

Clinical Pain Research

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Exploring how people with chronic pain understand their pain: a qualitative study

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Abstract

Objectives: A fundamental principle of pain management is educating patients on their pain using current neuroscience. However, current pain neurophysiology education (PNE) interventions show variable success in improving pain outcomes, and may be difficult to integrate with existing understanding of pain. This study aimed to investigate how people with chronic pain understand their pain, using qualitative exploration of their conceptualisations of pain, and how this understanding accommodated, or resisted, the messages of PNE.

Methods: Twelve UK adults with chronic pain were recruited through advertisements on online pain networks. Semi-structured interviews were conducted remotely, with responses elicited using the Grid Elaboration Method (GEM) and then a PNE article. Participants' grid elaborations and responses to PNE were analysed using thematic analysis (TA).

Results: Three main themes were extracted from participants' grid elaborations: communicating pain, explaining pain and living with pain. These themes incorporated varied, inconsistent sub-themes: of pain as simultaneously experiential and conceptual; in the body and in the mind; diagnosable and inexplicable; manageable and insuperable. Generalised, meta-level agreement was identified in participants' PNE responses, but with doubts about its practical value.

Conclusions: This study shows that people understand pain through inconsistent experiential models that may resist attempts at conceptual integration. Participants' elaborations showed diverse and dissonant conceptualisations, with experiential themes of restricted living; assault on the self; pursuit of understanding pain and abandonment of that pursuit. Responses, although unexpectedly compatible with PNE, suggested that PNE was perceived as intellectually engaging but practically inadequate. Experiential disconfirmation may be required for behavioural change inhibited by embedded fears and aversive experiences.

Ethical committee number: UCL REC# 17833/003.

Keywords: pain beliefs; pain education; PNE.

Introduction

Chronic pain is a leading global public health concern [1], affecting an estimated fifth of European adults [2]. It is associated with significant quality-of-life impairments [3], and individual and national economic burden [4]. Improving pain treatment and rehabilitation outcomes is increasingly urgent [5].

Pain is defined as an 'unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage' [6, 7], yet prevailing lay intuitions of all pain as meaning damage promote protective behaviours that can exacerbate chronic pain disability [8, 9]. Education is the basis of many rehabilitative pain treatments [10], aiming to counteract commonly held damage models and encourage previously avoided increases in activity [11]. Psychological treatments can reduce pain severity and disability [12], and carry less known risk of adverse effects than pharmacotherapy [13]. One widely propagated educational intervention, 'pain neurophysiology education' (PNE), emphasises desensitising neural systems by replacing tissue damage models with neuropsychological conceptualisation of pain [14, 15]. It has shifted the focus of pain education away from a

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biomedical account of local causes of pain towards a neuroscientific account of nervous system processing, including at a brain level [16].

However, despite some success in improving short-term pain severity and disability, evidence supporting PNE efficacy is mixed [16–19]. Systematic reviews show small effect sizes [20, 21], often equivalent to physiotherapy alone [19]. Although impressive results have emerged from individually delivered PNE [22, 23], a group RCT in which PNE was delivered by its originator found it to be no more effective than non-directive counselling [24].

Understanding how education interacts with prior pain beliefs requires appreciation of these beliefs. Inconsistencies or conflict between new and existing models do not necessarily motivate knowledge revision and conceptual change [25]. Few accounts of how people with chronic pain make sense of their pain capture individuals' implicit or explicit models [26]. One such study observed damage-oriented qualitative conceptualisations of persistent pain as complex, negative, immutable and representing 'a broken machine' [27]. Several qualitative studies highlight pursuit of understanding as core to chronic pain experiences [28, 29], but few have scrutinised sense-making directly. Even fewer studies examine sense-making in relation to PNE [22, 30, 31], with analytic focus on post-PNE reconceptualisation rather than on prior, unprimed sense-making.

This study explored pain understandings without direct priming, before asking participants to read and appraise PNE. Its primary research question was, 'How do people with chronic pain make sense of their pain?', and its second, 'How do participants engage with PNE in relation to their prior conceptualisations?'

Methods

Ethical approval was received from UCL Research Ethics Committee (ID 17833/003). The study used semi-structured, individual interviews of people with chronic pain to explore idiographic pain conceptualisations [32, 33]. In the first part of the interview, data were elicited using the Grid Elaboration Method (GEM) [34], and analysed using thematic analysis (TA) [35].

Participants

Participants were adults living in the UK with any type of chronic pain, recruited through local and national networks for people with chronic pain. A sample size of 12 participants was used, within the 6–15 participant range advocated for small-to-medium samples [36] and for studies scrutinising common perceptions or experiences [37].

Design

The GEM elicits immediate associations from participants, via a free association task (described below) [34], allowing relatively unconstrained description including inconsistent accounts. TA was used to locate explicit and latent patterns of meaning in the elaborations [38, 39], consistent with the framework of socially constructed understandings of pain shared by participants.

Core PNE concepts were presented in a short online article written by Moseley [40], the main author of PNE. Its brevity increased accessibility to participants, as intended [14], and using a written rather than video format allowed participants to digest the material at their preferred speed, re-reading if necessary. After reading the article, participants were asked to identify areas of agreement and disagreement between their own explanations of pain and explanations in the article. TA was chosen again as the method of analysis.

Procedure

All interviews were conducted through video-calls by the researcher (SK) between April and August 2020. Organisers of online patient groups, acquainted with the senior researcher (AW), were invited to share an information sheet with their pain networks. No incentive was offered for participation. Those who followed up the link on the information sheet were sent key details from the information sheet and a consent form for electronic signature. Upon returning the consent form and confirming an interview time, participants were emailed a numbered, 2 × 2, A4-sized grid (without instructions) and asked to print or draw it ready for the interview. An initial pilot interview provoked no substantive procedural adjustments but was excluded from TA.

