

Peoples' experiences of painful diabetic neuropathy: are pain management programmes appropriate?

B Davies PhD, MCSP ^{a*} (<https://orcid.org/0000-0002-6457-5124>)

F Cramp PhD, FCSP ^b (<https://orcid.org/0000-0001-8035-9758>)

J Gauntlett-Gilbert PhD, DClinPsy ^{b, c} (<https://orcid.org/0000-0002-8461-4151>)

CS McCabe PhD, RGN ^{b, d, e} (<https://orcid.org/0000-0002-3593-0027>)

^a Virgin Care, St Martins Hospital, Clara Cross Lane, Bath, BA2 5RP, UK.

^b Faculty of Health and Applied Sciences, University of the West of England, Blackberry Hill, Bristol, BS16 1DD, UK.

^c Bath Centre for Pain Services, Royal United Hospitals Bath, Bath BA1 3NG, UK.

^d Florence Nightingale Foundation, Deans Mews, 11-13 Cavendish Square, London W1G DAN

^e Dorothy House Hospice Care, Winsley, Bradford-On-Avon BA15 2LE

* Corresponding author: Ben.davies@virgincare.co.uk

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Abstract

Objective

Painful diabetic neuropathy (PDN) is a painful complication of diabetes. This study aimed to explore: 1) strategies used by participants to manage impacts of PDN, and 2) their perspectives on whether strategies from pain management programmes (PMPs) had applicability for PDN.

Design

Participants were recruited through local NHS diabetes and PDN clinics, and nationally from a diabetes support charity. One-to-one interviews were conducted. The transcribed data were analysed using inductive thematic analysis.

Results

Twenty-three people were interviewed who had PDN symptoms for mean 10 years. Four themes emerged from the data: Seeking help and advice, Pragmatic approach to management, Perspectives on physical activity, and Perspectives on Psychological coping strategies.

Conclusions

Some participants were open to the strategies advised by PMP strategies. There were also strong opinions that no exercise or psychological approach could help with diabetes-related pain. It is possible pain management programmes as currently delivered need to be adapted to maximise engagement from people with PDN. Research is required to understand the healthcare priorities of people with PDN and whether these priorities can be mapped to existing management strategies.

Introduction

Diabetes mellitus is a worsening global health problem, the Global Burden of Disease study found years lived with disability consequent to diabetes increased from 27,706 in 1990, to 46,823 in 2010, a rise of 69% (Murray *et al.*, 2012). Improvements in drug treatment have reduced mortality, but improved life expectancy increases the potential to develop systemic macro-vascular and micro-vascular complications (Alberti and Zimmet, 2013). One micro-vascular complication which affects approximately 20% of people with diabetes is painful diabetic neuropathy (PDN) (Sloan *et al.*, 2018). Clinically, this presents as sensory loss (neuropathy) accompanied by burning pain in a 'glove and stocking' distribution (Peltier, Goutman and Callaghan, 2014). The pain often has an unpredictable pattern and is of moderate to severe intensity (Hoffman *et al.*, 2010). PDN impacts on physical activity, walking tolerance and personal relationships with greater impact as pain severity worsens (Gore *et al.*, 2005). PDN is associated with higher rates of anxiety and depression and reduced quality of life, over and above the impact of diabetes alone (Alleman *et al.*, 2015). The global prevalence of insulin-resistance, a precursor to diabetes, is rising and so diabetes and complications are highly likely to increase in the future (Alberti and Zimmet, 2013).

Currently the management of PDN is nearly entirely pharmacological (NICE, 2013). Recommendations include Amitriptyline (number needed to treat (NNT) 3.6), Gabapentinoids (NNT 7.2-7.7) and Duloxetine (NNT 6.3) (Finnerup *et al.*, 2015). There are no recommendations for analgesic selection, other than medical contra-indications and patient response to treatment. Around 70% of people with PDN do not experience adequate pain management, or the consequent improvement in quality of life (Moore, Derry and Eccleston, 2013; Sadosky, Hopper and Parsons, 2014). NICE have recommended further research to understand the impact PDN has on peoples' lives and the potential for non-pharmacological treatment (NICE, 2013).

