

Painful Diabetic Peripheral Neuropathy: Results of a Survey Characterizing the Perspectives and Misperceptions of Patients and Healthcare Practitioners

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Abstract

Background Little information exists on the understanding and management of painful diabetic peripheral neuropathy (pDPN) between patients and healthcare practitioners (HCPs).

Objective The objective of this study was to characterize the patient perspective of pDPN and identify gaps in patient and HCP perceptions of pDPN.

Methods An online survey of patients with type 1 or 2 diabetes mellitus who reported experiencing any symptoms consistent with diabetic peripheral neuropathy (DPN) and HCPs who treat diabetes was conducted in 2012 in the USA. Patients were recruited via the Survey Sampling national consumer research panel, and HCPs were recruited from Epocrates' national research panel. Survey questions focused on the impact, understanding, and management of pDPN, and interactions between patients and their HCPs.

Respondents who reported pain were re-contacted to obtain further information on pain severity using a numerical rating scale (0 = no pain, 10 = most pain).

Results Respondents included 1,004 patients (53 % female, average age 55 years) and 500 HCPs (250 generalists, 150 specialists, and 100 nurses/physician assistants). While 83 % of patients reported pDPN symptoms, only 41 % of these patients had been diagnosed with DPN. Eighty-five percent of those with pDPN reported that it impacts daily activities. In contrast, HCPs estimated that of their patients who experienced any type of DPN symptom, 41 % experienced pain and 38 % had daily activity limitations because of their symptoms. Most HCPs (64 %) never had their patients complete a DPN assessment questionnaire, and only 41 % perform specific diagnostic tests on all patients who report DPN symptoms. Patients and HCPs both showed substantial clinical misperceptions regarding the cause and management of pDPN; 53 % of HCPs believed that adequate blood glucose control could reverse DPN, and 43 % of pDPN patients were not sure if DPN was reversible. There was also substantial discordance between patients and HCPs regarding discussions of DPN; only 49 % of pDPN patients reported that they speak about symptoms at "every" or "most" appointments with their HCP but 73 % of HCPs reported discussing DPN symptoms at "every" or "most" visits.

Conclusions Not only do misperceptions exist on the cause and management of pDPN among patients and HCPs, but there are additional disparities between the patient and HCP perspectives. These results suggests a need for (1) educational initiatives on pDPN that target patients and HCPs, and (2) initiating improved dialogue between patients and their HCPs for discussing appropriate management of pDPN that is distinct from treatment of the underlying diabetes.

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Key Points for Decision Makers

- Diabetic peripheral neuropathy and its painful symptoms are under-recognized.
- Disparities exist between patient and healthcare provider perspectives of the impact and need for management of diabetic peripheral neuropathy and its painful symptoms.
- Healthcare providers were characterized by substantial misperceptions regarding the cause and management of diabetic peripheral neuropathy.
- These disparities and misperceptions may act as barriers to appropriate patient management.

1 Background

Diabetes mellitus, with an estimated prevalence of 8.3 % in the US population and 1.9 million new cases reported in 2010, is a health problem that continues to increase as a result of both the aging of the population and unhealthy lifestyles in a younger demographic [1]. Diabetic peripheral neuropathy (DPN) can be a late complication of type 1 and 2 diabetes that is caused by decreased microvascular blood flow and lack of glycemic control and results in irreversible nerve damage [2–4]. When DPN is accompanied by painful symptoms it is known as painful diabetic peripheral neuropathy (pDPN). The painful symptoms generally manifest as sensations typically described by patients with neuropathic pain and may include the qualitative pain descriptors of burning, tingling, electric, sharp, shooting, and lancinating [5]. Estimates suggest that the overall prevalence of pDPN in the diabetic population is 15 % [6]. Since there is no cure for pDPN, management strategies have included slowing progression through maintenance of glycemic control, and symptomatic therapies, especially those targeting pain [7].

