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Title: A qualitative exploration of people's experiences of Pain Neurophysiological Education for chronic pain: the importance of relevance for the individual.

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ABSTRACT

Pain neurophysiology education (PNE) is a distinct form of patient education in pain management. The aims of this study were to explore the experience of PNE for people with chronic pain and to gain insight into their understanding of their pain after PNE. This was a qualitative study, based on Interpretive Phenomenology Analysis, using individual semi-structured interviews to collect data. We recruited a purposive sample of 10 adults with chronic musculoskeletal pain (men and women; mean age 48 years; with a mean pain duration of 9 years) who had recently completed PNE delivered as a single two-hour group session. The interview transcripts were analysed for emerging themes. We identified three themes: perceived relevance for the individual participant; perceived benefits for the individual participant; and evidence of reconceptualisation. An interlinking narrative was the importance of relevance. Eight participants viewed the session as relevant and reported benefits ranging from a better understanding of pain, improved ability to cope with the pain, and some suggested improved levels of physical activity. Four of these participants showed evidence of reconceptualisation, which we describe as partial and patchy. Two participants reported no benefit and did not perceive the material delivered within PNE to be relevant to themselves. Relevance to the individual needs of a person with chronic pain may be a key factor in the success of PNE, and this is a particular challenge when it is delivered in a group situation.

***Keywords*:** Chronic musculoskeletal pain, Patient education, Qualitative.

HIGHTLIGHTS

- Chronic pain patients received two hours of Pain Neurophysiology education (PNE)
- Patients were interviewed about their PNE experience
- The majority (8/10) of patients found PNE relevant to them and reported benefits
- A minority (2/10) did not find PNE relevant to them and reported no benefits
- There was evidence of pain reconceptualisation but it was partial and patchy

1. Background and context

Chronic musculoskeletal pain is a common long-term condition affecting 20% of people worldwide (Goldberg & McGee, 2011). Many people with chronic pain become disabled, resulting in a loss of identity, difficulty coping and a reduction in quality of life (Maniadakis & Gray, 2000). It is recommended that interventions that empower patients and encourage self-management should be utilised (Gifford, 1998; Frost *et al*., 2004; Turk & McCarberg, 2005). Education is an important component of this empowerment approach to pain management (Gifford, 1998). In principle, the better a person understands their condition, the better they will manage it.

Over the past 15 years a distinct approach to pain education, known as pain neurophysiology education (PNE), has emerged (Butler & Moseley, 2003; Clarke *et al.*, 2011; Moseley & Butler, 2015). PNE aims to facilitate people to reconceptualise their pain as less threatening (Van Oosterwijck *et al.*, 2011; Moseley, 2004). Pain reconceptualisation has been defined as shifting people's beliefs towards the understanding of four key points: 1*) that pain does not provide a measure of the state of the tissues; 2) that pain is modulated by many factors from across somatic, psychological and social domains; 3) that the relationship between pain and the state of the tissues becomes less predictable as pain persists; and 4) that pain can be conceptualised as a conscious correlate of the implicit perception that tissue is in danger* (Moseley, 2007).

The research literature describes a wide variety of formats in which PNE is delivered, with some studies using a single session lasting anywhere from 30 minutes to four hours, while other studies report multiple sessions (Louw et al. 2011). The greatest total

amount of education delivered (duration x frequency) was eight hours (Moseley 2002) while the lowest was 30 minutes (Meeus et al. 2010). Predominantly, PNE has been delivered on an individual basis (Louw et al. 2013), though group sessions have also been used (Moseley 2003a; Moseley 2003b; Pires et al. 2015). Some studies provided additional written information alongside the education session (Van Oosterwijck et al. 2013) while others did not (Meeus et al. 2010). Recent work has even suggested that PNE can be delivered, at least in part, online (Louw, 2014).

