Physiotherapy Pain Association

Painful diabetic neuropathy (PDN): an internet survey to the determine health-care priorities of people with PDN.

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Abstract

Aims

To determine the healthcare priorities of people with painful diabetic neuropathy (PDN) for managing the impacts of this condition.

Methods

An internet survey incorporating impacts of PDN developed from previous qualitative research, was distributed via diabetes support groups and on social media forum platforms. The survey asked respondents how frequently they experienced 58 impacts of PDN, how these impacts affected their quality of life, and the impacts they prioritised for better clinical management.

Results

The survey had 62 eligible and complete responses. The impacts with high frequency related to emotions, foot health and walking. The impacts with the greatest affect on quality of life related to psychological distress, social world, functional ability and sensory experiences. The impacts prioritised for better clinical management were: sleep, worry, functional ability and depression.

Conclusions

This study identified the top healthcare priorities of people with PDN, the topmost being help with sleep disturbance. There are existing evidence-based approaches, such as cognitive behavioural therapy for insomnia, which could help manage some of these priorities, but not all. These priorities could be used to develop a PDN-specific pain management programme.

Contribution of the paper

- People with PDN experience a wide range of impacts on their quality of life, it was unknown which of these impacts would be prioritised by them for better management
- This survey found sleep disturbance to be the key issue people wanted help with.
- There are treatment options for some priorities eg CBT for insomnia, but not for others.

Keywords

Painful diabetic neuropathy, patient experience

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% [1]. Improvements in drug treatment have reduced mortality but living longer allows more years for macro and micro-vascular complications to develop [2]. One micro-vascular complication which affects approximately 20% of people with diabetes is painful diabetic neuropathy (PDN) [3].

Painful diabetic neuropathy impacts on physical and mental health: people experience burning pain in a stocking and glove distribution which can be severe, levels of depression and anxiety over and above that associated with diabetes alone, and frequent sleep disturbance and work absenteeism – overall, a reduction in life quality [4]. Medication is the main approach to managing PDN with the National Institute for Health and Care Excellence (NICE) recommending amitriptyline, gabapentin, pregabalin or duloxetine, alone or in combination [5]. The odds ratio of being prescribed an anti-neuropathic pain medication increased 11% for each unit of sociodemographic deprivation index even when other factors (age, HbA1c, BMI, cardiovascular and kidney function) were controlled for [6], highlighting that, similar to other long-term

pain conditions, there are multiple physiological, psychological and social contributors to the case presentation of PDN. The recommended medications have a 'number needed to treat' (NNT) between 6 and 8, to achieve 30-50% pain reduction [7], so successful drug management of PDN symptoms is far from guaranteed [8].

For other persistent pain conditions, such as low back pain, pain management programmes (PMP) exist that use physical rehabilitation and psychological strategies to live well with persistent pain [9]. PMPs are usually delivered in-person by a multidisiplinary team, but have been adapted for online delivery due to COVID [10]. They range in duration from four hours content, to multi-day residential courses. Evidence from robust systematic reviews demonstrates PMP can improve physical function (Standardised mean difference (SMD) 0.23) and increase the likelihood of remaining in employment (Odds ratio 1.87) [11]. PMPs tend to be based on either Cognitive Behavioural (CBT), or Acceptance and Commitment Therapy (ACT) approaches. A recent Cochrane review found moderate evidence that CBT reduced disbability by SMD -0.12, but that ACT had no effect on disability [12]. Specifically for PDN, there is limited, low-quality research exploring psychological approaches for the management of neuropathic pain [13] or for combined physical and psychological approaches [14,15].

Research in PDN often uses validated outcome measures such as the Brief Pain Inventory, however we conducted interview research with people who experience PDN and found fifty-eight impacts including: embarrassment, anger, altered appetite and consequent effect on diabetes management, social isolation, loss of libido, independence and a reduction in their confidence to engage with society [16]. These results supported themes found in other qualitative focus-group research [17]. This breadth of impact is not represented by the usual outcome questionnaires, it is possible current PDN research does not focus on key issues for people with PDN.