Multi-disciplinary pain management programmes (PMPs) for persistent pain use physical activity and psychological coping strategies to help people live well with pain (Gauntlett-Gilbert and Brook, 2018). There is moderate evidence that PMPs for persistent low back pain, improve physical function (Standardised mean difference (SMD) 0.23) and increase likelihood of remaining in employment (Odds ratio 1.87) (Kamper *et al.*, 2015). However neuropathic pain can differ from low back pain (Daniel *et al.*, 2007) and these results cannot be assumed to be applicable to PDN. Research investigating these approaches specifically for PDN is scant. A systematic review of physical exercise for PDN found only two eligible studies, one study found engagement in 8-weeks of moderate intensity aerobic exercise had minimal effect on pain report (NeuroQOL pain domain, pre- 1.60 to post- 1.61) (Dixit, Maiya and Shastry, 2014), the second study found practice of regular Tai

Chi (1 hour, twice per week for 12 weeks) had positive effects on the bodily pain scale in the SF36 quality of life measure (Ahn and Song, 2012). Both studies reported significant pain reduction in the intervention arms that could be explained by deterioration in the control arms over time. No further studies were identified in a more recent review (van Laake-Geelen *et al.*, 2019).

Psychological approaches, specifically cognitive behavioural approaches, have been shown to reduce disability (SMD -0.12) and distress (SMD -0.09) in persistent pain (Williams *et al.*, 2020), but when the population focus was restricted to neuropathic pain conditions, only two studies could be included, each with a high degree of bias, resulting in no recommendations for treatment (Eccleston, Hearn and Williams, 2015).

No research to date has asked people with PDN whether they would find non-pharmacological pain management strategies, particularly physical and psychological approaches, to be acceptable or appropriate for the impacts of PDN they experience.

This study aimed to explore: 1) the strategies participants had developed to manage the impacts of PDN, and 2) the participants' perspectives on the utility of PMP strategies for coping with PDN.

Method

An interview study was designed to recruit people with confirmed PDN. This interview would seek to understand the strategies they had explored to manage their PDN, and it would explore their perspectives on the utility of PMP strategies for PDN.

Participant recruitment

Recruitment was (1) through local NHS diabetes and PDN-specialist clinics, where clinicians independent of the research team provided brief study information to eligible patients; and (2) by advertisement in Balance, the peer-support magazine of DiabetesUK, a leading UK-based diabetes support charity. Potential participants who contacted the research team and met eligibility criteria, were sent detailed study information and were able to ask any questions. An interview date was scheduled if participants met the eligibility criteria and gave informed consent.

Eligibility criteria

Participants recruited from NHS clinics were required to have a medical diagnosis of PDN. For participants recruited via Balance, self-report of a diagnosis along with symptoms consistent with PDN was deemed acceptable. This self-report needed to be consistent with the DN-4 interview questions for sensory profile and symptom distribution and response. No clinical exam was

conducted as the participants were remote (Spallone *et al.*, 2012). All participants had to be over 18 years of age, provide informed consent and be able to communicate in conversational English. There were no other exclusion criteria; this aimed for the widest range of PDN experience to be reflected by the study participants.

Interview process

If respondents met the criteria, and gave consent to be involved in this research study, one-to-one interviews were scheduled. These were conducted either at University premises, the person's home or by telephone. The participants' study information pack contained a mind-map that outlined strategies used in PMPs. This mind-map was developed from two existing PMP manuals (Taunton NHS Trust and Calderdale NHS Trust, UK) and the British Pain Society guidance document for PMPs (BPS, 2013). This mind-map stated strategies used in PMP for persistent pain, without suggesting whether they may be applicable to PDN and was used as a prompt within the interview. This mind map can be seen in Figure 1.

The interviews were semi-structured based on a schedule (S1 online supplementary) which had been developed by the research team and an Expert Patient Research Partner (EPRP), and was grounded in the existing literature, the research questions and the experience of the research team. The schedule was used to ensure all topics were covered during the interview. All interviews were conducted by the research student (BD), a physiotherapist who had extensive clinical experience of managing persistent musculoskeletal pain. The clinical profession of the interviewer was made clear in the study information and when the interviews were scheduled but not referred to again through the interview unless by the participant. Training in conducting semi-structured interviews and on-going supervision of the research interview process was provided by CM and FC who are experienced in training researchers in qualitative research approaches.

