

Peoples' experiences of painful diabetic neuropathy: a qualitative interview study.

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Abstract

Objective

Painful diabetic neuropathy (PDN) is a common complication of diabetes. This study explored the experience and impact of living with PDN.

Design

People with PDN were recruited through local NHS clinics and by national advertisement in diabetes support publications and social media forums. Semi-structured interviews were conducted either in person or by telephone. Data were analysed using inductive thematic analysis.

Results

Twenty-three people (12 female, 13 with Type-2 diabetes; 22 identified as White British) were interviewed who had PDN symptoms for mean 10 years (range 1-24 years). Four superordinate themes were identified from the data: The

experience of living with PDN, Affects those around me, A range of negative emotions and Life is a constant challenge.

Conclusions

People with PDN experience a wider range of impacts than those previously reported in research literature, for example: embarrassment, anger, altered diet, reduced intimacy and social isolation. Whilst further research is warranted with a diverse ethnic sample the findings indicate that the wide-ranging impact of PDN on quality of life needs to be recognised in clinical practice and incorporated into future research.

Contribution of the paper

- The majority of research into painful diabetic neuropathy uses validated outcome measures, there are very few qualitative studies investigating the impact of PDN.
- This paper highlights there are more and varied impacts of PDN, than captured by the existing research

Key words – diabetes, neuropathy, chronic pain, quality of life, qualitative research

Introduction

Diabetic peripheral neuropathy, leading to sensory loss, affects up to 50% of people [1,2]. Data suggest around 20% of people with diabetes experience sensory loss and pain, termed painful diabetic neuropathy (PDN) [2]. This presents as burning pain in a 'glove and stocking' distribution that is usually constant, daily and with moderate to severe intensity [3]. PDN is associated with a significant impact on physical and mental health and reduced quality of life, over and above the impact of diabetes alone [4,5].

Most research into the impact of PDN pain has been conducted using validated self-report questionnaires. Quality of life and functional state have been measured using the generic EQ5D [6,7], Brief Pain Inventory (BPI) [3,8] and SF36 questionnaires [9]. One limitation of questionnaire-based research is the preset range of questions and responses, which may not encompass all the factors experienced as a result of the health condition [10]. This is particularly the case where patient groups have not been involved in the development of core outcome measures [11]. A specific example of this is in rheumatoid arthritis where fatigue was identified by patients as missing from the core set of outcomes [12]. Development of a specific outcome measure and subsequent research findings have ensured that fatigue management strategies are now recommended as a key component of management for people with rheumatoid arthritis [13].

Current treatment recommendations for neuropathic pain [14] are entirely pharmacological, but the medications are often ineffective and/or have unwanted side effects [15]. Persistent pain of all causes is known to affect multiple quality of life

dimensions and cohort studies have demonstrated differences in symptom profile between neuropathic and nociceptive pain conditions [16]. Persistent pain conditions should not be considered homogenous [17]; the National Institute for Health and Care Excellence (NICE, UK) has recommended research into the factors which affect participation in life and quality of life, specifically in people with neuropathic pain [14].

In PDN there are few qualitative studies; Brod et al. present data from interviews and focus groups which highlight four domains where PDN impacts on quality of life: physical function, daily life, social/psychological functioning and sleep but this study was carried out in the USA and may not be of direct relevance to the UK population with different sociodemographic profiles and healthcare systems [18]. Kanera et al. explored specifically how physical activity levels were affected by fears related to PDN, pain and balance using a focus group [19].

The aim of this study was to explore the experiences of people living with PDN, and the impact it had on their lives.

Method

We carried out semi-structured interviews with people who self-reported a diagnosis of PDN, in order to understand the impacts PDN had on their lives.

Participant recruitment

Recruitment was 1) through local NHS diabetes and PDN-specialist clinics, where clinicians independent of the research 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. Individuals who contacted the research team and met eligibility criteria were sent detailed study information and given the opportunity to ask questions about the study. If, having received this information and had questions answered, they consented to be interviewed, an appropriate date for interview was scheduled.