We have asked people with PDN how appropriate PMP strategies appeared to be, for managing their experience of PDN [18]. Some participants were open to these strategies, but there were strong opinions that no physical activity or psychological approach could help with PDN. It is possible current PMPs curricula do not match peoples' priorities for treatment. Only one study has explored treatment priorities in PDN [19], this found activity level (29.3%) and walking ability (24.4%) were the most important outcomes. These results were from a large sample (n=2245), but priority selection was restricted to options based on the Brief Pain Inventory, so may not have included those pertinent to participants. Peoples' healthcare priorities warrant further research to understand what these priorities are, and whether they are amenable to any current evidenced-based approaches.

Study aims

To 1) explore the frequency and severity rating for a range of PDN-related impacts, and 2) determine which impacts of PDN were rated as priorities for better clinical management trategies.

Method

An internet survey, based on previous research with people with PDN [16], was developed to explore treatment priorities. People who reported symptoms consistent with PDN were recruited and asked to 1) rate the frequency and severity of a range of fifty-eight PDN impacts presented to them, and 2) select their top priorities for management from these impacts.

Participants and recruitment

The study information was disseminated by DiabetesUK (DUK), a leading UK-based diabetes charity, via email to the members of their peer-support networks. The information was also posted on PDN-related Internet discussion forums hosted by DUK (diabetes.org.uk), Diabetes Forum (diabetes.co.uk) and Diabetes-support (diabetes-support.co.uk). New threads were started to maintain the study information near the top of forum listings and the wording of the headline was altered to encourage participation. Each of these strategies for recruitment included a webpage address to access the survey. These recruitment processes were active between February and April 2016.

Inclusion criteria

Participants were included if they self-reported a diagnosis of type 1 or type 2 diabetes, and symptoms of PDN consistent with the DN-4 interview questions for sensory profile, bilateral symptom distribution and response [20].

Participants were excluded if their reported symptoms were inconsistent with a likely diagnosis of PDN (unilateral symptoms). Internet access was a further requirement.

Survey materials and questionnaires

A survey was created using an online platform (Qualtrics). Four initial screening questions assessed the likely presentation of PDN [20]. Preliminary questions recorded basic demographic data. The Pain Coping Strategies Questionnaire (PCSQ) [21] was included to measure respondents' approach to coping with pain using passive or active strategies. This measure has seven subscales covered by 14 items, such as "I think of things I enjoy doing", measured on a scale from 0 (never do that) to 6 (always do that) and has been validated for neuropathic pain [22].

The main focus of the study were participants' ratings of a list

of 58 statements about the potential impacts of PDN derived from previous interviews [16] (see Appendix 1). This study interviewed twenty-three people who had experienced PDN for between 1 and 24 years. Any description of PDN affecting aspects of life were coded and developed using inductive thematic analysis [23] into the impact statements used in the current study. Using these statements, rather than established questionnaires, ensures the survey reflected the experience of living with PDN articulated by these people. The statements were finalised in conjunction with two patient research partners who reviewed the wording to ensure no ambiguity and a series of changes were made based on this input. The survey was then piloted with the twenty-three participants from the previous interview study, suggested wording changes were incorporated into the final survey before being launched on-line.

Participants were asked to rate all 58 statements on a single 5-point Likert scale that allowed a frequency count, as well as an assessment of symptom impact severity. The scale was scored: 0 = never experienced, 1 = experienced but no impact on quality of life (QOL), 2 = experienced with small impact on QOL, 3 = experienced with moderate impact on QOL, and 4 = experienced with large impact on QOL. From these responses we derived an index of symptom frequency (i.e. participants scoring >=1), as well as impact severity. Participants were presented with the statements in a random order.

Finally, respondents were asked to review the 58 statements a second time, to select and prioritise the top-10 impacts they would want help to manage more effectively. Patients were not obliged to choose 10 impacts, and their responses were analysed irrespective of the number of impacts selected for their priority list.

Data analysis

Sociodemographic and clinical data were summarised with descriptive statistics. Impact data were summarised in three ways: 1) a frequency count of impacts reported by each respondent was used to check these statements (developed in qualitative research) were recognised and endorsed, 2) the mean severity rating for the impacts, and 3) a total impact severity score, this was calculated by summing the severity rating for each impact endorsed by the respondents. This total impact severity score provided a metric that reflected both the count and severity of the impacts experienced. Pearson's correlations were performed between the severity ratings and average pain score (NRS 0-10) for the past week, for the ten impacts that most affected quality of life.