In interview, participants were emailed GEM instructions: to write a word or phrase or to draw an image in each box that they associated with '*how [they] understand chronic pain – that is, how chronic pain works, why it starts, and carries on.*' Participants were given time to fill in the grid, but encouraged to follow their 'first thoughts'. Participants were then invited to elaborate on each grid response via open questions ('Can you tell me about what you've put here?'). Additional open questions were asked to elicit further elaboration ('Can you tell me more about that?'). Similar time spent elaborating on each grid box was encouraged but flexible ('Would you like to add anything?'). This interview stage took about 40 min, allowing time for elaboration.

Participants were then invited to read the PNE article, newly emailed to them, and introduced as a '*standard explanation of pain written by a famous pain neuroscientist.*' After reading, participants were asked: '*What, if anything, does this article change, or add to, or take away from the explanations you have given so far?*'; '*What parts of this article made the most sense to you, if any?*'; '*What parts made less sense to you, if any?*' Participants were allowed to answer each question without interruption before the next question was asked. If answers were brief, further elaboration was encouraged through open questions. Participants were then informed that the interview was concluded; asked brief demographic questions (though not including pain types); thanked for their involvement and given the opportunity to express queries or concerns.

Data analysis

An initial content analysis of participants' grid responses was conducted as a preliminary process of categorising the free associations and identifying their relative salience. This informed construction of the main coding frame (below) and sensitised the researcher to the overarching themes of participants' subsequent elaborations.

Interviews were transcribed from recordings, reproducing speech content verbatim but without intonational or other paraverbal information [41].

A coding frame of themes and sub-themes for TA was developed inductively from the transcribed elaborations. Coding and analysis were completed using the software package Atlas.ti.8, enabling systematic organisation and presentation of interrelated sub-themes. A reliability test was applied, whereby a third-party researcher blind-coded one sixth of the interviews and estimated coding similarity using Atlas.ti [42]. Quantifying agreement is contentious within qualitative epistemology, but comparison was made to check for notably idiosyncratic coding.

Because participants largely expressed agreement with the PNE and made no substantial elaborations on their GEM-derived pain concepts, initially planned framework analysis was replaced by a further TA, given its versatility [35].

Reflexive statement

Unintentional researcher influence on interviews and TA is inevitable [43]. The researcher (SK) is a highly educated white male in his mid-twenties with personal trust in scientific methods. At the outset of the study, his own conceptualisations of chronic pain, from friends' descriptions, featured neurological damage and skeletal disintegration; primary care doctors as invalidating and pain experts as impotent. He was unconvinced by the rhetoric of PNE proponents concerning its potency.

Results

Interviews

Nineteen people, from three online pain networks, responded to the invitation. Three withdrew before participating:

two because of technological problems, and one whose request to amend the interview transcript prior to analysis could not be granted. Four emailed after the 12 participant cut-off had been determined. Thus, 12 participants were interviewed – remotely, via video call, as per COVID-19 regulations. All participants completed all interview phases. Interview duration ranged from 47 to 70 min, with a median of 55 min. This variance was affected mainly by differences in time spent completing and sharing the grid; reading the article and debriefing after interview.

Participant characteristics are shown in Table 1. Chronic pains included diagnoses of fibromyalgia, complex regional pain syndrome and arthritis (mentioned in elaborations). Nine participants had attended prior pain management courses, and three had not.

Free associations

In a preliminary content analysis, participants' free-associative grid responses (Figure 1) were sorted into 10 broad thematic categories. Although participants occasionally wrote multiple ideas in a single box, all boxes except one cohered into one theme.

The most salient themes were pain as draining (e.g. 'tiring', 'heavy', 'overwhelming'); frustrating ('irritating', 'unfair', 'depressing') and needing management ('physio', 'prayer', 'balancing'): each identified in six grid responses. The second-most salient themes were causes ('childhood', 'trauma', 'weather') and variability ('erratic', 'up/down', 'boom/bust'), with five responses each, then neurological ('rewiring', 'pain centre in brain'); somatic ('muscles', 'joints;'); pervasive ('constant', 'life-changing') and restrictive ('antisocial', 'stuck') themes in four responses each. The smallest constellation was danger signal ('red alert', 'red stop light'), in three responses. Table 2 displays this scope and prevalence.

Table 1: Participant demographics.

Participant	Age	Ethnicity	Gender	Pain Duration	Pain management course attended?	Pain type mentioned
1	20–29	White British	Female	~6 years	Yes	Unspecified
2	50–59	White British	Male	~39 years	Yes	'Nerve pain'
3	50–59	British Caribbean	Female	~43 years	Yes	Musculoskeletal
4	20–29	White British	Non-binary	~5 years	Yes	Fibromyalgia
5	80–89	White European	Female	~20 years	Yes	Unspecified
6	50–59	White European	Male	~15 years	No	Multiple sclerosis
7	20–29	White British	Female	~11 years	Yes	Fibromyalgia
8	70–79	White European	Female	~10 years	No	Musculoskeletal
9	50–59	White	Female	~42 years	Yes	Fibromyalgia
10	40–49	White British	Male	~20 years	Yes	Musculoskeletal
11	50–59	White	Female	~13 years	No	Fibromyalgia
12	40–49	White British	Female	~30 years	Yes	CRPS, arthritis
Medians	52	–	–	~17.5 years	–	