Early evidence supports the potential of PNE to contribute, alongside other methods, towards the reduction of pain and disability, although the evidence is limited because of the few studies that have investigated this intervention (Moseley, 2003a, 2004; Ryan *et al.*, 2010; Clarke *et al.,* 2011; Van Oosterwijck *et al.,* 2011; Louw et al. 2011; Van Oosterwijck et al. 2013; Pires et al. 2015). There is evidence supporting claims that PNE, delivered in a variety of ways, can help to alter inappropriate beliefs, reduce catastrophizing and diminish fear, consistent with the claimed mechanism of reconceptualisaton (Clarke *et al.,* 2011; Van Oosterwijck *et al.,* 2011; Louw et al. 2011). These findings are based on responses from self-report questionnaires, which while accepted as valid, do not have sufficient scope to explore the extent of reconceptualisation that is claimed to be central to PNE. Nor do they provide insight into people's perceptions of the experience of taking part in PNE, which is extremely important information in evaluating its clinical effectiveness.

Qualitative methods provide the opportunity to explore a person's lived experience (first-hand insights and perceptions from someone who has experience of the phenomenon of interest) to gain a deeper insight into their understanding of a

phenomenon (Magilvy & Thomas, 2009). Qualitative interviews can explore issues in more depth than a questionnaire and help to uncover personal, often conflicting and complex beliefs that people can possess (Pope & Mays, 1995). Such an approach can allow exploration of the mechanisms by which an intervention works, facilitators of and barriers to the intervention, and identify potential opportunities to enhance it (Barbour, 2000). To date, there are no studies that have used qualitative methods to explore people's experiences as users of PNE.

The aims of this qualitative study, therefore, were to explore the experience of PNE for people with chronic pain and to gain insight into their understanding of their pain after PNE.

2. Methodology

2.1 *Study Design*

This was a qualitative study using an approach based on Interpretive Phenomenology Analysis (IPA) that enabled a detailed exploration of the processes through which participants make sense of their own experiences (Brocki & Wearden, 2006). Ethical approval was granted by the XXXXXXXXXXXXXXXXX Health Research Authority of the National Research and Ethics Service (NRES) (REC reference: 12/YH/0409). The study was reported using the consolidated criteria for reporting qualitative research (COREQ) (Tong *et al.*, 2007)

2.2 *Participants and recruitment*

Participants were patients attending an NHS Pain Clinic in a hospital in the North East of England for chronic pain management who had received PNE as part of their usual

care. This study aimed to recruit 10 participants as the literature suggests that this is an appropriate number to facilitate a detailed interpretative account using an IPA framework (Smith *et al.*, 1999; Reid *et al.*, 2005; Brocki & Wearden, 2006).

Purposive sampling was used to ensure that the sample contained a mix of people for whom the research question was significant (Smith & Osborne, 2008). The sought-after characteristics were men and women of a range of ages between 18 and 65 with recent completion of PNE. The sampling criteria excluded people if they did not have the capacity to give informed consent; if their pain was not musculoskeletal in nature i.e. post stroke or visceral pain; or if they did not have a sufficient level of English to take part in the interviews (We did not have sufficient resources to provide appropriate translation). Immediately after receiving a group PNE session as part of their usual care, those who were eligible for inclusion in the study were provided (by the administrative team in the pain clinic who were not members of the research team) with a participant information sheet and invited to indicate an interest to participate. The researcher (XX) then contacted everyone who had indicated interest in the study. In addition to the written information sheet the study was then verbally explained and those who wished to participate were recruited into the study. As neither the researcher responsible for contacting and interviewing the participants, nor the administrative staff responsible for providing the initial information to the participants, had any prior clinical contact with the participants or insight into their experience of PNE, this reduced the risk of sampling bias.

2.3 Procedure

PNE, based upon the manual *Explain Pain* (Butler & Moseley, 2003), was delivered to participants as part of their usual NHS care, within a group education setting, in a single, two-hour session. The groups contained a mix of participants in the study and others who were not participating. The participants had a range of pain conditions i.e. the groups were not specific to one particular pain condition such as back pain. The education was delivered in the same format that was used routinely in this clinic. This entailed using a combination of verbal communication, PowerPoint slides, prepared diagrams and free hand drawings. The delivery of the material was primarily didactic in nature using a standard lecture style format. Participants were encouraged to ask questions and occasional informal group discussions took place. No additional educational material was provided to the participants before or after the education. The physiotherapist delivering the education did not assess participants' current understanding of or beliefs about their pain before the education, nor did they familiarise themselves with their case notes to tailor the education to each specific situation. However, during the education when participants brought up their particular issues, the physiotherapist gave examples tailored to that participant.