The interviews were digitally recorded and transcribed verbatim by University-approved professional transcription services (Essential Secretary, UK). Contemporaneous field notes were taken to contextualise the interview but these were not included in the data analysed.

Data analysis

The transcribed text was imported to NVivo (NVivo 11 for Mac, QSR International) for management and analysed using an inductive thematic analysis approach (Braun and Clarke, 2014). This analytical approach was chosen as it encourages the researcher to start from a position of naivety and to have no assumptions about the perspectives participants bring to the interview. Each unique issue raised by participants was assigned a descriptive code, these codes were grouped into organising themes that contained a central concept. Themes were then further brought together as

superordinate themes where appropriate. The data coding and theme development was done by BD with supervision and support from a member of the research team (CM). CM has extensive experience of qualitative research in a variety of long-term health conditions.

Ethical approval

Ethical approval for this study was obtained from the UWE Health and Applied Sciences Faculty ethics committee, from the NHS National Research Ethics Committee (Frenchay) (Study identifier 13/SW/0125) and from University Hospitals Bristol NHS Foundation Trust (UH Bristol) Research and Innovation department (Study identifier ME/2013/4345).

Results

Sample demographics

Twenty-four people contacted the researcher and twenty-three were recruited (eight through NHS clinics, and 15 through Balance Magazine). They had a mean age of 62 years (range 24-86 years); 12 were women. All except one participant identified themselves as White British. Ten participants had Type 1 diabetes. Participants self-reported being diagnosed with diabetes for a mean of 23 years (range 7-50 years) and having experienced PDN for a mean of 10 years (range 1-24 years). A summary of participant characteristics is presented in Table 1. One person was not included in the study as they had diabetic neuropathy, but not pain.

*** Table 1 about here ***

Overview of Interview results

These interview data are presented in two parts, firstly themes which related to how participants seek help and action possible management strategies (*The patient management of PDN*), then secondly, their perspectives on pain management strategies (*Perspectives on physical activity* and *Perspectives on talking therapy*). Quotes are anonymous with gender (M/F) and age stated.

The patient management of PDN

This contains two themes: *Seeking Help and Advice* describes the sources of information participants accessed, and *Pragmatic approach to pain management* which itself contains four sub-themes describing the variety of strategies participants had experimented with to manage the impacts of PDN.

Seeking help and advice

The majority of participants were taking some analgesia for PDN, yet all had searched for additional help. They described few sources of information and help, other than the Internet. There was scepticism about the accuracy of Internet information and participants were cautious about any site claiming 'miracle' benefits or charging for supplements.

"I Googled it, there was a company in North America that was selling these vitamin B, extra strength vitamin B, and I took that for a while, which I suppose did help, I don't know if it really helped that much or not." Dawn, F68.

The Internet had led some participants to peer-support forums. There were both positive and negative experiences of accessing these forums. They described feeling less alone and isolated and benefited by hearing how other people were coping. However, some forum users were less helpful, posting replies which implied PDN was due to poor diabetes management and suggesting it was the individual's fault.

Participants prioritised information from clinicians which was trusted to be accurate and appropriate; and information that came from significant others, such as partners and close friends, and from other people who experienced PDN themselves.

"I think I was looking for somebody else with the same sort of problems I was having, it just felt good to know [...] they're all around the country and they're all experiencing really a mirrored image of what I'm going through." Mary, F44.

Pragmatic approach to pain management

This theme contains four subthemes: how participants kept going with PDN (*Keeping strong*), what approaches they had tried to alter the pain (*Managing the experience of PDN*), how they tried to manage disturbed sleep (*Getting some rest*) and a collection of all other strategies explored (*I'll try anything*).