The substantial disease burden associated with pDPN has been well-documented. This burden is related to the reductions in function, quality of life, and productivity experienced by patients, as well as to greater use of healthcare resources that results in higher costs relative to both the general population and patients with diabetes who do not have pDPN [8–13].

Despite the numerous studies evaluating quality of life and other patient-reported outcomes in pDPN, no published studies have characterized patient knowledge and perceptions of pDPN, although patients with pDPN were included in a patient-level survey of attitudes and barriers to treatment of neuropathic pain [14]. Furthermore, there is little information on gaps in the dialogue between patients and their healthcare practitioners (HCPs). Such gaps may be of clinical relevance with respect to appropriate management

strategies, since a previous study suggested some disparity between the perspectives of patients and their HCPs, especially with regard to rating pDPN severity [13, 15]. Therefore, a survey was conducted among patients with pDPN and among HCPs who treat diabetes to characterize their perceptions and identify any knowledge gaps or disparities that may be targeted for educational initiatives.

2 Methods

Versta Research (Evanston, IL, USA) conducted an online survey in the USA from 8 May through 16 May 2012 in collaboration with the American Chronic Pain Association. Adult patients (≥ 18 years of age) diagnosed with type 1 or 2 diabetes were recruited via the Survey Sampling national consumer research panel. For inclusion, patients were screened based on self-report of experiencing any symptoms consistent with DPN in the feet, hands, legs, or arms. These symptoms included sensations of burning or feeling of heat; electric shock-like feelings; extreme sensitivity to touch, even light touch; numbness, tingling, or inability to feel things; prickling or pins and needles; shooting pain or sharp jabbing; and stinging or throbbing.

HCPs were recruited from Epocrates' national research panel. Since the patient and HCP populations were independent, the HCPs were not necessarily providing care to the patient survey participants.

While the HCP survey focused on understanding the impact, cause, and management of DPN symptoms, both surveys (Electronic Supplementary Material Online Resources 1 and 2) included questions on DPN symptoms as well as specific questions on painful symptoms of DPN. Both surveys also included questions on interactions between patients and HCPs. Survey results reflect an unweighted population.

A subpopulation of patients who reported the presence of DPN pain (i.e., pDPN) was re-contacted in order to obtain additional information on pain severity. The pain severity was assessed using a 0–10 numerical rating scale, where 0 = no pain and 10 = the most pain, based on the question “How would you rate your pain on average when left untreated? That is, how would you rate your pain symptoms prior to taking any medication or pain remedy?” Pain severity was considered mild, moderate, and severe based on scores of 1–3, 4–6, and 7–10, respectively, which have previously been shown to correlate with these severity levels in patients with pDPN [16].

All statistical analyses were performed to evaluate significance at the 95 % level using SPSS[®] (IBM, Armonk, NY) and WinCross (The Analytical Group, Inc., Scottsdale, AZ). Bivariate data were analyzed using independent *t* tests for means and independent *z* tests for percentages.

3 Results

3.1 Respondent Populations

The patient population consisted of 1,004 adults in the USA diagnosed with type 1 or type 2 diabetes who self-reported symptoms consistent with DPN. The mean age was 55 years, there were slightly more women than men (53 vs. 47 %), and the mean time since diabetes diagnosis was 12 years. There was similar representation among the North (26.1 %), East (20.2 %), South (23.3 %), and West (30.4 %) regions of the USA, and, of note, the results presented below were generally similar among the four geographic regions.

The HCP survey encompassed a cross-section of 500 clinicians who treat patients with diabetes and consisted of 50 % generalist physicians (family practice, general practice, and internists), 30 % specialist physicians (endocrinologists, neurologists, pain medicine specialists, and podiatrists), and 20 % nurses/physicians assistants. Overall, 63 % of the HCPs reported that they saw >50 diabetes patients per month and 28 % saw between 21 and 50 per month. The patient and physician populations were derived independently, and thus the HCPs were not necessarily providing care to the patient survey participants.