The education was delivered by a member of the research team (XX), a senior physiotherapist with five years of experience working in chronic pain and four years of experience of delivering PNE. The therapist had previously completed an *Explain Pain* course run by the Neuro Orthopaedic Institute (NOI). The educational material contained stories and metaphors from the *Explain Pain* manual (Butler and Moseley, 2003). The biopsychosocial model, pain neuromatrix theory and central sensitisation were central parts of the education. Key messages such as "hurt does not equal harm" were emphasised and the role of psychosocial issues in the pain experience were

considered. The role of the sympathetic and para-sympathetic systems were discussed. The underlying neurophysiology of how pain related fears and anxieties impact upon the pain experience was also presented. Additionally, practical coping skills used within the *Explain Pain* manual (Butler and Moseley, 2003) such as pacing were discussed. Given the two hour duration of the education it was not possible to include material from all chapters of the *Explain Pain* manual.

Two weeks after their PNE session, each participant took part in one individual face-to-face interview in a private room in the Pain Clinic. The interviewer was a member of the research team (XX) and no-one else was present. The interviews were semi-structured using open-ended questions (Table 1) and they lasted from 19 to 56 minutes. Participants were encouraged to take a break if they felt tired. All interviews were audio-recorded and transcribed verbatim by the interviewer.

Insert Table 1 here

2.4 *Analysis*

Analysis was carried out by the interviewer (XX). Following the guidelines of Osborn and Smith (1998), the transcripts were read and re-read a number of times to get a general impression of the participants' perceptions. During this stage of analysis, notes were made of potential themes and significant statements were identified and coded. Groups of statements were brought together and categorised. From this, emergent themes were tentatively identified looking for commonalities across accounts while not discounting minority views. The themes were then further refined and structured to

produce a coherent account of the meaning and essence of the participants' experiences grounded in their own words.

To ensure credibility, the extent to which the findings were compatible with the participants' perceptions (Nicholls, 2009), a second member of the research team (XX) read the transcripts to ensure that the themes were logical and rooted in the data. The themes were discussed further with another of the researchers (XX). To add to the credibility of the research, the participants were telephoned (2-4 weeks after the interview) to ensure that our interpretations were an accurate and true reflection of what the participant said. All agreed that our interpretation was valid. To enhance the dependability of the data to reduce the risk of minority views being excluded, all voices and points of view were recognised, analysed and interpreted whether they were in the minority or not.

3. Results

3.1 *Participant characteristics*

Ten people, men and women with an average age of 48 years and a mean pain duration of nine years participated in this study (Table 2).

Insert Table 2 here

3.2 *Emergent themes*

Analysis of the transcripts identified three interlinked themes that respectively described the perceived relevance for the individual participant; perceived benefits for

the individual participant; and evidence of reconceptualisation. In each theme there were positive and negative experiences.

3.2.1 Perceived relevance for the individual participant

Eight out of the 10 participants found the PNE session to have relevance to their individual circumstances. They expressed this in positive comments about the session, such as:

> *I can't speak highly enough of what I got out of it.* (Participant A)
>
> *I was really surprised how much I did get from it.* (Participant F)

The other two participants, on the other hand, were clear that they did not find the session relevant to their individual circumstances.

> *No it wasn't [relevant to me]…because I'd already tried all of the things that he said.* (Participant G)
>
> *No [I don't view my pain any differently after PNE] because I sat in the room for 2 hours and I came out none the wiser…It just went straight over my head. I didn't have a clue half the time.* (Participant J)

The issue of relevance was also evident in participants' suggestions for improvements in the session: regardless of whether they were positive about the session or not the suggestions were all about increasing the relevance for the individual participant, such as ensuring that the group format offered the chance to discuss individual areas of need, and was sufficiently managed to provide this for all members of the group rather than a domineering few:

I wanted to ask him, so out of the 3 quite strong, sort of, pain inhibitors that I've had. Why am I still feeling the pain then?...well I, I didn't (get the chance to ask him). (Participant G)

...there was one particular patient who very nearly hijacked the meeting itself and she was possibly on the verge of taking nearly everything away from everybody else that was at it because it became a me, me, me meeting about her. (Participant A)

3.2.2 *Perceived benefits for the individual participant*:

All of the eight participants who viewed the session as relevant also reported some form of benefit in managing their pain. The benefits ranged from a better understanding of how pain was affecting them to feeling better able to cope with the pain, and some even alluded to improved levels of physical activity.

