themes in January 2025, bringing out aspects of subthemes further. CM was guided by Braun and Clarke (2022) in what a theme should be. In February 2025, CM talked the themes and terminology through with my lived experience advisor (KN) who also took part as a participant, and discussed the descriptors of the first theme and possibly alternate terms for dehumanising, including demoralising and stigmatising (deciding on 'dehumanising' in the end).

Summary points of Focus Group (and diaries) findings

Participants could relate to the accepting journey being circular, fluctuating and that this partly related to the nature of the painful experience, and other things that happen in life.

The journey was helped by receiving a diagnosis/ explanation that made sense, and pain management input.

Mental health is a big issue for people living with chronic pain – affecting life in many ways.

Some participants feel like different people from before their pain started due to the significant and overwhelming nature of their current situation with pain. Others have always had pain so didn't experience any different.

The meaning and experiences with 'acceptance' are individual and related to the condition/s, degree of losses, social situation and impact of pain. The word can be understood as dismissive.

Daily life includes the work of bearing the pain and the impact of the pain. Life includes the additional work of managing health conditions and factoring in the impact of pain, including with household tasks, coping with mental health, managing medications, interactions with healthcare and benefits systems.

Good days also occur and these might include being with family/ friends.

Participants described needs of healthcare professionals, care and wider systems, and these might include clear information, time, dialogue, empathy, referrals and support with navigating systems.

The GP having 'good knowledge' of chronic pain was associated with positive interactions whereas poor knowledge was associated with negative interactions.

People develop their own expertise in managing their painful condition and use this to manage daily life and flare ups. Being the expert might affect the power dynamic in relationships in healthcare. Dark chocolate gingers are the correct biscuit choice for a Lanarkshire focus group (!)

Summary of Focus group (and diaries) two

Participants have different views on how to talk about 'acceptance' – some think it's a good term, meaning a positive, peaceful state. Others prefer 'coming to terms', 'coping', 'compromising with your conditions and situation.'

Acceptance is like a turning point and is important but it is not a fixed state and it might vary from day to day and be harder on a 'bad' day.

Acceptance is about more than the pain itself, also the condition, situation incl. weather, lack of cure, limitations, expectations to work (affected by age).

While participants may accept aspects of their pain and condition, systems, others around them and healthcare may not accept the nature of chronic pain which causes stress, self-doubt and feeling mis-understood.

Working age and financially insecure participants in particular, experienced the benefits system as an incoherent and dehumanising experience, that exacerbates mental health difficulties and pain.

Judgements and cultural expectations might be internalised by participants, engaging in self-depreciation, or encouraged to act in a degrading way to 'prove' their ill health/ lack of capacity for work.
Suggestions to improve social security include – recognise differences; listen to people with knowledge about chronic pain; give people enough to live on; connection and interaction with healthcare in making assessment and examining individual cases.

Feeling understood, sharing with others in a similar situation, and gaining insight into others similar experiences, can help participants to feel validated and experience positive feelings, realising it's 'not just me.' Participants possibly describe this like a sense of solidarity.

Care that facilitates understanding, validation and sharing with others is helpful this could include groups earlier in the journey and to support the ongoing nature of the journey.

Continuity of care is important and seeing the same GP who knows you and your conditions is important but often not achieved. The type of appointment is important too - in person is valued to get complex needs across.

Pain management groups previously helped some participants to change their understanding, approach and attitude to living with pain. Access to ongoing support is desirable.

Having politicians who can represent people with chronic pain is important – they should be interested in helping people over saving money or 'lining pockets'.

Campaigns to raise awareness and writing to elected representatives could be helpful.

Ideas that make invisible illness visible such as the 'sunflower badge' could be helpful.

Removed portions of data analysis text

Relating to 'the rosebush' and meta-ethnography findings

The study started with inquiry about the ways in which participants did/ not relate their own experiences to the findings of the meta-ethnography study, and I understand this theme as *a-priori*. I used the ecosystem figure as a discussion prompt and participants therefore refer to the 'rosebush' or components of the imagery.