3.2 Painful Symptoms and their Impact

In the total population, 83 % (832 of 1,004) reported experiencing painful DPN symptoms, but only 41 % of these ($n = 343$ of 832) were diagnosed with DPN. Most of the patients who experienced pain (81 %) stated that this pain was different from other kinds of pain they were used to feeling, and they reported a wide range of sensory symptoms typical of neuropathic pain (Table 1). The most frequent of these symptoms was “numbness and tingling,” which was reported by 80 % of the symptomatic patients. DPN symptoms were reported as being experienced “most” or “all of the time” by 50 % of the symptomatic

patients, and 28 % of the symptomatic patients said that their symptoms were always painful.

Of the 832 patients who experienced painful symptoms of DPN (pDPN) and were re-contacted to obtain further information on pain severity, 393 responded (52 % female, average age 56 years); approximately half (49 %) reported severe pain, and 13 % and 38 % reported mild or moderate pain, respectively. Among those for whom pain severity data were available, greater proportions of patients reported the sensory symptoms at increasing levels of pain, and these proportions were significant for severe pain relative to mild and moderate pain across symptoms ($P < 0.05$) (Table 1). Among the patients with severe pain, 67 % reported experiencing symptoms “all” or “most of the time” compared with 18 % of those with mild pain and 38 % of those with moderate pain (both $P < 0.05$). Additionally, a significantly greater proportion of patients with severe pain reported DPN symptoms as always being painful (47 %) than in those with mild (10 %) and moderate pain (11 %) ($P < 0.05$ for both comparisons).

Overall, substantial proportions of patients reported that DPN impacts their daily function “a lot” or “somewhat” (Fig. 1). For all activities except for work, patients more frequently reported “somewhat” rather than “a lot” of impact, whereas the impact on work was more frequently reported as “a lot.” The most frequently affected function was sleep (61 %), followed by exercise (57 %) and the ability to walk (56 %). In the re-contacted subpopulation, the impact of pain was significantly greater at higher pain severity levels in all function categories ($P \leq 0.05$) (Fig. 2).

3.3 Patient–Physician Disparities

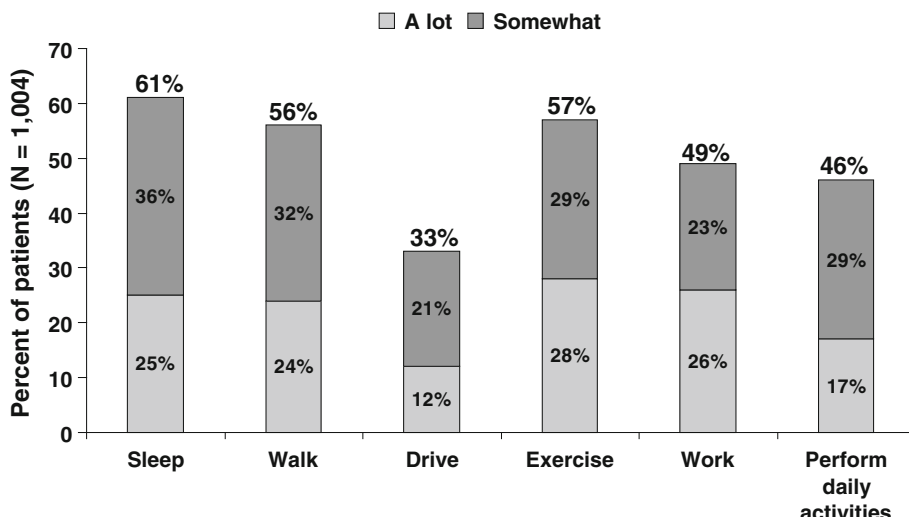
Despite the substantial presence of painful symptoms and their impact on daily activity reported by patients, there was considerable disparity between patient and HCP perspectives (Fig. 3). As shown in Fig. 3a, 83 % of patients reported that their symptoms are painful, but HCPs underestimated this prevalence by approximately 50 %;