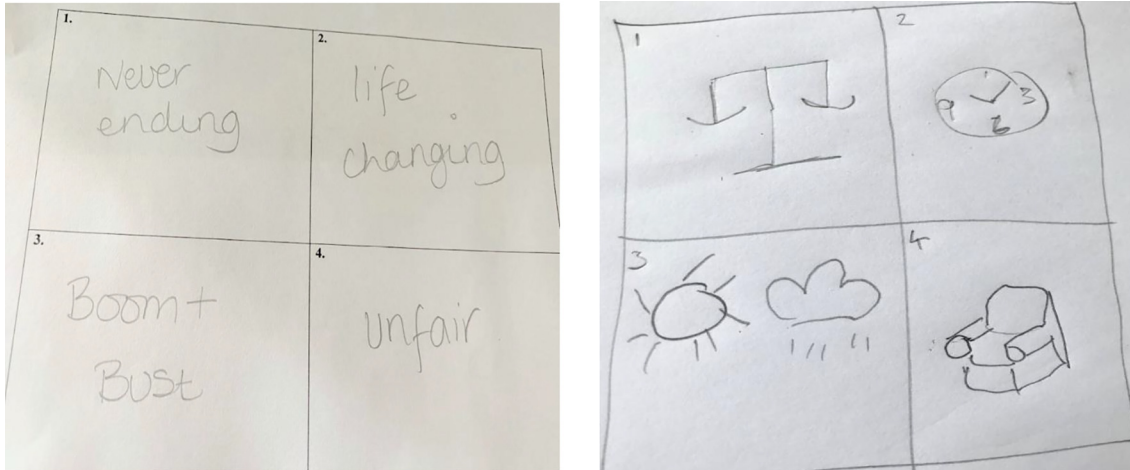


Figure 1: Grid responses from two participants.

Interview elaborations

In TA of participants' interview elaborations, three main themes emerged: communicating pain; explaining pain and living with pain. Numerous sub-themes comprised these themes, with the most salient delineated below.

Communicating pain

All participants elaborated on making sense of chronic pain through how they could (or could not) communicate it: via sensory description (9/12 of participants), metaphorical illustration (7/12) and personifying terms (7/12).

Participants communicated chronic pain as making most sense in sensory terms (“it’s uncomfortable, it’s

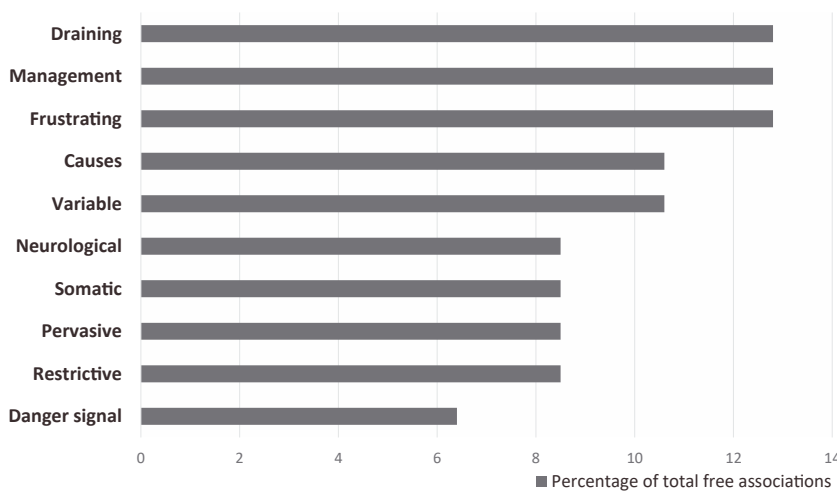
uncomfortable, it hurts”). These terms conveyed difficulty in communicating pain more conceptually. This difficulty was also expressed directly:

I experience it. I'm trying to understand what I'm supposed to be understanding, if that makes sense. Because I find that pain is an experience, it is not a concept. It is a concept for other people when they haven't got it, but it's not a concept for me, it is an experience. [Participant (P) 5]

Pain sensations themselves were conveyed through practical similes, suggested as necessary for other people to understand their pain:

the best thing to describe what it is like is to put stones in your shoes [...] if you do this experiment, you will see what it feels like for me. [P8]

Table 2: Prevalence of themes across grid responses.



More conceptual senses of chronic pain were also communicated, through impressionistic metaphors employed to illustrate the nature of chronic pain to peers who might otherwise not understand it:

chronic pain as this faulty [...] car alarm, or a faulty smoke alarm [...] quite a helpful way of trying to describe it to other people [...] because they can kind of understand. [P1]

Metaphors were often associated explicitly with neuropsychological concepts of pain modulation (“a tuner or a volume dial [...] that concept of modulation”), which some participants accredited to pain management courses:

I did a pain management course [...] and this is one of the main mental images [...] that stayed with me [...] where the system is really over-sensitized. [P2]

Neuropsychological pain concepts were further communicated saliently using personification. Participants attribute separate agency to their bodies (“nervous system is annoyed”), with a distinct human voice:

it's your body saying, 'You've been overdoing it. I'm not gonna let you damage yourself, so I'm cutting in early with a strong pain signal.' [P2]

The personification conveyed perceptions of their pain exerting its own volition against the executive desires of participants (“my body would be quite happy if I stayed in bed”). This communicated a dualistic battle between mind and body:

you're at war with your body [...] the body is and the mind, and it's conflicting, it's always conflicting. [P11]

Explaining pain

Participants further made sense of their pain through explaining how, and where, it operated: using medical terminology (9/12), focus on a damaged body (8/12) and focus on the mind (8/12).