Eligibility criteria

Participants were required to self-report painful neuropathy secondary to diabetes 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, one-to-one interviews were scheduled. These were conducted, either on University premises, at the person's home or by telephone according to individual preference. The interviews were semi-structured based on an interview schedule which had been developed by the research team and an Expert Patient Research Partner (EPRP). The schedule (online S1)

was grounded in the existing literature, the study 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 PhD research student (BD), a physiotherapist, who has 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 was not referred to again through the interview unless by the participant. No clinical advice was offered during the interview.

The interviews were digitally recorded and transcribed verbatim by professional transcription services. Contemporaneous field notes were taken to allow contextualization and reflection on the interview through the analysis phase.

Data analysis

The transcribed text was imported to NVivo (NVivo version 11 for Mac, QSR International) for management and analysed using an inductive thematic analysis approach [20]. The researcher examined the transcripts and assigned a 'code' to each substantive element mentioned by participants. These initial 'codes' were designed to represent the participant's point as closely as possible and were created with reference to that interview alone, irrespective of the other transcripts. This analysis made no assumptions about the experiences of interview participants. These codes were grouped into organising themes containing 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 senior member of the research team (CM). CM has extensive experience of qualitative research in a variety of long-term health conditions.

Results

Sample demographics

All except one individual who contacted the researcher were interviewed. The person excluded had neuropathy but no pain. Twenty-three participants were recruited with 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. The interviews lasted between 30 and 120 minutes.

Table 2 – code structure of themes

Superordinate theme	The impact of PDN			
Themes	The experience of living with PDN	Affects those around me	A range of negative emotions	Life is a constant challenge
Sub-themes <i>Individual codes</i>	A sensory experience <i>Numb feet</i> <i>Life pre-PDN</i> <i>Crying with pain</i> <i>Restless legs</i> <i>Skin sensitivity</i> <i>Feet look normal</i> <i>Headaches</i> <i>Getting breathless</i> <i>Getting cramp</i> <i>Self-image</i> <i>Foot position</i> <i>Chronic pain</i> <i>Templar torture</i> A very personal problem <i>What other people think</i> <i>A hidden problem no-one else sees</i> <i>Considering others</i> <i>Keeping it to myself</i> Making the most of life <i>Carry on with social life</i> <i>Always been independent</i> <i>Loss of independence</i>	<i>Effect on partner</i> <i>Effect on family</i>	<i>Emotional depression</i> <i>Emotional frustration</i> <i>Worries for the future</i> <i>Emotional anger</i> <i>Suicide</i> <i>Why me with PDN</i> <i>Emotional worry</i> <i>Worry about fitness</i> <i>Embarrassed emotion</i> <i>Loss of confidence</i> <i>No quality of life</i> <i>Pain makes me mean</i>	Increasingly on my own <i>Becoming socially isolated</i> <i>Struggling with social life</i> <i>Not going out</i> <i>Be on my own</i> A shrinking world <i>Losing mobility</i> <i>Had to stop driving</i> <i>Losing balance</i> <i>Fallen over</i> <i>Narrowing down life</i> <i>Become agoraphobic</i> <i>Stopped dancing</i> <i>Holidays affected</i> <i>Sleep and fatigue</i> <i>Sleep disturbance</i> <i>Sleep not disturbed</i> Harder to remain at work <i>Affecting concentration</i> <i>Not able to do my work</i> <i>Struggle to get up for work</i> <i>Worries about money</i> <i>Able to work</i> <i>Changing jobs</i> <i>Returning to work</i> Day to day life is a struggle <i>Affecting day to day activity</i> <i>Can't sit for too long</i> <i>PDN difficult to cope with</i> <i>Affecting all aspects of life</i> <i>Stepping back from physical activity</i> <i>Affecting memory</i> <i>Can't face food</i> <i>Loss of intimacy</i> <i>Morning pain not been moving</i> <i>Problem with footwear</i> <i>Regular foot checks</i> <i>Advice for foot care</i>

Table 1 – participant characteristics

Characteristic	N	Mean (range)
Participants	23	
Gender		
Female	12	
Male	11	
Age (years)		62.5 (24-86)
Ethnicity		
White British	22	
West Indian	1	
Type 1 diabetes	10	
Type 2 diabetes	13	
Duration with Diabetes (years)		23.5 (7-50)
Duration with PDN (years)		10.3 (1-24)
Current employment		
Retired	20	
Full time	2	
Other	1	

The participants described a wide variety of impacts due to PDN. For the majority of participants, most facets of everyday life were affected in some way. The codes were grouped into four main themes: those describing the subjective experience of PDN (The personal experience of living with PDN); the impact PDN had on the participant's wider social network (Affects those around me); the impact on mood state (A range of negative emotions); and lastly, the day-to-day impact of PDN (Life is a constant challenge). These four themes are outlined in Table 2, and in more detail in the next sections. Anonymous quotes are presented using pseudonyms with the participant's gender (M/F) and age.