Table 1 Type and prevalence of sensory symptoms among patients who reported pain associated with diabetic peripheral neuropathy

Sensory symptom	Patients experiencing painful symptoms (%) ($n = 832$)	Patients reporting pain severity (%) ($n = 393$)		
		Mild	Moderate	Severe
Numbness and tingling	80	62	79*	87* [†]
Prickling or pins and needles	72	60	68	79* [†]
Shooting pain or sharp jabbing	59	30	53*	76* [†]
Burning or feelings of heat	53	28	46*	60* [†]
Stinging or throbbing	52	28	47*	69* [†]
Electric shock-like feelings	49	32	42	63* [†]
Extreme sensitivity to even light touches	36	18	24	41* [†]

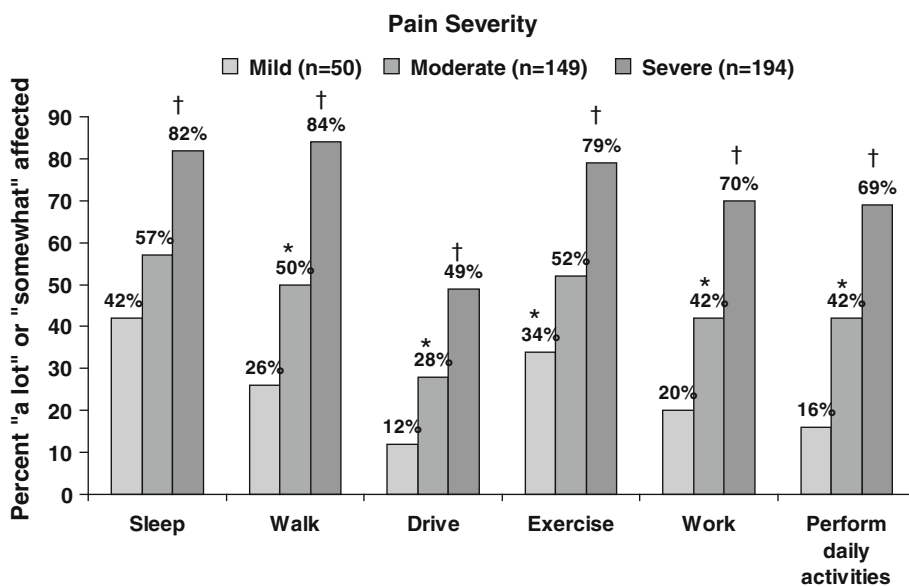
* $P < 0.05$ versus mild; [†] $P < 0.05$ versus moderate

Fig. 1 Patient-reported impact of diabetic peripheral neuropathy on daily functioning



How much do the symptoms affect your ability to:

Fig. 2 Relationship between pain severity and impact of painful diabetic peripheral neuropathy on daily function



* $P \leq 0.05$ versus mild; † $P \leq 0.05$ versus mild and moderate

HCPs estimated that only 41 % of their DPN patients experienced pain. Similarly, while daily activities were reported to be affected by DPN symptoms by 77 % of the patients, HCPs estimated that only 38 % of patients had their daily activities affected by DPN symptoms (Fig. 3a). Furthermore, these perceptual disparities regarding the presence and importance of DPN symptoms were highlighted by the report that 64 % of HCPs never have their patients complete a DPN assessment questionnaire, and that only 41 % perform specific diagnostic tests on all patients who report DPN symptoms. There was also discordance between patients and HCPs regarding the level of detail in which DPN symptoms were discussed (Fig. 3b); while most pDPN patients felt that their symptoms were

discussed only briefly or in passing, more HCPs than patients, 45 and 28 %, respectively, felt that DPN symptoms were discussed in detail. These differences in perception between patients and HCPs were consistent for all specific issues related to diabetes and DPN that were queried (Table 2). Although issues related to diabetes, such as glycemic control and diabetes-related medications, were reported to be frequently discussed by both patients and HCPs, there was a large disparity in the perception of how frequently diabetes sequelae were discussed, especially related to pDPN such as nerve damage, for which 61 % of HCPs reported discussing this issue with their patients at “every” or “most visits,” but only 39 % of pDPN patients reported discussing such damage with their HCP.