Visual review of the data indicated the greatest number of missing responses from the 'severity' ratings, meaning respondents reported experiencing an impact but omitted to score the severity on their quality of life. If missing severity data accounted for ≤7 questions (15% of 58 statements) the missing data were replaced with the respondent's mean severity score. If ≥8 data items were omitted the case was removed from the analysis.

The PCSQ was calculated to yield composite scores representing "active" and "passive" pain coping [21]. Pearson's correlation coefficients were calculated between the PCSQ sub-scales and 1) impact frequency, 2) mean impact severity and 3) total impact severity score.

Respondents were finally asked to rank up to ten impacts they would prioritise being addressed in treatment. The priority rankings assigned were transformed using an inverse scale (1st priority=10, 2nd priority=9 … 10th priority=1, not selected=0) and these scores were summed for each impact. The approach was based on research investigating priorities for pharmacological management of rheumatoid arthritis [24]. To balance the analysis, for example, to account for an impact being rated as medium priority by a majority of respondents, as opposed to being rated as high priority by a minority of respondents, it was important respondents who endorsed more priorities should not have a greater influence on data. To achieve this the maximum possible priority for an impact was defined as 100%, that is, if each respondent who selected an impact, ranked it first priority it would equal 100%. The sum of inversed priorities were presented as a percentage of this maximum possible priority. Presenting the data in this way, rather than a simple sum of priorities has two benefits for the analysis. Firstly, it helped address the balance between many respondents rating an impact as a low priority, and few respondents rating an impact as a high priority. Secondly, this approach ensured the calculation of priority was done for each impact, not each respondent. Respondents who prioritised more impacts would not have undue influence on the data, compared to respondents who prioritised fewer impacts.

Results

There were 107 individual responses to the survey. Twenty-nine participants were excluded for not meeting likely clinical criteria for the presence of PDN, leaving 78 eligible data sets. After removal of data sets with excess missing data, 62 complete surveys were considered.

Sample demographics

The sample was 52% female and 63% had Type 2 diabetes. Respondents had been diagnosed with diabetes for mean 17.9 (SD 12.4) years and had symptoms of PDN for mean 7.4 (SD 5.9) years. The respondents nearly all identified as White British (89%). See Table 1 for full details.

Table 1 - Survey respondent details

Characteristic	***N=62***	***% or Mean ± SD (range)***
Sex		
Male	29	48%
Female	33	52%
Ethnicity		
White British	55	89%
Asian/Asian British	3	5%
Mixed ethnic groups	1	1%
Other	3	5%
Work status		
Employed	19	30%
Unemployed	9	14%
Retired	31	50%
Other	2	5%
Missing	1	1%
Home status		
Living alone	17	27%
Living with partner	29	46%
Living with family members	15	24%
Other	1	1%
Type of diabetes		
Type 1	20	32%
Type 2	39	63%
Missing	3	5%
Self-rating of diabetes management		
Very good	14	22%
Good	19	30%
Moderate	24	38%
Poor	2	3%
Very poor	3	5%
Age		57 ± 13 (26-84 years)
Diabetes duration		17.9 ± 12.4 (1-53 years)
PDN duration		7.4 ± 5.9 (1-30 years)
Average pain score past week (NRS 0-10)		6 ± 2.4
		NRS – numerical rating scale

Impact based on frequency (Table 2)

Table 2 shows the ten most, and ten least frequently experienced impacts. A number of high frequency items related to emotions (worry, frustration, intolerance) and others grouped around foot health and walking (check my feet, numb feet, walking difficult). Only the last four impacts – frequent cramps, headaches, memory difficulty and suicidal ideation – were experienced by less than half the respondents.