Theme - The personal experience of living with PDN

Participants spoke about the challenge of living with PDN from two perspectives. They described the personal experience of PDN in sub-theme: A sensory experience.

Sub-theme - A sensory experience

There were evocative descriptions of experiencing PDN, such as *"like Templar Torture"*, from when Templar Knights had boiling oil poured over their feet to extract confessions. Participants described the contradiction between numb feet where there was no pain experienced from tissue damage versus a burning pain sensation serving no purpose.

"...you get that numbness and then on the other hand the extreme pain." Bob, M63.

There was a similar contradiction for patients whereby their feet looked normal despite the perceived pain.

"You know what I mean, they're not gnarled and knotty, they look quite ordinary feet and yet they've got this most incredible pains." Lisa, F69.

Sub-theme - A very personal problem

A second sub-theme described how people felt viewed by others and how their sense of self or identity had changed due to PDN. Participants described feeling that other people had negative perceptions of them because there was nothing to 'see' to explain the pain. A lack of validation led to participants not talking about the problem, instead, they kept their experience to themselves.

"I would say "oh, no it's been an ok day" when actually it's been an awful day." Mary, F44.

A counterview was captured in the sub-theme: Making the most of life. There were participants for whom PDN caused minimal interruption to their lives and did not greatly affect their quality of life. In order to cope positively, and make the most of life, some participants viewed PDN as a challenge to conquer. This required optimism and setting daily goals.

"What you don't do is waste it [energy], just feeling sorry for yourself, I'm in pain again, that's no good. You've got to feed that emotion into something else." Anne, F52.

Theme - Affects those around me

Participants described how PDN impacted people close to them and affected their relationships with partners and family.

"... back to, to the eighties and early nineties, it [PDN] caused a, it caused the divorce between me and my wife – she couldn't handle it anymore – and we had a divorce." Mark, M62.

It affected their communication and made them less tolerant of family and friends around them.

"... the pain takes over, um, and you might, sort of, turn around and you've spoken sharply [...] because sometimes [name] will say afterwards, 'you don't need to say it quite like that'." Ellen, F63

Participants demonstrated this reduced tolerance by being more easily irritated in conversation or by other peoples'

actions. They actively removed themselves from their social environment, choosing instead to be on their own.

"I think there's just really, if my wife comes and talks to me, I say to her, 'look, I'm sorry I can't, I can't answer you, I don't want to talk to you.'" Aaron, M75.

Theme - A range of negative emotions

Participants gave clear examples of negative emotions such as feeling angry with themselves or their feet.

"you know I do get bad tempered and I think 'why bloody me?' you know. You hate your feet in a way." Philip, M57.

Two participants indicated that they had attempted suicide because of the pain,

"...but I just get too down and I have tried to take my own life three or four times. Well I suppose by trying to take overdoses and things, I'm not coping with it [PDN]." Kate, F58.

They were embarrassed because of social restrictions and depressed because of the on-going problems they had to cope with.

"I had to go out in the garden and I had to make out that I felt sick because I was too embarrassed to say about these pains in my leg because there was nothing there, there was nothing to show and our son came and picked us up and we went home." Joan, F57.

There were clear examples of worry about specific issues such as money and health, as well as general concern about the future, the unknown and how their pain and disability might progress in the future.

"And the biggest [issue] probably, anxious problems about the future." Daniel, M67.

Participants described frustration from difficulty or inability to complete simple tasks due to symptoms they experienced and this frustration links to the next theme.

Theme - Life is a constant challenge.

This was a large theme that contained five sub-themes: Increasingly on my own, A shrinking world, Sleep and fatigue, Harder to remain at work and Day to day life is a struggle.

Sub-theme - Increasingly on my own

Participants described social isolation due to cancelling arrangements or limiting their social life

"It makes you a hermit ..." Bob, M63.