Keeping strong

Participants found PDN had pervasive effects on many aspects of life and this was draining and difficult to cope with. To cope, some participants used active coping strategies - maintaining a sense of self by looking their best despite PDN:

"I just felt that was a part of me I could control I could get up, will brush my [hair]... you know I will dress nicely when you don't feel like doing it." Mary, F44

others used more passive and avoidant strategies:

"I hate going out, and it's all to do with building up a castle around you where you've got some measure of control is the word." Bob, M63.

Participants described revising their expectations of themselves and their capacity for work, to maintain a positive outlook and avoid a sense of failure.

"You know the things and the places will always be there, they will be there the next day so if you don't achieve something today there is always tomorrow."
Joan, F57.

Managing the experience of PDN

This subtheme includes all the strategies participants explored to reduce the pain experience of PDN. Because PDN was often described as a 'burning' sensation, the application of cold to the affected body part was a common approach. For example, participants found short-term benefits from topical menthol gels, cold water baths, or cold drafts across their feet.

"I had to have the fan on all night on the feet just blowing cold, cool air on my feet and sometimes getting a frozen pack of peas or something like that" Aaron, M75.

Some participants had tried warmth, using warm water baths or hot water bottles. Again, they found benefits were short-term.

"Well I have done that, but you can't put your feet in warm water for eight hours a day. I've done it when it's that severe, I've tried it." Philip, M57.

Although participants described allodynia (pain with light touch), some found massage to their feet, either by themselves or their partner, could be beneficial. Some participants found mental distraction techniques useful in focussing their attention away from the experience of symptoms.

"Then I'm thinking, remember the ocean and blue sky and how it really, really rained. Immediately when this [pain] is going 'bang, bang, bang' like this, I'm over here thinking the very first time I took the children to Stonehenge. I think of all the little things that are trapped somewhere in my memory and they bring them out." Anne, F52.

Getting some rest

PDN often affected quality of sleep and rest and this led to consequent tiredness and reduced concentration.

“It tends to just appear at night-time when I’m lying down, which means that it disturbs my sleep, which is the biggest impact of the lot.” Sam, M53

These impacts were not universal, there were some people whose sleep was unaffected.

“I have no problem with sleep, no.” Mike, M65.

Participants explored various ways to manage their downtime. These included taking breaks from daily tasks, staying in bed and active relaxation strategies such as listening to music or breathing and body-scan techniques.

“I’ll put the music on and the headphones on. Then, before I get to that stage, I’ll put the music on and I will really try to calm down, it doesn’t always work.” Anne, F52.

Other participants were aware of relaxation but had never applied it consistently with the aim of managing their pain.

There were frequent references to strategies for a better night’s sleep. Some participants had been prescribed specific sleeping tablets, but often did not tolerate the side effects the next morning. No participant described receiving clinical advice for sleep strategies, though some had developed routines recognisable as sleep hygiene strategies (avoiding caffeine, some form of relaxation and time to wind down from the day).

“You concentrate on your breathing for a little while very deeply, and it takes your mind off other things that are happening in your body.” Barbara, F80.

I’ll try anything

This theme captured all the other approaches participants had tried. These included: fish pedicures, walking in stinging nettles, using cling film to wrap around their feet, excess alcohol and using cannabis.

“The most potent thing I’ve tried to work was stingy nettle funnily enough. Yeah, I’d take my shoes and socks off and I’d walk in stingy nettles tended to take away the other pain temporarily.” Bob, M63.

Despite diverse attempts, the participants found little benefit from any of these approaches.

“You get sometimes to the point where you think, I’d try anything...?” Ellen, F63

Patient perspectives on pain management strategies

Perspectives on physical activity

While there is a distinction between physical activity and exercise, participants did not necessarily make this distinction and so these terms were considered synonymous.

Participants frequently described anxiety and fear of falling when walking, due to pain and numbness in their feet. To mitigate this and maintain walking tolerance, some participants had adopted use of walking aids for balance and safety. Participants might have purchased or had been provided with mobility scooters or wheelchairs, though there was reluctance to use these as they were viewed as a further sign of disability.

“I miss steps and things like that. Sometimes I have to use a wheelchair, but I try not to, but I sometimes have to resort to that” Kate, F58.