Table 2 – Impacts by frequency; ten most, and least frequent

Rank	***Impact statement***	***% Experienced (1-4 Likert), n=62***
1	I have to check my feet regularly for possible injury	**94.8**
2	I am worried that my PDN will get worse in the future	**93.4**
3	My sleep is disturbed due to PDN	**91.8**
4	PDN causes me to have numb feet	**91.7**
5	PDN leads me to get frustrated	**89.7**
6	My feet look normal but I have this severe pain	**88.7**
7	PDN affects my ability to concentrate	**86.7**
8	PDN gives me a sense of restless legs	**85.0**
9	When PDN flares up I can be less tolerant to those around me	**84.5**
10	PDN makes walking difficult	**83.6**
…	…	**…**
49	PDN makes me worried about going out of the house	**55.9**
50	PDN makes me feel embarrassed	**55.4**
51	My PDN affects my close family	**55.2**
52	It bothers me what other people think of me due to the problems I have with PDN	**55.0**
53	I worry how our money will be affected because of PDN	**54.2**
54	I get more breathless than before I had PDN	**51.8**
55	I get cramp more frequently than before I has PDN	**50.0**
56	PDN affects my memory	**49.2**
57	PDN can lead me to have headaches	**46.6**
58	I have contemplated suicide due to my PDN	**29.3**

Impact based on severity (Table 3)

The most severe impacts are shown in Table 3, alongside the percentage who rated these as having moderately severe or very severe impact on quality of life. These impacts included: worry for the future (84%), perceptions of others (76%), cramp (76%), sleep disturbance (75%) and frustration (75%). There were clear similarities and contrasts between the frequency and severity ratings. For example, worry about PDN and sleep disturbance were rated as both frequent and severe, whereas impacts such as frustration, poor concentration and intolerance were rated as frequent but did not feature in the impact severity data. The impacts that most affect quality of life, all significantly correlated with average pain severity (between r=.31 and .70, see Table 3). This was true for items that were obviously related to pain (e.g. “I get cramp”) and also for items that seemed unrelated (e.g. “PDN causes me to have numb feet”).

Table 3 - Impacts by severity; ten most and ten least severe

Rank	***Impact statement***	***% 3/4 or 4/4*, n=62***	***Correlation with pain NRS***
1	I am worried that my PDN will get worse in the future	**84.2**	**.54****
2	It bothers me that other people can't see I have this problem	**76.3**	**.35***
3	I get cramp more frequently than before I has PDN	**75.9**	**.48****
4	My sleep is disturbed due to PDN	**75.0**	**.55****
5	PDN leads me to get frustrated	**75.0**	**.70****
6	PDN affects a wide range of activities that I want to do	**75.0**	**.64****
7	PDN causes me to have numb feet	**74.5**	**.31***
8	PDN can lead me to have headaches	**74.5**	**.41****
9	I have reduced my physical activity due to PDN	**74.5**	**.56****
10	PDN affects my social life	**74.2**	**.53****
…	…	**…**	
49	PDN hurts so much it brings tears to my eyes	**58**	
50	My skin is sensitive to the lightest touch	**57**	
51	PDN makes me feel embarrassed	**56**	
52	PDN affects my appetite for food	**55**	
53	I get more breathless than before I had PDN	**55**	
54	I worry how our money will be affected because of PDN	**55**	
55	I don't understand why I have PDN	**53**	
56	My overall quality of life is really affected by PDN	**49**	
57	PDN affects our family holidays	**48**	
58	PDN and balance problems lead me to fall over	**47**	
**3/4 – moderate impact on quality of life, 4/4 – severe impact on quality of life* ***p=<0.001, *p=<0.01*			

Correlation between impacts of PDN and the Pain Coping Strategies Questionnaire (PCSQ) (Table 4)

There was significant correlation between the use of passive coping strategies and impact frequency (r=0.54, p<0.001), mean impact severity (r=0.59, p<0.001), and the total impact severity score (r=0.62, p<0.001). There were no significant correlations between use of active coping strategies and these measures of PDN impact.

Table 4 - Correlation of impact and PCSQ

	PCSQ Active coping	***PCSQ Passive coping***
Impact frequency count	r=0.24, p=0.16	r=0.54, p<0.001
Mean impact severity	r=0.02, p=0.91	r=0.59, p<0.001
Total impact severity	r=0.16, p=0.32	r=0.62, p<0.001

Patient priorities for help in managing PDN (Table 5)

The top-10 priorities selected can be seen in Table 5. These include: sleep, worry for fitness and the future, mobility difficulties due to numbness and pain, and depression. There was some commonality with the impacts rated as most frequent, and as having most effect on quality of life. It was notable that impacts which specifically described the sensation of pain were not in the top-10 priorities.