Medical diagnostic language was employed to clarify the nature of pain experienced (“that's pain, that's fibromyalgia”). Diagnoses were introduced as illuminating pain mechanisms, yet simultaneously as abstract and limited:

I've got fibromyalgia, which, well, it is a name for a thing that they don't know. But, in that it's anything [...] the theory is that it's [...] your brain having rewired how it experiences pain. [P4]

Diagnostic explanations were seen as insightful yet frustratingly impractical for alleviating pain (“no one seems to understand how you like, re-rewire”). Participants

contrasted limited medical insights with their own theorisation:

I mean, they don't even know why, still, with fibromyalgia – so that's – obviously I have my own theories. [P11]

Participants' more personal pain clarifications focused on anatomical language of damaged tissue (“little tears in the muscle”). Pain persistence and exacerbation was explained as occurring through chain reactions of bodily degeneration:

I got very weak in the lower back. So I now had this neck pain [...] And what I then found was that the lower back pain was triggering the neck pain. [P2]

As pain was clarified through models of faulty musculature (“What makes pain carry on?” [...] that's kind of muscles”), a cure to pain was envisaged as the rectification of these dislocations:

I'm gonna be able to feel my foot, and everything else will click into place. And all the muscles will do what it's supposed to do. [P3]

Participants' elaborations also expressed pain as clarified more by mental processes (“what's in your mind”) than by – often absent – tissue damage:

but there's no damage in that knee [...] So it's a bit of mind over matter, I think, [...] there's nothing, there's nothing actually wrong. [P2]

Emphasis on the mind was accompanied by personal insights into pain as mediated not by bodily changes but by degrees of distraction:

Some people talk about flare-ups: I don't – to me it feels like, like it's a constant. I don't get so much of a flare-up, it's more of a 'I'm distracted' or 'I'm not distracted.' [P10]

Living with pain

Participants additionally made sense of chronic pain through accounts of how they lived with it: via attempted pain management (11/12), resultant restricted lifestyle (8/12) and pain's ultimate persistence (10/12).

Chronic pain was most often conceptualised in practical terms of managing it through daily life. Anticipating pain stressors was presented as empowering participants to regulate their behaviour and maintain equilibrium:

I know what causes flare-ups and things, so I know how to manage flare-ups. And I know how to pace and try and keep things on an even keel. [P12]

This self-knowledge was often expressed as more advanced in the “pain journey” than reliance on medication (“go through the journey of medication”). It was also appreciated as granting a sense of agency and self-efficacy in pain management:

I've learned more about how pain works [...] I feel like I've gained, I've taken back control of it. [P9]

Pain coping strategies were also conceptualised more negatively as restricting the lifestyles that participants wished to lead. In particular, resting was regarded as alleviating pain but also meant missing out:

Shall I go out somewhere and suffer, or shall I stay at home and do nothing? [...] So that's why it's very limiting in, in life. [Participant 8]

Restrictions imposed by chronic pain were stressed as pervasive, detracting from all areas of living, including the will to live itself:

it affects every single aspect of your life. It affects your home life, your family life, your work life, your love life, your social life, your actual life, your physical life: your choice about whether you want to continue your physical life. [P5]

Further, the mysteriousness of chronic pain was emphasised as defeating attempts to understand and fix it (“don't ask me why, but it does”). Plans to map and manage pain fluctuations were often regarded as somewhat superficial:

I don't necessarily know if it is as causal a relationship as I, like, think of it as sometimes. [P4]

Participants qualified discussions of management strategies with reminders of pain's ultimate persistence (“it will always be here”). Self-knowledge and pain management were conceived as helpful but “no actual cure”, as their pain returns all the same:

I've come to the conclusion, over many, many years of living with it, that things with fibromyalgia go around in a circle. [P9]

Responses to PNE article

Responses to the PNE article predominantly conveyed meta-level comment on the article's style, interest and general resonance with participants' own interviews and prior knowledge. The TA of these responses produced six themes, represented below in selected quotations.

Less to say

Responses were briefer and more hesitant than in the previous part of the interview. Participants reported having less to say: “I've run out of words” [P9]. They conveyed uncertainty about what else to say, often apologetically:

Yeah. Yeah, I think that's about ... Yeah. Sorry, not very helpful [...] Yeah, I don't think there's anything there. [P12]

Some ascribed this hesitancy to both fatigue and generalised agreement:

I think my brain has gone a bit fuzzled [...] I don't know, I think it all makes sense to be honest. [P11]

Echoing the interview

Participants mainly commented that the article corroborated their prior cognition about pain: “underlines my understanding” [P5], “confirmed a lot of my thoughts” [P6]. In particular, they felt it supported their grid elaborations – or vice versa:

I think some of the explanations I've given you so far reinforces what the article says. [P5]

Participants did not elaborate much on which of their ideas were corroborated, foregrounding their pleasure at the corroboration itself:

I continued to smile, through the whole thing, and felt: ‘Oh my gosh, did you listen to my conversation, and, and have you been in my life, and listened to what I've been saying to you, and then you wrote that article? [P3]

Confirmed beliefs

Beyond commentary on the content, participants conveyed that, overall, it “corresponds to”, “reinforces”, “reaffirms” their existing knowledge, particularly from pain education:

it ties in pretty much, very closely with what we were taught on our pain management programme. [P2]

Some participants also expressed preference for the article's concision over longer, in-person pain education:

it is essentially what [...] this physio or whatever explained. Although it would've been nice if they'd, like, given me this, rather than make me sit in a room for like five hours. [P4]

Participants often emphasised that their pain understanding was beyond lay levels: “I’m not the average person” [P9], “I’ve read lots of stuff and been to lots of events” [P11].