Some participants had lost confidence to go out by themselves.

"It's like I say we have got no social life whatsoever because I never know from one day to the next whether I am going to be alright to go out or not, it becomes embarrassing and I would rather just stay in." Joan, F57.

Sub-theme - A shrinking world

Participants described their lives being confined by PDN, due to reduced physical and specifically, walking capacity.

"... unfortunately the pain got greater and greater to where I couldn't walk. It gave you the impression that you're walking on broken glass." Philip, M57.

As well as reduced walking, participants struggled using foot pedals when driving and hence lost confidence.

"It's the same with driving, if you go on a long journey you'd be in that car and some days your feet would burn that much just by keeping it on the throttle." Philip, M57.

The combination of these restrictions led to loss of independence, and a sense that life had become increasingly narrow.

"You feel to be, sort of entering this funnel where the choice is, life choices are getting smaller and smaller because of the restrictions, you know, um, you'll learn what not to do." Jane, F68.

Sub-theme - Sleep and Fatigue

Most participants described difficulty initiating sleep and, or, remaining asleep.

"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

A common complaint was the weight of bedclothes on their feet. There were descriptions of how uncomfortable the lightest sheet could be.

"Even in bed at night, the sheet is too heavy on my feet. You feel as if you'd like a cradle." Ellen, F63.

They also described the consequences of poor sleep, particularly with maintaining concentration and ability for everyday activity and function.

"It's really, really bad and I'm just tired all the time, exhausted, I've totally forgotten about tiredness." Anne, F52

However, there were some participants who did not experience night pain or sleep disturbance due to PDN.

"I have no problem with sleep, no." Mike, M65.

Sub-theme - Harder to remain at work

Although most participants were retired, some were working and this had become challenging due to pain levels, pain interfering with concentration, and fatigue from frequently disturbed sleep. Participants found their work role was important in providing and maintaining a sense of self.

As a counter point, there were employed participants who did not find PDN affected their ability to perform their role.

"I've never, pretty much ninety-nine per cent of the time, never suffered with it when I've been at work or volunteering..." Sam, M53.

Sub-theme - Day to day life is a struggle

This sub-theme was constructed from descriptions about unique impacts of PDN which were separate and distinct from impacts outlined in previous sub-themes. This demonstrates the breadth of impact PDN had on everyday activity. The impacts include the physical difficulty of getting up from bed in the morning and the difficulty experienced in simply sitting still - people were unable to sit through a film or dinner with friends, without needing to get up and move. Participants found PDN could make them feel nauseous which affected their appetite for food and consequent diabetes management. Participants disclosed their intimate relationships with partners had diminished or ceased because of PDN. Because of sensory loss, participants were aware of the need for foot care and surveillance and, closely allied to this, some had problems buying appropriate fitting footwear. Participants reflected how life had altered since they developed symptoms of PDN; they particularly focused on lost independence and how their personality may have changed. Lastly, participants spoke generally about the restrictions to daily activity, the implication being that all aspects of life were affected by PDN.

"You try and get across what this pain does to you, it's a depravity, is that the word?" Anne, F52.

"I've had to have treatment for my eyes, for retinopathy and things like that, kidneys are okay, but it's, I guess it's the neuropathy that is so intrusive and painful at times." Dawn, F68.

Discussion

Previous research has highlighted that PDN is painful; makes walking, standing and general activity more difficult and affects sleep and mood adversely. Previous studies mainly used questionnaires to gather data and these questionnaires have a restricted range of questions and responses.

The findings from the current study add personal insight to the experience of living with PDN. The results are broadly in line with results from previous mixed focus group and interviews from the USA [18]. The findings from Brod et al [18] identified four domains by which PDN impacted on the lives of their participants and it is encouraging that the range of impacts in the current study are similar irrespective of the population differences and health care systems experienced by USA and UK participants. This suggests some universality of the experience of PDN, but caution must be taken not to necessarily extrapolate these findings, to other populations.

Additional aspects to the PDN experience not previously reported were identified in the current study including: restless leg-type symptoms, headaches, muscle cramps, and breathlessness. It is however unknown how common these symptoms maybe in this population.