Table 5 - Respondent priorities

Rank	***Impact statement***	***Total score (reversed score)***	***%***
1	My sleep is disturbed due to PDN	171	21.9
2	I worry about keeping my physical fitness due to PDN	110	14.1
3	PDN causes me to have numb feet	105	13.5
4	PDN makes walking difficult	94	12.1
5	I am worried that my PDN will get worse in the future	90	11.5
6	PDN leads me to feel depressed	86	11.0
7	I have to be careful walking due to my balance	78	10.0
8	PDN makes it difficult to buy shoes that are comfortable	78	10.0
9	PDN gives me a sense of restless legs	78	10.0
10	PDN affects my ability to do every day jobs	69	8.8

Discussion

We examined the impact of PDN in a population recruited online, asking about a much broader range of impacts than previous questionnaire-based research. Sixty-two respondents completed the survey in full, their demographics were representative of other studies into PDN (e.g [25]). All 58 impacts were experienced to some extent, endorsing the broad and diverse range of impacts presented. The most severe impacts on quality of life related to mood and functioning, but did not include the impacts which described the experience of pain. Fifty-six of 58 impacts were a priority to at least one respondent, which highlights the breadth of what people prioritise for better management.

Frequency of experienced impacts

Fifty-four of the 58 impact statements were recognised as experienced by at least half of the sample (Table 2), highlighting impacts developed from qualitative research had resonance for the respondents in this study. The impacts experienced most frequently were: feet checks, worry for the future, disturbed sleep, numb feet and frustration. Some of these – worry for the future, disturbed sleep and frustration – were also within the most severe impacts. The impact – "my feet look normal but I have this severe pain" – was endorsed by 88.7% of respondents, this might be considered a low percentage considering pain is the defining symptom of PDN. Only four impacts were experienced by less than half the sample, with the least frequent impact – suicidal thoughts – still endorsed by nearly 30% of the respondents.

Severity of experienced impacts

The impacts of PDN with the greatest effect on quality of life (Table 3), can be classed as psychological (worry, frustration), social (opinions of others, social life), functional (sleep, general activities, physical activity) and sensory (cramp, numbness and headaches). These domains have been found in other qualitative research into PDN [17]. The sensory impacts of cramp and numbness are also common with non-painful diabetic neuropathy [26]. The correlation analysis showed the top-10 severe impacts all correlated with pain ratings (Table 3), the worse someones pain is, the worse they rated their psychological, social, and functional status. However the impact directly related to pain ("My feet look normal but I have this severe pain" and "PDN hurts so much it brings tears to my eyes") were low in impact severity rankings (39th/58 and 49th/58, respectively). This could suggest the pain experience per se has less direct effect on quality of life than do the consequences of pain. There were commonalities between

the impacts rated as most frequent and most severe – future worry, sleep disturbance, numb feet and frustration, and also with the impacts that respondents prioritised for treatment.

Data from this study showed passive coping was clearly related to having more negative, and more severe impacts. This is consistent with much pain research showing the negative influence of passive coping (e.g. hoping for improvement) and implies reducing passive coping should be clinically beneficial. However, active coping (e.g. replaying pleasant experiences in my mind) was not associated with reducing these impacts of PDN.

Matching respondent priorities to treatments

To inform clinical management strategies, it is important to consider whether respondents' priorities align to existing evidence-based approaches and potentially incorporated into a novel PMP for PDN.

'My sleep is disturbed by PDN'

It is well established that pain can affect measures of sleep adequacy and quality, however, the stronger relationship is for disturbed sleep to worsen the pain experience [28]. Existing PMPs often include education on sleep hygiene strategies, but this component is less than in cognitive-behavioural programmes specifically for insomnia (CBT-I). A review of CBT-I with people in pain found some positive benefits, with improved sleep efficiency and reduced sleep onset latency, but no overall change to participants' pain ratings [28]. If incorporated into a PDN-specific PMP, it is unknown whether CBT-I would have clinically relevant changes to sleep quality and pain.