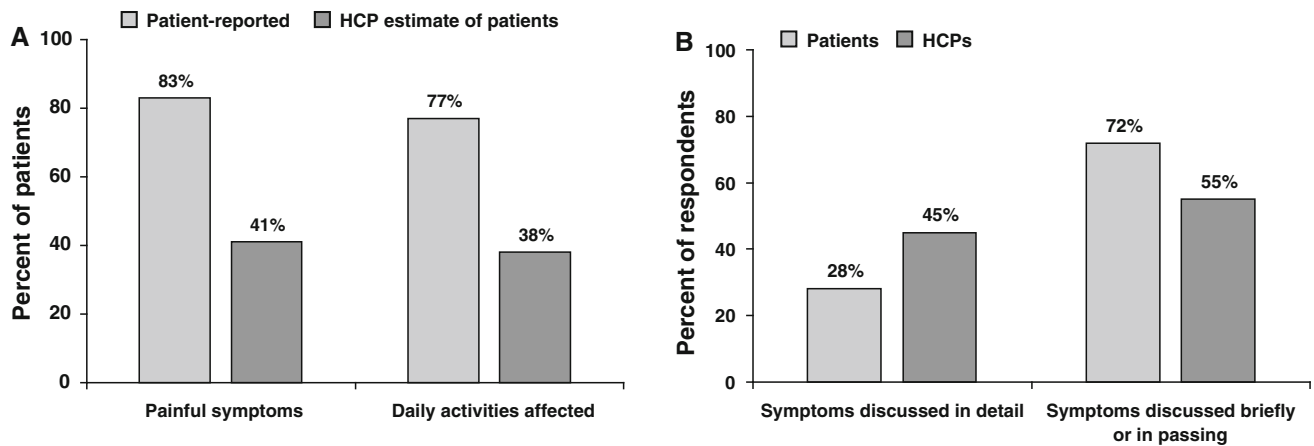


Fig. 3 Disparities between patient and healthcare practitioner perspectives. **a** Diabetic peripheral neuropathy symptoms and their impact (patient $n = 1,004$; healthcare practitioner $n = 500$). **b** Discussion of symptoms of diabetic peripheral neuropathy; proportions

reflect painful diabetic peripheral neuropathy patients who discussed their symptoms with their physician ($n = 724$), and all healthcare practitioners ($n = 500$). *HCPs* healthcare practitioners

Table 2 Proportion of respondents reporting diabetes mellitus issues discussed at “every” or “most” visits; *Italics indicate diabetic peripheral neuropathy-related issues*

Issue	Patients (%) ($n = 1,004$)	HCPs (%) ($n = 500$)
Blood sugar (glucose) levels	82	93
Medications for your diabetes	71	84
Eating habits and diet	53	82
Heart, lungs, and potential cardiovascular problems including high blood pressure	53	74
Exercise and lifestyle	49	83
<i>The symptoms in your feet, hands, arms, or legs that you described earlier</i>	46	73
<i>Foot-related issues</i>	42	68
<i>How the symptoms in your feet, hands, arms, or legs interfere with daily activities</i>	38	60
<i>Potential nerve damage</i>	36	61
Kidney function and the potential for problems	38	57
Eye and potential vision problems	36	60
The emotional toll of having diabetes	24	29

HCPs healthcare practitioners

Although patient discussion of DPN symptoms with their physician was reported more often with increasing levels of pain severity, the proportions of patients discussing their symptoms was low. Only 13 and 24 % of patients with mild and moderate pain, respectively, spoke in detail about their symptoms, and even among patients with severe pain, less than one-third (32 %) of patients discussed their symptoms in detail with their physician ($P < 0.05$ vs. mild and moderate pain).