Participants were concerned about their physical fitness and described general exercises to maintain their physical health. The aims of the exercise were variably to maintain strength, fitness, standing balance or body flexibility. No one had been given specific advice for exercises to engage in, or to avoid, which led to uncertainty and specific clinical advice would have been welcome for some people.

“I do sit and do some exercising of my feet [...] try to keep the muscles going there, but I’m sure that I’m not doing all I should do or couldn’t do, but I don’t know what else to do?” Lisa, F69.

Other participants had researched the role of exercise for PDN, and were pessimistic about the likely benefit.

“Well, I’ve read up on this thing quite widely, I’ve read up on the type of exercises you can do, some of the foot exercises you can do, some of the strategies you can use and I’ve tried many of them, I need to you know, the way I look at it, this pain originates from the damaged nerve and there is nothing you can do about nerve pain”. Aaron, M75.

Perspectives on psychological coping strategies

Of the twenty-three participants, two had received psychological therapy input specifically for PDN and one had attended PMPs in both the UK and Canada for persistent back pain. The majority of participants had not discussed psychological support with any health professional.

“But I don’t know, my pain is my pain, I don’t see how anyone else can help with it, I’ve had it now for four or five years and I’m coping with it the way I can”.
Aaron, M75.

For some participants, there was openness to the idea that mood, such as depression or anxiety, were relevant to PDN. There was acceptance that PDN-related issues, were more than pain and physical impediment alone. There was awareness that moods were difficult to manage and had a negative effect on overall life quality.

“I think the management of mood would be quite useful and how to cope with that because um, it’s just incredibly wearing at times.” Dawn, F68.

Similar to other persistent pain conditions, some participants had identified life stress as an aggravating factor: stress from living with PDN, from relationships and work were specifically identified. Participants viewed being able to talk about these stresses and experiences positively. Some found close family members, especially partners, to be best at listening and understanding. Other participants did not want to burden their partner further and preferred to talk to someone more removed. Rather than family and friends, some participants described potential benefits in talking with others who also experienced PDN and so understood the impact of it.

“...nobody understands what I’m going through unless it’s another diabetic or it’s somebody else suffering neuropathy because they’re going through the same thing.” Philip, M57

In a counter view to the previous theme, not all participants were open to the idea of psychology. They were very clear PDN was due to nerve damage and not effected by mood state, and could not see any benefit to psychological intervention as it would not alter their pain experience. They did not want advice from other people, particularly those who did not have PDN, and were not keen on any form of talking therapy.

“I’ve been offered them [counselling] by the doctor, you know, if you want to see someone, you can talk it through, or what-have-you. I don’t know if I believe in that sort of stuff.” Neil, M66.

The contribution of peer-support groups had both positive (see theme *Seeking help and advice*) and negative opinions. Some felt peer-support groups would not provide the support required and, if they were to talk to someone that should be a medical professional, otherwise it would not be 'proper'.

"If I spoke to a psychiatrist I'd want to know he was a properly qualified, not one of these pseudo-psychiatrist [laughing]." Lisa, F69.

There was ambivalence toward psychological therapy with some positive perspectives based on previous experiences, but also strong views that the pain experience in PDN had nothing to do with mood state, and hence targeted psychological approaches were irrelevant.

Discussion

This study explored the strategies participants had researched and trialled to manage their experience of PDN, and their opinions on whether established strategies from PMPs had any applicability to PDN. The majority of participants were taking analgesia for their PDN (18 of 23, see Table 1) but had explored additional strategies from cold and hot packs to walking in stinging nettles or having fish pedicures. Some participants wanted specific advice for the role of physical activity, but others were sceptical that activity had any relevance to their issues. Some participants were open to talking therapies to help them cope, while others were not.

Medication strategies for neuropathic pain are a clinical challenge, with excess side effects common and effective analgesia infrequent (Schneider *et al.*, 2011; Finnerup *et al.*, 2015). Participants had sought information from the Internet and peer-support forums. There was general scepticism toward Internet advice and therapeutic products but participants felt they needed to consider any option presented to them. These experimental trials usually ended with minimal and temporary change to pain.