'I worry about keeping my physical fitness due to PDN'

Promoting physical activity and exercise is central to all PMPs, so this seems a clear area of overlap [9]. A Cochrane meta-review included fourteen reviews investigating exercise in pain cohorts, and found clinically relevant improvement (small to moderate effect size) in physical function, for at least one follow-up time point [29].

The evidence for exercise in PDN is more sparse [14], this review found two studies, investigating Tai Chi and aerobic exercise. These interventions did not reduce pain, the significant differences between study arms was due to control arms worsening over the study period. This may emphasise that PDN has a trajectory of deterioration due to underlying pathophysiology. The studies did show some improvement in the exercise arms for secondary outcomes such as quality of life scales, but were not powered for these.

Having insensate feet is a consideration for exercise prescription, and regular foot surveillance is critical [30]. Such foot surveillance is not usually addressed in PMPs although adaptation is clearly possible, as partial and non-weight bearing exercise options exist. Clinicians should be able to help patients find appropriate exercise options, which could be beneficial to physical and mental health, as well as diabetes control [31].

'PDN makes walking difficult'

PDN affects walking due to both pain and loss of proprioceptive information (next priority). Walking despite pain is often prioritised in PMPs to aid daily function and PMPs use psychological strategies as well as physical training to this end [32]. Graded increases in walking could be adopted for PDN, with additional diligence for foot checks to mitigate ulceration risk .

'PDN causes me to have numb feet'

The wording of these statements were developed from qualitative research with people with PDN [16] and it is not strictly true to state PDN causes numbness, rather the peripheral sensory neuropathy can present with or without pain [33]. Nonetheless, participants were clearly concerned about sensory loss and identified it as a treatment priority. Currently there is no evidence from pharmacological or rehabilitation studies for any intervention reducing this loss of sensory function. People with established neuropathy need to accept this as an ongoing symptom to be managed.

Strength and balance exercises may help to maintain overall balance strategies and so reduce the risk of associated falls [34] and these could be incorporated into a PMP.

'I am worried PDN will get worse in the future'

The natural history of PDN is for pain to stay the same, or worsen, for the majority of people [26]. A person experiencing PDN already has substantial pathology related to their diabetes, and this can deteriorate futher. However, disruptive and upsetting worry is not an inevitable consequence and the presence of worry is unlikely to help a person already dealing with chronic health conditions.

More broadly, negative fears for the future are the cognitive hallmark of catastrophization which is a common thought pattern in people with chronic pain and is associated with lower physical activity levels, mental health and overall quality of life [35]. PMPs address catastrophization with cognitive-behavioural techniques, and improvements in catastrophising are associated with improvements in outcome measures such as physical disability ($\beta=0.15$, $p<0.005$) [36].

'PDN leads me to feel depressed'

Qualitative research has highlighted many contributors to people's depression – pain, work, finances, daily restrictions, and disturbed sleep [16]. A recent systematic review found depression, anxiety and disturbed sleep were all associated with PDN pain intensity, with small to large effect sizes [37]. The majority of included studies were cohort design, so causality could not be established.

The same research group have examined the role of psychological flexibility in PDN-related disability [25]. In multiple regression analyses, pain intensity was the largest predictor of functional disability (32.2%, $p<0.01$), depression severity (23.3%, $p<0.01$) and depression impact (13.2%, $p<0.01$). Variables of psychological flexibility contributed 4.5% ($p<0.01$) to models for function and 7.5% to models of depression severity. When pain is not managed by analgesia, quality of life maybe improved if these psychological variables could be better managed. Further studies offering on-line ACT for PDN recruited 30 people (from 225 eligible) to enrol, but only 12 completed the full course. Small sample sizes in psychological studies and bias from attrition are being challenged in a review of trial quality for psychological therapies [38]. The evidence for any specific approach to managing psychological issues in neuropathic pain such as PDN, remains lacking.

Limitations

The statements of impact used in this survey were derived from an interview study where 95% of the interviewees were White British; the current survey sample was again predominantly White British (89%). Caution should be exercised when extrapolating the results to populations with different backgrounds and cultures.

Due to the number of impacts to investigate, it was felt only practical to run this research online. The sample included people to 84 years old, so reduced access and ability to complete internet based research should not be assumed in an older population, but excluding people of any age without internet access may have created bias to the results.