Participants could relate to the circular, fluid and fluctuating nature of the journey with iterative steps. Within this journey, the daily experience with 'acceptance' also related to the nature of the painful experience, for example, whether one was experiencing a 'good' or 'bad' day.

P6-1: '*The chronic illness side of things and the disability side of things is like a total minefield… I've actually been a lot better recently, than what I was before, but again I have times that…as you say…it like, kind of goes in a circle…and then you need to kind of re-evaluate yourself again, and try and do all of the things that you did initially to make you feel a bit better…and use all your knowledge that you've already gained.*'

P2-1: related her experiences to the rosebush imagery of 'bad bits' i.e. thorns and 'good bits' i.e. the roses: '*On a good day when I'm fine, it's easy to accept it, but then when you start feeling bad and you canny get out your bed, you don't want to accept that is it…and you have to start the whole thing again… but…there is good bits in it as well, the days when you do feel good, and you do take the steps to try and better yourself*.'

P4-2: *I went to a dance show at the weekend there and it's took me days to get o'er… I knew before I went I was gonna be in agony because it's like theatre seats, and I just think when you wake up on they days, it's very hard to have the positive mind set… and say oh I totally accept what's happened to me the day, but on other days I don't feel as bad and I'm gonna make the best of what I feel…but it's hard and I don't think every day you could wake up and say I've accepted this, this is the way my life is*.

Six out of seven participants either explicitly described how receiving a diagnosis was a part of their accepting journey, or implicitly described accepting their long-term conditions, similar to the meta-ethnography findings.

P3-1: '*I needed the diagnosis tae accept that, I'm not saying that I 100% accept it now, cos there's some days and you just think, uch, this can't be me anymore, but it's just, it's just the way it is, but the diagnosis helped me accept it a wee toaty bit.*'

P6-1 '*I think just eventually with me, it was just getting the diagnosis eventually, and also the help from the pain management and everything, made it better for me, and whether it's acceptance, it doesn't really matter to me'*

Participants described a relationship with pain, acceptance and mental health states - the different ways that these concepts connect are illustrated below and this can occur in a positive or negative

direction. Later in the findings, mental health is connected with the experiences of the benefits system and also of health care.

P2-1' *I think that the rosebush is what it is… I think the first thing that I noticed about it was the failure word because that's the only thing that I felt…even before I had any diagnosis it was just [sighs] I couldn't do what other people could do… sometimes you can do everything right, you can go for the help, and you can do the CBT, and then you try your hardest and your body just still gives up on you, and then again, you feel like a failure*.'

P4-D '*I feel anxiety more than ever in my life since my accident. I definitely relate to feeling a failure/ burden. I worry constantly about finances…other people's perception of you, weighs on your mind'*
P1 noted a response, in his diary, to watching the video of the findings and experiencing some emotional relief in knowing he was not alone in his experiences: '*I felt quite emotional…I was listening to complete strangers describe much of the things I have to deal with on a daily basis - I wasn't alone… loneliness in a world of people who can do things I can't. Of feeling that I miss the things I used to do - the person I used to be. The video somehow brought it to me that I am still that person and I can still do these things although I might have to get a bit creative in how I do them - I can still do them*.'

P5 related in her diary to the desirable state of acceptance and the relationship with more positive mental health: '*Can be desirable and a hard and empowering. With an active adapting relationship with pain and it's impact. Whereas purpose to take responsibility to take action to deal with it…Acceptance – to being at peace within yourself*.'