I thought everything was getting worse, and I thought, like, I couldn't really see light at the end of the tunnel. And just from that session, like, knowing that not necessarily your pain isn't getting worse, it's probably the way you're thinking about it, and to be honest, it hit the nail on the head. (Participant F)

I began to think well am I losing my mind? Honestly. And then when he was going through things, and that's me that, yeah, that's me that…I thought God it's not me going crazy, you know it was brilliant. (Participant I)

It's starting to come back now; I'm starting to do a little bit of cycling, a little bit of walking. (Participant E)

On the other hand, the other two participants stated clearly that it did not benefit them. These were the same participants who did not feel that the session was relevant to them.

Their views are illustrative of a potential link between relevance and benefit. Participant G said that the session was not relevant; and also said that the session had "been educational" but of no benefit.

> *It educated me but it didn't help me...* (Participant G)

The apparent contradiction of the session being educational but of no benefit can be explained by the importance of relevance to this person, who felt himself to be particularly disabled and to have previously tried all the *things* suggested to him within the session: in the absence of personal relevance, a gain in general education was insufficient to achieve clinical benefit.

> *It didn't help me because…it might be your carburettor, it might be your differential, it could possibly be your gearbox. We could maybe do something about this, and we could probably do something about that and there's a chance if we do something about this there's a chance we could sort of help a little bit, but. In my case I thought you know, it's not my gearbox, it's not my carburettor, it's not my differential, it's like the whole chassis of my car is bent and twisted and its creaking and its groaning and it feels like it's gonna come apart, you know what I mean…*(Participant G)

> *No, it wasn't [relevant to me]…because I'd already tried all the things that he [the physiotherapist who delivered PNE] said…*(Participant G)

This observation was also noted in the account of Participant J who also did not see the session as relevant. His apparent understanding of pain in the analogy of stubbing one's

toe did not translate for him into an understanding of his back pain – relevance was absent.

> *It was just basically stubbing your toe…I don't want to know about my toe. I've stubbed my toe, fair enough and I know it last 3-4 days. But I want to know about why I've got the constant pain in my spine. And it just didn't materialise*. (Participant J)

3.2.3 *Evidence of reconceptualisation*

Four of the participants (A, B, C, E) who saw the session as both relevant and of benefit showed evidence of some of the aspects of reconceptualisation as described by Moseley (2007).

There were clear statements reflecting the aspect of reconceptualisation that pain does not reflect the state of the tissues nor does it equate to harm or damage.

> *It's made a huge difference just knowing you're not damaging yourself further.* (Participant E)

Interestingly, two of these participants (A and B) also made statements that were not consistent with reconceptualisation. For one the language of reconceptualisation seemed to be confined to a narrow context of the hurt or soreness of pain and didn't apply when considering its wider sensory aspects.

> *Pain is not always linked to injury.....it doesn't mean that there's something going to happen just because you've got the pain…but I'm…not just getting pain, I'm getting numbness, tingling, problems breathing and all sorts of other things as well…So I'm still a bit unsure whether there's something else going on there that we haven't got to the bottom of yet.* (Participant B)

The other participant's reconceptualisation when stating that hurt did not necessarily equal harm was not seen in his statement about the cause of his problems.

> *The fact that I wasn't damaging myself. Everything comes back to that specific point.* (Participant A)
>
> [Cause of the pain] *The same problem. The problem hasn't evaporated, it hasn't gone away, it's going to be there because obviously the narrowing hasn't gone away.* (Participant A)

The other of these participants was the only one who clearly expressed her reconceptualisation in terms of neural hypersensitivity. Alongside this, she too spoke of cause in terms of tissue damage.