The decision to exclude incomplete datasets at ≥8, was because this point appeared a 'cliff edge' for non-completion of the survey. We recognise the task of appraising 58 impact statements twice may have been too onerous and one explanation is people lost interest in completing the study at around this point. This study asked for priorities for treatment, it did not imply any cost that may be incurred for this treatment (not financial but rather time, engagement and investment by the person, the motivation required) and so potential trade-offs, or contingencies, were not part of this exploration. We also do not know if this population had tried and failed with analgesia, and so were more resigned to living with pain, compared to people who have not yet tried all NICE recommended analgesia, for whom pain reduction may have remained a higher priority.

Conclusions

People with PDN experience a wide range of impacts from PDN and they prioritised issues around physical functioning, mood and sleep. These were chosen ahead of the subjective pain experience, which is often the focus of research. When analgesia fails to successfully reduce pain, long-term support for people with PDN needs to be based on their priorities. This study found some priorities might be addressed by existing approaches (CBT-I), or by adaptations to advice for physical activity and exercise to mitigate risks of tissue damage. Psychological impact of PDN is clear, but there is limited evidence for any particular approach. Future research needs to define a PDN-specific PMP, and run a feasibility trial to explore the uptake and enagement with such a program and, having completed it, the participant evaluation of the PMP approach.

Ethical approval

The Research Ethics Committee for the Faculty of Health and Applied Sciences, University of the West of England, Bristol, UK granted permission for this survey (HAS/15/11/038).

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Conflict of interest statement

There are no known conflicts of interest.

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Appendix 1 - Survey statements

Impact	Survey statement
1	My sleep is disturbed due to PDN
2	PDN leads me to feel depressed
3	PDN makes walking difficult
4	PDN affects my ability to do every day jobs
5	PDN causes me to have numb feet
6	It bothers me what other people think of me due to the problems I have with PDN
7	I have become more socially isolated due to PDN
8	PDN stops me from sitting comfortably
9	PDN leads me to get frustrated
10	I don't cope well with PDN
11	It bothers me that other people can't see I have this problem
12	I am worried that my PDN will get worse in the future
13	My PDN has an effect on my partner
14	PDN affects a wide range of activities that I want to do
15	PDN leads me to feel angry
16	I keep my problem with PDN away from my close family
17	I am not the person I was before I developed PDN
18	I have to check my feet regularly for possible injury
19	PDN affects my ability to concentrate
20	I have to be careful walking due to my balance
21	I have difficulty doing my job due to PDN
22	I have reduced my physical activity due to PDN
23	PDN affects my social life
24	I have contemplated suicide due to my PDN
25	I don’t understand why I have PDN
26	PDN hurts so much it brings tears to my eyes
27	PDN leads me to worry more than I would if I didn’t have it
28	PDN makes me think about driving carefully
29	PDN affects my intimate relationships with a partner
30	My PDN affects my close family
31	PDN affects my memory
32	PDN affects my appetite for food
33	PDN and balance problems lead me to fall over
34	PDN stops me being as independent as I expect to be
35	PDN makes it difficult to buy shoes that are comfortable
36	PDN gives me a sense of restless legs
37	My skin is sensitive to the lightest touch
38	PDN affects me as soon as I put my foot to the ground in the morning
39	My feet look normal but I have this severe pain
40	PDN can lead me to have headaches
41	PDN affects our family holidays
42	My life had become more restricted due to PDN
43	I don't go out as much because of PDN
44	I struggle to get up for work due to the PDN

45	I worry how our money will be affected because of PDN
46	I worry about keeping my physical fitness due to PDN
47	When PDN flares up I just want to be on my own
48	PDN makes me worried about going out of the house
49	I always have to think about the needs of other people
50	PDN makes me feel embarrassed
51	I get more breathless than before I had PDN
52	I get cramp more frequently than before I has PDN
53	I have lost confidence to be myself due to PDN
54	My overall quality of life is really affected by PDN
55	When PDN flares up I can be less tolerant to those around me
56	My self-image has changed due to PDN
57	PDN has stopped me going dancing
58	I keep my problems with PDN away from my wider social network