There was general agreement regarding the role of HCPs in symptom management: 95 % of pDPN patients and 97 % of HCPs endorsed HCP responsibility for helping patients manage their symptoms. However, there were still several gaps in the avenues of communication between the two groups, manifested by the perceived roles that each population played in raising and discussing symptoms and their management. Patients reported that they raised issues relating to their symptoms on average 57 % of the time, and 49 % of pDPN patients stated that HCPs tend to discuss things only when asked. In contrast, HCPs felt that it was them who raised the issues 59 % of the time on average, and 70 % stated that they usually asked patients about DPN symptoms even if a patient did not talk about it. Several barriers to adequate communication were identified by pDPN patients, including that it was difficult for them to describe their symptoms (56 %), that they were reluctant to talk about their symptoms with their HCPs (37 %), and that their symptoms may have reflected poorly on how well they managed their diabetes (59 %).

Several key clinical misperceptions were identified as being common, including that substantial proportions of patients and HCPs had an unclear understanding of the relationship between blood glucose and DPN symptom management. Among pDPN patients, more than half (51 %) stated they believed that controlling blood sugar would help DPN symptoms go away, and 31 % were unsure. Almost one patient out of five (18 %) also believed that nerve damage from DPN was reversible, while 43 % were unsure. Similar misperceptions were observed among HCPs; 53 % believed that patients could reverse DPN with adequate blood glucose control, and 76 % believed that patients could alleviate DPN symptoms by maintaining low blood glucose levels.

Table 3 Request for more learning regarding diabetic peripheral neuropathy

Issue	Percentage wanting more information	
	Patients (<i>n</i> = 1,004)	HCPs (<i>n</i> = 500)
The link between diabetes mellitus and DPN	51	50
Cause of DPN	54	64
Difference between nerve pain and other types of pain	58	60
How DPN causes pain or numbness	58	64
When to see a doctor about DPN	49	–

DPN diabetic peripheral neuropathy, HCPs healthcare practitioners

Both populations acknowledged the value of learning more about DPN: at least half of DPN patients and HCPs expressed a desire for obtaining additional information on particular issues that could help them understand and treat this condition (Table 3). Educational topics included the relationship between diabetes and DPN, and the causes and manifestations of pDPN that distinguish it from other types of pain. Additionally, the majority of HCPs expressed a desire for more information specifically related to managing DPN-related pain, including non-pharmacologic strategies (87 %) and which medications have been approved by the US FDA to treat DPN pain (63 %).

4 Discussion

This survey, the first to characterize perceptions of DPN from the perspectives of patients and HCPs, highlights the existence of communication gaps between these two populations and identifies clinically relevant misperceptions regarding this condition. While these gaps and misperceptions likely act as barriers to disease management, their identification can also be used to inform the development of appropriate educational initiatives to promote better communication between patients and HCPs and a better understanding of DPN and its painful symptoms.

Since recognition of pDPN is essential to its treatment, it is especially relevant to note that HCPs underestimated the magnitude of patient-reported painful symptoms with respect to their prevalence and their impact on daily function. Both of these outcomes were reported by more than twice as many patients than was estimated by HCPs. This disparity may not necessarily be surprising given that a previous study also reported the presence of substantial discordance between patients and physicians with regard to rating pDPN severity, including underestimation of severity in almost half (46.7 %) of the patients who reported

severe pDPN [15]. Such discordance, especially with regard to patient-reported prevalence of symptoms, is likely to affect timely initiation of therapy and, ultimately, long-term outcomes. Although the proportion of patients who were being treated for pDPN was not captured in the current analysis, a cross-sectional study of patients with diabetes and pDPN by Daousi et al. [17] reported that 39 % of patients had never received treatment for their painful symptoms.