> *Because you assume if you're in constant pain its damage to the nerves and something you're doing is aggravating it and just what's causing the constant pain rather than it being (reinjured) and it was explained about the with the heightened sensitivity.* (Participant C).
>
> [Cause of the pain] *I believe it's the damage to the discs in my spine.* (Participant C)

There were no clear signs of reconceptualisation in the accounts of the other participants.

4. Discussion

The aim of this study was to explore people's experience of a single two-hour session of group PNE and to gain insight of into their understanding of their chronic pain having undertaken PNE. Three themes emerged: perceived relevance for the individual participant; perceived benefits for the individual participant; and evidence of

reconceptualisation. Within these themes there were examples of positive and negative experiences, the latter manifesting as lack of relevance, lack of benefit and lack of evidence of reconceptualisation. An interlinking narrative was the importance of relevance.

The strong majority view that the experience of PNE was positive emphasises its feasibility as an educational component within pain management, and endorses its particular focus on neurophysiology. The more negative views of two participants are a reminder that PNE will not be for everyone, or at least that PNE as delivered in this study (e.g. a single group session delivered in a didactic lecture style) will not be suitable for everyone. Like any intervention requiring active engagement by the user, it is unrealistic to expect a one-size-fits-all solution.

The benefits of PNE reported in this study are consistent with of the findings in the quantitative literature that PNE imparts a positive change in pain cognitions, attitudes, behaviour and physical performance (Moseley, 2003a, 2004; Ryan *et al.*, 2010; Clarke *et al.*, 2011; Van Oosterwijck *et al.*, 2011). Our observation that the relevance of the session to the individual may be a catalyst for such benefits appears to be important. The challenge of ensuring relevance in a group delivery compared to a one-to-one may be a factor in suggestions that the latter mode may be more clinically effective (Moseley et al., 2003a).

Our findings agree to an extent with previous studies reporting evidence of reconceptualisation following PNE (Moseley, 2003b, 2004; Van Oosterwijck et al., 2011). Those studies used quantitative designs assessing reconceptualisation through

a questionnaire/quiz that tests participants' knowledge of pain neurophysiology (Moseley, 2003b, 2004; Van Oosterwijck *et al.*, 2011). While results using that have been positive, showing statistically significant group increases with PNE, the measure does not cover the depth and breadth of the concept of reconceptualisation that can be covered in a qualitative study. The reconceptualisation we observed could be best described as partial and patchy. We observed apparent contradictions in some accounts where a participant would use language associated with reconceptualisation to describe one aspect of their experience but for other aspects the language was alien to the concept of reconceptualisation. In some cases reconceptualisation appeared to be described when people were talking about pain in theory but when talking about their own experience of pain they did so in terms of physical damage. Alongside this could be something akin to internalisation and objectification where there was a reliance on physical words and images to convey meaning about pain (Bullingdon, 2009). The achievement of partial and patchy reconceptualisation at this stage can be seen as positive given the limitations of the delivery method discussed below. Also, as discussed below, the lens through which we observed reconceptualisation here, our question structure, was not fully focused on reconceptualisation. As befits a qualitative investigation like this, our findings serve the useful purpose of raising interesting questions about reconceptualisation as a concept and its necessity and sufficiency in the success of PNE.

Our observations have resonance with adult learning theory about acquiring an understanding of new scientific concepts. For example, Posner et al (1982) outlined four conditions, internal to the person concerned, that were required for someone to achieve such conceptual change: ability to understand the concept being taught; the

plausibility of the concept; dissatisfaction with current understanding of the concept; and the practical usefulness of the new concept to everyday life. This emphasises the importance of relevance to the individual. It also provides a framework for designing educational programmes that has been put into practice in scientific education (Stofflett and Stoddart 1994). The PNE session, as delivered here, addressed some but not all of these steps to a greater or lesser extent.