"You get sometimes to the point where you think, I'd try anything..." Ellen, F63

Approaches to the evaluation of Internet health advice have been published (Chumber, Huber and Ghezzi, 2015) but the process of critical appraisal and evaluation may not be the foremost consideration for people in pain. Other than the use of hot and cold packs for temporary pain reduction, the strategies described would not be recommended as evidence-based by any pain management service. Pain management services do advocate graded physical activity and psychological strategies for living well with pain (Gauntlett-Gilbert and Brook, 2018).

Participants in this study had a range of views on the applicability of physical activity. Some were keen for clinical advice for what physical activity or exercises to do, others were much more dismissive that physical activity could have any benefit. The research to date suggests participant scepticism is well founded, the paucity of evidence for physical activity changing pain levels has been described earlier. The two studies included in van Laake-Geelen *et al.*, (2019) did find improvements in secondary outcome measures for quality-of-life (SF36 and NeuroQOL), but the studies were not powered to detect these with confidence. However, physical activity has been shown to benefit areas of function and quality of life for a variety of long-term conditions including spondyloarthropathy (Martey and Sengupta, 2020), oncology (Cramp *et al.*, 2013), spinal cord injury (Heutink *et al.*, 2012) and fibromyalgia (Karjalainen *et al.*, 2009), so engaging people with PDN to increase physical activity for these reasons would be clinically appropriate.

Some participants in our study had exposure to psychological coping strategies and found these of benefit, but other participants were not willing to consider psychological variables as relevant to their PDN experience. Participants in this study tended to focus on the potential analgesic effect of psychological interventions, whereas PMPs use these interventions to alter pain-related disability and distress. This depth of explanation was not given to the participants in the brief 'mind map' of PMP strategies.

A recent review of psychological therapies for chronic pain found Cognitive-Behavioural Therapy (CBT) (59 studies) can deliver very small improvements in distress (SMD -0.09) and disability (SMD -0.12) at post-treatment time points compared to active control interventions (Williams *et al.*, 2020). The evidence base for Acceptance and Commitment Therapy (ACT) was much smaller (5 studies) and no evidence of impact on pain (SMD -0.54), disability (SMD -1.51) or distress (SMD -0.61) was demonstrated. There was insufficient evidence on psychological interventions for specific neuropathic pain conditions to make treatment recommendations (Eccleston, Hearn and Williams, 2015).

One possible conclusion from these studies is that psychological support has no place in the management of PDN; based upon the fact that there is insufficient robust trial evidence, and the participants in the present study were not open to the idea of psychological support because they were mostly focussed on pain reduction. A study which explored the lived experience of PDN found that while the majority of people had functional limitations due to PDN, some described being able to 'get on with life' (Davies *et al.*, 2021). The study was not designed to quantify the psychological or behavioural determinates of pain and function, but there are similarities with the construct of pain acceptance. Change in pain acceptance has been shown to mediate improvement in pain ($\beta=-0.43$,

p=0.000) and pain-related disability ($\beta = -0.59$, p=0.000) in neuropathic pain conditions (Shaygan, Böger and Kröner-Herwig, 2018).

Pain acceptance is a key tenet of ACT and a recent cohort study has examined the psychological processes in distress and disability associated with PDN (n=255) (Kioskli, Winkley and McCracken, 2019). Although pain intensity was found to be the key driver of disability and distress, psychological processes made clear and independent contributions to functional impairment, depression and depression impact. The researchers suggest that ACT approaches may have small but clinically meaningful benefits to people with PDN.

Clinicians who already work within specialist pain services were interviewed as part of another study (Davies, 2017). They felt there were potential opportunities for improved quality of life in PDN using PMP strategies (i.e., including psychological approaches). In contrast, clinicians working within traditional diabetes services were very aware people with PDN experienced depression and anxiety, in addition to pain, but felt “clinically impotent” when the recommended medication strategies failed to reduce people’s pain.