Based on the present survey, it may be proposed that the observed disparities between patients and HCPs may be due, at least in part, to less than optimal communication between patients and clinicians. This proposal is also supported by Daousi et al. [17], where nearly 13 % of patients never reported their symptoms to their treating physician. Furthermore, reports of the lack of use of assessment questionnaires and diagnostic tests by a substantial proportion of HCPs in the current study may also be a contributing factor to the low HCP estimates, since such assessments would enable identification of the presence of pDPN even among patients who may be reluctant to discuss their pain because of perceptions of embarrassment regarding their diabetes management.

The types of sensory symptoms and frequency of pain reported by patients were consistent with a survey characterizing the nature and scope of the painful symptoms [5]. However, the proportion of patients with severe pain (49.4 %) was almost twice as high as that reported in two previous patient-level studies (~25 %) [9, 18], although it was similar to that of a different study (51 %) [19]. These differences may be a reflection of the sampled populations as well as the specific question used to elicit pain severity levels.

There appeared to be a significant association between pain severity and impact on daily function. Such a relationship of greater levels of pain severity with decreased function, as well as with poorer outcomes on other patient-reported measures, have been documented in several studies of pDPN [9, 18–20]. In this regard, it should also be noted that treatment-related reductions in DPN pain consequently result in improved functional outcomes [21]. However, despite this association between pain severity and function, relatively few patients, even those with severe pain, discussed their symptoms in detail with their physician.

Limited knowledge on the cause and treatment of pDPN may be expected among a proportion of patients. However, it was somewhat surprising to observe the rate with which HCPs demonstrated a poor understanding of the relationship between pDPN and diabetes, including a lack of knowledge of the irreversibility of DPN-associated nerve damage. While such misunderstandings on the part of HCPs have not previously been documented, it may

partially account for reports that pDPN is under- or sub-optimally treated, and that satisfaction with treatment is low among patients [22, 23].

Importantly, the identification of these misperceptions, and the willingness by patients and HCPs to obtain more information provides a focus for developing educational initiatives that promote greater understanding of pDPN and its treatment.

4.1 Limitations

As with any survey dependent upon respondents, an important limitation is potential selection bias, since patients and HCPs who agreed to participate may have characteristics and perceptions different from those who refused. A similar limitation is that the patient-level data on pain and symptoms were based on self-report, and as such may be subject to recall bias and human error. It should also be noted that this study did not capture other outcomes that may have contributed to patients' perceptions of the pain experience, such as mood, negative emotions and thoughts, poor pain control, or poor past interactions with HCPs. Nevertheless, these factors could be a potential source of sampling or recall bias contributing to the high proportion of patients reporting painful symptoms.

An additional limitation that was previously acknowledged is that the two samples were obtained independently (the patients surveyed were unlikely to be patients of the HCPs surveyed), and therefore were not necessarily related. It is therefore possible that if patients were surveyed together with their HCPs, the results might have been different with regard to the observed levels of disparity. The generalizability of these results to the clinical setting may also be limited; although the demographic and clinical characteristics were generally consistent with other US surveys that relied on web-based or clinical practice populations [13, 19, 23], the data reflect an unweighted population. However, an observed similarity of results across geographic regions suggests the robustness of the survey.

5 Conclusions

There was notable discordance between patients' and HCPs' perspectives not only on the presence and impact of pDPN symptoms, but also on how often these are discussed during clinical visits. While misperceptions regarding the cause and management of pDPN were common among patients and HCPs, both populations expressed a desire to learn more about its cause and appropriate management. These results suggest a need for educational initiatives on pDPN that target patients and their HCPs.

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Author contributions In collaboration with Pfizer, Joe Hopper provided the research and questionnaire design, collected and analyzed the data, confirmed the accuracy of all data cited in the manuscript, and reviewed all statements, inferences, and conclusions to ensure that they are consistent with and supported by the data. Alesia Sadosky and Bruce Parsons developed the format for and provided guidance in performing the pain severity analyses, and were responsible for the interpretation of data as well as the writing and finalization of the manuscript. Alesia Sadosky is the guarantor for the content of the manuscript.

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