Interesting science

The article was commended as intellectually compelling, offering scientific supplements to current knowledge:

I find it really interesting when I learn a bit more about how the system works from a scientific point. [P1]

One specific idea highlighted by several participants was the emphasis on the brain’s role in pain:

the first thing that sticks out in terms of how interesting it is [...] is the idea that the brain is [...] processing the information. [P2]

As well as curiosity (above), participants expressed personal appreciation for the article’s validating pain as still real:

if it’s your brain doing it, then it is in your head [...] Not saying it’s not real, but in your head. Doesn’t mean it’s not real. [P11]

Little disagreement

Participants expressed little disagreement with the PNE content, citing background knowledge as promoting comprehension: “because of my background, it all kind of speaks to me” [P5]. Asked which parts of the article, if any, made less sense to them, participants expressed difficulty in applying scepticism to an article that appeared cogent throughout:

I don’t think it doesn’t make sense [...] I didn’t experience that reaction when I was reading it [...] It all seemed perfectly sensible to me. [P2]

When asked what made most sense, participants emphasised generalised agreement with the article as a whole over agreement with individual points:

it all kind of makes sense, I guess. Um ... I guess, yeah, I dunno, it all kind of makes sense. I don’t have specific bits. [P4]

Participants praised the article’s language, more than its ideas, for supplying terms that they had been seeking:

I think the word ‘protection’ was maybe one that I was trying to think, or like mentally grasp. [P4]

As suggested above, it gave participants purchase on understanding they had already formed:

I came to certain conclusions, which I think this article put it more elegantly. [P8]

But what next?

Yet, most participants questioned the ‘point’ of the article, here injecting more vocal force than during prior agreement:

when you get to the end of it you go, “And?...” Dot dot dot dot dot. [...] like it’s building up to something. But what is it building up to? [P3]

Some participants mentioned inspiration (“I find it quite hopeful”) to “make ourselves feel safer, by various techniques’ [P2]. However, most expressed uncertainty of which techniques were being suggested – “I’m guessing it’s including things like ...” [P2] – or indeed, which would succeed:

what credible evidence I could, like, give my brain that actually it should like, calm the fuck down [...] I’m not like, consciously controlling the fact my brain is experiencing this thing. [P4]

As above, excitement for the article’s emphasis on psychological modulation was tempered with doubts that updating conscious understanding could affect participants’ lived experiences:

it doesn’t really alter stuff [...] because you still – yeah, you’re still living, you’re still having this [...] no, there’s not so much change: it’s more the understanding. [P7]

Some participants concluded that “droning on about” pain science was not enough:

that article is like, all well and good – you’re saying [...] how the mechanisms of it all is working, but actually, yeah, ‘And? And?’ [P3]

For those who wanted “help to be able to *manage* the pain” (emphasised vocally), understanding it seemed inconsequential:

I read everything there is on chronic pain and fibromyalgia. But then [...] I’ve just got to live my life [...] I don’t read that and really go, ‘Ooh, let’s look into that [...] there’s not gonna be a change in how you do stuff. [P7]

Discussion

Pain conceptualisations

The primary research aim of this study was to understand how people with chronic pain make sense of their pain. TA

of participants' GEM elaborations identified diverse pain conceptualisations with three main themes: explaining pain; communicating pain and living with pain. Sub-themes encompassed chronic pain experiences as both purely experiential and as more analysable phenomena. A tension was found between these two dimensions, encapsulated by a participant who prioritised impressionistic sensory terms ("pain is an experience, it is not a concept") but also explained pain using extended conceptual models (e.g. neuropsychological metaphors). Participants made sense of pain using multiple, sometimes incompatible cognitions: pain was both experiential and conceptual; in the body and in the mind; diagnosable and inexplicable; manageable and insuperable. These representations reflected pain beliefs identified in prior qualitative research, encompassing damage-oriented models [27] and struggles with diagnostic understanding [28].

Social representations theory (SRT) [44] was used as an epistemological lens with which to understand these findings. SRT posits that people incorporate unfamiliar or challenging ideas and phenomena that disrupt their previous frame of knowledge by representing them via more familiar ideas [45], and reinterpreting in existing schemas [46]. Chronic pain is hard to understand or explain by reference to familiar acute pain, except through models that imply damage. Anchoring (classifying into known categories) and objectification (representing the abstract in concrete imagery) [47] enable the incorporation of difficult ideas and experiences. Participants anchored chronic pain in concepts of diagnoses, a nervous system that learned and adapted and ways of controlling or mitigating pain (many from medical consultations and pain management advice). Meanwhile, they objectified pain in sensory terms and images of tissue damage, drawn from lived experience.

The GEM accommodates incongruous pain conceptualisations in separate, equivalent grid boxes, allowing participants to leave them unresolved. These incongruities suggest that conceptualisations of chronic pain vary in relation to salient contexts and frames of symbolic reference.

Responses notably lacked reference to dominant tissue damage models of chronic pain, in favour of more experiential or PNE-oriented cognitions; this is discussed below. Although some descriptions were quite concrete in terms of anatomical problems, none repudiated the role of the brain as represented in PNE.