It seems possible to change the physical and emotional impact of PDN with known psychological approaches, but there is a lack of treatment studies to demonstrate this. A review by Kioskli et al. (Kioskli *et al.*, 2019) could only include three studies, two of which have been included in previous work (van Laake-Geelen *et al.*, 2019). Kioskli et al. (Kioskli *et al.*, 2020) have recently published the results of a single-arm feasibility study of ACT for PDN, delivered online. This study assessed n=225 people for study eligibility but had n=57 decline enrolment due to the length of the treatment course (~150 minutes across five weeks) and n=65 for other/unknown reason. The study had n=30 start the online intervention and n=12 who completed all sessions. The recruitment figures for the study are not dissimilar to those found in musculoskeletal pain management programmes (Taylor *et al.*, 2016), but the course completion percentage is lower. A key difference maybe that pain management approaches are recognised in the orthopaedic/musculoskeletal fields and are included in many published clinical pathways (Price *et al.*, 2014; Smith *et al.*, 2013), yet have not been researched or ‘marketed’ in the diabetes world.

This leaves diabetes clinicians unaware of the therapeutic options offered by PMPs, and people with PDN not being offered these approaches, either in the form of research trials or evidence-based clinical pathways.

Limitations

The primary limitation of this study was the lack of sociodemographic diversity in the sample population. All except one participant identified as White British. The age of participants and duration they had diabetes and PDN were representative, but different ethnic backgrounds have differing prevalence rates for diabetes (Gujral *et al.*, 2013). Different social groups and religious affiliations also have tendencies toward different pain coping strategies (Wachholtz, Pearce and Koenig, 2007), so the themes expressed by participants cannot be assumed to apply in other demographics or cultures.

Only two participants in this study had been referred to specialist multidisciplinary pain management clinics for issues other than PDN. So, the majority of participants had no experience of PMP techniques and were making judgements, negative and positive, on the basis of speculation. Although they were 'primed' with a list of PMP techniques, they had not been exposed to the full philosophy of the PMP approach. For example, in most PMPs exercise and psychological interventions are aimed primarily at altering pain-related disability, distress and quality of life, rather than the pain experience itself. Many of the participants' comments stated this would not be their expectation of treatment interventions. As such, future research on 'treatment acceptability' should consider the level of clarity and depth with which participants are informed about treatment techniques, before they are asked to comment on suitability.

Clinical implications

There is evidence from diabetes research and other persistent pain condition research, that supports physical activity to optimise and maintain physical function, yet people with PDN are uncertain of the relevance. There is evidence from other pain conditions that psychological strategies can improve quality of life, yet people with PDN may not see the relevance. Clinical strategies to maximise engagement with these coping strategies is critical, as is further research to explore the role pain acceptance may have on quality of life with PDN.

Future research

PDN has wide ranging impact on many facets of life (Alleman *et al.*, 2015; Davies *et al.*, 2021), but evidence for the potential benefit of physical and psychological approaches to mitigate these impacts is scarce. The clinical model used by ACT would appear to offer some evidence for reducing the psychological burden of PDN but research needs to explore how this is operationalised with the PDN population. It would be beneficial to explore the healthcare priorities of people with PDN and whether management strategies can be matched to these (Davies, 2017).

Conclusions

Our study found that participants with PDN have experimented with a range of uncommon pain management strategies. Some participants would be open to physical activity, but others saw no role for physical activity in improving their pain related symptoms. Participants who had received psychological advice for other persistent pain conditions felt these strategies were useful for PDN, but there was ambivalence from some other participants. Research from other conditions supports PMP strategies, but this study highlights the need to explore how to adapt these strategies to have more relevance to people with PDN.

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Conflict of interest statement

There are no known conflicts of interest.

Author contributions

BD received PhD funding for the study. All authors conceptualized the study protocol and design, BD collected interview data, the data analysis was completed by BD with significant discussion and input from CM. The research team all approved the final thematic structure. BD drafted the first version of the manuscript. All authors contributed to the revision process and fully agreed the final version.

Data availability statement

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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Figure 1 Mind map sent to participants

Pain coping skills programmes often consist of these components..