4.1 Strengths and Limitations

A key strength of this work was the use of qualitative methods to generate novel insights into PNE. A limitation of the study was that the sample was demographically limited comprising white British ethnicity, middle-age and living in the North East of England. Additionally, in this study PNE was delivered as a single two-hour session via a didactic lecture style format. While this is within the range of methods by which PNE has been delivered within the literature (Louw et al., 2011) it may be that other delivery formats (e.g. multiple shorter sessions rather than a single longer session) would be more conducive to reconceptualisation, perhaps resulting in greater benefits and reduced negative experiences. Thus caution should be taken in transferring the results of our study to other patient groups and delivery styles. In addition, the participants were aware that the researcher undertaking the interviews was a physiotherapist within the pain clinic where they received PNE. This may have led to more socially desirable responses and reticence to give negative comments. However, to minimise this none of the participants received PNE from the researcher who carried out the interviews. Also, the interviews took place two weeks after the PNE session, which means that we do not have any insight into interesting questions about the issues raised here in the long term, such as whether they endure, grow or wither without further input.

The reflexivity of the authors is a source of limitation (Joana *et al.*, 2009).To that end, three of the authors have experience of delivering PNE clinically (XX, XX, & XX) and two currently do this routinely within the NHS (XX & XX). The author who undertook the interviews and was responsible for the initial analysis (XX) has worked clinically in pain management for 10 years. She routinely delivers PNE and believes that it is a useful intervention for patients with persistent pain. She feels the information is important for patients to understand and that the increased knowledge can help patients to positively change their behaviour. The other authors are in line with this view and all authors are of the opinion that there is room to improve PNE. Finally, an inherent limitation of a qualitative study like this is that the observations are illustrative and further work is required before they could be accepted as definitive.

4.2 Clinical implications

The findings add support to the use of PNE for people with chronic pain. While the group mode is attractive for its logistical efficiency, consideration needs to be given as to how best to ensure that the content and discussions are sufficiently relevant for the individual, especially for groups that are not condition-specific, as in this case, This may be helped further by allowing more time for patients' questions during and at the end of the session so that they can ask particularly pertinent questions to their situation which might help them, and others in the group, to contextualise the material being delivered to their situation.

4.3 Future work

Of the many pieces of work that could arise from this study, perhaps the most directly related to the findings would be to broaden the demographic boundaries of our sample; to explore how relevance to individual people could be ensured; and to explore how reconceptualisation could be enhanced and the role it takes in mediating the effect of the education. A particularly interesting piece of further work would be to investigate the importance of the conditions outlined by Posner et al. (1982) prior to taking part in PNE. At present, these areas would be most amenable to qualitative studies.

5. Conclusions

We observed useful benefits for most (8/10) but not all of the participants following PNE. Relevance to the individual needs of a person with chronic pain may be a key factor in delivering these benefits, and this is a particular challenge when it is delivered in a group situation. Clinicians should bear in mind that the purpose of pain education is to help the person understand their pain and how it affects them as opposed to understanding pain as a general topic: the education should be applied rather than academic. More research is needed to address interesting questions that were raised about the process of reconceptualisation and its importance in PNE.

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Table 1: Semi-structured interview schedule.

1. Having experienced *Explain Pain*, how do you view your pain? (Is that differently to before *Explain Pain*?)
2. What do you believe is causing your pain?
3. What information presented in *Explain Pain* do you feel was relevant to you?
4. Of the factors presented in *Explain Pain*, do you recognise any that may contribute to your pain?
5. Do you have any ongoing fears / worries associated with your pain? (If yes, what are your worries about your pain?)
6. Did *Explain Pain* change the way you manage your pain? (If yes, in what way?)

Table 2: Participant Characteristics

Patient I.D.	Male / female	Age (years)	Duration of pain (years)	Location of pain	Employment status
A	M	64	2	Total body pain, Neck and shoulder.	Retired
B	M	46	19	Ribs, arm, leg and low back pain.	Unemployed
C	F	39	3	Neck, thoracic and low back pain	Unemployed
D	M	55	5	Low back pain	Unemployed
E	M	53	3	Knee, elbow and wrist pain.	Self-employed
F	F	28	2	Total body pain.	Employed
G	M	47	9	Low back pain.	Employed
H	F	48	32	Low back pain.	Sick leave
I	F	52	2	Shoulder and arm pain.	Employed
J	M	53	15	Low back pain	Sick leave