PNE engagement

The secondary research aim was to understand how participants engaged with PNE in relation to their prior

conceptualisations; their responses to the brief PNE article suggested further cognitive inconsistencies. PNE-oriented themes, such as evocations of neuropsychological modulation, comprised a minority component of participants' grid elaborations. Yet, almost all participants endorsed the PNE as interesting and validating; and, notably, corroborative of their own explanations. Even when invited, participants were reluctant or unable to identify aspects of the PNE as less resonant with their experience. This agreement is striking, given the diverse conceptualisations earlier elicited. It might be that participants' other representations were decontextualised and displaced by the article's neuroscientific representations of pain: PNE fitted within their mixed conceptualisations, but may not have challenged those that were incompatible.

Some participants qualified their agreement, acknowledging that the article did not relate much to their particular pain; they found the neuroscience intellectually interesting and credible but doubted its utility ("What is it telling me to do differently?"). Participants also reported fatigue: whether with the interview process or with the difficulties of articulating their understandings was not clear.

The PNE thus presented acceptable ideas in a compelling style, but did not necessarily challenge some parts of participants' understanding, nor explain all their pain experiences. As described above, participants' discrete agreement with one pain model may not force change in their other representations in other contexts.

Relevance

The grid responses and elaborations resonated with previous qualitative research into patients' chronic pain experiences. They aligned particularly with the meta-ethnographic review by Toye et al. [28], which found common themes across qualitative studies of restricted, beleaguered living; grappling with the body; pursuing understanding through diagnosis and struggling with abandoning that pursuit. Responses also endorsed the sense of pain as an assault on the self [29]: pain as hostile in contrast to PNE's protective pain. Whether hostile or protective, these representations give pain its own voice, introducing a somewhat mystifying 'homunculus' into conceptions of volition [48]. These elaborations go further than prior research in highlighting the complexity of conceptualisations that pain education interventions seek to revise.

The lack of reference to tissue damage in the initial grid responses was unexpected, given the clinical focus on

challenging patients' damage models as important [49]. Perhaps damage beliefs are becoming less dominant among patients, ceding to more central nervous system models [50] although of course it is not possible to generalise from this sample. More importantly, responses to PNE elicited here did not suggest that agreement automatically implies a reversal of habitual avoidance as implied [15].

The PNE responses are relevant to research and clinical fields. Neuroscientific models may be compatible with people's chronic pain schemata – particularly after pain education – but where they are incompatible, they do not necessarily provoke reconceptualisation. The article aims to remove fear and reverse habitual avoidance, but participants did not articulate this. Prior research into reconceptualisation after PNE [22, 30, 31, 51] has highlighted the importance of perceived personal relevance of PNE; this study showed little interaction between PNE and participants' wider pain models, and described fluid, contextually contingent conceptualisations of chronic pain [52–55]. As belief in the practical helpfulness of a scientific concept is important in knowledge revision [56], responses may further clarify why some PNE trials have shown limited clinical benefits without additional physiotherapy [16, 19].

A very recent survey of pain education concepts most valued by patients after intervention [25] showed substantial integration of neuroscientific concepts by the majority who reported gains but, consistent with this study's findings, knowledge revision did not necessarily lead to behavioural change.

A recent meta-ethnography of 195 qualitative studies of chronic pain experience concluded that treatment may benefit from greater validation of patients' own conceptualisations [57]; the authors propose that interventions might usefully be more personalised and iterative. Further research might also explore barriers to reconceptualisation in those patients who do not benefit from PNE (excluded in [25]).

Strengths and limitations

A strength of this study is that it elicited chronic pain conceptualisations not directly informed by previous pain education. Although potentially informed by prior pain education, these conceptualisations are still owned by the participants, and tissue damage models can persist after PNE [27]. Further, to our knowledge, this was the first use of GEM in chronic pain research, eliciting incongruities in the conceptualisations that we addressed using SRT. However, the sample size, although adequate [22, 37], was sub-optimal for robust TA; a larger sample would have allowed

comparison of data in relation to previous PNE exposure [58] and including diagnosis in the demographic questions might have enriched our interpretation. Further comparison between unprimed elaborations and PNE responses, if sufficiently detailed, might use framework analysis productively. Remote interviewing (mandated by COVID-19) improved accessibility [59], but lacked precedents for the GEM, and it was difficult to constrain participants to one image, word or phrase per box [34]. Further, while the researcher attempted to introduce the PNE through neutral tone and emphasis of its authorship, his researcher status may have inhibited criticism. Lastly, the brief written PNE to which participants were exposed cannot be equated with a clinical application of PNE, so clinical implications should be made with caution.

Implications

This study identifies how people with chronic pain make sense of their pain through diverse, inconsistent conceptualisations. It illustrates conceptual and experiential pain representations in themes of communicating pain, explaining pain and living with it. It also indicates how PNE is acceptable within these representations, but with a risk of being held as a discrete belief set detached from practical implications. As participants only acknowledged this apparent detachment when expressly questioned, it may go unarticulated during PNE interventions.

Further, since some PNE interventions have failed to show expected outcomes, this study suggests that PNE might strengthen its practical recommendations. There is little basis to expect that education alone, however intellectually appealing, will be sufficient to overcome the threat of pain and to change behaviours that are deeply wired into mammalian systems [25, 60]. Where pain has interfered across many areas of life, direct behavioural interventions and experiential disconfirmations – multiple and repeated across contexts – may be required for lasting behavioural change.

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Ethical approval: Research involving human participants complied with all relevant national regulations, institutional policies and is in accordance with the tenets of the Helsinki Declaration (as amended in 2013), and has been approved by the authors' research ethical committee (UCL REC# 17833/003).