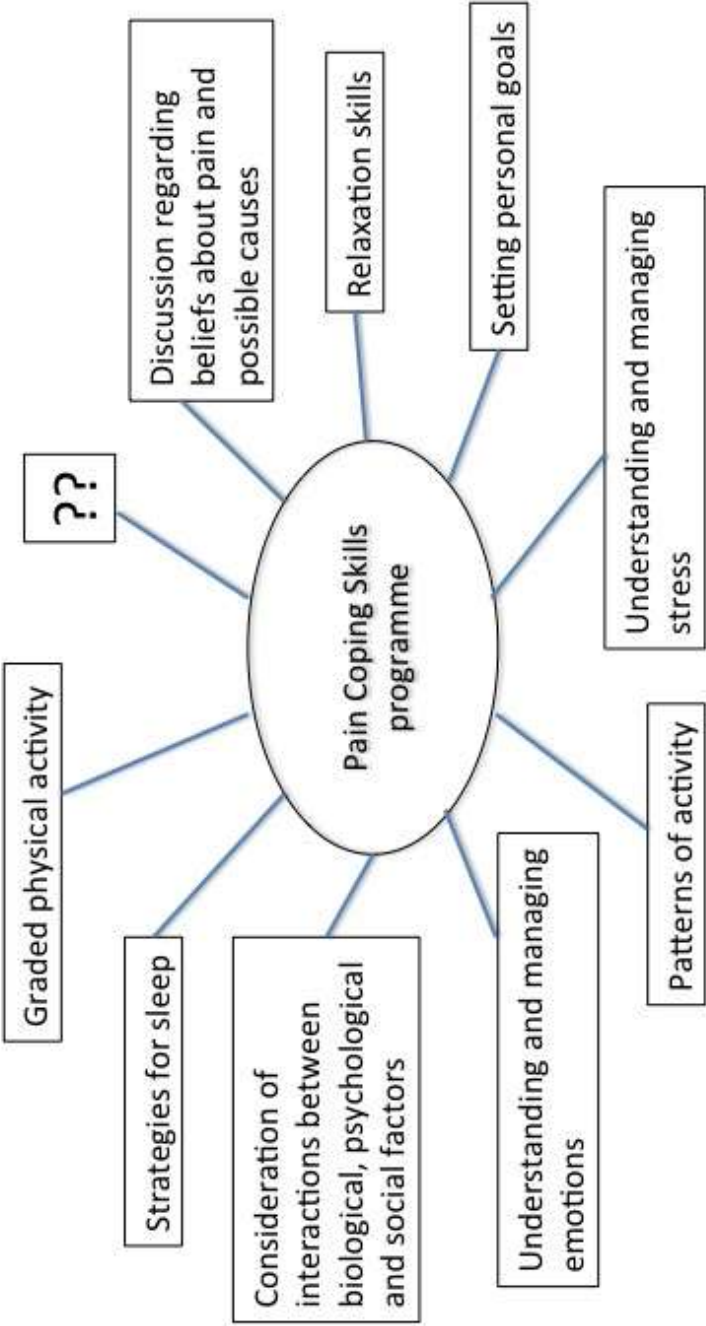


Table 1 – participant characteristics

Characteristic	Sample		NHS recruited		Balance recruited	
	N	Mean (range)	N	Mean (range)	N	Mean (range)
Participants	23		8		15	
Gender						
<i>Female</i>	12		5		8	
<i>Male</i>	11		3		7	
Age years		62.5 (24-86)		57 (44-69)		65 (24-86)
Ethnicity						
<i>White British</i>	22		8		14	
<i>West Indian</i>	1				1	
Type 1 diabetes	10		3		7	
Type 2 diabetes	13		5		8	
Duration with Diabetes (years)		23.5 (7-50)		23.5 (7-50)		23.5 (7-48)
Duration with PDN (years)		10.3 (1-24)		9 (5-15)		11 (1-24)
Current employment						
<i>Retired</i>	20		7		13	
<i>Full time</i>	2		1		1	
<i>Other</i>	1				1	
Current analgesia		2 (0-4)				
<i>Anti-epileptics</i>	9					
<i>Amitriptyline</i>	8					
<i>Strong opioids</i>	7					
<i>Paracetamol</i>	5					
<i>Duloxetine</i>	3					
<i>Co-codamol</i>	2					
<i>Capsaicin cream</i>	1					
<i>Nil analgesia</i>	5					