Participants experienced pain for which others could see no obvious cause, this created a feeling of invalidation for their experience, a finding that has been described in other persistent pain conditions. For example, in people with neuropathic pain a lack of understanding from other people, about the severity of their pain and the associated disability, had a negative effect on their personal relationships [21]. Similarly, non-specific low back pain is commonly experienced, yet not often associated with clear causative structural factors based on medical imaging investigations [22], this diagnostic ambiguity has led people to feel stigmatized by others [23–25].

Experiencing emotions such as depression and anxiety are common in persistent pain conditions [26] and in the population with diabetes [27]. A large cohort study using the Hospital Anxiety and Depression Scale in people with diabetes found 32% of respondents had mild to severe anxiety and 22% had mild to severe depression [27]. The presence of two or more diabetes-related complications, such as PDN, was associated with an odds-ratio of 2.75 for the presence of anxiety and 3.99 for the presence of depression. People with PDN co-exist in both these population groups and it is not surprising that the current data shows themes related to depression and anxiety, but there were also additional emotional issues such as: embarrassment, anger, frustration, loss of autonomy and suicidal thoughts.

Sense of embarrassment can link back to altered self-image, if one's functional ability is less than it 'should be'. Embarrassment has been studied in osteoarthritis, where qualitative research found participants described balancing the risk of pain versus embarrassment, when considering physical activity [28]. Osteoarthritis tends to be characterised by increasing pain with increasing activity [29], more so than in neuropathic pain conditions, when pain can be much more spontaneous and unpredictable [3]. The spontaneous nature of PDN pain was a factor in a previous focus group study [19], and led to increased fatigue, fear of falling, loss of identity and worsening self-evaluation. These last two issues link back to the sense of emotional frustration identified by participants in the current study.

Lastly, the increased sense of social isolation was captured in the theme Increasingly on my own. Social isolation and lack of social support has been associated with worsening diabetes control measured by HbA1c, blood pressure control and lipid levels [30]. The key driver for development of microvascular complications such as PDN is poor glycaemic control [31]. Similarly, persistent pain has been found more frequently in older adults who identify as lonely (odds ratio 1.23) [32], and social isolation is predictive of disability related to low back pain at 6-month follow up ($\beta = -0.91$) [33].

A full discussion of the concepts of social isolation, social support and loneliness are beyond the scope of this paper,

but it is clear these issues do not improve diabetes control, pain-related disability or quality of life [34]. Aiming to help people reduce social isolation and build social networks is supported by research but can often be difficult to action in clinical practice [35].

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 and duration of diabetes and PDN are transferable, but different genetic profiles and ethnic backgrounds have differing prevalence rates for diabetes [36]. Different social groups and religious affiliations also have tendencies toward different pain coping strategies [37].

Future research

Pharmacological management approaches alone are not fully successful in managing PDN. The breadth of impact identified in this study suggests multi-faceted and multidisciplinary approaches as used in pain management programmes may be required. However, neuropathic pain has a different clinical profile than musculoskeletal pain, and people with PDN have underlying diabetes and possibly other related co-morbidities, as well as pain, and strategies may require revision to be acceptable and appropriate to this group of people. To explore whether these impacts were more commonplace in the population with PDN, the current findings were used to inform an internet survey to quantify the frequency with which these impacts were experienced and explore which of these impacts would be a priority for treatment interventions [38].

Conclusions

Our study has shown PDN has wide-ranging impacts on quality of life, beyond those identified in previous research. There were a range of subjective experiences identified beyond pain alone, including a broad range of emotional responses including anger, embarrassment and frustration, and a strong theme of social isolation. It is as yet unknown how frequent these impacts are in the wider population with PDN or how they should be measured and managed clinically to optimise quality of life for 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, BD collected interview data, all authors discussed the data with overall analysis led by BD and CM, BD drafted the first version of the manuscript. All authors provided input to the final version of the manuscript.

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.

Ethical approval

Ethical approval for this study was obtained from the University of the West of England, 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 (UHBristol) Research and Innovation department (Study identifier ME/2013/4345).

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S1 - Online supplementary information

Main root question	Possible stem questions
Please tell me about your life with PDN?	• Tell me more about how it affects your working day? • Can you elaborate on how it affects your social life? • Are there ways in which this affects your relationships • In what ways do others close to you support you in managing this problem?