References

- Goldberg DS, McGee SJ. Pain as a global public health priority. *BMC Publ Health* 2011;11:770.
- Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. *Eur J Pain* 2006;10:287–333.
- Fredheim OMS, Kaasa S, Fayers P, Saltnes T, Jordhøy M, Borchgrevik PC. Chronic non-malignant pain patients report as poor health-related quality of life as palliative cancer patients. *Acta Anaesthesiol Scand* 2008;52:143–8.
- Breivik H, Eisenberg E, O'Brien T, OPENMinds. The individual and societal burden of chronic pain in Europe: the case for strategic prioritisation and action to improve knowledge and availability of appropriate care. *BMC Publ Health* 2013;13:1229.
- Price C, Williams AC, Smith BH, Bottle A. The National Pain Audit for specialist pain services in England and Wales 2010–2014. *Br J Pain* 2019;13:185–93.
- Raja SN, Carr DB, Cohen M, Finnerup NB, Flor H, Gibson S, et al. The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. *Pain* 2020;161:1976–82.
- Auvray M, Myin E, Spence C. The sensory-discriminative and affective-motivational aspects of pain. *Neurosci Biobehav Rev* 2010;34:214–23.
- Vlaeyen JW, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain* 2000;85:317–32.
- Baird A, Sheffield D. The relationship between pain beliefs and physical and mental health outcome measures in chronic low back pain: direct and indirect effects. *Healthcare* 2016;4:58.
- Engers AJ, Jellema P, Wensing M, Windt DA, Grol R, van Tulder MW. Individual patient education for low back pain. *Cochrane Database Syst Rev* 2008;1:CD004057.
- Watson JA, Ryan CG, Cooper L, Ellington D, Whittle R, Lavender M, et al. Pain neuroscience education for adults with chronic musculoskeletal pain: a mixed-methods systematic review and meta-analysis. *J Pain* 2019;20:1140.e1–22.
- Williams AC, Fisher E, Hearn L, Eccleston C. Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database Syst Rev* 2020;8:CD007407.
- Reddan MC, Wager TD. Brain systems at the intersection of chronic pain and self-regulation. *Neurosci Lett* 2019;702:24–33.
- Butler DS, Moseley L. *Explain pain*, 1st ed. Adelaide City West: Noigroup Publications; 2003.
- Louw A, Zimney K, Puentedura EJ, Diener I. The efficacy of pain neuroscience education on musculoskeletal pain: a systematic review of the literature. *Physiother Theory Pract* 2016;32:332–55.
- Moseley LG, Butler DS. Fifteen years of explaining pain: the past, present, and future. *J Pain* 2015;16:807–13.
- Van Oosterwijck J, Meeus M, Paul L, De Schryver M, Pascal A, Lambrecht L, et al. Pain physiology education improves health status and endogenous pain inhibition in fibromyalgia: a double-blind randomized controlled trial. *Clin J Pain* 2013;29:873–82.
- Ryan CG, Gray HG, Newton M, Granat MH. Pain biology education and exercise classes compared to pain biology education alone for individuals with chronic low back pain: a pilot randomised controlled trial. *Man Ther* 2010;15:382–7.
- Wood L, Hendrick PA. A systematic review and meta-analysis of pain neuroscience education for chronic low back pain: short-and long-term outcomes of pain and disability. *Eur J Pain* 2019;23:234–49.
- Clarke CL, Ryan CG, Martin DJ. Pain neurophysiology education for the management of individuals with chronic low back pain: a systematic review and meta-analysis. *Man Ther* 2011;16:544–9.
- Geneen LJ, Martin DJ, Adams N, Clarke C, Dunbar M, Jones D, et al. Effects of education to facilitate knowledge about chronic pain for adults: a systematic review with meta-analysis. *Syst Rev* 2015;4:132.
- King R, Robinson V, Elliott-Button HL, Watson JA, Ryan CG, Martin DJ. Pain reconceptualisation after pain neurophysiology education in adults with chronic low back pain: a qualitative study. *Pain Res Manag* 2018;2018:3745651.
- Moseley GL. Joining forces – combining cognition-targeted motor control training with group or individual pain physiology education: a successful treatment for chronic low back pain. *J Man Manip Ther* 2003;11:88–94.
- Traeger AC, Lee H, Hübscher M, Skinner IW, Moseley GL, Nicholas MK, et al. Effect of intensive patient education vs placebo patient education on outcomes in patients with acute low back pain: a randomized clinical trial. *JAMA Neurol* 2019;76:161–9.
- Leake HB, Moseley GL, Stanton TR, O'Hagan ET, Heathcote LC. What do patients value learning about pain? a mixed methods survey on the relevance of target concepts following pain science education. *Pain* 2021 Feb 18. <https://doi.org/10.1097/j.pain.0000000000002244> [Epub ahead of print].
- Pistrang N, Barker C. Varieties of qualitative research: a pragmatic approach to selecting methods. In: Cooper H, Camic PM, Long DL, Panter AT, Rindskopf D, Sher JK, editors. *APA handbook of research methods in psychology, vol 2. Research designs: quantitative, qualitative, neuropsychological, and biological*, 1st ed. Washington, D.C.: American Psychological Association; 2012:5–18 pp.
- Setchell J, Costa N, Ferreira M, Makovey J, Nielsen M, Hodges PW. Individuals' explanations for their persistent or recurrent low back pain: a cross-sectional survey. *BMC Musculoskel Disord* 2017;18:466.
- Toye F, Seers K, Hannink E, Barker K. A mega-ethnography of eleven qualitative evidence syntheses exploring the experience of living with chronic non-malignant pain. *BMC Med Res Methodol* 2017;17:116.
- Smith DJ, Osborn M. Pain as an assault on the self: an interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychol Health* 2007;22:517–34.
- King R, Robinson V, Ryan CG, Martin DJ. An exploration of the extent and nature of reconceptualisation of pain following pain neurophysiology education: a qualitative study of experiences of