Data primarily about the focus group and my research
P4-2 last time (in focus group 1), it makes me emotional talking aboot it, it does, cos it's just such a life changing thing that's happened and it just makes me dead emotional, like when I went hame, like once I had a wee greet I was alright…

P2-2 Things like this as well, and the fact that you've managed to put it into words exactly how not only I feel, but at least everybody in this room feels…and you feel kind of like, oh it's no happening, is it just me?… I actually, I might no be the problem, it might be the people who are supposed to be helping us…

P1-2 I was actually quite emotional… like I missed the session, but I know I told you, C…like I don't get emotional about stuff, but that [the findings video] really kind of, brought this thing, just to know that there were other people in on this, not maybe the same condition, but having to navigate their way through the same kind of ecosystem… so….yeah, it was just a very powerful introduction to it – that's why I was so annoyed at missing the first group

P5-2 I think you're spot on with what you've got there [summary of FG1 findings]. Like it feels like hope.

P5-2 I believe that when you're in a group like that [focus group 1], you tend to forget you're alone, and you share your conditions with everybody and go around and say how people have got their own struggles, so it's not just you struggling, there's people who are struggling as well.

P1-3 I spent since my diagnosis… it was just me but then when your study thing came along with these guys, I found myself thinking about these guys now…so I suppose there is a kind of sense of solidarity there…. We can appreciate, although we've no all got the same flavour of condition, emm, we can understand what each other are going through…it's a bit like a recovering alcoholic – they'll know what another recovering alcoholic is going through, that struggle, so I've got an appreciation of what these guys are having to go through. It has kind of given me that…it's not just me idea…so yeah, solidarity is definitely a part of something like this.

Ongoing group support has been suggested as an idea for improvement. Are you aware of the monthly Pain Association groups that run in Lanarkshire?...is this the type of thing you mean, or do you mean something different?

P1-3 I actually use the Pain Association website. I don't go tae the groups. I did go to one, one time, and it kinda dissolved into a general discussion…we didn't really end up talking about the issues. Emm, it became more of a social gathering…

P7-3 I mean group support is…is good… people do open up and you're understanding, you're listening, talk about the physical and the mental side of things and, the physical is what we're suffering. But even if you've got a stick or something and, like, if I was to wrap my hand up, in say like the bandages I had after my operation and put it in a sling, I guarantee there's be more questions or folk would be like 'oh what'…where like you say different people are… everybody's different you know, and you try and give them a bit of an insight tae, a comparison tae pain, like a toothache or something, you'd be like oh my God I want tae die here…but if people don't see it, like you see that wi doctors or down tae like your benefits system that's over a phone… cos you're constantly like having to explain.

P1-3 You can actually buy a T-shirt that says I'm not drunk, I have MS…cos you can't properly walk, you kind of stagger a wee bit..

P7-3 Group support is great for.. you know for individuals…especially when they're set up, for what you're doing C, and to make people aware that I don't know how long but hopefully not a life-time as such for it to be recognised, firstly as a medical condition, not just as like 'oh, chronic pain' which I believe if you are suffering from 3, 4 months with the same condition it's then considered chronic pain. It's when you have a condition there is no cure to, and it's about how to manage it, we're talking about pharmaceuticals and that. The struggle you have there. The struggle you have socially, like with your friends groups, you know, you're letting your friends down, beating yourself up that you can't do things, to get out, tae exercise, walk, tae just be sociable, and lock yourself away with a condition that deteriorates your body like is said earlier…terminal...it is… you know it's like that's the reality, it's like you want to scream from the rooftops…from group support, has to be an interlink, because people are coming to a group, there has to then be a link then to your medical practitioners to other systems.

Supplementary File 6: Lanarkshire Vernacular Table

Lanarkshire vernacular	English written language
Tae (tae accept it)	To (to accept it)
ye	you
Cannae	Can't
stookie	Plaster cast (on a body part)
wrang	wrong
wi	with
oot	out
greetin	crying
dae	do
Go off yer nut	go mad
aboot	about
ain	own
gies	gives
Heid roon aboot	my head around i.e. understanding
Yer oot the door	You are out of the room i.e. the consultation ends.
Oot wi ma pals	[Going] out with my friends
DWP	Department of Work and Pensions