- people with chronic musculoskeletal pain. *Patient Educ Counsel* 2016;99:1389–93.
31. Robinson V, King R, Ryan CG, Martin DJ. A qualitative exploration of people's experiences of pain neurophysiological education for chronic pain: the importance of relevance for the individual. *Man Ther* 2016;22:56–61.
 32. Johnson RB, Christensen L. *Educational research: quantitative, qualitative, and mixed approaches*, 5th ed. Los Angeles, CA; London, UK: SAGE; 2008.
 33. Tetnowski JA, Damico JS. A demonstration of the advantages of qualitative methodologies in stuttering research. *J Fluency Disord* 2001;26:17–42.
 34. Joffe H, Elsey JW. Free association in psychology and the grid elaboration method. *Rev Gen Psychol* 2014;18:173–85.
 35. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
 36. Braun V, Clarke V. *Successful qualitative research: a practical guide for beginners*, 1st ed. London, England: SAGE; 2013.
 37. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods* 2006;18:59–82.
 38. Daly JM, Gliksmann MD, Kellehear A. *The public health researcher: a methodological guide*, 4th ed. Oxford, UK: Oxford University Press; 2001.
 39. Joffe H. Thematic analysis. In: Harper D, Thompson AR, editors. *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*, 1st ed. Chichester, UK: Wiley-Blackwell; 2012:210–23 pp.
 40. Moseley L. *The Conversation. Explainer: what is pain and what is happening when we feel it?* Available from: <http://theconversation.com/explainer-what-is-pain-and-what-is-happening-when-we-feel-it-49040> [Accessed 5 Jan 2020].
 41. Barker C, Pistrang N, Elliott R. *Research methods in clinical psychology: an introduction for students and practitioners*, 2nd ed. Chichester, England: Wiley-Blackwell; 2002.
 42. O'Connor C, Joffe H. Intercoder reliability in qualitative research: debates and practical guidelines. *Int J Qual Methods* 2020;19:1609406919899220.
 43. Schwarz N. Cognitive aspects of survey methodology. *Appl Cognit Psychol* 2007;21:277–87.
 44. Moscovici S. The phenomenon of social representations. In: Farr RM, Moscovici S, editors. *Social representations*, 1st ed. Cambridge, UK: Cambridge University Press; 1984:3–69 pp.
 45. Joffe H. AIDS research and prevention: a social representational approach. *Br J Med Psychol* 1996;69:169–90.
 46. Moscovici S. Why a theory of Social Representations? In: Deaux K, Philogene G, editors. *Representations of the social: bridging theoretical traditions*, 1st ed. Oxford, UK: Blackwell; 2001:8–35 pp.
 47. Galli I, Fasanelli R. Public understanding of science and common sense: social representations of the human microbiome among the expert and non-expert public. *Health Psychol Open* 2020;7:1–14.
 48. Driver J, Monsell S, editors. *Attention and performance XVIII: control of cognitive processes*, 1st ed. Cambridge, MA; London, UK: The MIT Press; 2000.
 49. Main CJ, Spanswick CC. *Pain management: an interdisciplinary approach*, 1st ed. Edinburgh, UK: Churchill Livingstone; 2000.
 50. van Wilgen CP, Keizer D. The sensitization model to explain how chronic pain exists without tissue damage. *Pain Manag Nurs* 2012;13:60–5.
 51. Wijma AJ, Speksnijder CM, Crom-Ottens AF, Knulst-Verlaan JMC, Keizer D, Nijs J, et al. What is important in transdisciplinary pain neuroscience education? A qualitative study. *Disabil Rehabil* 2018;40:2181–91.
 52. Bunzli S, Watkins R, Smith A, Schütze R, O'Sullivan P. Lives on hold: a qualitative synthesis exploring the experience of chronic low-back pain. *Clin J Pain* 2013;29:907–16.
 53. Gonzalez-Polledo E, Tarr J. The thing about pain: the remaking of illness narratives in chronic pain expressions on social media. *New Media Soc* 2016;18:1455–72.
 54. Wallace LS, Wexler RK, McDougall L, Miser WF, Haddox JD. Voices that may not otherwise be heard: a qualitative exploration into the perspectives of primary care patients living with chronic pain. *J Pain Res* 2014;7:291–9.
 55. Werner A, Isaksen LW, Malterud K. 'I am not the kind of woman who complains of everything': illness stories on self and shame in women with chronic pain. *Soc Sci Med* 2004;59:1035–45.
 56. Posner GJ, Strike KA, Hewson PW, Gertzog WA. Accommodation of a scientific conception: toward a theory of conceptual change. *Sci Educ* 1982;66:211–27.
 57. Toye F, Belton J, Hannink E, Seers K, Barker K. A healing journey with chronic pain: a meta-ethnography synthesizing 195 qualitative studies. *Pain Med* 2021 Mar 5. <https://doi.org/10.1093/pm/pnaa373> [Epub ahead of print].
 58. Joffe H, Smith N. City dweller aspirations for cities of the future: how do environmental and personal wellbeing feature? *Cities* 2016;59:102–12.
 59. Wagner B, Horn AB, Maercker A. Internet-based versus face-to-face cognitive-behavioral intervention for depression: a randomized controlled non-inferiority trial. *J Affect Disord* 2014;152–154:113–21.
 60. Williams ACC. Persistence of pain in humans and other mammals. *Phil Trans Biol Sci* 2019;374:20190276.